

Discerning the Perception and Impact of Patients Involved in Evidence-based Practice Center Key Informant Interviews



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This report is based on research conducted by the University of Connecticut Evidence-based Practice Center (EPC) under contract to the Agency for Healthcare Research and Quality (AHRQ), Rockville, MD (Contract No. 290-2015-00012-I). The findings and conclusions in this document are those of the authors, who are responsible for its contents; the findings and conclusions do not necessarily represent the views of AHRQ. Therefore, no statement in this report should be construed as an official position of AHRQ or of the U.S. Department of Health and Human Services.

None of the investigators have any affiliations or financial involvement that conflicts with the material presented in this report.

The information in this report is intended to help EPCs and AHRQ understand the perceptions of patients, caregivers, and patient advocates who participate as Key Informants in systematic reviews and other projects. The information is targeted for the EPC program but has general applicability for any governmental or nongovernmental group interested in engaging a mixed group of clinical and nonclinical stakeholders and ensuring that the nonclinical/lay public representatives feel valued and contribute meaningfully to the discussion. This report is not intended to be a substitute for the application of good judgment. Anyone who makes decisions concerning the engagement of stakeholders should consider this report in conjunction with all other pertinent information (i.e., in the context of available resources and circumstances).

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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.

If you have 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, 5600 Fishers Lane, Rockville, MD 20857, or by email to epc@ahrq.hhs.gov.

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Discerning the Perception and Impact of Patients Involved in Evidence-based Practice Center Key Informant Interviews

Structured Abstract

Background. The Agency for Healthcare Research and Quality (AHRQ) Evidence-based Practice Center (EPC) program engages patients, caregivers, and patient advocates in several steps of a systematic review to ensure that their perspective is included. One place where patients, caregivers, and patient advocates are used extensively is as Key Informants (KIs). An EPC utilizes a panel of patients/patient advocates, researchers, and clinicians in the topic refinement phase of a project to ensure the EPC understands the issues important to these stakeholders. The EPCs use this feedback to refine the topic area's analytic framework; its Patient population, Interventions, Comparators, Outcomes, Timing, and Settings (PICOTS); and the Key Questions that when answered will contribute important information to the health care system.

Purpose. AHRQ and the EPCs want to understand how to most effectively engage patients, caregivers, and patient advocates in systematic reviews. Therefore, the main objective of the current project was to examine how patients, caregivers, and patient advocates who participated as Key Informants in prior systematic reviews regarded that experience and what their recommendations are for improving that process.

Methods. From 2016 to 2017, six caregivers and patient advocates who had participated as KIs in the past were interviewed individually to assess their satisfaction, experiences, and perceptions as KIs. The findings from the individual interviews were summarized and distributed to the participants prior to a focus group discussion that was conducted with all six KIs. As a group, they discussed the findings and reached consensus on recommendations for improving the process. A draft report was circulated to AHRQ and the KIs for review and feedback. The findings and recommendations were presented to AHRQ and the EPCs in a webinar in June 2017. Additional feedback provided during and after the webinar informed this final draft of the report.

Results/Recommendations. All six KIs reported that there was value in participating in the systematic review process, and no one regretted doing so. They agreed that in order to maximize the potential impact and utility of systematic reviews, it is critically important to seek out and include patient perspectives. However, they contended that the various ways in which EPCs have engaged patients in these reviews are not equally effective. The KI participants suggested several strategies that EPCs could use to improve the process for patients, caregivers, and patient advocates, such as: (1) recruit and sufficiently screen patients, caregivers, and patient advocates to ensure they have the relevant experiences/knowledge needed for the systematic review, (2) adequately prepare patients/patient advocates to participate in the review by explaining why they were chosen and how important their perspective is, delineating the expectations for their role, and providing easy-to-understand information about the purpose of the systematic review and what they should be prepared to discuss, (3) educate the researchers and clinicians about the important role that patients/patient advocates play and the valuable contributions they can make to the discussion, (4) select a facilitator with strong communication skills who knows how to

engage patients/patient advocates as well as researchers and clinicians, (5) structure the group stakeholder discussion to maximize patient/patient advocate involvement by setting aside a portion of the call specifically for the patients/patient advocates, and (6) keep patients/patient advocates engaged after the group stakeholder discussion by providing them with the timeline for project completion, sharing the results with them, and encouraging and empowering them to disseminate the results to their constituents.

Conclusions. AHRQ EPCs value and include the perspectives of patients, caregivers, and/or patient advocates in their systematic reviews. To maximize patients/patient advocates' participation, the utility and value of their contributions, and their satisfaction as participants, six KIs recommended the use of various strategies for effectively recruiting, preparing, and engaging patients/patient advocates before, during, and after group stakeholder discussions

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Background

The role of the Evidence-based Practice Centers (EPC) Program of the Agency for Healthcare Research and Quality (AHRQ) is to conduct comprehensive reviews of relevant scientific literature on various clinical and health services topics and to produce evidence reports that summarize the findings from these reviews. These reports can then be used to inform and develop clinical practice guidelines, research agendas, coverage decisions, quality measures, and educational materials and tools.

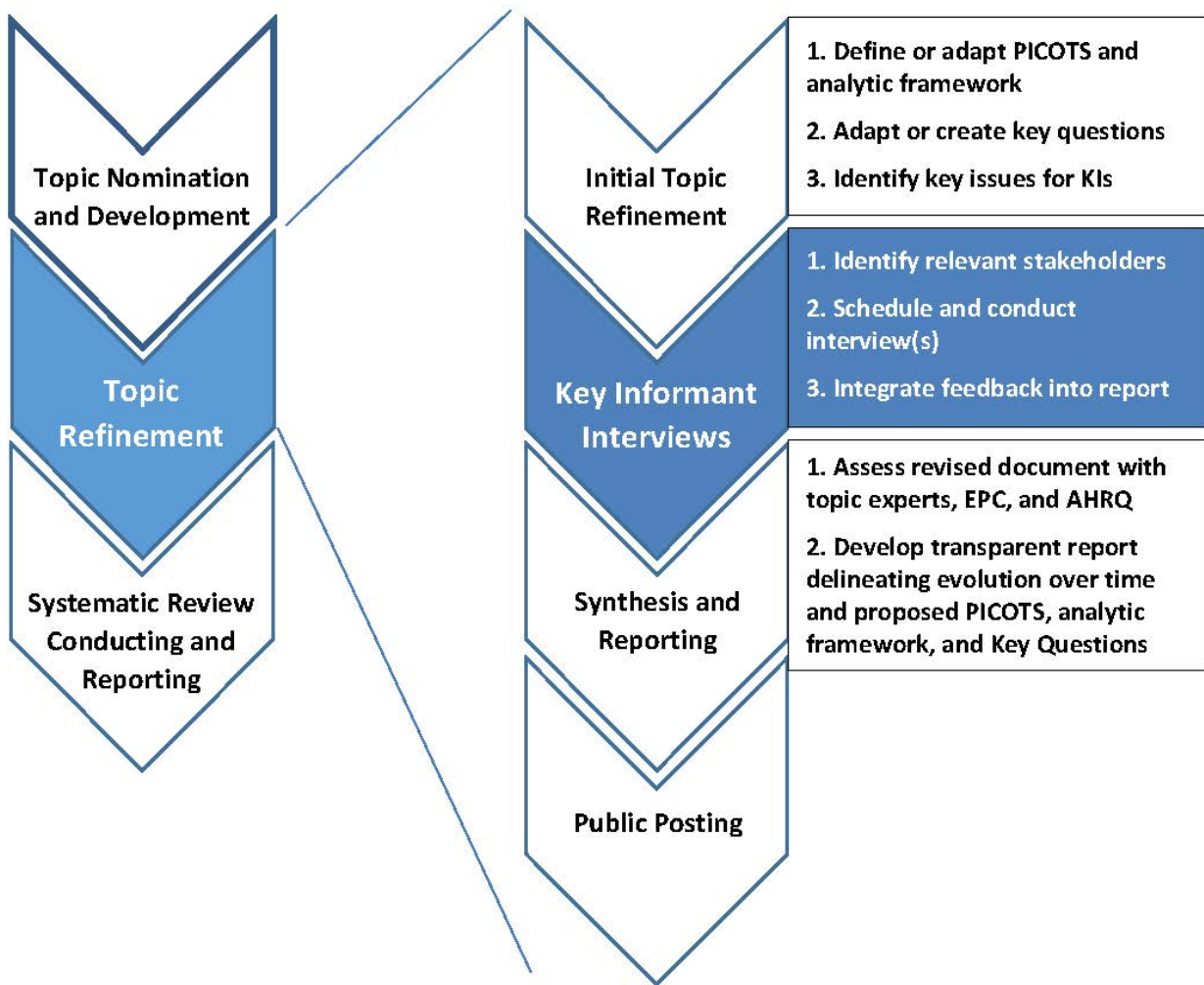
The public can participate in these reviews in a variety of ways, including proposing research topics in important areas. In addition, the public posting of Key Questions and draft evidence reports allows the public to provide insight and feedback at two key points of the systematic review process. And then providing the final reports and any translational products free of charge on its website (<https://effectivehealthcare.ahrq.gov/>) allows the general public to use the valuable information provided in these reports.

