SPOR Evidence Alliance
Strategy for Patient-Oriented Research

Alliance pour des données probantes de la SRAP
Stratégie de recherche axée sur le patient

Strategy for Patient-Oriented Research
SPOR
Putting Patients First

SPOR Evidence Alliance 2023 Patient and Public Health Research Topic Priority-Setting Exercise

Overview

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List of Abbreviations

AMSTAR-2 – A MeaSurement Tool to Assess systematic Reviews – version 2

CIHR – Canadian Institutes of Health Research

JLA – James Lind Alliance

QoL – Quality of Life

MA – Meta-analysis

RCT – Randomized Controlled Trials

RoB – Risk of Bias

SPOR – Strategy for Patient-Oriented Research

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Roadmap

Step 1

Evidence Checking of Health Research Topics

Interviews, scoping searches, and a feasibility assessment are conducted before the priority-setting exercise

Step 2

Priority-Setting Exercise with Steering Panel

Ranking all eligible topics to identify the top 20 health research topics

Step 3

Knowledge Synthesis of Selected Health Research Topics

Top 20 topics will be co-produced by patient and public partners and a nominated SPOR Evidence Alliance research team into a knowledge synthesis product

Step 4

Dissemination of Selected Health Research Topics

Introduction

The purpose of this priority-setting exercise is to systematically review and identify the top 20 patient and public submitted health research topics that address an important healthcare or health system concern that will be funded by the SPOR Evidence Alliance for further research. We have assembled a steering panel to review the list of 63 eligible topics *(87 submissions)* and identify and rank **the top 20 health research topics** for further research. The priority-setting exercise will involve a fair and transparent approach involving an online survey followed by a virtual consensus-building workshop to discuss and finalize topic selection. The steering panel will include patient and public partners, researchers, and healthcare providers. The steering panel members will be provided with detailed information about each health research topic to inform their ratings.

Our Priority-Setting Approach

Modified James Lind Alliance (JLA) approach to priority-setting

Brings patients, members of the public, healthcare providers, policy-makers together in an equal **Priority-Setting Partnership**.

Prioritizes unanswered health research topics identified by **patients and members of the public** as **most current and pressing gaps in research**.

Founded on principles **of inclusivity, transparency, appropriate disclosure and management of conflict(s) of interests, and a commitment to making evidence-informed health decisions**.

ELIGIBILITY OF THE SUBMITTED TOPICS

Eligible for the Priority-Setting Exercise:

- Topics submitted by patients and members of the public
- Topics that can be addressed by knowledge synthesis, guidelines, or knowledge translation

Ineligible for the Priority-Setting Exercise:

- Topics submitted by research groups, healthcare providers, policy-makers, or on behalf of professional societies or groups
- Topics that **cannot** be addressed by knowledge synthesis, guidelines, or knowledge translation (i.e., primary studies)

INTERVIEWS AND EVIDENCE CHECKING

1

Qualitative Interviews

- Gain a better understanding of individual experiences and intended impact of research.
- Semi-structured interviews with topic submitters.
- Qualitative descriptive approach to analysis.[4,5]

2

Scoping Literature Searches

- Conduct PubMed searches to identify existing evidence and prevent duplication of research.
- Searches limited to any reviews and/or guidelines in English/French, published in last 10 years

3

Feasibility Assessment

- Quality appraisal of scoping, rapid, systematic, and overview of reviews using the AMSTAR-2 tool.[10]

PRIORITY-SETTING EXERCISE

Recruitment of steering panel through the SPOR Evidence Alliance network to achieve 4:1 ratio of patients/public partners to researchers/policy-makers/healthcare providers.

4

Priority-Setting Survey

- Steering panel ranks eligible health research topics using online survey.
- Highest ranked and discrepant topics discussed at the consensus-building workshop.

5

Priority-Setting Workshop

- Steering panel discuss highest ranked and discrepant topics in virtual workshop.
- Steering panel selects top 20 health research topics for further research.[11]

