



**Using Respondent Driven Sampling to Unmask Disparities in
Social Determinants of Health and Health Outcomes for
Urban First Nations People Living in Hamilton, Ontario**

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4 **Using Respondent Driven Sampling to Unmask Disparities in Social Determinants**
5 **of Health and Health Outcomes for Urban First Nations People Living in Hamilton,**
6 **Ontario**
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ABSTRACT

Objective: Population based health information on urban Aboriginal populations in Canada is limited due to challenges with the identification of Aboriginal persons in existing health datasets. By implementing Respondent Driven Sampling (RDS), the Our Health Counts study in partnership with De dwa da dehs ney>s Aboriginal Health Access Centre (DAHC) aimed to generate a representative sample of First Nations individuals living in Hamilton, Ontario.

Design: Respondent-Driven Sampling.

Setting: Hamilton, Ontario, Canada.

Participants: 554 First Nations adults living in Hamilton were recruited using RDS.

Results: Among First Nations adults living in Hamilton, 78% earned less than \$20,000 per year and 70% lived in the lowest income quartile neighbourhoods. Mobility and crowded living conditions were also highly prevalent. Common chronic diseases included arthritis, hypertension, diabetes and COPD and rates of emergency room access were elevated.

Conclusions: RDS is an effective sampling method in urban Aboriginal contexts as it builds upon existing social networks and successfully identified a population-based cohort. The findings illustrate striking disparities in health determinants and health outcomes between urban First Nations individuals and the general population.

ARTICLE SUMMARY

Strengths and limitations of this study:

- Our study is the first in Canada to provide population based health assessment data for urban First Nations, documenting striking health and social inequities
- This study models best practices in academic-Aboriginal community research partnerships
- RDS has been demonstrated to be a promising tool for generating Aboriginal health assessment measures in urban areas where there are limited existing sampling frame options
- At present, multivariable regression analyses using RDS samples have not appropriately addressed the co-relation between observations and the unequal sampling probabilities inherent in RDS; therefore we present prevalence estimates for which methods are better established

INTRODUCTION

According to the 2006 Census, over 60% (150,570 people) of Aboriginal^a people living in Ontario live in urban areas.[1] Nearly seven out of ten Métis live in urban areas, and about three out of every four people in the off-reserve First Nations population live in urban areas.[1] First Nations people have historically been dislocated from their original homelands and may constitute diasporic, heterogeneous communities in urban areas.[2] Specifically, an increasing number of First Nations individuals are moving to urban centres to seek better housing, employment and education opportunities and for the services and amenities available.[3-5] According to the Canadian Census, First Nations, Inuit, and Métis populations experience ongoing disparities in social determinants of health such as income insecurity, unemployment, low levels of education, decreased food availability, and inadequate housing compared to non-Aboriginal Canadians, and these disparities are exacerbated with urban residence.[1,6,7]

Despite the growing size of the urban Aboriginal population in Canada, accessible and culturally relevant population health data for this population are almost non-existent.[8-11] While census data do exist, there are serious deficits in population health measures.[11] Some of the reasons behind this deficiency are limitations in the current health information system and data collection processes with respect to Aboriginal peoples.[12,13] Sampling frames are often biased and comprise non-random subpopulations such as lists of members or clients of particular programs and services in the community. When urban Aboriginal people have been included in census-based national surveys, these surveys were underpowered and often First Nations, Inuit, and Métis data could not be successfully disaggregated.[12,14] Additionally, studies based on Census data show that a significant number of Aboriginal people move from rural and reserve areas to cities, and back and forth as well as within and among cities.[4,15] These factors make it difficult to get reliable counts of the Aboriginal population of a city.

At the national level, the continued inability to identify Aboriginal peoples in healthcare databases leads to very poor coverage of Aboriginal populations in Canada, with a specific paucity of health information for First Nations, Métis, and Inuit living in urban areas. Provincial and territorial systems generally do not collect ethnic-specific utilization data, and their ethnic flags for vital statistics are inconsistent or absent.[16] The federal government's decision to cancel the long form of the Canadian national

^a "Aboriginal people" is a collective name for all of the original peoples of Canada and their descendants. The *Constitution Act* of 1982 specifies that the Aboriginal Peoples in Canada consist of three groups: Indians, Inuit and Métis. The term First Nations came into common use in the 1970s to replace Indian, which some people found offensive. Despite its widespread use, there is no legal definition for this term in Canada. In the United States, the term "Native American" is used to represent Indigenous peoples from North America, including Mexico. For alignment with the US Constitution and to ensure policy implications, the term "American Indian" is still used for Indigenous populations living within US borders, particularly the lower 48 states and parts of Alaska. "Indigenous" is a term used in the international context.

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3 census will further challenge the ability of researchers and communities to identify and
4 address social inequities across ethnic groups and will widen the existing health and
5 social policy vacuum.[17,18]
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8 In the absence of an accessible and accurate population based sampling frame for
9 urban Aboriginal people, we implemented respondent driven sampling (RDS) for the Our
10 Health Counts (OHC) study. RDS, like other chain-referral approaches, relies on
11 members of a population to recruit their peers.[19,20] However, RDS differs from other
12 methods because of estimation procedures that adjust for the participants' different
13 probabilities of being sampled.[20] RDS also differs from other chain-referral methods
14 because the number of recruitments any participant can make is limited, and it employs a
15 dual incentive structure where participants are rewarded both for participating and for
16 recruiting their peers.[21]
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19 There is limited literature on RDS in Indigenous contexts;[22] however, there is
20 evidence that links the success of RDS to the strength of social networks and
21 relationships.[23] Indigenous knowledge is wholistic, relational and embraces a fluidity
22 that allows for constant growth and change.[24,25] Aboriginal identity values the group
23 over the individual, thereby establishing models of kinship whereby everyone has the
24 right to give and receive according their own choices.[24] Therefore, we hypothesized
25 that RDS would be an appropriate and effective sampling methodology as it builds on
26 social networks and would draw on existing kinship systems known to be present in
27 Indigenous communities.[26]
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31 The main objective of the OHC project was to work in partnership with
32 Aboriginal stakeholders to generate a culturally relevant, representative baseline health
33 data set for three urban Aboriginal communities in Ontario, Canada. The results
34 presented here pertain specifically to the urban First Nations population in Hamilton
35 where the organizational project lead was the Ontario Federation of Indian Friendship
36 Centres (OFIFC) and the community partner was De dwa da dehs ney>s Aboriginal
37 Health Access Centre (DHAC).
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40 **METHODS**

41 **Community-based participatory research**

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43 This study upheld current ethical and scientific standards in Indigenous health
44 research[27-31] through a community based participatory research partnership between
45 the academic research team, OFIFC and DHAC. Data sharing and research agreements
46 ensured that DHAC led the governance and management of data throughout the course of
47 the study. In addition, a Governing Council, comprised of representatives from the core
48 urban Aboriginal provincial organizations was established to oversee all stages of the
49 research process. All members of the study team were from the Aboriginal community,
50 living in the general vicinity of the city of Hamilton. Formal ethics approval was
51 provided by the Research Ethics Board of St. Michael's Hospital in Toronto, Canada and
52 the OHC Governing Council.
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Study Site

The City of Hamilton is located in southern Ontario on what was traditionally Haudenosaunee (Iroquian) territory and is near two First Nations reserves: Six Nations of the Grand River and Mississaugas of the New Credit. According to the 2006 Census, the total Aboriginal population in Hamilton was 13,735 people, comprising 2.8% of the total population of the city.[32] The OFIFC identified the city of Hamilton as a promising community site based on its significant Aboriginal population and strong infrastructure of Aboriginal community services.

Recruitment

The RDS process was initiated through the purposive selection of individuals to begin recruitment, also called “seeds.” Inclusion criteria for participation in the study included 18 years of age, residence within the geographic boundaries of the City of Hamilton and self-identified as having First Nations identity. With the help of community partners, six seeds were identified and agreed to participate. Five of the six seeds produced referrals within the two weeks leading up to the December 2009 holiday closure at DAHC. In February and March 2010, three additional seeds were added.

Study participants, including seeds, provided informed consent and then completed a health assessment survey after which they received 3-5 coded coupons to refer a member of their social network into the study. Following the holiday closure of DHAC, the number of distributed coupons per recruit was increased from 3 to 5 in order to increase the rate of recruitment. Participants received a monetary reimbursement of \$20 for their time and participation. They also received an additional \$10 for every eligible person they recruited into the study. Study recruitment and interviews took place in an Aboriginal community centre.

For sample size calculation, we assumed 95% confidence intervals (CI), survey item prevalence ranges from 10% to 75% and a design effect of 2.[33] Based on this formula, the OCH study aimed to recruit 500 First Nations adults and 250 children.

Sources of Data

Community concept mapping was implemented to develop a community specific survey for First Nations in Hamilton, [34] which was comprised of 8 domains covering areas such as sociodemographics, physical, mental, and emotional health, First Nations identity and impacts of colonization, and access and barriers to care. The survey tool was piloted with First Nations community members, and minor modifications were made to improve face validity. Data were collected and compiled by computer-assisted personal interviewing with a computer based version of the survey tool developed by the research team using SPSS Data Collection Author and Collector.[35]

Upon completion of recruitment and survey, our sample of First Nations adults was linked to data holdings at the Institute of Clinical Evaluative Sciences (ICES) including provincial records of emergency room and hospital visits (Canadian Institutes of Health Information – Discharge Abstract Database and National Ambulatory Care

Reporting System: Emergency), and neighbourhood income quintiles (derived from Census data). Using health care system identification numbers (i.e. Ontario Health Card) provided by participants, we successfully linked 92% (N=725) of First Nations adults to the ICES database.

Analysis

Recruitment dynamics, adjusted population based estimates and confidence intervals were calculated using the RDS-I enhanced data smoothing estimator in the custom RDSAT software (version 7.1).[36] The RDS methodology anticipates that personal networks are not randomly distributed, and therefore adjusts for small to moderate levels of network clustering (people who have ties to others like them), in the form of post-sampling weights.

RESULTS

Among First Nations adults in Hamilton, 78.9% of participants were recruited via referral trees originating from two seeds. With 19 and 32 waves respectively, the lengths of both of these recruitment chains were long enough to overcome the original sampling bias, which usually happens after 6 or 7 waves of recruitment.[37]

Over a period of four and a half months a total of 790 persons were recruited, including 554 adults and 236 children. Demographic and social characteristics are presented in Table 1.

Table 1. Demographic and social characteristics of First Nations adults (Total N=554)

Characteristic	Prevalence % (95% CI)
Sex	
Male	59.9 (53.3, 67.2)
Age	
18-34	40.2 (33.3, 48)
35-49	35.4 (28.7, 41.6)
50+	24.4 (18.4, 30.8)
Education	
Some high school or less	57.3 (51.1, 64)
Completed high school	19.5 (14.5, 24.7)
Some or completed college	18.3 (13.3, 23.3)
Some or completed University	5 (2.4, 8)
Income sources for household	
Provincial or municipal social assistance or welfare (e.g. ODSP, Ontario Works)	69.2 (63.1, 75)
Wages and salaries	28.2 (22.1, 34.2)
Child Tax Benefit	17 (12.4, 21.8)
Any other income support	13.3 (9.2, 17.6)
Employment insurance	9.6 (5.4, 14.3)

Income from self-employment	7.7 (4.3, 11.7)
Child Support	3 (1.1, 4.6)
Individual annual income	
\$0-4,999	18.3 (13.4, 24.8)
\$5,000-5,999	23.1 (17.1, 28.5)
\$10,000-14,999	21.9 (16.3, 27.6)
\$15,000-19,999	14.8 (10.7, 20)
\$20,000+	21.8 (16, 27.6)
Mobility	
No moves in past 5 years	10.2 (6.2, 14.8)
1 move in past 5 years	15.5 (10.5, 20.6)
2 moves in past 5 years	20.2 (15.4, 26.4)
3-5 moves in past 5 years	41.1 (35, 48.6)
6-10 moves in past 5 years	10.4 (5.7, 13.4)
Overcrowding*	
<=1 persons per room	27.7 (21.6, 33.8)
1-2 persons per room	46 (40.5, 54.3)
>2 persons per room	26.3 (19.7, 30.8)
Food security	
You and others always had enough of the kinds of food you wanted to eat	26.7 (21.1, 32.8)
You and others had enough to eat, but not always the kinds of food you wanted	51.5 (45.3, 58)
Sometimes or often did not have enough to eat	21.8 (16.5, 27)

Note. CI = confidence interval.

*Following Statistics Canada standards: calculated by dividing the number of rooms in each household (excluding the bathroom) by the number of people residing in the home

The data presented in Table 2 for age, gender and income quintiles compare the OHC population estimates with the total Hamilton population and a random subset of 10% of the Ontario provincial population. The three populations were very similar with respect to the gender breakdown, however, the OHC sample was younger than the general Hamilton and Ontario populations which is consistent with Census data.[38] Over 70% of the First Nations population fell into the lowest income quartile compared to 25% of the general Hamilton population and 20% of the Ontario population. At the higher end of the income scale, we observed that while 15% of Hamilton residents and 20% of the Ontario population fell into the highest income quartile, only 3% of the study population was earning in this category.

Table 2. Gender, Age and Income Quintile for First Nations Adults, City of Hamilton and Ontario-10%

Variable	Sample			
	OHC (Total N=725*)	OHC-RDS- Adjusted	Hamilton (Total N=536,253)	Ontario-10% (Total N=1,324,241)

	Prevalence, %	Prevalence, % (95% CI)	Prevalence, %	Prevalence, %
Sex				
Female	49.4	37.6 (29.6, 43.6)	50.9	51.2
Male	50.6	62.4 (56.4, 70.4)	49.1	48.7
Age**				
18-34	37.4	41.9 (34.4, 49.9)	28.2	28.2
35-49	37.6	36.6 (29.9, 43.1)	28.1	29.5
50-64	22.9	20.7 (14.7, 26.9)	24.8	24.8
65+	2.1	0.8 (0.3, 1.6)	18.9	17.6
Income Quintile				
1-Low	71.76	73 (66.5, 79.2)	25.1	19.5
2	16.22	11.8 (7.7, 16)	22.8	19.8
3	6.3	7.4 (3.6, 10.5)	20.3	19.8
4	2.48	4.9 (2.5, 9.8)	17	20.4
5-High	1.34	3 (1.1, 5.4)	14.7	20.2

Note. CI = confidence interval; OHC = Our Health Counts; RDS = Respondent Driven Sampling.

*Total N reflects number of participants linked to ICES database

**Age of participants on 2010-04-01

The most common chronic conditions that had been diagnosed by a health care provider among First Nations adults (n=554) in Hamilton included arthritis (30.7%; 95% CI 25.4-36.8), hypertension (25.8%; 95% CI 20.3-31.6), asthma (19%; 95% CI 14.9-24.6), diabetes (15.6%; 95% CI 11.2-21.1), heart disease (8.4%; 95% CI 4.8-12.5) and COPD (8.4%; 95% CI 5.3-11.8). The prevalence of Hepatitis C was 8.7% (95% CI 4.3-11.7). 25% had been injured over the past 12 months. Upper respiratory tract infection (URTI) was common, with 73% (95% CI 67.9-79.9) of adults reporting URTI in the past 12 months.

Among First Nations adults (n=554), 16.7% (95% CI 11.4 – 22.1) felt that availability of health services in their community was excellent, 43.3% (95% CI 36.1 - 49.6) felt it was good, 28.9% (95% CI 23.3 – 35.2) felt it was fair and 11.1% (95% CI 7.9 – 15.6) felt availability was poor. Close to half (47.9%) of the First Nations living in Hamilton reported that long waiting lists were a barrier (95% CI 41.9 - 55.4). Other common barriers included: not being able to arrange transportation; doctor not available; not being able to afford direct costs and/or transportation; services not covered by Non-Insured Health Benefits and lack of trust in health care provider.

Both acute and non-acute emergency room visits were much more frequent among First Nations in Hamilton compared to the general Hamilton and Ontario populations. A striking 10.6% of the First Nations adult population in Hamilton reported 6 or more emergency room visits in the previous 2 years compared to 1.6% and 1.9% of the Hamilton and Ontario adult populations respectively (Table 3).

Table 3. Number of Emergency Room visits in the Previous 2 Years for Adults (18-64 years), First Nations, City of Hamilton and Ontario-10%

Frequency of ER visits	Sample			
	OHC (Total N=514*)	OHC RDS-Adjusted	Hamilton (Total N=360,378)	Ontario-10% (Total N=901,509)
	Prevalence, %	Prevalence, % (95% CI)	Prevalence, %	Prevalence, %
None	31.5	(25.8 – 37.5)	66.3	69.1
1	26.2	(20.7 – 32.8)	18.7	16.8
2-5	31.7	(25.9 – 37.8)	13.4	12.3
6+	10.6	(6.2 – 14.5)	1.6	1.9
ER visits (acute)				
None	50.2	(43.9 – 57.5)	78.4	80.1
1	24.7	(18.7 – 30.1)	14.2	13.1
2-5	20.7	(15.3 – 26.1)	6.8	6.3
6+	4	1.6 – 6.9)	0.6	0.6
ER visits (non-acute)				
None	54.3	(47.6 – 61.2)	79.4	81.2
1	22.4	(17.3 – 28.5)	14	12.2
2-5	20.4	(14.5 – 25.4)	6.3	6
6+	2.9	(1 – 5.6)	0.4	0.6

Note. CI= confidence interval; OHC = Our Health Counts; RDS = Respondent Driven Sampling

*Total N reflects number of adults aged 28-64 linked to ICES database

Rates of hospitalization were slightly higher among the First Nations population compared to the Hamilton and Ontario populations. This can partly be explained by a higher birth rate among First Nations populations compared to the general Canadian population,[39] which is reflected by higher rates of obstetrics hospitalization compared to the general Hamilton and Ontario population: 7.3% (95% CI, 3.9 – 10.9) of the Hamilton First Nations population between the ages of 18 and 64 years had been hospitalized at least once in the past 5 years for obstetrical reasons compared to 4% of both the general Hamilton and Ontario populations in the same age group and over the same time period. However, given the high rates of chronic diseases such as diabetes and heart disease and the much higher rates of emergency room use among the First Nations population, these findings were unexpected and therefore require further investigation.

