MuSE
MULTI-STAKEHOLDER
ENGAGEMENT CONSORTIUM

STAKEHOLDER ENGAGEMENT IN EVIDENCE SYNTHESIS

Campbell Collaboration Webinar Series
April 4th 2023

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PhD Candidate, University of Ottawa

WHAT IS THE MUSE CONSORTIUM?

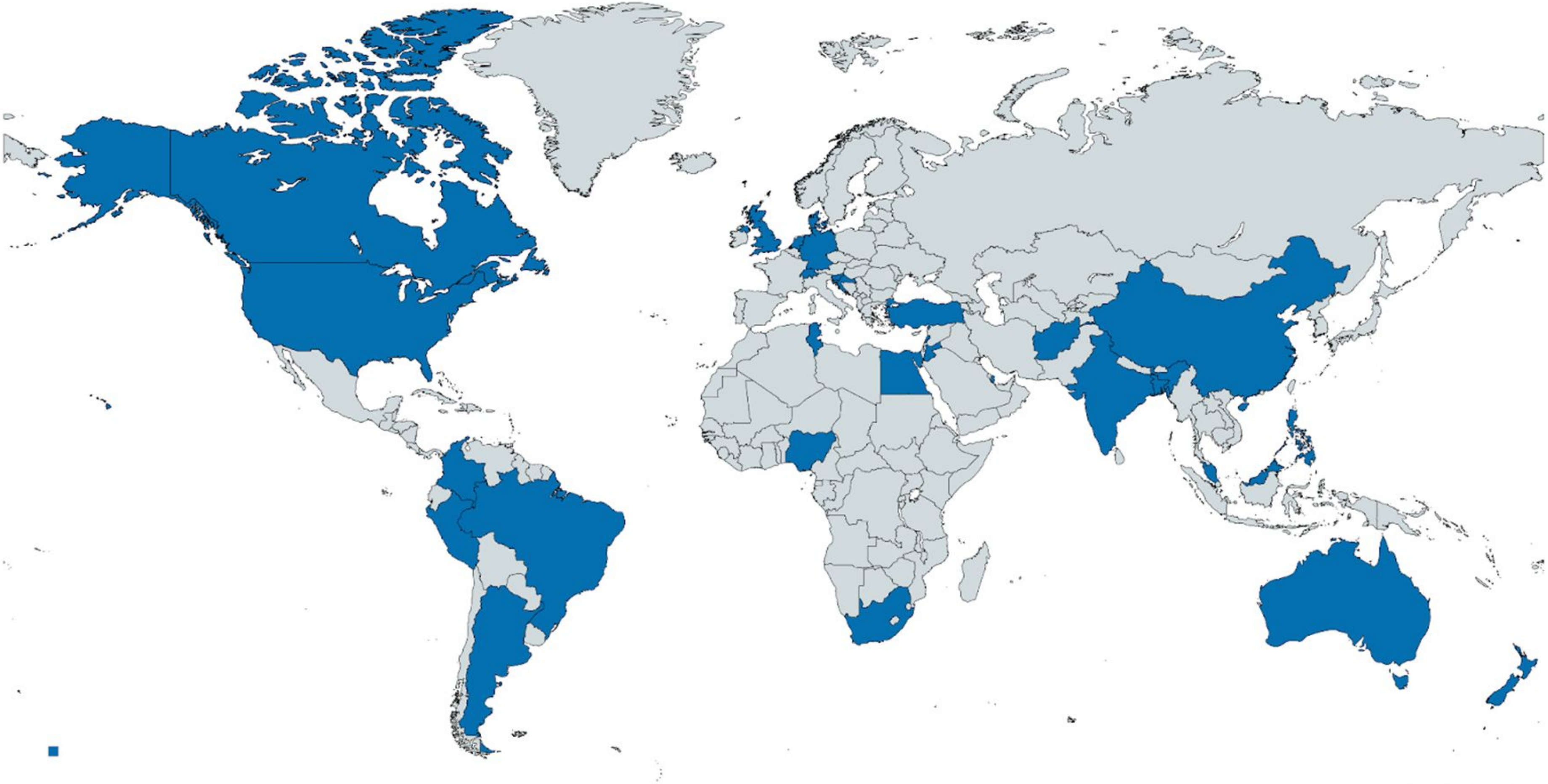
MuSE
MULTI-STAKEHOLDER ENGAGEMENT CONSORTIUM

- Established in 2015
- International team of over 120 stakeholders from diverse contexts and backgrounds
- Common interest in stakeholder engagement in research and guidelines

We currently have two funded projects:

1. Stakeholder engagement in guideline development (2018-2023)
2. Stakeholder engagement in evidence synthesis (2021-2025)