PUBLICATION AND PROMOTION OF TOP 20 TOPICS

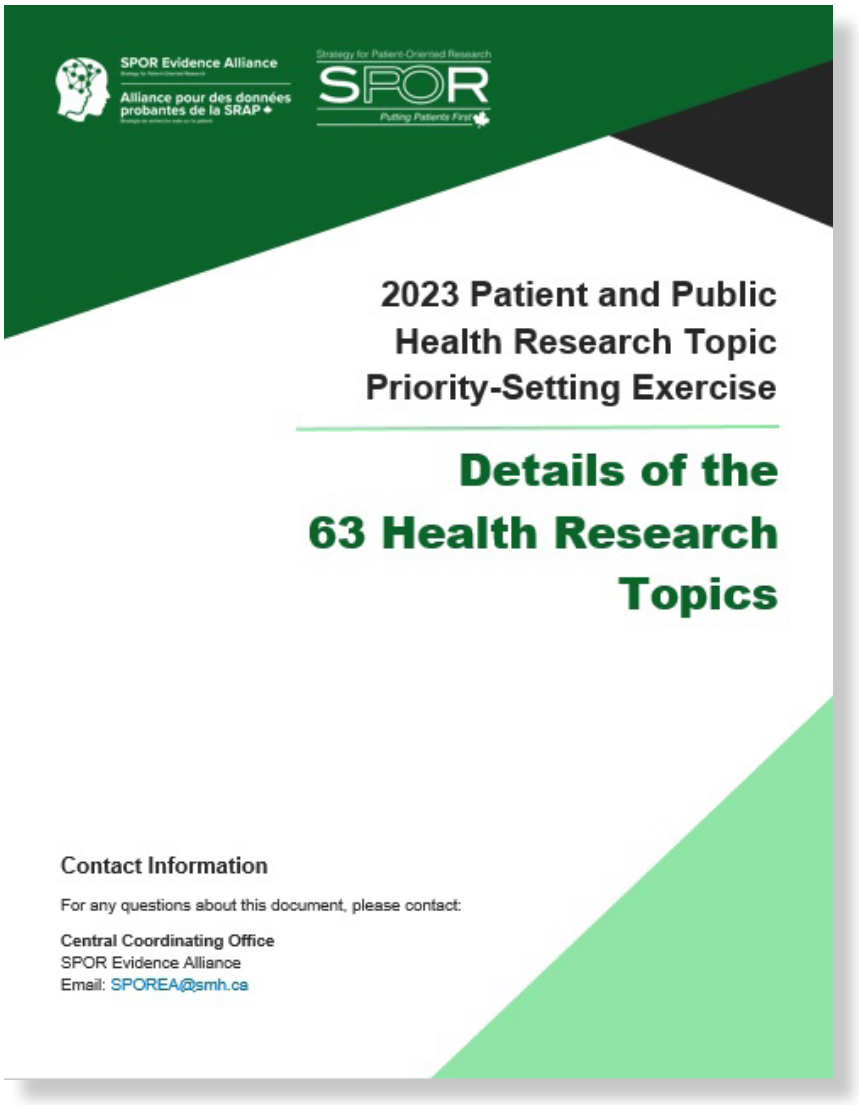
6

- Top 20 health research topics will be announced and developed into research projects co-led by patient/public partners and a research team.
- Top 20 health research projects will be fully funded by the SPOR Evidence Alliance.
- Knowledge synthesis products will be created and widely distributed to promote implementation.

List of Topics Received From Patients and Members of the Public

To view the complete list of 63 topics received from patients and members of the public, please view the ***SPOR Evidence Alliance 2023 Patient & Public Health Topic Priority-Setting Exercise: Details of the 63 Health Research Topics*** document, available on the SPOR Evidence Alliance website.

Link: https://sporevidencealliance.ca/key-activities/2023-priority-setting-exercise/



Glossary of Terms

AMSTAR 2.0 tool: An instrument for critically appraising only systematic reviews of randomised controlled clinical trials. A list of 16 questions which need to be considered to assess the quality of a systematic review or randomized control clinical trials, as per the AMSTAR 2.0 tool.[10]

Evidence-informed: Problem solving approach involving the best available research to make decisions.

Feasibility Assessment: Pieces of research done before a main study in order to answer the question "Can this study be done?". They are used to estimate important parameters that are needed to design the main study.

Knowledge Synthesis: The contextualization and integration of research findings of individual research studies within the larger body of knowledge on the topic. A synthesis must be reproducible and transparent in its methods, using quantitative and/or qualitative methods.

Knowledge Synthesis Products: Outputs as the result of the knowledge synthesis process, such as systematic reviews, policy briefs, clinical practice guideline.

Meta-analysis: A data analysis technique used to statistically combine data from several studies to compare effectiveness and safety between two treatment, health program/service, diagnostic test or prognostic test options.[12]

Overview of Reviews: Summarizes findings from other published knowledge syntheses (not primary studies) addressing the same research question.[13]

Patients: An overarching term inclusive of individuals with personal experience of a health issue and informal caregivers, including family and friends.[2]

Patient engagement: Meaningful and active collaboration in governance, priority setting, conducting research and knowledge translation. Depending on the context patient-oriented research may also engage people who bring the collective voice of specific, affected communities.

PICO Framework: PICO framework helps organize information into a research question using the components of Population, Intervention or Exposure, Comparator, and Outcome, allowing researchers to refine their literature searches and scope of study.[14]

Primary Studies: Studies that generate new data through observations from experiments, trials, natural occurrence, surveys, and interviews.[15]

Priority-Setting Exercise: An exercise that is designed to categorize a list of items (e.g., topics, requirements, or ideas) into most important to least important.

Public (i.e., citizen): Encompasses interested representatives of the general public, consumers of health services, patients, caregivers, advocates and representatives from affected community and voluntary health organizations.[16]

PubMed: Free resource supporting the search and retrieval of biomedical and life sciences literature with the aim of improving health – both globally and personally.

Quality Rating: The overall rating assigned to a review based on how many checklist items were satisfied.

Rapid Review: When a knowledge synthesis is conducted using accelerated process by streamlining or omitting specific methods of a specific knowledge synthesis type to produce evidence for decision-makers in a resource-efficient manner.[17]

Review: A summary of studies addressing a clear research question.

