

Engaging Stakeholders To Identify and Prioritize Future Research Needs



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Number 4

Engaging Stakeholders To Identify and Prioritize Future Research Needs

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The information in this report is intended to help health care researchers and funders of research make well-informed decisions in designing and funding research and thereby improve the quality of health care services. This report is not intended to be a substitute for the application of scientific judgment. Anyone who makes decisions concerning the provision of clinical care should consider this report in the same way as any medical research and in

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Preface

The Agency for Healthcare Research and Quality (AHRQ), through its Evidence-based Practice Centers (EPCs), sponsors the development of evidence reports and technology assessments to assist public- and private-sector organizations in their efforts to improve the quality of health care in the United States. The reports and assessments provide organizations with comprehensive, science-based information on common, costly medical conditions and new health care technologies and strategies. The EPCs systematically review the relevant scientific literature on topics assigned to them by AHRQ and conduct additional analyses when appropriate prior to developing their reports and assessments.

To improve the scientific rigor of these evidence reports, AHRQ supports empiric research by the EPCs to help understand or improve complex methodologic issues in systematic reviews. These methods research projects are intended to contribute to the research base in and be used to improve the science of systematic reviews. They are not intended to be guidance to the EPC program, although may be considered by EPCs along with other scientific research when determining EPC program methods guidance.

AHRQ expects that the EPC evidence reports and technology assessments will inform individual health plans, providers, and purchasers as well as the health care system as a whole by providing important information to help improve health care quality. The reports undergo peer review prior to their release as a final report.

We welcome comments on this Methods Research Project. They may be sent by mail to the Task Order Officer named below at: Agency for Healthcare Research and Quality, 540 Gaither Road, Rockville, MD 20850, or by e-mail to epc@ahrq.hhs.gov.

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Engaging Stakeholders To Identify and Prioritize Future Research Needs

Structured Abstract

Objectives. To describe methods used to engage stakeholders to prioritize future research needs from Comparative Effectiveness Reviews.

Data Sources. There were three complementary phases in this project: **Phase 1:** Literature Scan; **Phases 2 and 3:** Interviews with key informants (KIs) and Evidence-based Practice Centers (EPCs) with experience engaging stakeholders.

Methods. Phase 1: We searched and reviewed the literature from inception until August/September 2010 to identify methods used to engage stakeholders in identifying and prioritizing research. **Phase 2:** Between June 16 and July 9, 2010, KIs were interviewed about their experiences engaging stakeholders and the processes used to set research priorities. Investigators analyzed interview transcripts to identify common themes. **Phase 3:** The experiences of EPCs in engaging stakeholders to identify research gaps and prioritize future research needs were evaluated by: (1) review of EPC protocols and (2) semistructured interviews with EPC directors and staff.

Results. Phase 1: Fifty-six studies were identified. Important considerations in stakeholder engagement included the need for consistent terminology, the intended purpose for engagement, the explicit identification of stakeholder groups, and the distribution of stakeholders. Studies frequently used a mixed-methods approach for research prioritization, combining in-person venues with quantitative prioritization processes such as voting or Delphi. **Phase 2:** We conducted 13 interviews. KIs used e-mail, conference calls, focus groups, and the modified Delphi technique to engage stakeholders. Processes for prioritization ranged from no formal process to a structured process that consisted of multiple rounds of voting/ranking. **Phase 3:** Eight EPCs were interviewed. Group conference calls were the most common approach of stakeholder engagement, along with e-mail or Web-based prioritization. EPCs routinely identified three main challenges, including timing, restriction on number of stakeholders, and limited availability of Federal stakeholders.

Conclusions. Important considerations regarding stakeholder engagement to prioritize research include use of:

1. Consistent terminology and definitions throughout the process.
2. In-person methods for brainstorming, identifying topics, clarifying issues, and eliciting a deeper understanding.
3. Quantitative methods for prioritizing research.

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Executive Summary

Background

National attention has recently focused on engaging stakeholders to create a more patient-centered research agenda to improve health care decisionmaking in the United States.^{1,2} Specifically, patients and physicians seek to apply current research to their treatment decisions, and they require high-quality evidence that directly addresses their information needs.³ In response to this need, there is growing interest among the research community to engage the public in the research development process. Consumer involvement has been shown to positively impact research and its applicability to the public,⁴ and the Agency for Healthcare Research and Quality (AHRQ) has emphasized the importance of considering the patient perspective during all aspects of comprehensive comparative effectiveness reviews (CERs).

Engaging stakeholders to identify and prioritize future research for CERs is a new process, and the methods to delineate future research needs are not well developed. Evidence-based Practice Centers (EPCs) have engaged individuals and organizations outside of the EPC program in their reviews, especially in the early phases for input on topic development and topic refinement.⁵ Recently, some EPCs have initiated new activities engaging stakeholders to identify and prioritize future research needs following completion of CERs.

To develop guidance for a systematic approach to identifying future research needs for the EPCs, AHRQ requested that the Oregon and Vanderbilt EPCs conduct this project to better understand the various methods for engaging stakeholders in defining and prioritizing research needs. In response to this request, the Oregon and Vanderbilt EPCs conducted a methods project to identify and describe methods used in engaging stakeholders to prioritize research needs, evaluate the tradeoffs of different engagement methods, describe methods for analyzing stakeholder input, and to describe the experiences of EPCs who engaged stakeholders for their future research needs pilot studies. This is one of a series of methods projects to inform and systematize AHRQ's guidance related to identification and prioritization of future research needs.

Methods

This project consisted of three phases. Phase 1 involved a scan of the published literature for methods of stakeholder engagement to set research priorities. Phase 2 involved key informant (KI) interviews of individuals and organizations (i.e., researchers and policymakers) who engaged a broad range of stakeholders to identify research topics and prioritize research needs. Phase 3 involved interviews of EPCs that engaged stakeholders for their future research pilot studies in 2010.

Phase 1: Literature Summary

We searched PubMed/MEDLINE (OVID), PsychINFO (OVID), CINAHL (EBSCO), Cochrane Consumer Group, LocatorPlus (NLM catalog), and Sociological Abstracts (CSA) from inception until August or September 2010. We reviewed relevant literature to identify methods and processes used to engage stakeholders in identifying and prioritizing research.

Phase 2: Key Informant Interviews

Individuals known to have expertise engaging a broad range of stakeholders (i.e., consumers, clinicians, and policymakers) were invited to be KIs. We also asked them to recommend additional individuals and/or organizations for this project. Interviews were conducted between June 16 and July 9, 2010. Two investigators interviewed KIs about their experiences engaging stakeholders, the types of stakeholders engaged, the methods used to engage them, the processes used to set research priorities, and the impact of stakeholder engagement. After the interviews were completed, investigators analyzed interview transcripts to identify common themes.

Phase 3: EPC Interviews

We evaluated EPC experiences engaging of stakeholders to identify research gaps and prioritize future research needs for the 2010 pilot projects in two ways: (1) we reviewed EPC proposals to assess the methods proposed by EPCs to engage stakeholders in future research needs development and (2) we conducted semistructured interviews with EPC directors and staff at the conclusion of the pilots to identify lessons learned about the stakeholder engagement process. We received copies of each EPC's protocol for their Future Research Needs pilot project and extracted the information specific to methods for stakeholder engagement to prioritize future research. We then sent letters of inquiry to all EPC directors asking them to participate in brief, semistructured interviews to discuss their experience of engaging stakeholders in future research development. A list of potential questions was developed to guide the conversation.

Results

Phase 1: Literature Summary

We identified 56 studies that provided information about methods for engaging stakeholders specifically for the purpose of prioritizing future research. An important first step for evaluating stakeholder engagement is to have a common terminology; however, the literature lacked consistent terminology, definitions, or structured processes for stakeholder engagement. For the purposes of this report, stakeholders are individuals or organizations who have an interest, personal or professional, in the topic. We developed operational definitions of the major categories of stakeholders based on definitions, terms, and stakeholder categories reported by researchers.

Important considerations for stakeholder engagement included the intended purpose for engagement, the explicit identification of stakeholder groups, the distribution of the constituency (i.e., equal participation by group compared with other), the complexity of the topic, and the nature of the feedback that investigators want to see. The literature informed common practices around identification of stakeholders, recruitment of stakeholder representatives, and methods to prioritize and inform future research. Snowball sampling, which involves identifying stakeholders through referrals from others, was one of the most common methods used to identify stakeholders. However, because individuals may be more likely to recommend people who are similar to themselves, it is possible that bias could be introduced. While many studies did not provide details regarding the effectiveness of recruitment strategies, postal and electronic mailings were the most commonly reported contact methods regardless of stakeholder group. Studies frequently used a mixed-methods approach for research prioritization, combining in-person venues with quantitative prioritization processes. Studies used in-person methods to

clarify stakeholder questions and to allow for a deeper understanding of stakeholders' viewpoints, whereas they used quantitative methods such as voting, Delphi, questionnaire, or other explicit rating processes to arrive at final priorities.

Phase 2: Key Informant Interviews

To determine the methods used to engage stakeholders to prioritize future research and to identify important issues in engaging stakeholders and analyzing stakeholder input, we conducted a series of 13 interviews with a broad range of KIs from academic institutions, practice-based research networks, nonprofit organizations, and other organizations devoted to health care issues on local and national levels in the United States, Canada, and Europe.

Defining Stakeholders

Even among individuals with extensive experience engaging stakeholders, stakeholder terminology was unclear or inconsistently applied. The interviews emphasized the lack of consistency and clarity in this process.

Recruitment

KIs used several methods to recruit stakeholders that differed according to topic, organization, and the stakeholder groups engaged. Often, they recruited multiple groups of stakeholders for engagement. KIs most commonly used existing contacts and telephone or e-mail communication to identify and recruit stakeholders. Additional methods used to recruit consumers included use of the media, and Internet/Web. In addition, KIs noted that followup was essential to recruitment and stakeholder engagement.

Engagement

KIs engaged stakeholders using a variety of methods, including e-mail, conference calls or Webinars, focus groups, citizens' juries, workshops conferences, and the modified Delphi technique. They often used multiple methods (mixed methods) to engage the same stakeholder groups. The two most common methods that were used by KIs to engage stakeholders were one-to-one meetings (in person or by phone) and working group/committee/council meetings. According to KIs, the advantages of in-person meetings included: (1) ensuring a time of focused stakeholder attention to the subject, (2) fostering relationships among stakeholders, and (3) promoting a better understanding of the each other's needs and priorities through discussion.

KIs identified engagement strategies that were particularly effective for different stakeholder groups. For policymakers and research funders, KIs preferred to either engage them by phone, one-to-one meetings, or in small meetings. KIs differed in their views about the appropriate context for engagement of consumers and frontline clinicians. For clinicians, KIs used one-to-one meetings, e-mail, conference calls, committee meetings, and conferences. For consumers, KIs used methods similar to that of other stakeholder groups; however, the motivation and needs of consumers were seen to be quite different. KIs reported that it took a substantial amount of time to engage this group, and warned that often researchers underestimate the amount of time, patience, and attention that is required to engage consumers.

Prioritization

Specific Considerations for Engagement of Stakeholder Groups

There was considerable variation in the value KIs placed on involving consumers in their research prioritization processes. Some KIs advocated strongly for their inclusion and felt that input from these stakeholders was critical for setting a relevant research agenda. They noted that consumers were not only capable of understanding the research process, they linked researchers to the community and made important contributions during topic identification, study design, and manuscript preparation. In contrast, other KIs excluded consumers or dismissed their contributions because they lacked research experience, scientific knowledge, or technical expertise to meaningfully contribute to health care discussions or setting a research agenda.

Policymakers. KIs preferred to policymakers by phone, with one-to-one interviews, or in small meetings. Two KIs stressed the importance of having “off-the-record” discussions with policymakers so that they felt comfortable asking questions about research without representing a specific constituency or agency. Several KIs mentioned that it is important to understand the pressing time demands that these policymakers encounter on a daily basis.

Researchers. Engaging researchers as stakeholders can be challenging because though they are familiar with this process, they may not be accustomed to this type of collaboration.

Prioritization

Prioritization ranged from little or no formal process to a structured, formal prioritization process that consisted of multiple rounds of voting/ranking, with at least one vote occurring in person. An initial voting/ranking process was often used by KIs to limit the number of research topics discussed and prioritized at a subsequent in-person meeting. KIs reported that stakeholders used multiple criteria to prioritize research including: funding availability, current resources available, the burden of disease, community resonance, policy “shelf life,” and in the case of systematic reviews, having adequate primary research to conduct a systematic review.

Considerations in Working with Stakeholders

Regardless of the method used to engage stakeholders, KIs emphasized that leveraging contacts, establishing long-term partnerships, and building trust and credibility were critical. Bringing diverse stakeholders together may require as much attention to group dynamics as to the presentation of research topics and prioritization criteria. Several KIs reported that stakeholders’ busy schedules and competing demands for their time are common and having flexible engagement methods can help to ensure that critical stakeholders are engaged. In addition, KIs commented that individuals frequently encounter both logistic and financial barriers to providing input as stakeholders. KIs offered the following advice to foster stakeholder relationships: engage stakeholders early, find common ground, and foster partnership, understanding, and respect.

Phase 3: EPC Interviews

Review of Protocols

We reviewed the EPC future research pilot protocols and found that EPCs proposed a range of approaches to engaging stakeholders. Among these approaches included two who intended to

engage the support of the Effective Health Care Scientific Resource Center and two who intended to work with the Eisenberg Center in engaging stakeholders. Most centers intended to use group calls, with two EPCs using a formal Delphi process.

Semistructured Discussions with EPC Directors and Staff

We interviewed representatives from the eight EPCs that conducted the future research pilots about their experiences engaging stakeholders during those projects. Although these pilot projects were intended to develop and compare a range of approaches to developing future research documents, the EPCs had remarkably similar experiences and methods for engaging stakeholders. A defining feature associated with reporting fewer challenges in engaging stakeholders was the currency of the report itself. Reports published more recently and/or by the EPC doing the future research had a natural constituency from which to draw potential stakeholder members. These teams generally drew upon the investigators and the Technical Expert Panel (TEP) members from the original evidence report to participate in or suggest other individuals for the stakeholder group.

Stakeholder Constituencies

EPCs included between six and 30 stakeholders for their research gaps pilot projects. Target groups for stakeholder engagement included primary researchers, methodologists, patient/consumer advocates, policymakers, funders, payers, industry (for devices), and patients themselves. Of these, all EPCs targeted active researchers, with representation from the other groups varying. One EPC had three distinct stakeholder groups: authors of the report, a group of local experts (considered internal), and a group of stakeholders outside of their institution (external). Several EPCs identified particular barriers to engaging funders. EPCs reported that the need for high levels of clearance/approval for individuals to participate was ultimately time prohibitive. All EPCs discussed the question of whether and how to engage patients or consumers in the process of identifying research gaps and future research needs.

Methods for Identifying Stakeholders

All EPCs used a combination of approaches for identifying potential stakeholders, most of which began with individuals who were known to the EPC investigators, either because they were involved in the report for which future research recommendations were being developed or through professional relationships. EPCs did not select stakeholders at random, but based selections primarily on availability and convenience, knowledge, and personal contacts. Their most common approach, along with e-mail or Web-based prioritization, was group conference calls. One EPC presented a Webinar to bring stakeholders up to speed. EPCs varied in the numbers and types of contacts that occurred with stakeholders, including letters, one-to-one orientation calls, group calls, survey tools, e-mails, and Webinars.

Challenges Identified

EPCs routinely identified three main challenges, including timing, restriction on number of stakeholders, and limited availability of Federal stakeholders. The requirement that the project take place very quickly and during the summer made it difficult to coordinate schedules and likely resulted in an inability to engage some stakeholders, particularly academic researchers. Engaging more than nine nonfederal citizens with a structured survey on behalf of the United States Government would require a lengthy clearance process through the Office and Management and Budget. The time needed to obtain this clearance was prohibitive to timely

completion of this project, so the number of stakeholders engaged was kept to nine or less. This limited number was generally perceived as too few to capture the breadth of views of researchers and patients necessary for identifying research gaps. However, the EPCs reported not knowing what number would be optimal. Finally, the difficulty in engaging Federal stakeholders, primarily at the National Institutes of Health (NIH), was largely due to the need for permissions that took too long and resulted in several EPCs not including NIH representatives.

Conclusions

From the literature and the KI and EPC interviews, we identified the following considerations regarding stakeholder engagement to prioritize research:

1. Use of consistent terminology and definitions is important throughout the stakeholder engagement process, from planning to implementation to evaluation.
2. The intent of stakeholder engagement is important in determining the methods of engagement. In-person methods are helpful for brainstorming, identifying topics, clarifying issues, and eliciting a deeper understanding, while quantitative methods such as voting and Delphi are best applied to prioritize research. A flexible approach using mixed methods may be required to engage multiple stakeholder groups. We summarized the tradeoffs for engagement methods in this report to assist programs in their selection of feasible and effective methods for their project.
3. Engaging stakeholders early and maintaining relationships are important to building trust and credibility.
4. Assurance that representative samples of stakeholders are engaged is critical to the credibility and legitimacy of the stakeholder engagement process and results.
5. When multiple stakeholder groups are engaged, special consideration should be given to how to weight input from each group. The issue of weighting should be addressed at the outset during recruitment because it will affect the composition of stakeholder recruitment lists, and it should also be considered when synthesizing and analyzing stakeholder input.