MuSE Meeting (Toronto, Canada), September 2022



Created with mapchart.net

The MuSE Consortium

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ENGAGEMENT CONSORTIUM

GRADE

Campbell
Collaboration

ACTIVE

Ottawa Hospital
Research Institute
Institut de recherche
de l'Hôpital d'Ottawa

JOHNS HOPKINS
BLOOMBERG SCHOOL
of PUBLIC HEALTH

CMTP

S.T.A.R. Initiative©

Australian Government
National Health and
Medical Research Council
NHMRC

Bruyère
RESEARCH INSTITUTE

McMaster
University

AUB
American University of Beirut

Health Canada
Santé Canada

uOttawa

World Health
Organization

OHSU

AHRQ

Imperial College
London

LA TROBE
UNIVERSITY

Public Health Ontario
Santé publique Ontario

UNIVERSITY OF THE PHILIPPINES
MANILA

RAND
CORPORATION

WHO ARE STAKEHOLDERS?

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"… an individual or group who is responsible for or affected by health- and healthcare-related decisions" (Concannon et al. 2019).

Stakeholder groups : 11 P's framework	
Patients, caregivers, and patient organizations	Principal investigators (& their research teams)
Public	Peer review editors
Providers of care	Payers of health services
Policymakers	Payers of research
Program managers	Product makers
Producers and commissioners of reviews and/or guidelines	

ISSUES WITH ‘STAKEHOLDER’ TERMINOLOGY

In a colonial context, a stakeholder was the person who drove a stake into the land to demarcate the land they were occupying/stealing from Indigenous People.

Continued use of the term can be construed as disrespectful of Indigenous people as well as perpetuating colonization and re-traumatization.

Other options:

- Partners
- Knowledge Users
- Constituents
- Interested/affected parties, people and groups
- Decision makers
- End user
- Relevant group
- Special interest group

HELP US DECIDE ON NEW TERMINOLOGY!

Please help us determine a suitable replacement for rebranding and future work by participating in a survey! You can pick a replacement word from the list provided or offer recommendations for ones not listed.

SCAN ME

WHAT IS ENGAGEMENT?

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- ★ "...defined as an active partnership between stakeholders and researchers in production of new healthcare knowledge and evidence." (Frank et al., 2020)
- ★ … resulting in "informed decision-making about the selection, conduct, and use of the research"(Concannon et al., 2012).
- ★ Engagement may also be termed collaboration, involvement, or partnership (Petkovic et al., 2020).

LEVELS OF ENGAGEMENT

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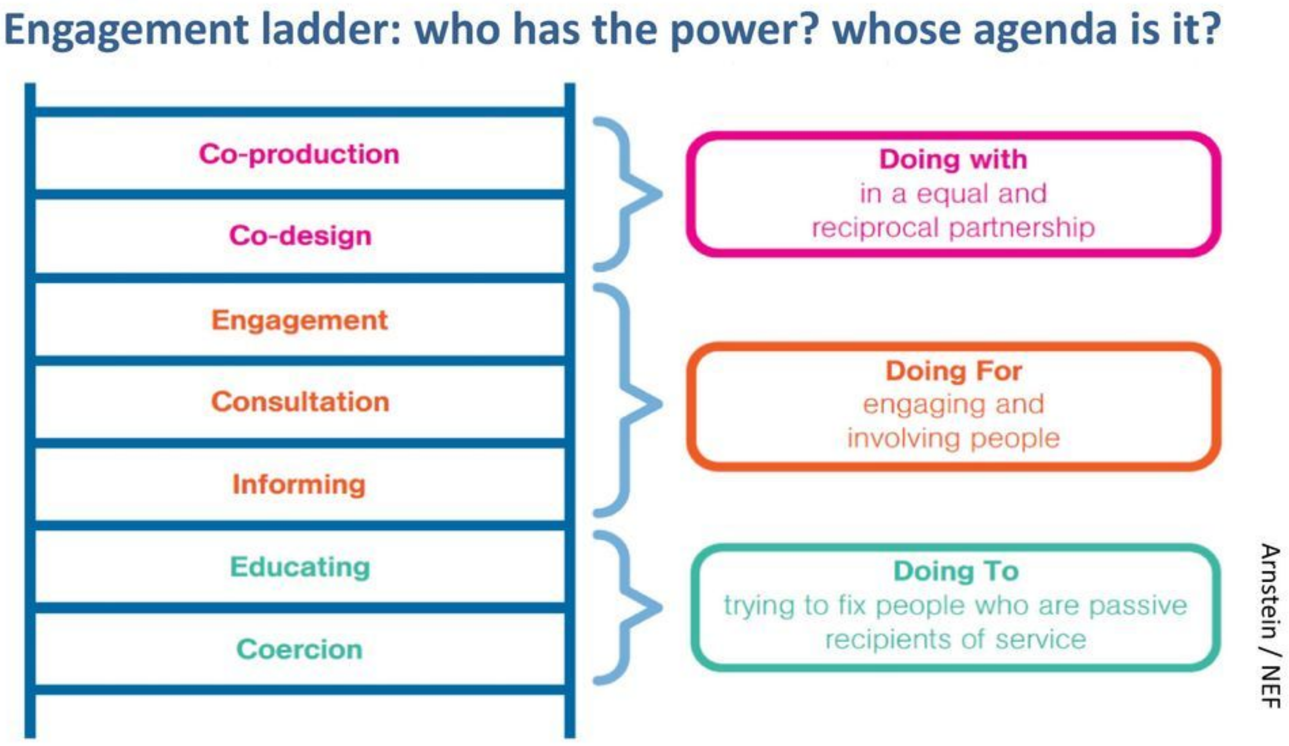

Engagement ladder: who has the power? whose agenda is it?