There are also times when members of the public are selected to participate on a panel or group to refine a project. Specifically, EPCs include patients, caregivers, and patient advocates in their systematic reviews (<https://www.effectivehealthcare.ahrq.gov/ehc/assets/File/How-to-get-involved-EHC-Program-Guide-130515.pdf>). The current project focuses on the inclusion of the patient perspective in Topic Refinement of a systematic review. A refined topic has three elements: (1) a clearly articulated population(s), intervention(s), comparator(s), outcome(s), timing, and setting(s) of interest, collectively referred to as the PICOTS, (2) Key Questions that are precise, detailed, and clearly focused, and (3) an analytic framework that represents the relationships between the elements of the PICOTS and the Key Questions (Figure 1). The Topic Refinement process includes a number of steps that begin with adapting preliminary materials from the initial topic nomination and development stage based on clinical expertise on the EPC team and a preliminary search of the literature, and ends with the refined topic and summary report being sent to the systematic review team for use in developing the systematic review protocol.

EPCs use an inclusive and transparent process to refine a topic, so Key Informants (KIs) are selected for a panel that includes a broad range of health care stakeholders such as clinicians, prominent researchers in the area, and individuals who can represent the patient perspective, such as patients, caregivers, and patient advocates. After being sent preparatory information, the KIs have a group conference call with a facilitator from the EPC and a Task Order Officer from AHRQ. Alternatively, a member of the KI panel can have an individual call with only the EPC and AHRQ representative. The feedback from the KIs is used by the EPC to refine and revise the Topic Refinement Document.

Over the years, AHRQ and the EPCs have developed a methods guide (<https://effectivehealthcare.ahrq.gov/ehc/products/60/318/CER-Methods-Guide-140109.pdf>) which includes a chapter on Topic Refinement. There is additional guidance and training for facilitators and a checklist for putting together the KI panel agenda to improve the value of the KI calls.

Figure 1. Systematic review process with focus on topic refinement



Purpose

The Agency for Healthcare Research and Quality (AHRQ) wants to better understand the ways in which patients, caregivers, and patient advocates are being engaged in systematic reviews. Consequently, in April 2016, they conducted focus groups with Evidence-based Practice Center (EPC) personnel who have facilitated group stakeholder discussions. While the focus group discussions were robust and helped elucidate some successful practices and barriers, it was felt that talking directly with the patients, caregivers, and patient advocates who had previously served as Key Informants (KIs) would be critical to establishing best practices. Consequently, the main objective of this project was to examine how patients, caregivers, and patient advocates who participated as KIs in systematic reviews regarded that experience and what their recommendations are for improving that process.

Procedure

At the spring 2016 EPC Program meeting, the University of Connecticut (UConn) EPC team introduced this quality improvement project to the other EPCs, including its purpose and the need for patients, caregivers, and patient advocates who could provide honest feedback about their experiences as a KI. EPCs were informed that with the variety of approaches used to engage KIs, this was an opportunity to assess how KIs were being involved in systematic reviews and solicit their recommendations for quality improvement.

On September 8, 2016, AHRQ reached out to EPC Program contractors via email to get recommendations for former KIs to interview (see [Appendix A](#) for the email and recruitment document). Because the UConn EPC was conducting the project, UConn was excluded from recommending KIs. Seven of 12 EPCs provided a total of 16 names of KIs and their contact information; recommendations ranged from one to five KIs per EPC.

The UConn EPC team contacted the KIs recommended by the seven EPCs. KIs from six of the 12 EPCs agreed to participate. Of the 16 KIs contacted by email, seven never responded, two indicated that they were too busy to participate, and one person was never reached because of an incorrect email address. The six KIs who participated in the project were white and primarily female (5 females, 1 male), with a mean age of 56 years. They had participated in prior systematic reviews between 2014 and 2016 that were conducted by EPCs from the Southeast (N=3), Northeast (N=2), and Midwest (N=1). The KIs were patient advocates (N=4) and caregivers (N=2). (See Table 1 below for more information).

Table 1. Demographics of Key Informant participants

DEMOGRAPHICS (N=6)		N	%
TYPE OF KI	Patient Advocate	4	67%
	Caregiver	2	33%
GENDER	Male	1	17%
	Female	5	83%
RACE / ETHNICITY	White	6	100%
	Non-White	0	0%
	Hispanic / Latino	0	0%
AGE (Mean Age = 56 years)	35-44	1	17%
	45-54	3	50%
	55-64	0	0%
	65-74	2	33%
KI DISCUSSION FORMAT	Mixed Group	4	67%
	Individual & Mixed Group	1	17%
	Individual	1	17%
EPC REGION	Northeast	2	33%
	Southeast	3	50%
	Midwest	1	17%
YEAR PARTICIPATED	2014	1	17%
	2015	3	50%
	2016	2	33%

Individual interviews were scheduled with each of the six KIs. Prior to the interviews, participants were provided with an Information Sheet (see [Appendix B](#)) describing the purpose of the project and procedures that would be followed. They were also asked to complete a very brief online questionnaire via Survey Monkey to collect relevant demographics information, such

as age, gender, race, ethnicity, and number and location of EPC projects in which they had participated (see [Appendix C](#)).

All six KIs participated in a one-hour individual interview followed by a focus group discussion (see [Appendix D](#) for the questions asked). The interview and focus group discussion focused on the KIs' experience participating in a systematic review, including:

- How prepared the KIs felt for their individual interview with an EPC member and/or their group stakeholder discussion with clinicians and researchers.
- What the experience was like participating in the interview and/or group stakeholder discussion.
- What type of follow-up there was, if any.
- Any recommendations they had for improving the process.

The UConn EPC team facilitated the individual interviews and the focus group discussion, which were conducted via WebEx and audio recorded. One member of the UConn EPC team took notes during each session and provided a summary of the notes to the other member and two representatives from AHRQ within a few hours of completion of the session. Individual interviews occurred on the following dates:

- October 14, 2016
- December 13, 2016
- December 14, 2016
- December 19, 2017
- January 19, 2017
- December 1, 2017

The focus group discussion was conducted on March 22, 2017, it was one hour in duration, and all six KIs participated. Prior to the focus group discussion, the KIs were sent a summary of the key issues that came out of the individual interviews. This summary was created following a detailed review of the transcription of each of the six audio-recorded interviews; recurring themes were identified and included in the summary. Once completed, the KIs were asked to review the summary prior to the focus group discussion and to indicate during the group discussion whether the summary accurately represented what was discussed during their individual interviews and if there were changes or additions that needed to be made. There was unanimous agreement that the summary was an accurate representation of what they had discussed during their interviews.

The focus group discussion centered on a review of what the KIs perceived as the strengths and weaknesses of the systematic review process in which they had participated and reaching consensus on their recommendations to the AHRQ about how EPCs can best engage patients, caregivers, and patient advocates in that process. Some additional recommendations came out of the focus group discussion that were not originally elicited during the individual interviews.

Following the focus group discussion, the transcriptions of the six individual interviews and the group discussion were again reviewed in detail for recurring themes. The summary of key issues that was created following the individual interviews and focus group discussion served as the basis for the current report, with modifications and additions being made based on a comprehensive review of the transcriptions. Key findings were elucidated with representative quotes from the participants. A draft of the report was then sent to AHRQ and all six KIs for their feedback.

Feedback From Key Informants

Preparation of Patient KIs for Systematic Reviews

Majority of KIs Reported Not Receiving Sufficient Information Prior to Discussion

There was a range of perspectives on how prepared KIs felt for the group stakeholder discussion. One of the participants stated that she *“felt very prepared in terms of what [they] were going to be discussing and what [she] could contribute to that discussion.”* However, most of the KIs did not feel that sufficient information was provided prior to the group stakeholder discussion about the AHRQ and EPCs, the purpose of the evidence report, the process and timeline for that report, and the other individuals who participated in that discussion. Most importantly, the majority of the participants reported that they did not fully understand their role in the development of the evidence report and were not clear on what was going to transpire during the group stakeholder discussion until they got on the call.

- *“I did not feel very prepared for the group discussion at all actually. I thought there would be more parents and that there would be more of a need for me, that they were looking for my input specifically, and that I would be giving them my input and they would be working with that.”*

For those who were both a patient and patient advocate, they were confused as to whether they were supposed to speak about their own experiences as a patient with the disease or represent the larger population of people with the disease.

KIs Who Understood Each Step of the Process Felt Better Prepared for the Discussion

Participants said the information that was provided to them prior to the individual interview/group stakeholder discussion was quite variable with some individuals receiving *“some general information...but no hints as to what kind of questions [they] were going to be asked.”* At least one participant indicated that the document provided prior to the group stakeholder discussion was full of *“lingo, scientific terminology, and technical language”* that was sometimes overwhelming and difficult to understand. The KI who felt the most prepared for the discussion reported being provided with *“extensive”* information prior to the call that was clear and easy to understand, including a meeting agenda, a description of how the actual review would work, the type of information that was being sought, how the panel was organized, what would be discussed, and a timeline for the entire process. All of the participants agreed that it was essential for KIs to be provided ahead of time with the questions most relevant to them so that they could prepare for the discussion. They felt that this is particularly important when there is only one patient/patient advocate participating in the discussion.