Additionally, we used results from all three phases to identify the following recommendations for stakeholder engagement to prioritize future research needs, including a proposed reporting checklist for EPC reports (Table A):

Table A. Recommendations for stakeholder engagement to identify and prioritize future research

Process	Tasks	Reporting Checklist
Engagement Purpose	<ul style="list-style-type: none"> • State purpose of stakeholder engagement (e.g., topic identification, prioritization, etc.) and desired results or outcomes (affects selection of recruitment, engagement, and prioritization methods) 	<ul style="list-style-type: none"> ✓ State purpose of stakeholder engagement
Stakeholder Orientation Information and Materials	<ul style="list-style-type: none"> • Provide orientation to the program (e.g., EHC and Systematic Evidence Reviews) • Communicate scope, aims, and desired product/outcome of engagement • Delineate stakeholder roles, responsibilities and expectations • Describe extent of commitment, including methods of engagement (e.g., single Webinar on a specific date), frequency of activities, project schedule • Explain compensation plan, if any (e.g., travel reimbursement, honorarium, or other compensation) • Inform of conflict of interest disclosure requirements • Provide contact information for project team (e.g., e-mail address and phone number of investigator and research staff contact) 	<ul style="list-style-type: none"> ✓ Report conflicts of interest and disposition ✓ Report any compensation
Stakeholder Recruitment	<ul style="list-style-type: none"> • Develop a priori list of relevant stakeholder groups, including numbers of stakeholders for each group • Identify specific individuals within each stakeholder group to contact • Plan one or more methods of contact (e.g., write e-mail scripts or telephone dialogue to convey expectations of stakeholders) • Plan recruitment followup (e.g., repeat e-mails or return calls for refusals or non-respondents) • Contact individual stakeholders and document results of individual responses for calculation of overall response rates • Monitor stakeholder representativeness and distribution of stakeholder groups; add individuals to recruitment as necessary to ensure target stakeholder groups are included 	<ul style="list-style-type: none"> ✓ State the types and proportions of stakeholders targeted by group and rationale for recruiting each group (similar to inception cohort) ✓ Report methods used to identify, sample, and contact each stakeholder group ✓ Document recruitment dates ✓ Report invitation and participation rates (similar to response rate) ✓ Report distribution of stakeholders planned and recruited
Methods of Engagement	<ul style="list-style-type: none"> • Assess and identify engagement methods and criteria for selection for each stakeholder group based on: <ul style="list-style-type: none"> ○ Purpose of engagement ○ Characteristics of stakeholders to be engaged (e.g., geographic locations, numbers of stakeholders, range of perspectives, existing relationships among stakeholders, familiarity with research area or research prioritization generally, technological capacity) ○ Context of engagement (e.g., staff, time, budget, technological capacity, complexity of research area) 	<ul style="list-style-type: none"> ✓ Report engagement method(s) and describe process for the identification of research topics ✓ Document number and types of engagements ✓ Report participation rates and distribution in each engagement

Table A. Recommendations for stakeholder engagement to identify and prioritize future research (continued)

Process	Tasks	Reporting Checklist
Prioritization Methods	<ul style="list-style-type: none"> • Provide criteria for prioritization if previously established (by the sponsor or by previous engagement activity) • Document individual or group development of criteria for prioritization if not previously established 	<ul style="list-style-type: none"> ✓ Document prioritization criteria ✓ Describe methods of prioritization of research topics
Analysis and Synthesis	<ul style="list-style-type: none"> • Document, review, synthesize, and report stakeholder research priorities <ul style="list-style-type: none"> ○ Overall and by stakeholder group ○ Weighting of input if applicable (e.g., do two votes from one organization count as one or two?) • Plan for review and validation of results by stakeholders to ensure their intended priorities are accurately communicated 	<ul style="list-style-type: none"> ✓ Provide assessment of stakeholder representativeness ✓ Provide details of synthesis and analytic methods including weighting of stakeholder group's responses and calculation of participation rates ✓ Provide results both overall and by stakeholder group ✓ Verify priorities with stakeholders
Conclusion	<ul style="list-style-type: none"> • Distribute final product or report to stakeholders • Express appreciation for participation and contribution • Gather input from stakeholders on engagement experience to evaluate the process • Advise stakeholders of opportunities for future participation and any plans for future contact (if relationship will be maintained) 	<ul style="list-style-type: none"> ✓ Provide prioritized list of future research topics (only after public posting/publication) ✓ Summarize lessons learned

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Background

National attention has recently focused on engaging stakeholders to create a more patient-centered research agenda to improve health care decisionmaking in the United States.^{1,2} Specifically, patients and physicians seek to apply current research to their treatment decisions, and they require high-quality evidence that directly addresses their information needs.³ In response to this need, there is growing interest among the research community to engage the public in the research development process. Consumer involvement has been shown to positively impact research and its applicability to the public,⁴ and the Agency for Healthcare Research and Quality (AHRQ) has emphasized the importance of considering the patient perspective during all aspects of comprehensive comparative effectiveness reviews (CERs).

Engaging stakeholders to identify and prioritize future research for CERs is a new process, and the methods to delineate future research needs are not well developed. Evidence-based Practice Centers (EPCs) have engaged individuals and organizations outside of the EPC program in their reviews, especially in the early phases for input on topic development and topic refinement.⁵ Recently, some EPCs have initiated new activities engaging stakeholders to identify and prioritize future research needs following completion of CERs.

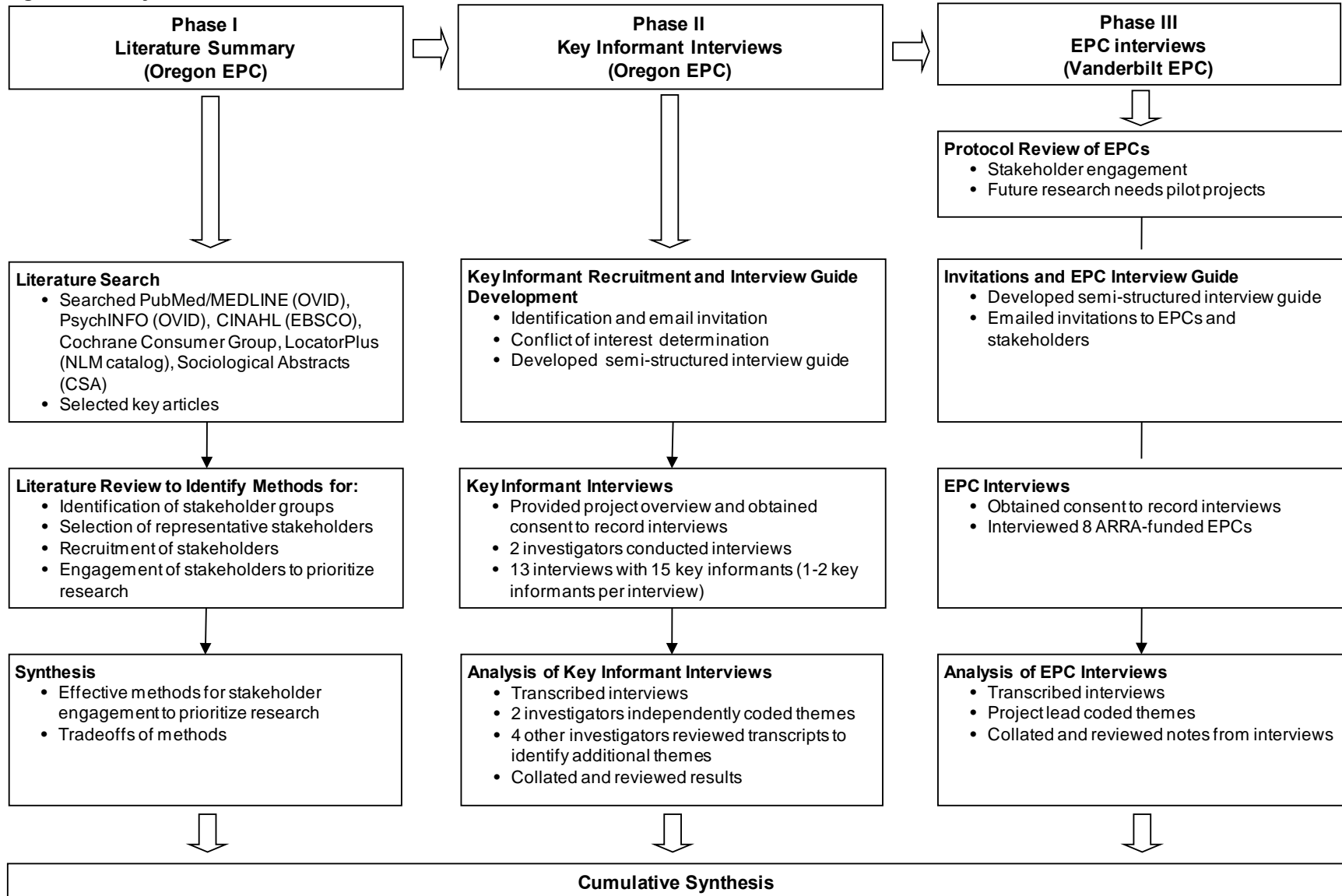
To develop guidance for a systematic approach to identifying future research needs for the EPCs, AHRQ requested that the Oregon and Vanderbilt EPCs conduct this project to better understand the various methods for engaging stakeholders in defining and prioritizing research needs. In response to this request, the Oregon and Vanderbilt EPCs conducted a methods project to identify and describe methods used in engaging stakeholders to prioritize research needs, evaluate the tradeoffs of different engagement methods, describe methods for analyzing stakeholder input, and describe the experiences of EPCs who engaged stakeholders for their future research needs pilot studies. This is one of a series of methods projects to inform and systematize AHRQ's guidance related to identification and prioritization of future research needs.

Methods

Study Overview

This project consisted of three phases, as shown in Figure 1. In phase 1 we searched the published literature for methods of stakeholder engagement to set research priorities. In phase 2 we conducted key informant (KI) interviews with individuals and organizations (i.e., researchers and policymakers) who engaged a broad range of stakeholders to identify research topics and prioritize research needs. In phase 3 we interviewed EPCs that engaged stakeholders for their future research pilot studies in 2010.

Figure 1. Study overview



Phase 1: Literature Summary

We searched PubMed/MEDLINE (OVID), PsychINFO (OVID), CINAHL (EBSCO), Cochrane Consumer Group, LocatorPlus (NLM online catalog), and Sociological Abstracts (CSA) from inception until August or September 2010 (see Appendix A for details). We reviewed relevant literature to identify methods and processes used to engage stakeholders in identifying and prioritizing research.

Phase 2: Key Informant Interviews

Individuals known to have expertise engaging a broad range of stakeholders were invited to be KIs. We also asked them to recommend additional individuals and/or organizations for this project. We then reviewed the resulting list of potential KIs to ensure that it contained individuals with a breadth of experience engaging a diverse group of stakeholders (i.e., consumers, clinicians, and policymakers), and we e-mailed a description of the project and an invitation to participate to 20 KIs (Appendix B). Interviews were conducted between June 16 and July 9, 2010.

We developed a semistructured interview guide for telephone interviews with KIs (Appendix C). The guide included questions regarding experiences engaging stakeholders, the types of stakeholders engaged, the methods used to engage them, the processes used to set research priorities, and the impact of stakeholder engagement. Two investigators conducted all telephone interviews and with the permission of KIs digitally recorded and transcribed them. At the start of each interview, KIs were provided with an overview of the project and assured their identity would be kept confidential. After the interviews were completed, two investigators independently listened to the digital recordings, reviewed the transcripts to identify and code themes, and reached consensus. Four additional investigators reviewed transcripts to identify themes. All investigators met to discuss themes and resolve discrepancies.

Disclosure and Evaluation of Conflicts of Interest

Each KI completed an EPC Conflict of Interest Disclosure Form prior to being interviewed by Oregon EPC investigators. Of the 15 KIs, 11 declared no conflicts, one provided information on financial as well as professional and business interests, and three provided information on professional and business interests. No conflicts disclosed precluded participation for any of those invited.

Phase 3: EPC Interviews

At the conclusion of the pilots, we used semistructured interviews to evaluate the experiences of the EPC directors and project team members who engaged stakeholders to prioritize future research for the 2010 pilot projects to identify lessons learned. First, we received copies of each EPC's protocol for the Future Research Needs project and extracted the information specific to methods for stakeholder engagement to prioritize future research to prepare for conversations. We specifically sought information on anticipated timing and approach to communication, source of stakeholders, and breadth of stakeholder engagement. We then sent letters of inquiry to all EPC directors asking them to participate in brief, semi-structured interviews to discuss their experience of engaging stakeholders in future research development (Appendix D) and

developed a list of potential questions to guide the interviews (Appendix E). The discussions took place between August 19 and September 21, 2010.

At the start of the call, EPC directors and staff were provided an overview of the project and informed that their identity would be kept confidential. They were asked to describe the methods by which they had engaged stakeholders in their future research pilot projects and to consider whether they achieved appropriate balance, whether there were unforeseen challenges to managing the stakeholder process, and how they might have done it differently. The interviews were recorded and summary notes were transcribed for review. One investigator reviewed the notes and calls to identify themes and summarized them in the results below.

Institutional Review Board

The Oregon Health & Science University and Kaiser Permanente Center for Health Research's Institutional Review Boards determined that phases 1 and 2 did not meet the definition of human subject research per 45 CFR 46.102. The Vanderbilt University Institutional Review Board determined that their phase 3 study met the 45 CFR 46.101 (b) category (2) and approved the request for exemption.

Peer Review

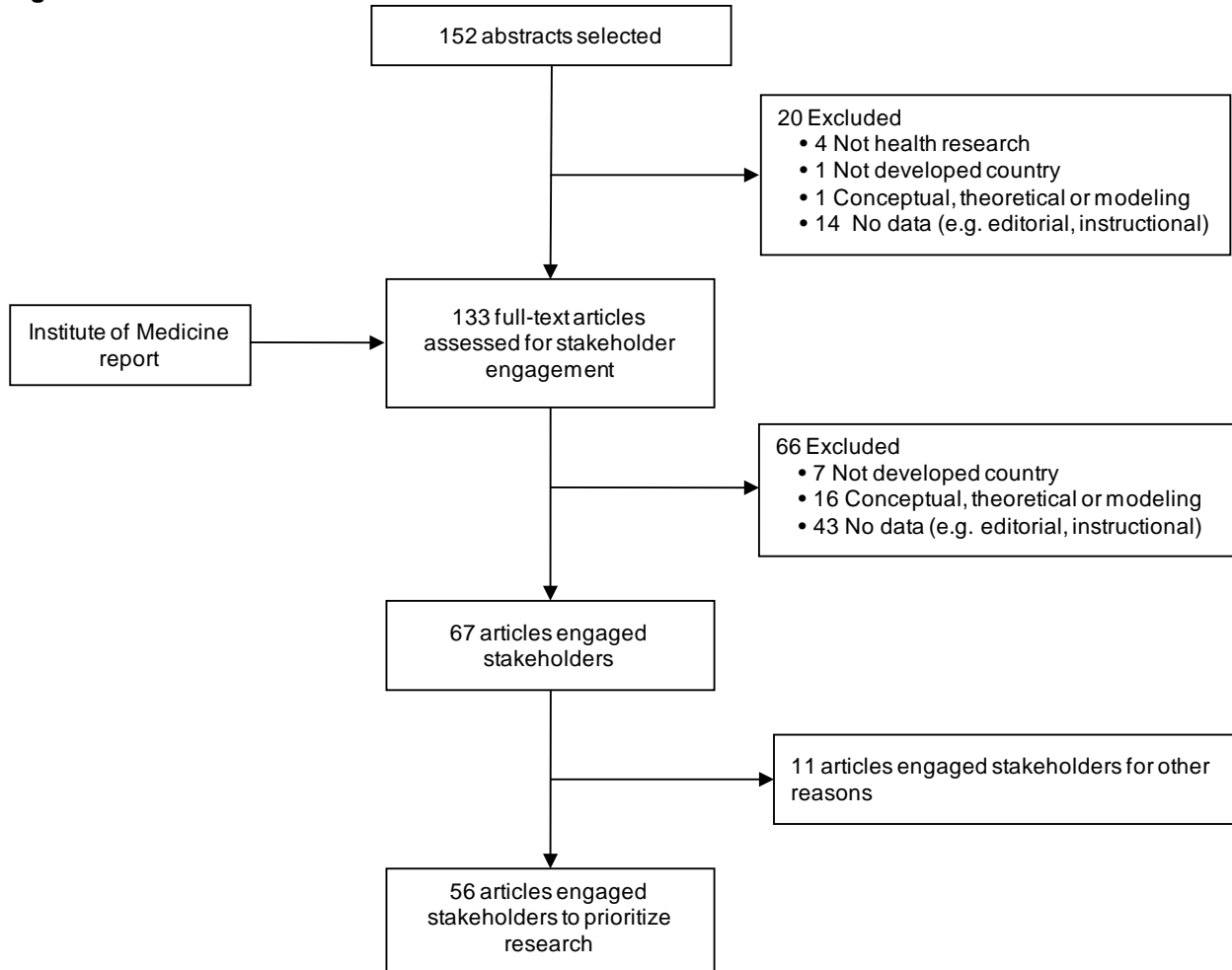
A draft of the report was sent to peer reviewers and to AHRQ. In response to the comments of the peer reviewers, revisions were made to the report and a summary of the comments and their disposition was submitted to AHRQ.

Results

Phase 1: Literature Summary

After the exclusion of editorials, commentaries, and studies that did not provide data for stakeholder engagement, 67 articles provided information about methods for engaging stakeholders, of which 56 focused specifically on engaging stakeholders to prioritize research (Figure 2).

Figure 2. Results from literature search



Definition of Stakeholder and Stakeholder Groups

We found that the term “stakeholder” and the categorization of stakeholder groups were inconsistently applied by researchers. For the purposes of this report, stakeholders are individuals or organizations who have a personal or professional interest in the topic. We developed operational definitions of the major categories of stakeholders based on definitions, terms, and stakeholder categories reported by researchers (Table 1).

