PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	Unmasking Health Determinants and Health Outcomes for Urban First Nations Using Respondent Driven Sampling
AUTHORS	Firestone, Michelle; Smylie, Janet; Maracle, Sylvia; Spiller, Michael; O'Campo, Patricia

VERSION 1 - REVIEW

REVIEWER	Ingeborg Zehbe, PhD Thunder Bay Regional Research Institute Thunder Bay, Ontario Canada
REVIEW RETURNED	18-Mar-2014

GENERAL COMMENTS	Ethics has been obtained from two different sources. This is acceptable but the certificate names/numbers are required. Within the tables there are some rows that are not clear: e.g. under income, in the last row it is not clear way the finding 3(1.1;4.6) refers to; similarly under food security what's the heading for the finding 21.8(16,5;27)? Overall, I appreciate the cautiousness that the authors used with their statistical analysis, considering how the RDS method likely induces a significant amount of bias. Their descriptive analysis is interesting but I think there should be a discussion of the response rates within the study participants. There isn't mention of missing data within the survey, aside from participants who were excluded because of ICES-linkages. I'm not sure if the survey software required an answer for each of the questions in OHC, but something should be mentioned about the "completeness" of the participants' surveys. Because the table only reported adjusted proportions, it would be interesting to see if participants felt comfortable answering all of the questions that were part of the survey. Most of the STROBE criteria are met but there is no mention of the checklist and the time interval of recruitment would be helpful. Since OHC was designed to collect baseline data, is there follow-up planned? Also, the "community-based participatory" methods weren't elaborated on - what does the Governing Council do?

REVIEWER	Dr. Annette J. Browne University of British Columbia Canada
REVIEW RETURNED	31-Mar-2014

GENERAL COMMENTS	Thank you for the opportunity to review this important manuscript. The aims of this paper, which I interpret to be: (a) to describe methods used to generate a Respondent Driven Sample (RDS), and (b) to present selected self-reported data from the survey, represent a significant step forward in generating data on health and social status using community-based methodologies that are respectful and rigorous. Abstract and Introduction: In the Abstract and the Introduction, the paper would be strengthened by more clearly and explicitly articulating the objectives of this paper, drawing on the larger Our Health Counts (OHC) study, given what I see as the two-fold purpose of the paper. In the Article Summary, under the Strengths and Limitations of this study, the first bullet point claims that "Our study is the first in Canada to provide population-based health assessment data for First Nations." This claim seems to overlook the data provided through the Aboriginal Peoples Survey (Statistics Canada, 2014), which provides population-based data on health, education, employment, language, income, housing and mobility, among other variables. As such, I think the first bullet point in this section should be revised to more specifically clarify that the authors' contribute one of the first (and perhaps, "the" first) RDS of self-identified First Nations people residing in an urban setting in Canada. The Introduction offers some important facts about the numbers of Aboriginal people residing in urban areas in Canada. The authors could consider drawing on Dr. Evelyn Peters' cutting-edge research on this very topic. See for example: Peters, E.J. and Andersen, C. (Eds). (2013). *Indigenous in the city: Contemporary identities and cultural innovation.* Vancouver, BC: UBC Press. In the Introduction, at the end of the third paragraph, the authors acknowledge that it is challenging to identify and address social inequities across ethnic groups in Canada. I encourage them to add a clause or a sentence that acknowledges that it is challenging to identify and address social inequities not only across ethnic groups, but across and within populations who experience racialization and the negative effects of structural discrimination in healthcare and other sectors. This is particularly important to acknowledge in a paper that aims to describe health status and social inequities within a segment of the First Nations population. Given the international readership of BMJ Open, the Introduction could include slightly more historical and socio-political contextual information. The interchangeable use of 'First Nations', 'Aboriginal people' and 'Indigenous people' in this paper may be confusing to an international readership. Adding brief definitions of terms will help to clarify.