- *“One of the things they gave us was called ‘Considerations for Key Informants,’ which were questions and issues for the Key Informant. So for example, one of the questions was, help identify comprehensive set of critical target outcomes for treatment of [the health condition]. We were supposed to go into that, have some thoughts on that.”*

Participation in KI Interviews and Group Stakeholder Discussions

All of the Participants Believe There is Value in Participating in Systematic Reviews

Participants' experience in systematic reviews ranged from very positive to frustrating. None of the participants, however, regretted participating in a systematic review, and all of them would do it again. Everyone believed that there was great value in clinicians and researchers hearing the perspectives of patients and patient advocates. And many of them felt that they learned something by listening to the researchers and clinicians. They commended AHRQ for requiring EPCs to include patients/patient advocates in systematic reviews.

KIs Feel More Engaged When They Understand Their Role and Their Contributions are Valued

Those who reported the most positive experience participating in a systematic review had been well-informed about the purpose of the review and the process involved, including what would happen during and after the group stakeholder discussion (e.g., review and comment on a draft report). Their role in that process was made clear to them, which increased their self-efficacy and level of engagement. Overall, they felt valued and respected, and they believed that their contributions were viewed as important and significant. Those who had a less positive experience reported more confusion about the purpose of the group stakeholder discussion and their involvement in that discussion, and they did not feel that sufficient efforts were made to involve them in it.

Some of the participants indicated that their perspective had been solicited and their contributions were valued, resulting in them feeling comfortable talking openly and honestly during the discussion. In contrast, there were others who felt minimally relevant:

- *“I’m not really sure what it was they were looking for from a patient or why I was involved. They just said they wanted to have a patient on the line.... I was never really asked to contribute except by one of the psychiatrists who said, ‘Well, we do have a patient on the call. Why don’t we ask him what his experience was like?’... Except for that one guy, I wasn’t really engaged in the discussion at all.”*

A Skilled Facilitator Is Key to Successful Engagement of Patient KIs

Everyone agreed that the key to successful engagement of patients, caregivers, and patient advocates is a strong, competent facilitator who works to ensure that everyone gets an opportunity to speak and contribute. According to the participants, some of the facilitators did a better job of this than others. Effective facilitators engaged both the patients/patient advocates and the clinicians/researchers, controlled the flow of the discussion so that dominant individuals did not take over and monopolize the discussion, and did not let others minimize or discount a person's contributions. In addition, effective facilitators understood what aspect of the discussion would benefit from the patient/patient advocate perspective and cued the patient/patient advocate at the appropriate time to give his/her perspective.

Facilitators who were less effective at engaging patients/patient advocates tended to direct fewer questions to the patients/patient advocates themselves and appeared to have the attitude that *“whoever wanted to speak up, could,”* and there was minimal effort to actively involve the

patients/patient advocates. Most of the participants indicated that the facilitator “*did a fine job*” but could have elicited more input from patients/patient advocates by specifically asking them “*what are your thoughts on this*” or “*do you have anything to add*” and making it comfortable for them to contribute.

Majority of Participants Voiced Frustration that Group Stakeholder Discussions were Highly Technical

All of the participants reported that there were opportunities for patients/patient advocates to speak during the group stakeholder discussions, but those opportunities tended to be limited relative to the scientific/technical portion of the discussion. A couple of the participants reported that “*for the most part, [they] were heard and that many of the things [they] said were validated by others in the group.*” However, some of the participants reported that the clinicians/researchers tended to talk amongst themselves during the group stakeholder discussion and did not engage the patients/patient advocates in the discussion. Some felt that the discussion was geared towards the clinicians/researchers with limited interest in the patient/patient advocate perspective. One of the participants reported feeling like an “*outsider looking in.*” S/he felt like the discussion was more to “*benefit them*” [the clinicians/researchers]. A few of the participants indicated there were some clinicians/researchers who were “*dismissive*” towards them. This experience was in sharp contrast to their experience in similar discussion groups sponsored by other organizations, in which there was reportedly great interest in what patients/patients advocates had to say.

All of the participants agreed that it is not a good use of a patient/patient advocate’s time if the vast majority of the call is highly scientific/technical. Patients/patient advocates are interested in the science, but if it goes on too long, they can get frustrated, feel intimidated, and lose interest because they often do not understand it and cannot contribute.

- “*I did not feel very prepared for the group discussion.... I wasn’t prepared for such an in-depth, deep discussion that was that far over my head. There were times when I had no idea what they were talking about.... I think once I started feeling I was over my head and that they were discussing things over my head, I kind of backed down because I didn’t want to say something wrong or inappropriate. ...I was afraid to say something stupid.*”

Rigid Interview Protocols Can be Very Unproductive

It is also exasperating for the patient/patient advocate when the questions being asked do not pertain to her/his experience/knowledge (i.e., there is a “*mismatch*”). A caregiver provided an example of an individual interview where all of the questions were about that parent’s experience with treatment. Even though the parent indicated early on in the interview that her children had never been treated for the condition, the interviewer continued to rigidly adhere to the protocol and ask questions about treatment. The “*disconnect*” between the questions and the parent’s experience, and the lack of flexibility in the interview protocol (script) meant that s/he could not contribute meaningfully to the discussion and resulted in a “*very frustrating experience*” for her/him.

Being the Only Patient/Patient Advocate in the Group Stakeholder Discussion Can be Intimidating

Participants reported that it can be difficult for a patient/patient advocate to meaningfully participate in a discussion when s/he is the only patient/patient advocate, and everyone else is a clinician/researcher with technical expertise. The patient/patient advocate often feels outnumbered which can be intimidating for her/him, particularly because the discussion is often highly scientific and technical, and the patient/patient advocate may not have been given the opportunity to read about the studies being discussed. Or if s/he was provided with the studies, they are difficult to understand because they are highly technical. Most of the clinicians/researchers are familiar with the studies being discussed, but the patients/patient advocates are not. As one participant stated,

- *“Within this group I was the only patient, or parent of a patient, and I felt that could have been worked out. Maybe it couldn’t have been, but even one more [patient] where it wouldn’t have felt like me up against all these really smart people.”*

In addition, being put in the position of having to represent all patients to a group of researchers and clinicians can be highly stressful and inhibit that person’s willingness to participate. Some participants reported that patient advocates tend to be more familiar with scientific and medical concepts and with speaking in groups so they are often less intimidated in these group stakeholder discussions than patients. Ideally, they felt there should be at least one patient and one patient advocate in each group stakeholder discussion to ensure representation of both perspectives and also to lessen the likelihood that they will feel isolated or overwhelmed and think that *“they do not have the right to voice their opinion.”*

Individual Interview Followed by Group Stakeholder Discussion Increases Patient KI Participation

While most of the participants participated in group stakeholder discussions with clinicians/researchers, two of them participated in individual interviews with EPC members. The two different formats were compared by the six participants during the focus group discussion, and overall, they liked the efficiency of the one-on-one format and the fact that an individual does not have to compete with others to be heard. In addition, they believed that relative to mixed group discussions, the one-on-one format allows patients to feel more comfortable about asking for clarification before answering and less intimidated about participating. However, when the participants were asked if only these individual meetings should occur, they consistently responded that there was great value for both the patients/patients advocates and the clinicians/researchers in being included in group stakeholder discussions and exchanging information. They felt it was particularly important for clinicians/researchers to hear the patient/patient advocate perspective. Therefore, they recommended that there be individual interviews of patients/patient advocates followed by a group stakeholder discussion with clinicians and researchers or a group stakeholder discussion with just patients/patient advocates followed by a mixed group discussion.

Audio-Only Meetings are Not Ideal for Engaging Patient KIs

Lastly, the participants agreed that patients/patient advocates are more readily engaged when discussions are face-to-face rather than over the phone. Given that these group stakeholder discussions involve people from across the country, they understood that in person face-to-face

meetings are not possible. When the UConn EPC team asked about the use of videoconferencing via something like WebEx, they all agreed this is a viable option that is preferable to audio only meetings but still inferior to face-to-face meetings.

