

Assessing Perceptions: A Scoping Review of Qualitative Research Tools for  
Engaging with Vulnerable Populations

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## **Abstract**

Community engagement has become an increasingly important component of health research. With respect to healthcare guidelines, incorporating the perspectives of communities, especially among vulnerable populations, helps to inform policies and practices that will result in improved health outcomes. This scoping review was conducted in order to guide the adaptation of a current stakeholder engagement tool used to assess perceptions of guideline recommendations (GRADE FACE) so that it is appropriate for vulnerable populations. Sources describing qualitative research tools for vulnerable populations were collected and mapped in this review. Information assessed included: tool type, modality of tool delivery, participant recruitment strategies, participant demographics, FACE components evaluated (e.g. feasibility, acceptability, cost, equity), and how these components were assessed.

This review was guided by widely accepted practices for scoping reviews. Six databases were searched for peer-reviewed and grey literature. Title and abstracts were screened for relevance, and full-texts were reviewed and data were mapped. References of included texts were reviewed for additional sources. Three additional grey literature sources were assessed. All relevant materials were reviewed and mapped.

995 sources were returned in the original search, of which 67 were assessed at the full-text level. 36 additional sources were identified from reference searches and three were recommended by a researcher. In total, 30 sources were included in this scoping review. Peer-reviewed literature was the most commonly identified source (n=28). Questionnaires were the most common tools used (n=20). Most participant recruitment occurred in a medical/healthcare context (n=22), with

homeless populations being engaged with the most (n=11). Of the FACE components guiding this review, acceptability most commonly identified in the literature (n=23). FACE criteria were evaluated predominantly with the use of Likert scales (n=20).

Understanding perceptions through research is essential in directing the development of effective and meaningful policies and interventions. The research shows that developing tools to engage with vulnerable populations and assess perceptions is an important area of interest. While some sources included a copy of the research tools used, more transparency is needed with respect tool publication, particularly for those used with vulnerable populations.

*Keywords:* vulnerable populations, qualitative research tools, community engagement, equity research

## **Introduction**

Incorporating the perspectives of multiple stakeholders on public health issues is an important step in developing effective interventions (Morton et al., 2017). This is especially important when these interventions are developed for populations recognized as being vulnerable, at-risk, or marginalized. A consistent and universally accepted definition of a 'marginalized population' is difficult to come by in the literature, however, this demographic can be characterized as "those excluded from mainstream social, economic, cultural, or political life" (Cook, 2008). This can include marginalization on the basis of race, age, financial status, health status, and institutionalization (Cook, 2008; The Belmont Report, 1979). Identifying groups as vulnerable or marginalized is contextually dependent and varies across different social situations (Cook, 2012).

Regardless of the definition used, incorporating the opinions and perceptions of vulnerable populations is increasingly recognized as a necessary component of

health research. Marginalized groups are more likely to experience significant health problems (e.g. HIV/AIDS, tuberculosis, mental health disorders), and tend to face poverty, violence, and exploitation (Government of Canada, 2017). Therefore, incorporating vulnerable persons in research provides an opportunity for such groups to raise concerns, voice opinions, and ensure they are appropriately represented, thus promoting greater equality between researchers and participants (Cook, 2008). This will lead to greater transparency between these two groups, promote relationships, and ultimately enhance the quality of evidence used to inform decision making on policies and programs (Government of Canada, 2019). This is especially important in the development of evidence-informed healthcare guidelines.

A previously developed stakeholder engagement tool to assess perceptions of healthcare guideline recommendations provides a framework for evaluating such recommendations on the basis of feasibility, acceptability, cost, and equity (the GRADE FACE tool) (Pottie et al., in press). This stakeholder survey tool assesses the perceptions of barriers or enabling factors that may affect guideline recommendation uptake and implementation (Pottie et al., in press). The GRADE FACE tool, however, is intended for professional stakeholders. Therefore, amendments to this existing tool are needed to facilitate its use with vulnerable populations.

This scoping review aims to provide an overview of the literature on qualitative research tools that have been developed and used with vulnerable populations. The questions this review aims to answer include: 1) what tools currently exist to assess perceptions and opinions of vulnerable populations, and 2) what are the characteristics of these tools? The results of this review will facilitate the

development of an enhanced equity-focused tool (E-FACE) to be used in assessing guideline recommendations.

