Interventions for Indigenous Peoples Making Health Decisions: A Systematic Review

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Abstract

Background: In general populations, shared decision-making (SDM) facilitates care provider and consumer collaboration for informed health decisions. This study identifies SDM interventions to support Indigenous peoples making health decisions.

Methods: A systematic review developed in dialogue with stakeholders using the Cochrane Handbook. A comprehensive search was conducted of electronic databases including all dates to present. Two independent researchers screened and quality appraised included studies. Findings were analyzed descriptively and reported using guidelines for equity focused systematic reviews.

Results: Of 1,769 citations screened, 1 study was eligible for inclusion. This study was a randomized control trial rated as low quality for randomization and unclear for the other risk of bias criteria (allocation concealment, performance, detection, attrition, reporting bias). The study was conducted in the US with 44 students ages 11–13, and representative of Pueblo, Navajo, Hopi, and Jicarilla Apache Indian Nations. A culturally relevant tool assessed student decision-making skills before and after intervention. Students demonstrated increased decision-making knowledge and were able to apply a four-step decision-making process to health situations.

Conclusions: There is a lack of studies evaluating SDM among Indigenous peoples. One study demonstrated that a culturally relevant approach improved knowledge and application of decision-making skills. Further studies are needed.

Key Words: Indigenous peoples, Aboriginal peoples; children and youth; First Nations, Inuit, Métis; decision-making; intervention studies; equity; systematic review.

Background

Globally, Indigenous populations are identified as experiencing significant inequities in health status (Commission on Social Determinants of Health [CSDH], 2008; Nettledon et al., 2007). Indigenous peoples are disadvantaged in the social determinants of health and are among the most vulnerable populations in terms of poor health related to socioeconomic and environmental factors (CSDH, 2008). The results of these disadvantages are health inequities, defined as preventable, systematic, and socially produced differences in health between and within populations (World Health Organization [WHO], 2010). The evidence of health inequity is an indicator that Indigenous populations require opportunities to participate in health care that meets their self-identified needs. Shared decision-making (SDM) has the potential to decrease health inequities among Indigenous populations by facilitating participation in health care that better meets their self-identified need.

SDM is a process that promotes collaboration between health care providers and recipients in decisions affecting health (Elwyn et al., 2000; Towle and Godolphin, 1999) and it is a central feature of patient-centred care (Dagone, 2009; Weston, 2001). SDM has been found to improve clinical decision-making and client satisfaction with the health care experience (Keisler and Auerbach, 2006; O’Connor and Jacobsen, 2007). Support for SDM approaches are emerging in health policy in Canada (Légare et al., 2011) the US (Senate and House of Representatives, 2010), and other international settings (Härter et al., 2010; McCaffery et al., 2011). Patient decision aids can facilitate SDM.
Patient decision aids, in the form of pamphlets, videos, and web-based programs, are interventions that make explicit the decision to be made; provide evidence based information on options, benefits, and risks; and help patients determine a preference and risks; and help patients determine a preference. This study addresses the following: to identify effective interventions to support Indigenous peoples making health decisions. To achieve this purpose, the objective of the review was to search for published studies conducted with populations identified as Indigenous and making health decisions. The following key databases were searched with no start date limitation, i.e., from the earliest data sources on each database, e.g., 1947 or earlier, and up to 16 September 2012: MEDLINE, OVID, EMBASE, PsychINFO, CINAHL, Proquest Nursing and Allied Health, ERIC, Cochran, and Sociological Abstracts, as well as a planned hand search of gray literature. The search strategy used by the librarian to conduct the database searches is shown in Figure 1. Details on the inclusion/exclusion criteria used to guide selection of studies may be found in Table 1. The search and selection details are also available elsewhere (Jull et al., 2012).