Co-production
Co-design
Engagement
Consultation
Informing
Educating
Coercion

Doing with
in a equal and
reciprocal partnership

Doing For
engaging and
involving people

Doing To
trying to fix people who are passive
recipients of service

Arnstein / NEF

Decision making

Advice or feedback

WHY ENGAGE STAKEHOLDERS IN EVIDENCE SYNTHESIS?

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- Identify evidence gaps and refine scope
- Avoid research waste
- Address barriers to the uptake of evidence
- Increase dissemination and utilization of findings
- Help make recommendations for research
- Make research more relevant, of higher quality and have a greater impact on healthcare
- Reduce health and social inequities.
- Influence review findings, contributing to a more equitable evidence base

“the insights they provide are the key to ethical decision making, which is the only sustainable solution to inequities”

(Cellier 2021; Dewidar 2022; Harris 2016; Petkovic 2020)

Factors to Consider During Identification and Invitation of Individuals in a Multi-stakeholder Research Partnership

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Highly desirable:

1. Ability and willingness to represent stakeholder group
2. Commitment and time capacity
3. Communication skills
4. Financial and non-financial relationships and activities, and conflicts of interest
5. Expertise or experience
6. Inclusivity (equity, diversity, and intersectionality)
7. Training, support, and funding needs.

Desirable:

1. Influence
2. Previous stakeholder engagement
3. Research relevant values.

(Parker et al., 2022)

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(Parker et al., 2022)

EQUITY AND DIVERSITY CHARACTERISTICS

PROGRESS-Plus is an acronym used to identify characteristics that stratify health opportunities and outcomes.

PROGRESS refers to:

Place of residence
Race/ethnicity/culture/language/ancestry
Occupation
Gender/sex
Religion
Education
Socioeconomic status
Social capital

Plus refers to:

1) personal characteristics associated with discrimination (e.g. age, disability)
2) features of relationships (e.g. smoking parents, excluded from school)
3) time-dependent relationships (e.g. leaving the hospital, respite care, other instances where a person may be temporarily at a disadvantage)

(O'Neill et al., 2014)

SUPPORTING EQUITY-CENTRED ENGAGEMENT

How can we prepare to engage in a way that centres equity?

- Understanding equity and related terms and concepts
- Recognizing why taking an equity-centred approach to engagement is needed
- Reflecting on our roles and positions

(Ul Haq et al., 2023; Public and Patient Engagement Collaborative and the Public Engagement in Health Policy team at McMaster University)

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How do we plan for engagement that centres equity?

- Thinking about who we want to engage with and why
- Understanding the populations we hope to engage with
- Setting goals for our engagement work proactively and collaboratively

(Ul Haq et al., 2023; Public and Patient Engagement Collaborative and the Public Engagement in Health Policy team at McMaster University)

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- Reaching diverse voices
- Reducing barriers to engagement

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- Ensuring participants feel safe, respected, and valued
- Addressing power imbalances

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How will we continue to foster equity after engagement is complete?

- Acting on participant input and following-up
- Ongoing learning and improvement

(Ul Haq et al., 2023; Public and Patient Engagement Collaborative and the Public Engagement in Health Policy team at McMaster University)

PRINCIPLES OF RESEARCH PARTNERSHIPS

Hoekstra *et al. Health Research Policy and Systems* (2020) 18:51
https://doi.org/10.1186/s12961-020-0544-9

