Author’s response to reviews

Title: Assessing service use for mental health by indigenous populations in Australia, Canada, New Zealand and the United States: A rapid review of population surveys

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Response to reviewers

Paper: Assessing service use for mental health by Indigenous populations in Australia, Canada, New Zealand and the United States: A rapid review of population surveys

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To the editor of BMC Health Research Policy and Systems,

We thank you for considering our paper for publication and the reviewers for putting in their time to make comments. Please find below our response to the two reviewers who provided feedback. Also attached is a new draft of our paper where we have incorporated the relevant changes using track changes.
Looking forward to your response,

Sincerely

Cecily McIntyre (on behalf of all other co-authors)

07/10/2017

Reviewer #1

Comment 1

The manuscript is quite lengthy and could be reduced in size.

Response

We have reduced the length of the Implications section of the Discussion. Details and data about specific evidence were removed, in favor of summary statements that cited the individual pieces of evidence.

Comment 2

However, in order to place the findings in context, several important questions must be addressed. First, the manuscript provides little information on the aims of each of the nine surveys examined. It would make sense to make comparisons about what information is being collected if each survey had the same or similar aims. However, differences in the type and quality of information being collected could be attributed to several factors, including, 1) the specific questions being asked; 2) the relevance of the questions to the particular indigenous population (while all the populations reside in former British colonies, the countries represented have different needs and different resources available to address those needs); 3) whether the surveys were intended to assess needs, test hypotheses, and/or monitor performance; and 4) the willingness of indigenous populations to provide the information or assign priority to the information being collected. It appears that some of the surveys listed were collected as part of specific research projects designed to ask specific questions about mental health services, while others represent administrative data sets designed to monitor health and health services use. It would not be surprising, therefore, that they collect different types of information.

Response
In response to the reviewer’s comment, we added an extra column, “Survey Aim(s) and Scope,” to Table 2.

We summarized these findings in narrative form in Step 1 of the Results (page 9):

“The surveys’ aims and scope varied with respect to their relative emphases on: the measurement of health or mental health; the measurement of mental disorders or more broadly defined mental health problems; aspects of service use assessed; the range of health-related characteristics assessed; and whether they were designed to facilitate comparison to other populations.”

We then described the effect the different aims may have had on survey content in Paragraph 2 of the Discussion (Page 14). Much of this content was pre-existing:

“That said, the variability between the surveys of Indigenous people may, in part, reflect their varying aims and scope. For example, those designed to enable comparability with other populations tended to include a large range of mainstream intervention types and health professionals consulted [23, 35]. One other designed for use in a discrete Indigenous community included questions about perceived barriers to care due to discrimination [32]. Some surveys considered health more broadly than just mental health, and did not measure service use for mental health independently from physical health service use. This makes disaggregating the former difficult [30, 31]. In contrast, surveys designed to focus on mental health specifically [23, 35] tended to include more detailed questions within and across the components of the framework.”

Comment 3

This relates to a second important question left unanswered by the manuscript, which is why were all the data recommended by the authors not being collected by these surveys. The authors suggest that indigenous surveys are not collecting the same or as much information as "mainstream surveys" on mental health services, but offer no explanation as to why this is the case. Even if we are to agree that such information is important, it is important to understand the reasons why such information is not being collected.

Response

While we cannot speculate on the reason why the surveys of Indigenous people did not collect all of the information collected by general population surveys, the different aims and scope of the surveys (see response to comment 2 above) do help to explain some omissions in question content.

Comment 4
The manuscript argues that sample sizes of indigenous populations in mainstream surveys are too small to make meaningful comparisons, but this precludes determining whether such information can be used to assess patterns of mental health services use in such populations.

Response

Please see this addressed in the Background section (Paragraph 5, Page 5) below.

“General population surveys rarely capture a large enough number of Indigenous respondents to draw conclusions about the extent and nature of their service use for mental health [22], although there are exceptions [23]. Even if they did include samples of sufficient size, question content may not acknowledge specialty Indigenous health services and interventions available or relevant for Indigenous people, such as traditional healers and culturally-based interventions [22].”

Comment 5

The manuscript summarizes the type of information being collected and not collected across all nine surveys. Despite the small sample size, it would have been helpful to know if there are differences across the countries examined. For instance, is more information available from the surveys conducted in the United States or Canada than the surveys conducted in Australia or New Zealand?

Response

We addressed this comment in the Results section by listing within each component of the service use framework the countries whose surveys included questions on that topic (in parentheses). Then, we aggregated this information into a sentence at the end of Step 3 of the Results section (Page 13).

“The survey from the US and the survey from New Zealand covered content from eight of the service use components; the three surveys from Canada covered from three to six components; and the survey from Australia covered five components.”