DISCUSSION

The OHC project generated a representative, urban Aboriginal health database. Through the successful application of RDS, a sample of urban First Nations individuals who might otherwise not have participated in mainstream surveys or the census was captured. In addition, given the current deficiency in public health information on urban First Nations populations, the statistically rigorous RDS sample allowed us to produce population-

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3 based estimates that can be utilized by local, regional, provincial and federal policy
4 makers as well as urban Aboriginal stakeholders to address social inequities and health
5 disparities facing this community.
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8 Striking levels of poverty were identified in this study. The income data
9 presented here may be a more representative income profile of the First Nations
10 population in Hamilton than the 2006 Census. Specifically, the OHC data were adjusted
11 for the sampling procedure using an RDS estimator and captured more 'hidden'
12 populations such as persons who are homeless, transient or who have low literacy skills,
13 who are known to be under-represented in the Census.[9,11] Further evidence of low
14 incomes among this population is provided by the RDS-adjusted ICES income quintile
15 data, which revealed that over 70% of the OHC cohort was in the lowest income quartile
16 compared to 25% of the general Hamilton population and 20% of the Ontario population.
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20 Accompanying high levels of poverty, housing and food insecurity were also
21 highly prevalent among First Nations persons living Hamilton. Over half of the study
22 population had moved at least 3 times in the past 5 years compared to 60% of the general
23 Hamilton population who had not moved at all for the past 5 years.[32] Compared to an
24 overcrowding rate of 3% for the general Canadian population in the 2006 Census,[1] 74%
25 of First Nations persons in Hamilton live in crowded conditions. These findings echo
26 those presented in the 2007 Urban Aboriginal Task Force (UATF) final report, which
27 documented persistent obstacles with finding affordable housing, obtaining stable and
28 secure employment and accessing appropriate services and resources among urban
29 Aboriginal people.[40] Similarly, the Toronto Aboriginal Research Project (TARP)
30 found that Aboriginal people in Toronto tend to concentrate in lower-income
31 neighbourhoods where a significant proportion, particularly men, live in poverty.[41]
32 While a growing proportion of urban Aboriginal people in Canada are achieving varying
33 degrees of economic success in a number of skilled professions,[5,41] there remains a
34 significant amount of unmet basic needs among this population.
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39 The burden of chronic conditions experienced by First Nations adults in Hamilton
40 is disproportionately high. For example, 19% of the OHC Hamilton population reported
41 having been told by a health care provider that they have asthma, which is more than
42 twice the self-reported asthma rate (9.3%) for the overall Hamilton population in the
43 2007 Canadian Community Health Survey (CCHS).[42] Likewise, rates of arthritis and
44 high blood pressure were 30.7% and 25.8% among First Nations adults in Hamilton
45 compared to 19.9% and 19.7% among all adults in Hamilton as reported in the 2007
46 CCHS.[42] For First Nations adults in Hamilton, the rate of diabetes diagnosed by a
47 health care provider was approximately three times the rate among the general Hamilton
48 population.[42] These findings are particularly disconcerting given the much younger
49 age demographic of the First Nations Hamilton population and the documented barriers
50 to receiving health care services including long wait lists, challenges with accessing and
51 affording transportation and the unavailability of physicians in the area. Furthermore,
52 45.8% (95% CI 38.9-52.4) of First Nations adults believed that their ability to engage in
53 preventative health activities (i.e. regular exercise, going to the doctor or nurse for health
54 screening tests, accessing preventative dental care) had been affected by financial
55 hardship.
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4 High rates of emergency usage by First Nations persons living in Hamilton are
5 likely linked to the problems in accessing non-emergency health care, as revealed by 40%
6 of the population who rated their access to health care as fair or poor and 48% who
7 indicated that wait lists are too long. In addition, as a result of primary healthcare
8 reforms,[43] patients may be told by their primary care providers to go to the emergency
9 department rather than a walk-in clinic when their primary care team is not available.[44]
10 Further examination is required to explore potential bias in hospital admission practices
11 and to differentiate between types of hospitalizations (i.e. mental health, surgical and
12 medical hospitalizations).
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14
15 There were a number of limitations of the study. Firstly, it should be noted that
16 we may have under sampled the elderly First Nations population living in nursing
17 homes or residences for senior citizens in Hamilton. During our initial seed selection,
18 we did not select any seeds from this population, and this population may have fewer
19 network ties than other population groups, which may have resulted in an under
20 representation of First Nations individuals over 65 years of age. Secondly, RDS
21 cannot guarantee a random sample of network members;[45] therefore, estimates are
22 unbiased to the degree that the assumptions of the RDS estimator are met. There is an
23 active literature on RDS and estimation using RDS data,[46,47] and there is debate
24 regarding the true design effects of RDS surveys.[48,49] Existing multivariable
25 regression analyses using RDS samples have not appropriately addressed the co-
26 relation between observations and the unequal sampling probabilities inherent in RDS,
27 therefore, we have focused on reporting prevalence estimates for which methods are
28 better established. Despite these limitations, RDS was used to effectively recruit an
29 urban Aboriginal population and allowed for the derivation of rigorous population
30 estimates and data linkages that have previously not been possible.
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35 Given the near absence of population health information for urban Aboriginal
36 people in Canada, this research is able to provide, for the first time, First Nations data
37 that clearly demonstrate alarming socio-economic inequities, a significant burden of
38 chronic disease, multiple barriers in access to health care and elevated emergency room
39 use. This newly established health database represents a significant contribution to
40 public health that will directly inform strategic directions for the improvement of health
41 and social status of urban Aboriginal people in Ontario. For example, this research will
42 support the development of RDS as a tool to effectively recruit a larger cohort for
43 longitudinal research with Aboriginal families in Ontario.
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CONTRIBUTORSHIP STATEMENT

M.F. contributed substantially to the study conception and design, co-led data interpretation and analysis and drafted multiple versions of the manuscript. J.S. co-led the study conception and design, data analysis and interpretation and made important contributions to the draft and final manuscript. S.M. contributed substantially to study conception and design, was a member of the governing council that guided each stage of research, represented the Aboriginal organizational lead of the research and made important revisions to the draft manuscript. DAHC was the Aboriginal community partner and supervised local data collection, participated in data analysis and interpretation. M.S. provided important technical support during data collection, co-led the data analysis and interpretation, and provided important revisions to the manuscript. P.O. contributed substantially to the study conception and design, analysis and interpretation of data and made important revisions to the draft manuscript.

COMPETING INTERESTS

None

DATA SHARING STATEMENT

A tri-party data sharing agreement was negotiated between the Institute of Clinical and Evaluative Sciences (ICES), the Our Health Counts Governing Council and the Centre for Research on Inner City Health at St Michael's Hospital in Toronto, Canada. Approval would need to be granted by these three parties for access to additional, unpublished data.

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STROBE 2007 (v4) checklist of items to be included in reports of observational studies in epidemiology*
Checklist for cohort, case-control, and cross-sectional studies (combined)

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	Yes, in title
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	Yes, pg 2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	Yes, pg 3-4
Objectives	3	State specific objectives, including any pre-specified hypotheses	Yes, pg 4
Methods			
Study design	4	Present key elements of study design early in the paper	Yes, pg 4-5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	Yes, pg 5
Participants	6	(a) <i>Cohort study</i> —Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up <i>Case-control study</i> —Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls <i>Cross-sectional study</i> —Give the eligibility criteria, and the sources and methods of selection of participants	Yes, pg 5
		(b) <i>Cohort study</i> —For matched studies, give matching criteria and number of exposed and unexposed <i>Case-control study</i> —For matched studies, give matching criteria and the number of controls per case	
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	Yes, pg 5-6
Bias	9	Describe any efforts to address potential sources of bias	Yes, pg 4
Study size	10	Explain how the study size was arrived at	Yes, pg 5
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	Yes, pg 6
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	Yes pg 6
		(b) Describe any methods used to examine subgroups and interactions	
		(c) Explain how missing data were addressed	
		(d) <i>Cohort study</i> —If applicable, explain how loss to follow-up was addressed <i>Case-control study</i> —If applicable, explain how matching of cases and controls was addressed	

		<i>Cross-sectional study</i> —If applicable, describe analytical methods taking account of sampling strategy	
		(e) Describe any sensitivity analyses	
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed (b) Give reasons for non-participation at each stage (c) Consider use of a flow diagram	
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders (b) Indicate number of participants with missing data for each variable of interest (c) <i>Cohort study</i> —Summarise follow-up time (eg, average and total amount)	Yes, pg 6-7
Outcome data	15*	<i>Cohort study</i> —Report numbers of outcome events or summary measures over time <i>Case-control study</i> —Report numbers in each exposure category, or summary measures of exposure <i>Cross-sectional study</i> —Report numbers of outcome events or summary measures	
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included (b) Report category boundaries when continuous variables were categorized (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	
Discussion			
Key results	18	Summarise key results with reference to study objectives	Yes, Pg 9-11
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	Yes, Pg 11
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	Yes, pg 9-11
Generalisability	21	Discuss the generalisability (external validity) of the study results	
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	Yes, pg 11-12

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.

BMJ Open

Unmasking Health Determinants and Health Outcomes for Urban First Nations Using Respondent Driven Sampling

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4 Unmasking Health Determinants and Health Outcomes for Urban First Nations Using
5 Respondent Driven Sampling
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42
43 **Keywords:** Canada; urban Aboriginal health; First Nations; Respondent-Driven
44 Sampling; Community-based Research
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ABSTRACT

Objective: Population based health information on urban Aboriginal populations in Canada is limited due to challenges with the identification of Aboriginal persons in existing health datasets. The main objective of the Our Health Counts (OHC) project was to work in partnership with Aboriginal stakeholders to generate a culturally relevant, representative baseline health data set for three urban Aboriginal communities in Ontario, Canada. **Design:** Respondent-Driven Sampling.

Setting: Hamilton, Ontario, Canada.

Participants: The OHC study, in partnership with De dwa da dehs ney>s Aboriginal Health Access Centre (DAHC) recruited 554 First Nations adults living in Hamilton using RDS.

Results: Among First Nations adults living in Hamilton, 78% earned less than \$20,000 per year and 70% lived in the lowest income quartile neighbourhoods. Mobility and crowded living conditions were also highly prevalent. Common chronic diseases included arthritis, hypertension, diabetes and COPD and rates of emergency room access were elevated.

Conclusions: RDS is an effective sampling method in urban Aboriginal contexts as it builds upon existing social networks and successfully identified a population-based cohort. The findings illustrate striking disparities in health determinants and health outcomes between urban First Nations individuals and the general population.

ARTICLE SUMMARY

Strengths and limitations of this study:

- Our study is the first RDS of self-identified First Nations people residing in an urban setting in Canada
- This study models best practices in academic-Aboriginal community research partnerships
- RDS has been demonstrated to be a promising tool for generating Aboriginal health assessment measures in urban areas where there are limited existing sampling frame options
- At present, multivariable regression analyses using RDS samples have not appropriately addressed the co-relation between observations and the unequal sampling probabilities inherent in RDS; therefore we present prevalence estimates for which methods are better established

INTRODUCTION

According to the 2006 Census, over 60% (150,570 people) of Aboriginal^a people living in Ontario live in urban areas.(1) Nearly seven out of ten Métis live in urban areas, and about three out of every four people in the off-reserve First Nations population live in urban areas.(1) First Nations people have historically been dislocated from their original homelands and may constitute diasporic, heterogeneous communities in urban areas.(2) Specifically, an increasing number of First Nations individuals are moving to urban centres to seek better housing, employment and education opportunities and for the services and amenities available.(3-5) There is a growing body of literature exploring the complexities of urban Indigeneity (6) and some of the elements which distinguish urban Aboriginal identity are social and economic marginalization, a growing middle class, and population diversity in term so cultural origins and legal status.(7) According to the Canadian Census, First Nations, Inuit, and Métis populations experience ongoing disparities in social determinants of health such as income insecurity, unemployment, low levels of education, decreased food availability, and inadequate housing compared to non-Aboriginal Canadians, and these disparities are exacerbated with urban residence.(1;8;9)

Despite the growing size of the urban Aboriginal population in Canada, accessible and culturally relevant population health data for this population are almost non-existent.(10-13) While census data do exist, there are serious deficits in population health measures.(13) Some of the reasons behind this deficiency are limitations in the current health information system and data collection processes with respect to Aboriginal peoples.(14;15) Sampling frames are often biased and comprise non-random subpopulations such as lists of members or clients of particular programs and services in the community. When urban Aboriginal people have been included in census-based national surveys, these surveys were underpowered and often First Nations, Inuit, and Métis data could not be successfully disaggregated.(14;16) Additionally, studies based on Census data show that a significant number of Aboriginal people move from rural and reserve areas to cities, and back and forth as well as within and among cities.(4;17) These factors make it difficult to get reliable counts of the Aboriginal population of a city.

At the national level, the continued inability to identify Aboriginal peoples in healthcare databases leads to very poor coverage of Aboriginal populations in Canada,

^a “Aboriginal people” is a collective name for all of the original peoples of Canada and their descendants. The *Constitution Act* of 1982 specifies that the Aboriginal Peoples in Canada consist of three groups: Indians, Inuit and Métis. The term First Nations came into common use in the 1970s to replace Indian, which some people found offensive. Despite its widespread use, there is no legal definition for this term in Canada. In the United States, the term “Native American” is used to represent Indigenous peoples from North America, including Mexico. For alignment with the US Constitution and to ensure policy implications, the term “American Indian” is still used for Indigenous populations living within US borders, particularly the lower 48 states and parts of Alaska. “Indigenous” is a term used in the international context.

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3 with a specific paucity of health information for First Nations, Métis, and Inuit living in
4 urban areas. Provincial and territorial systems generally do not collect ethnic-specific
5 utilization data, and their ethnic flags for vital statistics are inconsistent or absent.(18)
6 The federal government's decision to cancel the long form of the Canadian national
7 census will further challenge the ability of researchers and communities to identify and
8 address social inequities across and within populations who experience racialization and
9 the negative effects of structural discrimination in healthcare and other sectors , thus
10 widening the existing health and social policy vacuum.(19;20)
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14 In the absence of an accessible and accurate population based sampling frame for
15 urban Aboriginal people, we implemented respondent driven sampling (RDS) for the Our
16 Health Counts (OHC) study. RDS, like other chain-referral approaches, relies on
17 members of a population to recruit their peers.(21;22) However, RDS differs from other
18 methods because of estimation procedures that adjust for the participants' different
19 probabilities of being sampled.(22) RDS also differs from other chain-referral methods
20 because the number of recruitments any participant can make is limited, and it employs a
21 dual incentive structure where participants are rewarded both for participating and for
22 recruiting their peers.(23)
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26 There is limited literature on RDS in Indigenous contexts;(24) however, there is
27 evidence that links the success of RDS to the strength of social networks and
28 relationships.(25) Indigenous knowledges are wholistic, relational and embraces a
29 fluidity that allows for constant growth and change.(26;27) Aboriginal identities values
30 the group over the individual, thereby establishing models of kinship whereby everyone
31 has the right to give and receive according their own choices.(26) Therefore, we
32 hypothesized that RDS would be an appropriate and effective sampling methodology as it
33 builds on social networks and would draw on existing kinship systems known to be
34 present in Indigenous communities.(28)
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38 The main objective of the OHC project was to work in partnership with
39 Aboriginal stakeholders to generate a culturally relevant, representative baseline health
40 data set for three urban Aboriginal communities in Ontario, Canada. The results
41 presented here pertain specifically to the urban First Nations population in Hamilton
42 where the organizational project lead was the Ontario Federation of Indian Friendship
43 Centres (OFIFC) and the community partner was De dwa da dehs ney>s Aboriginal
44 Health Access Centre (DAHC).
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47 **METHODS**

49 **Community-based participatory research**

50 This study upheld current ethical and scientific standards in Indigenous health
51 research(29-33) through a community based participatory research partnership between
52 the academic research team, OFIFC and DAHC. We ensured that our Aboriginal
53 decision making partners were active in all aspects of the research through the following
54 mechanisms: Aboriginal leadership; research agreements which explicitly addressed
55 issues of project governance, community expectations, benefits, ownership, control,
56 access, and possession of information, and dissemination of project results; capacity
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3 building through staffing at community sites, data workshops and awareness building;
4 respect for the individual and collective rights of Aboriginal peoples with respect to their
5 health information; cultural relevance through the development and application of
6 culturally appropriate measures; representation of the urban Aboriginal population of
7 Ontario; and sustainability of the project to ensure that this database can be
8 geographically and longitudinally expanded. DAHC In addition, a Governing Council,
9 comprised of representatives from the core urban Aboriginal provincial organizations was
10 established to oversee all stages of the research process. Specifically, this body adhered
11 to governance protocols and ensured that individual and collective community rights
12 were respected, were kept informed about the project's progress and led the project
13 towards meaningful results, acted as a resource to the community on questions related to
14 various portions of the research project and controlled the release of all data generated by
15 the study.
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20 All members of the study team were from the Aboriginal community, living in the
21 general vicinity of the city of Hamilton. Formal ethics approval was provided by the
22 Research Ethics Board of St. Michael's Hospital in Toronto.
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24 **Study Site**

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26 The City of Hamilton is located in southern Ontario on what was traditionally
27 Haudenosaunee (Iroquian) territory and is near two First Nations reserves: Six Nations of
28 the Grand River and Mississaugas of the New Credit. According to the 2006 Census, the
29 total Aboriginal population in Hamilton was 13,735 people, comprising 2.8% of the total
30 population of the city.⁽³⁴⁾ The OFIFC identified the city of Hamilton as a promising
31 community site based on its significant Aboriginal population and strong infrastructure of
32 Aboriginal community services.
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35 **Recruitment**

