

Innovative Methods in Stakeholder Engagement: An Environmental Scan

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Preface

In 2005, the Agency for Healthcare Research and Quality (AHRQ) established the Effective Health Care (EHC) Program to provide understandable and actionable information as a basis for health care decisions. Central to the program's mandate is broad and ongoing consultation with stakeholders—patients, consumers, clinicians, policymakers, researchers, and others with a role in health care decision making. Stakeholder involvement at all stages of the comparative effectiveness research process helps ensure that the EHC Program responds to relevant and important issues, that it develops products that are accessible and user-friendly, and that ultimately research reaches its intended audiences.

This review of innovative methods in stakeholder engagement is part of a set of activities funded by the American Recovery and Reinvestment Act of 2009 to broaden and improve opportunities for stakeholder input to the EHC Program. With increasing recognition of the value of public participation and of the importance of transparency in many areas of civic life, diverse organizations—in education, in environmental protection, and in health care—have developed new ways and improved existing approaches to involving their stakeholders in their work. These approaches provide the potential for many more individuals to participate in guiding the work of a given organization. In addition, they open the door for qualitatively different types of stakeholder involvement. This review is intended to identify promising approaches that have the potential to expand and enhance the roles stakeholder play in the EHC Program. At the same time, AHRQ is committed to sharing information and experience that will enhance the ability of other health care organizations to work in collaboration with patients, clinicians, and other stakeholders.

For additional information on innovative approaches for engaging stakeholders, please visit <http://www.effectivehealthcare.ahrq.gov/index.cfm/tools-and-resources/how-to-get-involved-in-the-effective-health-care-program>. Visit AHRQ's Effective Healthcare Web site homepage (<http://www.effectivehealthcare.ahrq.gov>) to join an email list to learn about new Effective Healthcare program products and opportunities for input, or to see draft comparative effectiveness research questions and reports. We welcome comments on this report. They may be sent to Joanna Siegel at Joanna.siegel@ahrq.hhs.gov, or by mail to the Effective Health Care Program, Agency for Healthcare Research and Quality, 540 Gaither Road, Rockville, MD 20850.

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Abstract

Objective. This literature review presents a summary of the state of the art in methods that organizations use to involve stakeholders – patients, consumers, practicing clinicians, payers, and others – in health care research and in activities in related fields. This research was conducted by the Community Forum, a project funded by the Agency for Healthcare Research and Quality (AHRQ), to identify emerging strategies in stakeholder engagement to enhance stakeholder involvement in the Agency’s Effective Health Care Program and other health care research activities.

Data sources. We reviewed peer-reviewed literature, grey literature, and Web sites, and conducted interviews with key informants (KIs) experienced in stakeholder engagement.

Methods. To guide our search, we developed a conceptual framework for stakeholder engagement. We used the key word search terms listed in Appendix A to search peer-reviewed literature in academic databases and grey literature and Web sites using the Internet. We applied inclusion/ exclusion criteria (Table 1) that emphasized innovation including the use of technology. We then abstracted all sources and analyzed findings. The final review included 23 peer-reviewed articles, 15 grey literature documents, and 43 Web sites (Appendix B).

Additionally, we identified 11 key informants experienced in stakeholder engagement within and outside of health care. We used a semi-structured interview protocol designed to elicit information on innovations in stakeholder engagement. The KIs provided information on many of the methods described in this report, and suggested additional organizations and Web sites to explore in the concurrent literature scan.

Results. Based on the literature review, we describe types of organizations that work with stakeholders, the specific groups (eg., local residents, advocacy groups, or professional societies) that organizations identify as stakeholders, organizations’ motivations for involving stakeholders, points in the research process where stakeholders can contribute, how organizations prepare stakeholders to meaningfully participate, and stakeholders’ motivations for participating in research projects. We found very little that described the evaluation of stakeholder engagement processes or outcomes related to stakeholder engagement activities. A recurring theme in the literature was the importance of building trust, both for encouraging stakeholders to become involved and in maintaining their involvement.

We identified a number of uses for technology in working with stakeholders throughout the research process. Many organizations use their Web pages to post available research projects and recruit for research participants or use online matching services for available projects and participants. Online collaborative platforms are used to generate ideas, promote discussion about these ideas in an online forum, and then to rank or vote on the ideas. Online communities are used to recruit participants for idea generation, to elicit feedback on product development, and to disseminate research findings. Product development challenges – contests where organizations challenge their members or the public to submit ideas for or create a product – are used to recruit new members, increase awareness of the organization issuing the challenge, and provide insight on stakeholder preferences and needs.

Key informants (KIs) described examples of their stakeholders, definitions of innovation, examples of practices they have used and consider innovative, how they currently use technology, and challenges to engaging stakeholders. The KIs described a range of innovative practices, consistent with definitions of innovation that emphasized flexibility and effectiveness as well as non-traditional activities. For example a KI in health care uses blogging to translate complex material into concise and engaging articles for the organizations' stakeholders; multiple KIs mentioned using social media tools as means of eliciting input from stakeholders in prioritizing research projects and helping to design research. Overall, the key informants highlighted the importance of measures such as selecting stakeholders that recognize the issues under discussion as a priority, communicating to stakeholders the importance of their participation and the ways in which their input will be used, "tailoring the experience" to specific stakeholder populations, and appropriate approaches to presenting data. The group described use of technology in the form of social media marketing/advertising; social networking (Twitter, Facebook, blogs); and social media tools (IdeaScale, UserVoice, Salesforce).

The KIs identified challenges to engaging stakeholders that included attracting stakeholder interest in their organization, educating stakeholders concerning their organization, incorporating new technology and methods, and resource constraints on both stakeholders and organizations.

Conclusions. Based on our review, we identify five priority methods that researchers working with stakeholders may wish to consider to enhance the process of engaging stakeholders and stakeholders' ability to contribute meaningfully to the organization's activities. These methods are relevant for stakeholder recruitment and preparation and for stakeholder involvement in topic identification and prioritization, product development, and dissemination of research findings and products (Table 8). The five methods are:

- **Online collaborative platforms:** Computer software that enables interaction between an organization and its target audience through a Web site or virtual space. Collaborative platforms allow stakeholders to suggest, vote for, rank, or comment on ideas about a particular topic; they allow for frequent feedback by a forum facilitator and a feedback loop to keep stakeholders aware of how their input is being used.
 - **Product development challenges:** Contests in which an organization challenges its target audience to submit ideas for or to create products. Participants compete for a chance to win prizes from the host organization, while providing input on topics of interest and generating creative ideas for dissemination and implementation.
 - **Online communities:** Virtual communities where participants communicate, share ideas, and work together. Members are a subset of stakeholders that have voluntarily joined the community, making them more likely to be interested in the topic.
 - **Grassroots community organizing:** Efforts using a local, ground-up approach that can be useful for spreading awareness of and building trust in an organization, for recruitment, and for product dissemination.
 - **Collaborative research:** An approach to research that integrates stakeholders in stages in order to enhance the relevance of the work to the end users.
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1.0 Introduction

1.1 Purpose

Stakeholder involvement at all stages of the Agency for Healthcare Research and Quality (AHRQ) comparative effectiveness research process helps ensure that the Agency’s programs respond to the issues that are most pressing for health care decisionmakers and in ways that are accessible and useful. In 2009, AHRQ initiated its Community Forum project to expand and systematize the participation of the public and stakeholders in its Effective Health Care (EHC) program. As part of this effort, the Community Forum is examining new and innovative methods to engage stakeholders and assist AHRQ to incorporate promising approaches in the EHC program.

This report presents the results of a scan we undertook to identify new and emerging methods relevant to engaging patients and consumers, clinicians, and other stakeholders—i.e., others with a particular personal or professional interest—in comparative effectiveness and related health care research. We describe the methods used to review published and unpublished literature, to review Web sites, and to gather information from key informants. We then present our findings from each type of literature reviewed and from the key informant interviews. We end this report with a summary of promising methods and tools researchers may wish to consider when working with stakeholders.

2.0 Literature Review Methods

2.1 Peer-Reviewed Literature

We conducted a search of peer-reviewed literature in PubMed, ERIC, EBSCO’s Academic Search™ Premier, and socINDEX™ databases using keyword terms listed in Appendix A. We restricted searches for peer-reviewed articles to English-language items published between 2001 and 2011 for PubMed and between 2006 and 2011 for the other databases.

To limit the scope of the review to the topics of interest, we developed inclusion criteria that emphasized innovation and required materials to be quite detailed. We also developed exclusion criteria to eliminate items that were opinion pieces, as well as materials that provided justification for involving stakeholders without actually describing innovations or processes. Some of these inclusion and exclusion criteria are reflected in the search strategies, for example, excluding letters, editorials, and commentary articles. The remaining criteria were used during the review of abstracts or full text. A full description of inclusion and exclusion criteria is provided in Table 1. The search was designed to identify literature on innovations in stakeholder engagement outside as well as within the health care sector.