Due to the small number of surveys from each country, trends in how much information was collected were not evident across countries. Taking the United States as an example, the two state-wide surveys each collected information on fewer service use components and contained less Indigenous-specific content than the third US survey, the AI-SUPERPFP. Variability between how much information was collected was more easily accounted for by the different aims and scope (see response to Reviewer 1, Comment 2 above).
Comment 6

Did the indigenous peoples represented in these surveys participate in decisions as to what information would be collected and how it would be collected?

Response

We researched the reviewer’s question by examining surveys’ methodology reports available online and added our findings to Step 1 of the Results section.

“All nine surveys indicate in their methodology reports [23, 32, 33, 35, 37-41] that the survey’s sampling strategy and/or survey content was designed with cooperation or input from Indigenous people. In the information available online, more specific collaboration with Indigenous people was described for five surveys from Canada, New Zealand and the US [23, 32, 35, 39, 40]. For example, the First Nations Regional Longitudinal Health Survey was developed with Indigenous people and replaced a Western-based analytical framework with one based on First Nations principles. The culturally appropriate interpretation model served as a basis for the survey’s content design and allowed the information to be presented back to Indigenous communities in a way that was usable and reinforced a First Nations’ perspective [32].”

Comment 7

Finally, while the manuscript identifies a host of variables that should be incorporated into mental health surveys of indigenous populations, it would be helpful to know if there exist mainstream surveys that currently collect all of this information in the study countries and whether oversampling of indigenous populations in these surveys would address the problem. The manuscript should address the strengths and limitations of this approach relative to the design and implementation of indigenous surveys.

Response

This is now clarified in Step 2 of the Results section (Pages 9-10).

“Each general population survey collected information on eight or more of the nine service use components. Canada’s survey assessed all of the nine components. Within components, there was some variability, for example: the surveys from the US and New Zealand omitted questions about perceived need for care, and Australia’s survey did not include questions about treatment dropout.”

It is important to note that oversampling is only relevant where it is appropriate to the distribution of the population, and may not be an option in some contexts. Interestingly, the NZMHS, which did oversample Indigenous people, also included a supplementary interview schedule to ensure it captured Indigenous-specific health service use. However, it was beyond
the scope of this study to examine other survey design issues such as sampling methods, as noted in the Strengths and limitations section (pages 14-15):

“Finally, it was beyond the scope of this study to consider other aspects of survey design, such as sampling methods or the cultural challenges inherent to using surveys as an assessment tool among Indigenous communities [43]. Further work to develop the most Indigenous appropriate approach to assessment is needed [43].”

Reviewer #2:

Comment 1

It seems to me that this paper will be extremely useful in helping researchers to develop or redesign mental health service use surveys intended for use with Indigenous populations. With this in mind, it would be great if the authors could elaborate more on the differences in how, and what kind of, information is collected in Indigenous surveys versus "mainstream" surveys.

Response

The existing Results section includes a thorough summary of what kind of information is collected (by service use component) in surveys of Indigenous people, and how this differs from the general population survey content. For example, the section below (page 12) describes how the surveys of Indigenous people collect information on interventions received.

“Interventions received were not consistently assessed. Three surveys of Indigenous people (Australia, New Zealand and US) asked about interventions received, with a focus on counselling sessions [23, 34, 35]. One survey asked about alcohol treatment programs [35] and one asked about substance use education [35]. Other Indigenous-tailored questions included those about use of traditional medicine and wellness practices like tribal ceremonies [23, 35]. No surveys of Indigenous people included questions addressing the use of other forms of therapy such as psychotherapy, cognitive-behavioural therapy, or alternative therapies. No surveys of Indigenous people included questions about the use of web-based interventions for mental health and substance use treatment; however, these did not feature in general population surveys, most likely because they were conducted before most developments of this area occurred.”

Finally, we expanded the summary paragraph at the end of Results, Step 3 (Page 13) to include more specific examples of Indigenous-specific content identified in the surveys:

“Questions or response options tailored for the Indigenous context included: questions around spirituality; response options for Indigenous health professionals and traditional healers; response options for traditional health and wellness practices, alcohol treatment programs and substance use education programs; and response options for communication barriers, the service
not being culturally appropriate, and a dislike of doctors. Notable omissions from surveys of Indigenous people included […]”

Comment 2

The rationale for using mainstream surveys in the development of the authors’ review framework should be elaborated on and expanded (page 9, lines 16-36).

Response

A new sentence in Step 2 of the Methods section (page 7) justifies the approach of using the general population surveys as a framework:

The CIDI-based general population mental health surveys were used as a basis for the review framework because, collectively, they considered a broad range of topics in the assessment of mental health service use [18].

Comment 3

Omitting discussions in this review of sections of Indigenous surveys such as questions about perceptions of mental health (page 17, lines 39-47) could impede the development of future surveys; this should be discussed and clarified.

Response

A new sentence in the Strengths and Limitations section (pages 14-15) explains why these questions were out of scope for this review.