In the second last paragraph of the Introduction, the authors slip into what reads like essentialized conceptualizations of “Indigenous knowledge”, and “Aboriginal identity”. This could be avoided by editing this paragraph to allow for hybridity. For example, the sentences on p. 4, line 23-25, could be revised by discussing, “Indigenous knowledges” [plural] to avoid perpetuating notions of Indigenous knowledge as singular or uniform. In the following sentence, the authors could say, “Aboriginal identities tend to value….” vs constructing “Aboriginal identity” as singular.

Re: Methods:

This leads to another area of clarification needed. In the first paragraph of the Recruitment section, one of the inclusion criteria was self-reported “First Nations identity.” Given the shifting landscape of terminologies used to describe identity and ancestry in Canada, I encourage the authors to provide an explanation of how they defined “First Nations identity” to the respondents, to help the readers understand how the respondents either decided to self-select themselves into the study or not. (For example, was First Nations defined in ways that were consistent with Statistics Canada’s definitions?)

It would be useful to see some brief detail (e.g. sociodemographic characteristics) on the “seed” participants, and how and why they were purposively selected. Who were the seeds and how diverse were they?

In the section describing the Sources of Data, please add a brief example of the kinds of survey items that focused on impacts of colonization. Although the authors’ refer to full report on the OHC community survey (Ref #34 in the manuscript), and I accessed the report, it may not be readily accessible to others. This domain will be of particular interest to other researchers, so providing one or two examples of items that focused on this domain would be helpful.

Results:

In the opening paragraph, the authors state that recruitment chains usually overcome sampling bias after 6 or 7 waves of recruitment, however they do not explain why. Adding a brief explanation would help to further justify the rigor of this approach. Given the diversity of Aboriginal peoples in urban areas, it is important to explain how this diversity was captured (e.g. people of varying SES and people in different social circles).

Make it clearer throughout that the results are based on self-reported survey responses vs linked data sources (e.g., provincial records of emergency room visits, hospital visits,

and neighborhood income quintiles). For example, at first glance, in the last paragraph of the Results (just above the Discussion section), it is not clear whether the rates of hospitalization are self-reported or based on the ICES data.

Also in the Results section, when describing the 43.3% who rated the availability of healthcare as “good”, how does that relate to the common barriers to healthcare that are listed in the sentence that follows? These percentages would be better served by contextualizing them for the reader – otherwise, they read as decontextualized frequencies. This is particularly important given the authors’ aims, as identified in the discussion, to provide clear examples of health and socio-economic health status inequities.

The Results did not present health outcomes based on gender or family structure, although these are known to intersect with a broad range of social determinants to differentially influence the health of Aboriginal men and women. This will be important to consider in future analyses of this sample, and when using RDS in the future. I encourage the authors to briefly discuss this point.

Minor edits:

In Table 1: To interpret the prevalence of self-reported overcrowding, provide a brief definition from Statistics Canada (2013): “A higher value of ‘persons per room’ indicates a higher level of crowding”.

In the Results section, a barrier was “long waiting lists”. Provide examples of what people were waiting for (presumably referrals to specialists?).

References:

Statistics Canada (2013). Housing suitability of private household. Retrieved from http://www.statcan.gc.ca/concepts/definitions/dwelling-logement-07-eng.html

Statistics Canada (2014). Aboriginal Peoples Survey. Retrieved from http://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=3250&lang=en&db=imdb&adm=8&dis=2)

VERSION 1 – AUTHOR RESPONSE

Reviewer: 1
Reviewer Name Ingeborg Zehbe, PhD
Institution and Country Thunder Bay Regional Research Institute
Thunder Bay, Ontario
Canada
Please state any competing interests or state ‘None declared’: None declared

1. Ethics has been obtained from two different sources. This is acceptable but the certificate names/numbers are required.

Formal ethics was obtained only by St. Michael’s Hospital in Toronto. The Governing Council oversaw all stages of the research process, but was not a formal ethics review board. This has been clarified in the text (pg 6).