Table 1. Inclusion and exclusion criteria for assessing articles and materials

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"> • Applies to stakeholder engagement for our defined set of stakeholders • Provides descriptive detail on specific methods of and approaches to stakeholder engagement 	<ul style="list-style-type: none"> • Describes stakeholder input attained through methods other than stakeholder engagement (e.g., surveys) • Provides justification for stakeholder engagement but does not describe an example,

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"> • Addresses theory related to stakeholder engagement • Describes outcomes measurement for stakeholder engagement • Describes challenges, facilitators, and factors influencing participation in stakeholder engagement • Describes innovations in stakeholder engagement, including implications of technology • Seminal articles (any date) identified by literature scans or consultants 	<p>model, process, or application of theory</p> <ul style="list-style-type: none"> • Opinion or editorial pieces • Nonseminal articles published prior to 2001 • Focuses on public deliberation processes covered in recent review: Heil, S. et al., (2012). The use of deliberative methods in engaging the public in comparative effectiveness research: A review of public deliberation evidence. • Included in recent systematic review O’Haire, et al., (2010). Methods for Engaging Stakeholders to Identify and Prioritize Future Research Needs.

We identified a total of 506 articles in the database searches: 359 from PubMed, 73 from ERIC, and 74 from the EBSCO databases. Following a review for relevance, we selected 23 of these articles for full-text review.

2.2 Grey Literature and Web Sites

Given the focus on innovation, it seemed likely that many of the practices that we hoped to identify would not be the subject of articles published in peer-reviewed journals. Thus, we also conducted a search for applicable grey literature and Web sites. To find these, we polled our team members and asked key informants to suggest sites. In total, we reviewed 15 grey literature documents and 43 Web sites (see Appendix B for full listing of sources).

To collect information on key points regarding stakeholder engagement processes, evaluation and measurement, lessons learned, and the benefits and barriers of stakeholder engagement activities, we developed and tested a content abstraction template, programmed into a Microsoft Access database. We used this content abstraction template to extract information from the peer-reviewed literature, grey literature, and Web sites. We used a supplementary Microsoft Excel spreadsheet to record additional details of interest on Web sites because the Web sites, which were promotional in nature, contained a large quantity of general information and often focused on particular elements of the engagement process.

2.3 Key Informants

Interviews with key informants served as the final source of information for this review. We developed and refined a list of potential key informants, including those within and outside of the health care sector. This process identified both individuals and organizations. We asked these initial key informants to suggest additional individuals or organizations that might be valuable resources. Eleven key informants from 11 different organizations were interviewed.

We used an interview protocol to elicit information from our key informants about their experiences with innovations in stakeholder engagement. Following an institutional review board (IRB) approval of both the interview protocol and consent document, an experienced qualitative interviewer conducted a 30-minute interview with each key informant. Interview findings were then organized into themes.

3.0 Overview of the Literature and Web Sites

Our review yielded 23 peer-reviewed articles, 15 grey literature documents, and 43 Web sites related to innovative methods for engaging stakeholders (Table 2).

Table 2. Source material reviewed

Resource Type	Number Reviewed
Peer-reviewed articles	23
Grey literature	15
Web sites	43
Total	81

3.1 Purpose of Reviewed Literature and Web Sites

Most of the peer-reviewed articles and documents served multiple purposes, ranging from descriptions of conceptual frameworks to detailed presentations of stakeholder engagement activities (Table 3). Five articles described theory underlying stakeholder engagement, 4 described specific stakeholder engagement methods, and 15 described specific efforts. Nine articles described challenges faced in involving stakeholders, and 14 focused on best practices.

In addition to describing stakeholder engagement activities, Web sites recruited, prepared and/or engaged stakeholders; promoted products, tools, and techniques for engaging stakeholders; represented and advocated for stakeholders; or were communities of practice for stakeholder engagement. Some Web sites served multiple or even all of these purposes. Most Web sites were promotional in nature ($n = 33$), describing the stakeholder engagement activities of different organizations in varying detail and often directly engaging stakeholders through the site ($n = 27$). The remaining 10 Web sites described groups and initiatives that promote stakeholder engagement in research; studied and advanced stakeholder engagement methods and practice; and promoted specific products and techniques to facilitate stakeholder engagement. These Web sites had a practical rather than theoretical focus; however, two of the Web sites explicitly defined best practices in or challenges to the stakeholder engagement process.

3.2 Topics Addressed

Eighteen peer-reviewed articles and 10 grey literature documents addressed health care topics (Table 3). Others focused on education ($n = 4$), business/marketing practices ($n = 3$), the environment ($n = 2$), and general practices for public participation ($n = 1$). Eleven peer-reviewed articles described stakeholder engagement in the United States; the remaining seven focused on the United Kingdom, Canada, Western Europe, and the Middle East. Similarly, the majority of the grey literature described stakeholder engagement in the United States, with the exception of some belonging to organizations based in Australia and the United Kingdom.

Twenty-three Web sites focused on topics related to health care. Others concerned activities within the Federal Government ($n = 5$), education ($n = 4$), the environment ($n = 3$), corporate social responsibility and global citizenship ($n = 3$), products and services for stakeholder engagement ($n = 3$), community development and urban planning ($n = 2$), and a dialogue and

deliberation association (n = 1). Twenty-seven Web sites discussed stakeholder engagement by organizations, efforts, or initiatives wholly or primarily based in the United States. The remaining Web sites discussed stakeholder engagement in the United Kingdom, Canada, and Europe, or in the context of an international organization.

Table 3. Purpose, topic, and geographic focus of materials reviewed

	Peer-Reviewed	Grey Literature	Web Sites
Purpose	<ul style="list-style-type: none"> • Described specific stakeholder engagement methods • Described specific efforts • Described challenges faced in involving stakeholders • Focused on best practices 	<ul style="list-style-type: none"> • Communities of practice for stakeholder engagement • Discussed specific tools for identifying and voting on specific issues 	<ul style="list-style-type: none"> • Promotional in nature, • Described stakeholder engagement activities • Directly engaged stakeholders through the site • Described groups and initiatives that promote stakeholder engagement in research • Promoted specific products and techniques to facilitate stakeholder engagement • Defined best practices in or challenges to the stakeholder engagement process.
Topics Addressed	<ul style="list-style-type: none"> • Health care topics • Environment • Education • Business/marketing practices • General practices for public participation 	<ul style="list-style-type: none"> • Health care topics • Environment • General practices for public participation 	<ul style="list-style-type: none"> • Federal Government • Education • Environment • Corporate social responsibility and global citizenship • Products and services for stakeholder engagement • Community development and urban planning • Dialogue and deliberation association
Country/ Location	<ul style="list-style-type: none"> • United States • United Kingdom • Canada • Western Europe • Middle East 	<ul style="list-style-type: none"> • United States • Australia • United Kingdom 	<ul style="list-style-type: none"> • United States • United Kingdom

4.0 Findings

We organized our findings into the following categories: types of stakeholders and their motivation for participation, organizational characteristics and their motivation for involving stakeholders, information about preparing stakeholders to meaningfully participate, points in the

research process to optimally involve stakeholders, and outcomes of stakeholder engagement (for the participant and organization).

4.1 Types of Stakeholders and Their Motivation for Participation

The materials we reviewed most often referred to clinicians (primarily physicians) and consumers (patients, patient advocacy groups, and caregivers) as stakeholders, but also described engagement of other types of stakeholders (Table 4).

Almost half of sources reviewed described stakeholders' motivations for participation—although the majority of these descriptions reflected the authors' perspectives, not surveys of the participants themselves. These motivations included (a) stakeholders' interests were directly affected, (b) financial compensation or incentives, and (c) contributing to the common good.

Stakeholder interests. Multiple sources across the peer-reviewed literature, grey literature, and Web sites imply that stakeholders are motivated to participate in research or other activities when their interests are directly affected by those activities. Participation allows stakeholders to shape the policies that affect their lives and can strengthen service delivery. For example, community members who become involved in environmental issues are motivated “to take care of the environment and its habitats if it makes sense to them and meets their needs” (Council on Environmental Quality, 2007).

Financial compensation or incentives. Stakeholders were motivated by financial compensation in the form of honoraria, gift certificates, or payment for time or creative ideas. Kho et al. (2010) reported offering gift certificates to clinicians who completed a survey, and Culyer (2005) compensated participants for their time. Similarly, physicians who participated in market research conducted through the online community Sermo received honoraria for their input (Sermo, 2011). Challenges and contests offer a variation on the theme of financial incentives. For example, the AMA's Apportunity Knocks contest offered a \$2,500 prize to physicians, fellows, and medical students who developed the winning idea for a smartphone application to improve clinical practice (AMA, 2011).

