How To Get Involved in the Effective Health Care (EHC) Program:

A Concise Guide for Stakeholders

Effective Health Care Program

Contents

May 2013

About This Guide

The Agency for Healthcare Research and Quality (AHRQ) has designed this Guide to encourage patients, researchers, clinicians, and others to become involved in its Effective Health Care (EHC) Program. The Guide highlights opportunities to take part in the program and describes what to expect throughout the process.

What Is the Effective Health Care Program?

Effective Health Care Program Background

The extraordinary pace of medical innovation over the past few decades has created unprecedented opportunities to improve health care and health outcomes. To best realize these opportunities, everyone involved in the health system—from patients to clinicians to policy makers—must have accurate, reliable, and actionable information to help guide and inform their health care choices.

To support this goal, the Agency for Healthcare Research and Quality (AHRQ) launched the Effective Health Care (EHC) Program in 2005, to increase the value of the health care Americans receive and, ultimately, to improve health outcomes. The EHC Program is the Nation's first coordinated program of "comparative effectiveness" research, research that compares the benefits and risks of various approaches to health care. Comparative effectiveness research investigates different drugs, devices, surgeries, and health care delivery arrangements to determine which approaches work best, for which patients, and under what circumstances.

EHC Program research includes reviews of published evidence, analysis of data to address new questions, and the design and conduct of studies comparing health care interventions or modes of service delivery. The EHC Program then translates research findings into practical materials for patients, clinicians, and policy makers. AHRQ works with a range of partners to implement EHC Program efforts (see appendix A for a list of key partners and roles).

Effective Health Care Program Priorities

The EHC Program is guided by a set of priorities that help ensure that research efforts address the greatest needs and are designed to have the greatest impact. The program places a special focus on research that relates to health care products or services that

(1)   Impose high costs on Medicare, Medicaid, or the Children's Health Insurance Program (CHIP)
(2)   May be over- or underutilized
(3)   May significantly improve the prevention, treatment, or cure of diseases and conditions that impose high costs on patients or society
(4)   Address conditions that place a great burden on at-risk populations, including low-income and minority groups, women, children, the elderly, people with disabilities, those in need of chronic or end-of-life care, or those living in inner-city or rural areas

In addition, priority is given to research on certain medical conditions. The current priority medical conditions are

- Arthritis and nontraumatic joint disorders
- Cancer
- Cardiovascular disease, including stroke and hypertension
- Dementia and Alzheimer's disease
- Depression and other mental health disorders
- Developmental delays, attention deficit hyperactivity disorder (ADHD), and autism
- Diabetes mellitus
- Functional limitations and disability
- Infectious diseases, including HIV/AIDS
- Obesity
- Peptic ulcer disease and dyspepsia
- Pregnancy, including preterm birth
- Pulmonary disease/asthma
- Substance abuse

Involving Stakeholders

Stakeholders are people or groups—each with a unique perspective—who have an interest in health care decisions. The EHC Program seeks the involvement of a wide range of stakeholders throughout the research process. AHRQ firmly believes that involving stakeholders from the beginning improves research results, and helps ensure that findings are relevant to users' distinct concerns and have applications in real-world situations.

Who Are the EHC Program Stakeholders?

EHC Program stakeholders include

- Consumers, patients, caregivers, and patient advocacy organizations
- Clinicians and their professional associations
- Health care institutions, such as hospital systems and medical clinics, and their associations
- Health care policy makers at the Federal, State, and local levels
- Health care researchers and research institutions
- Health care industry representatives
- Purchasers and payers, such as employers and public and private insurers

How Can You Get Involved?

As stakeholders, you can contribute to the EHC Program in a variety of ways. As discussed in this Guide, opportunities include

- Suggesting a research topic
- Providing insights on research priorities
- Refining the research topic and develop key questions
- Helping develop a research approach
- Reviewing draft research findings
- Shaping and informing research products and tools
- Distributing research products and lead in implementation

Not all types of stakeholders are involved in all stages of the EHC Program research; instead, the program calls on stakeholders where they can have the most impact. Some are invited to take part, and others volunteer.

How To Use This Guide

This Guide is intended for all stakeholders. You can use it to help find out more about ways you can contribute to EHC Program research and what to expect. Throughout the Guide, we use examples drawn from one EHC Program activity, a diabetes medication review, to illustrate how stakeholders can contribute at different stages of EHC Program research. In the case of the diabetes medication review, stakeholder input shaped the final research reports and tools, which are now available to inform patients, providers, and others about diabetes care.

