

# Engagement in Health Research Literature Explorer Supplemental Methods Information

This document describes how PCORI created our [Engagement in Health Research Literature Explorer](#). It provides detailed information about our PubMed/MEDLINE search strategy, inclusion/exclusion criteria, article tagging definitions, and process. Please send any questions or comments about the search to [strategic@pcori.org](mailto:strategic@pcori.org).

## 1. PubMed/MEDLINE Search and Supplemental Sources

To keep this collection up-to-date, we regularly conduct a literature search through PubMed/MEDLINE. PubMed comprises more than 27 million citations for biomedical literature from MEDLINE, life science journals, and online books. Citations may include links to full-text content from PubMed Central and publisher websites.

Below is the search string that we built. We based it on previous systematic reviews,<sup>1,2,3</sup> as well as a content analysis of search results.

("Patient Participation"[Mesh] OR "patient input"[tw] OR "patient collaboration"[tw] OR "engaging patients"[tw] OR "engages patients"[tw] OR "engaged patients"[tw] OR "patient partner"[tw] OR "patient partnership"[tw] OR "patient partners"[tw] OR "patient participation"[tw] OR "stakeholder participation"[tw] OR "stakeholder collaboration"[tw] OR "engages stakeholders"[tw] OR "engage stakeholders"[tw] OR "engaged stakeholders"[tw] OR "engaging stakeholders"[tw] OR "stakeholder partnership"[tw] OR "stakeholder partners"[tw] OR "consumer participation"[tw] OR "community participation"[tw] OR "public participation"[tw] OR "patient engagement"[tw] OR "stakeholder engagement"[tw] OR "consumer engagement"[tw] OR "community engagement"[tw] OR "public engagement"[tw] OR "patient involvement"[tw] OR "stakeholder involvement"[tw] OR "consumer involvement"[tw] OR "community involvement"[tw] OR "public involvement"[tw] OR "public partners"[tw] OR "public partnership"[tw] OR "lay participation"[tw] OR "lay engagement"[tw] OR "lay involvement"[tw] OR "engaging community"[tw] OR "engaged community"[tw] OR "engaging communities"[tw] OR "engages communities"[tw] OR "engaged communities"[tw] OR "community partner"[tw] OR "community partnership"[tw] OR "community partners"[tw] OR "payer engagement"[tw] OR "payer involvement"[tw] OR "insurance participation"[tw] OR "employer involvement"[tw] OR "employer participation"[tw] OR "employer engagement"[tw] OR "pharmaceutical involvement"[tw] OR "engaging caregivers"[tw] OR "engaged caregivers"[tw] OR "caregiver engagement"[tw] OR "caregiver involvement"[tw] OR "caregiver participation"[tw] OR "caregiver partner"[tw] OR "consumer collaboration"[tw] OR "engaging consumers"[tw] OR "engaged consumers"[tw] OR "consumer partnership"[tw] OR "provider engagement"[tw] OR "provider participation"[tw] OR "provider involvement"[tw] OR "clinician engagement"[tw] OR "clinician involvement"[tw] OR "clinician participation"[tw] OR "engaged research"[tw] OR "engagement research"[tw] OR "research engagement"[tw] OR "engagement framework"[tw] OR "facilitating engagement"[tw] OR "Patient and public involvement"[tw] OR "partnered research"[tw] OR "participatory research"[tw] OR "participatory action research"[tw] OR "community-academic partnership"[tw] OR "community-engaged research"[tw] OR "engagement method"[tw] OR "Public Involvement Impact Assessment Framework"[tw] NOT "preference"[tw]) AND ("comparative effectiveness research"[tw] OR "CER"[tw] OR "randomized control

<sup>1</sup> Concannon TW, Fuster M, Saunders T, et al. A Systematic Review of Stakeholder Engagement in Comparative Effectiveness and Patient-Centered Outcomes Research. *Journal of General Internal Medicine*. 2014;29(12):1692-1701. doi:10.1007/s11606-014-2878-x.

<sup>2</sup> Domecq JP, Prutsky G, Elraiyah T, et al. Patient engagement in research: A systematic review. *BMC Health Services Research*. 2014;14:89. doi:10.1186/1472-6963-14-89.