Contributing to the common good. Stakeholder motivations included contributing to the common good and improving health outcomes for a wider population. An INVOLVE report describes motivations of consumers who participate in research from both the researcher and consumer perspective. In this instance, the motivations centered around the desire to improve specific services (e.g., adoption support services, health and social care needs, care for children with disabilities in mainstream schools, approach to teenage pregnancy prevention services) (Blackburn, Hanley, & Staley, 2010).

Table 4. Types of stakeholders in reviewed literature and Web sites

	Non–Health Care	Health Care
Consumers	<ul style="list-style-type: none"> • American people, citizens • Children and families • Communities, activists • Customers • General public • Local residents • Specific audiences (e.g., tribes) • Students and their families 	<ul style="list-style-type: none"> • Advocates and advocacy groups • Caregivers • Current and potential service users • General public • Patients • Patient families & friends
Professionals	<ul style="list-style-type: none"> • Criminal justice professionals • Education (teachers, academics) • Employees • Entertainment • Environmentalists • Human rights • Social workers • Teachers • Urban planning (planners, architects, developers) 	<ul style="list-style-type: none"> • Institutions (e.g., cancer centers) • Mental health providers • Medical students, residents & fellows • Professional societies • Providers (e.g., doctors, nurses) • Public health practitioners • Researchers (bench science, clinical public health, social sciences) • Social workers
Researchers	<ul style="list-style-type: none"> • Health care researchers 	<ul style="list-style-type: none"> • Environmental health researchers
Policymakers and Payers	<ul style="list-style-type: none"> • Employers • Government agencies and leaders (local, tribal, regional, State, Federal, and international) • Insurers 	<ul style="list-style-type: none"> • Clinical guideline developers • Employers • Funding agencies • Government • Labor unions
Industry	<ul style="list-style-type: none"> • Shareholders • Engineers • Suppliers • Corporations, businesses 	<ul style="list-style-type: none"> • Medical device manufacturers
Nongovernmental organizations (NGOs)	<ul style="list-style-type: none"> • Nonprofits and leaders • Venture philanthropists • Charities, foundations • Academia • Trade/labor unions 	

4.2 Organizational Characteristics and Motivations for Involving Stakeholders

All types of organizations engage stakeholders: private and public; for-profit and not-for-profit; large and small. Appendix B provides a brief description of organizations involved in stakeholder engagement activities from the peer-reviewed, grey literature, and Web sites.

Organizational motivations for engaging stakeholders vary (Table 5). Some Federally funded organizations are mandated to include stakeholders in their work. Private, not-for-profit organizations may engage stakeholders to ensure that research is more reflective of the needs of the users (e.g., James Lind Alliance [JLA]). Organizations that promote product development or implementation engage stakeholders to increase “buy-in” for those products or services. Along these lines, several organizations involved in research development engage stakeholders to increase the utilization of research.

Table 5. Organizations’ motivations for stakeholder engagement

Health Care Organizations
<ul style="list-style-type: none"> • Develop research that is more relevant to the public and more likely to be used • Ensure that issues that are identified and prioritized are important • Ensure that money and resources are not wasted • Ensure that outcome measures are important to the patient or end-user • Enlist people who use services to help with recruitment • Help identify and access priority populations • Help disseminate information, products, or services
Non–Health Care Organizations
<ul style="list-style-type: none"> • Signal willingness to become involved in socially responsible practices and/or those that are environmentally more satisfactory • Improve internal management practices among all parts of the company as a result of the partnership • Benefit from expertise on the issues of sustainable development Improve the company’s internal and external image • Open up to civil society • Escape or avoid crisis situations • Become a stakeholder in the community and civil society as a result of the nongovernmental organizations’ (NGO) or communities’ special understanding • Create innovation • Facilitate community development • Improve supply-chain transparency (better manage social, environmental, health, human rights, and reputation risks) • Enrich collaboration—codesign with suppliers • Strengthen attractiveness (internal and external) • Reduce ownership and creation costs in the long term • Strengthen the legitimacy of and relations with local authorities and the local community • Sustain, through social dialogue, customer service representative (CSR) action, making it more credible for external stakeholders because it is shared by all employees • Introduce new practices and themes justifying corporate performance and shareholder loyalty • SRI (socially responsible investment) corporate ratings and classifications to make CSR more tangible internally and allow further commitments to progress • Reply to specific, indepth expectations of SRI investors • Dialogue with rating agencies and the administrators of SRI asset indexes for strengthened understanding of the company’s specificities and integration in rating results

4.3 Identifying and Preparing Stakeholders to Meaningfully Participate

Adequately preparing stakeholders for their participation is essential for their meaningful involvement in the research process. It is important for stakeholders to understand the purpose of the research, their role in the process, and how their input will be used. This section presents our findings related to identifying and recruiting stakeholders, preparing them for participation in research, and providing appropriate education for active and engaged participation.

Recruitment and Connecting

Identifying the relevant stakeholders. A theme that emerged regarding the selection of stakeholders was the importance of targeting stakeholders for whom there is perceived value in the research activity. The example below describes the challenges of recruiting among stakeholder groups with varying degrees of interest in the research.

Researchers in Canada used publicly available membership lists from professional associations and organizations to identify clinicians, policymakers, and researchers/guideline developers who could potentially respond to surveys designed to improve a tool to evaluate the quality of clinical practice guidelines (Kho et al., 2010). The authors contacted these individuals directly via personalized letters, followed up with a personalized e-mail or telephone call, offered participants a \$100 gift certificate as an incentive, and sent multiple reminder notifications. Despite these efforts, clinicians and policymakers were more difficult to recruit than researchers. The authors attribute this to researchers' higher levels of awareness and interest in the study topic, and recommend a stronger emphasis on ensuring that prospective participants understand the relevance of the study to them and why their participation, in particular, is important.

Tools and methods. Our review found multiple ways to identify and recruit stakeholders, including direct methods (in-person interactions and personalized letters, emails, and phone calls) and indirect techniques (postings on Web sites, blogs, and newsletters; requests to stakeholder interest organizations; and referrals through existing stakeholders).

Initiatives directed toward broad populations (e.g., the general public) generally use multiple strategies to raise the audience's awareness of the effort and to publicize engagement opportunities. For example, the two organizations below use a variety of methods to publicize engagement opportunities and facilitate stakeholder involvement.

- The United Kingdom's National Institute for Health and Clinical Excellence (NICE) established a Patient and Public Involvement Unit (PIU) to involve consumers and caregivers in guideline development, decisionmaking, materials development, and dissemination (Kelson, 2005). Stakeholder organizations can register their interest in a particular topic and then are consulted during the guideline development process, provide comment on draft documents, submit evidence to inform documents, nominate members to committees and working groups that develop clinical guidelines, and nominate patient experts to attend meetings of committees that produce technology appraisal guidance. Opportunities for participation are communicated through the NICE Web site, patient interest groups, or the press.
 - The James Lind Alliance (JLA), a nonprofit initiative that brings patients, caregivers and clinicians together to identify and prioritize uncertainties, or "unanswered questions" about
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the effects of treatments, focuses exclusively on the priority setting process. The JLA provides information to patient and provider organizations and networks to encourage participation from their members. The JLA also makes use of targeted online message boards, magazines, and newsletters to direct patients, caregivers, and clinicians to its Web site and submit feedback regarding treatment uncertainties.

- Oxman et al. (2009) suggest (but do not describe) the following “forums for communication” for engaging consumers: one-on-one interviews, focus groups, Citizens’ Juries, town hall meetings, committee meetings, and working groups.

Technology for Recruitment. Few peer-reviewed articles specifically described the use of technology to recruit or involve stakeholders. However, use of technology as a primary component of recruitment efforts was more common in the Web sites and grey literature reviewed.

- INVOLVE’s People in Research (PIR) is an online resource that publicizes “opportunities for public involvement in clinical research.” The public (patients and consumers) can search a database of involvement opportunities, using filters to identify opportunities available remotely or suitable for individuals with little experience. The Web site also helps researchers and research organizations create advertisements describing exactly what they are looking for in a public stakeholder.
- Cancer Voices New South Wales’ (CVN’s) free online matching service connects researchers and research organizations with consumer representatives who have completed a consumer research training course. This service may eventually form the basis for an Australia-wide registry of trained cancer consumer research representatives.
- The National Charrette Institute (NCI) hosts a blog entitled the “National Charrette Institute Community Forum,” which is written and overseen by NCI staff members, to which anyone may contribute. Those interested in Charrettes can discuss personal experiences in this forum and engage in collaborative learning and problem solving.
- ChemicalRight2Know (CR2K) is a collaborative forum that facilitates access to a range of information including public data (specifically, the Environmental Protection Agency Toxics Release Inventory program data); links to research, reports, and analyses; Webinars; notices of training events; mashups (Web applications that allow sharing of detailed information about a key environmental issue); and blog posts written about relevant news items. (ChemicalRight2Know, 2011).