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37 The RDS process was initiated through the purposive selection of individuals to begin
38 recruitment, also called "seeds." Inclusion criteria for participation in the study included
39 18 years of age, residence within the geographic boundaries of the City of Hamilton and
40 self-identified as having First Nations identity. First Nations identity was determined
41 through open dialogue around family, experiences, and location while also explaining the
42 overall study goals and additional study sites in Ottawa. Questions such as: "What words
43 best describe you?" and "How do you see yourself?" were useful. With the help of
44 community partners, six seeds were identified and agreed to participate. In order for
45 seeds to reflect a diverse demographic of First Nations people living in Hamilton, factors
46 such as gender, age, family size, and occupations were considered in their selection. For
47 example, seeds were identified in the student population, among the steel workers union,
48 among artists, elders, housing and social assistance providers as well as members of local
49 Aboriginal organizations and boards. Five of the six seeds produced referrals within the
50 two weeks leading up to the December 2009 holiday closure at DAHC. In February and
51 March 2010, three additional seeds were added.
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57 Study participants, including seeds, provided informed consent and then
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3 completed a health assessment survey after which they received 3-5 coded coupons to
4 refer a member of their social network into the study. Following the holiday closure of
5 DAHC, the number of distributed coupons per recruit was increased from 3 to 5 in order
6 to increase the rate of recruitment. Participants received a monetary reimbursement of
7 \$20 for their time and participation. They also received an additional \$10 for every
8 eligible person they recruited into the study. Study recruitment and interviews took place
9 in an Aboriginal community centre.
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12 For sample size calculation, we assumed 95% confidence intervals (CI), survey
13 item prevalence ranges from 10% to 75% and a design effect of 2.(35) Based on this
14 formula, the OCH study aimed to recruit 500 First Nations adults and 250 children.
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17 Sources of Data

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19 Community concept mapping was implemented to develop a community specific survey
20 for First Nations in Hamilton, (36) which was comprised of 8 domains covering areas
21 such as sociodemographics, physical, mental, and emotional health, First Nations identity
22 and impacts of colonization (i.e. questions about Residential School attendance,
23 involvement of child protection agencies, dislocation from traditional lands and
24 discrimination), and access and barriers to care. The survey tool was piloted with First
25 Nations community members, and minor modifications were made to improve face
26 validity. Data were collected and compiled by computer-assisted personal interviewing
27 with a computer based version of the survey tool developed by the research team using
28 SPSS Data Collection Author and Collector.(37)
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32 Upon completion of recruitment and survey, our sample of First Nations adults
33 was linked to data holdings at the Institute of Clinical Evaluative Sciences (ICES)
34 including provincial records of emergency room and hospital visits (Canadian Institutes
35 of Health Information – Discharge Abstract Database and National Ambulatory Care
36 Reporting System: Emergency), and neighbourhood income quintiles (derived from
37 Census data). Using health care system identification numbers (i.e. Ontario Health Card)
38 provided by participants, we successfully linked 92% (N=725) of First Nations adults to
39 the ICES database.
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43 Analysis

44 Recruitment dynamics, adjusted population based estimates and confidence intervals
45 were calculated using the RDS-I enhanced data smoothing estimator in the custom
46 RDSAT software (version 7.1).(38) The RDS methodology anticipates that personal
47 networks are not randomly distributed, and therefore adjusts for small to moderate levels
48 of network clustering (people who have ties to others like them), in the form of post-
49 sampling weights.
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53 RESULTS

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55 Among First Nations adults in Hamilton, 78.9% of participants were recruited via referral
56 trees originating from two seeds. With 19 and 32 waves respectively, the lengths of both
57 of these recruitment chains were long enough to overcome the original sampling bias,
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which usually happens after 6 or 7 waves of recruitment.(39) The statistical theory is that if the chain-referral process consists of enough waves or cycles of recruitment, the composition of the final sample with respect to key characteristics and behaviors will become independent of the seeds from which it began. The point at which the sample composition becomes stable is termed “equilibrium” and is an indication that RDS has been implemented successfully.(21)

Over a period of four and a half months (November 2009 to March 2010) a total of 790 persons were recruited, including 554 adults and 236 children Overall, a high response rate for survey questions was observed. Specifically, non-response rates ranged from 2.5% to less than 0.5%. Even more sensitive questions around income, food security, and impacts of colonization had very low non-response rates under 2%. Such high response rates can be attributed to the survey tool itself, which reflected the health priorities of the community(40) and which was administered in a safe and culturally secure context. Demographic and social characteristics are presented in Table 1.

Table 1. Demographic and social characteristics of First Nations adults (Total N=554)

Characteristic	Prevalence % (95% CI)
Sex	
Male	59.9 (53.3, 67.2)
Age	
18-34	40.2 (33.3, 48)
35-49	35.4 (28.7, 41.6)
50+	24.4 (18.4, 30.8)
Education	
Some high school or less	57.3 (51.1, 64)
Completed high school	19.5 (14.5, 24.7)
Some or completed college	18.3 (13.3, 23.3)
Some or completed University	5 (2.4, 8)
Income sources for household	
Provincial or municipal social assistance or welfare (e.g. ODSP, Ontario Works)	69.2 (63.1, 75)
Wages and salaries	28.2 (22.1, 34.2)
Child Tax Benefit	17 (12.4, 21.8)
Any other income support	13.3 (9.2, 17.6)
Employment insurance	9.6 (5.4, 14.3)
Income from self-employment	7.7 (4.3, 11.7)
Child Support payments	3 (1.1, 4.6)
Individual annual income	
\$0-4,999	18.3 (13.4, 24.8)
\$5,000-5,999	23.1 (17.1, 28.5)
\$10,000-14,999	21.9 (16.3, 27.6)
\$15,000-19,999	14.8 (10.7, 20)
\$20,000+	21.8 (16, 27.6)

Mobility	
No moves in past 5 years	10.2 (6.2, 14.8)
1 move in past 5 years	15.5 (10.5, 20.6)
2 moves in past 5 years	20.2 (15.4, 26.4)
3-5 moves in past 5 years	41.1 (35, 48.6)
6-10 moves in past 5 years	10.4 (5.7, 13.4)
Overcrowding*	
<=1 persons per room	27.7 (21.6, 33.8)
1-2 persons per room	46 (40.5, 54.3)
>2 persons per room	26.3 (19.7, 30.8)
Food security	
You and others always had enough of the kinds of food you wanted to eat	26.7 (21.1, 32.8)
You and others had enough to eat, but not always the kinds of food you wanted	51.5 (45.3, 58)
Sometimes or often you did not have enough to eat**	21.8 (16.5, 27)

Note. CI = confidence interval.

*Following Statistics Canada standards: calculated by dividing the number of rooms in each household (excluding the bathroom) by the number of people residing in the home, where a higher value of 'persons per room' indicates a higher level of crowding(41)

** Collapsed sometimes and often you did not have enough food to eat

The data presented in Table 2 for age, gender and income quintiles compare the OHC population estimates with the total Hamilton population and a random subset of 10% of the Ontario provincial population. The three populations were very similar with respect to the gender breakdown, however, the OHC sample was younger than the general Hamilton and Ontario populations which is consistent with Census data.(42) Over 70% of the First Nations population fell into the lowest income quartile compared to 25% of the general Hamilton population and 20% of the Ontario population. At the higher end of the income scale, we observed that while 15% of Hamilton residents and 20% of the Ontario population fell into the highest income quartile, only 3% of the study population was earning in this category.

Table 2. Gender, Age and Income Quintile for First Nations Adults, City of Hamilton and Ontario-10%

Variable	Sample			
	OHC (Total N=725*)	OHC-RDS- Adjusted	Hamilton (Total N=536,253)	Ontario-10% (Total N=1,324,241)
	Prevalence, %	Prevalence, % (95% CI)	Prevalence, %	Prevalence, %
Sex				
Female	49.4	37.6 (29.6, 43.6)	50.9	51.2
Male	50.6	62.4 (56.4, 70.4)	49.1	48.7

Age**				
18-34	37.4	41.9 (34.4, 49.9)	28.2	28.2
35-49	37.6	36.6 (29.9, 43.1)	28.1	29.5
50-64	22.9	20.7 (14.7, 26.9)	24.8	24.8
65+	2.1	0.8 (0.3, 1.6)	18.9	17.6
Income Quintile				
1-Low	71.76	73 (66.5, 79.2)	25.1	19.5
2	16.22	11.8 (7.7, 16)	22.8	19.8
3	6.3	7.4 (3.6, 10.5)	20.3	19.8
4	2.48	4.9 (2.5, 9.8)	17	20.4
5-High	1.34	3 (1.1, 5.4)	14.7	20.2

Note. CI = confidence interval; OHC = Our Health Counts; RDS = Respondent Driven Sampling.

*Total N reflects number of participants linked to ICES database

**Age of participants on 2010-04-01

The most common self-reported chronic conditions that had been diagnosed by a health care provider among First Nations adults (n=554) in Hamilton included arthritis (30.7%; 95% CI 25.4-36.8), hypertension (25.8%; 95% CI 20.3-31.6), asthma (19%; 95% CI 14.9-24.6), diabetes (15.6%; 95% CI 11.2-21.1), heart disease (8.4%; 95% CI 4.8-12.5) and COPD (8.4%; 95% CI 5.3-11.8). The prevalence of self-reported Hepatitis C was 8.7% (95% CI 4.3-11.7). 25% reported having been injured over the past 12 months. Self-reported upper respiratory tract infection (URTI) was common, with 73% (95% CI 67.9-79.9) of adults reporting URTI in the past 12 months.

Among First Nations adults (n=554), 16.7% (95% CI 11.4 – 22.1) felt that availability of health services in their community was excellent, 43.3% (95% CI 36.1 - 49.6) felt it was good, 28.9% (95% CI 23.3 – 35.2) felt it was fair and 11.1% (95% CI 7.9 – 15.6) felt availability was poor. The fact that 40% of the population felt their level of access to health care was fair or poor, despite the geographic proximity to extensive health and social services that the City of Hamilton provides, substantiates the idea that just because the services are geographically proximate, does not mean that they are accessible to First Nations people. Close to half (47.9%) of the First Nations living in Hamilton reported that long waiting lists to see a specialist were a barrier (95% CI 41.9 - 55.4). Other common barriers included: not being able to arrange transportation; doctor not available; not being able to afford direct costs and/or transportation; services not covered by Non-Insured Health Benefits and lack of trust in health care provider.

Both acute and non-acute emergency room visits were much more frequent among First Nations in Hamilton compared to the general Hamilton and Ontario populations. According to data linkages with ICES, a striking 10.6% of the First Nations adult population in Hamilton made 6 or more emergency room visits in the previous 2 years compared to 1.6% and 1.9% of the Hamilton and Ontario adult populations respectively (Table 3).

Table 3. Number of Emergency Room visits in the Previous 2 Years for Adults (18-64 years), First Nations, City of Hamilton and Ontario-10%

Frequency of ER visits	Sample			
	OHC (Total N=514*)	OHC RDS-Adjusted	Hamilton (Total N=360,378)	Ontario-10% (Total N=901,509)
	Prevalence, %	Prevalence, % (95% CI)	Prevalence, %	Prevalence, %
None	31.5	(25.8 – 37.5)	66.3	69.1
1	26.2	(20.7 – 32.8)	18.7	16.8
2-5	31.7	(25.9 – 37.8)	13.4	12.3
6+	10.6	(6.2 – 14.5)	1.6	1.9
ER visits (acute)				
None	50.2	(43.9 – 57.5)	78.4	80.1
1	24.7	(18.7 – 30.1)	14.2	13.1
2-5	20.7	(15.3 – 26.1)	6.8	6.3
6+	4	1.6 – 6.9)	0.6	0.6
ER visits (non-acute)				
None	54.3	(47.6 – 61.2)	79.4	81.2
1	22.4	(17.3 – 28.5)	14	12.2
2-5	20.4	(14.5 – 25.4)	6.3	6
6+	2.9	(1 – 5.6)	0.4	0.6

Note. CI= confidence interval; OHC = Our Health Counts; RDS = Respondent Driven Sampling

*Total N reflects number of adults aged 28-64 linked to ICES database

Based on ICES data linkages, rates of hospitalization were slightly higher among the First Nations population compared to the Hamilton and Ontario populations. This can partly be explained by a higher birth rate among First Nations populations compared to the general Canadian population,(43) which is reflected by higher rates of obstetrics hospitalization compared to the general Hamilton and Ontario population: 7.3% (95% CI, 3.9 – 10.9) of the Hamilton First Nations population between the ages of 18 and 64 years had been hospitalized at least once in the past 5 years for obstetrical reasons compared to 4% of both the general Hamilton and Ontario populations in the same age group and over the same time period. However, given the high rates of chronic diseases such as diabetes and heart disease and the much higher rates of emergency room use among the First Nations population, these findings were unexpected and therefore require further investigation.

DISCUSSION

The OHC project generated a representative, urban Aboriginal health database. Through the successful application of RDS, a sample of urban First Nations individuals who might otherwise not have participated in mainstream surveys or the census was captured. In addition, given the current deficiency in public health information on urban First Nations populations, the statistically rigorous RDS sample allowed us to produce population-

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3 based estimates that can be utilized by local, regional, provincial and federal policy
4 makers as well as urban Aboriginal stakeholders to address social inequities and health
5 disparities facing this community.
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8 Striking levels of poverty were identified in this study. The income data
9 presented here may be a more representative income profile of the First Nations
10 population in Hamilton than the 2006 Census. Specifically, the OHC data were adjusted
11 for the sampling procedure using an RDS estimator and captured more 'hidden'
12 populations such as persons who are homeless, transient or who have low literacy skills,
13 who are known to be under-represented in the Census.(11;13) Further evidence of low
14 incomes among this population is provided by the RDS-adjusted ICES income quintile
15 data, which revealed that over 70% of the OHC cohort was in the lowest income quartile
16 compared to 25% of the general Hamilton population and 20% of the Ontario population.
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20 Accompanying high levels of poverty, housing and food insecurity were also
21 highly prevalent among First Nations persons living Hamilton. Over half of the study
22 population had moved at least 3 times in the past 5 years compared to 60% of the general
23 Hamilton population who had not moved at all for the past 5 years.(34) Compared to an
24 overcrowding rate of 3% for the general Canadian population in the 2006 Census,(1) 74%
25 of First Nations persons in Hamilton live in crowded conditions. These findings echo
26 those presented in the 2007 Urban Aboriginal Task Force (UATF) final report, which
27 documented persistent obstacles with finding affordable housing, obtaining stable and
28 secure employment and accessing appropriate services and resources among urban
29 Aboriginal people.(44) Similarly, the Toronto Aboriginal Research Project (TARP)
30 found that Aboriginal people in Toronto tend to concentrate in lower-income
31 neighbourhoods where a significant proportion, particularly men, live in poverty.(45)
32 While a growing proportion of urban Aboriginal people in Canada are achieving varying
33 degrees of economic success in a number of skilled professions,(5;45) there remains a
34 significant amount of unmet basic needs among this population.
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39 The burden of chronic conditions experienced by First Nations adults in Hamilton
40 is disproportionately high. For example, 19% of the OHC Hamilton population reported
41 having been told by a health care provider that they have asthma, which is more than
42 twice the self-reported asthma rate (9.3%) for the overall Hamilton population in the
43 2007 Canadian Community Health Survey (CCHS).(46) Likewise, rates of arthritis and
44 high blood pressure were 30.7% and 25.8% among First Nations adults in Hamilton
45 compared to 19.9% and 19.7% among all adults in Hamilton as reported in the 2007
46 CCHS.(46) For First Nations adults in Hamilton, the rate of diabetes diagnosed by a
47 health care provider was approximately three times the rate among the general Hamilton
48 population.(46) These findings are particularly disconcerting given the much younger
49 age demographic of the First Nations Hamilton population and the documented barriers
50 to receiving health care services including long wait lists, challenges with accessing and
51 affording transportation and the unavailability of physicians in the area. Furthermore,
52 45.8% (95% CI 38.9-52.4) of First Nations adults believed that their ability to engage in
53 preventative health activities (i.e. regular exercise, going to the doctor or nurse for health
54 screening tests, accessing preventative dental care) had been affected by financial
55 hardship.
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High rates of emergency usage by First Nations persons living in Hamilton are likely linked to the problems in accessing non-emergency health care, as revealed by 40% of the population who rated their access to health care as fair or poor and 48% who indicated that wait lists are too long. In addition, as a result of primary healthcare reforms,(47) patients may be told by their primary care providers to go to the emergency department rather than a walk-in clinic when their primary care team is not available.(48) Further examination is required to explore potential bias in hospital admission practices and to differentiate between types of hospitalizations (i.e. mental health, surgical and medical hospitalizations).

There were a number of limitations of the study. Firstly, it should be noted that we may have under sampled the elderly First Nations population living in nursing homes or residences for senior citizens in Hamilton. During our initial seed selection, we did not select any seeds from this population, and this population may have fewer network ties than other population groups, which may have resulted in an under representation of First Nations individuals over 65 years of age. Secondly, RDS cannot guarantee a random sample of network members;(49) therefore, estimates are unbiased to the degree that the assumptions of the RDS estimator are met. There is an active literature on RDS and estimation using RDS data,(50;51) and there is debate regarding the true design effects of RDS surveys.(52;53) Existing multivariable regression analyses using RDS samples have not appropriately addressed the correlation between observations and the unequal sampling probabilities inherent in RDS, therefore, we have focused on reporting prevalence estimates for which methods are better established. Despite these limitations, RDS was used to effectively recruit an urban Aboriginal population and allowed for the derivation of rigorous population estimates and data linkages that have previously not been possible.

Given the near absence of population health information for urban Aboriginal people in Canada, this research is able to provide, for the first time, First Nations data that clearly demonstrate alarming socio-economic inequities, a significant burden of chronic disease, multiple barriers in access to health care and elevated emergency room use. This newly established health database represents a significant contribution to public health that will directly inform strategic directions for the improvement of health and social status of urban Aboriginal people in Ontario. For example, this research will support the development of RDS as a tool to effectively recruit a larger cohort for longitudinal research with Aboriginal families in Ontario.