Table 1. Definitions of stakeholder groups

Stakeholder	Definition
Consumer (general public, patient, and caregiver)	An individual or advocacy group representing individuals who use health care services (e.g., patients and their families) and/or who is a member of the community (e.g., patient, parent, neighbor) <ul style="list-style-type: none"> • General public • General public advocacy group • Individual patient with condition/disease • Individual patient without condition/disease • Patient advocacy group – condition/disease specific • Patient advocacy group – not condition/disease specific • A person acting as a proxy or providing care to a patient with condition/disease
Clinician (Health Professional)	Health care provider (academic, rural/frontier, community) <ul style="list-style-type: none"> • Condition/disease specific • Not condition/disease specific • Practicing/nonpracticing Medical organizations <ul style="list-style-type: none"> • Condition/disease specific • Not condition/disease specific
Policymaker	An individual or organization who is involved in health care policy (e.g., local, state, provincial and Federal legislators and staff) <ul style="list-style-type: none"> • Medical organizations • Governmental organizations (e.g., VA, AHRQ, government officials)
Researcher	An individual who conducts and/or facilitates research activities: <ul style="list-style-type: none"> • Basic science • Translational science • Clinical science • Research methodology • Health service • Systematic review
Research Funder	A public or private organization that funds research (e.g., National Institute of Health, Department of Defense, Robert Wood Johnson Foundation, Susan G. Komen Foundation, American Cancer Society)
Insurer/Payer	An organization or agency that pays for health-related goods and services (e.g., Blue Cross Blue Shield, Medicaid, Medicare) or a business group that pays for health insurance (e.g., employers and government)
Manufacturer	A business group that produces health-related items (e.g., pharmaceuticals and medical devices)

Abbreviations: AHRQ, Agency for Healthcare Research and Quality; VA, Veterans Affairs.

Note: It is possible for stakeholders to represent multiple perspectives and stakeholder groups. For example, Medicaid directors could be both Policymakers and Insurers/Payers.

A Priori Identification of Relevant Stakeholder Groups

An important step to ensure that representative stakeholders are engaged is to list the relevant stakeholder groups prior to initiating recruitment. This step makes it possible to monitor and maintain representativeness of stakeholders during recruitment and analysis.

Identifying individuals or organizational stakeholder groups can be challenging. The methods that studies used to identify these groups are listed in Table 2. Snowball sampling was one of the most commonly reported methods used to identify stakeholders.^{6-8,9,7,10,11,21} It is thought to be a particularly useful method to identify members of special populations that are more difficult to locate (i.e., people with rare conditions). Because individuals may be more likely to recommend people who are similar to themselves, it is possible that bias could be introduced with this method or generalizability issues may arise. In contrast, random sampling, which is less likely to

introduce bias, was the least common identification method used. Random sampling was reported for three studies that recruited the public, patients, health professionals, and researchers.^{8,12,13} But it may not always be feasible, for example, when searching for patients with rare health conditions.

Table 2. Literature results: Methods for identifying and selecting stakeholders

Stakeholders	Recommendations by Study Team ^{a,b}	Snowball Sampling	Searching Published Literature	Searching Databases/ Directories	Internet Searches of Individuals and Organizations	Random Sampling
Consumers	7, 14-16	6-8		13, 17, 18		12, 13
Clinicians	14, 19	9	15	9, 20	19	8
Policymakers	14, 19, 21	7, 10, 11	11	20	19	
Manufacturers	19	10			19	
Researchers	14, 19	6, 7, 22	8, 10, 11, 15, 19	10, 20	19	8
Research Funders		7				

^a Numbers indicate citations (see References section).

^b Blank cells indicate no studies found.

Note: Sampling methods not specified or incomplete description of methods.²³⁻²⁷

Contacting Stakeholders

Once investigators identified the stakeholders that they wanted to reach, the next step was to choose a method for contacting stakeholders. Table 3 details the methods reported in the literature. Regardless of stakeholder group, investigators most commonly reported contacting stakeholders using postal and electronic mailings. Because many studies did not report recruitment details, we were unable to evaluate the effectiveness of these methods for each stakeholder group.

Table 3. Literature results: Methods for contacting stakeholders

Stakeholders	Postal Letters ^{a,b}	E-mail	Phone Calls	Presentations/ Informational Sessions	Advertisements in Journals, Newspapers, and Web	Posters
Consumers	12, 17, 28-31	31, 32	17, 29, 32	31, 33, 34	17	35
Clinicians	28, 30, 31	9, 16, 20, 31		31, 36	37	38
Policymakers	10, 28, 30, 31	10, 16, 20, 31		31		
Manufacturers	10, 31	10, 31		31		
Researchers	10, 28, 30, 31	10, 16, 20, 31		31		
Research Funders	24	24				

^a Numbers indicate citations (see References section).

^b Blank cells indicate no studies found.

Engaging Stakeholders To Prioritize Research

The process of engaging stakeholders was intended to make research relevant to the real-world decisions faced by the public and clinicians. Table 4 lists the methods that researchers

used to engage stakeholders in discussions about future research. Among the methods used, two may be less familiar than others—citizens’ juries and town meetings. Citizens’ juries bring together diverse members of the public as jurors who are given information relevant to the issue under debate by expert witnesses, followed by a facilitated discussion. The end result may be a report by the jurors or questionnaire responses from the jurors. Town meetings bring together community members in a public meeting to discuss issues of interest. Town meetings are often loosely organized, with a relaxed atmosphere. More detailed information about engagement methods appears in Appendix F (descriptions of the engagement methods found in the literature) and G (descriptions of each method’s strengths and limitations).

Table 4. Literature results: Methods used to engage stakeholders and prioritize research

	Engagement					Prioritization			Engagement and Prioritization	
	1:1 Meetings (in-person or telephone) ^{a,b}	Focus Groups	Citizens' Juries	Town-Meetings	Symposia/ Workshops/ Conferences/ Forums	Consensus	Voting	Nominal Group Technique	One-Time Priority Questionnaire	Delphi Technique
Consumers	11, 13, 14, 39	7, 13, 14, 16, 25, 26, 28, 29, 39-45	12, 17, 46, 47	48, 49	11, 30, 35, 43, 50 6, 32	13, 26, 31, 42, 44, 45, 48, 50, 51	31, 49	30, 52	8, 18, 34, 40, 43, 51, 53-55	15, 33, 38, 56, 57
Clinicians	14, 16, 39	14, 19, 27, 39, 44, 48, 58		48		27, 31, 44, 48, 50, 51, 58	31	27, 28, 30, 52	8-10, 20, 51, 53-55	15, 33, 36-38, 56-59
Polymakers	10, 11, 14, 16	7, 14, 19, 27, 44, 58		48	11, 20, 21, 23, 30, 50, 60	23, 27, 31, 44, 48, 50, 58		27, 30, 52	8, 10, 20, 21, 55	11, 28, 33, 56, 58
Manufacturers		19, 44				31, 44, 50		30, 52		
Researchers	14, 16, 28, 39	7, 14, 19, 22, 27, 39, 44, 45, 48, 58, 61		48	6, 20, 23, 30, 50, 60	44, 48, 50 7, 27, 31, 45, 58, 60		27, 28, 30, 52	8, 10, 20, 54, 55	11, 15, 28, 58
Research Funders	24, 39	7, 44			14, 50, 60	44, 50		30	8, 55	

^a Numbers indicate citations (see References section).

^b Blank cells indicate no studies found.

Note: Methods of stakeholder engagement are described in Appendix F.

The methods for engaging stakeholders were largely determined by the intended purpose of stakeholder engagement (i.e., topic generation, study design, study implementation, policy development, and prioritization of research). Investigators most commonly reported engaging stakeholders to discuss research using in-person methods such as focus groups, forums, and conferences, either alone or in combination with other methods.^{7,14,16,23,25,29,38-43} In-person methods are advantageous because they allow for exchange of information to clarify participants' questions and they elicit a deeper understanding of viewpoints through rich narratives. Investigators often used a structured system such as voting, Delphi, questionnaire, or other explicit rating process in concert with in-person methods to arrive at final priorities. However, two studies^{35,43} tallied the frequency that an item was mentioned during focus group discussions and used this process to provide a ranked list, and one study⁴⁰ created a questionnaire from identified themes to determine final priorities.

The next most commonly reported prioritization methods were the Delphi or modified Delphi technique, used in seven studies,^{15,33,36,37,56,58,59} and rankings from responses to questionnaires. The Delphi technique administered a series of two to five questionnaires sequentially to a panel of stakeholders to rate or rank importance of items. After each round of questionnaires, answers were tabulated and fed back to participants to allow them to reorder or to arrive at consensus. Advantages of the Delphi method include: (1) Delphi questionnaires can be administered to large groups of people (studies reported ranged from 50 to 621 participants) across a wide geographical area; (2) the process is designed to arrive at consensus, thus a final rank list of priorities can be produced; (3) stakeholders may be more comfortable expressing their opinions in a less public venue; and (4) the method helps to ensure that every participant's priorities are known. While designing the questionnaire that underlies the Delphi method may be particularly challenging for complex topics or stakeholder groups who are unfamiliar with the research topic or process, three studies^{15,33,56} reported using this technique with patients, public, or caregivers. Two of the three Delphi studies of consumers reported high response rates with each round (range from 78 percent to 90 percent),^{15,33} with the largest study reporting a 44 percent response rate.⁵⁶ In this study, the participants had difficulty rating research priorities to identify future research in hospice care for children.

A related but shorter method involved questionnaires that used rankings and/or frequencies for respondents rating survey items using a Likert or other scale.^{8-10,12,18-20,22,53,55} Among the 10 studies that used this method, 4 involved the public, patients, or caregivers.^{8,12,18,53} In this context, the electronic or paper-based questionnaires were either administered alone or in the context of citizens' juries or workshops. Finally, questionnaires were commonly chosen by studies aimed at engaging expert researchers or clinicians.^{8-10,20,51,53-55}

Four studies used a nominal group technique during which members of a group individually listed all their ideas, usually on a piece of paper.^{27,28,30,52} A facilitator asked each person to explain their ideas to the group and address any questions. The group then voted on a ranking of the ideas. The point of the nominal group was to ensure that each individual participated and had a voice. This method retained some of the benefits of focus groups, such as being able to provide more in-depth context of the research topic(s) to resolve possible confusion while also providing a mechanism to count every view.

Overall, a mixed methodological approach¹⁹ may be optimal because the in-person discussions allow for explanations and clarification of concepts, while questionnaires, Delphi, or voting allow for quantitative analysis (either totals for all individuals or weighted for groupings). The Institute of Medicine (IOM) used a process to develop national priorities for comparative

effectiveness research that may be particularly informative regarding the use of mixed methodological approaches.³¹ It created a multidisciplinary committee comprised of health care providers, researchers, consumer advocates, an insurer, and one health system representative. The committee identified relevant groups of stakeholders a priori: (1) consumer/patient/advocacy groups; (2) Federal government agencies; (3) health care providers and researchers; (4) insurers; (5) integrated health systems; (6) manufacturers; and (7) state government agencies. They posted all announcements for in-person meetings on the IOM Web site and distributed by electronic mail to general IOM lists, including 20,000 mailings and held a one-day meeting during which 54 stakeholders gave 3- to 5-minute presentations about setting research priorities to the committee and a public audience. The distribution of speakers represented diverse stakeholder groups, with 56 percent health care providers and researchers, 18 percent consumers, 15 percent manufacturers, 6 percent insurers, and 4 percent Federal or state government agencies. Following these presentations and discussions, a Web-based questionnaire was distributed via e-mail and public postings (including Web posting) to generate a list of priorities. The committee considered input from all venues in their final decisionmaking.

Assessing the Representativeness of Stakeholder Involvement

Failure to recruit a representative sample of stakeholders introduces potential bias and reduces confidence in reliability of results. One potential method to assess representativeness is through participation or response rates. Among the 56 studies that engaged stakeholders to prioritize research, fewer than one-third of studies reported this level of detail.^{8,10,15,16,20,32,33,37,40,41,50,53,56,57,59} As shown in Appendix H, participation rates ranged from a low of zero (of 20 contacted) for a workshop of consumers designed to understand barriers in developing public health research³² to a high of 100 percent in a Delphi study of caregivers to identify mental health research priorities by stakeholder groups.³³ Because the number of studies that provided these data were few, it was not possible to identify a clear association between engagement methods and response rates.

Response rates may not provide an accurate reflection of representation. For example, response rates do not accurately address representativeness of populations if the stakeholders who were initially recruited were not representative to begin with. Furthermore, for studies such as the IOM report that advertises through Web sites, it is difficult to know the total number of people that were reached (the denominator) in order to calculate the response rate.³¹ For such studies, comparing the intended (a priori) list of stakeholders to the actual proportion of stakeholders engaged may be a more meaningful measure. While no gold standard currently exists, reporting the details of stakeholders engaged for each step provides the reader with a method to evaluate overall representation.

Unanswered Questions

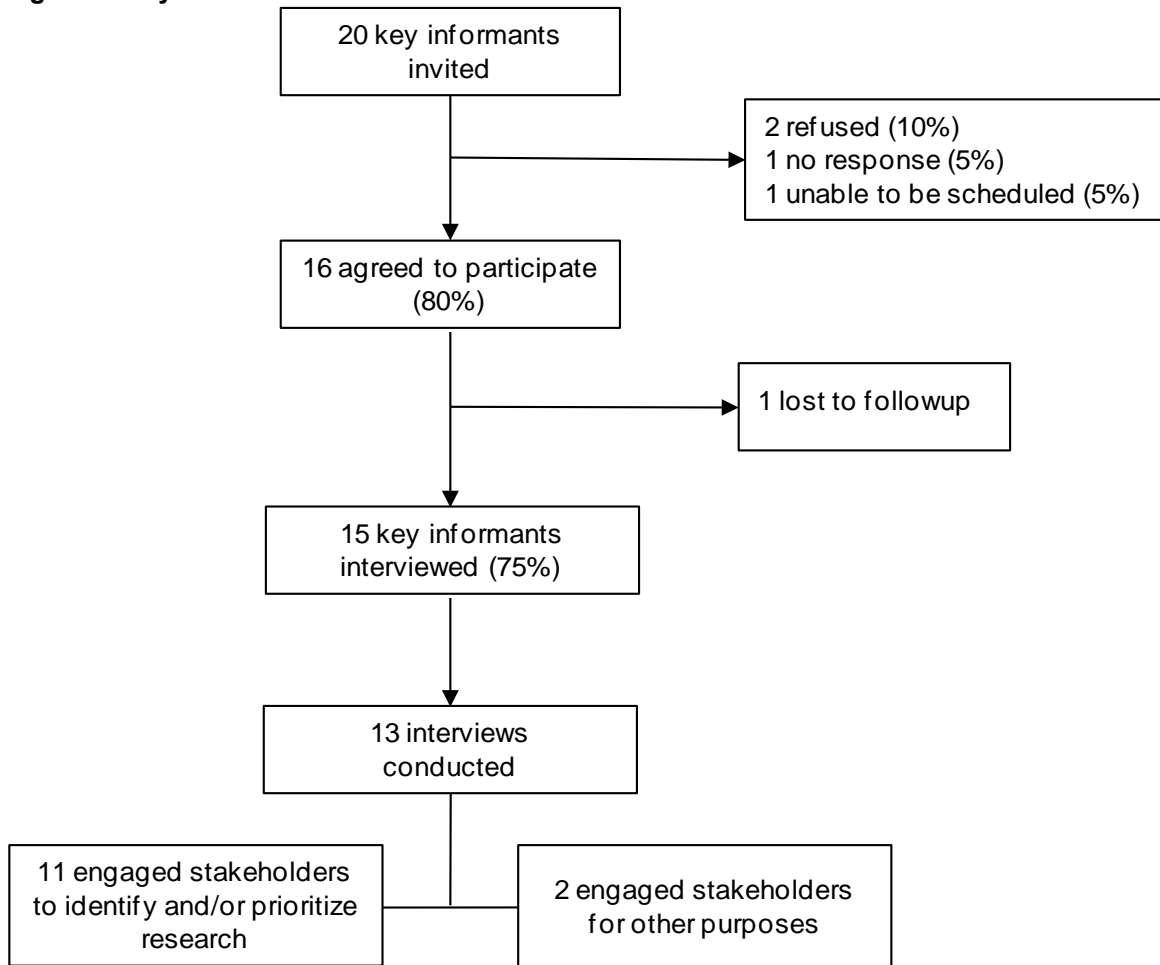
There are considerations for analysis of stakeholder feedback that have not been resolved by the literature. For example, is it important to know that every individual had a voice in determining the final priorities? Additionally, and especially when multiple stakeholder groups are involved, should priorities be based upon an equal weighting of all participating individuals votes, or should the results be unequally weighted by stakeholder group, organization, or other factor? Commonly, studies report consensus without knowing explicitly the contributions of the individuals. Others, whether questionnaire (single or Delphi) or voting, counted every individual and presented overall results.

In summary, important considerations for stakeholder engagement include the intended purpose of engagement, the explicit identification of stakeholder groups, the distribution of the constituency (i.e., equal participation by group compared with other), the complexity of the topic, and the nature of the feedback that investigators want to see. Important considerations for analysis include the most appropriate way to present the data. Should stakeholder responses be presented in aggregate or averaged? Should the responses be presented for all stakeholders who were engaged or should they be stratified by stakeholder group? These considerations, in addition to resources and time available, will largely determine the optimal approach.

Phase 2: Key Informant Interviews

We conducted a series of interviews with a broad range of KIs to identify important issues and elicit recommendations for engaging stakeholders and analyzing stakeholder input. Twenty individuals were contacted for interviews and ultimately, 13 semistructured telephone interviews were conducted with 15 KIs in the United States, Canada, and the United Kingdom (75 percent participation rate). KIs were from academic institutions, practice-based research networks, nonprofit organizations and other organizations devoted to health care issues on local and national levels in the United States, Canada, and Europe. Each interview lasted up to one hour. Of the 13 interviews, 11 were conducted with KIs who had experience engaging stakeholders to identify and/or prioritize future research. In the two other interviews, stakeholders were engaged for other purposes, including allocation of health care resources and implementation of public health programs and policies (Figure 3).

