

## **Engaging Stakeholders in Comparative Effectiveness Research (CER)**

**Evidence Prioritization** 

**Evidence Prioritization Tool: Ten Steps to Evidence Prioritization** 

## Step #1

Agree on common definitions for your stakeholder engagement activity.

You may decide to adopt each definition as described on this site, or modify definitions to meet your project's needs. Your research team's agreement about these terms will help to minimize confusion and misunderstandings during the prioritization activity.

Definitions for your stakeholder engagement activity	
Stakeholder	
Engagement	
Comparative effectiveness research (CER)	
Patient-centered outcomes research (PCOR)	
Evidence prioritization	

### Step #2

Agree on the purpose and scope of your stakeholder engaged evidence prioritization activity.

To establish agreement on the purpose and scope of your stakeholder engagement activity, talk to your research team about what type of evidence prioritization activity is needed. Ask yourselves:

- Are the mission, vision and objectives for research already clear?
- Are the priority topics, populations, conditions and interventions that you wish to address already clear?
- Have all relevant research questions been nominated? Do these questions need refinement?



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## Step #3

Identify appropriate stakeholder groups for your project.

To begin, use the 7Ps to develop a list of relevant stakeholder groups.

List of appropriate stakeholder groups for our project	
Patients and the public	
Providers	
Purchasers	
Payers	
Policy Makers	
Product makers	
Principal Investigators	

Next, customize the list of relevant stakeholders to your research topic by asking your research team each of the following questions:

What topic(s) does the evidence prioritization activity address?	
Priority populations	
Clinical conditions	
Service offerings	
Other	



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What kinds of health care decision(s) will the evidence prioritization inform?	
Clinical care	
Healthcare strategies, including team science, payment strategies and other	
Health services	
Health policy	
Public health	
Research methods	
Who are the primary decision makers? Use the 7Ps to identify them.	

Who are the primary decision makers? Use the 7Ps to identify them.	
Patients and the public	
Providers	
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Product makers	
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Who will be affected by these decisions?	Detailed description of <b>how</b> they will be affected
Patients and the public	
Providers	
Purchasers	
Payers	
Policy Makers	
Product makers	
Principal Investigators	

### Step #4

Determine the appropriate size of your stakeholder evidence prioritization group and ensure balanced representation.

Use the 7Ps to start building your stakeholder group and make sure every relevant viewpoint is represented. Within each of the 7Ps, consider every type of stakeholder. For example: providers may include individual clinicians representing different specialties and levels of care; institutional providers such as hospital and nursing home administrators, school nursing programs or community health centers. Consider every type of stakeholder who has an interest or stake in the outcome of your research.

Once you have built your list, consider the relative balance of stakeholder groups with potentially competing viewpoints. For example: stakeholders with a commercial interest in the outcomes of research – including product makers, specialty providers and some payers – should represent a minority in evidence prioritization activities or may need to be excused from participating. Participation by stakeholders involved in providing or using health care services should be balanced by participation by stakeholders who pay for them. You should also ensure balanced representation by primary care physicians and specialists, since their needs may be different.

Also consider whether your research is subject to regulation under the Paperwork Reduction Act (PRA) of 1995 (http://www.archives.gov/federal-register/laws/paperwork-reduction/). If your project is funded through a Federal contract, it must comply with the PRA (note: projects funded privately, by states, and by Federal grants and cooperative agreements are not subject to this requirement). Evidence prioritization often concludes with a voting, balloting or survey exercise, and any of these exercises qualify as a federally-funded "survey" if they are funded through a Federal Contract and involve more than nine individuals who are not Federal employees.



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## Step #4 (continued)

Qualifying surveys must be approved by the Federal government before they are used, and this process can take several months. With these facts in mind, you may wish to limit the size of your stakeholder board to nine individuals plus federal employees.

### Step #5

Clarify for your research team and stakeholders how stakeholder-engaged evidence prioritization can lead to informed decision-making for your community.

Share your answers to the following questions with your team.

- How would the engagement of stakeholders in evidence prioritization improve the relevance of research evidence for the decision makers whom your research program or community is attempting to inform?
- How would the engagement of stakeholders in evidence prioritization activities enhance the transparency of research for decision makers, and why does this matter?
- How would the engagement of stakeholders in evidence prioritization accelerate the application of research evidence into use for the decisions that these decision makers have to make?

### Step #6

Develop an evidence prioritization protocol.

An evidence prioritization protocol is a thorough description of the scope, objectives, and proposed methods by which you hope to arrive at a mission for research, a prioritized list of research topics, or a prioritized list of research questions. You can use this protocol to assure that every team member and stakeholder understands the process.

### Begin writing your protocol by summarizing the work you completed in steps #1 through #5, and then add:

• Conflict of Interest and Disclosure of Interest Plan

This may be as simple as developing a form on which stakeholders can declare their financial interests, prior to engaging in the evidence prioritization exercise. For examples, please refer to the AHRQ EHC DOI Form (<a href="http://www.ahrq.gov/research/findings/evidence-based-reports/stakeholderguide/stakeholdr.pdf">http://www.ahrq.gov/research/findings/evidence-based-reports/stakeholderguide/stakeholdr.pdf</a> and <a href="http://www.ahrq.gov/research/findings/evidence-based-reports/stakeholderguide/appendixf.html">http://www.ahrq.gov/research/findings/evidence-based-reports/stakeholderguide/appendixf.html</a>) or other standard DOI forms (use Elsevier (<a href="http://www.elsevier.com/authors/author-rights-and-responsibilities#permissions">http://www.elsevier.com/authors/author-rights-and-responsibilities#permissions</a>) or HSR (<a href="http://grants.nih.gov/grants/policy/coi/coi/faqs.htm">http://grants.nih.gov/grants/policy/coi/coi/faqs.htm</a>)).