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Contributorship

M.F. contributed substantially to the study conception and design, co-led data interpretation and analysis and drafted multiple versions of the manuscript. J.S. co-led the study conception and design, data analysis and interpretation and made important contributions to the draft and final manuscript. S.M. contributed substantially to study conception and design, was a member of the governing council that guided each stage of research, represented the Aboriginal organizational lead of the research and made important revisions to the draft manuscript. DAHC was the Aboriginal community partner and supervised local data collection, participated in data analysis and interpretation. M.S. provided important technical support during data collection, co-led the data analysis and interpretation, and provided important revisions to the manuscript. P.O. contributed substantially to the study conception and design, analysis and interpretation of data and made important revisions to the draft manuscript.

Data sharing

A tri-party data sharing agreement was negotiated between the Institute of Clinical and Evaluative Sciences (ICES), the Our Health Counts Governing Council and the Centre for Research on Inner City Health at St Michael's Hospital in Toronto, Canada. Approval would need to be granted by these three parties for access to additional, unpublished data.

Competing Interests

None

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9 Unmasking Health Determinants and Health Outcomes for Urban First Nations Using
10 Respondent Driven Sampling ~~Using Respondent Driven Sampling to Unmask~~
11 ~~Disparities in Social Determinants of Health and Health Outcomes for Urban First~~
12 ~~Nations People Living in Hamilton, Ontario~~
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ABSTRACT

Objective: Population based health information on urban Aboriginal populations in Canada is limited due to challenges with the identification of Aboriginal persons in existing health datasets. ~~By implementing Respondent Driven Sampling (RDS), the Our Health Counts study in partnership with De dwa da dehs ney>s Aboriginal Health Access Centre (DAHC) aimed to generate a representative sample of First Nations individuals living in Hamilton, Ontario. The main objective of the Our Health Counts (OHC) project was to work in partnership with Aboriginal stakeholders to generate a culturally relevant, representative baseline health data set for three urban Aboriginal communities in Ontario, Canada.~~

Design: Respondent-Driven Sampling.

Setting: Hamilton, Ontario, Canada.

Participants: ~~The OHC study, in partnership with De dwa da dehs ney>s Aboriginal Health Access Centre (DAHC) recruited~~ 554 First Nations adults living in Hamilton ~~were recruited~~ using RDS.

Results: Among First Nations adults living in Hamilton, 78% earned less than \$20,000 per year and 70% lived in the lowest income quartile neighbourhoods. Mobility and crowded living conditions were also highly prevalent. Common chronic diseases included arthritis, hypertension, diabetes and COPD and rates of emergency room access were elevated.

Conclusions: RDS is an effective sampling method in urban Aboriginal contexts as it builds upon existing social networks and successfully identified a population-based cohort. The findings illustrate striking disparities in health determinants and health outcomes between urban First Nations individuals and the general population.

ARTICLE SUMMARY

Strengths and limitations of this study:

- Our study is the first ~~in Canada to provide population based health assessment data for urban First Nations, documenting striking health and social inequities~~ RDS of self-identified First Nations people residing in an urban setting in Canada
- This study models best practices in academic-Aboriginal community research partnerships
- RDS has been demonstrated to be a promising tool for generating Aboriginal health assessment measures in urban areas where there are limited existing sampling frame options

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- At present, multivariable regression analyses using RDS samples have not appropriately addressed the co-relation between observations and the unequal sampling probabilities inherent in RDS; therefore we present prevalence estimates for which methods are better established

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INTRODUCTION

According to the 2006 Census, over 60% (150,570 people) of Aboriginal^a people living in Ontario live in urban areas.(1) Nearly seven out of ten Métis live in urban areas, and about three out of every four people in the off-reserve First Nations population live in urban areas.(1) First Nations people have historically been dislocated from their original homelands and may constitute diasporic, heterogeneous communities in urban areas.(2) Specifically, an increasing number of First Nations individuals are moving to urban centres to seek better housing, employment and education opportunities and for the services and amenities available.(3-5) There is a growing body of literature exploring the complexities of urban Indigeneity (6) and some of the elements which distinguish urban Aboriginal identity are social and economic marginalization, a growing middle class, and population diversity in term so cultural origins and legal status.(7) According to the Canadian Census, First Nations, Inuit, and Métis populations experience ongoing disparities in social determinants of health such as income insecurity, unemployment, low levels of education, decreased food availability, and inadequate housing compared to non-Aboriginal Canadians, and these disparities are exacerbated with urban residence.(1;8;9)

Despite the growing size of the urban Aboriginal population in Canada, accessible and culturally relevant population health data for this population are almost non-existent.(10-13) While census data do exist, there are serious deficits in population health measures.(13) Some of the reasons behind this deficiency are limitations in the current health information system and data collection processes with respect to Aboriginal peoples.(14;15) Sampling frames are often biased and comprise non-random subpopulations such as lists of members or clients of particular programs and services in the community. When urban Aboriginal people have been included in census-based national surveys, these surveys were underpowered and often First Nations, Inuit, and Métis data could not be successfully disaggregated.(14;16) Additionally, studies based on Census data show that a significant number of Aboriginal people move from rural and reserve areas to cities, and back and forth as well as within and among cities.(4;17) These factors make it difficult to get reliable counts of the Aboriginal population of a city.

At the national level, the continued inability to identify Aboriginal peoples in healthcare databases leads to very poor coverage of Aboriginal populations in Canada,

^a “Aboriginal people” is a collective name for all of the original peoples of Canada and their descendants. The *Constitution Act* of 1982 specifies that the Aboriginal Peoples in Canada consist of three groups: Indians, Inuit and Métis. The term First Nations came into common use in the 1970s to replace Indian, which some people found offensive. Despite its widespread use, there is no legal definition for this term in Canada. In the United States, the term “Native American” is used to represent Indigenous peoples from North America, including Mexico. For alignment with the US Constitution and to ensure policy implications, the term “American Indian” is still used for Indigenous populations living within US borders, particularly the lower 48 states and parts of Alaska. “Indigenous” is a term used in the international context.

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with a specific paucity of health information for First Nations, Métis, and Inuit living in urban areas. Provincial and territorial systems generally do not collect ethnic-specific utilization data, and their ethnic flags for vital statistics are inconsistent or absent.(18) The federal government’s decision to cancel the long form of the Canadian national census will further challenge the ability of researchers and communities to identify and address social inequities across and within populations who experience racialization and the negative effects of structural discrimination in healthcare and other sectors across ethnic groups and will, thus widening the existing health and social policy vacuum.(19;20)

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In the absence of an accessible and accurate population based sampling frame for urban Aboriginal people, we implemented respondent driven sampling (RDS) for the Our Health Counts (OHC) study. RDS, like other chain-referral approaches, relies on members of a population to recruit their peers.(21;22) However, RDS differs from other methods because of estimation procedures that adjust for the participants’ different probabilities of being sampled.(22) RDS also differs from other chain-referral methods because the number of recruitments any participant can make is limited, and it employs a dual incentive structure where participants are rewarded both for participating and for recruiting their peers.(23)

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There is limited literature on RDS in Indigenous contexts;(24) however, there is evidence that links the success of RDS to the strength of social networks and relationships.(25) Indigenous knowledges are holistic, relational and embraces a fluidity that allows for constant growth and change.(26;27) Aboriginal identity-identities values the group over the individual, thereby establishing models of kinship whereby everyone has the right to give and receive according their own choices.(26) Therefore, we hypothesized that RDS would be an appropriate and effective sampling methodology as it builds on social networks and would draw on existing kinship systems known to be present in Indigenous communities.(28)

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The main objective of the OHC project was to work in partnership with Aboriginal stakeholders to generate a culturally relevant, representative baseline health data set for three urban Aboriginal communities in Ontario, Canada. The results presented here pertain specifically to the urban First Nations population in Hamilton where the organizational project lead was the Ontario Federation of Indian Friendship Centres (OFIFC) and the community partner was De dwa da dehs ney>s Aboriginal Health Access Centre (DHACDAHC).

METHODS

Community-based participatory research

This study upheld current ethical and scientific standards in Indigenous health research(29-33) through a community based participatory research partnership between the academic research team, OFIFC and DHACDAHC. We ensured that our Aboriginal decision making partners were active in all aspects of the research through the following mechanisms: Aboriginal leadership; research agreements which explicitly addressed issues of project governance, community expectations, benefits, ownership, control,

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8 access, and possession of information, and dissemination of project results; capacity
9 building through staffing at community sites, data workshops and awareness building;
10 respect for the individual and collective rights of Aboriginal peoples with respect to their
11 health information; cultural relevance through the development and application of
12 culturally appropriate measures; representation of the urban Aboriginal population of
13 Ontario; and sustainability of the project to ensure that this database can be
14 geographically and longitudinally expanded. Data sharing and research agreements
15 ensured that DHAC/DAHC led the governance and management of data throughout the
16 course of the study. In addition, a Governing Council, comprised of representatives from
17 the core urban Aboriginal provincial organizations was established to oversee all stages
18 of the research process. Specifically, this body adhered to governance protocols and
19 ensured that individual and collective community rights were respected, were kept
20 informed about the project's progress and led the project towards meaningful results,
21 acted as a resource to the community on questions related to various portions of the
22 research project and controlled the release of all data generated by the study.

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24 All members of the study team were from the Aboriginal community, living in the
25 general vicinity of the city of Hamilton. Formal ethics approval was provided by the
26 Research Ethics Board of St. Michael's Hospital in Toronto, ~~Canada and the OHC~~
27 ~~Governing Council.~~

28 Study Site

29
30 The City of Hamilton is located in southern Ontario on what was traditionally
31 Haudenosaunee (Iroquian) territory and is near two First Nations reserves: Six Nations of
32 the Grand River and Mississaugas of the New Credit. According to the 2006 Census, the
33 total Aboriginal population in Hamilton was 13,735 people, comprising 2.8% of the total
34 population of the city.⁽³⁴⁾ The OFIFC identified the city of Hamilton as a promising
35 community site based on its significant Aboriginal population and strong infrastructure of
36 Aboriginal community services.

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37 Recruitment

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39 The RDS process was initiated through the purposive selection of individuals to begin
40 recruitment, also called "seeds." Inclusion criteria for participation in the study included
41 18 years of age, residence within the geographic boundaries of the City of Hamilton and
42 self-identified as having First Nations identity. First Nations identity was determined
43 through open dialogue around family, experiences, and location while also explaining the
44 overall study goals and additional study sites in Ottawa. Questions such as: "What words
45 best describe you?" and "How do you see yourself?" were useful. With the help of
46 community partners, six seeds were identified and agreed to participate. In order for
47 seeds to reflect a diverse demographic of First Nations people living in Hamilton, factors
48 such as gender, age, family size, and occupations were considered in their selection. For
49 example, seeds were identified in the student population, among the steel workers union,
50 among artists, elders, housing and social assistance providers as well as members of local
51 Aboriginal organizations and boards. Five of the six seeds produced referrals within the
52 two weeks leading up to the December 2009 holiday closure at DAHC. In February and
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8 March 2010, three additional seeds were added.
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10 Study participants, including seeds, provided informed consent and then
11 completed a health assessment survey after which they received 3-5 coded coupons to
12 refer a member of their social network into the study. Following the holiday closure of
13 ~~DHACDAHC~~, the number of distributed coupons per recruit was increased from 3 to 5 in
14 order to increase the rate of recruitment. Participants received a monetary reimbursement
15 of \$20 for their time and participation. They also received an additional \$10 for every
16 eligible person they recruited into the study. Study recruitment and interviews took place
17 in an Aboriginal community centre.
18

19 For sample size calculation, we assumed 95% confidence intervals (CI), survey
20 item prevalence ranges from 10% to 75% and a design effect of 2.⁽³⁵⁾ Based on this
21 formula, the OCH study aimed to recruit 500 First Nations adults and 250 children.
22

23 Sources of Data

24 Community concept mapping was implemented to develop a community specific survey
25 for First Nations in Hamilton, ⁽³⁶⁾ which was comprised of 8 domains covering areas
26 such as sociodemographics, physical, mental, and emotional health, First Nations identity
27 and impacts of colonization ([i.e. questions about Residential School attendance,](#)
28 [involvement of child protection agencies, dislocation from traditional lands and](#)
29 [discrimination](#)), and access and barriers to care. The survey tool was piloted with First
30 Nations community members, and minor modifications were made to improve face
31 validity. Data were collected and compiled by computer-assisted personal interviewing
32 with a computer based version of the survey tool developed by the research team using
33 SPSS Data Collection Author and Collector.⁽³⁷⁾
34

35 Upon completion of recruitment and survey, our sample of First Nations adults
36 was linked to data holdings at the Institute of Clinical Evaluative Sciences (ICES)
37 including provincial records of emergency room and hospital visits (Canadian Institutes
38 of Health Information – Discharge Abstract Database and National Ambulatory Care
39 Reporting System: Emergency), and neighbourhood income quintiles (derived from
40 Census data). Using health care system identification numbers (i.e. Ontario Health Card)
41 provided by participants, we successfully linked 92% (N=725) of First Nations adults to
42 the ICES database.
43

44 Analysis

45 Recruitment dynamics, adjusted population based estimates and confidence intervals
46 were calculated using the RDS-I enhanced data smoothing estimator in the custom
47 RDSAT software (version 7.1).⁽³⁸⁾ The RDS methodology anticipates that personal
48 networks are not randomly distributed, and therefore adjusts for small to moderate levels
49 of network clustering (people who have ties to others like them), in the form of post-
50 sampling weights.
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52 RESULTS

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Among First Nations adults in Hamilton, 78.9% of participants were recruited via referral trees originating from two seeds. With 19 and 32 waves respectively, the lengths of both of these recruitment chains were long enough to overcome the original sampling bias, which usually happens after 6 or 7 waves of recruitment.(39) The statistical theory is that if the chain-referral process consists of enough waves or cycles of recruitment, the composition of the final sample with respect to key characteristics and behaviors will become independent of the seeds from which it began. The point at which the sample composition becomes stable is termed “equilibrium” and is an indication that RDS has been implemented successfully.(21)

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Over a period of four and a half months (November 2009 to March 2010) a total of 790 persons were recruited, including 554 adults and 236 children Overall, a high response rate for survey questions was observed. Specifically, non-response rates ranged from 2.5% to less than 0.5%. Even more sensitive questions around income, food security, and impacts of colonization had very low non-response rates under 2%. Such high response rates can be attributed to the survey tool itself, which reflected the health priorities of the community(40) and which was administered in a safe and culturally secure context. Demographic and social characteristics are presented in Table 1.

Table 1. Demographic and social characteristics of First Nations adults (Total N=554)

Characteristic	Prevalence % (95% CI)
Sex	
Male	59.9 (53.3, 67.2)
Age	
18-34	40.2 (33.3, 48)
35-49	35.4 (28.7, 41.6)
50+	24.4 (18.4, 30.8)
Education	
Some high school or less	57.3 (51.1, 64)
Completed high school	19.5 (14.5, 24.7)
Some or completed college	18.3 (13.3, 23.3)
Some or completed University	5 (2.4, 8)
Income sources for household	
Provincial or municipal social assistance or welfare (e.g. ODSP, Ontario Works)	69.2 (63.1, 75)
Wages and salaries	28.2 (22.1, 34.2)
Child Tax Benefit	17 (12.4, 21.8)
Any other income support	13.3 (9.2, 17.6)
Employment insurance	9.6 (5.4, 14.3)
Income from self-employment	7.7 (4.3, 11.7)
Child Support <u>payments</u>	3 (1.1, 4.6)
Individual annual income	
\$0-4,999	18.3 (13.4, 24.8)
\$5,000-5,999	23.1 (17.1, 28.5)

\$10,000-14,999	21.9 (16.3, 27.6)
\$15,000-19,999	14.8 (10.7, 20)
\$20,000+	21.8 (16, 27.6)
Mobility	
No moves in past 5 years	10.2 (6.2, 14.8)
1 move in past 5 years	15.5 (10.5, 20.6)
2 moves in past 5 years	20.2 (15.4, 26.4)
3-5 moves in past 5 years	41.1 (35, 48.6)
6-10 moves in past 5 years	10.4 (5.7, 13.4)
Overcrowding*	
<=1 persons per room	27.7 (21.6, 33.8)
1-2 persons per room	46 (40.5, 54.3)
>2 persons per room	26.3 (19.7, 30.8)
Food security	
You and others always had enough of the kinds of food you wanted to eat	26.7 (21.1, 32.8)
You and others had enough to eat, but not always the kinds of food you wanted	51.5 (45.3, 58)
Sometimes or often <u>you</u> did not have enough to eat**	21.8 (16.5, 27)

Note. CI = confidence interval.

*Following Statistics Canada standards: calculated by dividing the number of rooms in each household (excluding the bathroom) by the number of people residing in the home, where a higher value of 'persons per room' indicates a higher level of crowding(41)

** Collapsed sometimes and often you did not have enough food to eat

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The data presented in Table 2 for age, gender and income quintiles compare the OHC population estimates with the total Hamilton population and a random subset of 10% of the Ontario provincial population. The three populations were very similar with respect to the gender breakdown, however, the OHC sample was younger than the general Hamilton and Ontario populations which is consistent with Census data. (42)(40) Over 70% of the First Nations population fell into the lowest income quartile compared to 25% of the general Hamilton population and 20% of the Ontario population. At the higher end of the income scale, we observed that while 15% of Hamilton residents and 20% of the Ontario population fell into the highest income quartile, only 3% of the study population was earning in this category.