Building trust. A recurring theme in the literature was the important role of trust building in encouraging stakeholder involvement and ongoing engagement. While building stakeholder trust is generally recognized as a priority once stakeholders are engaged, it can also be valuable in increasing stakeholder interest in participation. Gaining the trust of potential participants and providing them with materials necessary to foster meaningful participation may be especially relevant in situations where there are differing levels of education or understanding of the research topic among stakeholder groups.

- One case study highlighting the importance of building stakeholder trust described the ways in which researchers accomplished this through individualized communication with stakeholders to listen to their concerns (e.g., time constraints), understand and respond to their changing needs, and inform them about the expected benefit of the evaluation and of the stakeholders' role within it (Taut, 2008).
- In an effort to recruit consumers at a community-based behavioral health care facility to provide feedback on research about evidence-based services for depression (Stirman et al., 2010), authors cite the importance of building trusting relationships and ensuring that all stakeholders recognize some short-term benefit to their participation. Indirect recruitment efforts, including newsletter articles and signs in waiting rooms, as well as direct outreach by clinicians to their patients, were unsuccessful. A shift to less formal, shorter term commitments (e.g., one-time discussions) increased consumer participation and frequency of interaction between researchers and consumers, which in turn led to stronger trust between consumers and researchers, as well as greater consumer awareness of the research process and its benefits.
- Journalists can be an effective conduit for reaching stakeholders and building trust (Oxman, Lewin, Lavis, & Fretheim, 2009). The media can raise public awareness and, as a result, prepare the public to be receptive to engagement opportunities. Tools to facilitate a productive role for the media include targeted training in areas such as accurate use of medical terminology, reliable sources of information, and research techniques. Other ways to assist journalists in this role include preparing (a) structured press releases (for example, summarizing policy briefs or systematic reviews); (b) fact boxes to succinctly communicate information on benefits, harms, and costs of treatment options; (c) press conferences to allow journalists to directly communicate with policymakers; (d) stories or case studies for journalists to feature in reports (for example, illustrating the use of evidence in decisionmaking); and (e) tip sheets with key research questions for journalists to use in researching, interviewing, and writing. The authors note that efforts to equip journalists with information, tools, and skills can result in higher quality health policy reporting and, consequently, a better informed public that is more interested and able to participate in health policy development and implementation.

Stakeholder Education

Several articles underscore the need for input by the organization prior to stakeholder involvement, notably, the role of informational materials as a means of preparing stakeholder participants. In general, identifying and addressing stakeholder needs for informational resources or training is vital to ensuring a stakeholder's ability to meaningfully contribute to a discussion or process. It is also important to equip individuals with information on their role in the research process and how they might be affected by the outcomes of the research.

- One article examined five case studies of projects to involve stakeholders in Comparative Effectiveness Research (CER), including ones specifically to engage stakeholders in setting research priorities and refining research questions (Hoffman, Montgomery, Aubry, & Tunis, 2010). A key principle the authors identify is the need to clearly explain stakeholder roles. In one case, a patient participating in a working group to determine priorities for methods development in CER indicated that his limited understanding of the clinical information
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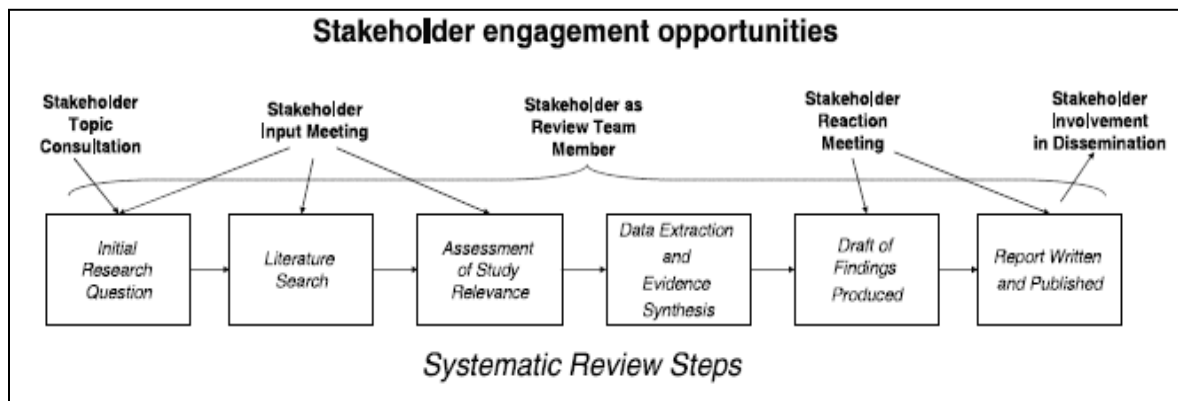
being discussed would limit his ability to participate in the conversation. In response, the convening organization prepared easy-to-understand informational materials targeting participants without clinical backgrounds and held interactive information sessions with these individuals prior to the working group meetings.

- The JLA recognizes that workshop participants may have varying degrees of familiarity with the research process when convening patients, caregivers, and clinicians to identify unanswered treatment questions. To prepare stakeholders for in-person priority-setting workshops, the JLA distributes background information, including participant biographies, explanation of technical terms, and an explanation of the decisionmaking process.
- As part of an effort to involve clinician stakeholders in providing input into research on evidence-based services for depression, researchers recognized that the clinicians’ involvement was contingent on their awareness of research gaps as well as their interest in the research (Hoffman et al., 2010). Researchers made sure the clinicians were familiar with the current body of research by incorporating presentations about research projects and findings into monthly clinical meetings, forming committees to discuss upcoming research studies at the institution, and engaging in informal conversations with clinicians.

4.4 Points of Stakeholder Engagement

The literature reflects the engagement of stakeholders at specific points in research including topic nomination, product development, and dissemination of research or findings. For example, Keown, Van, & Irvin (2008) described how Canada’s Institute for Work & Health engaged stakeholders in the systematic review process. This article indicated that stakeholders could be engaged in the points illustrated in Figure 1, below.

Figure 1. Stakeholder engagement opportunities (Keown et al., 2008)



Most health care peer-reviewed articles focused on topic nomination and prioritization, while many of the non-health care articles focused on product or program development and implementation. Among the documents and Web sites assessed, examples of idea generation were more prevalent than were formal priority-setting processes focused on topic prioritization issues.

In this section, we present findings on methods for engaging stakeholders organized around the point in the research process. We begin with a discussion of facilitating the research process, an

activity that cuts across all points of engagement. The remaining findings are organized by points of engagement: idea generation and prioritization, product development, and research dissemination. Use of technology is discussed within each of these points.

Facilitating Stakeholder Processes

Articles noted the key role of experienced and impartial facilitators in situations where different types of stakeholders are expected to participate in a collaborative process.

Hoffman et al. (2010), in a review of case studies related to involving stakeholders in CER, noted the importance of employing skilled and neutral facilitators who can foster a safe environment for information sharing. The role of facilitators in eliciting productive conversations is especially important where varying stakeholder interests may be perceived as incompatible or when consensus among stakeholders must be achieved.

Idea Generation and Prioritization

A variety of activities can be used in idea generation (topic nomination or refinement) and prioritization. Multiple articles focused on topic nomination and prioritization and commonly cited more traditional approaches such as electronic or mail surveys, citizen juries, small and large group discussions, and stakeholder working groups. We also reviewed methods that incorporated technology such as online platforms.

- One recent systematic review provides insights into the most frequently used methods for involving stakeholders in prioritizing future research needs (O’Haire et al., 2010). The researchers identified 56 studies and found that researchers most frequently used traditional mixed methods approaches including in-person meetings and a quantitative voting or Delphi processes.
 - The JLA uses a sequence of steps to prioritize unanswered questions about treatments submitted by patients, caregivers, health care professionals, researchers, and organizations. In the first step, partner organizations consult with their members to determine their priorities and vote for their top treatment uncertainties via e-mail or post. A steering group creates a short list from the entries submitted by these partner organizations. Individuals from a selected group of stakeholder organizations determine a final prioritized list through a “nominal group technique” at an in-person meeting. The nominal group technique, which encourages equal participation from all participants, involves dividing participants into small groups and working from individual to group priorities.
 - Researchers involved stakeholders from nine Middle Eastern and North African countries in a participatory effort to determine health-related policy concerns and research priorities (El-Jardali et al., 2010). The research team identified local researchers who had access to target stakeholders. The local researchers, in turn, identified key informants within each country (policymakers, health professional organizations, academic researchers, and nongovernmental organizations) and met with the research team to develop interview and focus group protocols for the discussions with these informants. Participants also used a three-point Likert scale to rank policy concerns and research priorities. Policy concerns identified by the key informants were discussed at a workshop with a subset of the key
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informants. The process resulted in a list of the top five policy-relevant research priorities for the next 3–5 years.