## **Methods**

The framework for scoping reviews developed by Arksey & O'Malley (2003) was used to guide the development of this review.

### *Identifying the Research Question*

The aim of this scoping review was to map the existing literature on qualitative research tools in order to identify and evaluate tools used to report and assess perceptions of vulnerable populations. In particular, this scoping review focused on finding sources that assessed at least one component of the GRADE FACE tool (e.g. feasibility, acceptability, cost, equity). The questions '*which tools currently exist for qualitative research on perceptions of vulnerable populations?*' and '*what are the characteristics of these tools?*' guided search strategy development.

### *Identifying the Relevant Literature*

A preliminary assessment of the literature directed the development of search terms. This involved identifying key papers and tools that helped to answer the two guiding questions of this review. Search strings were then developed and included a tool type, tool function, followed by a target population. No publication year limitation was imposed in order to maximize the scope of articles caught in the search. The full search strategy is included in Appendix A.

The literature search was conducted on October 11, 2018. Databases searched included Embase Classic+Embase, Health and Psychosocial Instruments, Ovid MEDLINE(R) ALL, PsycINFO, EBM Reviews - Cochrane Central Register of Controlled Trials, and ERIC. The references of relevant articles were also searched and included if found to be relevant to the scoping review.

Additional grey literature sources supplemented this search. These sources were included based on a researcher's recommendation, as work with vulnerable populations and tool development for this demographic may not be adequately represented in the peer-reviewed literature.

### Relevance Screening

The titles and abstracts from all sources were screened by a single reviewer for relevance to the research questions. The search strategy and resulting citations were imported in Rayyan (Ouzzani, Hammady & Fedorowicz, 2016) where the screening took place. Duplicates were resolved at this stage. Only literature that discussed qualitative research, tool development and testing with real populations (i.e. not statistical tests), assessment of perceptions of interventions, and vulnerable or marginalized populations in high-income countries were included at this stage of the review process.

All articles deemed relevant after the title and abstract screening phase were imported into Mendeley (Elsevier, 2018) for full-text screening and data mapping. All relevant data from the literature were entered into a Microsoft Excel (2019) spreadsheet for descriptive analysis.

### **Results**

The search strategy found 995 sources. After the title and abstract screening stage, 67 documents were imported into Mendeley (Elsevier, 2018) and assessed at the full-text level. Through citation searches of these articles, an additional 36 documents were considered at the full-text level. Of the 67 original documents, 9 were found to be relevant to this scoping review. Of the 36 sources identified through reference searches, 19 were included. Consultation with a researcher resulted in the consideration of 3 additional grey literature sources, 2 of which were included. A total

of 30 sources were included in the final review (Figure 1). A full list of included sources is available in Appendix B.