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Table 2. Gender, Age and Income Quintile for First Nations Adults, City of Hamilton and Ontario-10%

Variable	Sample			
	OHC (Total N=725*)	OHC-RDS- Adjusted	Hamilton (Total N=536,253)	Ontario-10% (Total N=1,324,241)
	Prevalence, %	Prevalence, % (95% CI)	Prevalence, %	Prevalence, %

Sex				
Female	49.4	37.6 (29.6, 43.6)	50.9	51.2
Male	50.6	62.4 (56.4, 70.4)	49.1	48.7
Age**				
18-34	37.4	41.9 (34.4, 49.9)	28.2	28.2
35-49	37.6	36.6 (29.9, 43.1)	28.1	29.5
50-64	22.9	20.7 (14.7, 26.9)	24.8	24.8
65+	2.1	0.8 (0.3, 1.6)	18.9	17.6
Income Quintile				
1-Low	71.76	73 (66.5, 79.2)	25.1	19.5
2	16.22	11.8 (7.7, 16)	22.8	19.8
3	6.3	7.4 (3.6, 10.5)	20.3	19.8
4	2.48	4.9 (2.5, 9.8)	17	20.4
5-High	1.34	3 (1.1, 5.4)	14.7	20.2

Note. CI = confidence interval; OHC = Our Health Counts; RDS = Respondent Driven Sampling.

*Total N reflects number of participants linked to ICES database

**Age of participants on 2010-04-01

The most common **self-reported** chronic conditions that had been diagnosed by a health care provider among First Nations adults (n=554) in Hamilton included arthritis (30.7%; 95% CI 25.4-36.8), hypertension (25.8%; 95% CI 20.3-31.6), asthma (19%; 95% CI 14.9-24.6), diabetes (15.6%; 95% CI 11.2-21.1), heart disease (8.4%; 95% CI 4.8-12.5) and COPD (8.4%; 95% CI 5.3-11.8). The prevalence of **self-reported** Hepatitis C was 8.7% (95% CI 4.3-11.7). 25% **had reported having** been injured over the past 12 months. **Self-reported** Upper respiratory tract infection (URTI) was common, with 73% (95% CI 67.9-79.9) of adults reporting URTI in the past 12 months.

Among First Nations adults (n=554), 16.7% (95% CI 11.4 – 22.1) felt that availability of health services in their community was excellent, 43.3% (95% CI 36.1 - 49.6) felt it was good, 28.9% (95% CI 23.3 – 35.2) felt it was fair and 11.1% (95% CI 7.9 – 15.6) felt availability was poor. **The fact that 40% of the population felt their level of access to health care was fair or poor, despite the geographic proximity to extensive health and social services that the City of Hamilton provides, substantiates the idea that just because the services are geographically proximate, does not mean that they are accessible to First Nations people.** Close to half (47.9%) of the First Nations living in Hamilton reported that long waiting lists **to see a specialist** were a barrier (95% CI 41.9 - 55.4). Other common barriers included: not being able to arrange transportation; doctor not available; not being able to afford direct costs and/or transportation; services not covered by Non-Insured Health Benefits and lack of trust in health care provider.

Both acute and non-acute emergency room visits were much more frequent among First Nations in Hamilton compared to the general Hamilton and Ontario populations. **According to data linkages with ICES, a** striking 10.6% of the First Nations adult population in Hamilton **reported made** 6 or more emergency room visits in the

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previous 2 years compared to 1.6% and 1.9% of the Hamilton and Ontario adult populations respectively (Table 3).

Table 3. Number of Emergency Room visits in the Previous 2 Years for Adults (18-64 years), First Nations, City of Hamilton and Ontario-10%

Frequency of ER visits	Sample			
	OHC (Total N=514*)	OHC RDS-Adjusted	Hamilton (Total N=360,378)	Ontario-10% (Total N=901,509)
	Prevalence, %	Prevalence, % (95% CI)	Prevalence, %	Prevalence, %
None	31.5	(25.8 – 37.5)	66.3	69.1
1	26.2	(20.7 – 32.8)	18.7	16.8
2-5	31.7	(25.9 – 37.8)	13.4	12.3
6+	10.6	(6.2 – 14.5)	1.6	1.9
ER visits (acute)				
None	50.2	(43.9 – 57.5)	78.4	80.1
1	24.7	(18.7 – 30.1)	14.2	13.1
2-5	20.7	(15.3 – 26.1)	6.8	6.3
6+	4	1.6 – 6.9)	0.6	0.6
ER visits (non-acute)				
None	54.3	(47.6 – 61.2)	79.4	81.2
1	22.4	(17.3 – 28.5)	14	12.2
2-5	20.4	(14.5 – 25.4)	6.3	6
6+	2.9	(1 – 5.6)	0.4	0.6

Note. CI= confidence interval; OHC = Our Health Counts; RDS = Respondent Driven Sampling

*Total N reflects number of adults aged 28-64 linked to ICES database

Based on ICES data linkages, rates of hospitalization were slightly higher among the First Nations population compared to the Hamilton and Ontario populations. This can partly be explained by a higher birth rate among First Nations populations compared to the general Canadian population, (43)(41) which is reflected by higher rates of obstetrics hospitalization compared to the general Hamilton and Ontario population: 7.3% (95% CI, 3.9 – 10.9) of the Hamilton First Nations population between the ages of 18 and 64 years had been hospitalized at least once in the past 5 years for obstetrical reasons compared to 4% of both the general Hamilton and Ontario populations in the same age group and over the same time period. However, given the high rates of chronic diseases such as diabetes and heart disease and the much higher rates of emergency room use among the First Nations population, these findings were unexpected and therefore require further investigation.

DISCUSSION

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9 The OHC project generated a representative, urban Aboriginal health database. Through
10 the successful application of RDS, a sample of urban First Nations individuals who might
11 otherwise not have participated in mainstream surveys or the census was captured. In
12 addition, given the current deficiency in public health information on urban First Nations
13 populations, the statistically rigorous RDS sample allowed us to produce population-
14 based estimates that can be utilized by local, regional, provincial and federal policy
15 makers as well as urban Aboriginal stakeholders to address social inequities and health
16 disparities facing this community.

17
18 Striking levels of poverty were identified in this study. The income data
19 presented here may be a more representative income profile of the First Nations
20 population in Hamilton than the 2006 Census. Specifically, the OHC data were adjusted
21 for the sampling procedure using an RDS estimator and captured more 'hidden'
22 populations such as persons who are homeless, transient or who have low literacy skills,
23 who are known to be under-represented in the Census.^(11;13) Further evidence of low
24 incomes among this population is provided by the RDS-adjusted ICES income quintile
25 data, which revealed that over 70% of the OHC cohort was in the lowest income quartile
26 compared to 25% of the general Hamilton population and 20% of the Ontario population.

27
28 Accompanying high levels of poverty, housing and food insecurity were also
29 highly prevalent among First Nations persons living Hamilton. Over half of the study
30 population had moved at least 3 times in the past 5 years compared to 60% of the general
31 Hamilton population who had not moved at all for the past 5 years.⁽³⁴⁾ Compared to an
32 overcrowding rate of 3% for the general Canadian population in the 2006 Census,⁽¹⁾ 74%
33 of First Nations persons in Hamilton live in crowded conditions. These findings echo
34 those presented in the 2007 Urban Aboriginal Task Force (UATF) final report, which
35 documented persistent obstacles with finding affordable housing, obtaining stable and
36 secure employment and accessing appropriate services and resources among urban
37 Aboriginal people.⁽⁴⁴⁾⁽⁴²⁾ Similarly, the Toronto Aboriginal Research Project (TARP)
38 found that Aboriginal people in Toronto tend to concentrate in lower-income
39 neighbourhoods where a significant proportion, particularly men, live in poverty.⁽⁴⁵⁾⁽⁴³⁾
40 While a growing proportion of urban Aboriginal people in Canada are achieving varying
41 degrees of economic success in a number of skilled professions,^{(5;45)(5;43)} there
42 remains a significant amount of unmet basic needs among this population.

43
44 The burden of chronic conditions experienced by First Nations adults in Hamilton
45 is disproportionately high. For example, 19% of the OHC Hamilton population reported
46 having been told by a health care provider that they have asthma, which is more than
47 twice the self-reported asthma rate (9.3%) for the overall Hamilton population in the
48 2007 Canadian Community Health Survey (CCHS).⁽⁴⁶⁾⁽⁴⁴⁾ Likewise, rates of arthritis
49 and high blood pressure were 30.7% and 25.8% among First Nations adults in Hamilton
50 compared to 19.9% and 19.7% among all adults in Hamilton as reported in the 2007
51 CCHS.⁽⁴⁶⁾⁽⁴⁴⁾ For First Nations adults in Hamilton, the rate of diabetes diagnosed by a
52 health care provider was approximately three times the rate among the general Hamilton
53 population.⁽⁴⁶⁾⁽⁴⁴⁾ These findings are particularly disconcerting given the much
54 younger age demographic of the First Nations Hamilton population and the documented
55 barriers to receiving health care services including long wait lists, challenges with

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accessing and affording transportation and the unavailability of physicians in the area. Furthermore, 45.8% (95% CI 38.9-52.4) of First Nations adults believed that their ability to engage in preventative health activities (i.e. regular exercise, going to the doctor or nurse for health screening tests, accessing preventative dental care) had been affected by financial hardship.

High rates of emergency usage by First Nations persons living in Hamilton are likely linked to the problems in accessing non-emergency health care, as revealed by 40% of the population who rated their access to health care as fair or poor and 48% who indicated that wait lists are too long. In addition, as a result of primary healthcare reforms, ~~(47)(45)~~ patients may be told by their primary care providers to go to the emergency department rather than a walk-in clinic when their primary care team is not available. ~~(48)(46)~~ Further examination is required to explore potential bias in hospital admission practices and to differentiate between types of hospitalizations (i.e. mental health, surgical and medical hospitalizations).

There were a number of limitations of the study. Firstly, it should be noted that we may have under sampled the elderly First Nations population living in nursing homes or residences for senior citizens in Hamilton. During our initial seed selection, we did not select any seeds from this population, and this population may have fewer network ties than other population groups, which may have resulted in an under representation of First Nations individuals over 65 years of age. Secondly, RDS cannot guarantee a random sample of network members; ~~(49)(47)~~ therefore, estimates are unbiased to the degree that the assumptions of the RDS estimator are met. There is an active literature on RDS and estimation using RDS data, ~~(50:51)(48:49)~~ and there is debate regarding the true design effects of RDS surveys, ~~(52:53)(50:51)~~ Existing multivariable regression analyses using RDS samples have not appropriately addressed the co-relation between observations and the unequal sampling probabilities inherent in RDS, therefore, we have focused on reporting prevalence estimates for which methods are better established. Despite these limitations, RDS was used to effectively recruit an urban Aboriginal population and allowed for the derivation of rigorous population estimates and data linkages that have previously not been possible.

Given the near absence of population health information for urban Aboriginal people in Canada, this research is able to provide, for the first time, First Nations data that clearly demonstrate alarming socio-economic inequities, a significant burden of chronic disease, multiple barriers in access to health care and elevated emergency room use. This newly established health database represents a significant contribution to public health that will directly inform strategic directions for the improvement of health and social status of urban Aboriginal people in Ontario. For example, this research will support the development of RDS as a tool to effectively recruit a larger cohort for longitudinal research with Aboriginal families in Ontario.

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8 course of several months. The Our Health Counts project would not have been possible
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STROBE 2007 (v4) checklist of items to be included in reports of observational studies in epidemiology*
Checklist for cohort, case-control, and cross-sectional studies (combined)

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	Yes, in title
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	Yes, pg 2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	Yes, pg 3-4
Objectives	3	State specific objectives, including any pre-specified hypotheses	Yes, pg 4
Methods			
Study design	4	Present key elements of study design early in the paper	Yes, pg 4-5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	Yes, pg 5
Participants	6	(a) <i>Cohort study</i> —Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up <i>Case-control study</i> —Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls <i>Cross-sectional study</i> —Give the eligibility criteria, and the sources and methods of selection of participants	Yes, pg 5
		(b) <i>Cohort study</i> —For matched studies, give matching criteria and number of exposed and unexposed <i>Case-control study</i> —For matched studies, give matching criteria and the number of controls per case	
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	Yes, pg 5-6
Bias	9	Describe any efforts to address potential sources of bias	Yes, pg 4
Study size	10	Explain how the study size was arrived at	Yes, pg 5
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	Yes, pg 6
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	Yes pg 6
		(b) Describe any methods used to examine subgroups and interactions	
		(c) Explain how missing data were addressed	
		(d) <i>Cohort study</i> —If applicable, explain how loss to follow-up was addressed <i>Case-control study</i> —If applicable, explain how matching of cases and controls was addressed	

		<i>Cross-sectional study</i> —If applicable, describe analytical methods taking account of sampling strategy	
		(e) Describe any sensitivity analyses	
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed (b) Give reasons for non-participation at each stage (c) Consider use of a flow diagram	
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders (b) Indicate number of participants with missing data for each variable of interest (c) <i>Cohort study</i> —Summarise follow-up time (eg, average and total amount)	Yes, pg 6-7
Outcome data	15*	<i>Cohort study</i> —Report numbers of outcome events or summary measures over time <i>Case-control study</i> —Report numbers in each exposure category, or summary measures of exposure <i>Cross-sectional study</i> —Report numbers of outcome events or summary measures	
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included (b) Report category boundaries when continuous variables were categorized (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	
Discussion			
Key results	18	Summarise key results with reference to study objectives	Yes, Pg 9-11
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	Yes, Pg 11
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	Yes, pg 9-11
Generalisability	21	Discuss the generalisability (external validity) of the study results	
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	Yes, pg 11-12

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.

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Unmasking Health Determinants and Health Outcomes for Urban First Nations Using Respondent Driven Sampling

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4 **Unmasking Health Determinants and Health Outcomes for Urban First Nations**
5 **Using Respondent Driven Sampling**
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ABSTRACT

Objective: Population based health information on urban Aboriginal populations in Canada is limited due to challenges with the identification of Aboriginal persons in existing health datasets. The main objective of the Our Health Counts (OHC) project was to work in partnership with Aboriginal stakeholders to generate a culturally relevant, representative baseline health data set for three urban Aboriginal communities in Ontario, Canada. **Design:** Respondent-Driven Sampling.

Setting: Hamilton, Ontario, Canada.

Participants: The OHC study, in partnership with De dwa da dehs ney>s Aboriginal Health Access Centre (DAHC) recruited 554 First Nations adults living in Hamilton using RDS.

Results: Among First Nations adults living in Hamilton, 78% earned less than \$20,000 per year and 70% lived in the lowest income quartile neighbourhoods. Mobility and crowded living conditions were also highly prevalent. Common chronic diseases included arthritis, hypertension, diabetes and COPD and rates of emergency room access were elevated.

Conclusions: RDS is an effective sampling method in urban Aboriginal contexts as it builds upon existing social networks and successfully identified a population-based cohort. The findings illustrate striking disparities in health determinants and health outcomes between urban First Nations individuals and the general population which have important implications for health services delivery, programming and policy development.

ARTICLE SUMMARY

Strengths and limitations of this study:

- Our study is the first RDS of self-identified First Nations people residing in an urban setting in Canada
- This study models best practices in academic-Aboriginal community research partnerships
- RDS has been demonstrated to be a promising tool for generating Aboriginal health assessment measures in urban areas where there are limited existing sampling frame options
- At present, multivariable regression analyses using RDS samples have not appropriately addressed the co-relation between observations and the unequal

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sampling probabilities inherent in RDS; therefore we present prevalence estimates for which methods are better established

For peer review only

INTRODUCTION

According to the 2006 Census, over 60% (150,570 people) of Aboriginal^a people living in Ontario live in urban areas.[1] Nearly seven out of ten Métis live in urban areas, and about three out of every four people in the off-reserve First Nations population live in urban areas.[1] First Nations people have historically been dislocated from their original homelands and may constitute diasporic, heterogeneous communities in urban areas.[2] Specifically, an increasing number of First Nations individuals are moving to urban centers to seek better housing, employment and education opportunities and for the services and amenities available.[3-5] There is a growing body of literature exploring the complexities of urban indigeneity [6] and some of the elements which distinguish urban Aboriginal identity are social and economic marginalization, a growing middle class, and population diversity in terms of cultural origins and legal status.[7] According to the Canadian Census, First Nations, Inuit, and Métis populations experience ongoing disparities in social determinants of health such as income insecurity, unemployment, low levels of education, decreased food availability, and inadequate housing compared to non-Aboriginal Canadians, and these disparities are exacerbated with urban residence.[1;8;9]

Despite the growing size of the urban Aboriginal population in Canada, accessible and culturally relevant population health data for this population are almost non-existent.[10-13] While census data do exist, there are serious deficits in population health measures.[13] Some of the reasons behind this deficiency are limitations in the current health information system and data collection processes with respect to Aboriginal peoples.[14;15] Sampling frames are often biased and comprise non-random subpopulations such as lists of members or clients of particular programs and services in the community. When urban Aboriginal people have been included in census-based national surveys, these surveys were underpowered and often First Nations, Inuit, and Métis data could not be successfully disaggregated.[14;16] Additionally, studies based on Census data show that a significant number of Aboriginal people move from rural and reserve areas to cities, and back and forth as well as within and among cities.[4;17] These factors make it difficult to get reliable counts of the Aboriginal population of a city.

^a “Aboriginal people” is a collective name for all of the original peoples of Canada and their descendants. The *Constitution Act* of 1982 specifies that the Aboriginal Peoples in Canada consist of three groups: Indians, Inuit and Métis. The term First Nations came into common use in the 1970s to replace Indian, which some people found offensive. Despite its widespread use, there is no legal definition for this term in Canada. In the United States, the term “Native American” is used to represent Indigenous peoples from North America, including Mexico. For alignment with the US Constitution and to ensure policy implications, the term “American Indian” is still used for Indigenous populations living within US borders, particularly the lower 48 states and parts of Alaska. “Indigenous” is a term used in the international context.