- In an example describing stakeholder engagement in a systematic review process, a steering committee identified potential review topics which were then ranked by each target stakeholder audience (Keown et al., 2008). The stakeholders' feedback determined the review topics and helped the researchers understand how stakeholders could use the resulting review findings.
- AIRNET, a thematic network project (2002–2004) initiated to stimulate interaction between researchers in air pollution and stakeholders in Europe, facilitated workshops for stakeholders from four European countries, to address issues related to health and pollution (Sanderson et al., 2006). A national AIRNET coordinator in each country, such as a Government representative or scientist, selected a local communication agency to carry out a stakeholder analysis and identify potential stakeholders interested in air pollution in health, including researchers/knowledge institutes, patient support/health organizations, industry and business groups, public health professionals, environmental nongovernmental organizations, and policymakers. Once identified, stakeholders were asked to participate in preparatory focus groups and interviews so that AIRNET could understand their needs and interests, ascertain their expectations, and identify their preferred modes for communication with other stakeholders. Stakeholders commented that actively involving participants in the planning of each meeting helped create an event that addressed participants' needs and interests. AIRNET used traditional communication formats such as seminars and roundtable discussions, and also nontraditional activities such as silent wall discussions, speaker's corners, and literature tables. Overall, the national workshops held by AIRNET offered a way to improve communication among the different stakeholders around health and pollution issues.

Technology for idea generation and prioritization. We reviewed several online platforms that facilitate submitting ideas, discussing them via online forums, and ranking and voting on these ideas. Democrasoft and IdeaScale products have this functionality, and IdeaScale was used to conduct the 2009 Open Government Dialogue, an initiative that allowed the public to submit priorities and discuss them online as part of the larger White House Open Government Initiative. Idea generation tools are often discussed in the context of innovation. IdeaScale describes its tools as helping organizations leverage valuable customer insight in a way that brings the most valuable ideas forward. Democrasoft describes its tools as helping to capture “valuable ideas” and “optimize [a] group’s potential.”

Product Development

In the peer-reviewed literature, face-to-face communication is almost always described as the primary method for engaging stakeholders in the development of products, such as reports or recommendations, or designing specific programs or initiatives. Generally, this face-to-face communication occurs in small groups that include many types of stakeholders. These small groups may be focus groups, workshops, juries, advisory panels, and/or workgroup groups. In addition to face-to-face communication, there is also a role for the use of technology in product development.

- Institute for Work & Health, in Canada uses “reaction meetings,” in-person meetings with 6–10 stakeholders, to review reports and recommendations and provide feedback on what the review findings mean to them, within the context of their work (Keown et al., 2008).
- NICE uses face-to-face methods, specifically a deliberative citizen’s council approach, to engage the general public in making treatment recommendations based on available evidence (Culyer, 2005; Kelson, 2005). Its Citizen’s Council has 30 members representative of the demographics of England and Wales. It meets twice yearly for a 3-day session; its members are paid £150 per day, plus expenses; and it is managed at arm’s length from NICE by Vision 21, a company specializing in research and community consultation, thus enabling the council to maintain its independence (Culyer, 2005). NICE engages stakeholders in clinical guideline development (Culyer, 2005). The Government determines guideline topics, which are then developed by National Collaborating Centers (NCCs) in cooperation with a guideline development group that includes health professionals, patient organizations, and technical experts. NICE also has appraisal committees consisting of health care professionals, patient representatives, and health care organizations that examine systematic reviews to appraise medical technologies. The appraisal committees may also commission primary research and submit final appraisal determinations to the United Kingdom’s National Health Service (NHS).
- The Boston School Yard Initiative brought together groups of parents, school officials, and city officials in numerous in-person meetings to plan and establish playgrounds in neighborhoods across Boston. The initiative used community organizers to facilitate groups of stakeholders involved in the planning and implementation of school playgrounds. In the meetings, the participants had to come to a consensus and make decisions regarding the playgrounds. Authors (Lopez, Campbell, & Jennings, 2008) noted that the process was time consuming, making it difficult for many working parents to participate.

As noted earlier, several articles observed the importance of a neutral and experienced facilitator when convening face-to-face groups for product development. Hoffman et al. (2010) describe the way a neutral facilitator helped a group of regulatory officials and providers move beyond their “conflicting perspectives” to design pharmaceutical clinical trials.

Technology for product development. There is a role for technology in product development in the form of product development challenges and the use of online communities to elicit stakeholder feedback. Product development challenges are contests in which an organization challenges its target audience to submit ideas for or create products. Challenges are often helpful to an organization in expanding its outreach. These products might be logos, mobile applications, or software, for the purpose of generating creative ideas to assist with recruitment, incorporating research into practice, and disseminating findings. The host organization generally offers prizes such as cash or funding to create the product. Challenges can be used to engage a broad array of stakeholders.

- DiabetesMine (2011), an online resource founded and run by patients, ran a challenge to develop an “innovative new diabetes device.” This challenge targeted patients and consumers; students in design, business, and other disciplines; entrepreneurs; engineers;
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developers; and business and industry leaders. A past challenge winner now works at a leading device manufacturer designing next-generation insulin pumps. Thus, DiabetesMine helped set the agenda in the diabetes device marketplace with a very small up-front investment of time and money.

- The AMA App Challenge invited U.S.-licensed physicians, residents, fellows, and medical students to submit ideas for “innovative” medical applications (apps) that would “be of use in their daily careers” (American Medical Association, 2011). The challenge not only helped the AMA with obtaining useful information on the everyday problems that physicians encounter in the course of patient care, but it also engaged a younger demographic, which represents a major source of future members.
- Sermo is an online community for physicians where, in addition to accessing resources and continuing medical education (CME), they can share information and collaborate on clinical topics related to patient care, devices, and medications (Sermo, 2010). Sermo’s clients are health care organizations that pay to engage physicians using social media. This allows them to capture physician insights into treatments, medications, and devices to inform the development of products and resources.

Dissemination

Stakeholders are frequently involved in product dissemination activities. The peer-reviewed literature showed primarily traditional methods for disseminating research findings such as partnering with specific stakeholder organizations to disseminate information to members, conference presentations, and distribution of materials through the media.

- NICE works with patient advocacy groups to disseminate information on recommendations directly to their members (Kelson, 2005).
- AIRNET hosts workshops with the specific purpose of encouraging researchers to disseminate their work to policymakers (Sanderson et al., 2006).
- The Institute for Work & Health in Canada uses presentations at conferences and individual briefings to small groups of stakeholders to disseminate their reports (Keown et al., 2008). These individual briefings usually involve the researchers giving “interactive presentations.”
- SUPPORT, a South-African organization that works to improve the use of research in policy and management decisionmaking, has developed a series of 19 articles (“SUPPORT Tools for Policymakers,” or STP) that describe processes to ensure that relevant research is identified, appraised, and used appropriately to inform health policymaking (Oxman et al. 2009). These products are primarily distributed through mass media.

Technology for dissemination. Online tools such as Web pages, blogs, and online communities can be used for dissemination of research findings and products. Online communities often have blogs that share new products and reports with their members and post links to trusted sites. Stakeholders may be more likely to use products and information disseminated through these trusted organizations.

- Patientslikeme is a Web-based environment where patients share experiences and learn from one another to improve their care. Vetted research findings and products from external trusted organizations are often disseminated to the members through the Web site and blog posts.
- The Cochrane Consumer Network (CCNet) facilitates consumer communication and training to provide a consumer perspective to Cochrane reviews and other activities within The Cochrane Collaboration. Their Web site posts links to information, products, and reports from partner organizations such as AHRQ and PCORI.
- EngagingCities is a blog that discusses strategies and new technologies to foster public engagement in urban planning. Research and tools on public engagement are presented for members to discuss.
- CR2K is an online community of practice built around the EPA TRI data. It describes itself as a “one-stop shop” for non-Federal stakeholders interested in learning about the EPA program and sharing with other stakeholders. The primary purpose is to disseminate information to citizens about toxic chemical releases in their areas.

4.5 Outcomes of Stakeholder Engagement

Very few articles described the evaluation of stakeholder engagement processes or outcomes related to stakeholder engagement activities. The most common evaluation method we did identify was semistructured interviews with stakeholders. For example, the Patient and Public Involvement Unit (PIU) of NICE conducted individual semistructured interviews with patients and caregivers to evaluate their experiences participating in guideline development. Other stakeholder engagement initiatives, notably Web sites and other social media outlets, allow stakeholders to comment or provide testimonials. However, published comments are promotional in nature and not a true evaluation.

Nowell (2009) described rigorous methodology to assess impacts of stakeholder activities. These researchers used survey and social network data to assess the impacts of collaborative groups (roughly described as community-based groups with various stakeholders). The authors found that cooperative stakeholder relationships were a strong predictor of systems change outcomes.