- Time frame
- Set dates for each part of the stakeholder engagement exercise, so your stakeholders know what to expect.
- Engagement plan

Engagement with stakeholders may proceed through individual communication, or group communication, or both. Individual contact may be best for formative and inductive stages for topic nomination, voting and ranking, and can be conducted via email, web, in-person discussions, or Key Informant interviews. Group contact may be best for summative and deductive stages, such as discussion on nominated topics and reviewing results from a first round of ranking. Group contact can be conducted via conference calls, webinars, and focus groups.

#### Honoraria

Consider paying honoraria to thank stakeholders for participating. Each stakeholder should be paid the same amount, with one exception: federal employees can participate in this work (and sometimes they are important stakeholders) but are not legally able to accept honoraria.

Special considerations for patients and the public

Engagement strategies must be responsive to the values and interests of each stakeholder. A central consideration involves the strategies that will be used to support the participation of patients, patient advocates, and the public;



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### Step #6 (continued)

their full participation is not guaranteed by issuing an invitation to sit on a board. General principles can be drawn from community-based participatory research, which underscores that engagement is a relationship-building process. Researchers and stakeholders should be committed to the process at the outset; neutral and expert facilitators should be used to guide research discussions; connections among stakeholders should be encouraged; and an environment of mutual respect should be fostered.

### • Ranking criteria and instructions on how to use them.

Select ranking criteria. These are guidelines on how to give priority rankings, and may include appropriateness, magnitude, severity, importance, desirability, equity, feasibility, and impact. The terms you use and the descriptions you offer for your ranking criteria should be as clear as possible. For examples, review the AHRQ criteria (<a href="http://effectivehealthcare.ahrq.gov/index.cfm/submit-a-suggestion-for-research/">http://effectivehealthcare.ahrq.gov/index.cfm/submit-a-suggestion-for-research/</a>), IOM criteria (<a href="http://www.iom.edu/~/media/Files/Report%20Files/2009/ComparativeEffectivenessResearchPriorities/CER%20report%20brief%2008-13-09.pdf">http://www.iom.edu/~/media/Files/Report%20Files/2009/ComparativeEffectivenessResearchPriorities/CER%20report%20brief%2008-13-09.pdf</a>), and PCORI criteria (<a href="http://www.pcori.org/research-we-support/priorities-agenda/getting-specific/">http://www.pcori.org/research-we-support/priorities-agenda/getting-specific/</a>).

### • Ranking methods and mechanisms

How you conduct a ranking exercise is critical. You will need to decide whether you want your stakeholders to work as a group and develop a consensus rank; in small groups by stakeholder type; or individually, as in a voting exercise.

The mechanisms you use to develop a priority list are also important. If your objective is to develop a consensus ranking, consider using a Delphi or modified Delphi approach. If you wish to elicit and record a variety of opinions, consider using a ballot exercise. Balloting can be broken down further into two types: ranking ballots, in which every individual ranks the full list of candidate topics or questions from their highest to their lowest priority; and voting ballots, in which every individual chooses a small number of priority topics (with or without rank) from the whole list and the research team combines votes to establish a group ranking.

### Step #7

Recruit individuals to fill the priority list of stakeholders for your evidence prioritization process.

### Recruit potential stakeholders using any one of the following methods:

### Snowball

Start by making contact with individuals with whom you have personal relationships. These individuals may be suitable to serve as stakeholders on your evidence prioritization project, or they may be able to help you find someone who is suitable. Experience from the AHRQ EPC program (<a href="http://www.ahrq.gov/legacy/clinic/epc/">http://www.ahrq.gov/legacy/clinic/epc/</a> and <a href="http://www.ahrq.gov/legacy/clinic/epcix.htm">http://www.ahrq.gov/legacy/clinic/epcix.htm</a>) shows it is best to start by contacting people you know for personal referrals to targeted individuals. Cold contacts may result in many refusals. (O'Haire, AHRQ Report, 2011)

- Search for investigators on research-in-progress (e.g., clinicaltrial.gov, CRISP)
- Peer review published literature search (e.g., Medline, Econlit, www.CEAreagistry.org, Cochrane)
- **Grey literature search** (e.g., Google)

Once you have identified potential stakeholders, send a letter with a brief description of your evidence prioritization process, an outline of their proposed roles and responsibilities, and information about honoraria. Once a commitment is obtained, collect disclosure of interest (DOI) forms and other information from the stakeholder, as necessary.



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### Step #8

### Conduct the evidence prioritization exercise.

Follow the protocol you developed in Step #6.

## Step #9

### Evaluate and report on the evidence prioritization exercise.

Report stakeholder activities in manuscripts and contract reports. As the evidence base grows, implement changes in future evidence prioritization activities.

As changes are adopted, an iterative assessment process should follow. For evidence prioritization that is funded through a Federal contract, all public reports must be 508 Compliant (<a href="https://www.section508.gov">https://www.section508.gov</a>).

## **Step #10**

### Sustain relationships with your stakeholders.

Share the results of your evidence prioritization exercise with each stakeholder and invite stakeholders to share the results with others, including health decision makers and those who may be affected by health decisions.

Invite stakeholders to participate in follow-up engagement activities. If your community or research program will use the results of this prioritization exercise to inform future research, invite stakeholders from the evidence prioritization process to continue working on the research.