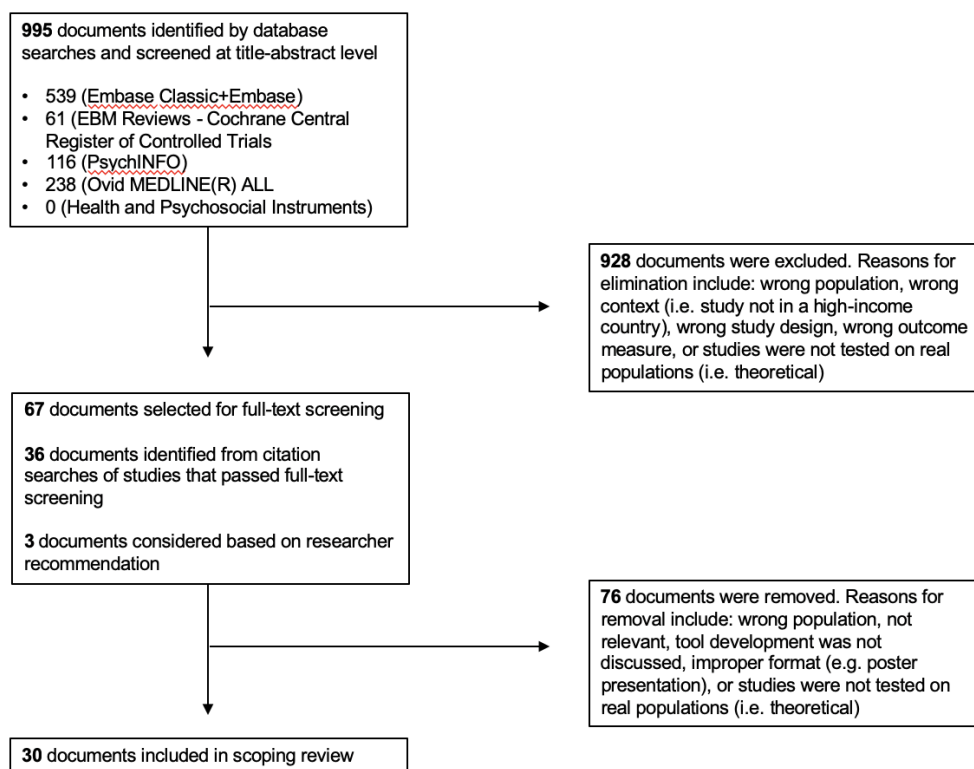


Figure 1: PRISMA diagram depicting document screening and selection process for inclusion in the scoping review.

Most of the sources were primary research articles (n=28), with two sources classified as grey literature. A majority of the studies were produced in North America (USA: n=15, Canada: n=5), followed by Europe (n=8). One study included populations from the USA, UK, Canada, Australia, and New Zealand.

Mapped data were organized into 6 categories: 1) tool type, 2) modality of tool delivery, 3) participant recruitment, 4), participant demographics, 5) FACE components evaluated (e.g. feasibility, acceptability, cost, equity), and 6) how the FACE components were assessed. Defining questions of the FACE components and their interpretation for analogous themes can be found in Appendix C, Table 1.

A total of 28 unique tools were identified; 20 of which were questionnaires, 8 were interviews for which guides were developed. Two sources identified using a combined methods approach, which used both questionnaires and interviews to collect data.

Tools were administered using a variety of techniques and personnel. Among the questionnaires, two methods identified as most common were self-completion by participants (n=8), and verbal administration by a member of the research team (n=8). The next most common strategies included trained volunteers (n=2), and nurses (n=2). Among the interviews, researchers (n=4) conducted them most often, followed by medical personnel (e.g. nurses, medical school students and faculty) (n=4). One study did not indicate how or by whom the tool was administered. Power imbalances were recognized, and 14 sources described specific methods used to mitigate power imbalances between researchers and participants. A full description of these strategies is provided in Appendix C, Table 2.

Methods for participant recruitment varied among the different sources identified in this scoping review. All sources except one discussed recruitment methods. One study reported using multiple methods to recruit participants, which included social marketing (e.g. posters), community outreach (e.g. community contacts), and the use of healthcare systems (e.g. patient databases). The majority of studies reported approaching participants in a medical/healthcare context (n=22). This involved using techniques such as having researchers or healthcare staff approach potential subjects for participation, as well as using databases such as patient/client registries. The next most common strategy was community outreach (n=5), which included snowball sampling, and connecting with key informants of the



target population. Lastly, social marketing (e.g. study advertisements) was identified as another method for participant recruitment (n=2).

There were a variety of populations engaged with in the literature. There were six overarching groups within which participant populations could be classified. This included individuals who were homeless, of low-income, patients, immigrants, women, and elderly. These are not necessarily mutually exclusive groups. For the purposes of this review, the number of categories has been expanded so as to provide a more refined assessment of the demographics captured. Homeless and vulnerably housed groups were engaged with the most (n=11). Of this demographic, participants were most commonly patients (n=7), followed by ethnic minorities (n=2), female youth (n=1), and those who were drug-dependent (n=1). The next most common demographic was low-income individuals (n=6). This included individuals from low-resource contexts (e.g. non-affluent communities) (n=2), immigrants (n=1), individuals with limited education (n=1), and those who did not own their own home (n=1). The next most common demographic included patients with potentially stigmatizing health concerns (n=5). This included those with mental health disorders (n=3), and those with chronic illnesses (n=2). Women were another identified demographic (n=2), with one study focusing on pregnant women specifically. Finally, the elderly (n=2), and male veterans (n=1) were other groups engaged with in the sources identified.

A breadth of terminology was used to discuss the perceptions evaluated in the literature. Therefore, inferred similarities were drawn between the FACE component definitions, and measures of interest in the included tools (see Appendix C, Table 1). Among the tools identified, the most common measurement was related to the

concept of acceptability (n=23). The next most common assessment was for feasibility (n=13), followed by equity (n=11), and lastly cost (n=5).