**Figure 1. Flow Chart for Included and Excluded Studies**

<table>
<thead>
<tr>
<th>Title Screening</th>
<th>Abstract Screening</th>
<th>Full Text Screening</th>
</tr>
</thead>
<tbody>
<tr>
<td>Citations identified through database (n=2,160)</td>
<td>Duplicates removed (n=843)</td>
<td>Citations included (n=1,317)</td>
</tr>
<tr>
<td>Abstracts screened (n=609)</td>
<td>Citations excluded (n=1,342)</td>
<td>Citations excluded (n=962)</td>
</tr>
<tr>
<td>Abstracts unsuitable noted on full text screening (n=215)</td>
<td>Full text screening (n=14)</td>
<td>Citations excluded (n=11)</td>
</tr>
<tr>
<td>Studies excluded (n=13)</td>
<td>Studies included (n=1)</td>
<td>Population (n=3)</td>
</tr>
</tbody>
</table>

**Table 1: Criteria for Study Eligibility**

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Included</th>
<th>Excluded</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population</td>
<td>People defined as Aboriginal/Indigenous and as making a health or social decision for themselves and/or a family member.</td>
<td>Aboriginal/Indigenous people are not identified as a distinct group.</td>
</tr>
<tr>
<td>Intervention</td>
<td>Interventions to influence health or social decision-making.</td>
<td>Intervention does not involve a decision that affects health.</td>
</tr>
</tbody>
</table>

**Methods**

Systematic reviews involve a process of searching, selecting, appraising, and synthesizing research studies to answer a specific question (Higgins and Green, 2011). They can help build an evidence base about effective interventions for improving health outcomes (Kelly et al., 2007). Within the area of Indigenous health this review will contribute to an evidence base that can be used to promote practices, such as SDM interventions, that may minimize health inequities among Indigenous populations. This systematic review was based on the Cochrane Handbook (Higgins and Green, 2011), which provides reporting guidelines that promote completeness and transparency in the research methods and reporting of results. The assessing the Methodological Quality of Systematic Reviews (AMSTAR) (Shea et al., 2007) criteria were used in developing this systematic review. The Preferred Reporting Items for Systematic Reviews and Meta-analysis Equity 2012 (PRISMA-E) (Welch et al., 2012) was used to report the results. A study protocol for this systematic review was previously published (Jull et al., 2012), and includes details on methods used. The only change in study methods was the use of the PRISMA-E Equity 2012 (Welch et al., 2012) instead of PRISMA (Moher et al., 2009), as the PRISMA-E includes criteria to assess for intervention effects on health equity (Appendix A). The following provides a brief summary of the study methods.

**Results**

Of the 1,769 citations identified, 1 study was eligible for inclusion (Figure 2). Of the 34 studies which...
Table 2. List of Excluded Studies

<table>
<thead>
<tr>
<th>Reason for Exclusion: Population</th>
<th>Reason for Exclusion: Methodological</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ho, L.S., Gittelsohn, J., Rima, L.R., Treuth, M.S., Sharma, S., Rosecrans, M.R. (2012). The decisional balance sheet to promote healthy behavior.</td>
<td>To be excluded due to the focus on the decisional balance sheet.</td>
</tr>
<tr>
<td>Fahrenwald, N.L., Belitz, C., and Keckler, A. (2010). Outcome evaluation of a school-based nutrition intervention for urban Native American youth.</td>
<td>To be excluded due to the focus on school-based nutrition intervention.</td>
</tr>
<tr>
<td>Filling the void: A multi-component, culturally adapted smoking prevention program incorporating Western and non-Western therapies.</td>
<td>To be excluded due to the focus on smoking prevention.</td>
</tr>
<tr>
<td>Marron, J.R. and Bussey, M. (2007). Results of an alcohol prevention program in Native American urban settings.</td>
<td>To be excluded due to the focus on alcohol prevention program.</td>
</tr>
<tr>
<td>Fehr, G., Schieber, S., and Wettstein, D. (2007). Age, sex and ethnic differences in health-related quality of life among Native American youth.</td>
<td>To be excluded due to the focus on age, sex and ethnic differences.</td>
</tr>
<tr>
<td>Gellert, K.S., Aubert, R.E., and Mikami, J.S. (2010). Ke ‘Ano Ola: Hawaii Statewide Native Hawaiianheart Health Program.</td>
<td>To be excluded due to the focus on the Native Hawaiianheart Health Program.</td>
</tr>
</tbody>
</table>