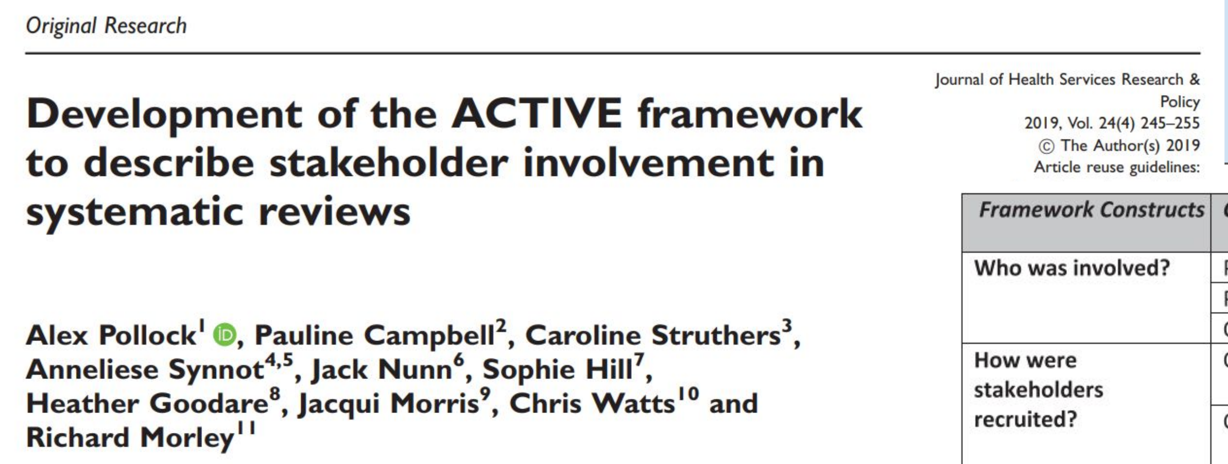
Health Research Policy
and Systems

REVIEW **Open Access**

A review of reviews on principles, strategies, outcomes and impacts of research partnerships approaches: a first step in synthesising the research partnership literature

F. Hoekstra[1,2], K. J. Mrklas[3,4], M. Khan[5], R. C. McKay[1,2], M. Vis-Dunbar[6], K. M. Sibley[5,7], T. Nguyen[8,9], I. D. Graham[10,11], SCI Guiding Principles Consensus Panel and H. L. Gainforth[1,2*]

1. Relationship between researchers and stakeholders
2. Co-production of knowledge
3. Meaningful stakeholder engagement
4. Capacity-building, support and resources
5. Communication between researchers and stakeholder
6. Ethical issues of collaborative research activities.



Original Research

Journal of Health Services Research & Policy
2019, Vol. 24(4) 245–255
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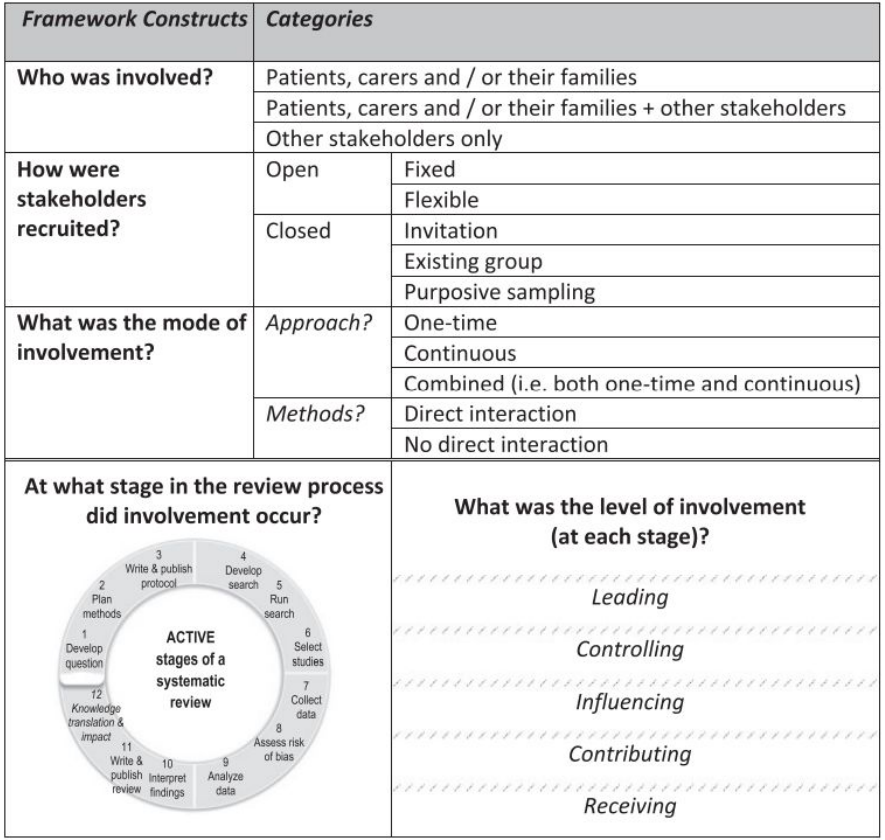
Article reuse guidelines:

Development of the ACTIVE framework to describe stakeholder involvement in systematic reviews

Alex Pollock[1], Pauline Campbell[2], Caroline Struthers[3], Anneliese Synnot[4,5], Jack Nunn[6], Sophie Hill[7], Heather Goodare[8], Jacqui Morris[9], Chris Watts[10] and Richard Morley[11]

- A structure to guide authors on how to involve stakeholders in the systematic review process
- Proposes the ACTIVE continuum of involvement based on the tasks and roles of stakeholders
- Adds to existing generic guidance on reporting of stakeholder involvement in research (e.g., GRIPP2)



Framework Constructs	***Categories***	
Who was involved?	Patients, carers and / or their families	
	Patients, carers and / or their families + other stakeholders	
	Other stakeholders only	
How were stakeholders recruited?	Open	Fixed
		Flexible
	Closed	Invitation
		Existing group
		Purposive sampling
What was the mode of involvement?	*Approach?*	One-time
		Continuous
		Combined (i.e. both one-time and continuous)
	Methods?	Direct interaction
		No direct interaction

At what stage in the review process did involvement occur?