The most common tool for assessing perceptions related to the FACE criteria was with a Likert scale (n=20). 5-point Likert scales (n=8) were used the most, followed by 4-point scales (n=4), 7-point scales (n=3), 3-point scales (n=2), 10-point scales (n=2), and lastly a 6-point scale (n=1). The next most common method for perception assessment involved thematic analysis of open-ended responses (n=10). The least commonly used method was a multiple-choice model, where participants chose their preferred response from a list of options pertaining to a given situation (n=2).

## **Discussion**

This scoping review assessed the literature on current qualitative tools used to assess perceptions of vulnerable populations in a research context. In particular, this review looked at tools that assessed components similar to those highlighted in the GRADE FACE tool in order to facilitate its adaptation for non-professional, vulnerable populations.

The scope of tools identified was broad and unique, with very little overlap in tools used across the included literature. The target populations and measures of interest were also diverse. These emphasize the varied research needs across different contexts and highlight the necessity for health service research that is cognisant of the unique needs and interests of target communities (Canadian Institutes in Health Research, 2018). In order for similarities to be drawn between these different groups, however, having standard tools and measures is essential. Therefore, the development research tools that can be adapted to different contexts and needs of the target populations is critical.

Questionnaires were identified as the most common tool type used in the research. Questionnaires are useful tools in qualitative research as they allow researchers to quantify the frequency of perceptions or opinions held by a target population (Rowley, 2014). An equal number of sources used questionnaires that were either self-administered, or verbally administration by a researcher (n=8). Self-administered questionnaires may be preferred because they eliminate interviewer bias, promote more honest responses from participants, reduce time spent by researchers on questionnaire administration, and are easier to administer to larger numbers of participants (WHO, n.d.). Despite these benefits, this tool requires an assessment of both the questions themselves (e.g. ensuring questions are interpreted in the same way across all study participants), as well as the format so as to ensure ease of use by participants (Wolf, 2008). Self-administered questionnaires may be restrictive when studying vulnerable populations, especially if literacy is a concern. Verbally administering questionnaires by researchers may be a way to circumvent issues of low literacy. This was a strategy adopted by two studies captured in this scoping review (e.g. Vedam et al., 2017; Marrone et al., 2016).

In qualitative research, the relationships between researchers and participants can greatly influence the data (McGinn, 2008). It is important to be particularly sensitive about this dynamic when working with vulnerable populations and develop strategies to mitigate any potential negative effects. There have been historical incidences where this power imbalance has had negative implications on study participants (The Belmont Report, 1979). Several sources captured in this review described ways in which power dynamics were mitigated (n=16). A full description of these different techniques is available in Appendix C, Table 2. To summarize, strategies can include developing studies that are cognisant of the ways in which

social and physical barriers affect behaviours (e.g. Gelberg-Andersen Behavioral Model for Vulnerable Populations), separating research from healthcare delivery (e.g. researchers are not healthcare providers for participants), consulting with experts in question design and participant recruitment (e.g. developing an expert panel to review questions, consulting with professionals before recruiting participants who are at higher risk of negative effects as a result of research participation), and creating an environment that is appropriate for participants (e.g. using translators for participants who may not have English as their first language, offering visual tools such as scales for participants to refer to during verbal data collection, offering free child care services during data collection, using researchers who may be more appropriate for research with a particular demographic).

It is important to be cognisant of methods of participant recruitment so as to collect data that will provide the greatest depth and insight into the research phenomena being studied (Eide, 2008). Vulnerable populations are particularly challenging to recruit due to a myriad of barriers at the institutional, research, and individual levels (Uyibico, Pavel & Gross, 2007; Levkoff & Sanchez, 2003). In this review, the most common method of participant recruitment was in a medical context (e.g. clinics). A systematic review by Uyibico et al. (2007) identified medical settings as the most effective locations for recruiting participants from vulnerable populations. Therefore, the results of this review appear to be congruent with the literature in this regard. Although the systematic review identified community outreach as the least successful method of participant recruitment (Uyibico et al., 2007), this was the second most common method used for participant recruitment in this review. This may be due to the fact that this method facilitates the development of strong community-researcher relationships and builds trust between institutions and

communities (Levkoff & Sanchez, 2003). This is essential for longterm work with vulnerable populations.