Effective Health Care Program: Stakeholder Roles

Suggest a Research Topic Identify real-world questions for health and health care decisions	**Provide Insight on Research Priorities** Provide input to develop and prioritize research gaps	**Refine Research Topics and Develop Key Questions** Ensure key questions accurately describe decisional dilemmas
Help Develop a Research Approach Provide input on methods, clinical relevance, and appropriate outcomes to assess	**Review Draft Research Findings** Provide input to improve quality and responsiveness of research reports	**Shape and Inform Research Products and Tools** Help craft meaningful messages
Distribute Research Reports and Products and Lead in Implementation Share information with others; take the lead in using evidence to inform health care practices		

Suggest a Research Topic

The EHC Program regularly seeks ideas for research and accepts topic suggestions from any individual or organization. Stakeholders can send their ideas directly to AHRQ, or they may be invited to take part in a group discussion.

Topic suggestions can be submitted via

- Web site: http://www.effectivehealthcare.ahrq.gov/index.cfm/submit-a-suggestion-for-research/ (click the "Submit a Suggestion for Research" link)
- Mail: Complete and email or mail the form available from the EHC Program at http://www.effectivehealthcare.ahrq.gov/index.cfm/submit-a-suggestion-for-research/
- In-person meetings: by invitation to join discussion groups to provide insights and help identify research topics

Along with the topic suggestion, you will be asked to provide related background information, including

- Related health care condition
- The specific intervention or service involved
- How you expect this research to affect health care
- Patient population affected by the issue
- Any supporting documentation

> **What are the best oral medicines to treat for type 2 diabetes?**
> —*Topic submitted by the American College of Physicians, a professional association representing 132,000 medical practitioners across the Nation*

Providing more information at the start facilitates the process of selecting research topics. Once a topic has been submitted, the decision process typically takes 3 to 4 months.

After suggesting a topic, you may be asked to

- Answer questions or further clarify the suggestion, if necessary.
- Consider serving in other stakeholder roles if the topic goes forward for research.
- Take part in a group discussion that further explores the research necessary for a particular condition. These discussion meetings often take place in person; past meetings of this type have included Issues Exploration Forums, and Disease Consortia.

Provide Insight on Research Priorities

To make the best use of limited research funds, the EHC Program needs to focus on the highest priority research areas. Thus, the program may invite stakeholders to participate in conference calls or in-person meetings, to discuss priorities for research topics.

To hear about these opportunities and other activities of the EHC Program, sign up for e-mail updates at http://www.effectivehealthcare.ahrq.gov/index.cfm/contact-the-effective-health-care-program/.

Refine Research Topics and Develop Key Questions

If the EHC Program selects a topic, it will move forward with topic refinement, to clarify the scope of the topic and define specific research questions. The program may invite the person who suggested the topic to play a part.

> **I believe that patients are a really important voice and they have viewpoints that are not necessarily easy to see from a clinical standpoint. It's important to get these views captured at the very beginning of the development process.**
> —*Georgiana Bell, Executive Director, Restless Legs Foundation*

- **Key Informant Calls and Multistakeholder Meetings** Stakeholders may be invited to serve as key informants to help narrow the scope of a research topic and establish specific research questions that accurately describe

decisional dilemmas. One or several key informant calls or multistakeholder meetings may be used to gather this input.

- **Public Comment on Key Questions**
  After draft key questions are developed, they are posted on the EHC Program Web site for public comment. During the public comment period, you may submit comments and/or encourage others to do so. Anyone who wishes to comment on the key questions should expect to

  – Post their comments on the Web site,
    at http://www.effectivehealthcare.ahrq.gov/index.cfm/research-available-for-comment/
  – Share their names and contact information with the EHC Program for potential consultation on future work (users may opt out of this if they wish)

To receive an e-mail alert when Key Questions are posted, you can sign up at http://www.effectivehealthcare.ahrq.gov/index.cfm/join-the-email-list1/.

Help Develop the Research Approach

The type of research the EHC Program conducts will vary according to the topic and how much information is currently available. Research may include a systematic review of the scientific literature (Research Review) or the development of new research (Original Research). In general, the Research Review process can take as long as 12 months, during which time researchers thoroughly and methodically examine scientific literature, analyze the quality of existing studies and data, and review other information. Original Research may take several years, to allow for protocol development, monitoring, and evaluation of the research.

The EHC Program contacts a group of stakeholders to provide input into research that it undertakes.