What was the level of involvement (at each stage)?

Leading

Controlling

Influencing

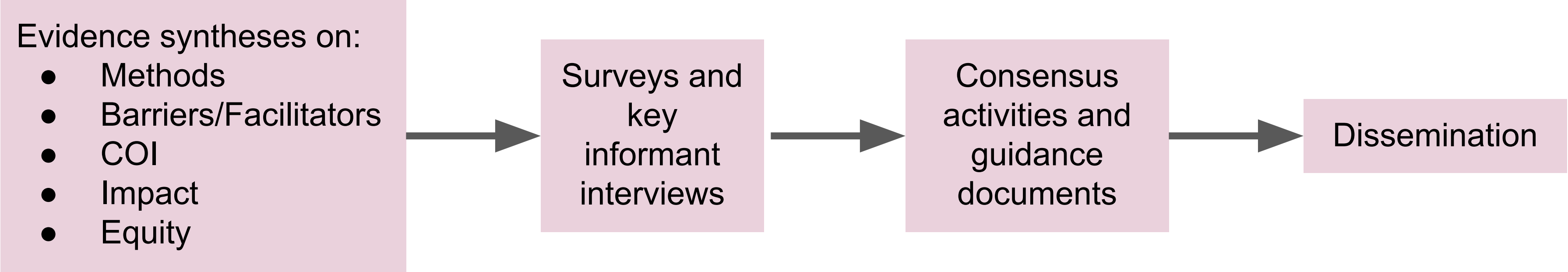
Contributing

Receiving

The MuSE Evidence Synthesis Project

We have received funding (2021-2025) to:

- Develop **guidance on methods** of stakeholder engagement in evidence syntheses.
- Develop or adapt existing **reporting guidelines** for stakeholder engagement in evidence syntheses
- Develop guidance on methods of **evaluating** stakeholder engagement in evidence syntheses



Evidence syntheses on:

- Methods
- Barriers/Facilitators
- COI
- Impact
- Equity

Surveys and key informant interviews

Consensus activities and guidance documents

Dissemination

WHEN CAN WE ENGAGE STAKEHOLDERS?

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Steps for a systematic review

Research question
Find a problem to be solved & define a research question.

Scoping search
Check if your research question is answered already & doesn't need further research.

Study design decision
Determine if a systematic review is the best methodology for your research question.

Building a team
For conducting a proper systematic review you need clinical & methodological expertise.

Protocol registration
Write and register a protocol for your systematic review.

Literature search
Carry out a thorough search of the relevant literature.

Screening of results
Screen and select studies based on your inclusion & exclusion criteria.

Data extraction
Extract the relevant data from the included studies.

Quality assessment
Assess the quality of the studies you want to include (critical appraisal).

Synthesis of research
Synthesize the results. (Perform a statistical meta-analysis).

Interpretation
Interpret the findings.

Write & publish
Write and publish a systematic review.

Adobe Stock

HOW CAN WE ENGAGE STAKEHOLDERS?

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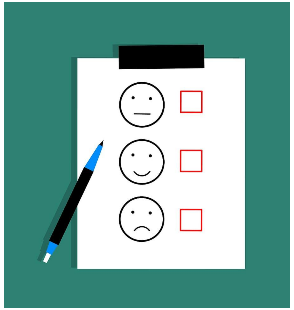
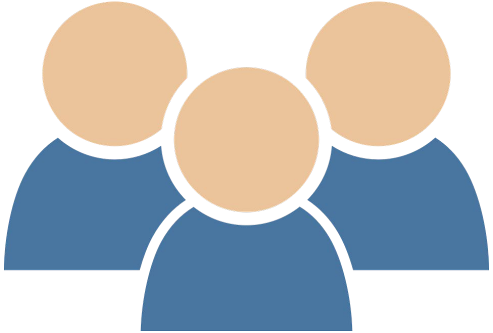
Review team member
(co-author)



Survey/delphi



Steering or advisory
committee

Workshop /
community consultation

…and more (?). To be determined!