Followup to Group Stakeholder Discussions

Majority of KIs Reported Not Reviewing the Draft Report

As with the actual group stakeholder discussion, engagement of the patients and patient advocates in the review of the draft report was quite variable across the EPCs. Some of the participants reported not being involved at all in the review of the report, and others were intimately involved. A participant who had a very positive experience indicated that s/he interacted with the EPC on a regular basis from the moment s/he was first contacted through to completion of the final report. After the group stakeholder discussion, s/he received an email that thanked her/him for her/his work and provided her/him with an outline of the next steps for the review. S/he was then sent a list of the parameters/questions that were going to be investigated in the draft report, which s/he was asked to comment on. And then when a draft report was available, s/he participated in a phone call to provide feedback on it. S/he felt very much engaged in the process and believed that her/his perspective was well-represented in the final report; s/he was “*very satisfied*” with the entire process, as indicated by her/his statement below:

- *“What I thought they did well was they sent out the document to all of us to review, they welcomed feedback on it, they allowed things that we provided as input to be corrected if we didn’t feel it was represented the way we wanted it. There were a couple of different ‘back and forths’ on that from a variety of people - it was a reply all, so nobody was excluded from that. And then the final copy was sent, and also [we were] told where it was going to be posted for final review. So I thought they did really well with communication on that at the end.”*

Some of the KIs reported that they were not given the opportunity to review the draft report and had no idea what happened after the group stakeholder discussion. Another participant said that she did not hear anything for months after the group stakeholder discussion and then was sent the final report with no opportunity to provide feedback.

- *“There wasn’t follow-up. I think that an email of ‘we’re moving into this stage’ or ‘we are submitting it’ or even a ‘hey, we got published, here’s the link if you want to read it.’ I think that would have been helpful to follow up on what I contributed and how it helped and what it turned into.”*

Some of the patients/patient advocates did not take the opportunity to read and comment on the draft report provided to them, because they felt it was mainly scientific and not their area of expertise. All of the participants agreed that if a patient/patient advocate did not feel engaged in the group stakeholder discussion, s/he is much less likely to read the draft version of the report when it is made available.

Outreach to Patient KIs after Group Stakeholder Discussion can Facilitate Continued Involvement

Because participating in the group stakeholder discussion can be an intimidating experience for patients/patient advocates, it was suggested by one of the participants that the facilitator reach out to the patient/patient advocate after the call to determine if there is anything that s/he wants

to add or if s/he has any questions that s/he did not feel comfortable asking on the phone. Participants indicated that this is often a much safer format for patients/patient advocates who were hesitant to talk in the group stakeholder discussion, who did not understand something and were worried about asking it, or who had time to think about what was discussed and have further comments or questions. They agreed that active follow-up by an EPC staff member can be very useful for engaging patients, caregivers, and patient advocates, and for collecting additional input.

All KIs Indicated a Desire to Know What Happens After Evidence Report is Completed

All of the participants believed that there was great value in producing these evidence reports, but they had concerns about what happens to the final report after it is completed. They would like to know whether the recommendations that come out of the report *“are being used in a clinical setting or changing the way physicians are treating or processing patients.”* Is the information getting to the people who need it? As one participant stated, *“I think that patients can be left feeling, ‘Well, that seemed important, but I’m not quite sure what happens next.’”* There was consensus among the participants that it would be highly beneficial to distribute this information to patient advocates so that they can provide it to patients, families, and other key stakeholders. One of the participants reported that she actually presented the report that came out of her group stakeholder discussion at a national conference. Patient advocates are very motivated to disseminate the information in the report to their community: *“It may be beneficial to have... a meeting where we could bring stakeholders together to discuss the findings and think about next steps and what needs to be done.”*

Recommendations

Each of the six participants provided recommendations during her/his individual interview on how to best engage patients, caregivers, and patient advocates in systematic reviews. At the completion of the individual interviews, all of the recommendations were compiled and duplicate recommendations deleted. Although there were a few recommendations that were made by a single participant, the vast majority of the recommendations were made by multiple participants; there was remarkable consistency across the six participants.

The compiled recommendations were organized into themes within a single document, which was emailed to the participants for their review prior to the focus group discussion. The list of recommendations was then discussed extensively during the focus group discussion, and some additional recommendations were added to the list. Every one of the recommendations listed below was suggested by one or more participants, and every recommendation was discussed by the group. There was no disagreement among the six participants about these recommendations.

Patient KI Recruitment

1. **Do not ask a patient/patient advocate to participate unless the EPC is truly interested in and ready for a patient/patient advocate perspective.** Do not involve a patient/patient advocate simply because AHRQ requires EPCs to do so. Some of the participants felt they were asked to do so in order to “*fulfill a requirement*” and that the EPC was not truly interested in their perspective.
 - “*You do get the feeling that you’re just kind of an afterthought or you’ve been put on this because that’s a requirement.... It seemed like they had not really thought through what our role in all of this is.*”
2. **When recruiting patients/patient advocates from patient advocacy and other organizations, provide sufficient detail to allow the most appropriate individuals to be selected to participate in the systematic review.** Additionally, conduct an initial screening process to ensure that the patient/patient advocate has the experience/knowledge required to answer the target questions and is the correct “*match*” for the systematic review. Do not waste a patient/patient advocate’s or an interviewer’s time. One KI suggested that a brief screening questionnaire be sent to the patient/patient advocate to ensure that the person has had the relevant experiences needed for the systematic review (e.g., do not invite a patient to answer questions about his/her experience with treatment if his/her disease was never treated).

Preparation of Patient KIs to Participate in Systematic Review

1. **Inform the patients/patient advocates why they were chosen to represent patients and why their participation is so important.** Explain how important the patient perspective is, why the person has been chosen, and why this group of Key Informants has a patient in it and the important role that a patient plays in this process. Say something to the effect of “*we value your voice in the discussion,*” and “*we want you to use it during this call.*” This will help empower the patients/patient advocates to participate more fully.

2. **Provide clear expectations for the patient/patient advocate's role.** Indicate whether they are there to discuss their personal experiences with the disease/condition or as a representative of the larger group of patients with the disease/condition. Indicate the specific questions that they, as patients/patient advocates, will be asked, so they can prepare themselves for the discussion and feel they are making a significant contribution.
3. **Educate the researchers and clinicians about the important role that patients/patient advocates play and the valuable contributions they can make to the discussion.** Unless researchers and clinicians understand what patients/patient advocates bring to the table, they are likely to be dismissive and discount what the patients/patient advocates say.
4. **Provide easy-to-understand information to the patient/patient advocate prior to the call about: (1) the mission of the AHRQ and EPCs, (2) the overarching goal of the systematic review and group stakeholder discussion, (3) what will transpire before, during, and after the interview/group stakeholder discussion, (4) the issues that will be discussed during the interview/group stakeholder discussion, (5) what her/his role is as a patient/patient advocate, (6) what s/he should be prepared to discuss (e.g., specific questions), and (7) who will be on the call (i.e., name and background) and the role of each of those individuals in the group stakeholder discussion.**

Everything needs to be spelled out in a clear, easy-to-understand way. There should be no confusion about what is involved in participating in a systematic review; KIs should understand each step of the process. Providing a brief bio for each of the individuals who will participate in the group stakeholder discussion helps orient the patients/patient advocates as well as the clinicians/researchers. It is very common for the researchers and clinicians to run in the same circles and know each other, whereas the patient/patient advocate is unlikely to have this baseline relationship, which can cause her/him to feel like an outsider during the discussion. Providing some background information on everyone in the group helps to minimize that sense of alienation. Informing patients/patient advocates about the format of the discussion and what they should be prepared to talk about allows them to prepare for the discussion. Understanding what questions will be asked of them is very important for engaging the patients/patient advocates, minimizing their anxiety, increasing their self-efficacy, and having a productive discussion with them. Ideally, there should be an agenda provided prior to each discussion/meeting, and minutes provided afterwards.

- *“If they did... a preview before the call to set that up and say: ‘Here’s what will occur. Here’s the background of the people that will be on the call. Here’s what they will address, and here’s where your input would be valued in the following way, or here’s what we want to hear. Here’s the questions that are likely to come up.’ Not to have it absolutely highly scripted, but to have that expectation a little bit more out on the table.”*
- *“Every call we had, there was an agenda.... Had agendas for everything. We knew exactly what the meeting and the call was going to be about - some of the questions that were going to be asked.... All of them were well-organized, and you weren’t left not knowing what’s taking place, and since that meeting, I will tell you, we’ve had ongoing communication. Like this is where we are now and this is what’s happening.”*

5. **Provide a layman's summary of the studies being discussed prior to the call.** The articles themselves may be too technical for some of the patient/patient advocates so scientific information needs to be provided in terms that are less technical and easier to understand. It can be overwhelming and intimidating for some people to read highly technical information prior to the discussion, and fear of appearing stupid or uninformed can discourage people from participating. For those who are more experienced at reading and understanding scientific information, links can be provided to the actual studies and more detailed information. Because patients and patient advocates have a range of backgrounds and expertise, it is important to provide easy-to-understand information with the option to read more technical information, if they so desire. Some of the participants suggested that KIs with greater medical expertise might find participating in the group stakeholder discussion "*less inviting*" if the information is "*too basic*."
6. **Have a member of the EPC contact the patient KI after the information about the upcoming discussion is sent out to ensure that the person understands what was sent and to answer any questions prior to the call.** Although emailing information may be sufficient for some, there are others who would prefer to speak with someone over the phone. At the very least, the KI should be provided with a contact person whom s/he can reach out to with any questions.