Figure 2. Results: 1 Database: OVID MEDLINE(R) in Process & Other Non-Cited Indexes and OVID MEDLINE(R) (1946 to Present) Search Strategy:

1. Choice Behavior/
2. Decision Support Techniques/
3. Educational technology/
4. Decision making Behavior/
5. (decision adj3 aid$).tw.
6. (decision adj3 aid$).tw.
7. (decision adj3 tool$).tw.
8. decision support tw.
9. decision making tw.
10. (decision$ or choices or preference$).tw.
11. (patient$ or consumer$ or client$) adj1 (decision$ or choices or preference$).mp.
12. (patient$ or consumer$ or client$) adj1 (decision$ or choices or preference$).mp.
13. exp Health Behavior/
14. exp Health Education/
15. informed consent mp.
16. or/15-40
17. (personal or interpersonal or individual or parent$) adj (decision$ or choices or preference$).mp.
18. ((personal or interpersonal or individual or parent$) adj (decision$ or choices or preference$).mp.
19. informed consent.REF.
20. and/16-19
21. (decision$ or choices or preference$).tw.
22. exp Attitude to Health/
23. exp Health Behavior/
24. exp Health Education/
25. exp Health Promotion/
26. exp Public Health Nutrition/
27. exp Social Sciences /
28. maori$.tw.
29. aborigin$.tw.
30. eskimo$.tw.
31. pacific islander$.tw.
32. maori$.tw.
33. aborigin$.tw.
34. eskimo$.tw.
35. pacific islander$.tw.
36. maori$.tw.
37. aborigin$.tw.
38. (native adj1 alaskan$).tw.
39. (native adj1 asian$).tw.
40. or/24-39

Search Strategy:

1. ((patient$ or consumer$ or client$) adj1 (decision$ or choices or preference$)).mp.
2. exp Health Behavior/
3. exp Health Education/
4. exp Social Sciences /
5. (decision adj3 aid$).tw.
6. (decision adj3 aid$).tw.
7. (decision adj3 tool$).tw.
8. decision support tw.
9. decision making tw.
10. (decision$ or choices or preference$).tw.
11. (personal or interpersonal or individual or parent$) adj (decision$ or choices or preference$).mp.
12. (personal or consumer$ or client$) adj (decision$ or choices or preference$).mp.
13. informed consent.mp.
14. or/18-21
15. 10 or/17 or 22
16. (decision$ or choices or preference$).tw.
17. native indian$.tw.
18. macor$.tw.
19. aborigin$.tw.
20. first nation$.tw.
21. amerindian$.tw.
22. or/18-21
23. 24 and 40
24. aborigin$.tw.
25. aborigin$.tw.
26. aborigin$.tw.
27. aborigin$.tw.
28. aborigin$.tw.
29. aborigin$.tw.
30. aborigin$.tw.
31. aborigin$.tw.
32. aborigin$.tw.
33. aborigin$.tw.
34. aborigin$.tw.
35. aborigin$.tw.
36. aborigin$.tw.
37. aborigin$.tw.
38. aborigin$.tw.
39. aborigin$.tw.
40. or/24-39

Characteristics of the Included Study:

The included study was a randomized controlled trial (see Table 3). The study enrolled 44 male and female adolescents and final results are reported in the study for 45 adolescents. One participant from the intervention group withdrew from the study but no rationale was provided. In the study, participants were described as randomly assigned by computer to the intervention group (daytime health class decision making skill: n=23) or control group (evening class not learning about decision making skill: n=22).