Figure 3. Key informants invited and interviewed



KIs were selected for their experience engaging a broad range of stakeholders including consumers, clinicians, policymakers, researchers, research funders, insurers/payers, and/or manufacturers (Table 5).

Table 5. Key informant interviews: Stakeholder groups engaged by KIs

Key Informant Interview	Consumers	Clinicians	Policymakers	Manufacturers	Research Funders	Researchers
1			●			●
2	●	●	●			●
3	●		●			●
4			●			●
5	●	●	●		●	●
6	●					
7	●	●	●			●
8		●	●	●		●
9		●	●		●	●
10	●	●	●			
11	●	●			●	●
12			●		●	●
13	●	●				●

Defining Stakeholders

Even among individuals with extensive experience engaging stakeholders, stakeholder terminology was unclear or inconsistently applied. The interviews emphasized the lack of consistency and clarity in this process. Examples are provided below:

Unclear Terminology	<p>“When we started the project, we had to define who the stakeholder was . . . and that in itself really proved to be quite challenging.” (KI interview 4)</p> <p>“...when you say ‘stakeholders,’ you’re talking about anybody who will benefit from...the research or from the evidence...am I understanding your definition of stakeholder?” (KI interview 6)</p>
Clear categorization is important	<p>“There’s opportunity for public comment. Number one, public input is the term that we use, but with respect to the highly technical stuff that we do, it’s a misnomer. Public input is industry input.” (KI interview 7)</p>

Recruitment

<p>Interview Highlights</p> <ul style="list-style-type: none"> • The media and Internet/Web can be used to recruit consumers. • Leveraging existing contacts is frequently used and effective. • For some situations, stakeholder recruitment depends on establishing relationships, building connections, and networking. • It is useful to begin with a broad list of potentially relevant stakeholder groups. • Assign staff with strong communication skills to engage in recruitment activities. • Recruit individuals who are passionate about the research topic. • Cold calling is a concept from business that may be used to recruit stakeholders in health research. • Caller identification makes cold calling a recruitment challenge. • Special consideration should be given to the cost of mailing letters and the high return rate for incorrect addresses. • Followup is essential.

KIs recommended recruiting individuals who are passionate about the research topic to facilitate the recruitment and engagement process. They emphasized that recruiting these

individuals helps to ensure that stakeholders will remain engaged throughout the research prioritization process. KIs used several methods to recruit stakeholders that differed according to topic, organization, and the stakeholder groups engaged. Often, researchers recruited multiple groups of stakeholders for engagement. Contacting stakeholders by phone or e-mail was common. One KI commented on the importance of the personality of the person responsible for calling when using cold calls as a recruitment strategy:

“In fact, I hired a college student to cold call every practice . . . and he was this young pre-med student, and he had a nice winsome voice. . . How could you say no to that guy? . . . everybody said, ‘Yes.’” (KI interview 11)

Another KI recommended using letters for consumer engagement even though only 30 percent to 40 percent of the letters sent were returned. One KI asked consumers if they would be more likely to respond to a mailed letter or a call when contacted by unknown individuals. Consumer participants reported that they would be more likely to respond to a letter than a cold call, and several said they would never respond to a cold call (one stated that they used caller identification to avoid answering a call from an unknown source).

An additional challenge to stakeholder recruitment was that the stakeholder identified and initially contacted may refer the project to another individual who does not have the desired characteristics or is not representative of the target stakeholder group. KIs cautioned to be mindful that this could occur and that the intended perspective may not be maintained.

“So we would invite [policymakers], and they would either ignore it or they would [refer us] to somebody lower in the hierarchy. We would end up with a midlevel decisionmaker who’s less likely to have influence over policy than the person we invited.” (KI interview 12)

KIs suggested that a variety of strategies may need to be employed simultaneously to recruit stakeholders:

“...[when] we had a specific contact, we would reach out by e-mail. In some cases we sent letters to organizations. We did a lot of essentially cold calling with organizations where we didn’t have a contact, where we would call the organization’s general number, and try to work our way through to an appropriate contact for our project.” (KI13)

Engagement

Interview Highlights

Methods used for stakeholder engagement include:

- In-person meetings (one-to-one meetings, advisory committee, public forums, and focus groups)
- Telephone interviews, conference calls
- Webinars, e-mail
- Citizens’ juries
- Questionnaire: online
- Modified Delphi technique
- Mixed methods (for example, in-person meetings and electronic questionnaires).

KIs engaged stakeholders using a variety of methods, including e-mail, conference calls or Webinars, focus groups, citizens' juries, workshops conferences, and the modified Delphi technique, and often used multiple methods (mixed methods) to engage the same stakeholder groups. (A description of engagement methods is provided in Appendix F.) The two most common methods that were used by KIs to engage stakeholders were one-to-one meetings (in person or by phone) and working group/committee/council meetings. According to KIs, the advantages of in-person meetings included: (1) ensuring a time of focused stakeholder attention to the subject, (2) fostering relationships among stakeholders, and (3) promoting a better understanding of the each other's needs and priorities through discussion. One KI commented:

“... people know they have materials to review, but they only understand it to the extent of ...the time available. When they're brought together and have blocked off time to actually focus on the questions and discussion, they absolutely shift [their priorities].” (KI interview 13)

KIs reported that one-to-one telephone interviews, e-mail, and conference calls were particularly useful for engaging stakeholders who were geographically dispersed or whose schedules were very busy.

Specific Considerations for Stakeholder Engagement

KIs identified strategies that were particularly useful when engaging policymakers, clinicians, and consumers. Strategies varied based on the context of the situation, the dynamics of the relationship, and whether the researcher and stakeholder had a previous relationship.

Clinicians. KIs used one-to-one meetings, e-mail, conference calls, committee meetings, and conferences to engage clinicians. Several KIs indicated that when engaging this group, it was important to be sensitive to the time constraints of their clinical responsibilities and to use flexible methods of engagement. One KI noted that the method of engagement that works best for clinicians depends on their practice:

“...trying to get every major health care professional in the practice in the same room at the same time is quite challenging. So we've learned to try other methods...where people can provide input by e-mail, react to memos, and even have Webinars or conference calls, as ways to try to elicit that input.” (KI interview 8)

When initially engaging clinicians, one KI recommended that individuals with a similar level of training or a similar role should engage the target stakeholder (i.e., doctor:doctor or nurse:nurse) and commented:

“But it requires that first step of relationship building, between two people. And frequently, if the clinic is run by a doctor, it requires another doctor.” (KI interview 11)

One KI noted that a common mistake that researchers make is not engaging frontline clinicians as stakeholders. Several KIs felt that frontline clinicians were instrumental in setting research priorities because they are involved in the day-to-day operations and can identify key questions that need to be asked. In addition, engaging frontline clinicians in research

prioritization processes was considered essential to creating a meaningful, focused research agenda with the potential to achieve “pivotal” changes in health care practice. One KI stated that failing to include such stakeholders could result in wasting precious resources on the wrong research question.

“A common mistake we certainly made is not engaging the clinicians themselves in the practices, as stakeholders... with top down [organizations] there’s this real risk of the agenda being driven by the people that run the [organization] or even by the funders that support the [organization]. And the frontline clinicians in the practices where the research is supposed to be conducted are not involved in identifying questions...or eliciting buy-in...and that’s a huge mistake. For one thing, you miss the opportunity to identify really key questions for the research to address.” (KI interview 8)

Consumers. Although the methods that KIs used to engage consumers was similar to that of other stakeholder groups, consumers’ motivations and needs as stakeholders were viewed quite differently. KIs noted that consumers were focused on identifying research that addressed their personal health care needs and the needs of their communities. In contrast to policymakers and clinicians, KIs reported that it takes a substantial amount of time to engage consumers because they are unfamiliar with the research process and/or research topics. Several KIs warned that often researchers underestimate the duration of time, patience, and attentiveness required. One KI commented:

“And the reality is that if a researcher will take the time..., and that’s extremely important, ask the questions, nurture a relationship, and patiently listen, that the community is very happy to engage and participate.” (KI interview 6)

KIs reported that consumers can be intimidated by the language of research, protocols, and Institutional Review Boards. They need guidance, patience, and the opportunity to ask questions about the technical aspects of the research and research topics to overcome initial apprehension. They also mentioned difficulties in obtaining the intended stakeholder during recruitment.

“It’s a real challenge to get the right sort of patient representative... someone who isn’t intimidated by...the technical and scientific discussion, and is comfortable...voicing their opinion...our target population is often pretty sick...[but] what we’re getting is someone who’s at the healthier and more educated, and more health literate end of our patient population.” (KI interview 9)

We found considerable variation in the value KIs placed on involving consumers in their research prioritization processes. Some KIs excluded consumers or dismissed their contributions because they lacked research experience, scientific knowledge, or technical expertise to meaningfully contribute to health care discussions or setting a research agenda. In contrast, other KIs advocated strongly for their inclusion and noted that they provided critical contributions to a research agenda that represented the needs of consumers and reflected health care issues commonly faced by their communities. They felt that consumers were not only capable of understanding the research process, but they also made important contributions during topic identification, study design, and manuscript preparation.

Policymakers. KIs preferred to either engage policymakers by phone, with one-to-one interviews, or in small meetings. Two KIs stressed the importance of having “off-the-record” discussions with policymakers so that they felt comfortable asking questions about research without representing a specific constituency or agency. Several KIs mentioned that it is important to understand the pressing time demands that these policymakers encounter on a daily basis.

Researchers. KIs found that engaging researchers as stakeholders can be challenging because though they are familiar with this process, they may not be accustomed to this type of collaboration. A KI commented,

“One of the challenges is to merge the interest of academic researchers with those of the other stakeholder groups in a way that everybody gets something that they need out of it.” (KI interview 5)

KIs suggested using a skilled facilitator and/or qualitative researchers to facilitate discussions and address issues of dominance (i.e., when conducting focus groups).

Prioritization

Interview Highlights

- Quantitative methods such as voting, Delphi, and ranking were often used to determine priorities.
- KIs felt that prioritization occurred naturally through discussion within a long-term relationship.
- Stakeholders may need information on resources or feasibility to advise on research prioritization.
- Multiple criteria are used to prioritize research: burden of disease, funding availability, and policy shelf life.

KIs used prioritization processes and criteria presented in Table 6. They used little or no formal process to a structured, formal prioritization process that consisted of multiple rounds of voting/ranking, with at least one vote occurring in person. One KI commented:

“I’m not sure I could define a process...we’re struggling to [develop] something that’s researchable in a way that is useful to the policymaker” (KI interview 12).

KIs often used an initial voting/ranking process to limit the number of research topics discussed and prioritized at a subsequent in-person meeting. They noted that having the opportunity to eliminate research topics from a broad list prior to the meeting offered several advantages, including: (1) a pared-down list of research topics allowed staff to provide detailed materials on the research topics that were being prioritized, and (2) the work of the stakeholders during the day of the meeting was made easier because they could focus on the most important items for voting and ranking. In one interview, KIs described using an audience response system to elicit stakeholder input at an in-person meeting, which proved particularly helpful in eliciting the priorities of all stakeholder attendees. By using this tool, they felt that they heard and recorded all stakeholders’ research priorities. A KI commented:

“We had two clinical experts who were part of our project team. They helped us to conduct a literature review and identify a comprehensive set of potential research questions. We took

that set of research questions out to the technical working group...brought them together as a group on a conference call, to discuss it, and then sent them...an online ranking tool...where they ranked the questions.... We gathered the information from that ranking process, and then brought them together to the in-person meeting where they talked about the ranking, and they discussed their views that were driving their...selection of the priorities...that's how we came to our final list of research questions.” (KI interview 13)

Finally, while formal quantitative methods were helpful for arriving at a prioritized list, KIs also felt there was value to in-person meetings in this process:

“The difference wasn't so much in the completion of the [voting/ranking], but in your ability to explain the questions...because the research questions to be prioritized can be read, in different ways, depending on how they're worded...So being able to explain it was beneficial. I think we got more accurate impressions when people were actually in person.” (KI interview 13)

Criteria Used To Prioritize Research

KIs reported that stakeholders used multiple criteria to prioritize research including funding availability, current resources available, the burden of disease, community resonance, policy “shelf life,” and in the case of systematic reviews, having adequate primary research to conduct a systematic review (Table 6).

One KI described an innovative approach applying prioritization criteria using an interactive analytic feedback model. Stakeholders were able to make adjustments using different prioritization criteria and compare the potential impact of multiple research projects on each criterion (i.e., burden of disease, cost of treatment, and potential maximum impact of intervention/quality initiative are included in the model).

“We've actually have been experimenting with...a decisionmaking model in working with stakeholders to help them look at that process, and so they can punch in some numbers...and they can show how much impact that would have on health outcomes...”

The model could say, ‘Given the number of strokes, given the effectiveness of thrombolysis, if we got it from 10 to 20 percent, here's how many [persons] would be affected, and here's how much it would help outcomes.’ And then [the stakeholder] could say, ‘All right, well how about preventing stroke?’

“We've found that to be very helpful in testing people's gut assumptions about what the highest priorities are to work on. Then plugging some of those numbers into a model, and then feeding that information back to the people, was very helpful in shaping the discussion about where the priorities ought to be.” (KI interview 9)

Table 6. Key informant interviews: Prioritization methods and criteria

Purpose of Engagement	Key Informant Interview Number^a	Frequency of Engagement	Prioritization Method	Prioritization Criteria
Identify research topics for reviews to inform policy	1	Ongoing (once yearly)	Two voting sessions: One vote during e-mail/online followed by multiple votes in person	Policy “shelf life” and interest Enough evidence to inform review
Identify research topics for reviews to inform policy	4	Ongoing (frequency not stated)	Two voting sessions: One vote during e-mail/online followed by multiple votes in person	Policy “shelf life” and interest Enough evidence to inform review
Set research priorities for organization	5	Ongoing (once yearly)	Consensus (in person discussion) If no consensus, vote	Funding opportunities
Set research priorities for organization	6	Ongoing (frequency not stated)	Consensus (in person discussion)	Burden of disease Resonance with community Funding opportunities
Set research priorities and identify topics for systematic reviews	8	Ongoing (frequency not stated)	None described	Potential for policy/clinical practice change
Identify research priorities	9	Ongoing (frequency not stated)	Consensus (in person discussion) Experimenting with interactive analytic feedback model	Disease burden Quality of care gaps (known) Potential of research to improve health outcomes or clinical practice Cost
Identify research topics for evidence/systematic reviews	10	Ongoing (approximately once every two years)	Specialized area/topics: Multiple votes (in person) Broader topics: Modified Delphi	Cost of research Current resources
Set research priorities for organization	11	Ongoing (not stated)	Consensus (in person)	Feasibility (need resources to carry out) Disease burden Funding opportunities
Prioritize a research agenda	13	Single	Online ranking followed by in person ranking (audience response)	No specific criteria

^a For two key informant interviews, future research was identified, but not prioritized. In two other interviews, key informants did not identify or prioritize research.

Considerations in Working with Stakeholders

Regardless of the method used to engage stakeholders, KIs emphasized that leveraging contacts, establishing long-term partnerships, and building trust and credibility were critical.

Interview Highlights

Barriers to Stakeholder Engagement

- Lack of time on the part of stakeholders (busy)
- Lack of release time and compensation for members of the public
- Researcher need for quick response (timeframe too short for community to weigh in)
- Stakeholder needs not met in previous engagement

Factors in Successful Engagement

- Engage stakeholders early in the process
- Prior to engagement, clearly detail expectations (e.g., anticipated commitment of time and types of activities)
- Maintaining ongoing relationships is important to building trust and credibility
- Provide opportunities for people to ask questions before meetings (particularly for consumers or others who are unfamiliar with research)
- Premeeting information materials promote comfort with the topic and enable informed discussion
- Premeeting “icebreakers,” especially when engaging stakeholders with differing experiences/perspectives
- Having someone with similar training to the stakeholder can be helpful—particularly thought to be important for clinicians
- No stakeholder’s comment is considered superior or inferior to another perspective
- Followup presentation of results is important to stakeholders
- Be clear about the stakeholder role—do not expect community members to do academic duties
- Be sensitive to the time constraints of all stakeholders

Facilitators Can Be Useful For Stakeholder Engagement

- Trained/neutral facilitator encourages participation and focuses discussion at in-person meetings
- Facilitator knowledgeable of various stakeholder environments (cultural understanding)
- Skilled facilitator ensures all stakeholders are heard and manages dominance issues

Bringing diverse stakeholders together may require as much attention to group dynamics as to the presentation of research topics and prioritization criteria, which may be an unaccustomed concern for some researchers:

“It’s been a huge learning curve for everybody. And I think, at this point, we work really well together, and we’ve got it down, but it was a struggle in the very beginning. The culture of [researchers] is very different than a state policymaker who’s being called in front of a public committee next week and needs an answer. And it took us a while to sort of get to the middle, where everybody understood each other’s perspectives, and the thing that I will say that we have learned time and again, and has serves us really well, is that we pay a lot of attention to process.” (KI interview 10)

Barriers to Stakeholder Engagement

KIs described several challenges they encountered when they engaged stakeholders, and offered advice for navigating these issues. Several KIs reported that stakeholders’ busy schedules and competing demands for their time are common, and having flexible engagement methods can help to ensure that critical stakeholders are engaged. In addition, KIs commented that individuals frequently encounter both logistic and financial barriers to providing input as

stakeholders. One KI mentioned that some individuals have difficulty getting time off from work. Two KIs mentioned that the geographic dispersion of stakeholders made engaging individuals who were representative of stakeholder groups difficult and recommended paying for their travel and compensating them for missed time from work. KIs recommended limiting the frequency of travel required of stakeholders by using interim engagement methods such as Webinars, conference calls, and e-mail. Limited resources, including staff, made it difficult to engage all of the stakeholder groups that they targeted a priori and made it difficult to maintain relationships over time. The latter was felt to be particularly challenging since KIs reported that it takes time to establish credibility with stakeholders.