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4 At the national level, the continued inability to identify Aboriginal peoples in
5 healthcare databases leads to very poor coverage of Aboriginal populations in Canada,
6 with a specific paucity of health information for First Nations, Métis, and Inuit living in
7 urban areas. Provincial and territorial systems generally do not collect ethnic-specific
8 utilization data, and their ethnic flags for vital statistics are inconsistent or absent.[18]
9 The federal government's decision to cancel the long form of the Canadian national
10 census will further challenge the ability of researchers and communities to identify and
11 address social inequities across and within populations who experience racialization and
12 the negative effects of structural discrimination in healthcare and other sectors , thus
13 widening the existing health and social policy vacuum.[19;20]
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17 In the absence of an accessible and accurate population based sampling frame for
18 urban Aboriginal people, we implemented respondent driven sampling (RDS) for the Our
19 Health Counts (OHC) study. RDS, like other chain-referral approaches, relies on
20 members of a population to recruit their peers.[21;22] However, RDS differs from other
21 methods because of estimation procedures that adjust for the participants' different
22 probabilities of being sampled.[22] RDS also differs from other chain-referral methods
23 because the number of recruitments any participant can make is limited, and it employs a
24 dual incentive structure where participants are rewarded both for participating and for
25 recruiting their peers.[23]
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29 There is limited literature on RDS in Indigenous contexts;[24] however, there is
30 evidence that links the success of RDS to the strength of social networks and
31 relationships.[25] Indigenous knowledges are wholistic, relational and embraces a fluidity
32 that allows for constant growth and change.[26;27] Aboriginal identities tend to value
33 the group over the individual, thereby establishing models of kinship whereby everyone
34 has the right to give and receive according their own choices.[26] Therefore, we
35 hypothesized that RDS would be an appropriate and effective sampling methodology as it
36 builds on social networks and would draw on existing kinship systems known to be
37 present in Indigenous communities.[28]
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41 The main objective of the OHC project was to work in partnership with
42 Aboriginal stakeholders to generate a culturally relevant, representative baseline health
43 data set for three urban Aboriginal communities in Ontario, Canada. The results
44 presented here pertain specifically to the urban First Nations population in Hamilton
45 where the organizational project lead was the Ontario Federation of Indian Friendship
46 Centres (OFIFC) and the community partner was De dwa da dehs ney>s Aboriginal
47 Health Access Centre (DAHC).
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49 **METHODS**

50 **Community-based participatory research**

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52 This study upheld current ethical and scientific standards in Indigenous health
53 research[29-33] through a community based participatory research partnership between
54 the academic research team, OFIFC and DAHC. We ensured that our Aboriginal
55 decision making partners were active in all aspects of the research through the following
56 mechanisms: Aboriginal leadership; research agreements which explicitly addressed
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3 issues of project governance, community expectations, benefits, ownership, control,
4 access, and possession of information, and dissemination of project results; capacity
5 building through staffing at community sites, data workshops and awareness building;
6 respect for the individual and collective rights of Aboriginal peoples with respect to their
7 health information; cultural relevance through the development and application of
8 culturally appropriate measures; representation of the urban Aboriginal population of
9 Ontario; and sustainability of the project to ensure expansion of the database. In addition,
10 a Governing Council, comprised of representatives from the core partner urban
11 Aboriginal provincial organizations was established to oversee all stages of the research
12 process. Specifically, this body adhered to governance protocols and ensured that
13 individual and collective community rights were respected, were kept informed about the
14 project's progress and led the project towards meaningful results, acted as a resource to
15 the community on questions related to various portions of the research project and
16 controlled the release of all data generated by the study.
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21 All members of the study team were from the Aboriginal community, living in the
22 general vicinity of the city of Hamilton. Formal ethics approval was provided by the
23 Research Ethics Board of St. Michael's Hospital in Toronto.
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25 **Study Site**

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27 The City of Hamilton is located in southern Ontario on what was traditionally
28 Haudenosaunee (Iroquian) territory and is near two First Nations reserves: Six Nations of
29 the Grand River and Mississaugas of the New Credit. According to the 2006 Census, the
30 total Aboriginal population in Hamilton was 13,735 people, comprising 2.8% of the total
31 population of the city.[34] The OFIFC identified the city of Hamilton as a promising
32 community site based on its significant Aboriginal population and strong infrastructure of
33 Aboriginal community services.
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36 **Recruitment**

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38 The RDS process was initiated through the purposive selection of individuals to begin
39 recruitment, also called "seeds." Inclusion criteria for participation in the study included
40 18 years of age, residence within the geographic boundaries of the City of Hamilton and
41 self-identified as having First Nations identity. First Nations identity was determined
42 through open dialogue around family, experiences, and location while also explaining the
43 overall study goals and additional study sites in Ottawa. Questions such as: "What words
44 best describe you?" and "How do you see yourself?" were useful. With the help of
45 community partners, six seeds were identified and agreed to participate. In order for
46 seeds to reflect a diverse demographic of First Nations people living in Hamilton, factors
47 such as gender, age, family size, and occupations were considered in their selection. For
48 example, seeds were identified in the student population, among the steel workers union,
49 among artists, elders, housing and social assistance providers as well as members of local
50 Aboriginal organizations and boards. Five of the six seeds produced referrals within the
51 two weeks leading up to the December 2009 holiday closure at DAHC. In February and
52 March 2010, three additional seeds were added.
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3 Study participants, including seeds, provided informed consent and then
4 completed a health assessment survey after which they received 3-5 coded coupons to
5 refer a member of their social network into the study. Following the holiday closure of
6 DAHC, the number of distributed coupons per recruit was increased from 3 to 5 in order
7 to increase the rate of recruitment. Participants received a monetary reimbursement of
8 \$20 for their time and participation. They also received an additional \$10 for every
9 eligible person they recruited into the study. Study recruitment and interviews took place
10 in an Aboriginal community centre.
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14 For sample size calculation, we assumed 95% confidence intervals (CI), survey
15 item prevalence ranges from 10% to 75% and a design effect of 2.[35] Based on this
16 formula, the OCH study aimed to recruit 500 First Nations adults and 250 children.
17

18 Sources of Data

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20 Community concept mapping was implemented to develop a community specific survey
21 for First Nations in Hamilton, [36] which was comprised of 8 domains covering areas
22 such as sociodemographics, physical, mental, and emotional health, First Nations identity
23 and impacts of colonization (i.e. questions about Residential School attendance,
24 involvement of child protection agencies, dislocation from traditional lands and
25 discrimination), and access and barriers to care. The survey tool was piloted with First
26 Nations community members, and minor modifications were made to improve face
27 validity. Data were collected and compiled by computer-assisted personal interviewing
28 with a computer based version of the survey tool developed by the research team using
29 SPSS Data Collection Author and Collector.[37]
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34 Upon completion of recruitment and survey, our sample of First Nations adults
35 was linked to data holdings at the Institute of Clinical Evaluative Sciences (ICES)
36 including provincial records of emergency room and hospital visits (Canadian Institutes
37 of Health Information – Discharge Abstract Database and National Ambulatory Care
38 Reporting System: Emergency), and neighbourhood income quintiles (derived from
39 Census data). Using health care system identification numbers (i.e. Ontario Health Card)
40 provided by participants, we successfully linked 92% (N=725) of First Nations adults to
41 the ICES database.
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44 Analysis

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46 Recruitment dynamics, adjusted population based estimates and confidence intervals
47 were calculated using the RDS-I enhanced data smoothing estimator in the custom
48 RDSAT software (version 7.1).[38] The RDS methodology anticipates that personal
49 networks are not randomly distributed, and therefore adjusts for small to moderate levels
50 of network clustering (people who have ties to others like them), in the form of post-
51 sampling weights.
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54 RESULTS

Among First Nations adults in Hamilton, 78.9% of participants were recruited via referral trees originating from two seeds. With 19 and 32 waves respectively, the lengths of both of these recruitment chains were long enough to overcome the original sampling bias, which usually happens after 6 or 7 waves of recruitment.[39] The statistical theory is that if the chain-referral process consists of enough waves or cycles of recruitment, the composition of the final sample with respect to key characteristics and behaviors will become independent of the seeds from which it began. The point at which the sample composition becomes stable is termed “equilibrium” and is an indication that RDS has been implemented successfully.[21]

Over a period of four and a half months (November 2009 to March 2010) a total of 790 persons were recruited, including 554 adults and 236 children. Overall, a high response rate for survey questions was observed. Specifically, non-response rates ranged from 2.5% to less than 0.5%, including sensitive questions around income, food security, and impacts of colonization, which had non-response rates under 2%. Such high response rates can be attributed to the survey tool itself, which reflected the health priorities of the community[40] and which was administered in a safe and culturally secure context. Demographic and social characteristics are presented in Table 1.

Table 1. Demographic and social characteristics of First Nations adults (Total N=554)

Characteristic	Prevalence % (95% CI)
Sex	
Male	59.9 (53.3, 67.2)
Age	
18-34	40.2 (33.3, 48)
35-49	35.4 (28.7, 41.6)
50+	24.4 (18.4, 30.8)
Education	
Some high school or less	57.3 (51.1, 64)
Completed high school	19.5 (14.5, 24.7)
Some or completed college	18.3 (13.3, 23.3)
Some or completed University	5 (2.4, 8)
Income sources for household	
Provincial or municipal social assistance or welfare (e.g. ODSP, Ontario Works)	69.2 (63.1, 75)
Wages and salaries	28.2 (22.1, 34.2)
Child Tax Benefit	17 (12.4, 21.8)
Any other income support	13.3 (9.2, 17.6)
Employment insurance	9.6 (5.4, 14.3)
Income from self-employment	7.7 (4.3, 11.7)
Child Support payments	3 (1.1, 4.6)
Individual annual income	
\$0-4,999	18.3 (13.4, 24.8)
\$5,000-5,999	23.1 (17.1, 28.5)

\$10,000-14,999	21.9 (16.3, 27.6)
\$15,000-19,999	14.8 (10.7, 20)
\$20,000+	21.8 (16, 27.6)
Mobility	
No moves in past 5 years	10.2 (6.2, 14.8)
1 move in past 5 years	15.5 (10.5, 20.6)
2 moves in past 5 years	20.2 (15.4, 26.4)
3-5 moves in past 5 years	41.1 (35, 48.6)
6-10 moves in past 5 years	10.4 (5.7, 13.4)
Overcrowding*	
<=1 persons per room	27.7 (21.6, 33.8)
1-2 persons per room	46 (40.5, 54.3)
>2 persons per room	26.3 (19.7, 30.8)
Food security	
You and others always had enough of the kinds of food you wanted to eat	26.7 (21.1, 32.8)
You and others had enough to eat, but not always the kinds of food you wanted	51.5 (45.3, 58)
Sometimes or often you did not have enough to eat**	21.8 (16.5, 27)

Note. CI = confidence interval.

*Following Statistics Canada standards: calculated by dividing the number of rooms in each household (excluding the bathroom) by the number of people residing in the home, where a higher value of 'persons per room' indicates a higher level of crowding[41]

** Collapsed sometimes and often you did not have enough food to eat

The data presented in Table 2 for age, gender and income quintiles compare the OHC population estimates with the total Hamilton population and a random subset of 10% of the Ontario provincial population. The three populations were very similar with respect to the gender breakdown, however, the OHC sample was younger than the general Hamilton and Ontario populations which is consistent with Census data.[42] Over 70% of the First Nations population fell into the lowest income quartile compared to 25% of the general Hamilton population and 20% of the Ontario population. At the higher end of the income scale, we observed that while 15% of Hamilton residents and 20% of the Ontario population fell into the highest income quartile, only 3% of the study population was earning in this category.

Table 2. Gender, Age and Income Quintile for First Nations Adults, City of Hamilton and Ontario-10%

Variable	Sample			
	OHC (Total N=725*)	OHC-RDS- Adjusted	Hamilton (Total N=536,253)	Ontario-10% (Total N=1,324,241)
	Prevalence, %	Prevalence, % (95% CI)	Prevalence, %	Prevalence, %

Sex				
Female	49.4	37.6 (29.6, 43.6)	50.9	51.2
Male	50.6	62.4 (56.4, 70.4)	49.1	48.7
Age**				
18-34	37.4	41.9 (34.4, 49.9)	28.2	28.2
35-49	37.6	36.6 (29.9, 43.1)	28.1	29.5
50-64	22.9	20.7 (14.7, 26.9)	24.8	24.8
65+	2.1	0.8 (0.3, 1.6)	18.9	17.6
Income Quintile				
1-Low	71.76	73 (66.5, 79.2)	25.1	19.5
2	16.22	11.8 (7.7, 16)	22.8	19.8
3	6.3	7.4 (3.6, 10.5)	20.3	19.8
4	2.48	4.9 (2.5, 9.8)	17	20.4
5-High	1.34	3 (1.1, 5.4)	14.7	20.2

Note. CI = confidence interval; OHC = Our Health Counts; RDS = Respondent Driven Sampling.

*Total N reflects number of participants linked to ICES database

**Age of participants on 2010-04-01

The most common self-reported chronic conditions that had been diagnosed by a health care provider among First Nations adults (n=554) in Hamilton included arthritis (30.7%; 95% CI 25.4-36.8), hypertension (25.8%; 95% CI 20.3-31.6), asthma (19%; 95% CI 14.9-24.6), diabetes (15.6%; 95% CI 11.2-21.1), heart disease (8.4%; 95% CI 4.8-12.5) and COPD (8.4%; 95% CI 5.3-11.8). The prevalence of self-reported Hepatitis C was 8.7% (95% CI 4.3-11.7). 25% reported having been injured over the past 12 months. Self-reported upper respiratory tract infection (URTI) was common, with 73% (95% CI 67.9-79.9) of adults reporting URTI in the past 12 months.

Among First Nations adults (n=554), 16.7% (95% CI 11.4 – 22.1) felt that availability of health services in their community was excellent, 43.3% (95% CI 36.1 - 49.6) felt it was good, 28.9% (95% CI 23.3 – 35.2) felt it was fair and 11.1% (95% CI 7.9 – 15.6) felt availability was poor. The fact that 40% of the population felt their level of access to health care was fair or poor, despite the geographic proximity to extensive health and social services that the City of Hamilton provides, substantiates the idea that just because the services are geographically proximate, does not mean that they are accessible to First Nations people. Close to half (47.9%) of the First Nations living in Hamilton reported that long waiting lists to see a specialist were a barrier (95% CI 41.9 - 55.4). Other common barriers included: not being able to arrange transportation; doctor not available; not being able to afford direct costs and/or transportation; services not covered by Non-Insured Health Benefits and lack of trust in health care provider.

Both acute and non-acute emergency room visits were much more frequent among First Nations in Hamilton compared to the general Hamilton and Ontario populations. According to data linkages with ICES, a striking 10.6% of the First Nations adult population in Hamilton made 6 or more emergency room visits in the previous 2

years compared to 1.6% and 1.9% of the Hamilton and Ontario adult populations respectively (Table 3).

Table 3. Number of Emergency Room visits in the Previous 2 Years for Adults (18-64 years), First Nations, City of Hamilton and Ontario-10%

Frequency of ER visits	Sample			
	OHC (Total N=514*)	OHC RDS-Adjusted	Hamilton (Total N=360,378)	Ontario-10% (Total N=901,509)
	Prevalence, %	Prevalence, % (95% CI)	Prevalence, %	Prevalence, %
None	31.5	(25.8 – 37.5)	66.3	69.1
1	26.2	(20.7 – 32.8)	18.7	16.8
2-5	31.7	(25.9 – 37.8)	13.4	12.3
6+	10.6	(6.2 – 14.5)	1.6	1.9
ER visits (acute)				
None	50.2	(43.9 – 57.5)	78.4	80.1
1	24.7	(18.7 – 30.1)	14.2	13.1
2-5	20.7	(15.3 – 26.1)	6.8	6.3
6+	4	1.6 – 6.9)	0.6	0.6
ER visits (non-acute)				
None	54.3	(47.6 – 61.2)	79.4	81.2
1	22.4	(17.3 – 28.5)	14	12.2
2-5	20.4	(14.5 – 25.4)	6.3	6
6+	2.9	(1 – 5.6)	0.4	0.6

Note. CI= confidence interval; OHC = Our Health Counts; RDS = Respondent Driven Sampling

*Total N reflects number of adults aged 28-64 linked to ICES database

Based on ICES data linkages, rates of hospitalization were slightly higher among the First Nations population compared to the Hamilton and Ontario populations. This may partly be explained by a higher birth rate among First Nations populations compared to the general Canadian population,[43] which is reflected by higher rates of obstetrics hospitalization compared to the general Hamilton and Ontario population: 7.3% (95% CI, 3.9 – 10.9) of the Hamilton First Nations population between the ages of 18 and 64 years had been hospitalized at least once in the past 5 years for obstetrical reasons compared to 4% of both the general Hamilton and Ontario populations in the same age group and over the same time period. However, given the high rates of chronic diseases such as diabetes and heart disease and the much higher rates of emergency room use among the First Nations population, these findings were unexpected and therefore require further investigation.

