ELSEVIER

Journal of Clinical Epidemiology 66 (2013) 666−674

Journal of Clinical Epidemiology

A practice-based tool for engaging stakeholders in future research: a synthesis of current practices

Jeanne-Marie Guise[a,b,c,*], Christen O'Haire[d], Melissa McPheeters[e], Carole Most[b], Lia LaBrant[f], Kathy Lee[e], Erika K. Barth Cottrell[a,b], Elaine Graham[b]

[a]*Division of Maternal Fetal Medicine, Department of Obstetrics and Gynecology, Oregon Health & Science University, Portland, OR, USA*

[b]*Department of Medical Informatics and Clinical Epidemiology, Oregon Evidence-based Practice Center, Oregon Health and Science University, Mail Code: BICC, 3181 SW Sam Jackson Park Road, Portland, OR, 97239-3098, USA*

[c]*Department of Public Health & Preventive Medicine, Oregon Health & Science University, Mail Code: CB 669, 3181 S.W. Sam Jackson Park Road, Portland, OR, 97239-3098, USA*

[d]*School of Nursing, Oregon Health & Science University, 3455 SW US Veterans Hospital Road, Portland, OR, 97239-2941, USA*

[e]*Vanderbilt Evidence-based Practice Center, Vanderbilt University, 2525 West End Avenue, Suite 600, Nashville, TN, 37203-1738, USA*

[f]*Department of Obstetrics and Gynecology, Cedars Sinai, 8700 Beverly Boulevard, Los Angeles, CA 90048, USA*

Accepted 23 December 2012; Published online 13 March 2013

Abstract

Objective: A major goal of patient-centered outcomes and comparative effectiveness research is to increase the involvement of stakeholders throughout the research process to provide relevant and immediately actionable information. In this report, we review the current practices for engaging stakeholders in prioritizing research.

Study Design and Setting: To evaluate the range of approaches to stakeholder engagement, we reviewed the relevant literature and conducted semistructured interviews with (1) leading research organizations in the United States, Canada, and the United Kingdom; and (2) eight Evidence-based Practice Centers that engage stakeholders in comparative effectiveness research.

Results: We identified 56 articles related to stakeholder engagement in research prioritization. Studies and research organizations interviewed frequently used mixed methods approaches combining in-person venues with structured ranking or voting processes such as Delphi. EPCs similarly used group web/conference calls combined with Delphi ranking or voting. Research organizations reported difficulties engaging the public and policy makers, and EPCs reported challenges engaging federal stakeholders.

Conclusion: Explicit and consistent use of terminology about stakeholders was absent. In-person techniques were useful to generate ideas and clarify issues, and quantitative methods were important in the prioritization of research. Recommendations for effective stakeholder engagement and a reporting checklist were developed from the accumulation of findings.

Keywords: Evidence-based medicine; Qualitative research; Comparative effectiveness research; Consumer participation; Delphi technique; Research design

1. Introduction

Clinicians, patients, policy makers, and other stakeholders regularly face medical decisions in complex areas that have little or no published scientific evidence [1]. To inform this process and ensure a patient-centered research agenda in the United States, national health policy and research organizations have initiated patient-centered outcomes research and comparative effectiveness research to inform and improve health care [2,3]. Consumer involvement has been shown to positively affect research by increasing its relevance to patients, families, and communities [4]. However, the best methods to engage a wide range of stakeholders in prioritizing research are largely unknown. To support a new future research needs initiative [5] by the Agency for Healthcare Research and Quality (AHRQ), we undertook a project to describe stakeholder engagement methods used by a range of academic institutions, practice-based research networks, nonprofit organizations, and other organizations devoted to health care issues on local and national levels in the United States, Canada, and Europe.

Disclaimer: The authors of this document are responsible for its content. Statements in the report should not be construed as endorsement by the Agency for Healthcare Research and Quality or the US Department of Health and Human Services.

* Corresponding author. Division of Maternal Fetal Medicine, Department of Obstetrics and Gynecology, Mail Code: L-466, 3181 SW Sam Jackson Park Road, Portland, OR 97239-3098, USA. Tel.: +503-494-2101; fax: +503-346-6815.

E-mail address: guisej@ohsu.edu (J.-M. Guise).