Selection of Facilitator With Strong Communication Skills

1. **Select a facilitator who has "*really good communication skills*."** The facilitator is key to the successful engagement of patients, caregivers, and patient advocates in a discussion. Effective facilitation requires a certain set of skills and not everyone has those skills, although they can be learned. Many of the facilitators are chosen for their technical expertise in meta-analyses, meta-regression, patient statistics, and/or other scientific concepts, rather than for their facilitation skills. Just because someone has expertise in a particular health condition or is a researcher does not mean s/he knows how to engage people in a group discussion.

- "*I mean these were great researchers, but their communication skills were really flat lining.*"

The facilitator must have strong communication skills, take an active role in managing the discussion, and ensure that everyone has the opportunity to contribute and feels that her/his input is valued. This individual must be aware of who is on the call and actively engage the patients/patient advocates by directly asking them questions that are specifically relevant to them. The discussion needs to have structure but also flexibility so that people can also make contributions spontaneously. An effective facilitator (1) ensures that the questions are clear and relevant, and allows sufficient time to answer the questions, (2) makes sure that the patients/patient stakeholders feel relevant and valued, (3) is active in controlling the discussion and does not allow anyone to monopolize it, and (4) ensures that all voices are heard and that everyone is treated with respect and is not dismissed or denigrated. This does not mean that every aspect of a group KI discussion requires patient/patient advocate input, but they should know they are free to contribute, and their feedback should be directly solicited during pertinent portions of the discussion.

- "*I think it behooves people who are conducting the interview to have some really good responses that let the person who is responding know that no matter what they*

say, their responses are respected.... Sometimes it felt to me on different calls like I dropped a penny in the well and never heard a response. And sometimes that almost feels like a judgment.... Hearing a response or some kind of 'I'm glad you mentioned that' or 'Thank you for your input' or 'That's important to us' – some set of stock phrases that could really communicate that human dimension of gratitude.”

Structuring Group Stakeholder Discussion To Maximize Patient KI Involvement

1. **Be flexible and not overly structured when interviewing a patient/patient advocate.** Listen carefully to what the patient/patient advocate is saying, and do not adhere to a rigid question protocol (script) if it does not apply. Not only can rigid protocols be frustrating when there is a mismatch, they can also result in important information being missed. If the questions are not relevant to the patient/patient advocate, either modify the questions or end the interview with the patient/patient advocate. Do not waste the patient/patient advocate's or the interviewer's time.
2. **Structure calls so that patient/patient advocates know when and what they have to contribute.** The scientific/technical portion of the discussion can be overwhelming for many patients/patient advocates. Bring patients/patient advocates into the discussion when it is relevant to them, and present information in layman's terms. There can be a portion of the call devoted to patient/patient advocate input, a portion of the call that is highly scientific, and a portion where there is overlap. Patients and patient advocates can drop off from the portion of the call that is science-based and technical. Be sure to allocate a dedicated period of time for patient/patient advocate input. At the start of the call, inform patients that a portion of the call will be highly technical, and they are welcome to remain on the call or they can leave the call; it is up to them. Because patient/patient advocates have different levels of knowledge and expertise, do not assume that they cannot participate in the technical portion of the discussion.
 - *“I think when it's so scientific, I think there needs to be a better set up or thoughtfulness in using folks' time to sit in on these calls. I think there's some value to having us on, but not when it's specifically science and we can't add to that.... Maybe there's some overlap where you need both of us, and there's specific time devoted to the patient advocate and the patient. And then there's specific science-based, and you don't need the patient advocate or the patient; maybe then they drop off the call.... I think there's some value of having everybody participate and hear each other, though.”*
 - *“I have a unique situation in that I have both a scientific and medical background.... The call I was on, I was knowledgeable of the disease and although sometimes the science was a little bit beyond the scope of my background, I didn't really feel intimidated or at a loss. In fact, it encouraged me to do some more reading.”*
3. **Carefully manage the discussion so that clinicians and researchers do not become critical of how the patients or their children were, or are currently being, treated for their health condition.** Facilitators need to be sensitive to the fact that these KIs are patients and caregivers, and if the KIs hear from the clinicians and researchers that they or their children should have received different treatment, it can be stressful and upsetting for them.

Lessening the Stress of Participating as a Lone Patient

1. **Consider having a one-on-one call with the patient/patient advocate prior to the group stakeholder discussion.** Being the only patient/patient advocate in a group stakeholder discussion can be daunting and overwhelming. Her/his anxiety can potentially be lessened by interviewing her/him one-on-one prior to engaging her/him in the group discussion. Another option is to have a group call with patients/patient advocates and a separate group call with clinicians/researchers prior to bringing them together for a joint call. According to the participants, it is important for clinicians/researchers to hear from patients/patient advocates, so a joint call is also critical.
2. **Include at least one patient and one patient advocate in every group stakeholder discussion.** Do not assume that a single individual can adequately represent an entire disease or health condition. Patients and patient advocates bring different perspectives to the discussion. Patients will talk about their own personal experience with the disease/condition, whereas patient advocates will provide a broader perspective about patients with the disease/condition. Additionally, having more than one patient/patient advocate participating in the group discussion will be less intimidating for them and encourage greater engagement and participation.
 - *“I think patients should be there because hearing directly from a patient is important. But then the patient advocate/patient organization can also bring a different perspective from a general population of patients, and not just be focused on a specific type of disease.... I think they bring in different perspectives; it shouldn’t just be one or the other. I think both a patient and a patient organization/patient advocate should be represented.”*

Online Videoconferencing To Increase Participation of KIs

1. **Ensure that all of the KIs and the facilitator can see one another during interviews and group stakeholder discussions.** Face-to-face meetings are ideal but not feasible in most cases. Second best are phone meetings with video. It is harder to become distracted and disengaged if an individual in the group can see the other participants and if s/he knows that others can see her/him. It is too easy to focus on other tasks (e.g., reading emails) if the discussion is conducted via audio only.
 - a. *“I think that video [WebEx] would be a lot more helpful because putting a face to what people are saying is helpful. It makes you feel more engaged; it makes you feel more part of the conversation.”*

Followup With KIs After Group Stakeholder Discussion To Keep Them Engaged

1. **Follow up with the patients/patient advocates after the group stakeholder discussion.** Provide them with a timeline so they know when they can expect to hear from an EPC staff member again. Do not leave them in the dark for months at a time.
 - a. *“I think follow-up calls or a follow-up email that says, ‘A report is coming’ or ‘We’re interested in your feedback on the report,’ I think that is helpful. The feeling that it is not a ‘one-and-done’ kind of moment, and you have some kind of continuity where*

you see that what you said or what you're involved in is going someplace, has gravitas going forward, that something is going to be made of your participation as part of that group."

2. **Consider providing minutes after every call/meeting.** This allows KIs to check to see if their contributions are accurately represented, and it also gives them the opportunity to review what occurred and follow up with questions or additions. Along with the minutes, provide the name and contact information of someone at the EPC they can reach out to if they have additional questions/comments or feel that their perspective was not accurately reflected in the minutes.
3. **Provide a copy of the draft report to the patients/patient advocates who participate in the group stakeholder discussion, and actively encourage them to provide feedback on the report.** Patients/patient advocates will not be motivated to read the draft report unless they feel actively engaged in the group stakeholder discussion and believe that they made a meaningful contribution. Consider having a second call to review the main recommendations of the report and ensure that people's perspectives have been accurately represented.

Outreach to KIs To Disseminate Findings From Evidence Report

1. **Consider following up with patients/patient advocates to indicate how the information provided in the final report is eventually used.** Patient KIs indicated a great interest in knowing what happened to the final report in which they participated and whether it has had any practical, real-world impact. They stated that patients/patient advocates will be much more inclined to get involved in this process if they believe that their participation will make a difference. In other words, patient KIs want to know, for example, if the information in the report impacts how treatment is provided in the clinical setting. Does it affect how clinicians are treating patients? The participants were not entirely clear on who should follow up with and provide this information to patient KIs, but there was some discussion about AHRQ doing it.
 - *"If you felt, as a patient, that your input may have resulted in an element or a part of a course of action, you could feel that you really did have a sense of contribution to an important area."*
2. **Consider providing an opportunity for patient advocates to disseminate the recommendations/findings in the report to patients, their families, and other stakeholders.** Patient advocates are very invested in providing information to others, and they are a mechanism for distributing the report more broadly to those who will make use of it. As AHRQ strives for greater dissemination of the knowledge gained from EPC reports, patient advocates who are prominent in their organizations can be internal champions if they feel engaged and relevant during the process.

Limitations

This report summarized the perceptions of and recommendations from six patient advocates and caregivers who participated in UConn EPC's quality improvement project. Although the findings were consistent across the participants, there are some limitations that should be noted:

1. Patient advocates and caregivers were interviewed from only six of the 13 EPCs, and only a very small number of the patient advocates and caregivers who were involved in the EPC program over the past several years were included. This limits the generalizability of the findings.
2. It is unclear how representative those KIs who agreed to participate are of the greater population of KIs. Those who saw the email invitation and agreed to participate might be very different from those who never responded to the email or who responded and declined to participate.
3. In addition to participating in an EPC systematic review, some of the KIs had participated in individual interviews and group discussions with other organizations, which no doubt impacted their perceptions. Because this was not systematically assessed, it is unclear in what way these other experiences influenced KIs' perceptions and recommendations.
4. Due to the small number of participants, a formal coding system and rigorous qualitative analyses were not used to analyze the data. Rather the transcripts were reviewed in detail for recurring themes and for recommendations. All recommendations were included in this report. To ensure that perceptions and recommendations were accurately represented, participants were asked to review them prior to the focus group discussion and then again in the draft report. The participants agreed with the findings as presented.
5. Some of the perceptions and recommendations elicited may not be relevant to all EPCs because of the heterogeneity in EPCs' approach to systematic reviews.