DISCUSSION

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3 The OHC project generated a representative, urban Aboriginal health database. Through
4 the successful application of RDS, a sample of urban First Nations individuals who might
5 otherwise not have participated in mainstream surveys or the census was captured. In
6 addition, given the current deficiency in public health information on urban First Nations
7 populations, the statistically rigorous RDS sample allowed us to produce population-
8 based estimates that can be utilized by local, regional, provincial and federal policy
9 makers as well as urban Aboriginal stakeholders to address social inequities and health
10 disparities facing this community.
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14 Striking levels of poverty were identified in this study. The income data
15 presented here may be a more representative income profile of the First Nations
16 population in Hamilton than the 2006 Census. Specifically, the OHC data were adjusted
17 for the sampling procedure using an RDS estimator and captured more 'hidden'
18 populations such as persons who are homeless, transient or who have low literacy skills,
19 who are known to be under-represented in the Census.[11;13] Further evidence of low
20 incomes among this population is provided by the RDS-adjusted ICES income quintile
21 data, which revealed that over 70% of the OHC cohort was in the lowest income quartile
22 compared to 25% of the general Hamilton population and 20% of the Ontario population.
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26 Accompanying high levels of poverty, housing and food insecurity were also
27 highly prevalent among First Nations persons living Hamilton. Over half of the study
28 population had moved at least 3 times in the past 5 years compared to 60% of the general
29 Hamilton population who had not moved at all for the past 5 years.[34] Compared to an
30 overcrowding rate of 3% for the general Canadian population in the 2006 Census,[1] 74%
31 of First Nations persons in Hamilton live in crowded conditions. These findings echo
32 those presented in the 2007 Urban Aboriginal Task Force (UATF) final report, which
33 documented persistent obstacles with finding affordable housing, obtaining stable and
34 secure employment and accessing appropriate services and resources among urban
35 Aboriginal people.[44] Similarly, the Toronto Aboriginal Research Project (TARP)
36 found that Aboriginal people in Toronto tend to concentrate in lower-income
37 neighbourhoods where a significant proportion, particularly men, live in poverty.[45]
38 Similar experiences have been reported in other urban jurisdictions across
39 Canada.[46;47] While a growing proportion of urban Aboriginal people in Canada are
40 achieving varying degrees of economic success in a number of occupations,[5;45] there
41 remains a significant amount of unmet basic needs among this population.
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46 The burden of chronic conditions experienced by First Nations adults in Hamilton
47 is disproportionately high. For example, 19% of the OHC Hamilton population reported
48 having been told by a health care provider that they have asthma, which is more than
49 twice the self-reported asthma rate (9.3%) for the overall Hamilton population in the
50 2007 Canadian Community Health Survey (CCHS).[48] Likewise, rates of arthritis and
51 high blood pressure were 30.7% and 25.8% among First Nations adults in Hamilton
52 compared to 19.9% and 19.7% among all adults in Hamilton as reported in the 2007
53 CCHS.[48] For First Nations adults in Hamilton, the rate of diabetes diagnosed by a
54 health care provider was approximately three times the rate among the general Hamilton
55 population.[48] These findings are particularly disconcerting given the much younger
56 age demographic of the First Nations Hamilton population and the documented barriers
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3 to receiving health care services including long wait lists, challenges with accessing and
4 affording transportation and the unavailability of primary care providers including
5 physicians, nurses, and other healthcare providers in the area. Furthermore, 45.8% (95%
6 CI 38.9-52.4) of First Nations adults believed that their ability to engage in preventative
7 health activities (i.e. regular exercise, going to the doctor or nurse for health screening
8 tests, accessing preventative dental care) had been affected by financial hardship.
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11 High rates of emergency usage by First Nations persons living in Hamilton are
12 likely linked to the problems in accessing non-emergency health care, as revealed by 40%
13 of the population who rated their access to health care as fair or poor and 48% who
14 indicated that wait lists are too long. In addition, as a result of primary healthcare
15 reforms,[49] patients may be told by their primary care providers to go to the emergency
16 department rather than a walk-in clinic when their primary care team is not available.[50]
17 High rates of emergency room visits may also reflect a perceived lack of access to
18 community-based or primary care settings and the extent to which high proportions of
19 First Nations people continue to be dismissed or disregarded when attempting to access
20 healthcare, despite geographic proximity. [51-53]Further examination is required to
21 explore potential bias in hospital admission practices and to differentiate between types
22 of hospitalizations (i.e. mental health, surgical and medical hospitalizations).
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27 There were a number of limitations of the study. Firstly, it should be noted that
28 we may have under sampled the elderly First Nations population living in nursing
29 homes or residences for senior citizens in Hamilton. During our initial seed selection,
30 we did not select any seeds from this population, and this population may have fewer
31 network ties than other population groups, which may have resulted in an under
32 representation of First Nations individuals over 65 years of age. Secondly, RDS
33 cannot guarantee a random sample of network members;[54] therefore, estimates are
34 unbiased to the degree that the assumptions of the RDS estimator are met. There is an
35 active literature on RDS and estimation using RDS data,[55;56] and there is debate
36 regarding the true design effects of RDS surveys.[57;58] Existing multivariable
37 regression analyses using RDS samples have not appropriately addressed the co-
38 relation between observations and the unequal sampling probabilities inherent in RDS,
39 therefore, we have focused on reporting prevalence estimates for which methods are
40 better established. Despite these limitations, RDS was used to effectively recruit an
41 urban Aboriginal population and allowed for the derivation of rigorous population
42 estimates and data linkages that have previously not been possible.
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47 Given the near absence of population health information for urban Aboriginal
48 people in Canada, this research is able to provide, for the first time, First Nations data
49 that clearly demonstrate alarming socio-economic inequities, a significant burden of
50 chronic disease, multiple barriers in access to health care and elevated emergency room
51 use. This newly established health database represents a significant contribution to
52 public health that will directly inform strategic directions for the improvement of health
53 and social status of urban Aboriginal people in Ontario. For example, this research will
54 support the development of RDS as a tool to effectively recruit a larger cohort for
55 longitudinal research with Aboriginal families in Ontario.
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Unmasking Health Determinants and Health Outcomes for Urban First Nations Using Respondent Driven Sampling

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Keywords: Canada; urban Aboriginal health; First Nations; Respondent-Driven
Sampling; Community-based Research

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ABSTRACT

Objective: Population based health information on urban Aboriginal populations in Canada is limited due to challenges with the identification of Aboriginal persons in existing health datasets. The main objective of the Our Health Counts (OHC) project was to work in partnership with Aboriginal stakeholders to generate a culturally relevant, representative baseline health data set for three urban Aboriginal communities in Ontario, Canada. **Design:** Respondent-Driven Sampling.

Setting: Hamilton, Ontario, Canada.

Participants: The OHC study, in partnership with De dwa da dehs ney's Aboriginal Health Access Centre (DAHC) recruited 554 First Nations adults living in Hamilton using RDS.

Results: Among First Nations adults living in Hamilton, 78% earned less than \$20,000 per year and 70% lived in the lowest income quartile neighbourhoods. Mobility and crowded living conditions were also highly prevalent. Common chronic diseases included arthritis, hypertension, diabetes and COPD and rates of emergency room access were elevated.

Conclusions: RDS is an effective sampling method in urban Aboriginal contexts as it builds upon existing social networks and successfully identified a population-based cohort. The findings illustrate striking disparities in health determinants and health outcomes between urban First Nations individuals and the general population which have important implications for health services delivery, programming and policy development.

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ARTICLE SUMMARY

Strengths and limitations of this study:

- Our study is the first RDS of self-identified First Nations people residing in an urban setting in Canada
- This study models best practices in academic-Aboriginal community research partnerships
- RDS has been demonstrated to be a promising tool for generating Aboriginal health assessment measures in urban areas where there are limited existing sampling frame options
- At present, multivariable regression analyses using RDS samples have not appropriately addressed the co-relation between observations and the unequal

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8 sampling probabilities inherent in RDS; therefore we present prevalence estimates for
9 which methods are better established
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INTRODUCTION

According to the 2006 Census, over 60% (150,570 people) of Aboriginal^a people living in Ontario live in urban areas. [1](4) Nearly seven out of ten Métis live in urban areas, and about three out of every four people in the off-reserve First Nations population live in urban areas. [1](4) First Nations people have historically been dislocated from their original homelands and may constitute diasporic, heterogeneous communities in urban areas. 2 Specifically, an increasing number of First Nations individuals are moving to urban centres to seek better housing, employment and education opportunities and for the services and amenities available. 3-5 There is a growing body of literature exploring the complexities of urban indigeneity 6 and some of the elements which distinguish urban Aboriginal identity are social and economic marginalization, a growing middle class, and population diversity in terms of cultural origins and legal status. 7 According to the Canadian Census, First Nations, Inuit, and Métis populations experience ongoing disparities in social determinants of health such as income insecurity, unemployment, low levels of education, decreased food availability, and inadequate housing compared to non-Aboriginal Canadians, and these disparities are exacerbated with urban residence. 1;8-9

Despite the growing size of the urban Aboriginal population in Canada, accessible and culturally relevant population health data for this population are almost non-existent. 10-13 While census data do exist, there are serious deficits in population health measures. 13 Some of the reasons behind this deficiency are limitations in the current health information system and data collection processes with respect to Aboriginal peoples. 14;15 Sampling frames are often biased and comprise non-random subpopulations such as lists of members or clients of particular programs and services in the community. When urban Aboriginal people have been included in census-based national surveys, these surveys were underpowered and often First Nations, Inuit, and Métis data could not be successfully disaggregated. 14;16 Additionally, studies based on Census data show that a significant number of Aboriginal people move from rural and reserve areas to cities, and back and forth as well as within and among cities. 4;17 These factors make it difficult to get reliable counts of the Aboriginal population of a city.

^a “Aboriginal people” is a collective name for all of the original peoples of Canada and their descendants. The *Constitution Act* of 1982 specifies that the Aboriginal Peoples in Canada consist of three groups: Indians, Inuit and Métis. The term First Nations came into common use in the 1970s to replace Indian, which some people found offensive. Despite its widespread use, there is no legal definition for this term in Canada. In the United States, the term “Native American” is used to represent Indigenous peoples from North America, including Mexico. For alignment with the US Constitution and to ensure policy implications, the term “American Indian” is still used for Indigenous populations living within US borders, particularly the lower 48 states and parts of Alaska. “Indigenous” is a term used in the international context.

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At the national level, the continued inability to identify Aboriginal peoples in healthcare databases leads to very poor coverage of Aboriginal populations in Canada, with a specific paucity of health information for First Nations, Métis, and Inuit living in urban areas. Provincial and territorial systems generally do not collect ethnic-specific utilization data, and their ethnic flags for vital statistics are inconsistent or absent.^{[18](48)} The federal government’s decision to cancel the long form of the Canadian national census will further challenge the ability of researchers and communities to identify and address social inequities across and within populations who experience racialization and the negative effects of structural discrimination in healthcare and other sectors, thus widening the existing health and social policy vacuum.^{[19;20](49;20)}

In the absence of an accessible and accurate population based sampling frame for urban Aboriginal people, we implemented respondent driven sampling (RDS) for the Our Health Counts (OHC) study. RDS, like other chain-referral approaches, relies on members of a population to recruit their peers.^{21;22} However, RDS differs from other methods because of estimation procedures that adjust for the participants’ different probabilities of being sampled.^{22} RDS also differs from other chain-referral methods because the number of recruitments any participant can make is limited, and it employs a dual incentive structure where participants are rewarded both for participating and for recruiting their peers.^{23}

There is limited literature on RDS in Indigenous contexts;^{24} however, there is evidence that links the success of RDS to the strength of social networks and relationships.^{25} Indigenous knowledges are wholistic, relational and embraces a fluidity that allows for constant growth and change.^{26;27} Aboriginal identities tend to value the group over the individual, thereby establishing models of kinship whereby everyone has the right to give and receive according their own choices.^{26} Therefore, we hypothesized that RDS would be an appropriate and effective sampling methodology as it builds on social networks and would draw on existing kinship systems known to be present in Indigenous communities.^{28}

The main objective of the OHC project was to work in partnership with Aboriginal stakeholders to generate a culturally relevant, representative baseline health data set for three urban Aboriginal communities in Ontario, Canada. The results presented here pertain specifically to the urban First Nations population in Hamilton where the organizational project lead was the Ontario Federation of Indian Friendship Centres (OFIFC) and the community partner was De dwa da dehs ney>s Aboriginal Health Access Centre (DAHC).

METHODS

Community-based participatory research

This study upheld current ethical and scientific standards in Indigenous health research^{29-33} through a community based participatory research partnership between the academic research team, OFIFC and DAHC. We ensured that our Aboriginal decision making partners were active in all aspects of the research through the following mechanisms: Aboriginal leadership; research agreements which explicitly

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8 addressed issues of project governance, community expectations, benefits, ownership,
9 control, access, and possession of information, and dissemination of project results;
10 capacity building through staffing at community sites, data workshops and awareness
11 building; respect for the individual and collective rights of Aboriginal peoples with
12 respect to their health information; cultural relevance through the development and
13 application of culturally appropriate measures; representation of the urban Aboriginal
14 population of Ontario; and sustainability of the project to ensure ~~expansion of that this the~~
15 database ~~can be geographically and longitudinally expanded.~~ DAHC In addition, a
16 Governing Council, comprised of representatives from the core ~~partner~~ urban Aboriginal
17 provincial organizations was established to oversee all stages of the research process.
18 Specifically, this body adhered to governance protocols and ensured that individual and
19 collective community rights were respected, were kept informed about the project's
20 progress and led the project towards meaningful results, acted as a resource to the
21 community on questions related to various portions of the research project and controlled
22 the release of all data generated by the study.

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24 All members of the study team were from the Aboriginal community, living in the
25 general vicinity of the city of Hamilton. Formal ethics approval was provided by the
26 Research Ethics Board of St. Michael's Hospital in Toronto.

27 Study Site

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29 The City of Hamilton is located in southern Ontario on what was traditionally
30 Haudenosaunee (Iroquian) territory and is near two First Nations reserves: Six Nations of
31 the Grand River and Mississaugas of the New Credit. According to the 2006 Census, the
32 total Aboriginal population in Hamilton was 13,735 people, comprising 2.8% of the total
33 population of the city. ~~34~~ The OFIFC identified the city of Hamilton as a promising
34 community site based on its significant Aboriginal population and strong infrastructure of
35 Aboriginal community services.

36 Recruitment

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38 The RDS process was initiated through the purposive selection of individuals to begin
39 recruitment, also called "seeds." Inclusion criteria for participation in the study included
40 18 years of age, residence within the geographic boundaries of the City of Hamilton and
41 self-identified as having First Nations identity. First Nations identity was determined
42 through open dialogue around family, experiences, and location while also explaining the
43 overall study goals and additional study sites in Ottawa. Questions such as: "What words
44 best describe you?" and "How do you see yourself?" were useful. With the help of
45 community partners, six seeds were identified and agreed to participate. In order for
46 seeds to reflect a diverse demographic of First Nations people living in Hamilton, factors
47 such as gender, age, family size, and occupations were considered in their selection. For
48 example, seeds were identified in the student population, among the steel workers union,
49 among artists, elders, housing and social assistance providers as well as members of local
50 Aboriginal organizations and boards. Five of the six seeds produced referrals within the
51 two weeks leading up to the December 2009 holiday closure at DAHC. In February and
52 March 2010, three additional seeds were added.

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Study participants, including seeds, provided informed consent and then completed a health assessment survey after which they received 3-5 coded coupons to refer a member of their social network into the study. Following the holiday closure of DAHC, the number of distributed coupons per recruit was increased from 3 to 5 in order to increase the rate of recruitment. Participants received a monetary reimbursement of \$20 for their time and participation. They also received an additional \$10 for every eligible person they recruited into the study. Study recruitment and interviews took place in an Aboriginal community centre.

For sample size calculation, we assumed 95% confidence intervals (CI), survey item prevalence ranges from 10% to 75% and a design effect of 2.^{35} Based on this formula, the OCH study aimed to recruit 500 First Nations adults and 250 children.

Sources of Data

Community concept mapping was implemented to develop a community specific survey for First Nations in Hamilton, ^{36} which was comprised of 8 domains covering areas such as sociodemographics, physical, mental, and emotional health, First Nations identity and impacts of colonization (i.e. questions about Residential School attendance, involvement of child protection agencies, dislocation from traditional lands and discrimination), and access and barriers to care. The survey tool was piloted with First Nations community members, and minor modifications were made to improve face validity. Data were collected and compiled by computer-assisted personal interviewing with a computer based version of the survey tool developed by the research team using SPSS Data Collection Author and Collector.^{37}

Upon completion of recruitment and survey, our sample of First Nations adults was linked to data holdings at the Institute of Clinical Evaluative Sciences (ICES) including provincial records of emergency room and hospital visits (Canadian Institutes of Health Information – Discharge Abstract Database and National Ambulatory Care Reporting System: Emergency), and neighbourhood income quintiles (derived from Census data). Using health care system identification numbers (i.e. Ontario Health Card) provided by participants, we successfully linked 92% (N=725) of First Nations adults to the ICES database.

Analysis

Recruitment dynamics, adjusted population based estimates and confidence intervals were calculated using the RDS-I enhanced data smoothing estimator in the custom RDSAT software (version 7.1).^{38} The RDS methodology anticipates that personal networks are not randomly distributed, and therefore adjusts for small to moderate levels of network clustering (people who have ties to others like them), in the form of post-sampling weights.

RESULTS

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Among First Nations adults in Hamilton, 78.9% of participants were recruited via referral trees originating from two seeds. With 19 and 32 waves respectively, the lengths of both of these recruitment chains were long enough to overcome the original sampling bias, which usually happens after 6 or 7 waves of recruitment.¹³⁹⁽³⁹⁾ The statistical theory is that if the chain-referral process consists of enough waves or cycles of recruitment, the composition of the final sample with respect to key characteristics and behaviors will become independent of the seeds from which it began. The point at which the sample composition becomes stable is termed “equilibrium” and is an indication that RDS has been implemented successfully.¹²¹⁽²¹⁾

Over a period of four and a half months (November 2009 to March 2010) a total of 790 persons were recruited, including 554 adults and 236 children. Overall, a high response rate for survey questions was observed. Specifically, non-response rates ranged from 2.5% to less than 0.5%, including ~~Even more~~ sensitive questions around income, food security, and impacts of colonization, which had ~~very low~~ non-response rates under 2%. Such high response rates can be attributed to the survey tool itself, which reflected the health priorities of the community¹⁴⁰⁽⁴⁰⁾ and which was administered in a safe and culturally secure context. Demographic and social characteristics are presented in Table 1.

