

Online Appendix B. Data Extraction Form

Extractor Initials. Use your first and last initial

Author, Year. First author, publication year

Pubmed ID. Found at the end of the pdf file name

Name of journal

Preliminary Screening Questions

Answer the following four questions and follow the skip pattern instructions.

Screening Q. 1. In what country did the study take place?

- US
- Non- US

Screening Q. 2. Mark the option that best describes this article

- Stakeholder engaged research
- Synthesis of stakeholder engaged research

Screening Q. 3. Is this article describing a research study?

- Yes
- No (program report)

Screening Q. 4. Does this article cover Research Stage 2-5? Stages 2-5 include: (2) Evidence generation, (3) evidence synthesis, (4) evidence interpretation, and (5) dissemination and application.

- Yes
- No

Program description

What is the target population of this program?

Describe the program presented in this article. Please provide brief description

Basic Study Information

Complete the following questions, leaving no question blank.

- If No Data reported, write or select "ND"
- If Not Applicable, write or select "NA"

1a. What was the research question or objective, as stated by the investigators? Copy and paste the research question and/or study objective, typically stated at the end of the introduction section.

1b. Describe the research question or objective for the study. If including text from the actual article, please add quotations (" ")

1c. What stage of research is this article reporting on? Choose the option that fits best.

- Evidence Prioritization: establishing a vision and mission for research, identifying topics, setting priorities, and refining questions
- Evidence Generation: methods including clinical trials, practical trials, observational studies, etc.
- Evidence Synthesis: what is known, what is not known, and what methods have been used
- Evidence Interpretation and Integration: decision analysis, simulation modeling, cost-effectiveness analysis

- Dissemination and Application: active distribution of research findings to decision makers, adoption and implementation of research findings in real-world settings
- Feedback and Assessment: active review and revision of its processes over time
- Other:

2. *Study setting: Select the appropriate option.*

- Hospital
- Community
- Other Non-profit Organization
- Company
- ND
- NA
- Other:

3a. *Copy and paste relevant methodology description, as stated by the investigators.*

3b. *Describe the methods used in the study. Summarize content from 3a*

4. *What methods were used?*

- Qualitative (for example: interviews, focus groups, observation, ...)
- Quantitative (for example: survey, statistical analysis...)
- Mixed Methods
- ND
- NA
- Other:

5a. *What was the unit of analysis in this study? Unit of analysis refers to the 'what' or 'whom' being studied.*

- Patients
- Population (Public health), including community individuals
- Provider organizations (hospitals, health centers...)
- Clinicians
- Geographic / administrative boundaries (counties)
- ND
- NA
- Other:

5b. *Describe the study population. Describe baseline characteristics such as age, gender, income, etc.*

6. *Describe any interventions and comparators analyzed in the study.*

7. *List any outcomes analyzed in the study.*

Details of Stakeholder Engagement

Complete the following questions, leaving no question blank.

- If No Data reported, write or select "ND"
- If Not Applicable, write or select "NA"

8a. *Were a priori targets identified prior to stakeholder recruitment? "A priori targets" are a pre-specified number of stakeholders within a stakeholder group or type. Please answer based on what is reported in the article.*

- Yes (Please describe in 8c)
- No

8b. *How were stakeholders recruited? Mark the option(s) that apply. If not reported, select ND. Provide details in question 8c.*

- Recruited through a personal or professional network (non-random)

- A random sample from the population
- ND: Recruitment strategy not specified
- Other:

8c. *What was the recruitment process for stakeholders?* Provide details from questions 8a and 8b. If not reported, write "ND".

9. *With which types of stakeholders have researchers reported engagement?*

- Patients (current)
- Public / Consumers (potential consumers of patient-centered health care and population-focused public health, their caregivers, families, and patient and consumer advocacy organizations)
- Providers (individual and organizations that provide care to patients and populations)
- Payers (Insurers, Medicare and Medicaid, state insurance exchanges, individuals with deductibles, and others responsible for reimbursement for interventions and episodes of care)
- Policy Makers (The White House, Department of Health and Human Services, Congress, states, professional associations, intermediaries, and other policymaking entities)
- Product Makers (Drug and device manufacturers)
- Principle Investigators (Other researchers and their funders)
- Purchasers (Employers, the self-insured, government and other entities responsible for underwriting the costs of health care)
- Other:

10. *In what stages of research have researchers reported engagement with stakeholders?* If not sure, write description / possible answer under "other".