EXAMPLE

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Engaging people with lived experience of homeless in a series of systematic reviews (2017-2020)

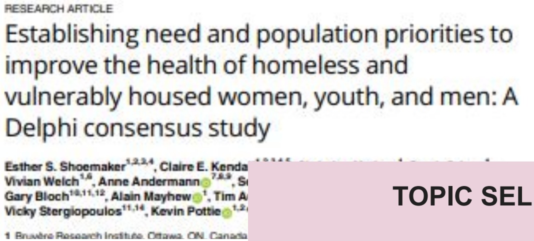
Purpose: To inform Canada’s first clinical practice guideline for the care of people with lived experience of homelessness

Engaging people with lived experience of homeless in a series of systematic reviews (2017-2020)

Purpose: To inform Canada's first clinical practice guideline for the care of people with lived experience of homelessness

Community scholar program goal and objectives

1. Ensure the meaningful engagement and participation of people with lived experience in the conduct of systematic reviews and evidence based guideline development.
2. Ensure that people with lived experience are adequately compensated such that they are able to devote the time and energy needed to actively participate in the research and guideline development process as part of the team.



RESEARCH ARTICLE

Establishing need and population priorities to improve the health of homeless and vulnerably housed women, youth, and men: A Delphi consensus study

Esther S. Shoemaker[1,2,3,4], Claire E. Kenda
Vivian Welch[1,6], Anne Andermann[7,8,9], S
Gary Bloch[10,11,12], Alain Mayhew[1], Tim A
Vicky Stergiopoulos[11,14], Kevin Pottie[1,2

1 Bruyère Research Institute, Ottawa, ON, Canada

TOPIC SELECTION

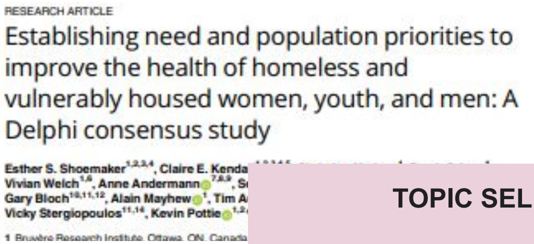
Who? 84 health professionals and 76 persons with lived experience of homelessness

How? Delphi survey (3 rounds)

Where? Canada

→

Topics and populations



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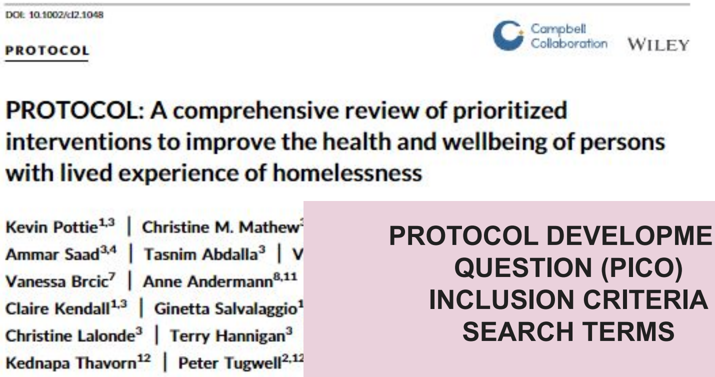


DOI: 10.1002/cl2.1048

PROTOCOL

Campbell Collaboration WILEY

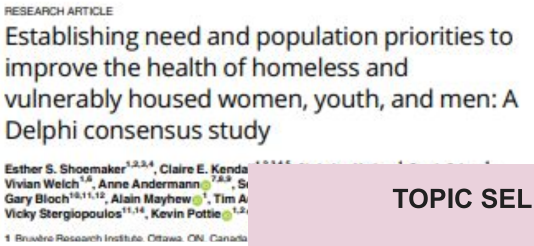
PROTOCOL: A comprehensive review of prioritized interventions to improve the health and wellbeing of persons with lived experience of homelessness

Kevin Pottie[1,3] | Christine M. Mathew
Ammar Saad[3,4] | Tasnim Abdalla[3] | V
Vanessa Brcic[7] | Anne Andermann[8,11]
Claire Kendall[1,3] | Ginetta Salvalaggio
Christine Lalonde[3] | Terry Hannigan[3]
Kednapa Thavorn[12] | Peter Tugwell

PROTOCOL DEVELOPMENT
QUESTION (PICO)
INCLUSION CRITERIA
SEARCH TERMS

Who? Community Scholars with lived experience of homelessness

How? Review team member (co-author)



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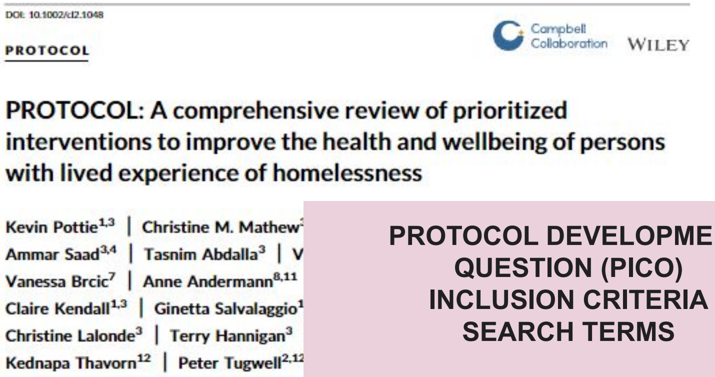

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Systematic review evidence

HOMELESS HEALTH SUMMIT

TORONTO, NOV. 25-27TH 2018

A two-day event to spark
how evidence-based guic
transition of homeless pop
into community housing a
health care.