In this scoping review, the most commonly identified FACE component measured was acceptability (n=23). The least commonly assessed component was cost (n=5). This disparity may highlight the need for more ways to measure and ask questions about 'cost', and ensure they are adequately tested with target populations to determine the most valid way of assessing this measure. Cost may be interpreted in different ways, such as monetary expenses or opportunity costs. The nuances in how cost is interpreted by study participants may limit the validity of this measure if the term is not adequately defined or understood.

The use of clear, comprehensible language is essential. The use of plain and accessible language is important throughout the research process (Block et al., 2012), however this may be especially important for developing a valid E-FACE tool. To ensure the E-FACE tool measures the intended phenomena appropriately, consideration must be paid to hidden meanings associated with different terminology. For instance, certain terms used in research may be interpreted differently by target populations, and can even have different definitions within populations based on an individual's age or gender (Stanford School of Medicine, n.d.).

The most commonly used technique for FACE criteria assessment was with a Likert scale. These types of tools are useful in qualitative research because they allow researchers to calculate a numerical score to assess more abstract concepts that are not easily quantifiable (Rowley, 2014). This may be particularly useful for the E-FACE tool, especially when attempting to characterize the degree to which guideline recommendations are approved or disapproved of by the target population.

There are a few limitations of this scoping review that should be noted. This review was conducted by a single reviewer, which may have resulted in a bias in the sources that were included. Additionally, the sole reviewer's interpretation of the FACE components may have limited the measures of feasibility, acceptability, cost, and equity identified in the literature. With respect to the sources captured in this review, most were peer-reviewed literature. This may be a limitation of the searched databases, as grey literature may not have been captured. Grey literature is an important source of information when conducting literature reviews (Paez, 2017). It can be a source of information that may not otherwise be published in academic publications, and therefore including these sources can reduce the risk of publication bias (Paez, 2017). Additionally, not all of the research articles included a version of the assessment tool used. This poses a challenge for thoroughly assessing the nature of the questions asked, as well as tool design qualities. This lack of consistency in tool publication poses a challenge for future researchers who wish to study vulnerable perspectives and adopt the most effective tool characteristics (e.g. plain language, question structuring). Therefore, including research tools as supplementary documents in online publications may help improve their dissemination to investigators, and offer a repository of effective tools that can be referred to in future research.

## **Conclusion**

In summary, this scoping review has identified qualitative research tools to assess perceptions of vulnerable populations with respect to the previously determined FACE criteria (feasibility, acceptability, cost, and equity). Future directives may consider ways in which the current GRADE FACE tool can be adapted for different cultural contexts. Additionally, future work is needed to establish

the best terminology to use in order to ensure the language adopted by tools is valid for assessing perceptions of guideline recommendations with respect to the FACE components.

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## Appendix A: Full search strategy for the scoping review

Database: Embase Classic+Embase <1947 to 2018 October 11>, Health and Psychosocial Instruments <1985 to July 2018>, Ovid MEDLINE(R) ALL <1946 to October 11, 2018>, PsycINFO <1806 to October Week 2 2018>, EBM Reviews - Cochrane Central Register of Controlled Trials <September 2018>, ERIC <1965 to August 2018>

Search Strategy:

- 
- 1 (Tool\*or checklist\* or instrument\* or assessment\* or survey\* or interview\* or focus group or questionnaire\*).ti. (1347861)
  - 2 exp patient participation/ (50113)
  - 3 exp consumer advocacy/ (6371)
  - 4 exp patient advocacy/ (44247)
  - 5 exp decision making/ (649057)
  - 6 ((Community or patient or client or stakeholder) adj2 (engagement or involvement or participation or perspective\* or collaboration or experience\* or opinion\*)).ti,ab. (137336)
  - 7 or/2-6 (856739)
  - 8 (homeless\* or underhouse\* or roofless\* or unhouse\* or squatter\* or shelter\* or unsheltered or vulnerabl\* or marginali?ed or at risk or equity).ti,ab. (887924)
  - 9 1 and 7 and 8 (995)

## Appendix B: Sources Included in Scoping Review

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**Appendix C: Descriptive Tables**

Table 1: FACE tool components, questions, and interpretations (adapted from Pottie et al., 2017)