Study participants had a mean age of 12.6 years and were described as of American Indian descent and representing the Pueblo, Navajo, Hopi, and Jicarilla Apache Indian Nations. The study setting was described as a boarding school exclusively for American Indian youth and promoting academic excellence. The school, operating under the Indian Self-Determination Act (PL 93–638), was not intended for children with emotional, psychological, or social problems (Okwumabua and Duryea, 1989).

Quality assessment of the study using the Cochrane Risk of Bias tool revealed low risk of bias for randomization and unclear for other five criteria (allocation concealment, performance, detection, attrition, and reporting bias) due to inadequate reporting (Table 4).

Characteristics of Interventions:

The study intervention consisted of teaching a four-step decision-making process to participants, as described in Table 3. A modified version of the decision making tool (Centres for Disease Control, 1984) was used to assess the students' baseline and post-intervention decision-making skill level. The decision making tool was modified to be culturally relevant by incorporating realistic aspects of American Indian culture and social environments in each decision scenario. The tool was also reduced from five to four steps (Okwumabua and Duryea, 1989).
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Characteristics of Outcome Measures

Outcomes measures of the decision making tool included the students’ knowledge and application of the four-step decision making process at pre- and post-intervention. The tool consisted of a series of scenarios describing a person in the act of making a decision. For each scenario, selections from the four-step decision-making intervention were provided, either in the scenario or in a series of choices that followed the scenario. Students were expected to read the scenario, determine which steps had been taken, select the next step that should be taken to make a “wise” decision. The decision-making tool was modified by curriculum specialists and participating teachers to ensure that it was easy to understand and culturally relevant, and adapted from being a five-step to a four-step process (define decision, identify alternatives, weigh costs/benefits, make a decision). This was based on the methodology that was used. After completing all questions, the test was entered into the computer and students were given feedback.

Study Results

Pre-intervention results indicated no significant differences between or within the control and intervention groups for knowledge of the four steps of decision-making (Table 3). Post-intervention between-group analyses demonstrated that the experimental group demonstrated higher knowledge scores (Table 3). Within-group analyses demonstrated no significant differences in score distribution post-intervention for the control group; however, the experimental group analyses showed that the experimental group had significantly increased knowledge in comparison to usual activities, students in the study align with four of the nine essential elements identified for client-health professional SDM (Stacey and Hill, 2013). Interventions that train health care consumers or members of the general population (i.e., those that are not in a care provider role) to manage decisions that affect their health are not yet evident in the published literature.

The one included study in this review, now more than 20 years old, employed a role-playing strategy for teaching the four-step decision-making process to participating students. The use of a role-playing approach for training in SDM is consistent with more recent and on-going work that has been effective in health care provider populations (Stacey and Hill, 2013). Role-playing has been found to link with behaviour change in care providers and is a key part of the decision coaching curriculum (Ontario Hospital Research Institute, 2012).

These findings indicate that despite the diversity found between participants in the one included study (students, care consumers, Indigenous) and the broader literature about training in SDM
approaches (adult, Western trained care providers, unspecified cultural backgrounds), there may be commonalities in SDM training interventions. Techniques that have been found to successfully promote SDM behaviours in adult care provider populations may also be used in a range of care consumer populations. The important role played by culture in initiatives promoting behaviour change, however, cannot be neglected.

**Importance of Culturally Appropriate Support for Making Health Decisions**

Exploration of concepts relating to SDM, health decisions, and specific subgroups of Indigenous populations in the literature emphasize the role that culture plays in health settings, and highlights a gap in intervention studies for Indigenous people making health decisions. The broader literature concentrates on generating descriptions of health decision-making in Indigenous populations (Edgcombe, 2006; Kelly and Minta, 2007; Minone et al., 2004), in advanced care planning (Kaufert et al., 1998; Paulette, 1993; Thomas et al., 2008), as well as health equity issues and the factors influencing participation of Indigenous women in routine medical screening (Canales, 2004; Canales and Geller, 2004; Canales and Rakowski, 2006). In particular, these studies emphasize the ways in which culture influences individual choice in the health care system rather than focusing on how effective interventions are for particular populations.