0895-4356/$ - see front matter
http://dx.doi.org/10.1016/j.jclinepi.2012.12.010

What is new?

- Increasing emphasis is placed on engaging stakeholders in research.
- Consistent and explicit terminology to describe stakeholders and engagement methods is essential.
- In-person techniques are useful to explain topics and to clarify and develop a deeper understanding of stakeholders' perspectives.
- Quantitative methods such as voting, survey, and Delphi technique are useful for prioritization.
- We developed a checklist of practices and reporting in stakeholder engagement to promote consistency and advance the field.

AHRQ created the Evidence-based Practice Centers (EPCs) in 1997 to conduct research reviews for the Effective Health Care Program. Housed at major universities, medical centers, and research institutions in the United States and Canada, the EPCs synthesize existing scientific literature about important health care topics and promote evidence-based practice and decision making. EPCs apply rigorous systematic review methods to produce systematic evidence reviews and comparative effectiveness reviews on medications, devices, and other health care services, with the goal of helping patients, physicians, and policy makers make better decisions about treatments. In addition to synthesizing the evidence, the reviews identify the gaps in evidence that limited the ability to answer the systematic review questions. AHRQ has worked with a formal, broad-based stakeholder group at the agency level, and stakeholder engagement is welcome throughout the phases of the EPC systematic review process (Fig. 1). In 2010, AHRQ expanded its support for EPCs to work with various stakeholders to further develop and prioritize the future research needed by decision makers. To develop guidance for this effort, AHRQ commissioned the Oregon and the Vanderbilt EPCs to conduct a collaborative multidimensional project to outline best practices for engaging stakeholders in defining and prioritizing research needs.

2. Methods

This project consisted of three complementary activities that occurred between May and September 2010, as shown in Fig. 2. We searched the published literature for methods of stakeholder engagement to set research priorities (phase I), conducted interviews with leading research organizations in the United States, Canada, and the United Kingdom known to engage stakeholders in their work (Phase II), and interviewed EPCs that engaged stakeholders for their future research pilot studies in 2010 (phase III). The project protocol was submitted to the relevant Institutional Review Boards, which determined that phases I and II did not meet the definition of human subject research per 45 Code of Federal Regulations (CFR) 46.102 and that the phase III study was exempt per 45 CFR 46.101.

2.1. Phase I: Literature summary

We searched PubMed/MEDLINE (OVID), PsychINFO (OVID), CINAHL (EBSCO), Cochrane Consumer Group, LocatorPlus (National Library of Medicine catalog), and Sociological Abstracts (Cambridge Scientific Abstracts) from inception through September 2010. Search terms included both keywords and subject headings: *consumer participation, exploded patient participation, stakeholder*, consumer*, citizen*, policy maker, policymaker*, policy makers, research, *Health Services Research, *Community-Based Participatory Research, *Comparative Effectiveness Research, exp *Biomedical Research, exp *Translational Research, priorit*, research agenda, research agendas,* and English language. We reviewed relevant literature to identify methods and processes used to engage stakeholders in identifying and prioritizing research.

2.2. Phase II: Interviews with leading research and policy making organizations

Organizations (Table 1) known to have expertise engaging a broad range of stakeholders (i.e., consumers, clinicians, and policy makers) were invited to participate in interviews between June and July 2010. Each key informant (KI) completed an ''EPC Conflict of Interest Disclosure Form'' before being interviewed and no conflicts disclosed precluded participation for any of the invited organizations. Two investigators interviewed KIs about their experiences engaging stakeholders, using a semistructured interview guide that included questions regarding experiences engaging stakeholders, the types of stakeholders engaged, the methods used to engage them, the processes used to set research priorities, and the impact of stakeholder engagement. All telephone interviews were digitally recorded and transcribed, and the transcripts were reviewed to identify and code themes. Four additional investigators who did not participate in interviews independently reviewed transcripts to identify themes. All investigators (six: two interviewers and four additional investigators) met to discuss themes and resolve discrepancies.

2.3. Phase III: EPC interviews

We evaluated EPC experiences of engaging stakeholders in two ways: (1) we reviewed EPC proposals to assess the methods proposed by EPCs to engage stakeholders in future research needs development and (2) we conducted semistructured interviews with EPC directors and staff at