Despite these limitations, we believe that the feedback was largely consistent across the six participants, which provides greater confidence in the applicability of the findings.

Conclusion

Based on the individual interviews and focus group discussion with the KI participants, they seemed open and honest and truly invested in AHRQ and the EPC program being as successful as possible. Key findings include the following:

- None of the participants regretted participating in a systematic review, and all indicated that they would be willing to do so again in the future.
- There was consensus among the participants that patients and patient advocates should be carefully selected for systematic reviews to ensure that they have the relevant experience and expertise.
- Participants agreed that easy-to-understand information should be provided to patients/patient advocates prior to the group stakeholder discussion so that there is no confusion about what their role is and the questions they should be prepared to answer.
- The person who facilitates the discussion needs to be an effective communicator who knows how to manage the group stakeholder discussion and ensure that everyone is given the opportunity to participate and feels valued and respected.
- Patients/patient advocates should be informed that there will be time allocated for them to share their perspective, the discussion will be highly technical at times, and although they are welcome to participate in the entire discussion, they can choose to withdraw from it when it becomes technical.
- There should be ongoing follow-up with the patient/patient advocates after the group stakeholder discussion to keep them abreast of what is happening with respect to the report and to maintain their involvement in the process.

It is important to keep in mind that while many of the recommendations from the patient advocates and caregivers who participated in this project may be worthwhile, they may not be feasible to implement or consistent with what AHRQ and the EPC program are trying to accomplish. However, they do represent a starting point in a discussion about best practices for selecting, engaging, and utilizing patients, caregivers, and patient advocates in systematic reviews. Also, the recommendations presented here along with the rest of the report need to be viewed in light of the aforementioned quality improvement project led by Amanda Borsky, DrPH, MPP, which directly solicited feedback from EPC discussion facilitators about how they engaged patients and patient advocates in group stakeholder discussions. It could be highly informative to compare the current patient/patient advocate report with the facilitator report and to use those findings to inform the development of consistent guidelines around patient/patient advocate engagement.

Lastly, we believe that creating some type of toolkit that specifies how to most effectively engage patients, caregivers, and patient advocates in systematic reviews could be extremely beneficial to EPCs and AHRQ. This toolkit could include the various recommendations enumerated in this report, as well as detailed information about how to be an effective facilitator. Patients, caretakers, and patient advocates are extremely valuable resources who can make significant and substantial contributions to systematic reviews if given the opportunity and support to do so.

Appendix A. Email and Recruitment Document

From: Borsky, Amanda (AHRQ/CEPI)
Subject: Help Requested - Recommend 2 patients from prior KIs
Date: Thursday, September 08, 2016 8:02:19 AM
Attachments: [Attachment Recruitment.docx](#)

Good morning EPC PMs:

Attached please find a one-page summary of the **patient engagement methods project** (attachment

1) the University of Connecticut EPC will be conducting over the Fall of 2016. Like we discussed at the Spring 2016 Director's Meeting we are hoping to identify patient-perceived best practices for patient stakeholder engagement that EPCs can use during their systematic reviews. But, to make the project a success, we need to find 9 patients from 9 different EPCs who would be willing to participate.

Would you please identify two patients that you have used in the past and provide us with the project they participated in, their contact information, and how well you felt they were engaged? If you could identify one person who you perceived had a positive experience and one who had a less than perfect experience, that would be most helpful to us in our work but we understand that you might be able to remember or assess their experience. **More recent participants (those over the past 3 years) will have fewer issues with recall and be preferred.** We will provide patients with a \$40 gift card incentive for fully participating.

We would like to be able to start contacting patients **as soon as possible (by no later than September 30, 2016)** so it would be very helpful if you could make contact over the next few weeks. We will follow-up with them and answer any additional questions they might have if they are interested in hearing more.

If you have any questions, please don't hesitate to contact Charles.White@uconn.edu or Deborah.Cornman@uconn.edu. Please also send your suggestions directly to Mike and Deborah. Thank you!

Best regards,
Amanda

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Attachment 1:**Discerning the Perception and Impact of Patients Involved in
Evidence-based Practice Center Key Informant Interviews**
University of Connecticut Evidence-based Practice Center, Storrs, CT**BACKGROUND:**

In April 2016, AHRQ sought to discern the ways in which patients or caregivers were being engaged and held focus groups with EPC personnel who run stakeholder discussions. While the discussion was robust and elucidated some successful practices and barriers, it was felt that directly querying the patients who had supported our projects in the past would be a vital piece to establishing best practices.

SPECIFIC AIMS:

- Discern the general level of satisfaction that patients had as a result of participating.
- Elucidate how patients were invited to participate, what information was provided to them, and how their feedback was incorporated.
- Compare and contrast the responses between the patients and those in the focus group of EPC personnel conducted previously.

METHODS:

Patients (n=9) involved as stakeholders in EPC projects are eligible if they are US citizens \geq 18 years and have the ability to speak and understand English. EPCs will contact patients that they used as stakeholders in the past, and if the patients are amenable to participating or hearing more about the quality improvement projects, they will be contacted by the quality improvement team for this project.

In individual interviews, we will focus on the individual's experiences in the program, the process that was followed by the EPC when s/he was identified, educated, and utilized in the project and her/his feelings about that.

In focus group interviews, we will assess differences in approach and sentiment as to how these stakeholders were engaged and ask for thoughts on comparative strengths and weaknesses of the approaches. They will also be asked to identify approaches that have not been used in the EPC program but have been used elsewhere. We feel that the focus group as an extension of the personal interviews will allow us to gain insight from these stakeholders in two complementary approaches that replicate the ways in which patients are currently used in the EPC program (i.e., individually engaged without being a part of the larger group or in a large group with all stakeholders being present).

Data will be audio recorded and then transcribed, reviewed, analyzed, and summarized by the investigative team. Data will be assessed individually and then will be compared and contrasted to the responses the EPC personnel provided in their aforementioned focus group on patient engagement.

TIMELINE:

The quality improvement investigative team will present information at the Spring EPC Director's Meeting and ask for EPCs to start identifying patients or caregivers that would be amenable to participating and contacting them. We will follow-up with an email explaining the project and the need for EPC support in identifying participants. Individual and focus group meetings will be conducted over the Fall with results available for the Spring EPC Director's Meeting.

Appendix B. Information Sheet



Project Leaders: Deborah H. Cornman, PhD and C. Michael White, PharmD, FCP, FCCP

Project Title: *Discerning the Perception and Impact of Patients Involved in Evidence-based Practice Center Key Informant Interviews*

Sponsor: Agency for Healthcare Research and Quality (AHRQ)

Introduction

You are invited to participate in a project that is examining the experience of patients who have served as Key Informants for systematic reviews conducted by the Agency for Healthcare Research and Quality's Evidence-based Practice Center (EPC) program. The purpose of this quality improvement project is to learn from you and other patients who have served as Key Informants how you were originally identified, prepped for the group stakeholder discussion, and treated during that discussion, and to get specific recommendations from you on how best to increase patient involvement and improve the experience of patients in these systematic reviews.

What are the project procedures? What will I be asked to do?

If you choose to be in the project, you will be asked to participate in an individual interview followed by a focus group discussion with up to 8 other patients, caretakers, and patient advocates who have previously participated in systematic reviews. You will also be asked to complete a brief one-page background questionnaire, with questions about your age, gender, race, ethnicity, and the number and location of EPC projects you have been involved in. The interview and focus group discussion will focus on how prepared you felt for the group stakeholder discussion, what the experience was like participating in a systematic review, what type of follow-up there was, and any recommendations that you have for improving the process.

Both the individual interview and focus group discussion will be conducted over the phone by trained clinical psychologist Debbie Cornman. Project Leader Michael White and a member of the AHRQ will also be on the call and may ask some follow-up questions. These conversations will be audio recorded and transcribed. It is expected that the interview will take no more than 60 minutes, and the focus group discussion (conducted at a later date) will take up to 1½ hours. Any personally identifying information will be removed from the transcripts before they are analyzed. The audio recordings will be deleted after they have been transcribed.

What are the risks or inconveniences of this project?

Your involvement in this project does not require you to have procedures or treatments, and you are not being asked about any diseases or disorders that you have. Since you are only being asked about your experience as a Key Informant in a systematic review, the risks to you are minimal.

There is a slight risk that your participation in this project may become known to others outside of this project if someone in the focus group discussion reveals your identity, but that is unlikely because the group discussion is being conducted over the phone, and we are asking participants not to identify themselves by name during the discussion. And the researchers themselves are required to keep your identity and the information that you provide confidential.