While the influence of culture is a critical factor which affects the way health decisions are made, there is evidence that interventions using decision-making approaches may successfully be modified to accommodate cultural needs. For example, in one study conducted with a small group of Native American and Latin women, it was concluded that while cultural adaptation to a process of consultation planning (creation of a question list before physician visit) was necessary, the use of strategies typically applied within those of nonminority groups was successful (Belkora et al., 2009). These findings align with those in this systematic review, in which the one included study employed a decision-making approach developed for non-Indigenous children and youth, which was culturally modified for use with the Indigenous student population (Okuwumabua and Duruya, 1989).

Despite findings that suggest SDM approaches may be adapted for use within Indigenous populations, intervention studies which employ decision-making strategies with this population have focused on compliance, rather than building skills for making health decisions. This is evident in the literature exploring what is presented as health decision-making with Indigenous populations.

**Focus on Compliance versus Decision-Making Skills**

Although some of the studies excluded at level 3 screening (Table 2) promoted decision-making in lifestyle choices, these studies were excluded because the focus was on promoting compliance. Specifically, these intervention studies used decision-making strategies aimed at educating Indigenous participants to comply with particular health behaviours, such as self management in cardiac care (Cook et al., 2010), tobacco use cessation (Montgomery et al., 2012) and preschool dental care practices (Lawrence et al., 2010), in addition to strategies aimed at educating parents to make the “right” choice, rather than to acquire skills to negotiate the challenges of making preference-sensitive decisions.

Instead of directing people in their choices, SDM aims to uphold the principle of autonomy in health settings, and to support people to participate in making decisions about their health (McDonald and Clayman, 2006c). Educational approaches encouraging compliance fail to align with the principles of client-centred care and undermine client-centred, informed choice. Moreover, a focus on compliance will not help clients to manage decisional conflict, make commonly associated medical decisions, or negotiate preference-sensitive decisions (Legat et al., 2010).

In the mental health literature, a focus on compliance has been criticized as failing to help people negotiate difficult decisions with long-term implications for health and well-being (Deegan and Drake, 2006). Additionally, adolescent health literature exploring issues of compliance in disease treatment promotes strategies that facilitate relationships between the care provider and client, encouraging health care providers to engage with and develop understandings of the adolescent and to tailor information to meet the adolescent’s needs — essentially encouraging an SDM approach ( Dmitriev and Muller, 2002; Niggeman, 2005). In the educational literature, “critical thinking skills” training, described as training for adolescents in decision skills, are considered important for academic success, and promoted as crucial for making good decisions that influence health (Elías and Kress, 2009). These views align with the approach taken in the included study in which students were trained in skills that promoted their autonomy in making decisions that would be beneficial for their health (Okuwumabua and Duruya, 1989).

For populations identified as vulnerable to oppression, promoting approaches that facilitate participation in health decisions is of particular relevance. The findings in this review demonstrate that there is a need for further research to promote skills in decision-making, and to equip people to negotiate the complexities associated with difficult choices with implications for health and well-being. SDM is a collaborative process that engages health care professionals and the health care client in making health decisions and is fundamental for informed consent and patient-centred care. More and better designed intervention studies will contribute to building evidence for Indigenous communities and their representatives, as well as policy and decision makers, to better address issues related to health decision-making within Indigenous populations.

**Limitations and Strengths**

The potential limitations of this review included poor indexing of studies in databases and a lack of tested protocols for conducting systematic reviews in the area of Indigenous health. Given the poor indexing of studies in electronic databases, it is possible that some studies were missed; however, there is transparency in the extensive search strategy used. While the systematic reviews of the literature addressing Indigenous issues are not yet well established and have been challenged (MacDonald, Priest, Doyle, Anderson & Waters, 2010), there is a growing evidence base supporting the role of systematic reviews for conducting and promoting health equity. Additionally, the use of the PRISMA-E in this review to structure the reporting of findings provides a standardized approach, and will enable it to contribute to building evidence on best standards for systematic reviews supporting equity in health (Welch et al., 2012).