2. Within the tables there are some rows that are not clear: e.g. under income, in the last row it is not clear way the finding 3(1.1;4.6) refers to; similarly under food security what's the heading for the finding 21.8(16,5;27)?

The tables have been revised to read more clearly.

3. Overall, I appreciate the cautiousness that the authors used with their statistical analysis, considering how the RDS method likely induces a significant amount of bias. Their descriptive analysis is interesting but I think there should be a discussion of the response rates within the study participants. There isn't mention of missing data within the survey, aside from participants who were excluded because of ICES-linkages. I'm not sure if the survey software required an answer for each of the questions in OHC, but something should be mentioned about the "completeness" of the participants' surveys. Because the table only reported adjusted proportions, it would be interesting to see if participants felt comfortable answering all of the questions that were part of the survey.

The reviewer raises a very important point here. Overall, a high response rate for survey questions was observed, which can be attributed to the survey tool itself, which reflected the health priorities of the community and which was administered in a safe and culturally secure context. We have provided more details about the data, including response rates and ‘completeness’ in the second paragraph of the Results section on page 8.

4. Most of the STROBE criteria are met but there is no mention of the checklist and the time interval of recruitment would be helpful. Since OHC was designed to collect baseline data, is there follow-up planned? Also, the "community-based participatory" methods weren't elaborated on - what does the Governing Council do?

The time interval of recruitment has been clarified (pg 8). The community-based participatory action approach was to promote balance in the relationships between the Aboriginal organizational partners, academic research team members, Aboriginal community participants and collaborating Aboriginal and non-Aboriginal organizations throughout the health information adaptation process, from initiation to dissemination. Integral to this approach was to ensure that our Aboriginal decision making partners were active in all aspects of the research. This was accomplished through the following: Aboriginal leadership and the Governing Council; research agreements which explicitly addressed issues of project governance, community expectations, benefits, ownership, control, access, and possession of information, and dissemination of project results; capacity building through staffing at community sites, data workshops and awareness building; respect for the individual and collective rights of Aboriginal peoples with respect to their health information; cultural relevance through the

development and application of culturally appropriate measures; representation of the urban Aboriginal population of Ontario; and sustainability of the project to ensure that this database can be geographically and longitudinally expanded.

The Governing Council, comprised of representatives from the core urban Aboriginal provincial organizations was established to oversee all stages of the research process. This group adhered to governance protocols and ensured that individual and collective community rights were respected, were kept informed about the project's progress and led the project towards meaningful results, acted as a resource to the community on questions related to various portions of the research project and controlled the release of all data generated by the study.

We have revised the manuscript by providing a summary of these points in the methods section under community based participatory research (pg 5-6).

Reviewer: 2
Reviewer Name Dr. Annette J. Browne
Institution and Country University of British Columbia
Canada
Please state any competing interests or state 'None declared': None declared

Although I am recommending major revision, these can be readily done within the current structure of the paper.

Thank you for the opportunity to review this important manuscript. The aims of this paper, which I interpret to be: (a) to describe methods used to generate a Respondent Driven Sample (RDS), and (b) to present selected self-reported data from the survey, represent a significant step forward in generating data on health and social status using community-based methodologies that are respectful and rigorous.

Abstract and Introduction:

1. In the Abstract and the Introduction, the paper would be strengthened by more clearly and explicitly articulating the objectives of this paper, drawing on the larger Our Health Counts (OHC) study, given what I see as the two-fold purpose of the paper. In the Article Summary, under the Strengths and Limitations of this study, the first bullet point claims that "Our study is the first in Canada to provide population-based health assessment data for First Nations." This claim seems to overlook the data provided through the Aboriginal Peoples Survey (Statistics Canada, 2014), which provides population-based data on health, education, employment, language, income, housing and mobility, among other variables. As such, I think the first bullet point in this section should be revised to more specifically clarify that the authors' contribute one of the first (and perhaps, "the" first) RDS of self-identified First Nations people residing in an urban setting in Canada.