- Evidence Prioritization: establishing a vision and mission for research, identifying topics, setting priorities, and refining questions
- Evidence Generation: methods including clinical trials, practical trials, observational studies, etc.
- Evidence Synthesis: what is known, what is not known, and what methods have been used
- Evidence Interpretation and Integration: decision analysis, simulation modeling, cost-effectiveness analysis
- Dissemination and Application: active distribution of research findings to decision makers, adoption and implementation of research findings in real-world settings
- Feedback and Assessment: active review and revision of its processes over time
- Other:

11a. *Select the option(s) that best describe the programmatic role of stakeholders.* Select the best option and add details/description in Q11b.

- Investigator or co-investigators (might be referred as "partners" in CBPR)
- Staff
- Consultants
- Research subjects
- ND
- NA

11b. *Describe the level of engagement of stakeholders, as reported by the study authors.*

12. *Select the option that best describes the stakeholder participation in the study*

- Formulation of research question
- Defining essential characteristics of study participants, comparators and outcomes
- Monitoring of study conduct and progress
- Dissemination and implementation of research results

- Information obtained from stakeholders was used to inform other parts of the study (when stakeholders are subjects)
- Interpretation and analysis
- ND
- Other:

13a. *What modes of engagement have researchers reported?*

- Individual - Survey
- Individual - Key informant interview
- Individual - Other (specify on 13d)
- Group - Focus group
- Group - Panel (e.g. technical expert panel, consumer advisory board)
- Group - Other (specify on 13d)
- Public Review
- ND
- Other:

13b. *What were the mechanisms of interaction with stakeholders?*

- Face to face / in-person
- Telephone / teleconference
- Webinar / web-based interface
- e-mail / mail / fax
- ND
- Other:

13c. *How was the feedback from stakeholders synthesized?*

- Voting / Ranking methods
- Delphi method
- Quantitative survey methods
- Qualitative synthesis of written notes or transcripts / free text analysis / factor analysis
- Joint decision-making (e.g., when stakeholders are also staff or co-investigators)
- ND
- Other:

13d. *Describe the specific modes of stakeholder contact employed by the study.* Provide more details from Q. 13a-13c. If different strategies were used with different stakeholder groups, please specify/describe in the space below.

14. *What was the frequency and duration of contact with stakeholders?*

15. *At which point were the stakeholders engaged?* Select all that apply

- Before research
- During research
- After research was conducted
- NA- A research study was not conducted
- ND

16a. *Was a special provision reported for the engagement of patients, consumers and/or community members?* If patients were included on a stakeholder panel with other stakeholders, were they offered extra support for participation?

- Yes (Please specify in Q. 16b.)
- No
- NA – patients, consumers and community members were either not engaged or were engaged as the sole stakeholder group.

16b. *(If yes in Q.16a) Please select the option(s) that best describe the special provisions for patients / consumers.*

- Researchers provided Incentives for participation as stakeholders

- Researchers provided separate communication
- Meetings were separated from the other stakeholders
- Provided background literature or information
- ND
- NA
- Other:

17a. Select the option(s) that best describe the any positive reported outcomes from engaging stakeholders in research. If none apply, please include under "other". Please describe in Q17b.

- Made research relevant
- Increased understanding of research process
- Made research more transparent
- Improved research adoption
- Improved trust in research / researchers
- Mutual learning
- ND
- Other:

17b. Describe, in your own words, any positive outcomes researchers reported from engaging stakeholders in research.

18. Describe any reported challenges or negative outcomes associated with the engagement of stakeholders in this research.

Thank you! Please add your initials to the tracking sheet.

19. Final comments from extractor. Use this space for any relevant comment related to the article, if not already included in form.

20. Use this space to include any questions or concerns regarding the form or information extracted.