Factors in Stakeholder Engagement

KIs mentioned several strategies for stakeholder engagement. Nearly all KIs emphasized that the key to establishing credibility and engagement of stakeholders for future research prioritization is to establish trust and facilitate ongoing, long-term relationships with stakeholders. Especially for consumers and others who were unfamiliar with the topic, providing pre-meeting materials that were easily understood by nonexperts and/or providing opportunities for the stakeholders to ask questions before the meeting were noted to be helpful to group meetings. Pre-meeting “icebreaker” sessions were also thought to be helpful when conducting in-person meetings with multiple stakeholders with different expertise or experiences (i.e., policymakers, clinicians, and consumers). They noted that these pre-meeting opportunities also helped the KI team target important topic areas that they may have otherwise overlooked. Lastly, KIs reported that a good facilitator was an important feature of group meetings. The facilitator was helpful in ensuring that meetings stayed on track and that one stakeholder’s agenda did not dominate the meeting.

KIs offered the following advice to foster stakeholder relationships:

Engage stakeholders early	“One of the mistakes is to circle back to them well into the project for input...and then you get the message from them: Well, if you really had wanted to study this, you should have done this completely differently. Come to them at the very beginning with the first sparkle of the idea, and start getting their reactions.” (KI interview 8)
Finding common ground	“One of the challenges is to merge the interest of academic researchers with those of the other stakeholder groups in a way that everybody gets something that they need out of the interaction.” (KI interview 5)
Partnership	“...community engagement is a lot like a marriage...if it’s a long-term relationship...you start having to prioritize stuff. But most of it’s not explicit...It’s that you’re in a relationship with someone. And the relationship bounces that back and forth, all the time, and it’s ongoing.” (KI interview 11)
Understanding needs	“It’s trying to reach common ground through the research. It’s really working hard to understand what it is the policymakers needs are, and then...helping to translate that into a research question, or set of research questions that are really answerable requires a back and forth. So each person, coming to a better understanding of the other’s world, and what’s possible in both environments.” (KI interview 12)
Respect	“It’s very important to convey a sense of respect for both their knowledge and their time in contributing to the research. I think people react differently if they feel like their views and time is valued.” (KI interview 8)
Trust	“People really respect each other, trust each other, and are very forthright and feel very comfortable talking, expressing their views, disagreeing, and it’s a very nice dynamic. There isn’t any holding back or any feeling of disparagement for disagreeing with somebody else.”(KI interview 4)
Commitment	“What’s really important is how the researcher approaches a community group...this idea of time and commitment and patience is really important...more and more with community engagement...It’s not just this: a couple of focus meetings and I’ll get the information I want, and I’m on my way. That’s not going to work. You better be committed to me for as long as this project’s lasts, and maybe longer, and be as willing to become interested and committed to this community as I am.” (KI interview 6)

Phase 3: EPC Interviews

Review of Protocols

We reviewed the EPC future research pilot protocols and found that EPCs proposed a range of approaches to engaging stakeholders, as described in Appendix I. Included among these approaches were two who intended to engage the support of the Effective Health Care Scientific Resource Center and two who intended to work with the Eisenberg Center in engaging stakeholders. Most centers intended to use group calls, with two EPCs using a formal Delphi process.

Semistructured Discussions with EPC Directors and Staff

We interviewed representatives from eight EPCs regarding their experiences engaging stakeholders during their future research needs pilot projects. Although these pilot projects were intended to develop and compare a range of approaches to developing future research needs documents, the EPCs had remarkably similar experiences and methods for engaging stakeholders. A defining feature associated with reporting fewer challenges in engaging stakeholders was the currency of the report itself. Reports published more recently and/or by the EPC doing the future research had a natural constituency from which to draw potential stakeholder members. These teams generally drew upon the investigators and Technical Expert

Panel (TEP) from the original report to participate in or suggest other individuals for the stakeholder group.

The EPCs were interested in discussing the appropriate role for and strategic goal for engaging stakeholders in a research gaps process. They noted that although gathering input from stakeholders is one purpose, the two-way relationship means that the process could also be an opportunity to influence stakeholder sensitivity to issues raised through identification and prioritization of research needs.

Stakeholder Constituencies

EPCs included between 6 and 30 stakeholders for their research gaps pilot projects. Target groups for stakeholder engagement included primary researchers, methodologists, patient/consumer advocates, policymakers, funders, payers, industry (for devices), and patients themselves. Of these, all EPCs targeted active researchers, with representation from the other groups varying. One EPC had three distinct stakeholder groups: authors of the report, a group of local experts from their institution (considered internal) and a group of stakeholders outside of their institution (external).

All EPCs considered their stakeholder panels to be well balanced in terms of representing different constituencies. However, several questioned how “representative” should be defined, absent empirical evidence about numbers and breadth of stakeholders required for optimal input. Four of the EPCs noted that their expertise was in the conduct of systematic reviews and not as facilitators or qualitative researchers, suggesting that engagement of stakeholders in the future research needs work was fairly far afield from their usual activities and that they would welcome guidance on the process. The Effective Health Care Program has since released a Stakeholder Engagement Curriculum and Facilitation Primer, both available on the program’s internal Web site.

Several EPCs identified barriers to engaging funders, particularly Federal funders. EPCs reported that the need for high levels of clearance/approval for individuals to participate was ultimately time prohibitive. In part, several suggested that the agencies they were trying to engage were unaware of the project and that it could be helpful to have agency-to-agency communication, or to have the task order officer cosign letters of inquiry. One EPC reported that extramural scientists at the National Institutes of Health (NIH) told them that permission to participate would take too long, while intramural scientists indicated that it would be inappropriate to participate as it would constitute giving advice to researchers. The three EPCs that engaged funders noted that although there was early concern that combining funders and researchers in this process might stifle conversation, this concern did not play out in practice. Perceived barriers in the process may very well be due to the pilot nature of the work, and may be eliminated as the EPCs gain more experience. All EPCs discussed the question of whether and how to engage patients or consumers in the process of identifying research gaps and future research needs. Two of the EPCs felt strongly that patients did not have a role in this particular process, one felt strongly that the patient participation in their project changed the outcome in a positive way, and the remainder were unsure about whether patients should be included. All EPCs felt that patients should be included as stakeholders in other EPC processes; however, they questioned whether patients would contribute to identifying and specifying research gaps. In part, this may be due to the focus of at least two EPCs on methodological research gaps, rather than content areas. Two EPCs questioned their ability to most effectively engage patient stakeholders and expressed concern about ensuring that patients have a positive experience in

making their contributions to the process. Certainly the questions of when and how to engage patients are ones that warrant further conversation among the EPCs, and guidance from AHRQ, some of which is now available through materials published by the Effective Health Care Program on methods for stakeholder engagement. One EPC chose to include a “proxy” for the patient perspective and involved an individual who worked closely with patients on a daily basis.

Those EPCs that did support the involvement of patients and consumers in this particular process also noted the need to find the right person and to manage the relationship in such a way as to maximize involvement and ensure that the patient voice was heard. One important challenge is determining whether this is best accomplished with an individual patient or a patient advocacy group, in which case the representative may or may not be a patient.

Methods for Identifying Stakeholders

All EPCs used a combination of approaches for identifying potential stakeholders, most of which began with individuals who were known to the EPC investigators, either because they were involved in the report for which future research recommendations were being developed or through professional relationships. The selection of stakeholders was not random, but based primarily on availability and convenience, knowledge, and personal contacts. EPCs uniformly looked to individuals who had been involved in the original review, such as TEP members or peer reviewers, suggesting that for continuing the process of developing separate future research documents, the EPC program might envision a more extended role for TEP members and/or peer reviewers. If this does occur, it will be important to ensure that these individuals understand the extended nature of their role, which may include participation during the development of a future research needs document that follows preparation of the comparative effectiveness review itself.

Processes for Gathering Stakeholder Input

Details of the processes used to gather stakeholder input are available in the full reports developed by each EPC and are available on the AHRQ Effective Health Care Web site (available at: www.effectivehealthcare.ahrq.gov). EPCs most commonly used group conference calls along with e-mail or Web-based prioritization, and one presented a Webinar to bring stakeholders up to speed. The number and types of contacts that occurred with stakeholders varied, including letters, one-to-one orientation calls, group calls, survey tools, e-mails, and Webinars. Several stressed the importance of being flexible to meet the stakeholders’ communication needs. For example, two EPCs invited stakeholders to choose whether they would like to contribute via phone or electronically, with the most popular choice being electronic communication or prioritization. Another EPC noted that calls were scheduled outside of work hours to accommodate busy schedules. Taken together, these observations may indicate that some stakeholders find it challenging to provide adequate time during the workday to contribute and prefer times to participate outside of work, as well as methods that they can access on their own timeframe.

Challenges Identified

EPCs routinely identified three main challenges:

- (1) *Timing*: The requirement that the project take place very quickly and over the summer made it difficult to coordinate schedules and likely resulted in an inability to engage some stakeholders. This was particularly true of academic researchers engaged as stakeholders.

- (2) *Restriction on number of stakeholders:* Engaging more than nine nonfederal citizens with a structured survey on behalf of the United States Government would require a lengthy clearance process through the Office of Management and Budget. The time needed to obtain this clearance was prohibitive to timely completion of this project, so the number of stakeholders engaged was kept to nine or less. This limited number was generally perceived as too few to capture the breadth of views of researchers and patients necessary for identifying research gaps.
- (3) *Engaging Federal partners:* The difficulty in engaging Federal stakeholders, primarily at the NIH, was due primarily to the need for permissions that took too long to obtain and resulted in several EPCs not including NIH representatives.

Value of Stakeholder Involvement

Six of eight EPCs considered the involvement of stakeholders to be of value in identifying research gaps, with caveats noted above about being able to engage too few stakeholders and questions about whether the group was appropriately representative. Some emphasized the value of engaging individuals involved in primary research for understanding gaps, methodological challenges, and implications of recommending certain avenues for research. Stakeholders were noted to have identified previously unrecognized areas of importance, and also were helpful in reframing or rephrasing specific questions to make them more concise and clear. One stakeholder noted that no matter how much internal expertise the EPCs have, there will always be additional information or perspectives to be gained from including stakeholders.

EPC Lessons Learned

We asked EPCs to make recommendations or describe lessons learned that might help the Effective Health Care Program optimize the use of stakeholders in identification of research gaps and future research needs. Across all EPCs, the lessons learned and recommendations made were remarkably consistent.

- (1) The EPCs would welcome input on achieving an optimal balance of stakeholders, including target numbers of stakeholders. Three EPCs noted specifically that nine stakeholders is too few and that especially with a small number of stakeholders, one or two voices can have undue influence on the project. Even with a small number, scheduling busy people can be unduly difficult to get the work done in a short time period. Conversely, too many stakeholders can lead to an unwieldy process that does not produce actionable results. Related to this is the need to explicitly describe the strategic goal intended in engaging stakeholders.
- (2) Along these lines, EPCs noted that the process of identifying, contacting, and bringing stakeholders on board takes longer than anticipated in the protocols. It would be helpful to have a realistic assessment of the timeline for this activity based on the experience of the EPCs to date. The Effective Health Care Scientific Resource Center might also provide some guidance on how much time to allot for engaging stakeholders.
- (3) Assistance in engaging individuals from Federal agencies is requested from AHRQ. One specific suggestion was that AHRQ task order officers cosign initial letters of inquiry. EPCs also noted that as an increasing number of projects are done using stakeholders, it will be important to ensure that multiple EPCs are not unduly tasking the same individuals or groups.

- (4) The role of patients and patient advocates on identifying research gaps and specifying future research warrants discussion by EPC leadership. It was noted that for some projects—especially those with a strong methodological focus—patient participation may not be appropriate. When the patient or consumer voice is needed, EPCs recommended budgeting additional process time and effort to make sure that these individuals are oriented to the project and that their input is heard and assimilated.
- (5) EPCs and AHRQ should communicate clearly with the stakeholders about the trajectory of the work, both in terms of timeline and likely number of hours anticipated for the project. For example, for several EPCs, the stakeholder involvement was concentrated during a particular phase of the project. If an option going forward is to have TEP members continue with the Future Research process, they should be informed of this extended opportunity for participation including the timeline and likely effort involved. Clear instructions and documentation about the role of a stakeholder would be helpful, and ideally would be developed for the Effective Health Care program as a whole to increase consistency.
- (6) As EPCs increase their work in a particular clinical concentration, they are likely to build relationships with certain stakeholders and identify stakeholders that are particularly helpful at identifying research gaps. EPCs see this as a benefit; however, they note that stakeholder fatigue could be an issue if these same individuals are approached too frequently.
- (7) Three EPCs noted it might have been helpful to compensate stakeholders engaged in the future research needs pilot projects. (Under AHRQ policy, compensation is allowable but not required.)
- (8) Each KI received conflict of interest disclosure instructions and an EPC disclosure form to complete prior to being interviewed by Oregon EPC investigators. For future activities, it would be helpful to add definitions of KIs and stakeholders to the disclosure instructions and edit the form to include KIs and stakeholders. As EPCs continue to engage stakeholders for developing research questions, refining methods, identifying research gaps, and prioritizing research needs, these changes are important to clearly identify the nature of the input that we are seeking and avoid confusion about the expected roles of KIs and stakeholders.

Discussion

National attention has recently focused on engaging patients, clinicians, and policymakers to create a more patient-centered research agenda to improve health care decisionmaking in the United States.^{1,2} Stakeholder involvement also serves to increase researchers' understanding of decisional dilemmas facing stakeholders, thus increasing the relevancy of the research and research agenda. We conducted this project to identify and recommend methods of stakeholder engagement that EPCs can apply in prioritizing future research from comparative effectiveness reviews.

Throughout the literature and in KI and EPC interviews, researchers often leveraged contacts and called upon stakeholders that they had used for other projects to identify potential new stakeholders to identify and prioritize future research. Often, researchers recruited stakeholders by e-mail. Researchers largely determined their choice of engagement method by the project's purpose, the experience and expertise of the research team, and considerations such as budget, timeframe of the project, and type of stakeholder engaged. In general, in-person meetings, whether one-to-one or group, worked well to identify research topics or bring additional detail and meaning to priority items, whereas quantitative methods, such as voting, questionnaire, or Delphi survey, were used more frequently to produce ranked priorities. Throughout our investigation, reports in the literature and interviews with KIs and EPCs described combining quantitative and qualitative methods to engage multiple stakeholder groups to identify and prioritize research. To guide researchers' choice of methods for stakeholder engagement and prioritization, we summarized the suitability of the engagement methods in Table 7.

Table 7. Considerations for stakeholder engagement to prioritize research

	Engagement							Prioritization			Engagement and Prioritization	
	1:1 Meetings (in-person)	1:1 Meetings (telephone)	Focus/ Working Groups	Group Virtual Meetings ^a	Citizens' Juries	Town-Meetings	Symposia/ Conferences	Consensus (in-person)	Voting (in-person)	Nominal Group Technique	One-Time Survey	Delphi Technique
Short Timeframe	+	+++	++	+++	+	++	++	++	++	++	+++	++
Limited Budget	++	+++	+	+++	+	++	++	++	++	++	+++	++
Geographic/ Transportation Barriers	+	+++	++	+++	++	++	++	++	++	++	+++	+++
Differing Perspectives	+++	+++	++	++	+++	++	+++	++	++	+++	+++	+++
Lack of Existing Relationships	+++	+++	++	++	+++	+++	+++	++	++	++	+++	++
Limited Stakeholder Availability	+	+++	++	++	++	+	++	+	+	++	+++	++
Large Number of Participants	+	+	++	+++	+++	+++	+++	++	++	++	+++	+++
Multiple Stakeholders Groups (e.g., consumers and clinicians)	+++	+++	++	++	NA	+++	+++	++	++	+++	+++	+++
Stakeholders with Lack of Research Experience	+++	+++	+++	++	+++	+++	+++	++	++	++	++	+
Complex Program/ Initiative	+++	+++	+++	++	+++	++	+++	++	++	+++	+	++

Adapted from Preskill⁶²

^aIncludes Web and conference calls.

Abbreviations: NA=not applicable.

Scale: +++ indicates that the method of engagement and/or prioritization is very useful for addressing the consideration. ++ indicates that the method is useful for addressing the consideration but other methods are better. + indicates that this method is not recommended.

Note: Methods for stakeholder engagement are described in Appendix F.

KIs and EPCs offered many suggestions for stakeholder engagement:

- Engage stakeholders early in the process
- Be attentive to building relationships and maintaining credibility and trust between the investigative team and stakeholders
- Establish credibility by consistently producing and disseminating high-quality project products
- Use multiple methods (i.e., in-person meeting and voting to obtain both details of thought and ranking of research priorities)
- Allow the time needed for engagement of all relevant stakeholder groups (for instance, consumers may require more time to recruit and engage than other groups)
- Engage stakeholders with staff who have a similar occupation or role (i.e., doctor:doctor and nurse:nurse)
- Document all stakeholder input, including audio or video recordings, that can be transcribed
- For group discussions (in person or online) employ a skilled, neutral facilitator to ensure balanced participation and focused discussions
- Plan strategies for managing disruptive or dominating stakeholders and for resolving conflicts that may arise
- If prioritizing broad or complex research topics, pare down the list in advance (i.e., through electronic vetting) or through sequential processes to ease stakeholder workload and focus attention on key topics
- Conduct icebreaker sessions at in-person activities whenever stakeholders have diverse backgrounds or are not already acquainted
- Provide brief, easy-to-understand informational materials at the beginning of engagement for complex initiatives or for stakeholders who are unfamiliar with the engagement process or the topic
- Offer opportunities for clarification of research topics (discussion or question-and-answer session). If conducting an in-person meeting, also offer these opportunities prior to the meeting.