Lastly, there is the possible inconvenience of having to spend a combined total of 2½ hours of your time on the interview and focus group discussion.

What are the benefits of this project?

There is no potential direct benefit to you unless you participate in another systematic review and group stakeholder discussion. The feedback that you and the other participants provide will be used to better understand how to effectively engage patient stakeholders in the Evidence-based Practice Center (EPC) systematic review process. The feedback provided during the interviews and focus group discussion will be given in summary form to both the Agency for Healthcare Research and Quality (AHRQ) and the EPCs, who will use it to decide what changes need to be made to improve patients' involvement in systematic reviews. Since the EPCs conduct projects on an ongoing basis, you might be asked to participate on another systematic review in the future, and if that occurs, you could benefit directly from any improvements that are made to the EPC program.

Will I receive payment for participation?

You will receive a \$40 gift card after you complete the focus group discussion.

How will my personal information be protected?

Numerous steps will be taken to protect your personal information:

- (1) Your name and contact information will be stored on a secure server at University of Connecticut and not shared with anyone outside of the project team. This information will be stored in a separate file from the responses that you provide during the project.
- (2) All audio recordings, transcripts, and background questionnaire responses will be stored on a secure server at University of Connecticut. Access to this information will be limited to project staff.
- (3) We will not use your name during the interview or the focus group discussion, and we will not reveal what you say to anyone outside of the project team, including the EPCs. All responses will be provided in summary form and will not indicate who said what.
- (4) Any personal information that is revealed by you during the interview or focus group discussion will be removed from the transcript prior to analysis. The audio recordings will be deleted once the transcripts have been completed.
- (5) All group participants will be asked to maintain the confidentiality of the group members.
- (6) All group participants will be given the opportunity to review and comment on the draft summary report prior to it being distributed to the AHRQ and the EPCs.

We will do our best to protect the confidentiality of the information we gather from you, but we cannot guarantee 100% confidentiality.

Can I stop being in the project, and what are my rights?

Participation in this project is voluntary, and you do not have to be a part of this project if you do not want to be. If you agree to be in the project, but later change your mind, you may drop out at any time. There are no penalties or consequences of any kind if you decide that you do not want to participate; it will not affect your medical care, your relationships with your health care staff, or your opportunity to participate again in an EPC systematic review. In addition, you are free to skip any questions that you do not wish to answer, for any reason.

Whom do I contact if I have questions about the project?

Take as long as you like before you make a decision about whether to participate. We will be happy to answer any questions you have about this project. If you have further questions or concerns about this project, you may contact Debbie Cornman at 860-208-3035 or at deborah.cornman@uconn.edu.

Appendix C. Key Informant Background Questionnaire

BACKGROUND QUESTIONNAIRE FOR EPC PATIENT ENGAGEMENT PROJECT

1. What is your age in years? _____ years
2. What is your gender?
_____ Female _____ Male
3. What is your race? (*Tick all that apply.*)
_____ American Indian or Alaska Native _____ Native Hawaiian or Other Pacific Islander
_____ Asian _____ White
_____ Black or African American _____ Other (please specify) _____
4. What is your ethnicity?
_____ Hispanic or Latino _____ Not Hispanic or Latino
5. How many times have you participated in an interview or discussion with the Agency for Healthcare Research and Quality (AHRQ) Evidence-based Practice Center program? _____
6. How were you initially contacted about participating in a project?
_____ Through my doctor's office
_____ From a patient organization, medical organization, or support group
_____ Other (please specify) _____
7. Please indicate which Evidence-based Practice Centers you have worked with on projects. (*Tick all that apply.*)
_____ Brown University
_____ Duke Medicine
_____ ECRI Institute - Penn Medicine
_____ Johns Hopkins University
_____ Kaiser Permanente Research Affiliates
_____ Mayo Clinic
_____ Minnesota Evidence-based Practice Center
_____ Pacific Northwest Evidence-based Practice Center - Oregon Health & Science University
_____ RTI International - University of North Carolina at Chapel Hill
_____ Southern California Evidence-based Practice Center - RAND Corporation
_____ University of Alberta
_____ University of Connecticut
_____ Vanderbilt University
8. To the best of your recollection, when did you last participate in an Evidence-based Practice Center project?
(*You can put the month and year or just the year if you cannot recall the month.*) _____

9. Please list the health topic or topics (e.g., appendicitis, colorectal cancer, celiac disease, diabetes, insomnia, sleep apnea, etc.) that you discussed as part of the Evidence-based Practice Centers program?

Thank you!

Appendix D. KI Individual Interview and Focus Group Discussion Protocols

Protocols for Patient Key Informant Interviews and Focus Group Discussion

ONE-ON-ONE INTERVIEW PROTOCOL

INTRODUCE PROJECT AND GET CONSENT:

- I want to thank you for agreeing to speak with us today. My name is Debbie Cornman, and I am a Clinical Psychologist at the University of Connecticut.
- Michael White from the University of Connecticut Evidence-based Practice Center is also on this call. *[Allow Michael White to introduce himself.]*
- I will be conducting the interview with you. Michael will mainly listen and take notes, but he will be given the opportunity to provide some information and ask some follow-up questions at various points.
- The recording has not yet started. I will turn it on once I have finished describing the project and you agree to continue.
- You have been invited to participate in today's interview because you previously provided input to at least one of the Evidence-based Practice Centers *[specify the EPC]* on one or more health topics *[specify the health topic(s)]*.
- The University of Connecticut Evidence-based Practice Center is working with the Agency for Healthcare Research and Quality to better understand what that experience was like for you and what can be done to improve it.
- Since patients are the central focus of the health care system, to truly understand the most important aspects for the diagnosis and treatment of diseases, patients have to be at the table helping to shape research.
- We want to understand how can we best incorporate your and other *[patients'/patient advocates'/parents']* feedback and experiences into the Agency for Healthcare Research and Quality systematic reviews.
- We want to understand your own experience with the AHRQ Evidence-based Practice Centers program, and your thoughts on what has and has not worked.
- You and other *[patients/patient advocates/parents of patients]* bring important expertise to the program, and we want to ensure that we are making the best use of that expertise and that *[patients/patient advocates/parents of patients]* are truly given the opportunity to contribute meaningfully to the program.
- Therefore, it is extremely important that you be as honest as possible with us about what you feel worked well and what did not, and how we can improve the process.
- There are no right or wrong answers to the questions that we will ask you today.
- Different Evidence-based Practice Centers have involved patients and patient advocates in different ways in systematic reviews, and we want to learn about the various approaches that Centers have used and the advantages and disadvantages of those approaches. So we are speaking individually with up to 9 patients, patient advocates, and parents of patients who have worked with Evidence-

based Practice Centers around the country to learn about each person's experience participating in a systematic review.

- After we conduct individual interviews with each of the participants, we will bring all of you together to have a focus group discussion about what we learned during the interviews and talk in greater detail about suggestions for improvements to the AHRQ Evidence-based Practice Centers program.
- The day and time for that group discussion will be determined after all of the interviews have been completed.
- It is important for you to know that your interview today and the subsequent focus group discussion will be audio recorded so that we can review them at a later time. The audio recordings help ensure that we do not miss anything that you and others say.
- The audio recordings will be transcribed and then erased. All names will be removed from the transcripts so that no one can be identified.
- The only people who will have access to the transcripts are those conducting today's interview. The audio recordings (until they are erased) and the transcripts will be saved on a secure server at University of Connecticut.
- Everything that is said here today and in the focus group discussion will be kept confidential. All information from the individual interviews and the focus group discussion will be provided in summary form to AHRQ (Agency for Healthcare Research and Quality) and the Evidence-based Practice Centers (EPCs), and the summary will not indicate who said what. You and the other individuals who participate in this project will be given the opportunity to review and comment on the summary report prior to it being distributed.
- Please know that you are free to withdraw from the interview and the focus group discussion at any time without any consequences to you, including your medical care.
- You will see that we have provided you with a brief background questionnaire. We are collecting this information so that we can summarize the range of people who participate in this project. We ask that you NOT put your name on it so that we can maintain your confidentiality.
- Please know that you do not have to answer any questions on the questionnaire or during the interview or focus group discussion that make you feel uncomfortable.
- All of the information that I have presented to you is on the Information Sheet that we have provided to you. Please read it over, if you have not already done so.
- Do you have any questions about the interview or the focus group discussion or your participation in this project?
- Please take as long as you need before you make a decision about whether to participate.

CONDUCT INTERVIEW:

We would like to understand your involvement in the Evidence-based Practice Centers program, from recruitment through completion. If you could briefly walk us through that experience, it would be very helpful. First, we will talk about the process and then about what worked and did not work with respect to that process.