- **Expert Input via Technical Expert Panels**
  Stakeholders serving on Technical Expert Panels help focus the research protocol. For a Research Review, this might include helping to focus the literature search, identifying criteria, or assisting in the evaluation of available evidence. For Original Research, stakeholders might advise on the treatment options to evaluate, the study populations to include, and the outcomes to assess.

  Technical Expert Panels are made up of researchers, clinical experts, statisticians, and specialists who can help ensure the methodological rigor of the research report. Patients, consumers, and caregivers also serve on Technical Expert Panels, to provide their first-hand expertise in a condition or treatment.

Technical Experts should expect to

– Submit a "Disclosure of Interest" form.
– Submit a brief description of their experience with the topic.
– Participate in at least one phone call, possibly several. Typically, each call lasts 1 hour and uses a toll-free number. These sessions may also take place in in-person meetings instead of calls.
– Be available to answer questions if the research team requires additional information.
– Share their names and contact information with the EHC Program for potential consultation on future work (users may opt out of this if they wish).

Aside from those invited to attend Technical Expert meetings, there is limited opportunity for communication with the institution conducting the research.

Review Draft Research Findings

The EHC Program presents its research results in a report. Once the report becomes available, there are further opportunities for stakeholder input, including

> **A patient advocacy organization evaluates the draft research report to see if it is relevant to the concerns of patients.**
>
> —*Technical Expert contribution from the American Diabetes Association (ADA), a patient advocacy organization*

- **Public Comment on Research Reports**
  Once the EHC Program develops a draft report, the EHC Program Web site posts it for public comment. During the public comment period, you may submit comments and/or encourage others to do so.

  Stakeholders who wish to comment on the Research Report should expect to

  – Post their comments through the Web site, at http://www.effectivehealthcare.ahrq.gov/index.cfm/research-available-for-comment/
  – Share their names and contact information with the EHC Program for potential consultation on future work (users may opt out of this if they wish)
  – Share their names in the disposition of comments that the EHC Program posts on the Web site

  To receive an e-mail alert when materials are posted, you can sign up at http://www.effectivehealthcare.ahrq.gov/index.cfm/join-the-email-list1/.

- **Peer Review of Research Reports**
  Research reports undergo a peer review process to ensure scientific integrity and quality. During this process, the EHC Program solicits and reviews comments and makes

modifications to the final report, as appropriate. The EHC Program identifies peer reviewers for specific topics. Organizations such as professional societies are encouraged to suggest experts to participate in peer review. You can suggest peer reviewers by contacting EffectiveHealthCare@ahrq.hhs.gov.

Peer reviewers should expect to

– Complete their reviews of the draft research by the specified deadline
– Share their names and contact information with the EHC Program for potential consultation on future work (users may opt out of this if they wish)

> **Being involved in the process of selecting the topics to be reviewed, you can select those that are the most important for family medicine. We know the process that's used is very scientifically sound, and we trust the work that comes out of AHRQ and the EHC program.**
>
> *—Bellinda Schoof, Scientific Affairs Manager, American Academy of Family Physicians*

Once public and peer review comments have been received, the final report is prepared and posted on the EHC Program Web site at http://www.effectivehealthcare.ahrq.gov/. A notice of availability is also sent to those who have signed up through the AHRQ listserv to receive announcements.

To receive an e-mail alert when materials are posted, sign up at http://www.effectivehealthcare.ahrq.gov/index.cfm/join-the-email-list1/.

To support AHRQ's commitment to the transparency of its review processes, the following are posted on the EHC Program Web site within 3 months after posting of a final report: (1) all comments received from the public and (2) all responses by the authors of a draft report to the public comments (i.e., the disposition of comments).

Shape and Inform Research Products and Tools

After the final Research Report is complete, the EHC Program often—although not always—generates research summaries and other resources (called research products) based on the report. The program designs these materials to serve as practical decisionmaking tools, to help guide patients, clinicians, and policy makers as they navigate health care decisions on specific topics. Research products may include the following:

• Summaries of the research for patients and consumers, clinicians, and policy makers
• Interactive case studies
• Continuing education modules for clinicians
• Web content
• Patient decision aids

AHRQ enlists stakeholders to review research products and tools, to ensure that these EHC Program materials effectively address their information needs. Input from stakeholders is critical to the creation of these research products. There are several ways in which the EHC Program solicits feedback from key audiences. These include

- **Audience Insights To Inform Materials Development**
  The development of materials often starts with information from the intended audience. The EHC Program may invite patients, clinicians, and policy makers to participate in interviews or group discussions about experiences with a specific health condition and about the way they make decisions about treatments for the condition. In this role, stakeholders should expect to

  – Participate in a 30- to 45-minute conversation, either in person or over the telephone and either alone or with other stakeholders. The program records and transcribes this conversation, but does not include individual reviewer names in the transcript or report them.
  – Prior to the session, provide informed consent for participation.
  – Discuss their own health and medical experiences, their values and preferences, and their approach to collecting information about health care conditions.
  – Discuss the challenges that they have encountered in making decisions for the condition being studied.
  – Receive compensation for their time spent in conversation.