“First, our review focused on survey content relating to respondents’ use or perceived need for mental health services. We recognise, however, that the surveys assess other factors that may influence individuals’ help-seeking. Notably, for example, three surveys of Indigenous people captured respondents’ general perceptions of the availability of mental health care in the community, including culturally appropriate mental health services. These questions were asked of all respondents, regardless of whether they had used or wanted mental health care. It was beyond the scope of this review to examine such factors, but these could be the focus of a future review.”

Comment 4
The background and abstract cite the poor mental health of Indigenous peoples in Australia, New Zealand, Canada and the United States as part of the rationale for the study. These disparities are, however, highly uneven within and among Indigenous populations in each of these countries and information on health disparities tends to be limited, not easily comparable, or excludes certain Indigenous populations. While in aggregate, health disparities are a concern, highlighting the poor mental health of Indigenous peoples as a generality can lead to portrayal of Indigenous communities as "damaged" (Tuck, 2009). Further, there is a strong rationale for this study in the limited nature of currently available information on mental health service use by Indigenous peoples (e.g. page 5, lines 13-34) - even if rates of mental health problems were the same for Indigenous and non-Indigenous populations. I would suggest focusing on addressing gaps in information because of the disparities in how information is collected in Indigenous populations versus non-Indigenous populations, rather than focusing on the poor mental health of Indigenous peoples as the rationale for carrying out this review.

Response

We thank the reviewer for this thoughtful comment. In response, we elaborated on the complexity of the situation in paragraph 2 of the Background section (Page 3), using the results of one US Indigenous survey as an example. We also incorporated the Tuck citation. We do, however, believe it important to at least briefly refer to the documented disparity in mental health status as a profound rationale for this review.

“While wary of the danger of pathologizing Indigenous communities [2], some epidemiological surveys and anecdotal evidence suggests that Indigenous populations in these four countries experience a higher disability and mortality burden from mental disorders and substance abuse than their non-Indigenous counterparts [3-7]. However, findings are not consistent across studies; this may reflect methodological differences as well as within and between-group diversity across Indigenous populations. For instance, an epidemiological study in the US that looked at mental disorders among the Southwest and Northern Plans American Indians found that neither group experienced a higher overall burden of mental disorders as compared to the general US population, yet both experienced disparities (to different degrees) in particular disorders, such as lifetime alcohol dependence and lifetime posttraumatic stress disorder [8].”

Comment 5

A brief discussion of what "service use" means and the debates in the literature around defining access and service use would be beneficial.

Response
We inserted a sentence in the Background section (Page 4, Paragraph 4) on the meaning of service use.

“The definition of service use has also been debated and is evolving; with the focus shifting from the types and volume of services received, toward a multi-dimensional approach that encompasses quality of care, person-centeredness, comprehensiveness, integration, continuity, accessibility and cost of health care [17].”

Comment 6
I would capitalize the word "Indigenous," throughout.

Response
We have made this change.

Comment 7
A brief overview of the mental health service systems in each country would also be useful; for example, do differences between public universal health care and private health care plans need to be taken into account in survey design? Do these differences account for some of the inconsistencies between surveys?

Response
Using information from four sources, we created a new table (Table 1) that summarizes the different health service systems in the four countries (health service system and private insurance role; funding for mental health; and health service system applicable to Indigenous populations). This background knowledge is cited in the Background section.

The relationship between countries’ health service systems and the content of their respective surveys is also then considered in the Discussion section (Paragraph 2, Page 14).

Finally, health service system differences that might need to be taken into account in survey design, as well as differences that might have accounted for existing omissions, have been pointed out, where relevant, in individual topic sections of the Discussion (Hospital admissions; Health professionals consulted; and Number, duration, payment and location of health professional consultations).

Comment 8
Page 18, line 54 or 55: what do "hospital separations" refer to?

Response

This line was removed as part of our edits to reduce the length of the paper. However, “hospital separations” (a term used in Australia) are referred to as “hospital dispositions” in the United States – a “separation” occurs any time a patient leaves a hospital due to death, discharge, or departure against medical advice.

Comment 9

The findings of this study will be very useful for other researchers as well as Indigenous organizations and communities. Overall, more clarity on how other researchers can make use of these findings would be helpful. If the goal is "greater comprehensiveness and uniformity" (page 28, line 5/6) among surveys, then a discussion of how this can be achieved while also taking into account culture- and nation-state-specific contexts of service delivery and use would help other researchers to incorporate these findings into their own work.

Response

Our review considered the assessment of mental health service use by examining how it has been assessed in general population surveys and in surveys of Indigenous people. This has yielded examples and ideas that may be useful for future survey designs, but which ones are relevant and how they are applied will depend upon the survey purpose and scope, feasibility, and the culture- and nation-state-specific contexts of service delivery. This is explained in Implications (Paragraph 1, Page 5).

“That said, the extent to which particular aspects of service use, or response options, may apply to the design of future surveys will depend on the aim and scope of those surveys, feasibility, and the culture- and nation state-specific contexts of service delivery.”