1. Let's start with how you first got involved with [*specify EPC project KI was involved in*]. How did you first learn about the project? Who told you about it?
2. How clearly was the purpose of the project explained to you?
3. What was the reason that you agreed to participate in the discussion about [*specify health topic focused on in KI's group stakeholder discussion*]?
4. What happened after you agreed to participate?
5. What information, if any, were you given prior to the call to help you prepare?
6. How prepared did you feel for the discussion?
7. When the discussion occurred, was it a group discussion or were you the only person along with the discussion leader?
8. If it was a group discussion: What types of individuals participated in the group? Was it entirely [*patients and patient advocates/parents of patients*], or were there other people involved in the discussion as well, such as doctors and researchers?
9. What happened during the discussion? How much input did you have the opportunity to provide?
10. How comfortable did you feel talking openly and honestly during the discussion?
11. To what extent did you feel that your input was heard and mattered to those in the group?
12. What, if anything, surprised you about the discussion? Was there anything that happened during the discussion that you did not expect?
13. What, if anything, happened after the phone call discussion? Was there any follow-up?
 - a. Were you notified when the draft report was released?
 - b. Were you asked to review the draft report?
 - c. Were you told how your feedback was used in the report?
14. Did you review the draft report, and if so, what was that process like?

[Allow Michael White to provide information on the purpose of EPC systematic reviews and group stakeholder discussions.]

Let's talk now about what worked well and what recommendations you have for changes to the Evidence-based Practice Centers program.

15. Thinking about when you were first contacted about the project, what recommendations, if any, do you have for providing [*patients and patient advocates/parents of patients*] with a clearer understanding of the purpose of a project?
16. What, if anything, could have helped you feel more prepared for the phone discussion?
 - a. Was there particular information that you would have liked to have received prior to the call?
17. What recommendations, if any, do you have for making the phone call discussion more useful to the participants and to the program as a whole?
 - a. What could the person leading the discussion have done differently to improve the discussion?
18. What suggestions, if any, do you have for follow-up after the phone discussion?

19. How could Evidence-Based Practice Centers make better use of [*patients'/patient advocates'/parents'*] expertise and experiences? What suggestions do you have for how to best incorporate [*patients'/patient advocates'/parents'*] feedback?
20. How representative do you think you are of [*patients/parents of patients*] with [*specify health topic*]? How similar do you think your experiences with [*specify health topic*] are to other [*patients'/patient advocates'/parents'*] experiences?
21. How likely would you be to participate in a similar type of project in the future? And why?

Ask Michael White if he has any other questions for the participant.

Ask the participant if s/he has any questions for the project team.

Thank you for participating in this interview. We truly do appreciate your honesty and your willingness to help us improve the process. Your feedback and the feedback from the other [*patients/patient advocates/parents*] being interviewed will be used to inform what we talk about in the focus group discussion. It is very important that we come out of the individual interviews and the focus group discussion with specific recommendations for the Evidence-based Practice Centers and AHRQ about how to make the systematic review process work as effectively and efficiently as possible. We hope you will join us and be an active participant on that call as well.

FOCUS GROUP DISCUSSION PROTOCOL

EXPLAIN FORMAT AND EXPECTATIONS FOR GROUP DISCUSSION:

Welcome to our group discussion. In case you do not remember, my name is Debbie Cornman, and Michael White is also on the call. We have spoken with each of you individually to get a better understanding of the particular Evidence-based Practice Center project in which you were involved, the process that you went through, and the strengths and weaknesses of that process. Based on those individual discussions, we understand that there was a range of approaches used by the various Evidence-based Practice Centers and that some approaches may have worked better than others. Today we will review what we learned about your experiences in systematic reviews and discuss the suggestions that all of you made for how to improve this program. Ideally, we would like to come up with specific recommendations that we can make to AHRQ and the Evidence-Based Practice Centers about what can be done to better involve patients, patient advocates, and caregivers in systematic reviews.

Your input is very important to us, so we would like to hear from all of you during the discussion today. We would appreciate it if you would give everyone a chance to speak. Also, because it is a bit more challenging to do this over the phone, it would be greatly appreciated if you would talk one at a time and try not to talk over one another.

Just as in the individual discussions, there are no right or wrong answers here. Our goal today is to come up with recommendations for how to better involve patients and patient advocates in systematic reviews that are conducted by Evidence-based Practice Centers. We do not expect everyone to agree with one another, but we do ask you to respect each other's experiences and opinions. We want to have as honest and frank a discussion as possible. There is a lot of wisdom in this group, and we can learn a lot from one another.

This is a confidential group, so whatever is talked about here must stay here. It is important that you understand that whatever we talk about today will not be revealed to anyone other than our project staff. Any information provided to others will be provided in summary form, and they will not be told who said what. It is important that all of you also maintain the confidentiality of this group.

Even though we are asking everyone here to maintain one another's confidentiality, we cannot guarantee that your name and comments made by you will not be revealed outside of this group by one or more of the other group members. Please keep this in mind when participating in this group discussion.

The group discussion will be audio recorded so that we can review it at a later time. The audio recording will be transcribed and then deleted. All names will be removed from the transcript so that you cannot be identified. All information from this group discussion will be provided in summary form, and it will not indicate who said what.

Please feel free not to answer any questions that make you feel uncomfortable. And you are free to leave the group discussion at any time for any reason.

Do you have any questions about the group discussion before we get started?

LEAD GROUP DISCUSSION:

1. Prior to today's discussion, we sent out a summary of the key issues that came out of the individual interviews with the 6 of you. How many of you got a chance to read the summary, and what were your reactions to it?

2. Some of you indicated that you had a clear understanding of your role as a patient Key Informant and others of you were confused about it. What should Evidence-based Practice Centers do to ensure that patients and patient advocates fully understand their role before participating in a group stakeholder discussion?
 - a. Some of the recommendations provided by you during the individual interviews include the following: *[summary of recommendations from individual interviews]*. Which of those recommendations do you agree with and why?
3. Let's talk now about preparation for a group stakeholder discussion. Some of you said that the Evidence-based Practice Center did a very good job of preparing you for the call, and others of you said that it was insufficient. What do you recommend as the best way for Evidence-based Practice Centers to prepare patients and patient advocates for a group stakeholder discussion?
 - a. Some of the recommendations provided by you during the individual interviews include the following: *[summary of recommendations from individual interviews]*. Which of those recommendations do you agree with and why?
 - b. What do patient/patient advocates need to be told ahead of time about the group stakeholder discussion so that they are able to fully participate in it? What type of information would be helpful to have prior to the call (e.g., goals of AHRQ and EPCs, background information on KIs participating in the group stakeholder discussion, Key Questions to be answered during the discussion, timeline of entire process)?
 - c. In what form should information be provided (e.g., electronic, hard copy, verbal), and how much information is too much information?
4. What recommendations do you have for Evidence-based Practice Centers, and group facilitators in particular, to ensure that patient/patient advocates have the opportunity to provide feedback during the group stakeholder discussion? What is helpful and what is not helpful for engaging patients/patient advocates in the discussion? What could they do to help patients/patient advocates feel more comfortable about participating openly and honestly in the discussion?
 - a. Some of the recommendations provided by you during the individual interviews include the following: *[summary of recommendations from individual interviews]*. Which of those recommendations do you agree with and why?
5. Two of you participated in a one-on-one interview with an EPC staff member. All but one of you participated in a group stakeholder discussion that included clinicians and researchers. Only one of you had another patient in your group. For the rest of you, you were the only patient/patient advocate in the group. What do you think is the most effective way to involve patients and patient advocates and get their honest input?
 - a. What are the relative advantages and disadvantages of the different formats?
6. When asked about what type of follow-up occurred with you after the group stakeholder discussion, some of you said that there was ongoing follow-up by the EPC, and others of you said that you never heard from them again after the group discussion. How important is it to keep patients and patient advocates informed of progress on the project?
7. What recommendations do you have for follow-up after the group stakeholder discussion?

- a. Some of the recommendations provided by you during the individual interviews about follow-up include the following: *[summary of recommendations from individual interviews]*. Which of those recommendations do you agree with and why?
 - b. What do you think about the following forms of follow-up: (1) providing patients with a summary of the discussion so that they can assess whether their comments were accurately represented by the discussion leader, (2) notifying patients when the draft report has been completed so that they can review it, if they so choose?
8. When we asked you about whether you would agree to participate in a similar project in the future, all of you said that you would even though some of you were frustrated with how the process was conducted. What could the Evidence-based Practice Centers or AHRQ do to make it more likely that patients and patient advocates would participate in EPC systematic reviews?
 9. Looking at the entire systematic review process from beginning to end, what additional recommendations do you have for the Evidence-based Practice Centers and AHRQ to make the process more effective and user-friendly, particularly for patients and patient advocates?

Ask the participants if they have any questions for the UConn EPC project team or anything else they would like to share.

Thank you so much for participating in this project. We will be compiling all of the feedback that you provided during the individual interviews and the focus group discussion into a summary report that will be distributed to the Evidence-based Practice Centers and AHRQ so that they can better understand what they are doing well and what they need to improve upon. Before sending it to them, however, we would like to give you the opportunity to review the report and provide feedback on it.

We want to thank you for being so generous with your time and effort. The information that you provided to us is extremely important and valuable, and I have no doubt that it will be used to make the Evidence-based Practice Centers program as effective and useful as possible.