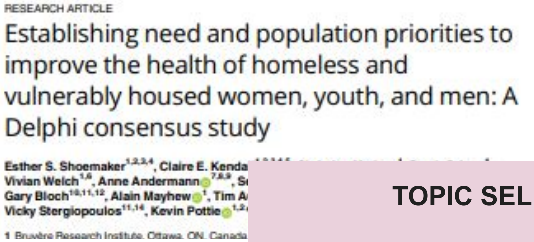
Follow us on Twitter!

Homeless Health Research Network
@HealthHomeless

INTERPRETATION

Who? Community Scholars with lived experience of homelessness, health care professionals, policymakers and program managers.

How? Homeless Health Research Summit (1-day event)



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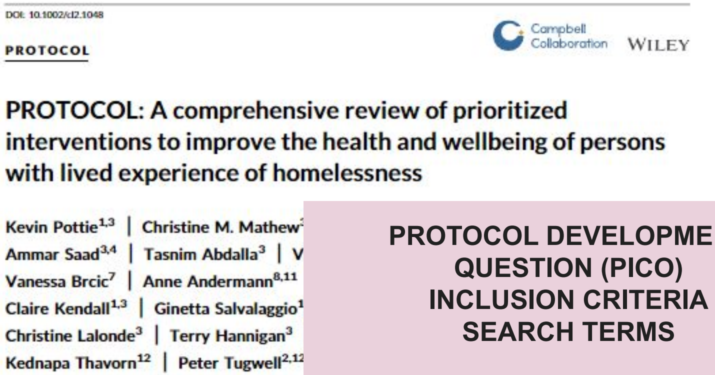

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INTERPRETATION

Who? Community Scholars with lived experience of homelessness, health care professionals, policymakers and program managers.

How? Homeless Health Research Summit (1-day event)

Evidence based recommendations

International Journal of Environmental Research and Public Health

MDPI

Article

Determinants of Implementation of a Clinical Practice Guideline for Homeless Health

Olivia Magwood[1,2], Amanda Hanem
Gary Bloch[6,7,8], Aliza Moledina[9], Nico
Alexandra Aliferis[12], Victoire Kpade[13],

DISSEMINATION AND UPTAKE

Community-based study
Clinical practice guideline
13 academic publications
1 book chapter
Radio interviews and conference presentations

PLOS | ONE

RESEARCH ARTICLE

The effectiveness of substance use interventions for homeless and vulnerably housed persons: A systematic review of systematic reviews on supervised consumption facilities, managed alcohol programs, and pharmacological agents for opioid use disorder

Olivia Magwood[1], **Ginetta**
Victoire Kpade[1,5], **Wahab D**
Ellen Snyder[7], **Tim O'Shea**
Kevin Pottie[1,4]*

1 C.T. Lamont Primary Health C
2 Department of Family Medicin
University of Toronto Dept of Psy
of Epidemiology and Public Healt
McGill University, Montreal, QC,
7 Public Health and Preventative
8 Department of Medicine, Popu
Canada, **9** Department of Family
Medicine, University of Ottawa, C

* kpottie@uottawa.ca

Abstract

Background

Substance use is dispropor
housed. We performed a sy
harm reduction and pharma
people who use substances

Methods and finding

We searched MEDLINE, EI
Database of Systematic Re
August 2019. We conducte
selected reviews that synth
alcohol programs and pharr
abstracted data specific to h
tainty of the evidence using

PLOS ONE

RESEARCH ARTICLE

The effectiveness of case management interventions for the homeless, vulnerably housed and persons with lived experience: A systematic review

David Ponka[1], **Eric Agbata**[2], **Claire Kendall**[3,4,5], **Vicky Stergiopoulos**[6], **Oreen Mendonca**[3], **Olivia Magwood**[3], **Ammar Saad**[3,7], **Bonnie Larson**[8], **Annie Huiru Sun**[3], **Neil Arya**[9], **Terry Hannigan**[3], **Kednapa Thavorn**[5,7], **Anne Andermann**[10], **Peter Tugwell**[11], **Kevin Pottie**[3,4]*

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Abstract

Background

Individuals who are homeless or vulnerably housed are at an increased risk for mental illness, other morbidities and premature death. Standard case management interventions as well as more intensive models with practitioner support, such as assertive community treatment, critical time interventions, and intensive case management, may improve healthcare navigation and outcomes. However, the definitions of these models as well as the fidelity and adaptations in real world interventions are highly variable. We conducted a systematic review to examine the effectiveness and cost-effectiveness of case management interventions on health and social outcomes for homeless populations.