A final way to measure or evaluate stakeholder engagement, especially if it occurs online, is via usage statistics. Most organizations track—and many advertise—their usage statistics. Alliance Health Network characterizes DiabeticConnect.com as the “largest social network for people affected by diabetes, with more than 500,000 registered members and 1.2 million unique monthly visits” (Alliance Health Networks, 2011). PatientsLikeMe reports data on almost 150,000 users with more than 1300 conditions (<http://www.patientslikeme.com/>). The Love/Avon Army of Women displays a counter on its home page that updates daily; as of spring 2011, the organization had recruited almost 350,000 women. Sermo reports that its physician members spend 35,000 hours a month on the Sermo Web site (Sermo, 2011). In fall 2010, CVN reported, “over 60 trained and informed consumer representatives sitting at 116 decisionmaking tables (boards, committees, working parties)” (Cancer Voices NSW, 2010). However, the benefits associated with usage, beyond increased profit or increased funding for the organization, are not established.

5.0 Findings from Key Informant Interviews

We conducted key informant interviews (KIIs) with individuals experienced in stakeholder engagement within and outside of health care. Key informants were from Government agencies, non-Government research alliances, nonprofit organizations, and other organizations that rely on stakeholder input.

The key informants provided information on many of the methods described in this report and suggested additional organizations and Web sites to explore in the concurrent literature and Web site scan. In addition, key informant interviews were designed to provide more detail on how these informants are currently using innovative and effective methods to work with stakeholders. We first present how the interviewees conceptualized their stakeholders and their definitions of innovation. We then present examples of innovative practices, how technology is currently used, and challenges to stakeholder engagement.

5.1 Definitions of Stakeholders

Interviewees defined stakeholders broadly as:

- Anyone affected by an issue, who may or may not be formally involved in decisionmaking about the issue.
- Anyone who might influence an organization’s ability to achieve its mission or who can provide input on whether the mission is achieved.

Interviewees generally saw stakeholders as comprising the following three categories: (a) decisionmakers, (b) the general public (civil society) or individuals or communities affected by a particular decision, and (c) individuals or organizations that aimed to raise awareness about an issue. They might be involved with or affected by decisionmaking, or might disseminate information about decisions to target audiences (e.g., advocacy organizations to the community, pharmaceutical companies to policymakers).

Two interviewees distinguished between external stakeholders, which they defined using the criteria outlined above, and internal stakeholders, who were individuals within the organization who might be affected by or involved in decisionmaking about internal processes. Interviewees managing Web-based efforts defined stakeholders as the online community frequenting the Web site, along with advertisers.

Most interviewees stated that their organizations engaged a broad range of stakeholder groups (Table 6).

Table 6. Types of stakeholder groups mentioned by interviewees

General Stakeholders	Stakeholders in Health Care
<ul style="list-style-type: none"> • Policymakers • Legislators, Government officials • Issue leaders • Academia 	<ul style="list-style-type: none"> • Patients • Caregivers • Clinicians and other health professionals • Commercial medical groups

General Stakeholders	Stakeholders in Health Care
<ul style="list-style-type: none"> • University-based researchers • Industry, business • Venture capitalists, investors • Voluntary health organizations • Nonprofit leaders • Nonprofit organizations • Community members • Community leaders 	<ul style="list-style-type: none"> • Safety net organizations • Health plans • Health administrators • Pharmaceutical companies

5.2 Definitions of Innovation

We asked interviewees how they define innovation in stakeholder engagement, in order to gain a deeper understanding of what they saw as the purpose of building new practices to involve stakeholders and to discover what characteristics they attributed to innovative practices. We also asked them to identify innovative activities within their organizations and describe the ways in which these practices are innovative. In this section, we provide an overview of interviewees’ perceptions of innovation in stakeholder engagement.

Definition 1: Innovation does not have to be driven by a new idea. It can be a different approach to active problem solving. Multiple interviewees advised against a focus on novelty when defining innovation. Two interviewees explained that a practice does not have to be rooted in a new idea to be considered innovative. A more telling indicator is whether the approach is planned and delivered in a manner that focuses on making it most effective with the target audience.

Definition 2: Innovation can involve finding an effective approach to implementing an existing idea. One interviewee asserted that, in a current environment where traditional but ineffective approaches are widely used, innovative practices are simply ones that are firmly embedded in accepted core principles of engagement and that are designed with a goal of maximizing their likelihood of success.

We are innovative because we recognize [commonly used methods] have failed. It’s less about novelty and more about rigorous refinement of new strategies that are not as new anymore, but need to be refined and aren’t widespread. . . . They’re innovative because they’re effective. They are innovative because they really challenge the core assumptions that most people [have] in understanding, naming, framing, or addressing the problems that they have. I would caution against going after novelty, rather than going after what are the alternatives to business as usual.

An interviewee from a Government agency expanded on this sentiment to describe innovation as an approach that looks for how an idea can be effectively implemented with a particular audience given available resources.

“[Defining innovation] is really not that critical in my mind, mostly because . . . all of the various definitions of innovation contain the same fundamental idea.

Innovation is not a new idea. Innovation is a new idea that gets put to practical use.”

Definition 3: Innovation includes nontraditional activities. Some interviewees took an alternative approach to defining innovation in stakeholder engagement. An interviewee from a Government agency viewed innovation as activities that are not traditionally performed within the organization, such as using technology to solicit stakeholder feedback. An interviewee from a nationwide research and polling company similarly defined an innovative approach as one that is used uniquely in application or rarely used in the field.

5.3 Innovative Stakeholder Engagement Processes

We asked interviewees to describe innovative activities carried out by their organizations. Below, we describe themes that emerged regarding the implementation of these activities and related examples.

Focus on stakeholders that are most interested and affected by the issue. When identifying which stakeholders to involve in the research process, interviewees highlighted the importance of focusing on stakeholders who are interested in and affected by the issue being considered, and concentrating information collection efforts on these groups. To ensure that the activities result in active engagement, the issue should be recognized as a priority by the stakeholder audience. This supports finding from section 4.3 on identifying relevant stakeholders.

An interviewee from a Government agency described soliciting external feedback to improve the agency’s Web site. To engage stakeholders outside the agency, they used IdeaScale, a Web-based platform where stakeholders can submit their responses to a specific question (e.g., What is one thing you would change about this Web site?) and vote on the submitted ideas. The agency anticipated a far greater response from stakeholders than it received. This interviewee noted that one possible reason for the shortfall in feedback was that the agency attempted to engage a very broad array of stakeholders instead of targeting groups that were most likely to be interested in the issue.

Informing stakeholders that their participation is important and helping them understand how their input will be used. Consistent with our findings in section 4.3 on stakeholder education, an interviewee affiliated with a project that involved information gathering from students in charter high schools described how researchers identified and were responsive to the students’ expectations of the engagement process. Students in focus groups indicated that their most important consideration when deciding whether to participate was whether their feedback would be taken seriously by their schools. Project staff addressed this concern by establishing a kickoff process where they showed a video to highlight instances in which similar schools implemented changes on the basis of student feedback. The project had an average student response rate of 77 percent and achieved 100 percent response rates in some schools.

Tailoring the experience to the specific stakeholder population. Multiple interviewees spoke about tailoring the experience to the stakeholder group. This includes tailoring the message, the method of soliciting feedback (e.g., the tools used), and the way data are fed back to the stakeholders. Innovative practices adapt the ways they gather feedback, depending on the stakeholders involved, rather than using one approach across stakeholder groups.

Tailoring the method of soliciting feedback to the specific target stakeholder group. One interviewee described how their project tailored its message, as well as its tools, to the target audience. Since the targeted stakeholder group was students, the project chose an online survey administered during the school day in an effort to achieve the desired response rates. To ensure that the surveys were appropriate for the audience, the researchers carried out formative focus groups and pilot testing with students prior to the survey's implementation. The surveys contained open-ended questions in addition to closed-ended, to allow student to present their thoughts candidly and in their own words. Project researchers found that resource constraints in lower-income schools limited the availability of computers and resulted in longer wait times for students who wanted to complete the online survey. To compensate, the researchers allowed these schools more time to implement the survey.

Presenting data in a manner consistent with stakeholder needs. Interviewees noted strategies for effectively using data to aid stakeholder decisionmaking. One interviewee viewed innovation as presenting information to stakeholders in a manner that they find interesting, and that allows them to understand an issue and become better-informed decisionmakers.

The way that policymakers get information is through policy briefs. That is often a failed strategy for engaging policymakers. ... There's this misconception that if you give people information they'll do what they need to do and make the right kind of decisions, but that's not really how people [form] judgments. You need to start with people's starting point—their concerns, what are the things most important to them.

Another interviewee explained that innovative approaches relay data to stakeholders in a manner that supports the effective use of those data.