Component	FACE Questions	Interpretation
Feasibility	<p>Would the recommendation be sustainable?</p> <p>Would there be important barriers that are likely to limit the feasibility of implementing the intervention?</p>	<p>Sustainability (e.g. perceived long-term usefulness/benefit, ability to maintain status quo in the future)</p> <p>Barriers (e.g. social or physical limitations in access to goods/services)</p>
Acceptability	<p>Do you feel the recommendation would be acceptable to stakeholders?</p>	<p>Satisfaction (e.g. with treatments, relationships with healthcare providers, etc.)</p> <p>Preference (e.g. preferred method of treatment, housing, etc.)</p>
Cost	<p>Do you feel the recommendation would be costly to stakeholders? Would the current costs of the intervention be large?</p>	<p>Monetary expenditure (e.g. fees for goods/services or access to them)</p> <p>Opportunity costs (e.g. resource allocation to address pertinent issues)</p>
Equity	<p>Do you feel the recommendation would positively impact health equity compared to current status?</p> <p>Are there groups or settings (taking into account burden, access and treatment) that might be disadvantaged in</p>	<p>Feelings of marginalization (e.g. in access to services, feelings of being disrespected, feelings of being understood or having personal knowledge considered)</p> <p>Fairness (e.g. support resources for individuals)</p>

	relation to the recommendation considered?	identified as having more extensive needs)
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Table 2: Strategies for mitigating power imbalances between researchers and vulnerable study participants

Strategy	Description	Source(s)
Use of behaviour model underpinning research design	Developing research methodology to reflect that human behaviours are dictated by social and physical barriers	Azarpazhooh A, Dao T, Figueiredo R, Krahn M, Friedman S. A Survey of Patients' Preferences for the Treatment of Teeth with Apical Periodontitis. 2013) <i>Journal of Endodontics</i> , 39(12)p. 1534-1541
Considerations of study location and researcher identity	<p>1. Enhanced efforts to maintain participant anonymity:</p> <p>If research is conducted at a clinic/shelter:</p> <ul style="list-style-type: none"> <li>-Conducting study in private rooms away from others</li> <li>-Using researchers who are not involved in participants' healthcare or services</li> </ul> <p>2. Using a researcher who would be more accepted by the study population</p> <ul style="list-style-type: none"> <li>-Female nurses leading women's health research, and taking time to address health concerns of participants after research was conducted</li> </ul>	<p>Calgary Homeless Foundation. (2009). <i>Rehousing Triage and Assessment Survey Toolkit</i>. Calgary.</p> <p>Coyle J, Williams B. Valuing people as individuals: development of an instrument through a survey of person-centredness in secondary care. (2001). <i>Journal of Advanced Nursing</i> 36(3):450–9. Available from: <a href="http://doi.wiley.com/10.1046/j.1365-2648.2001.01993.x">http://doi.wiley.com/10.1046/j.1365-2648.2001.01993.x</a></p> <p>Ensign, J., &amp; Panke, A. (2002). Barriers and bridges to care: voices of homeless female adolescent youth in Seattle, Washington, USA. <i>Journal of</i></p>