<sup>3</sup> Esmail L, Moore E, Rein A. Evaluating patient and stakeholder engagement in research: moving from theory to practice. *J Comp Eff Res*. 2015;4(2):133-45. doi: 10.2217/ce.14.79.

trial"[tw] OR "randomized clinical trial"[tw] OR "randomized controlled trial"[tw] OR "RCT"[tw] OR "clinical trial"[tw] OR "clinical control trial"[tw] OR "clinical controlled trial"[tw] OR "observational study"[tw] OR "comparative study"[tw] OR "pragmatic trial"[tw] OR "pragmatic clinical trial"[tw] OR "meta-analysis"[tw] OR "systematic review"[tw] OR "comparative effectiveness trial"[tw] OR Clinical Trial[ptyp] OR Comparative Study[ptyp] OR Meta-Analysis[ptyp] OR Observational Study[ptyp] OR Pragmatic Clinical Trial[ptyp] OR Randomized Controlled Trial[ptyp] OR Editorial[ptyp] OR Letter[ptyp] OR Comment[ptyp] OR "conceptual model"[tiab] OR "practical model"[tiab] OR "conceptual framework"[tiab] OR "practical framework"[tiab] OR systematic[sb] OR Evaluation Studies[ptyp]) AND English[lang]

In addition to articles identified via PubMed searches, we screened articles for possible inclusion by reviewing highly relevant journals not yet indexed in PubMed (e.g., *Research Involvement and Engagement*), and PCORI staff recommendations.

## 2. Criteria for Publication Inclusion and Exclusion

We screen articles for inclusion in the literature explorer in two phases, using the abstracts and full text.

We will provide additional information regarding the number of articles screened at each phase upon request.

| <b>Inclusion and Exclusion Criteria</b><br><b>Engagement in Health Research Literature Explorer</b>  |  |
|--|--|
| <p><b>Inclusion Criteria</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> English</li> <li><input type="checkbox"/> Health research (NOT limited to exclusively CER)</li> <li><input type="checkbox"/> Article addresses engagement in <b>research</b> (e.g., in planning, conducting, or disseminating research)</li> <li><input type="checkbox"/> One of the following article types:               <ul style="list-style-type: none"> <li>○ Manuscripts with a primary objective of reporting on health research that provide an example of engaging patients and stakeholders in at least one phase of the research.</li> <li>○ Manuscripts with a primary objective of describing research engagement methodologies within the context of health research.</li> <li>○ Manuscripts that include a formal evaluation of engagement within the context of a health research study, or a study with the primary objective to evaluate engagement in health research.</li> <li>○ Manuscripts that express a theoretical view on engagement in health research including, scientific commentaries, opinion briefs, or conceptual pieces such as models or frameworks.</li> </ul> </li> </ul> | <p><b>Exclusion Criteria</b></p> <p>Exclusion at <b>abstract and full-text screening:</b><br/><i>Abstracts excluded for the reasons below <u>would not</u> be forwarded for full-text screening, unless additional information was needed.</i></p> <ul style="list-style-type: none"> <li>• Duplicate</li> <li>• Not in English</li> <li>• Not health-related research (e.g., agricultural, occupational health, environmental health)</li> <li>• Studies evaluating engagement in health care rather than engagement in research</li> <li>• Patient preference studies (healthcare preference) (e.g., research exclusively asking what patients prefer or want in their care)</li> <li>• Patient/stakeholder administering intervention is the <b>ONLY</b> role in the task. No other forms of patient/stakeholder engagement in the research task.</li> <li>• For relevant article types: No description of effects of engagement in research (i.e., study only mentions they engaged patients in research without describing, at minimum, how learnings from partners were incorporated, changes made as result of engagement, or other perceived impact of engagement).</li> <li>• Protocols that describe how stakeholders will be engaged in the future, instead of reflections or evaluations of past engagement activities.</li> <li>• Studies focusing on stakeholder involvement only for recruitment of study participants.</li> <li>• Studies focusing on stakeholder involvement in developing clinical guidelines, rather than in developing the research process/content itself.</li> </ul> |

### 3. Article Tagging

For articles meeting the inclusion criteria, we apply tags across three engagement-related categories, if applicable, after reading the full articles.