RESEARCH ARTICLE

Common trust and personal safety issues: A systematic review on the acceptability of health and social interventions for persons with lived experience of homelessness

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Abstract

Background

Persons experiencing homelessness and vulnerable housing or thos
of homelessness have worse health outcomes than individuals who
Structural violence can dramatically affect their acceptance of interv
a systematic review to understand the factors that influence the acce
health interventions among persons with lived experience of homele

Methods

We searched through eight bibliographic databases and selected grey
cles that were published between 1994 and 2019. We selected primary
the experiences of homeless populations interacting with practitioners
working in permanent supportive housing, case management, interven
income assistance, and women- and youth-specific interventions. Each
dently assessed for its methodological quality. We used a framework a
findings and used the GRADE-CERQual approach to assess confiden

Findings

Our search identified 11,017 citations of which 35 primary studies m
Our synthesis highlighted that individuals were marginalized, dehum

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Effectiveness of permanent supportive housing and in
assistance interventions for homeless individuals in
high-income countries: a systematic review

Tim Aubry, Gary Bloch, Vanessa Brcic, Ammar Saad, Olivia Magwood, Tasnim Abdalla, Qasem Alkhateeb, Edward Xie, Christine M
Terry Hannigan, Chris Costello, Kednapa Thavorn, Vicky Stergiopoulos, Peter Tugwell, Kevin Pottie

Summary

Background Permanent supportive housing and income assistance are valuable interventions for homeles
Homelessness can reduce physical and social wellbeing, presenting public health risks for infecti
disability, and death. We did a systematic review, meta-analysis, and narrative synthesis to investigate the
and cost-effectiveness of permanent supportive housing and income interventions on the health and so
of individuals who are homeless in high-income countries.

Methods We searched MEDLINE, Embase, CINAHL, PsycINFO, Epistemonikos, NIHR-HTA, NHS EE
the Cochrane Central Register of Controlled Trials from database inception to Feb 10, 2020, for studies
supportive housing and income interventions for homeless populations. We included only randomis
trials, quasi-experimental studies, and cost-effectiveness studies from high-income countries that rep
one outcome of interest (housing stability, mental health, quality of life, substance use, hospital admi
income, or employment). We screened studies using a standardised data collection form and pool
published studies. We synthesised results using random effects meta-analysis and narrative synthesis
certainty of the evidence using the Grading of Recommendations Assessment, Development, ar
approach.

Findings Our search identified 15 908 citations, of which 72 articles were included for analysis (
permanent supportive housing across 41 publications, ten studies on income interventions across 15
and 21 publications on cost or cost-effectiveness). Permanent supportive housing interventions increa
(6 year) housing stability for participants with moderate support needs (one study; rate ratio [RR]
1·01–1·26]) and high support needs (RR 1·42 [1·19–1·69]) when compared with usual care. Permane
housing had no measurable effect on the severity of psychiatric symptoms (ten studies), substance use (
income (two studies), or employment outcomes (one study) when compared with usual social serv
interventions, particularly housing subsidies with case management, showed long-term improvements i
of days stably housed (one study; mean difference at 3 years between intervention and usual servic
p<0·004), whereas the effects on mental health and employment outcomes were unclear.

Interpretation Permanent supportive housing and income assistance interventions were effective
homelessness and achieving housing stability. Future research should focus on the long-term effects o
income interventions on physical and mental health, substance use, and quality-of-life outcomes.

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EVALUATING ENGAGEMENT

MuSE
MULTI-STAKEHOLDER ENGAGEMENT CONSORTIUM

PEIRS

Patient Engagement In Research Scale

The Patient Engagement In Research Scale (PEIRS-22) is a valid and reliable questionnaire for assessing the degree of meaningful patien

The PEIRS-22 is comprised of 2

standardized assessment of er

Public and Patient Engagement Evaluation Tool

The **Public and Patient Engagement Evaluation Tool (PPEET)** is a series of three questionnaires to evaluate public and patient engagement. The tool was developed primarily for use within health system organizations but has also been used to evaluate engagement within other contexts (e.g., health research).

TAKE HOME MESSAGES

MuSE
MULTI-STAKEHOLDER ENGAGEMENT CONSORTIUM

- ➢ Stakeholder engagement can improve the relevance and uptake of review evidence
- ➢ We have identified 11 types of stakeholders that review teams should consider
- ➢ Stakeholders can be engaged with varying levels of intensity in many steps of an evidence synthesis
- ➢ Review authors should commit to a set of principles to guide their engagement activities, and consider whether equity-centered engagement is relevant for their research context
- ➢ The MuSE Consortium aims to produce guidance for review authors on who should be engaged in evidence syntheses, and when/how they should be engaged.

Contact us!

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🌐 https://methods.cochrane.org/equity/projects/stakeholder-engagement-guideline-development

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