The published literature and interviews reflected inconsistencies in terminology and a lack of clarity on concepts such as what constitutes a stakeholder, the categories and constituency of stakeholder groups, recruitment methods, and the intent and process of engagement. Establishing a common language is an important step to advancing a field. For this reason we outlined a common terminology based upon the literature (see Table 1).

Similarly, published studies often did not provide sufficient detail to evaluate the representativeness of stakeholder engagement and consideration of their input. Assurance that representative samples of stakeholders are engaged is critical to the credibility, validity, and legitimacy of the stakeholder engagement process and results. Concerns were raised by both EPCs and KIs that the stakeholders engaged were not representative of their target stakeholder populations. To our knowledge, there are not published recommendations for reporting stakeholder engagement as there are for specific types of clinical studies (e.g., CONSORT, MOOSE). We synthesized information obtained from the literature and KI and EPC interviews and created a proposed checklist to guide EPCs in the steps of stakeholder engagement and reporting (Table 8).

Table 8. Recommendations for stakeholder engagement to identify and prioritize future research

Process	Tasks	Reporting Checklist
Engagement Purpose	<ul style="list-style-type: none"> • State purpose of stakeholder engagement (e.g., topic identification, prioritization, etc.) and desired results or outcomes (affects selection of recruitment, engagement, and prioritization methods) 	<ul style="list-style-type: none"> ✓ State purpose of stakeholder engagement
Stakeholder Orientation Information and Materials	<ul style="list-style-type: none"> • Provide orientation to the program (e.g., Effective Health Care and Systematic Evidence Reviews) • Communicate scope, aims, and desired product/outcome of engagement • Delineate stakeholder roles, responsibilities and expectations • Describe extent of commitment, including methods of engagement (e.g., single Webinar on a specific date), frequency of activities, project schedule • Explain compensation plan, if any (e.g., travel reimbursement, honorarium or other compensation) • Inform of conflict of interest disclosure requirements • Provide contact information for project team (e.g., e-mail address and phone number of investigator and research staff contact) 	<ul style="list-style-type: none"> ✓ Report conflicts of interest and disposition ✓ Report any compensation
Stakeholder Recruitment	<ul style="list-style-type: none"> • Develop a priori list of relevant stakeholder groups, including numbers of stakeholders for each group • Identify specific individuals within each stakeholder group to contact • Plan one or more methods of contact (e.g., write e-mail scripts or telephone dialogue to convey expectations of stakeholders) • Plan recruitment followup (e.g., repeat e-mails or return calls for refusals or non-respondents) • Contact individual stakeholders and document results of individual responses for calculation of overall response rates • Monitor stakeholder representativeness and distribution of stakeholder groups; add individuals to recruitment as necessary to ensure target stakeholder groups are included 	<ul style="list-style-type: none"> ✓ State the types and proportions of stakeholders targeted by group and rationale for recruiting each group (similar to inception cohort) ✓ Report methods used to identify, sample, and contact each stakeholder group ✓ Document recruitment dates ✓ Report invitation and participation rates (similar to response rate) ✓ Report distribution of stakeholders planned and recruited
Methods of Engagement	<ul style="list-style-type: none"> • Assess and identify engagement methods and criteria for selection for each stakeholder group based on: <ul style="list-style-type: none"> ○ Purpose of engagement ○ Characteristics of stakeholders to be engaged (e.g., geographic locations, numbers of stakeholders, range of perspectives, existing relationships among stakeholders, familiarity with research area or research prioritization generally, technological capacity) ○ Context of engagement (e.g., staff, time, budget, technological capacity, complexity of research area) 	<ul style="list-style-type: none"> ✓ Report engagement method(s) and describe process for the identification of research topics ✓ Document number and types of engagements ✓ Report participation rates and distribution in each engagement

Table 8. Recommendations for stakeholder engagement to identify and prioritize future research (continued)

Process	Tasks	Reporting Checklist
Prioritization Methods	<ul style="list-style-type: none"> • Provide criteria for prioritization if previously established (by the sponsor or by previous engagement activity) • Document individual or group development of criteria for prioritization if not previously established 	<ul style="list-style-type: none"> ✓ Document prioritization criteria ✓ Describe methods of prioritization of research topics
Analysis and Synthesis	<ul style="list-style-type: none"> • Document, review, synthesize, and report stakeholder research priorities <ul style="list-style-type: none"> ○ Overall and by stakeholder group ○ Weighting of input if applicable (e.g., do two votes from one organization count as one or two?) • Plan for review and validation of results by stakeholders to ensure their intended priorities are accurately communicated 	<ul style="list-style-type: none"> ✓ Provide assessment of stakeholder representativeness ✓ Provide details of synthesis and analytic methods including weighting of stakeholder group's responses and calculation of participation rates ✓ Provide results both overall and by stakeholder group ✓ Verify priorities with stakeholders
Conclusion	<ul style="list-style-type: none"> • Distribute final product or report to stakeholders • Express appreciation for participation and contribution • Gather input from stakeholders on engagement experience to evaluate the process • Advise stakeholders of opportunities for future participation and any plans for future contact (if relationship will be maintained) 	<ul style="list-style-type: none"> ✓ Provide prioritized list of future research topics (only after public posting/publication) ✓ Summarize lessons learned

In KI and EPC interviews, researchers differed in their views about the appropriate context for engagement of consumers. Some investigators dismissed contributions by consumers because they were felt to lack essential research experience, scientific knowledge, or technical expertise to meaningfully contribute to health care discussions or setting a research agenda. In contrast, others advocated for the inclusion of consumers and noted that they provided critical contributions to a research agenda that represented the needs of consumers and reflected health care issues commonly faced by their communities. They felt that consumers meaningfully contributed to all phases of their research process including identification and prioritization of research topics, study design, analyses, drafting of manuscripts, and presenting research results.

Specifically regarding EPCs, many were interested in having assistance with the engagement process, including identifying who to engage, to what extent to engage each stakeholder group, how to measure the representativeness of each stakeholder, and the optimal balance of stakeholders that should be used to identify and prioritize future research needs. Some EPCs reported a lack of qualitative expertise. Others reported challenges in engaging certain stakeholders such as Federal stakeholders. They would appreciate the help of AHRQ in encouraging Federal participation in future research needs projects.

When scanning literature and interviewing KIs and EPCs, investigators often did not consider how to weigh input obtained from each stakeholder group. Engagement of multiple stakeholders groups is very common and was reported in a majority of the studies that were reviewed and the interviews that were conducted with KIs and EPCs. Should input be weighted equally for each group? The issue of weighting should be considered during recruitment because it will affect the composition of stakeholder recruitment lists, and it should also be considered when synthesizing and analyzing stakeholder input. For example, if a researcher wanted to elicit both consumer and clinician input but valued consumer input more, the researcher could engage

20 consumers and 10 clinicians and prioritize research by one vote per person. This would unequally weight the prioritization process in favor of consumers. In the analytic phase, the same researcher could weigh the votes differently if she wanted them to have equal input. For example, consumers' votes could be weighted by 0.5 rather than 1. There are several ways that this can be accomplished. Careful thought should be given to both the selection and analytic strategies when engaging multiple groups. In addition, the strategies should be explicit.

Conclusions

To identify methods of stakeholder engagement to set research priorities, we conducted a literature scan, interviewed KIs with experience in engaging stakeholders to prioritize research, and interviewed EPCs about their recent projects to engage stakeholders in identifying and prioritizing future research needs for a previously completed comparative effectiveness review. As part of this process, we identified the following considerations:

- (1) Use of consistent terminology and definitions is important throughout the stakeholder engagement process, from planning to implementation to evaluation.
- (2) The intent of stakeholder engagement is important in determining the methods of engagement. In-person methods are helpful for brainstorming, identifying topics, clarifying issues, and eliciting a deeper understanding, while quantitative methods such as voting and Delphi are best applied to prioritize research. A flexible approach using mixed methods may be required to engage multiple stakeholder groups.
- (3) Engaging stakeholders early and maintaining relationships are important to building trust and credibility. Nearly all KIs emphasized that the key to establishing credibility and engaging stakeholders for future research prioritization is to establish ongoing, long-term relationships with stakeholders. Further feedback for fostering stakeholder relationships included finding a common ground, partnership, understanding needs, respect, trust, and commitment.
- (4) Assurance that representative samples of stakeholders are engaged is critical to the credibility and legitimacy of the stakeholder engagement process and results.
- (5) When multiple stakeholder groups are engaged, special consideration should be given to how to weight input from each group. The issue of weighting should be addressed at the outset during recruitment because it will affect the composition of stakeholder recruitment lists, and it should also be considered when synthesizing and analyzing stakeholder input.

This research project is one of the first efforts to identify and recommend methods for EPC stakeholder engagement for future research identification and prioritization. KI interviews provided critical, practical information from researchers with extensive experience engaging a broad range of stakeholders. The KIs interviewed were a select group of researchers, most of whom were known by the EPC staff, and while leveraging contacts helped to ensure participation from KIs within a short timeframe, their experiences reflected only a small part of the stakeholder engagement experience. Despite this limitation, our synthesis of information from the literature scan and the interviews with EPCs and KIs generally agreed on basic themes. Our understanding of the stakeholder engagement process for research identification and prioritization is evolving, and we expect that the stakeholder engagement and prioritization recommendations will continue to be refined as we expand methodology for future research needs documentation as part of the comparative effectiveness review process.

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Abbreviations

AHRQ	Agency for Healthcare Research and Quality
CDC	Centers for Disease Control and Prevention
COI	Conflict of Interest
EPC	Evidence-based Practice Center
IOM	Institute of Medicine
KI	Key Informant
NIH	National Institutes of Health
TEP	Technical Expert Panel
VA	Veterans Affairs

Appendix A. Engaging Stakeholders: Literature Review Search Strategies

Database: Ovid MEDLINE(R) and Ovid OLDMEDLINE(R) <1947 to September Week 1 2010>, Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations <September 21, 2010>

Date Searched: 9/22/2010

Search Strategy:

-
- 1 *Health Services Research/ (10736)
 - 2 exp *Community-Based Participatory Research/ (270)
 - 3 exp *Comparative Effectiveness Research/ (139)
 - 4 exp *Biomedical Research/ (22652)
 - 5 exp *Translational Research/ (276)
 - 6 *Research/ (116380)
 - 7 1 or 2 or 3 or 4 or 5 or 6 (147771)
 - 8 *Consumer Participation/ (6637)
 - 9 exp *Patient Participation/ (7180)
 - 10 "stakeholder*".ab,ti. (7173)
 - 11 8 or 9 or 10 (20669)
 - 12 "priorit*".ab,ti. (42997)
 - 13 7 and 11 and 12 (127)
 - 14 "consumer*".ab,ti. (29730)
 - 15 "stakeholder*".ab,ti. (7173)
 - 16 "citizen*".ab,ti. (9151)
 - 17 "policy maker".af. (99)
 - 18 "policy makers".af. (6717)
 - 19 "policymaker*".af. (3418)
 - 20 14 or 15 or 16 or 17 or 18 or 19 (54221)
 - 21 research.ab,ti. (587579)
 - 22 "priorit*".ab,ti. (42997)
 - 23 21 and 22 (9960)
 - 24 20 and 23 (843)
 - 25 "research agenda".ab,ti. (2132)
 - 26 "research agendas".ab,ti. (230)
 - 27 25 or 26 (2335)
 - 28 setting.af. (263446)
 - 29 27 and 28 (208)
 - 30 13 or 24 or 29 (1063)
 - 31 limit 30 to english language (1030)

Database: PsycINFO <1806 to September Week 3 2010>

Date Searched: 9/22/2010

Search Strategy:

- 1 health services research.mp. (565)
- 2 community-based participatory research.mp. (307)
- 3 comparative effectiveness research.mp. (36)
- 4 biomedical research.mp. (581)
- 5 translational research.mp. (393)
- 6 *research/ (29991)
- 7 1 or 2 or 3 or 4 or 5 or 6 (31440)
- 8 consumer participation.mp. (152)
- 9 exp *Patient Participation/ (791)
- 10 "stakeholder*".ab,ti. (5999)
- 11 8 or 9 or 10 (6904)
- 12 "priorit*".ab,ti. (14412)
- 13 7 and 10 and 12 (36)
- 14 consumer*.ab,ti. (24345)
- 15 "stakeholder*".ab,ti. (5999)
- 16 "citizen*".ab,ti. (12093)
- 17 "policy maker".af. (134)
- 18 "policy makers".af. (6998)
- 19 "policymaker*".af. (4594)
- 20 14 or 15 or 16 or 17 or 18 or 19 (51976)
- 21 research.ab,ti. (467262)
- 22 "priorit*".ab,ti. (14412)
- 23 21 and 22 (4782)
- 24 20 and 23 (484)
- 25 "research agenda".ab,ti. (2312)
- 26 "research agendas".ab,ti. (352)
- 27 25 or 26 (2641)
- 28 setting.af. (124314)
- 29 27 and 28 (304)
- 30 13 or 24 or 29 (778)
- 31 limit 30 to english language (767)

Date Searched: 8/20/10
 CINAHL (EBSCO)

#	Query	Results
S31	S24 or S29 Limiters - English Language	333
S30	S24 or S29	338
S29	S27 and S28	114
S28	setting	70777
S27	S25 or S26	1094
S26	"research agendas"	95
S25	"research agenda"	1013
S24	S20 and S23	228
S23	S21 and S22	2408
S22	priorit#	6990

S21	research	328696
S20	S14 or S15 or S16 or S17 or S18 or S19	44593
S19	policymaker#	1180
S18	"policy makers"	2678
S17	"policy maker"	32
S16	citizen#	2481
S15	stakeholder#	3468
S14	consumer*	36039
S13	S7 and S11 and S12	10
S12	priorit#	6990
S11	S8 or S9 or S10	8269
S10	stakeholder#	3468
S9	patient participation	467
S8	(MM "Consumer Participation")	4580
S7	S1 or S2 or S3 or S4 or S5 or S6	10125
S6	(MM "Research")	7352
S5	translational research	400
S4	biomedical research	463
S3	comparative effectiveness research	177
S2	community-based participatory research	308
S1	(MM "Health Services Research")	1608

[after deduplication 168 unique references]

Search Date: 8/25/10

Database: Sociological Abstracts (CSA)

Search Strategy:

((KW=(consumer* or stakeholder* or citizen*) or KW=((policy maker) or (policy makers) or policymaker*)) and((TI=research or AB=research) and(TI=priorit* or AB=priorit*))) or((TI=((research agenda) or (research agendas)) or AB=((research agenda) or (research agendas))) and(KW=setting)) (Copy Query)

221 Published Works results found

Date Range: Earliest to 2011

Limited to: English Only

Appendix B. Key Informant Interview Invitation and Conflict of Interest Request

Dear <<insert Key Informant name>>,

<<Insert name of interviewer>> previously contacted you about interviews for the EPC Future Research Methods Project. The Oregon EPC, along with the Vanderbilt University EPC, is conducting a project to better understand the various methods that have been used to engage stakeholders in identifying and prioritizing research needs. The ultimate goal is to identify a process that all EPCs could use at the conclusion of each systematic review to identify and prioritize research gaps related to a given topic.

We are scheduling telephone interviews with individuals who have engaged stakeholders (e.g., patients, clinicians, policy makers, researchers, etc.) in the past to explore the strengths and challenges of engaging various stakeholders and to identify the methods that are most effective for working with different stakeholder groups. We would like to know more about your experience in this area through your work with <<insert relevant work here>>. Would you be available for a telephone interview on <<insert date>> between <<insert time>>? We anticipate that the interview will take no longer than one hour.

We appreciate your participation in this important research and look forward to speaking with you. AHRQ requires that we provide COI documentation for each person who is interviewed. As such, we ask that you please complete the Conflict of Interest form (COI) (attached) and return it to us by <<insert date>>. To return it to us, please use one of the following options:

By email: Scan the COI and email to <<insert email>>

By fax: <<insert fax number>>

Attention: <<insert name>>

By mail:

<<insert address>>

Please do not hesitate to contact us if you have any questions regarding this project and your participation.

Thank you,

Oregon Evidence-based Practice Center
Oregon Health and Science University
3181 SW Sam Jackson Park Road
Mail code: BICC
Portland, Oregon 97239-3098

Appendix C. Key Informant Interview Guide

Respondent Name	
Title	
Phone	
Interviewers	
Date Completed	
COI Received	
Interview File	

I. Introduction

- **Introduce yourself:**

Good afternoon, is this (name of KI)?

Interviewer 1: *Hello, This is (name of interviewer 1). I am an investigator with the Oregon Evidence-based Practice Center (aka EPC). Thank you for joining us today. (Name of interviewer 2) is also here with me and I will let (interviewer 2) her introduce herself.*

Interviewer 2: *Introduces self.*

- **Explain project:**

Interviewer 1: *As mentioned in our e-mail,*

The Oregon Evidence-based Practice Center, along with the Vanderbilt University EPC, is conducting a project to better understand methods that have been used to engage stakeholders (such as policymakers, clinicians, researchers, and consumers) to identify and prioritize research needs. Currently, the EPCs use a variety of methods to engage stakeholders throughout the systematic review process and use their input to set priorities for future research.

Our goal is to identify a process that they could be used by ALL EPCs at the conclusion of each systematic review to identify and prioritize research gaps related to a given topic.

To achieve this goal, we are conducting interviews with individuals who have engaged stakeholders. We want to explore the strengths and challenges of engaging various types of stakeholders and identify the methods that are most effective for working with different stakeholder groups. We are particularly interested in hearing about your experience in this area through your work with (insert individual's company/organization information below):

Interviewer 1: Before we start, we want to let you know that we will be recording this interview and it will be transcribed to ensure that all of the information that we document is accurate. Results from interviews will not specifically identify individuals interviewed or their organizations. Rather, the results will be reported in aggregate and by the types of stakeholders that have been engaged. Do you have any questions? Is it ok to begin the interview?