Table 1. Demographic and social characteristics of First Nations adults (Total N=554)

Characteristic	Prevalence % (95% CI)
Sex	
Male	59.9 (53.3, 67.2)
Age	
18-34	40.2 (33.3, 48)
35-49	35.4 (28.7, 41.6)
50+	24.4 (18.4, 30.8)
Education	
Some high school or less	57.3 (51.1, 64)
Completed high school	19.5 (14.5, 24.7)
Some or completed college	18.3 (13.3, 23.3)
Some or completed University	5 (2.4, 8)
Income sources for household	
Provincial or municipal social assistance or welfare (e.g. ODSP, Ontario Works)	69.2 (63.1, 75)
Wages and salaries	28.2 (22.1, 34.2)
Child Tax Benefit	17 (12.4, 21.8)
Any other income support	13.3 (9.2, 17.6)
Employment insurance	9.6 (5.4, 14.3)
Income from self-employment	7.7 (4.3, 11.7)
Child Support payments	3 (1.1, 4.6)
Individual annual income	
\$0-4,999	18.3 (13.4, 24.8)

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\$5,000-5,999	23.1 (17.1, 28.5)
\$10,000-14,999	21.9 (16.3, 27.6)
\$15,000-19,999	14.8 (10.7, 20)
\$20,000+	21.8 (16, 27.6)
Mobility	
No moves in past 5 years	10.2 (6.2, 14.8)
1 move in past 5 years	15.5 (10.5, 20.6)
2 moves in past 5 years	20.2 (15.4, 26.4)
3-5 moves in past 5 years	41.1 (35, 48.6)
6-10 moves in past 5 years	10.4 (5.7, 13.4)
Overcrowding*	
<=1 persons per room	27.7 (21.6, 33.8)
1-2 persons per room	46 (40.5, 54.3)
>2 persons per room	26.3 (19.7, 30.8)
Food security	
You and others always had enough of the kinds of food you wanted to eat	26.7 (21.1, 32.8)
You and others had enough to eat, but not always the kinds of food you wanted	51.5 (45.3, 58)
Sometimes or often you did not have enough to eat**	21.8 (16.5, 27)

Note. CI = confidence interval.

*Following Statistics Canada standards: calculated by dividing the number of rooms in each household (excluding the bathroom) by the number of people residing in the home, where a higher value of 'persons per room' indicates a higher level of crowding.^{41}

** Collapsed sometimes and often you did not have enough food to eat

The data presented in Table 2 for age, gender and income quintiles compare the OHC population estimates with the total Hamilton population and a random subset of 10% of the Ontario provincial population. The three populations were very similar with respect to the gender breakdown, however, the OHC sample was younger than the general Hamilton and Ontario populations which is consistent with Census data.^{42} Over 70% of the First Nations population fell into the lowest income quartile compared to 25% of the general Hamilton population and 20% of the Ontario population. At the higher end of the income scale, we observed that while 15% of Hamilton residents and 20% of the Ontario population fell into the highest income quartile, only 3% of the study population was earning in this category.

Table 2. Gender, Age and Income Quintile for First Nations Adults, City of Hamilton and Ontario-10%

Variable	Sample			
	OHC (Total N=725*)	OHC-RDS-Adjusted	Hamilton (Total N=536,253)	Ontario-10% (Total N=1,324,241)
	Prevalence, %	Prevalence, % (95% CI)	Prevalence, %	Prevalence, %

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Sex				
Female	49.4	37.6 (29.6, 43.6)	50.9	51.2
Male	50.6	62.4 (56.4, 70.4)	49.1	48.7
Age**				
18-34	37.4	41.9 (34.4, 49.9)	28.2	28.2
35-49	37.6	36.6 (29.9, 43.1)	28.1	29.5
50-64	22.9	20.7 (14.7, 26.9)	24.8	24.8
65+	2.1	0.8 (0.3, 1.6)	18.9	17.6
Income Quintile				
1-Low	71.76	73 (66.5, 79.2)	25.1	19.5
2	16.22	11.8 (7.7, 16)	22.8	19.8
3	6.3	7.4 (3.6, 10.5)	20.3	19.8
4	2.48	4.9 (2.5, 9.8)	17	20.4
5-High	1.34	3 (1.1, 5.4)	14.7	20.2

Note. CI = confidence interval; OHC = Our Health Counts; RDS = Respondent Driven Sampling.

*Total N reflects number of participants linked to ICES database

**Age of participants on 2010-04-01

The most common self-reported chronic conditions that had been diagnosed by a health care provider among First Nations adults (n=554) in Hamilton included arthritis (30.7%; 95% CI 25.4-36.8), hypertension (25.8%; 95% CI 20.3-31.6), asthma (19%; 95% CI 14.9-24.6), diabetes (15.6%; 95% CI 11.2-21.1), heart disease (8.4%; 95% CI 4.8-12.5) and COPD (8.4%; 95% CI 5.3-11.8). The prevalence of self-reported Hepatitis C was 8.7% (95% CI 4.3-11.7). 25% reported having been injured over the past 12 months. Self-reported upper respiratory tract infection (URTI) was common, with 73% (95% CI 67.9-79.9) of adults reporting URTI in the past 12 months.

Among First Nations adults (n=554), 16.7% (95% CI 11.4 – 22.1) felt that availability of health services in their community was excellent, 43.3% (95% CI 36.1 - 49.6) felt it was good, 28.9% (95% CI 23.3 – 35.2) felt it was fair and 11.1% (95% CI 7.9 – 15.6) felt availability was poor. The fact that 40% of the population felt their level of access to health care was fair or poor, despite the geographic proximity to extensive health and social services that the City of Hamilton provides, substantiates the idea that just because the services are geographically proximate, does not mean that they are accessible to First Nations people. Close to half (47.9%) of the First Nations living in Hamilton reported that long waiting lists to see a specialist were a barrier (95% CI 41.9 - 55.4). Other common barriers included: not being able to arrange transportation; doctor not available; not being able to afford direct costs and/or transportation; services not covered by Non-Insured Health Benefits and lack of trust in health care provider.

Both acute and non-acute emergency room visits were much more frequent among First Nations in Hamilton compared to the general Hamilton and Ontario populations. According to data linkages with ICES, a striking 10.6% of the First Nations adult population in Hamilton made 6 or more emergency room visits in the previous 2

years compared to 1.6% and 1.9% of the Hamilton and Ontario adult populations respectively (Table 3).

Table 3. Number of Emergency Room visits in the Previous 2 Years for Adults (18-64 years), First Nations, City of Hamilton and Ontario-10%

Frequency of ER visits	Sample			
	OHC (Total N=514*)	OHC RDS-Adjusted	Hamilton (Total N=360,378)	Ontario-10% (Total N=901,509)
	Prevalence, %	Prevalence, % (95% CI)	Prevalence, %	Prevalence, %
None	31.5	(25.8 – 37.5)	66.3	69.1
1	26.2	(20.7 – 32.8)	18.7	16.8
2-5	31.7	(25.9 – 37.8)	13.4	12.3
6+	10.6	(6.2 – 14.5)	1.6	1.9
ER visits (acute)				
None	50.2	(43.9 – 57.5)	78.4	80.1
1	24.7	(18.7 – 30.1)	14.2	13.1
2-5	20.7	(15.3 – 26.1)	6.8	6.3
6+	4	1.6 – 6.9)	0.6	0.6
ER visits (non-acute)				
None	54.3	(47.6 – 61.2)	79.4	81.2
1	22.4	(17.3 – 28.5)	14	12.2
2-5	20.4	(14.5 – 25.4)	6.3	6
6+	2.9	(1 – 5.6)	0.4	0.6

Note. CI= confidence interval; OHC = Our Health Counts; RDS = Respondent Driven Sampling

*Total N reflects number of adults aged 28-64 linked to ICES database

Based on ICES data linkages, rates of hospitalization were slightly higher among the First Nations population compared to the Hamilton and Ontario populations. This ~~can~~ **may** partly be explained by a higher birth rate among First Nations populations compared to the general Canadian population, ~~43~~ which is reflected by higher rates of obstetrics hospitalization compared to the general Hamilton and Ontario population: 7.3% (95% CI, 3.9 – 10.9) of the Hamilton First Nations population between the ages of 18 and 64 years had been hospitalized at least once in the past 5 years for obstetrical reasons compared to 4% of both the general Hamilton and Ontario populations in the same age group and over the same time period. However, given the high rates of chronic diseases such as diabetes and heart disease and the much higher rates of emergency room use among the First Nations population, these findings were unexpected and therefore require further investigation.

DISCUSSION

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The OHC project generated a representative, urban Aboriginal health database. Through the successful application of RDS, a sample of urban First Nations individuals who might otherwise not have participated in mainstream surveys or the census was captured. In addition, given the current deficiency in public health information on urban First Nations populations, the statistically rigorous RDS sample allowed us to produce population-based estimates that can be utilized by local, regional, provincial and federal policy makers as well as urban Aboriginal stakeholders to address social inequities and health disparities facing this community.

Striking levels of poverty were identified in this study. The income data presented here may be a more representative income profile of the First Nations population in Hamilton than the 2006 Census. Specifically, the OHC data were adjusted for the sampling procedure using an RDS estimator and captured more 'hidden' populations such as persons who are homeless, transient or who have low literacy skills, who are known to be under-represented in the Census.^{[11;13](41;43)} Further evidence of low incomes among this population is provided by the RDS-adjusted ICES income quintile data, which revealed that over 70% of the OHC cohort was in the lowest income quartile compared to 25% of the general Hamilton population and 20% of the Ontario population.

Accompanying high levels of poverty, housing and food insecurity were also highly prevalent among First Nations persons living Hamilton. Over half of the study population had moved at least 3 times in the past 5 years compared to 60% of the general Hamilton population who had not moved at all for the past 5 years.^{34} Compared to an overcrowding rate of 3% for the general Canadian population in the 2006 Census,^{[1](4)} 74% of First Nations persons in Hamilton live in crowded conditions. These findings echo those presented in the 2007 Urban Aboriginal Task Force (UATF) final report, which documented persistent obstacles with finding affordable housing, obtaining stable and secure employment and accessing appropriate services and resources among urban Aboriginal people.^{44} Similarly, the Toronto Aboriginal Research Project (TARP) found that Aboriginal people in Toronto tend to concentrate in lower-income neighbourhoods where a significant proportion, particularly men, live in poverty.^{45} Similar experiences have been reported in other urban jurisdictions across Canada.^[46;47] While a growing proportion of urban Aboriginal people in Canada are achieving varying degrees of economic success in a number of skilled professions occupations.^{5;45} there remains a significant amount of unmet basic needs among this population.

The burden of chronic conditions experienced by First Nations adults in Hamilton is disproportionately high. For example, 19% of the OHC Hamilton population reported having been told by a health care provider that they have asthma, which is more than twice the self-reported asthma rate (9.3%) for the overall Hamilton population in the 2007 Canadian Community Health Survey (CCHS).^{[48](46)} Likewise, rates of arthritis and high blood pressure were 30.7% and 25.8% among First Nations adults in Hamilton compared to 19.9% and 19.7% among all adults in Hamilton as reported in the 2007 CCHS.^{[48](46)} For First Nations adults in Hamilton, the rate of diabetes diagnosed by a health care provider was approximately three times the rate among the general Hamilton

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population.^{[48](46)} These findings are particularly disconcerting given the much younger age demographic of the First Nations Hamilton population and the documented barriers to receiving health care services including long wait lists, challenges with accessing and affording transportation and the unavailability of primary care providers including physicians, nurses, and other healthcare providers physicians in the area. Furthermore, 45.8% (95% CI 38.9-52.4) of First Nations adults believed that their ability to engage in preventative health activities (i.e. regular exercise, going to the doctor or nurse for health screening tests, accessing preventative dental care) had been affected by financial hardship.

High rates of emergency usage by First Nations persons living in Hamilton are likely linked to the problems in accessing non-emergency health care, as revealed by 40% of the population who rated their access to health care as fair or poor and 48% who indicated that wait lists are too long. In addition, as a result of primary healthcare reforms,^{[49](47)} patients may be told by their primary care providers to go to the emergency department rather than a walk-in clinic when their primary care team is not available.^{[50](48)} High rates of emergency room visits may also reflect a perceived lack of access to community-based or primary care settings and the extent to which high proportions of First Nations people continue to be dismissed or disregarded when attempting to access healthcare, despite geographic proximity.^[51-53] Further examination is required to explore potential bias in hospital admission practices and to differentiate between types of hospitalizations (i.e. mental health, surgical and medical hospitalizations).

There were a number of limitations of the study. Firstly, it should be noted that we may have under sampled the elderly First Nations population living in nursing homes or residences for senior citizens in Hamilton. During our initial seed selection, we did not select any seeds from this population, and this population may have fewer network ties than other population groups, which may have resulted in an under representation of First Nations individuals over 65 years of age. Secondly, RDS cannot guarantee a random sample of network members:^{[54](49)} therefore, estimates are unbiased to the degree that the assumptions of the RDS estimator are met. There is an active literature on RDS and estimation using RDS data,^{[55:56](50:51)} and there is debate regarding the true design effects of RDS surveys.^{[57:58](52:53)} Existing multivariable regression analyses using RDS samples have not appropriately addressed the co-relation between observations and the unequal sampling probabilities inherent in RDS, therefore, we have focused on reporting prevalence estimates for which methods are better established. Despite these limitations, RDS was used to effectively recruit an urban Aboriginal population and allowed for the derivation of rigorous population estimates and data linkages that have previously not been possible.

Given the near absence of population health information for urban Aboriginal people in Canada, this research is able to provide, for the first time, First Nations data that clearly demonstrate alarming socio-economic inequities, a significant burden of chronic disease, multiple barriers in access to health care and elevated emergency room use. This newly established health database represents a significant contribution to public health that will directly inform strategic directions for the improvement of health

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and social status of urban Aboriginal people in Ontario. For example, this research will support the development of RDS as a tool to effectively recruit a larger cohort for longitudinal research with Aboriginal families in Ontario.

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Contributorship statement: MF contributed substantially to the study conception and design, co-led data interpretation and analysis and drafted multiple versions of the manuscript. JS co-led the study conception and design, data analysis and interpretation and made important contributions to the draft and final manuscript. SM contributed substantially to study conception and design, was a member of the governing council that guided each stage of research, represented the Aboriginal organizational lead of the research and made important revisions to the draft manuscript. MS provided important technical support during data collection, co-led the data analysis and interpretation, and provided important revisions to the manuscript. PO contributed substantially to the study conception and design, analysis and interpretation of data and made important revisions to the draft manuscript.

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Data sharing: No additional data are available.

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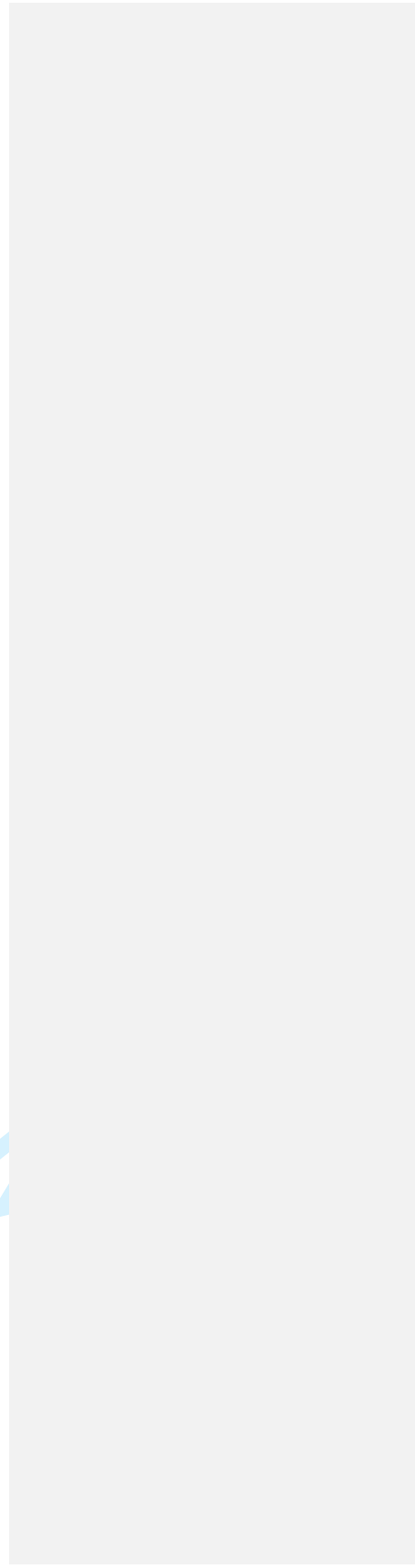
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For peer review only



STROBE 2007 (v4) checklist of items to be included in reports of observational studies in epidemiology*
Checklist for cohort, case-control, and cross-sectional studies (combined)

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	Yes, in title
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	Yes, pg 2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	Yes, pg 3-4
Objectives	3	State specific objectives, including any pre-specified hypotheses	Yes, pg 4
Methods			
Study design	4	Present key elements of study design early in the paper	Yes, pg 4-5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	Yes, pg 5
Participants	6	(a) <i>Cohort study</i> —Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up <i>Case-control study</i> —Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls <i>Cross-sectional study</i> —Give the eligibility criteria, and the sources and methods of selection of participants	Yes, pg 5
		(b) <i>Cohort study</i> —For matched studies, give matching criteria and number of exposed and unexposed <i>Case-control study</i> —For matched studies, give matching criteria and the number of controls per case	
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	Yes, pg 5-6
Bias	9	Describe any efforts to address potential sources of bias	Yes, pg 4
Study size	10	Explain how the study size was arrived at	Yes, pg 5
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	Yes, pg 6
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	Yes pg 6
		(b) Describe any methods used to examine subgroups and interactions	
		(c) Explain how missing data were addressed	
		(d) <i>Cohort study</i> —If applicable, explain how loss to follow-up was addressed <i>Case-control study</i> —If applicable, explain how matching of cases and controls was addressed	

		<i>Cross-sectional study</i> —If applicable, describe analytical methods taking account of sampling strategy	
		(e) Describe any sensitivity analyses	
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed (b) Give reasons for non-participation at each stage (c) Consider use of a flow diagram	
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders (b) Indicate number of participants with missing data for each variable of interest (c) <i>Cohort study</i> —Summarise follow-up time (eg, average and total amount)	Yes, pg 6-7
Outcome data	15*	<i>Cohort study</i> —Report numbers of outcome events or summary measures over time <i>Case-control study</i> —Report numbers in each exposure category, or summary measures of exposure <i>Cross-sectional study</i> —Report numbers of outcome events or summary measures	
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included (b) Report category boundaries when continuous variables were categorized (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	
Discussion			
Key results	18	Summarise key results with reference to study objectives	Yes, Pg 9-11
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	Yes, Pg 11
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	Yes, pg 9-11
Generalisability	21	Discuss the generalisability (external validity) of the study results	
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	Yes, pg 11-12

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.