Strengths of this review included the comprehensive search strategy developed in collaboration with an academic librarian, use of two independent reviewers at each screening stage, and the iterative and ongoing consultation with an interprofessional team of researchers having expertise in Indigenous health, health decision-making, and systematic review methods.

**Conclusions**

Little is known about effective interventions for supporting Indigenous peoples to participate in health decisions. The findings of this systematic review indicate that more and well-designed studies are needed in the area of promoting SDM for Indigenous populations, and that specific studies must be developed which engage the communities for which the SDM interventions would be relevant. The evidence of health inequity shows that Indigenous peoples could benefit from opportunities presented through the use of SDM to participate in making decisions about their unique health needs. This study identified one randomized control trial study, which, while conducted over 20 years ago, demonstrated that a culturally relevant approach to SDM could improve the knowledge and application of decision-making skills affecting the health of youth representative of the Pueblo, Navajo, Hopi, and Jicarilla Apache Indian Nations. While cultural relevance of SDM approaches or tools have not yet been established in Indigenous populations, the one included study in this review is evidence that builds on two other studies conducted within diverse, although non-Indigenous populations. This suggests that promoting SDM may be acceptable and appropriate for facilitating client-centred processes of decision-making, thereby improving control over health decisions. These studies must be interpreted together cautiously, as the issues underpinning the poor health of Indigenous populations are situated in a unique colonial social and historical context.
and interventions found to be effective within one population cannot be assumed to be generalizable. This review identified a significant gap in the literature in studies evaluating SDM among Indigenous peoples. Better designed and inclusive intervention studies will contribute both to building an evidence base, as well as developing effective approaches to further identify theoretical and methodological issues in health decision-making for Indigenous populations. In this way, effective SDM contributions may be made for addressing health equity issues within Indigenous populations. Systematic review methods in the area of Indigenous health must continue to be developed in a collaborative manner that best meets the needs of those who use them—decision makers, health care providers, and most importantly, that of health care clients.