> **I like the charts that list the benefits and side effects of the different medicines, but it would be helpful to highlight the brand name of the drug somehow and not just the generic medication name.**
>
> *—Audience review feedback shared by a diabetes patient that resulted in a design change to the consumer guide*

- **Technical Review**
  The purpose of technical reviews is to ensure the scientific accuracy of the materials and to confirm the usefulness of the content. Typically, AHRQ and its partners invite individuals to review and provide feedback on draft products. Reviewers include those involved throughout the research process, as well as those who have not been involved and can provide a fresh perspective.

  Product reviewers should expect to

  – Receive information products and decision tools by mail or electronic delivery for review
  – Review products using a set of instructions and a formal review form
  – Complete reviews according to the timeline provided and follow a specified return path for submitting comments
  – Receive compensation for time spent reviewing

Reviewers' feedback helps the program revise and improve the content and/or graphics of the materials.

> **I think it's important that there is readily available, clear information about important health topics for people who need to use it. I just try to help make the summaries more understandable by someone who does not have a medical background.**
>
> *— Sally Hurme, Project Advisor, AARP*

- **Stakeholder Feedback on Products**

The EHC Program invites potential users of the products to provide feedback on the ease of comprehension, usefulness, and actionability of draft research products. Stakeholder feedback helps the program revise and improve the content and/or graphics of the materials. The EHC Program may request several "rounds" of feedback, to confirm that changes are leading to a more understandable and useful information product or decision tool. Interviews generally last from 60 to 90 minutes.

Stakeholders involved in testing products should expect to

- Receive samples of a draft research product, either in print or electronic form
- Attend a feedback session by phone or in person, during which the EHC Program will observe the stakeholders' interaction with the research product
- Prior to the session, provide informed consent for their participation
- Answer specific questions about interaction with the products
- Provide honest feedback and suggestions for making the products more understandable or useful
- Receive compensation for time spent in conversation
- Share the name of the stakeholder organization and contact information with the EHC Program for potential consultation on future work (users may opt out of this if they wish)

After the EHC Program incorporates feedback from all audience and technical reviews, the research products are made available online at the EHC Program Web site.

Distribute Research Reports and Products and Lead in Implementation

> **The American Nurses Association promoted the new diabetes clinician guide via their listserv and added a link from their Web site to the PDF.**
>
> *—Partners sharing EHC resources to help reach more providers and clinicians*

The EHC Program uses a variety of strategies to share products, including distribution of resources through consumer, patient, and professional organizations; through databases, such as the National Library of Medicine; and through electronic clinical decision support services. Stakeholders play an important role by distributing, talking about, modeling usage of, and reporting outcomes from the use of EHC Program research products and reports.

Stakeholders can get involved by

- Distributing research reports and products to their organizations' members or clients
- Sharing information about the EHC Program and its products in the organizations' newsletters or other communications
- Participating in efforts to measure the use and impact of the products, programs, or policies from EHC reports
- Linking to the EHC Program Web site and/or the EHC Program products
- Making presentations to their organizations or other audiences regarding the EHC Program or any of its products, including successes from using them

To obtain EHC Program products or tools, visit http://www.effectivehealthcare.ahrq.gov/ or call the AHRQ Publications Clearinghouse at 1–800–358–9295 to request copies.

Other Ways To Get Involved

The EHC Program also involves stakeholders outside the research process on a specific topic. For example:

- **Listening Sessions.** These sessions, conducted as the need arises, offer the chance to provide focused comments on issues important to the EHC Program, such as research topics, program structure, and scientific methods. To hear about these opportunities and other activities of the Effective Health Care Program, sign up for the EHC Program e-mail updates http://www.effectivehealthcare.ahrq.gov/index.cfm/contact-the-effective-health-care-program/
- **General Comments and Suggestions.** Stakeholders are encouraged to make suggestions and comments by sending e-mails to http://www.effectivehealthcare.ahrq.gov/index.cfm/contact-the-effective-health-care-program/
- **The AHRQ Community Forum** (http://www.effectivehealthcare.ahrq.gov/index.cfm/who-is-involved-in-the-effective-health-care-program1/ahrq-community-forum/) improves and expands public and stakeholder engagement in research supported by AHRQ's Effective Health Care Program.