The objective of the paper has been made more explicit in the abstract. The first bullet of the article summary has been revised based on the reviewer's comment and suggestions.

2. The Introduction offers some important facts about the numbers of Aboriginal people residing in urban areas in Canada. The authors could consider drawing on Dr. Evelyn Peters' cutting-edge research on this very topic. See for example: Peters, E.J. and Andersen, C. (Eds). (2013). Indigenous in the city: Contemporary identities and cultural innovation. Vancouver, BC: UBC Press.

The reviewer highlights a very important body of work by Dr. Evelyn Peters. We have supported our background section with reference to this literature (pg 4).

3. In the Introduction, at the end of the third paragraph, the authors acknowledge that it is challenging to identify and address social inequities across ethnic groups in Canada. I encourage them to add a clause or a sentence that acknowledges that it is challenging to identify and address social inequities not only across ethnic groups, but across and within populations who experience racialization and the negative effects of structural discrimination in healthcare and other sectors. This is particularly important to acknowledge in a paper that aims to describe health status and social inequities within a segment of the First Nations population.

The reviewer raises a very important issue. We acknowledge that racism and structural discrimination play a very important role in creating and maintaining social inequities not only across ethnic groups and have made this clear in the third paragraph of the introduction.

4. Given the international readership of BMJ Open, the Introduction could include slightly more historical and socio-political contextual information. The interchangeable use of 'First Nations', 'Aboriginal people' and 'Indigenous people' in this paper may be confusing to an international readership. Adding brief definitions of terms will help to clarify.

There is a footnote at the bottom of pag 4 which provides clear definitions of these terms for the reader.

5. In the second last paragraph of the Introduction, the authors slip into what reads like essentialized conceptualizations of "Indigenous knowledge", and "Aboriginal identity". This could be avoided by editing this paragraph to allow for hybridity. For example, the sentences on p. 4, line 23-25, could be revised by discussing, "Indigenous knowledges" [plural] to avoid perpetuating notions of Indigenous knowledge as singular or uniform. In the following sentence, the authors could say, "Aboriginal identities tend to value…." vs constructing "Aboriginal identity" as singular.

This is valuable input and we have edited the paragraph based on the reviewer's suggestions.

Re: Methods:

6. This leads to another area of clarification needed. In the first paragraph of the Recruitment section, one of the inclusion criteria was self-reported "First Nations identity." Given the shifting landscape of terminologies used to describe identity and ancestry in Canada, I encourage the authors to provide an explanation of how they defined "First Nations identity" to the respondents, to help the readers understand how the respondents either decided to self-select themselves into the study or not. (For example, was First Nations defined in ways that were consistent with Statistics Canada's definitions?)

The recruitment section has been updated to include a more detailed explanation of how "First Nations identity" was defined. Unlike the Statistics Canada definition, we were able to base these criteria on a more open dialogue and conversation between participants and trusted community site coordinators and interviews working at DAHC (pg 6).

7. It would be useful to see some brief detail (e.g. sociodemographic characteristics) on the "seed" participants, and how and why they were purposively selected. Who were the seeds and how diverse were they?

A more detailed description of the sociodemographic characteristics of the seeds has been provided (pg6).

8. In the section describing the Sources of Data, please add a brief example of the kinds of survey

items that focused on impacts of colonization. Although the authors' refer to full report on the OHC community survey (Ref #34 in the manuscript), and I accessed the report, it may not be readily accessible to others. This domain will be of particular interest to other researchers, so providing one or two examples of items that focused on this domain would be helpful.

Examples of the survey measures that focused on impacts of colonization have now been highlighted in the text (pg 7).

Results:

9. In the opening paragraph, the authors state that recruitment chains usually overcome sampling bias after 6 or 7 waves of recruitment, however they do not explain why. Adding a brief explanation would help to further justify the rigor of this approach. Given the diversity of Aboriginal peoples in urban areas, it is important to explain how this diversity was captured (e.g. people of varying SES and people in different social circles).