**References**


### Table 1: Checklist of Items for Reporting Equity-Focused Systematic Reviews

<table>
<thead>
<tr>
<th>Section</th>
<th>Item</th>
<th>Standard PRISMA Item</th>
<th>Pg #</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Title</td>
<td></td>
<td></td>
<td></td>
<td>Identify the report as a systematic review, meta-analysis, or both.</td>
</tr>
<tr>
<td>Abstract</td>
<td></td>
<td></td>
<td>519</td>
<td>Identify equity as a focus of the review, if relevant, using the term equity</td>
</tr>
<tr>
<td>Structured summary</td>
<td>2</td>
<td>Provide a structured summary including, as applicable: background, objective(s), data sources, study eligibility criteria, participants, and interventions; study appraisal and on-study methods; results; limitations; conclusions and implications of key findings; systematic review registration number.</td>
<td>539</td>
<td>State research question(s) related to health equity.</td>
</tr>
<tr>
<td>JA</td>
<td></td>
<td></td>
<td>N/A</td>
<td>N/A, never restriction limits.</td>
</tr>
<tr>
<td>JB</td>
<td></td>
<td></td>
<td>519</td>
<td>Describe sources and limits of applicability to disadvantaged populations of interest.</td>
</tr>
<tr>
<td>Introduction</td>
<td>3</td>
<td>Describe the rationale for the review in the context of what is already known.</td>
<td>540</td>
<td>Describe assumptions about mechanism(s) by which the intervention is assumed to have an impact on health equity.</td>
</tr>
<tr>
<td>JA</td>
<td></td>
<td></td>
<td>N/A</td>
<td>N/A.</td>
</tr>
<tr>
<td>Objectives</td>
<td>4</td>
<td>Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).</td>
<td>540</td>
<td>541 Describe how disadvantage was defined if used as criterion in the review (e.g. for selecting studies, conducting analysis or judging applicability).</td>
</tr>
<tr>
<td>JA</td>
<td></td>
<td></td>
<td>N/A</td>
<td>State the research questions being addressed with reference to health equity.</td>
</tr>
<tr>
<td>Methods</td>
<td>5</td>
<td>Indicate if a review protocol exists, if and where it can be accessed (e.g. Web address), and, if available, provide registration information including registration number.</td>
<td>540</td>
<td></td>
</tr>
<tr>
<td>Eligibility criteria</td>
<td>6</td>
<td>Specify study characteristics (e.g., PICOS, length of follow-up) and review characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving justification.</td>
<td>541</td>
<td>Describe the rationale for including particular study designs related to equity research questions.</td>
</tr>
<tr>
<td>JA</td>
<td></td>
<td></td>
<td>N/A</td>
<td>N/A.</td>
</tr>
<tr>
<td>Information sources</td>
<td>7</td>
<td>Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and data last searched.</td>
<td>541</td>
<td>541 Describe information sources (e.g., health, non-health, and grey literature sources) that were searched that are of specific relevance to address the equity questions of the review.</td>
</tr>
<tr>
<td>Search</td>
<td>8</td>
<td>Specify electronic search strategy for at least one database, including any limits used, such that it could be replicated.</td>
<td>541</td>
<td>541 Specify search terms (e.g., piloted terms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.</td>
</tr>
<tr>
<td>Study selection</td>
<td>9</td>
<td>Specify the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).</td>
<td>541</td>
<td></td>
</tr>
<tr>
<td>Data collection process</td>
<td>10</td>
<td>Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.</td>
<td>541</td>
<td></td>
</tr>
</tbody>
</table>
Data items

11. List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.

541. All measures or variables reported.

11. List and define data items related to equity where such data were sought (e.g. using WHO/SES data or other criteria, context).

541

12 Risk of bias in individual studies

Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level); and how this information is to be used in any data synthesis.

541

Summary measures

State the principal summary measures (e.g., risk ratio, difference in means). 

541 and Table 1.

Theory

Description of the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., for each such meta-analysis).

Descriptive analysis

541

Table 3

545–547

Synthesis of results

541 Table 4.

Describe methods of synthesizing findings on health inequities (e.g. presenting both relative and absolute differences between groups).

541, 545–547

Additional analyses

Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.

541

Risk of bias across studies

545 Table 8.

Describe any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).

Risk of bias across studies

545

Table 4.

Additional analyses

Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.

541

Results

Study selection

Figure 1.

Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.

Study characteristics

545, 546 Table 1.

For each study, present characteristic data for which data were extracted (e.g., study size, PICOS, follow-up period) and provide citations.

541–543; Table 1.

Risk of bias within studies

Figure 1.

Present data on risk of bias for each study and, if available, any outcome level assessment (see item 12).

Risk of bias within studies

545 Table 8.

Results of individual studies

Table 1.

For all outcomes considered (e.g., deaths or harms), present for each study (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.

Synthesis of results

541

Present results of each meta-analysis, including confidence intervals and measures of consistency.

541–543; Table 1.

Risk of bias across studies

545 Table 8.

Present results of any assessment of risk of bias across studies (see item 12).

Additional analyses

Table 1.

545–546

Present results of additional analyses if done (e.g., sensitivity or subgroup analyses, meta-regression) (see item 13).

Discussion

545 Table 8.

Summarize the main findings including the strength of evidence for each main outcome, consider their relevance to key groups (e.g. health providers, users, and policy makers).

545–548

Limitations

Discuss limitations at study and outcome level (e.g., risk of bias), and at review level (e.g., incomplete retrieval of identified research, reporting bias).