II. Possible Key Informant Interview Questions

Engaging Stakeholders

1. Can you describe your experience in engaging stakeholders?

Note: For each research purpose or stakeholder group, repeat questions a-b.

- a. What are general groups of stakeholders that you have engaged?
 - i. How did you select these stakeholder groups?
 1. If provide detailed list ask why did you select these types of stakeholders?
 - a. Purpose: Want to know how selected and purpose of engagement?
 - ii. How did you approach them? What was most effective? Least effective?
 1. Did you initially try other methods of engagement?
 - iii. Were there methods of stakeholder engagement that facilitated their participation? What were they?
 - iv. Were there barriers to engaging important stakeholder groups?
 1. If so, what were they?
 - v. Do you feel that all relevant stakeholder groups were able to be engaged?
 1. **IF NO**, what additional stakeholder group(s) would you like to have included?
 - b. In general, what were your response rates?
2. What strategies did you use to bring stakeholders together or to elicit feedback from them?

(Prompt: Have you ever used...individual calls, group calls, Web-based applications, in-person meetings?)

 - a. Were the methods that you used the same or different for different types of stakeholders that you engaged? If so, how did that work?
 - b. You mentioned you've used ----- (method).

Note: Repeat questions for each method

- i. Why did you choose this method?
- ii. What do you think is the right time to engage stakeholders?
- iii. Did you do anything to keep them engaged?
- iv. Was it successful?
- v. What were the strengths of using this method?
- vi. What were the limitations or challenges associated with using this method?
- vii. When you used this method, was this the first strategy that you used to engage stakeholder?
- viii. **IF NO**, what was the first method that you used?
 - a. Why change?
- ix. **IF A METHOD WAS USED THAT ENGAGED MULTIPLE GROUPS SIMULTANEOUSLY** (e.g. focus groups), did you feel that the responses were balanced or were they weighted by the input of a few individuals?
 - How did this impact your research?

- **IF NOT BALANCED:** Are there strategies that you think could help to create more balanced input in future stakeholder engagements?
 - **IF BALANCED:** What strategies did you use to create balanced input?
- c. How was information organized in order to facilitate stakeholder input? Were there any documents or presentations given to stakeholders to provide background information to facilitate these processes? Was this successful? Were other formats considered?
3. What impact did involving stakeholders have on making decisions or setting priorities?
 4. In the process you just described, what do you think were the critical elements that helped you be successful in gathering stakeholder input?
 5. If you were recommending one or more methods to use to engage stakeholders in setting research questions and priorities, which method or methods would you recommend?
Note: May want to ask also about methods to obtain balanced input
 6. In thinking about the types of information you've gathered from stakeholders, what has been the best strategy for synthesizing and/or analyzing their input?
(Prompt: How have you gone about analyzing data for stakeholder input?)
 - a. For each method
 - i. Why did you choose this method?
 - ii. How long did it take to synthesize and analyze/assess their input?
 - iii. Was it resource intensive (trying to get at whether or not it was worth the effort)?
 7. How has stakeholder engagement impacted future projects?
 8. How do you measure success of stakeholder engagement?

Setting Priorities

We are also interested in understanding how criteria are defined for prioritizing research gaps and how research needs are prioritized.

1. Have you been involved with setting research priorities?
 - a. In your opinion, what approach(es) have been the most successful for research prioritization? Why?
 - i. Does this differ by stakeholder?
 - ii. Does this differ by project purpose?
 - b. Did you provide stakeholders with specific criteria to prioritize?
 - c. What criteria did you provide for stakeholders to prioritize? *(If they mention specific criteria, ask if they could e-mail any written criteria that they have used)*

- i. Did you use the same criteria for different groups of stakeholders? IF YES, for each stakeholder group which criteria did you use and why did you choose it?
 - ii. Did you use the same criteria for different research questions? IF YES, which criteria did you use for each research questions?
2. How has stakeholder prioritization impacted future projects?
3. How do you measure success of stakeholder prioritization?

III. Conclusions

- **Interviewer 1:** *Thank you very much for your time and for sharing your experiences with us.*

Do you have any additional comments or insight about the processes of stakeholder engagement and research prioritization?

Do you have any questions for us?

Again thank you very much.

Have a good day.

Appendix D. Invitation Letter to Evidence-based Practice Centers

Good morning.

Thank you very much for sending us your Future Research Pilot Protocol as part of our methods project on engaging stakeholders. It is time for the next step in our project; namely, for us to conduct interviews with appropriate EPC team members/staff. We hope to conduct these interviews during the month of August. Our goal will be to understand:

- (1) The degree to which your intended approach to engaging stakeholders succeeded;
- (2) Specific elements of your approach that you felt facilitated engaging stakeholders; and
- (3) Challenges that you encountered in the process

We will collate all of the information into “lessons learned” and combine this information with similar data being gathered from groups outside of the EPC program, with a track record in engaging stakeholders for setting research agendas.

Ideally, we will also speak with stakeholders about their experiences, so please consider whether you would be willing to identify 2-3 individuals from your project with whom you recommend we speak.

Involvement includes participation in the following:

- Listing any knowledge gaps you feel are related to stakeholder engagement or the EPC future research project by online submission of information or individual phone conversations (up to 1 hour)

Participation in this project is completely voluntary, and you may discontinue your participation at any time.

Confidentiality:

All the information we receive from you, including your name and any other identifying information (if applicable), will be strictly confidential and will be on password protected server maintained by computer services at Vanderbilt University. We will not identify you or use any information that would make it possible for anyone to identify you in any presentation or written report about this project. Individual and group conference calls will be recorded so that a comprehensive transcript can be produced. Digital files of the recordings will be destroyed upon completion of the transcript approximately 7-10 days after the call and names and other identifying information will be deleted from all electronic and paper copies of transcripts.

Since names are not required as part of the study data, no identifying information such as the participants' names will be part of the study data. If this information is recorded on phone conversations or documents we receive from you it will be kept only to determine that we have received all responses and will be destroyed or deleted within 7 days of the submission of the final report on or about September 30, 2010.

Risks and Benefits of Participating:

There is a slight risk your organization's name could be disclosed, but all efforts are made to reduce this possibility. The benefit of participating in this project is the knowledge that you are assisting AHRQ and the Vanderbilt Evidence-based Practice Center in moving the research related to engaging stakeholders forward. Responses from each participant will be combined with those from representatives of other organizations and a summary of this information will be generated by analysts at the Vanderbilt EPC. No individual names will be mentioned in the summary.

If you have questions about the rights of participants in a research project, you may contact the Vanderbilt Institutional Review Board directly at 1-866-224-8273 or www.mc.vanderbilt.edu/irb.

If you have any questions regarding this project, you may "reply" to this email and we will respond to your questions as soon as possible. You may also call us at (615) 936-5357.

Please let us know the right person, at your EPC, to request this interview by contacting Kathy Lee by email at kathy.e.lee@vanderbilt.edu or by phone at (615) 936-5357. We would very much appreciate hearing from you by **August 19, 2010**. Once we have the correct contact, we will be in touch to schedule the interview.

Thank you,

Kathy Lee for

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Appendix E. Interview Guide for EPC Interviews

For continuous quality improvement, we are collecting EPC director feedback on the recent engagement process with/for _____ (*identify project*). We will be having a conversation to that I can better understand your perspective on the process of engaging stakeholders in decisionmaking and how satisfied you are with the outcome of the project. Please be open and honest in your responses. This interview will be audio-recorded. Audio tapes will not be released. We will not quote you.

1. Were you able to identify and bring together the right balance of stakeholders? Were there any significant stakeholders you would have liked to have included in the process but could not access?
2. Do you think the stakeholders understood why they were invited to engage? Did they understand the issues you wanted them to engage on?
3. At the start of the project, were there any conflicts of interest?
4. How did you communicate the scope, aims and objectives to all stakeholders? Did the scope, aims and objectives change over the course of the project timeline?
5. Did you elicit input on the engagement strategy? Was it helpful?
6. Did you establish clear ground rules? Did all members adhere to the ground rules?
7. When members failed to adhere to the ground rules, did you feel equipped to handle the breach?
8. Did other stakeholders handle the breach? Which approach was successful?
9. In retrospect, do you feel that there were ground rules that were not established but needed?
10. Did any stakeholders dominate the conversation? Were any disruptive?
11. How comfortable were you managing the relationship between stakeholders?
12. How well did you manage our relationship with each stakeholder?
13. Did you notice that stakeholder fatigue set in? (*If no, skip to Q13.*) How did you manage it?
14. Did you notice any conflict between stakeholders? (*If no, skip to Q14.*) How did you manage conflict between stakeholders?
15. Was there a formal mechanism for stakeholders to reviewing decisions and addressing disagreement constructively?
16. How did you coordinate communication to stakeholders? How effective was that?
17. How did you communicate the process to stakeholders?
18. How satisfied were you with the level of stakeholder involvement in the decision-making process?
19. What was the value of the engagement? Did it really lead to better decisionmaking? Did it legitimize the decisionmaking process and outcome? Did it build trust -- between research institutions, professional organizations, and AHRQ? Was it worth taking the time to involve stakeholders in this manner or would you suggest taking a different approach next time?
20. Overall, how satisfied were you with the process.
21. Overall, how satisfied were you with the outcome.

Thank you for your time and thoughtful answers.

Appendix F. Descriptions of Stakeholder Engagement Methods

Interviews:

Includes in-person, phone and group interviews based on a series of questions related to a topic of interest to generate ideas, elicit feedback and/or answer a set of pre-determined questions.

One-on-one interviews (including telephone):

Stakeholders are engaged individually, either formally or informally. In formal interviews, a one on one interview guide (e.g. semi-structured interviews) may be used for evaluation. Informal procedures are flexible and sometimes include ad-hoc conversations that can allow you to gather additional information from stakeholders.

Semi-structured interviews:

Generally used to engage individuals or a very small group (two or three individuals), semi-structured interviews are conducted with an open framework which allow for focused, conversational, two-way communication. Structured questions are designed and phrased ahead of time and are typically asked of during all interviews. Questions are also created during the interview, allowing both the interviewer and the person being interviewed the flexibility to probe for details or discuss issues.

Focus/working groups:

A planned discussion in a small (4 to 12 members) group of stakeholders facilitated by a skilled moderator. It is designed to obtain information about preferences and opinions in a relaxed, non-threatening environment. The topic is introduced and, in the ensuing discussion, group members influence each other by responding to ideas and comments. The moderator may use some pre-determined questions as prompts to encourage discussion or to return the conversation to the intended focus of the discussion.

Questionnaire:

A questionnaire is a means of eliciting the opinions, beliefs and attitudes of some sample of individuals. As a data collection instrument, it is structured or unstructured. A questionnaire is usually concise with a preplanned set of questions designed to yield specific information to meet a particular need for research information.

Citizens' juries:

Used to elicit views of members of the public about a variety of health and other issues. Based on the principles of “deliberative democracy” and active citizenship, they aim to promote decision-making based on process of ‘careful consideration,’ debate, and respect for different viewpoints. They bring together diverse members of the public as jurors who are given information relevant to the issue under debate by “expert witnesses,” (innovators, patients, health care policy-makers, and clinicians) and the discussion has a facilitator or moderator present to guide the process. The session can include small and large group priority-setting exercises based on actual examples of technologies under consideration for assessment by local and national bodies. The end result is often a written report authored by the jurors, which can also be in the form of a questionnaire with juror responses.

Town meetings:

Individuals residing in a specific geographic area are invited to a public meeting to discuss issues relevant to their community. Often, this meeting is announced by the local media and attended by residents as well as other individuals including state and local officials, health care providers, researchers, manufacturers, and topic experts. In general, everyone is offered the opportunity to speak in a relaxed environment, the meetings are often loosely organized and used to identify and a broad list of research topics/interests. Voting to prioritize research items may also occur.

Conferences/forums/symposia/workshops:

Meetings or conferences for discussion of a topic, especially one in which the participants both form an audience and make presentations.

Nominal group technique:

Structured problem-solving or ideas-generating activity in which individuals' ideas are gathered and combined in a face-to-face, nonthreatening group environment. The process is intended to promote creative participation in group problem -solving. Each member of the group is invited to express their opinions that are used to generate a list of priorities. Members may be asked to vote or rank priorities from the list either formally or informally. The voting process may occur multiple times. Nominal group technique is designed to promote the free exchange of opinions and the generation of a list of priorities in a structured and nonhierarchical discussion forum (maximizes creative participation and ensures balanced output while utilizing each participant's experience and expertise to reach consensus on complex topics). The purpose is to provide structure to a group discussion when the group is facing the challenge of reaching agreement on complex topics. Examples of variations in use of the technique include:

Example 1

- (1) Introduction to technique
- (2) Individual generation of ideas—each participant writes their ideas
- (3) Sharing of ideas—every member is asked to present their ideas and brief explanation
- (4) Voting/ranking

Example 2

- (1) Survey of members to get participants ideas
- (2) Removal of duplicates
- (3) Structured/facilitated groups discussion all members of nominal group for each participants list with explanations, resolve ambiguities
- (4) Voting/analysis

Delphi technique:

The Delphi technique uses a series of consecutive questionnaires to determine the perceptions of a group of individuals. The Delphi method allows respondents to communicate their opinions anonymously. Each questionnaire is considered a round. The method is often used to prioritize research/topics. For example, Hauck¹ and colleagues conducted the following study to identify research priorities of clinic staff working with the community:

- (1) Round 1: This questionnaire was used to create a list of five important questions relating to future research in care for children in this community. Content analysis was used to analyze and summarize the responses and develop the second

- questionnaire. All issues were discussed, assigned a general category and then described as a research topic.
- (2) Round 2: The clinical staff was asked to prioritize the research ideas/suggestions using a 7-point Likert-type response format, with one indicating a low priority and seven, the highest priority.
 - (3) Round 3: The top 10 research topics were identified. Both clinicians and clients were asked to rank the topics identified.

Modified Delphi technique:

The modified Delphi technique is similar to the Delphi technique in terms of both intent of engagement (i.e., to predict future events and to arrive at consensus) and the procedure by which research priorities are determined (i.e., a series of rounds with selected experts). The major difference between the two is that Round 1 of the Modified Delphi technique already includes preselected research topics; in contrast, the Delphi technique uses the first round of questionnaires to elicit research topics. The pre-selected research topics used in Round 1 of the Modified Delphi technique may be drawn from various sources including reviews of the literature, and interviews with key informants.²

Modeling

Value of information (VOI)/expected value of information (EVOI):

VOI/EVOI provides a methodological framework that explicitly considers the uncertainty surrounding the decision of a health care system to adopt a health technology. Specifically, using existing evidence, this method focuses on the likelihood of making a wrong decision if the technology is adopted. The value of additional research is based on the extent to which further information will reduce this decision uncertainty. VOI/EVOI includes the following:

- (1) Estimating the effective population that may benefit from additional evidence, including time horizons for different technologies and incorporating this uncertainty in the estimates of value of information
- (2) Estimating the value of information for correlated parameters
- (3) Estimating the over value of information based on estimates of the value of information for patient subgroups
- (4) Presenting the value of information and the value of full implementation of guidance on use within the same framework of analysis

Other

Scoping study:

Literature review of published and grey literature, followed by focus group and interview consultations: scoping studies aim to map key concepts underpinning a research area and the main sources and types of evidence available. They include a literature review and consultation phase that may be used to (a) examine the extent, range and nature of research activity, (b) determine the value of undertaking a full systematic review, (c) summarize and disseminate research findings, or (d) identify research gaps in the existing literature. For example, a scoping study may start with a literature review followed by a series of focus groups and key informant interviews to prioritize research.

Concept mapping:

This is an approach particularly designed for facilitating consensus in the understanding and organization for various concepts. Mapping is based on multivariable statistical analyses in which statements produced during a brainstorming session are grouped in weighted clusters. Cluster mapping includes the following five stages: focusing on the question, brainstorming session, rating and sorting statements, data analysis and interpretation of maps.

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Appendix G. Strengths and Limitations of Stakeholder Engagement Methods

Method	Strengths	Limitations
Delphi ¹	<ul style="list-style-type: none"> • Consensus-building nature of Delphi technique combines rigor of traditional surveys and the collaborative effect of focus groups. • Anonymity eliminates potential sources of conflict and enables participants to express views freely. • Multiple rounds provide opportunities for revising individual views in response to group trends. Particularly effective when: <ol style="list-style-type: none"> (1) Consensus is sought in an area where none previously existed; (2) Research problem does not lend itself to precise analytical approaches but can be illuminated by subjective collective judgments; (3) Study participants have diverse backgrounds in their expertise and consensus cannot easily be reached; (4) More research participants are needed than can effectively interact face-to-face; and (5) Frequent meetings of all participants are not feasible. 	<ul style="list-style-type: none"> • Large time commitment precludes some participants from participating in every round. • Anonymity may lower the incentive for accountability and negatively impact response rates. • Potential for manipulation of consensus; multiple rounds may limit ability to remain impartial in light of others views and social desirability bias may influence participants' responses.
Focus Groups ^{2,8}	<ul style="list-style-type: none"> • Participants are able to draw upon their own experiences to stimulate and guide discussion. Flexible nature of questioning allows exploration of wide range of opinions, attitudes and perceptions. • Ability to focus discussions on issues specific to each group and how research could address them. • Particularly useful when dealing with sensitive subjects • More efficient use of time and resources than one-on-one interviews. • Effective method for engaging consumers. 	<ul style="list-style-type: none"> • Time consuming, difficult to coordinate and carry out. • Some individuals may be reticent to express their opinions in a group context. • Group dynamics may hamper prioritization process. • Framing of issues by the interviewer may influence the prioritization process. • Small sample size limits generalizability of findings. • May produce divergent views and can be difficult to reach consensus.
In-Person Interviews ^{9,10}	<ul style="list-style-type: none"> • Effective method for capturing community and individual perspectives. • Low cost if limited geographic dispersion. • Good way to facilitate collaboration and identify priorities with decisionmaker buy-in. 	<ul style="list-style-type: none"> • Sample size usually too small to support statistical analysis of differences in perspectives; results not generalizable. • Time consuming if want to engage many stakeholders. • Difficult when stakeholders are geographically dispersed. • Inability to establish consensus among stakeholders.