Scoping Literature Search: Searches of existing literature designed to help gain an overview of the range and depth of research that exists for a particular research idea. It is used to gain insight into the current gaps in knowledge.

Scoping Review: Used to systematically map the breadth of evidence available on a particular topic, field, concept, or issue, often irrespective of source (i.e., primary studies, secondary studies, non-empirical evidence) within or across particular contexts.[18]

Semi-structured Interview: An interview in which the interviewer does not strictly follow a formalized list of questions. Instead, they will ask more open-ended questions, allowing for a discussion with the interviewee rather than a straightforward question and answer format.

Systematic Review: A summary of studies addressing a clear question, using systematic and explicit methods to identify, select, and critically appraise relevant studies, and to collect and analyse data from them.

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Appendices

Appendix 1: Qualitative Interview Questions

Interview Questions

1. Let's dive right into the topic you have submitted, [TOPIC]. Can you please tell me a bit more about why you chose this topic and why it is important to you?
   - *Prompts (if needed):*
     - Personal experience as a patient, person with lived experience, or caregiver?
     - Someone you know that is affected?
     - Research/readings about this topic?
     - Anything that anyone would like to add?
     - Other

2. What do you hope to learn from researching this topic?
   - *Prompts (if needed):*
     - Clarifying PICO:
   - Which group of individuals do you feel this impacts the most?
   - How might research on this create or effect change?
   - What information would you like to know more about?

3. Who needs to know about the findings?
   - *Prompts (if needed):*
     - Patient advocacy groups
     - Healthcare providers
     - Policy-makers
     - General public
     - Who/which groups of people do you think could potentially benefit from these findings?
     - How would you like the findings to be shared?

4. Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?
   - *Prompts (if needed):*
     - Are there any additional comments you might have towards first steps in the research or ideas about methodology?

5. Are there any other details that you would like to share with me that we have not had the chance to discuss so far?

6. Do you have any questions for me?

Appendix 2: A MeaSurement Tool to Assess systematic Reviews – version 2 (AMSTAR-2)

The AMSTAR-2 tool (A MeaSurement Tool to Assess systematic Reviews – version 2) was applied to provide an indication of the reliability of review findings and was conducted in duplicate by two research coordinators.

The tool includes a checklist of 16 items to consider when assessing the quality of a review by looking at the review methodology. Of the 16 items, 7 items are considered to be critical steps for conducting a high-quality review, while 9 items are non-critical but still worth noting. **Table 1** below provides a list of the 16 AMSTAR-2 critical appraisal items and their description. The *blue* rows in the table indicate those items that are critical steps for conducting a high-quality review.

An overall quality rating is given to each review based on how many of the critical checklist items are addressed. **Table 2** below summarizes the categories for quality ratings.

Table 1: List of 16 AMSTAR-2 critical appraisal items and their description

AMSTAR-2 Critical Appraisal Items	Description
1. PICO Components	The research questions and inclusion criteria for the review included the PICO components
2. A Priori Design	The report of the review contained an explicit statement that the review methods were established prior to the conduct of the review and justified any significant deviations from the protocol
3. Rationale for Study Selection	The review authors explained their selection of the study designs for inclusion in the review
4. Literature Search	The review authors used a comprehensive literature search strategy
5. Duplicate Selection	The review authors performed study selection in duplicate
6. Duplicate Abstraction	The review authors performed data extraction in duplicate
7. List of excluded studies	The review authors provided a list of excluded studies and justified the exclusions
8. Description of included studies	The review authors described the included studies in adequate detail
9A. Risk of Bias Assessment in RCTs	The review authors used a satisfactory technique for assessing the RoB in individual studies that were included in the review
9B. Risk of Bias Assessment in non-randomized studies	The review authors used a satisfactory technique for assessing the RoB in individual studies that were included in the review
10. Funding sources	The review authors reported on the sources of funding for the studies included in the review
11. Appropriate MA methods	If MA was performed, the review authors used appropriate methods for statistical combination of results
12. Used RoB in MA	If MA was performed, the review authors assessed the potential impact of RoB in individual studies on the results of the MA

AMSTAR-2 Critical Appraisal Items	Description
13. Used RoB in interpreting results	The review authors accounted for RoB in individual studies when interpreting/discussing the results of the review
14. Discussion of heterogeneity	The review authors provided a satisfactory explanation for, and discussion of, any heterogeneity observed in the results of the review
15. Publication Bias	If the review performed quantitative synthesis, the review authors carried out an adequate investigation of publication bias and discussed its likely impact on the results of the review
16. Conflict of interest	The review authors reported any potential sources of conflict of interest

Table 2: AMSTAR-2 quality ratings and their meaning

Quality rating	Meaning of quality rating
HIGH quality rating ●●●●	Addressed all checklist items (i.e., no critical flaws or one non-critical flaw)
MODERATE quality rating ●●●○	Partially addressed all checklist items (i.e., more than one non-critical flaw)
LOW quality rating ●●○○	Missing 1 checklist item (i.e., one critical flaw with or without non-critical flaw)
CRITICALLY LOW quality rating ●○○○	Missing 2 or several checklist items (i.e., more than one critical flaws with or without non-critical flaw)