541, Table 4.

Conclusions

541

Provide a general interpretation of the results in the context of other evidence and implications for future research.

541

11–17

Present extent and limits of applicability to disadvantaged populations of interest and describe the evidence and logic underlying these judgments.

16

Funding

541

Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.

541

Janet Jull

OTT (Cmt.), PhD(c) conceived of and coordinated the review, conducted the study screening/selection, drafted and circulated the final paper. She trained as an occupational therapist at the University of Western Ontario and worked for 14 years throughout Northern and Western Canada, then obtained a post professional Master’s degree focused on informed consent (Dalhousie University). Janet has also worked in health care management and policy settings. She is currently a PhD candidate in the University of Ottawa Population Health doctoral program and has also obtained a graduate diploma in Health Services and Policy Research at the University of Ottawa. Janet’s current work is focused on exploring the health decision making needs of urban First Nations, Metis and Inuit women, and the ways in which these women can be engaged in culturally adapting an approach to shared decision making.

James A.G. Crispo

MSc, PhD(c) contributed study screening/selection and contributed to the writing of the final paper. He was born and raised in northern Ontario (Blind River) and is of Metis ancestry. He completed his Honours BSc Biochemistry and MSc Chemical Sciences at Laurentian University/Northern Ontario School of Medicine (Sudbury, ON) before beginning his PhD in Population Health at the University of Ottawa. James current doctoral research focuses on pharmaceutical use in knowledge translation tools such as decision aids and policy briefs. Vivian is a co-convener to the Campbell and Cochrane Equity methods Group; a member of the international Grading Recommendations Assessment, Development and Evaluation (GRADE) working group, and a member of the International Clinical Epidemiology Network (INCLEN). As part of her work on methods for considering health equity, Vivian led the development of a reporting guideline for equity-focused systematic reviews, as an extension to the PRISMA statement (Preferred Reporting items for Systematic reviews and Meta Analyses), which was used in this paper.

Vivian Welch

PhD (Population Health) contributed intellectually, conducted the search of the literature and contributed to the writing of the final paper. She has worked in academic libraries and with various research groups in the areas of knowledge synthesis and knowledge translation. She currently works with the Knowledge Translation group at the Li Ka Shing Knowledge Institute.

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Yvonne Boyer, JD, LLM, PhD (LLD) contributed intellectually to the study and the writing of the final paper. She is a Métis from Saskatchewan who received her Doctorate in Law at the University of Ottawa in 2011, Master of Laws in 2003 and Juris Doctorate in 1997. She is a member of the Law Society of Saskatchewan and the Law Society of Upper Canada and specializes in Aboriginal health and the law. Yvonne holds a Research Chair in Aboriginal Health and Wellness at Brandon University, and has been a member of the board of Minwaashin Lodge since 2006. She has acted as the guardian of the Ownership, Control, Access and Possession requirements between the Lodge and this important work on shared decision making.

Dawn Stacey RN PhD CON(C) contributed intellectually during the study development, study screening/selection, and writing of the final paper. She holds a Research Chair in Knowledge Translation to Patients and is Associate Professor, School of Nursing at the University of Ottawa. She is a Scientist at the Ottawa Hospital Research Institute where she is Director of the Patient Decision Aids Research Group. She is the principal-investigator for the Cochrane Review of Patient Decision Aids, co-chair of the Steering Committee for the International Patient Decision Aid Standards Collaboration (IPDAS), and co-investigator for the Cochrane Review of Interventions to Improve the Adoption of Shared Decision Making. Her research includes: knowledge translation to patients; patient decision aid development, evaluation and appraisal; decision coaching; implementation of decision aids and decision coaching into practice; telephone-based care, and interprofessional approaches to shared decision making. She is collaborating with the Ministry of Health in Saskatchewan to implement shared decision making and patient decision aids across the province. She has over 100 publications and 80 invited national and international presentations. Her research program website is http://decisionaid.ohri.ca.