Another challenge that we faced is ...that people [need] the time to digest the data and figure out how it fits in and complements other data sources that they get.... We would bring together schools for a half-day meeting to talk about strategies for sharing data back for the communities and ... how to interpret these data and how to make changes from the data. The goal is ... to provide the data in a user-friendly way. So much data are out there, but it's not comparative, not rigorously collected, so it is not reliable. And when no one has the appetite to use the data, it is such a waste of resources.

Understanding that brand recognition can have a strong effect on stakeholders' receptiveness to engagement. Just as it is important for researchers to understand their stakeholder audiences, it can be equally important for stakeholders to be familiar with the organizations that aim to engage them. This is consistent with the findings in section 4.3 around building trust. An interviewee from a nationwide polling firm noted that low recognition of the agency could hinder stakeholders' receptiveness to the agency's activities.

We poll on people's recognition on those in the Government. NASA polls at [greater than] 70 percent. It can go as high as 90 percent in terms of recognition. CDC polls in the 40s. Not all health agencies are the same, mostly because some

you see on the news more than others. If people know what you're doing, then people are more likely to defend you.

Focusing on meaningful engagement rather than on innovations. One interviewee noted that there is little innovation taking place in stakeholder engagement and that the more important focus is the separate issue of “meaningful” stakeholder engagement, which, she believed, is happening in health care research. The interviewee contended that organizations or institutions could engage stakeholders—patients, patient advocates, and interested observers—by identifying a limited number of stakeholder representatives who understand that they represent a broad array of stakeholders with a similar disease history but who have had varying experiences. She emphasized that institutions should clarify expectations for the stakeholder representatives and ensure that they receive necessary background information or training to understand the medical condition being studied, their relationship to other stakeholders present, and the ways they might contribute to the discussion. She added that meaningful contribution could only be achieved if an organization engages multiple stakeholder representatives in discussions, rather than expecting them to act alone.

You need to have people deeply rooted in the thing you are talking about, who can see past their own experience, but don't need to tell their own story again and again. And the patient or patient representative should never be alone.

5.4 Use of Technology To Engage Stakeholders

The use of technology and its link to innovative practices in stakeholder engagement was one of the focus points in our review. Use of technology was a criterion for selecting our key informant organizations, and we asked specific questions about the use of technology. Through our key informant interviews, we found that technology has infiltrated stakeholder engagement in numerous ways, with specific themes emerging that relate to (a) social media marketing and advertising; (b) social networking; and (c) social media tools, all of which we describe below.

Social Media Marketing and Advertising

Many of our key informants discussed the importance of social media marketing and advertising as a means to help create a large following, crucial to the process of effective stakeholder engagement in their organizations. One of the non-Government entities used “pay search engines,” to market their organization. This allowed them to bid on keywords that Internet users might input into the search engines, in order to have their Web site located in users' search results. Another strategy for Internet marketing involved the establishment of linking partnerships, in which organizations agreed to post one another's Web site links on their Web pages. These strategies increase user traffic to an organization's Web site and can be one strategy to increase an organizations' outreach to stakeholders.

Another key informant discussed the value of social media marketing through creating viral messages and public service announcements. Although the interviewee stated that these strategies might be costly, he noted that organizations such as Autism Speaks, which have been able to create and broadly disseminate their messages, have made a large group of people aware of their organization and work.

Social Networking: Twitter, Facebook, and Blogs

A number of our key informants specifically identified Twitter and Facebook as methods they use to reach and become more accessible to stakeholders and disseminate information. As the use of social networking Web sites continues to grow, the expectation that organizations will use these methods may also increase. As one interviewee mentioned, the use of social networking has created a shift for organizations to engage with stakeholders more regularly.

One interviewee spoke of Web sites such as Twitter and Facebook as channels that might offer “more outreach rather than engagement or participation.” The interviewee expressed skepticism over how effective a site like Twitter, which only allows 140 characters for each post, might be for meaningful dialogue; however, he emphasized that these sites might be useful for helping stakeholders find an organization or project and learn more about specific programs.

Social networking can also be a means of disseminating information. One interviewee uses blogging to translate a large amount of complex material into concise and entertaining articles. This method allows readers to sign up for a periodic digest and receive information that they might otherwise find too long, technical, or unappealing to read.

Blog posts and Twitter messages from authorities within an organization often have greater influence than messages from other staff. As the interviewee explained, messages from trusted authorities create an “incredibly powerful voice,” which has an increased likelihood of being picked up by the media, and increases the potential to reach more stakeholders.

Social Media Tools: IdeaScale, UserVoice, Salesforce, Public Polling, Online Voting, and Texting

Our key informants mentioned a variety of social media tools that they are currently using as means of eliciting input from stakeholders in prioritizing research projects and helping to design research. Multiple participants mentioned the use of IdeaScale, an online platform that can be used to engage stakeholders in submitting ideas, commenting on others’ ideas, and voting or ranking ideas. One interviewee mentioned UserVoice and Salesforce as similar online feedback tools. IdeaScale, UserVoice, and Salesforce all have mobile device and Facebook applications.

One interviewee highlighted the flagging feature in the Salesforce and UserVoice platforms. The flagging feature allows the organization to indicate when a stakeholder’s input is reviewed, considered, or implemented. Flags provide important feedback to the stakeholder, demonstrating that his or her input is being used. The interviewee further emphasized the importance of keeping stakeholders in the loop after the project has been completed to show accountability, keep stakeholders engaged, and contribute to the success of the overall project.

A few key informants discussed their use of public polling and online voting to involve stakeholders in their work. These interviewees highlighted the usefulness of surveys, polling, and voting through Web sites to allow the public and stakeholders to have a say in the question at hand without needing to be physically present. Online methods can be especially useful for engaging the 30- to 40-year-old population, which may not be fully represented in face-to-face meetings because of work and family obligations, and appreciate the opportunity to participate online.

Finally, one interviewee mentioned the use of texting programs as a way to gain feedback from stakeholders without having to send out surveys. This tool has proved valuable, as the response is far quicker and allows real-time evaluations of current programs and projects. Even though organizations varied in their use of technology tools and in their beliefs regarding the effectiveness of technology, each of our key informants spoke of at least one use of technology in stakeholder engagement.

5.5 Challenges in Engaging Stakeholders

We asked our key informants to describe the challenges their organizations faced in involving stakeholders in their work. Interviewees discussed challenges that they were currently facing relative to (a) awareness of the organization; (b) new use of technology and methods; and, (c) resource constraints on both stakeholders and organizations.

Awareness of the Organization and Ongoing Interest

As mentioned previously, effective stakeholder engagement relies on stakeholders' being aware of the work at hand and how they may get involved in the engagement process. A few key informants specifically addressed lack of awareness of the organization and/or the program as a challenge for stakeholder engagement. Organizations need to create a following in order to utilize engagement tools such as social networking Web sites or media tools.

After overcoming the initial challenge of raising awareness, there is an added challenge of maintaining the trust of stakeholders, as described in section 4.3. For instance, one interviewee pointed out that his organization's stakeholders were often skeptical of how—or even if—their input would be used. Interviewees also spoke of the difficulty of keeping stakeholders' interest in the organization or process over time because research processes are often slow and it is difficult to show how input was used in an expeditious manner so that stakeholders feel that their input was valued.

New Use of Technology and Methods

New uses of technology or methods can in themselves be challenges to implement. One interviewee that used public polling for stakeholder engagement found it was difficult to find a credible firm that is able to conduct public polling in an effective way. While many polling firms in the field are academic, the interviewee described important differences between public polling and academic polling.

Additional key informant interviews highlighted the struggle in using new technology to reach specific audiences. The use of computers, online surveys, or mobile device applications might be effective in reaching a select type of stakeholder but could leave out stakeholders who do not have access to these technologies. Some stakeholders may not have Internet access at home or may not have mobile devices with the technical capabilities needed for running certain types of software. One interviewee pointed out that even when audiences have the ability to access social media or new technology, they may not respond through these methods. For example, while the younger generation may be familiar with technology such as the use of social networking sites, they may not be interested in using their Twitter and Facebook accounts for participatory projects.

Finally, one interviewee discussed a few of the limitations in the use of social media tools and online feedback platforms, such as IdeaScale and UserVoice. Specifically, he highlighted challenges in facilitating discussions through these methods.

These ideation platforms ... have their flaws in terms of how you can facilitate them. Often times, for example, a group starts hijacking a process, and there's a lack of facilitation tools for large amounts of input in order to make sure that topics can be flagged as off-topic.

Another challenge with online feedback projects is assessing and managing the number of participants providing input into the Web site. One way projects report participants is by showing how many people they have had visit the Web site. However, there may be a large discrepancy in the level of engagement of a visitor and an actual participant. There is a conflict between accurately measuring participation rates for the project and allowing easy access to the Web site. Having visitors complete a registration process provides a more accurate picture of participants, but it may deter participation because of the time required to register.

Resource Constraints on Stakeholders and Organizations

Perhaps one of the greatest challenges identified through our key informant interviews was time and resource constraints of both the organization and the stakeholders.