Method	Strengths	Limitations
Questionnaires <small>7,11,12</small>	<ul style="list-style-type: none"> • Ability to include individuals from a range of socioeconomic and professional backgrounds and with varying levels of experience with the topic. • Easy to complete and can be provided in a wide variety of formats. • Stakeholders do not need to be present and can complete the questionnaire when it is convenient for them. • Anonymity enables stakeholders to share their views without concern for the reactions of others. • Ability to query a large sample of stakeholders. 	<ul style="list-style-type: none"> • Low response rate. Anonymity can lead to low levels of accountability. • Inability to clarify responses or to further probe as to meaning behind different opinions and perspectives. • Inability to establish consensus among stakeholders.
Symposiums/ Conferences <small>13,14</small>	<ul style="list-style-type: none"> • Ability to identify overarching themes. • Can be used to check validity of research priorities generated by key informant interviews and focus groups. 	<ul style="list-style-type: none"> • Difficult to plan and coordinate. • Expensive. • Sample may not be representative. • Some participants may not feel comfortable expressing their opinions in a formal group context • Prioritization process may be dominated by a vocal minority.
Citizen's Jury <small>12,15-17</small>	<ul style="list-style-type: none"> • Useful method for actively engaging and eliciting views from the public. • Provides an opportunity to bring together diverse set of citizens. • Bridges the gap between “top down” and “bottom up” involvement. • Program flexibility allows discussion to reach natural conclusion. • All jurors have an equal opportunity to participate in the process and express their views and even minority views are included in final outcome. • Includes an education component not typically included in other methods. • Allows space for findings to contain disagreement and uncertainty. 	<ul style="list-style-type: none"> • Overall influence of jury on research activity difficult to assess. • Costly and time-consuming process. • Findings not always generalizable to the larger population. • Can be challenging to educate general public on the topic to be discussed in such a short time frame. • Jurors often struggle to separate research from service provision. • Strong personalities can sway jurors and inhibit discussion.
Nominal Group Technique ¹⁸	<ul style="list-style-type: none"> • Particularly good for a collaborative, community based project. • Enables all workshop participants to have an equal voice. • Ensures that ideas of members are shared and commented on in a non-threatening environment. 	<ul style="list-style-type: none"> • Difficult to prioritize future research needs. • Costly and time-consuming. • Samples often not representative and findings not generalizable to larger population.
Scoping Study (Literature Review With Key Informant Interviews and Focus Groups) ¹³	<ul style="list-style-type: none"> • Incorporates two methodological approaches: (1) a search and analysis of existing literature and (2) expert opinions and perspectives from stakeholders in the field. 	<ul style="list-style-type: none"> • Lack of methodological quality review can lead to uncertainty regarding how to weigh grey literature when identifying strengths and shortcomings of the evidence. • Does not incorporate non-expert opinions and priorities.

References: Appendix G

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Appendix H. Literature Results: Stakeholder Participation Rates by Engagement Method

Method of Engagement	Purpose	Participants	Stakeholder Group(s)	A priori Identification	Invited (N)	Accepted/ Replied (n _a)	Declined (n _d)	Participated (n _p)	Participation Rate (n _p)/N
1:1 Interviews and Focus Groups	To identify research priorities in nursing and midwifery services ¹	(1) Service users (2) Researchers, policymakers, health professionals	Consumers Researchers Clinicians Policy-makers	Yes	(1) 126 (2) 100			(1) 32 (2) 64	(1) 25% (2) 64%
Focus Groups	To determine patients' priorities in health care ²	Patients	Consumers	Yes	25	24	1	19	76%
Consensus Forum	To collect and report seating and wheeled mobility research priorities ³	Clinicians Policymakers Manufacturers Federal research funders Researchers	Clinicians Policy-makers Manufacturers Research funders Researchers	Yes	110	90	NR	67	61%
Workshop	To engage consumers to understand barriers in participation in developing public health research agendas ⁴	20 consumers/ organizations Community service organizations (7), consumer health groups (5), unions (3), employer organizations (3), local government (1) agency and self-employed individuals(2)	Consumers	Yes	20 organizations and individuals	15	5 (no response or not interested)	0	0%
Questionnaire	Open-ended and structured questions to compare and clinician preferences for research on homeless veterans ⁵	(1) Veterans (2) Health Professionals working for VA	Consumers Clinicians	Yes	Unclear		NR	(1) 87 (2) 28	(1) 61% of eligible veterans (2) 82% of health professionals working on those three days

Method of Engagement	Purpose	Participants	Stakeholder Group(s)	A priori Identification	Invited (N)	Accepted/ Replied (n _a)	Declined (n _d)	Participated (n _p)	Participation Rate (n _p)/N
	Web-based questionnaire to prioritize research needs in infectious disease research ⁶	Clinicians, decisionmakers and researchers	Clinicians Policy-makers Researchers	Yes	563 sent questionnaire	185 (returned questionnaire)	NR	147 (complete questionnaire received)	147/563= 26%
	To examine the current distribution of mental health research in Australia and to compare with priorities of various stakeholder groups ⁷	A. Random sample of researchers, general practitioners, psychiatrists, clinical psychologists, and mental health nurses B. Funders (grant panel from National Mental Health Review Panel) C. Research Committee Members of research funder (ARHRF) D. NMHWG E. Consumer/ Caregiver Advocacy Organizations F. Consumers and caregivers by snowball sampling	Consumers Clinicians Researchers Research funders	Yes	A. 200 per group B. 11 C. 10 D. 9 E. 83 F. 179			A. 100, 58, 105, 106, 120 B. 11 C. 10 D. 9 E. 83 F. 179	Reported as number responded/(number samples-number not contactable) A. 100 (56%), 58 (30%), 105 (53%), 106 (53%), 120 (60%) B. 10 (91%) C. 8 (80%) D. 6 (67%) E. 59 (72%) F. 114 (64%)
	Questionnaire developed with WHO to determine mental health research priorities in low and middle-income countries ⁸	(1) Researchers (2) Decisionmakers, university administrators and consumers	Researchers Policy-makers Consumers	Yes	(1) 4633 (2) 3829, sent questionnaire				(1) 21.1% (2) 10.1%
	To determine research priorities in patients with COPD ⁹	Patients	Consumers	Yes	(1) 1042			(1) 244	(1) 23.4%

Method of Engagement	Purpose	Participants	Stakeholder Group(s)	A priori Identification	Invited (N)	Accepted/ Replied (n _a)	Declined (n _d)	Participated (n _p)	Participation Rate (n _p)/N
Delphi Technique	To identify and compare research priorities within mental health care by different stakeholder groups ¹⁰	(1) Consumers (2) Cares (3) Health Professionals (4) Service Managers	Consumers Clinicians	Yes	(1) 34 (2) 26 (3) 35 (4) 23				Round 1 (1) 29 (85%) (2) 26 (100%) (3) 31 (89%) (4) 23 (100%) Round 2: (1) 27 (79%) (2) 26 (100%) (3) 34 (97%) (4) 21 (91%) Round 3: (1) 25 (74%) (2) 26 (100%) (3) 33 (94%) (4) 22 (96%)
	To reach consensus on research priorities for cerebral palsy ¹¹	(1) Consumers (2) Researchers/ clinicians	Consumers Researchers Clinicians	Yes	(1) 50 (2) 180 (3) 80				Round 1 (1) 20 (38%) (2) 76 (42%) (3) 31 (39%) Round 2 (1) 20 (38%) (2) 45 (25%) (3) 19 (24%) Round 3 (1) 19 (38%) (2) 32 (18%) (3) 18 (23%)
	To prioritize low back research ¹²	Health Professionals	Clinicians	Yes	86			70	Round 1=70 (81%) Round 2=52 (60%) Round 3=50 (58%)
	To identify research priorities in hospice care for children ¹³	Consumers, health professionals and policymakers	Consumers Clinicians Policy-makers	Yes	621			274	Round 1 (N/A: Focus groups) Round 2= 274 (44%) Round 3=204 (33%)
	To identify research priorities for midwifery in Ireland ¹⁴	Clinicians (midwives)	Clinicians	Yes	334			142	Round 1=142 (43%) Round 2=121 (36%) Round 3=98 (29%)
	To identify top research priorities in health care ¹⁵	Policymakers, health professionals and consumer advocates	Policy-makers Clinicians Consumers	Yes	293				Round 1 = NR Round 2=165 (56%)

Abbreviations: ARHRF=Australian Rotary Health Research Fund; COPD=chronic obstructive pulmonary disease; NMHWG=National Mental Health Working Group; NR=not reported; VA=Veterans Affairs; WHO=World Health Organization

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Appendix I. Evidence-based Practice Center Future Research Needs Document Pilot Projects: Protocols for Engaging Stakeholders

Project Title	Stakeholder Engagement Protocols
Future Research Needs of Treatments of Localized Prostate Cancer	<ul style="list-style-type: none"> • A key informant group will assist with the prioritization process via interdisciplinary discussion among a small group (less than 10 participants) with an orientation to improving evidence in therapies for clinically localized prostate cancer. This approach is primarily qualitative and builds on TEC’s expertise in building productive interdisciplinary groups. • Stakeholders will be national experts who are supportive of evidence-based medicine and well-versed in the obstacles faced in conducting multiple, large clinical trials—especially in the context of prostate cancer. • Short, structured interviews will be conducted via phone with key informants to inform them about the project and solicit input on research gaps. • Once prioritization criteria for research gaps and topics are drafted and distributed, there will be three conference calls (1 hour) involving key informants to participate and give feedback.
Future Research Needs for Angiotensin Converting Enzyme (ACE) Inhibitors or Angiotensin II Receptor Blockers (ARBs) added to Standard Medical Therapy for Treating Stable Ischemic Heart Disease	<ul style="list-style-type: none"> • Stakeholder workgroup (representing patients, researchers, clinical experts, and funders) will include members from the original technical expert panel for the CER, researchers involved in some of the primary RCTs included in the CER, other clinical experts and researchers in the content area, representatives from relevant professional societies, healthcare decision and policy makers, and representatives from related consumer and patient advocacy groups. • Stakeholder conference call will be held to orient the workgroup to the original report the identified evidence gaps, the developed decision analytic framework, and Duke’s planned value of information analyses. • After needed evidence is gathered from published literature and information is synthesized and analyzed, findings will be disseminated to relevant stakeholders • Incorporate feedback from stakeholders on value of information findings and needed extensions. • After research needs document is drafted, there will be a second stakeholder call with the stakeholder group to discuss findings, value of information process, and to review the draft report.

Project Title	Stakeholder Engagement Protocols
<p>Future Research Needs for the Comparison of Percutaneous Coronary Interventions With Bypass Graft Surgery in Nonacute Coronary Artery Disease</p>	<ul style="list-style-type: none"> • Will seek feedback from stakeholders in the form of key informant interviews. • Key informants will be identified through the Scientific Resource Center and AHRQ. Ideally, informants will represent the perspective of patients, physicians, payers/policy makers and funders. • One or more key informant teleconferences will be held to receive feedback on the identified evidence gaps. • Teleconferences with key informants will: finalize (verify/modify) the list of identified evidence gaps, further refine the draft description of the dimensions of the decisional context, and refine the draft analytic framework and if possible recast it as a simplified decision tree to explicate the important parameters. • After key informant teleconferences, will conduct phone interviews where key informants will describe: <ul style="list-style-type: none"> – whether and how they would use this information – how familiar they are with systematic reviews, meta-analyses, evidence mapping, decision analysis, cost-effectiveness analysis, and value of information analysis – how receptive they are to conclusions drawn from different methodologies, and what reservations they have, if any – how receptive they are to learning more about the more quantitative methodologies to be able to use their conclusions correctly and fully; if the users do not buy in, it may be a moot process – what information would the ideal research needs prioritization document contain, and what minimum level of detail they would accept in terms of the recommendation itself (e.g., specificity by defining characteristics as per the PICO formalism) and the methodology it is based on (e.g., description of the process, model, assumptions) – what is the ideal presentation of the research needs prioritization information (graphical, tabular, formulas, in an interactive piece of software, other).
<p>Future Research Needs for Outcomes of Weight Gain in Pregnancy</p>	<ul style="list-style-type: none"> • Working with the Scientific Resource Center (SRC) to develop a group of stakeholder individuals and organizations with interest in the topic of maternal weight gain. • We will ask for nominations in four areas: advocacy, clinical practice, research, and research funding priorities. Request for nomination from stakeholders will be done initially by mail and e-mail, with personal phone call followup as needed. Stakeholders that Vanderbilt wishes to invite (including an “oversample” to accommodate anticipated lack of availability) will receive letters that include a description of the EHC program, the role of the EPCs, the pilot project, and the time commitment and role of the stakeholders. • The EPC will use a modified Delphi process to elicit, collate, and prioritize information from stakeholders and to arrive at a sense of hierarchy of the importance of the recommendations. The group will be guided through consideration of the State-of-the Science Framework and oriented to the ultimate goal of creating a final Research Gaps Analysis and Future Research Recommendations document. • To maximize ability to engage stakeholders who are our Delphi Process participants and to explore which approaches are preferred by them, we will offer stakeholders three choices for participation in the first phase of Inquiry and Concept Building (snowballing of ideas): online submission of information, individual phone conversations (as a semi-structured interview from an interview guide), or group conference call. All methods will be provided and stakeholders will self-select into the form of participation that is most suitable to their communication style. • A one day DesignShop will be held where stakeholders (local or national) can stimulate thinking and discussion of Future Research Priorities for Understanding Maternal Weight Gain. • A followup survey will be conducted using the pilot evaluation tool to solicit information on the experience of the stakeholders.

Project Title	Stakeholder Engagement Protocols
Future Research Needs to Reduce the Risk of Primary Breast Cancer in Women	<ul style="list-style-type: none"> • The Eisenberg Center for Clinical Decisions and Communications Science will be contacted first to identify stakeholders who were engaged in the process of developing materials for consumers, clinicians, and policy-makers for this CER to ensure representation beyond these individuals. • The stakeholder workgroup (up to 18 members) will be recruited through snowball sampling. Potential stakeholders will be sent an introductory letter, the executive summary of the CER, the full CER, the anticipated timeline and activities, instructions for agreeing to participate, and informed consent documentation. The stakeholder workgroup will be split into two homogenous groups based on the type of organization they represent and their stake in future research. • Oregon will host a 1-2 hour web based presentation that will orient the stakeholder workgroup on the review and the identified future research needs. All materials from the presentation will be provided to participants. • After the presentation, two electronic questionnaires will be posted for stakeholder workgroups to complete. Both questionnaires will be tailored to the specific group to which they are administered.
Future Research Needs for Treatment of Common Hip Fractures	<ul style="list-style-type: none"> • Stakeholders will receive an invitation letter outlining a brief description of the project and the stakeholder's expected role, along with background information (i.e. executive summary of the original report). • Initial meeting with stakeholders will be conducted through a group conference call. Summaries of group calls will be circulated among all participants to allow for further feedback processes. Individual e-mail and telephone calls for specific questions will also be anticipated. • Stakeholders for the prioritization of research questions and projects will be provided the research questions and projected developed by the EPC, and instructions for the prioritization process. • All stakeholders will complete disclosure forms, and will be instructed to include information on related current research in which they are involved.
Pilot Study: Identifying Future Research Needs for Management of Gestational Diabetes	<p>There will be two groups of stakeholders:</p> <ol style="list-style-type: none"> (1) A small, local group will provide detailed input including on the framing of questions, issues of study design and feasibility. The local group will include clinicians, nutritionists and patient advocates (social workers). Initial engagement of this group will be through an online feedback form, addressing questions on study design and feasibility of research. There will be two face-to-face meetings to present a summary of the electronic responses and to discuss in more depth any issues arising from those responses. (2) A larger group of external stakeholders will prioritize the research questions and be engaged in the modified Delphi process. This group will include two people from each of the identified types of stakeholders (total of 10). Feedback from the local group will be used to revise the research questions and to develop the Delphi questionnaire. This group will be engaged in the modified Delphi process.

Project Title	Stakeholder Engagement Protocols
Future Research Needs for Integration of Mental Health/Substance Abuse and Primary Care	<ul style="list-style-type: none"> • An internal kick-off meeting will be held to discuss potential stakeholders. Team members will include UNC's mental health and primary care experts, with input from the Minnesota group. • Recruitment of approved stakeholders for participation in the project will begin with an introductory email invitation with a brief description of the project. The executive summary will also be provided along with a link to the original report. Conflict of interest (COI) disclosures will also be obtained to screen for potential conflicts of interest. • A list of current gaps in literature will be presented to stakeholders by teleconference asking for feedback on anything that may have been missed in the search. A moderator will ensure a voice for each stakeholder, and to further ensure that all stakeholder opinions are recorded, all notes from the call will be forwarded to the stakeholders along with a followup call for additional clarification and additions. • Stakeholders identified as funders for ongoing research will be informed of findings by the library team. • Stakeholders will be emailed a document with the refined list of research gaps to be prioritized according to their preference and knowledge of the area, using ranks and a Likert scale. Once results are compiled and synthesized, a summary of the results will be presented by teleconference the whole stakeholder group for a consensus decision. At this teleconference, the pros and cons of pursuing future research for the gaps identified will be discussed, and stakeholders will be asked to rank their top 3-5 future research priorities out of all those identified.