- Learn more about getting involved with the EHC Program online at http://www.effectivehealthcare.ahrq.gov/tools-and-resources/how-to-get-involved-in-the-effective-health-care-program/

Appendix A

Effective Health Care Program Partners

The Effective Health Care (EHC) Program
(http://www.effectivehealthcare.ahrq.gov/index.cfm/what-is-the-effective-health-care-program1/) works with networks of researchers and clinical teams across North America, to conduct timely and relevant comparative effectiveness research. EHC Program partners include

- Individual investigators and their research groups at academic institutions and other research centers, who generate new evidence from original research
- The Evidence-based Practice Centers (EPCs) (http://www.effectivehealthcare.ahrq.gov/index.cfm/who-is-involved-in-the-effective-health-care-program1/about-evidence-based-practice-centers-epcs/), which perform indepth reviews of existing evidence
- The DEcIDE (Developing Evidence to Inform Decisions about Effectiveness) Research Network (http://www.effectivehealthcare.ahrq.gov/index.cfm/who-is-involved-in-the-effective-health-care-program1/about-the-decide-network/), which gathers new knowledge on specific treatments and health care services
- The Centers for Education & Research on Therapeutics (CERTs) (http://www.effectivehealthcare.ahrq.gov/index.cfm/who-is-involved-in-the-effective-health-care-program1/about-certs/), which conduct research and educate clinicians and consumers about drugs, biologicals, and medical devices
- The Scientific Resource Center (http://www.effectivehealthcare.ahrq.gov/index.cfm/who-is-involved-in-the-effective-health-care-program1/about-the-scientific-resource-center1/), which provides scientific support for the EHC Program
- The John M. Eisenberg Center for Clinical Decisions and Communications Science (http://www.effectivehealthcare.ahrq.gov/index.cfm/who-is-involved-in-the-effective-health-care-program1/about-the-eisenberg-center/), which organizes the research results into guides and tools that are useful to clinicians, health care policy makers, and patients

For more information about each of the EHC Program components, visit the EHC Web site at http://www.effectivehealthcare.ahrq.gov/index.cfm/who-is-involved-in-the-effective-health-care-program1/.

Appendix B

Effective Health Care Program

Suggesting a Topic for Effective Health Care Research

The Effective Health Care Program (EHC) researches available health care tests and treatments to determine whether there are significant advantages or disadvantages with different approaches. The results of this comparative effectiveness research can help people make better decisions about what health care they want to have, and can help clinicians and health care purchasers to focus on the best tests and treatments.

SEARCH FOR EXISTING EHC PRODUCTS

The process of identifying, selecting, and developing important research topics for research reviews or new research is a key aspect of the EHC program. The process is enhanced by strong involvement of stakeholders, maintaining transparency and public accountability, and striving for continuous self-evaluation and improvement. The program uses an established set of criteria to guide the process of topic selection. This form is organized by these selection criteria. (http://www.effectivehealthcare.ahrq.gov/index.cfm/search-for-guides-reviews-and-reports)

SEE HOW YOUR TOPIC WILL BE EVALUATED

We would like to understand important aspects of the health care service you are interested in, including to whom it applies, what benefits or harms are of greatest interest, and with what other health care services or tests you think it should be compared. **Your answers to these questions will help us phrase your suggestion as one or more research questions that could be answered through AHRQ EHC comparative effectiveness or effectiveness products.** (http://www.effectivehealthcare.ahrq.gov/index.cfm/submit-a-suggestion-for-research/how-are-research-topics-chosen/)

LEARN MORE ABOUT THE EHC PROGRAM

To nominate a topic for research in this program, please complete the on-line form from the EHC Program at http://www.effectivehealthcare.ahrq.gov/index.cfm/submit-a-suggestion-for-research/ and click on "submit" at the end. If you prefer to submit a paper copy, instructions are available at the same web site. If you have any supporting documents you would like to include with your nomination, you can include them (if mailing), send them as additional attachments (if e-mailing), or you can upload them while submitting the online form. All topic nominations, including those submitted on paper, will appear in the read suggested topics for research section (http://www.effectivehealthcare.ahrq.gov/index.cfm/submit-a-suggestion-for-research/read-suggested-topics-for-research/).

Thank you for participating in the program!

May 2013