An additional statement about how sampling bias was overcome has been added (pg8). Diversity was captured through the selection of diverse seeds as indicated above and on page 6.

10. Make it clearer throughout that the results are based on self-reported survey responses vs linked data sources (e.g., provincial records of emergency room visits, hospital visits, and neighborhood income quintiles). For example, at first glance, in the last paragraph of the Results (just above the Discussion section), it is not clear whether the rates of hospitalization are self-reported or based on the ICES data.

Clarification around self-reported vs. linked ICES data has been made throughout the results section.

11. Also in the Results section, when describing the 43.3% who rated the availability of healthcare as "good", how does that relate to the common barriers to healthcare that are listed in the sentence that follows? These percentages would be better served by contextualizing them for the reader – otherwise, they read as decontextualized frequencies. This is particularly important given the authors' aims, as identified in the discussion, to provide clear examples of health and socio-economic health status inequities.

While, 43% felt availability of health care was good, 40% of the population felt their level of access to health care was fair or poor. Given the geographic proximity to extensive health and social services that the City of Hamilton provides, this substantiates the idea that just because the services are geographically proximate, does not mean that they are accessible to First Nations people. We have highlighted this finding in order to better contextualize the barriers to healthcare which are listed in the same paragraph (pg 10).

12. The Results did not present health outcomes based on gender or family structure, although these are known to intersect with a broad range of social determinants to differentially influence the health of Aboriginal men and women. This will be important to consider in future analyses of this sample, and when using RDS in the future. I encourage the authors to briefly discuss this point.

This is an excellent point. As we develop methodologies around RDS and multivariate analyses, we will be able to explore these findings more in depth and can look at gender and family structure and how they intersect with a range of social determinants to influence health outcomes for Aboriginal men and women.

Minor edits:

13. In Table 1: To interpret the prevalence of self-reported overcrowding, provide a brief definition from Statistics Canada (2013): “A higher value of ‘persons per room’ indicates a higher level of crowding”.

This has been added and referenced in the footnote under table 2.

14. In the Results section, a barrier was “long waiting lists”. Provide examples of what people were waiting for (presumably referrals to specialists?).

Yes, this clarification has been made on page 10.

References:

Statistics Canada (2013). Housing suitability of private household. Retrieved from http://www.statcan.gc.ca/concepts/definitions/dwelling-logement-07-eng.html

Statistics Canada (2014). Aboriginal Peoples Survey. Retrieved from http://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=3250&lang=en&db=imdb&adm=8&dis=2)

VERSION 2 – REVIEW

REVIEWER	Ingeborg Zehbe Scientist, Thunder Bay Regional Research Institute, Canada Adjunct professor, Lakehead University, Canada
REVIEW RETURNED	13-May-2014

GENERAL COMMENTS	A few minor editorial corrections needed: page 3, first paragraph page 7, second paragraph

REVIEWER	Annette J. Browne University of British Columbia School of Nursing Canada
REVIEW RETURNED	24-May-2014

GENERAL COMMENTS	The authors could do a better job of relating aspects of their findings to what is already known in the existing literature. Doing so would broaden the relevance and significance of their work, and make it seem less like a "one off" project. The authors have addressed many of the recommendations in my prior review. There are several additional revisions that I would classify as minor before publishing this paper.

VERSION 2 – AUTHOR RESPONSE

Reviewer: 1

A few minor editorial corrections needed:
page 3, first paragraph

Minor corrections were made to the first paragraph, however the terms “diasporic” and “indigeneity” remain. Diasporic is used here as an adjective to refer to a group that has been dispersed outside its traditional homeland. In 1991, the World Bank adopted the following definition of indigeneity. Indigenous Peoples can be identified in particular geographical areas by the presence in varying degrees of the following characteristics:
a) Close attachment to ancestral territories and to the natural resources in these areas;
b) Self-identification and identification by others as members of a distinct cultural group;
c) An indigenous language, often different from the national language;
d) Presence of customary social and political institutions; and
e) Primarily subsistence-oriented production.

page 7, second paragraph

Minor editorial adjustments have been made to improve clarity in this paragraph.