	<p>3. Allow participants to choose the location that best suits them (e.g. more accessible places via transportation)</p>	<p><i>Advanced Nursing</i>, 37(2), 166–172.  <a href="http://doi.org/10.1046/j.1365-2648.2002.02067.x">http://doi.org/10.1046/j.1365-2648.2002.02067.x</a></p> <p>Macnee CL, McCabe S. Satisfaction With Care Among Homeless Patients: Development and Testing of a Measure. (2004) <i>Journal of Community Health Nursing</i>;21(3):167–78. Available from: <a href="https://www.tandfonline.com/action/journalInformation?journalCode=hchn20">https://www.tandfonline.com/action/journalInformation?journalCode=hchn20</a></p> <p>Priebe S, Huxley P, Knight S, Summary SE. Application and results of the Manchester Short Assessment of Quality of Life (MANSA) Background based on experience and empirical evidence gained in studies using the Lancashire Quality of Life Profile (LQLP), the Manchester Short. <i>International Journal of Social Psychiatry</i>, 45(1). p. 7-12. [Internet]. Available from: <a href="https://journals-scholarsportal.info.subzero.lib.uoquelp.ca/pdf/00207640/v45i0001/7_aarotmsaoql.xml">https://journals-scholarsportal-info.subzero.lib.uoquelp.ca/pdf/00207640/v45i0001/7_aarotmsaoql.xml</a></p> <p>The Homeless Hub. (n.d.) <i>Table of Homelessness-Specific Tools</i>. Retrieved from <a href="https://www.homelesshub.ca/sites/default/files/attachments/ScreeningforHF-Table-Nov17.pdf">https://www.homelesshub.ca/sites/default/files/attachments/ScreeningforHF-Table-Nov17.pdf</a>.</p>
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<p>Empowering participants during data collection process</p>	<p>In interview-style questionnaires, providing participants with a hard-copy version of the scale so they can refer to it, thus avoiding repeated requests for verbal description of the scale</p> <p>Using a translator to help clarify questions for participants</p>	<p>Gagnon, M., Hébert, R., Dubé, M., &amp; Dubois, M.-F. (2006). <i>Development and Validation of the Health Care Satisfaction Questionnaire (HCSQ) in Elders. Journal of Nursing Measurement</i>, 14. Retrieved from <a href="https://search.proquest.com/docview/206323166/fulltextPDF/2D4BC2C9B1B74FA0PQ/1?accountid=11233">https://search.proquest.com/docview/206323166/fulltextPDF/2D4BC2C9B1B74FA0PQ/1?accountid=11233</a></p> <p>Marrone G, Mellgren Å, Eriksson LE, Svedhem V. (2016). High Concordance between Self-Reported Adherence, Treatment Outcome and Satisfaction with Care Using a Nine-Item Health Questionnaire in InfCareHIV. <i>PlosONE</i>, 11(6): e0156916. <a href="https://doi.org/10.1371/journal.pone.0156916">https://doi.org/10.1371/journal.pone.0156916</a></p>
<p>Develop questions with input from experts</p>	<p>Having a panel of experts (e.g. professionals, people with lived experience) review the questions to ensure they are appropriate for the potential research</p>	<p>Nyamathi, A. M., &amp; Flaskerud, J. (1992). A community-based inventory of current concerns of impoverished homeless and drug-addicted minority women.</p>



	participants	<p><i>Research in Nursing &amp; Health</i>, 15(2), 121–129.  <a href="http://doi.org/10.1002/nur.4770150206">http://doi.org/10.1002/nur.4770150206</a></p> <p>Vedam, S., Stoll, K., Martin, K., Rubashkin, N., Partridge, S., Thordarson, D., &amp; Jolicoeur, G. (2017). The Mother’s Autonomy in Decision Making (MADM) scale: Patient-led development and psychometric testing of a new instrument to evaluate experience of maternity care. <i>PLOS ONE</i>, 12(2), e0171804. doi: 10.1371/journal.pone.0171804</p>
Consideration of potential negative effects of being involved in research	Consulting with physicians to determine if there are any potential participants who may be at greater risk for experiencing negative effects as a result of being involved in research, and excluding them from participation	Salisbury, C., Burgess, A., Lattimer, V., Heaney, D., Walker, et al. (2005). Developing a standard short questionnaire for the assessment of patient satisfaction with out-of-hours primary care. <a href="http://doi.org/10.1093/fampra/cmi050">http://doi.org/10.1093/fampra/cmi050</a>
Offering supports to promote participation	Providing free childcare services while participants engage in research activities	Schaffer MA, Mather S, Gustafson V. (2000). Service Learning: A Strategy for Conducting a Health Needs Assessment of the Homeless. <i>Journal of Healthcare for the Poor and Underserved</i> , 11(4):385–99. Available from: <a href="https://doi.org/10.1353/hpu.2010.0746">https://doi.org/10.1353/hpu.2010.0746</a> <a href="https://muse.jhu.edu/article/269761/summary">https://muse.jhu.edu/article/269761/summary</a>

<p>Developing inclusive environments for participants</p>	<p>Not excluding participants who do not meet inclusion criteria, but allowing them to continue with study with their peers (e.g. focus group)</p>	<p>Storms H, Claes N, Aertgeerts B, Van den Broucke S. (2017). Measuring health literacy among low literate people: an exploratory feasibility study with the HLS-EU questionnaire. <i>BMC Public Health</i> 17(1):475. Available from: <a href="http://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-017-4391-8">http://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-017-4391-8</a></p>
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