#### a) Topic (not mutually exclusive)

|  |
|--|
| <b>a) Example of Engagement in Health Research</b>   |
| Manuscripts with a <i>primary objective</i> of reporting on a health research study that engaged partners in at least one phase of the research and describe at least one impact of engagement on their work.            |
| <b>b) Detailed Description of Engagement in Health Research</b>  |
| Manuscripts with a <i>primary objective</i> of reporting a detailed description of the conduct and/or impacts of engagement within the context of a health research study.   |
| <b>c) Evidence for Engagement</b>  |
| Manuscripts that include a formal evaluation of engagement within the context of a health research study, or a study with the primary objective to evaluate or synthesize engagement methods/impacts in health research. |
| <b>d) Framework, Editorial, Commentary</b>   |
| Manuscripts that express a theoretical view on engagement in health research, including scientific commentaries, opinion briefs, or conceptual pieces such as models or frameworks.                                      |

#### b) Stakeholder Involvement (not mutually exclusive)

Stakeholder groups actively engaged in the research as described in the article, if applicable.

| Stakeholder Group       | Description  | Example   |
|-------------------------|--|---|
| Clinicians              | Providers of health care in a clinical setting, including physicians, nurses, mental healthcare providers, and other healthcare professionals            | Family physician in direct patient care in a small group practice |
| Patients                | People with current or past experience of illness or injury; People at risk for a condition or who consume healthcare services                           | A man who has grown up with Type I diabetes                       |
| Caregivers              | Family members or other unpaid person who provides care to patients  | The wife of a man receiving home hospice care for advanced ALS    |
| Hospital/Health Systems | Organizations where care is delivered, including public and private hospitals, community health centers, and organizations representing these facilities | Clinic administrator of a multispecialty physician practice       |
| Industry                | Companies that design, invest in, or manufacture diagnostics, devices, pharmaceuticals, and other similar industries                                     | Chief medical officer of a device manufacturer                    |
| Purchasers              | Those who purchase health benefits for employees and their dependents, including   | Health benefits manager of a large, ERISA-covered employer        |

|                       |   |  |
|-----------------------|---|--|
|                       | individual businesses and business groups   |  |
| Payers                | Those who function as financial intermediaries in the health system, including private and public insurers                    | Chief medical officer of health insurance cooperative      |
| Learning Institutions | Those who deliver health professional education, including trade or professional associations representing these institutions | Dean of a nursing school                                   |
| Policy Makers         | Those who help craft public policy at any level of government   | State Medicaid director                                    |
| Other                 | Other groups not covered by the categories above  | Executive director of a stroke patient advocacy foundation |

**c) Phases of Research Engagement** (not mutually exclusive)

Phase(s) of research in which stakeholders were engaged as described in the article, if applicable.

| <b>Phase of Research in Which Engagement Occurs</b> | <b>Description of Engagement Activities</b>   | <b>Example of Engagement Activities</b>  |
|---|---|--|
| Research Topic and Agenda                           | Identifying, refining, and/or prioritizing topics and populations to study  | Providing insight about the concerns and priorities of the patient population or stakeholder groups  |
| Research Questions and Aims                         | Developing and/or refining the research questions and aims of the study   | Reframing aims of the research study to highlight health issues within certain communities   |
| Study Comparators and Content                       | Selecting, designing, and/or refining interventions to be tested in the study   | Altering delivery mode of intervention to be more appealing to patients  |
| Study Outcomes                                      | Selecting and/or refining study outcomes and deciding how to measure them   | Selecting endpoints that are important to patients and other stakeholders  |
| Study Design  | Contributing to a specific plan or protocol for conducting the study, including what inclusion criteria should be used to select participants; helping select what methods will be used to conduct the research | Suggesting to use a study design that takes patients' preferences into account instead of using randomization, in order to better appeal to the study population         |
| Participant Recruitment and Retention               | Refining approaches and/or materials for finding patients who are eligible to participate in the study, enrolling them into the study, and/or making it easier for them to participate and stay in the study.   | Rewording the consent form to include clearer descriptions of study activities   |
| Data Collection                                     | Developing and/or refining approaches and methods to best collect data from study subjects  | Improving the timing of data collection to better align with clinic flow   |
| Results Review and Analysis                         | Analyzing collected data or reviewing study results to help interpret and explain research findings   | Assisting with the transcription and coding of qualitative data; interpreting preliminary findings   |
| Translation   | Applying study results to real-world practice, health condition management, policy, or future research  | Contributing to the development of clinical practice guidelines  |
| Dissemination                                       | Planning, creating, and/or presenting materials that share information about the study or the results of the study  | Suggesting the best means of returning results and other study findings to study participants; giving presentations at conferences to spread results to a wider audience |