Reviewer: 2

The authors have addressed most of the recommendations in my initial review, and have integrated new literature on urban Indigenous populations, which was missing in the initial draft. There remain some missed opportunities to connect the points raised in this paper concerning health determinants and access to healthcare for urban First Nations to the extant literature. Doing so will help to enhance the relevance and significance of this paper to other contexts and jurisdictions. For example, the points on page 23, lines 13-16, and page 31 lines
17-20, echo the points made the authors below in relation to use of emergency departments for health issues that, ostensibly, could be addressed in community-based clinics, and the extent to which high proportions of First Nations people continue to be dismissed or disregarded when attempting to access healthcare (Browne et al., 2012; Browne et al., 2011; Kurtz, 2008). I am providing examples of literature below, not to promote these papers in particular, but because they link directly to many of the points raised in authors’ paper, and it is important to situate their paper in relation to existing literature, particularly in the Canadian context.

Browne, A. J., Smye, V. L., Rodney, P., Tang, S. Y., Mussell, B., & O'Neil, J. D. (2011). Access to primary care from the perspective of Aboriginal patients at an urban emergency department. Qualitative Health Research, 21(3), 333-348. doi: 10.1177/1049732310385824

Browne, A. J., Varcoe, C. M., Wong, S. T., Smye, V. L., Lavoie, J. G., Littlejohn, D., et al. (2012). Closing the health equity gap: Evidence-based strategies for primary health care organizations. International Journal for Equity in Health, 11(59), 1-15. doi: 10.1186/1475-9276-11-59

Kurtz, D. L. M., Nyberg, J. C., Van Den Tillaart, S., & Mills, B. (2008). Silencing of voice: An act of structural violence: Urban Aboriginal women speak out about their experiences with health care. Journal of Aboriginal Health, 4(1), 53-63.

The reviewer raises some excellent points and highlights some important work being done in this area. We have contextualized the high rates of emergency room use in order to reflect these issues and have included references to this relevant research.

5. The authors have tried to address the tendency to make essentialist claims about Aboriginal people but this still occurs in some areas. Page 23, line 31 could be revised to say, “Aboriginal identities tend to value the group over the individual…” vs framing this in absolutes.

This sentence has been revised to reflect the reviewers’ comments.

Page 29, line 9 at end of paragraph: the authors could add some interpretation, that the high rates of emergency room visits may also reflect a perceived lack of access to community-based or primary care settings, despite geographic proximity.

As indicated above, we have added more interpretation around the high rates of emergency room visits in the discussion (pg. 13).

Page 30, line 36: add that other research also shows that people tend to concentrate in lower income neighborhoods (Peters & Andersen, 2013). It’s not just in Toronto where this is occurring. You cite Peters & Andersen but are not drawing on them to broaden this point to other jurisdictions.

The authors have included references to indicate that this is occurring in other urban jurisdictions in Canada.

Page 30, line 39: consider revising “skilled professionals” to “occupations”, which implies a broader range of employment categories than the notion of “skilled professionals”.

The change has been made.

Page 31, line 8: revise the clause re: “the unavailability of physicians” to refer to the “unavailability of primary care providers including physicians, nurses, and other healthcare providers”. The problem is not just the unavailability of physicians, as the literature shows repeatedly.

The clause has been revised.

Minor edits:

In the abstract, if words permit, add one sentence about the implications of using RDS to illustrate disparities (e.g., to guide health services delivery, programming, policy).

The implications of RDS with respect to services and policy has been added to the abstract.

Page 23, line 32, values should be singular.
Page 24, line 15 – there is a typo. Lines 18-22: the sentence structure needs correcting.
Page 29, line 40: Consider changing to, “This may [vs can] be partly be explained by a higher birth rate.

The manuscript has been revised to reflect these changes.