As many key informants mentioned, stakeholders need to have the time, resources, and interest to participate in a project. Many organizations indicated that their biggest challenge was getting stakeholders to show up for meetings. In these cases, key informants mentioned the importance of strong incentives for interviewees, whether monetary or other inducements. One organization suggested raffles, prizes, refreshments, or programs for small children (such as a childcare program or pizza party) while parents participated in the stakeholder meeting. Two interviewees identified the lack of computers as a resource constraint in some of their stakeholder audiences. As mentioned above, when an organization is trying to use an online survey to gain input from stakeholders, it may face a challenge in reaching all intended audiences if many audience members do not have access to computers and/or the Internet.

Organizations also face resource and time constraints for stakeholder engagement activities. As mentioned above, stakeholders need to be aware of the organization and programs; yet advertising this information to the public and stakeholders can be costly. It can also be costly to simply host in-person stakeholder meetings when considering compensation for stakeholder time, meeting space, providing food, and any additional incentives. Online tools may be a long-term solution to the expense of hosting in-person meetings; however, there are resources involved with creating and maintaining the tools.

In terms of time constraints, one interviewee discussed how Government projects are often held to short timeframes for eliciting feedback. Ideation platforms used, such as IdeaScale and UserVoice, might only be open for feedback for one month before closing. Such a short timeframe makes it difficult to maintain stakeholders in an ongoing participatory process.

6.0 Summary

Organizations that involve stakeholders in research may consider incorporating emerging approaches to expand and improve their current activities. In particular, five methods we identified appear to hold particular promise:

- **Online collaborative platforms** enable interaction between an organization and its target audience through a Web site or virtual space. These platforms feature tools that allow users to communicate, share information, and work together, while also promoting transparency, participation, and collaboration. Moreover, online collaborative platforms can allow for constant feedback to stakeholders about how their input is being used, which we have learned is critical to maintaining engagement. Examples from the review include IdeaScale, Democrasoft, and Salesforce.
- **Product development challenges** are contests in which an organization challenges its target audience to submit ideas for or to create products. These products might be logos, mobile applications, or software. Through their submissions, participants compete for a chance to win prizes from the host organization (e.g., cash, funding, or management support), while providing input on topics of interests and in generating creative ideas for dissemination and implementation. Examples from the review include the AMA app challenge and the DiabetesMine challenge.
- **Online Communities** are virtual communities where people communicate, share ideas, and work together without the barriers of geography and time. They can be either open or closed Web-based environments. Open environments are easier to access and join, while closed environments may be by invitation only or restricted to members of an organization or target group. Example communities from the review include Sermo, Involve People in Research, ChemicalRight2Know, and PatientsLikeMe.
- **Grassroots community organizing efforts** take a local level, ground-up approach to facilitating interaction and engagement between organizations and their target audiences. It can be useful for spreading awareness of and building trust in an organization's initiatives, contributing to stages in the research process, and implementation. Examples from the review include MomsLikeMe and AIRNET.
- **Collaborative research** aims to integrate the unique information, values, skills, and perspectives that different stakeholders have about a defined topic, in order to enhance the relevance of the project. The efforts include stakeholders in all aspects of the research process including the planning process, product development, and dissemination. Examples from the review include the James Lind Alliance (JLA) and NICE.

Table 7 presents a summary chart of these methods. Included are examples from the review, key stages of the research process for which the method may be appropriate, and key features. Of note, we found limited evaluation data measuring outcome effectiveness of the proposed methods.

Table 7. Summary of promising methods for engaging stakeholders in research process

Method	Primary Purpose (Stage in Research Process)	Key Features	Example(s)
Online collaborative platforms/ Ideation platforms	<ul style="list-style-type: none"> • Idea generation and prioritization 	<ul style="list-style-type: none"> • Allows stakeholders to suggest, vote for, rank, or comment on ideas about a particular topic • Efficient way of gathering input • Allows constant feedback by the forum facilitator • Flagging systems allow for maintaining feedback loop to keep stakeholders aware of how their input is being used • Allow stakeholders to engage virtually and at their own convenience • Do not require a significant time commitment. • Organizations can make use of free or low-cost platforms that are available for public use. 	<ul style="list-style-type: none"> • Ideascale • Democrasoft
Product development challenges	<ul style="list-style-type: none"> • Recruitment • Idea generation and prioritization • Product development 	<ul style="list-style-type: none"> • Challenges can be used to increase awareness of organization • Provides organization with insight into stakeholder preferences and needs, such as how and when would like to be reached and what types of products they would find useful • Increases likelihood that stakeholders, as end-users, will use a product or tool 	<ul style="list-style-type: none"> • American Medical Association App Challenge • Challenge.gov • DiabetesMine
Online communities	<ul style="list-style-type: none"> • Recruitment • Stakeholder preparation • Idea generation and prioritization • Product development • Dissemination 	<ul style="list-style-type: none"> • Online community members are a subset of stakeholders that have voluntarily joined the community, making them more likely to be interested in the topic • Stakeholders can participate in virtual meetings and provide continuous input without needing to travel • Stakeholders can interact and build relationships with others—may increase continued participation • Stakeholders can provide input on their needs to host organization • Findings and products can be disseminated within communities 	<ul style="list-style-type: none"> • PatientsLikeMe.com • Sermo • Healthtalkonline

Method	Primary Purpose (Stage in Research Process)	Key Features	Example(s)
Grassroots community organizing	<ul style="list-style-type: none"> Recruitment Stakeholder preparation Idea generation and prioritization Product development Dissemination 	<ul style="list-style-type: none"> Local community level initiatives, including partnering with local press, advocacy organizations, or local events can spread awareness Targeted efforts at the local level can help stakeholders feel a more personal connection to an organization, building trust in the organization's initiatives Can be used for recruitment and dissemination efforts through community-based ad campaigns/ advocacy programs within a target community to leverage existing relationships 	<ul style="list-style-type: none"> Environmental Protection Agency Community Engagement Initiative Momslikeme.com
Collaborative research	<ul style="list-style-type: none"> Recruitment Stakeholder Preparation Idea generation and prioritization Product development Dissemination 	<ul style="list-style-type: none"> Helps maintain trust throughout the engagement process by providing feedback to stakeholders on the results and on the ways their input is being used Allows stakeholders to provide input on effective messages to recruit others and to disseminate findings Allows stakeholders to provide input on identifying, designing, and funding research programs for which there are research gaps 	<ul style="list-style-type: none"> Service User Research Enterprise (United Kingdom) Office of Congressionally Directed Medical Research Programs James Lind Alliance

Recommended Practices and Considerations for Stakeholder Involvement

Finally, several themes emerged in the course of this review and interviews as important elements to consider when working with stakeholders. We summarize these themes below (Table 8).

Table 8. Recommended practices for working with stakeholders

Recommended Practice	Rationale
Gain trust of potential stakeholders and continue building trust throughout the engagement process.	Gaining the trust of stakeholders prior to their participation can assist in their recruitment. Trust should be developed and maintained throughout the engagement process, to ensure meaningful participation from all stakeholders.
Select stakeholders for whom the decision or research has important consequences.	The literature described many different types of stakeholders, but there was consensus that recruited stakeholders should have a vested interest in the research or topic.

Recommended Practice	Rationale
Prepare stakeholders for their role, responsibilities, and the topic being discussed.	Training programs can vary, but some education is needed to prepare stakeholders—especially consumers—for their role. Several articles indicated that education and training should include a “job description” of the stakeholders’ role and other information about their responsibilities.
Provide resources or compensation for stakeholders—especially consumers or practicing clinicians—to support their participation.	For example, compensation should cover travel, childcare, and lost wages for time away from jobs.
Utilize technology when appropriate, keeping goals, audience, and resources in mind.	Technology can be especially useful in recruitment efforts, research training courses, and dissemination.
Utilize trained and neutral facilitators.	Skilled facilitators can create a safe atmosphere for honest, productive discussion and can handle any problems that arise in discussion.
Involve stakeholders as early as possible.	Involving stakeholders in research or other program development as soon as possible, even in the planning stages, helps ensure that the product will meet the needs of the stakeholders or end-users.
Provide feedback to stakeholders on the results and on the ways their input is being used.	Informing stakeholders during and after their engagement activities of how their input affected changes, decisions, or outcomes.

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Appendix A: Keyword Search Terms

Database	Search Statement	Number of Records Downloaded (Duplicates Excluded)
PubMed	Stakeholder*[ti] AND (engagement OR engage OR engages OR engaged OR engaging OR involve OR involvement OR involved OR participat* OR input OR panel OR panel OR public policy OR public policies) NOT (editorial[pt] OR letter[pt] OR comment[pt]) Limits Activated: English, Publication Date from 2001 to 2011	301
	Stakeholder*[ti] AND (technolog*[tiab] OR web 2.0[tiab] OR social media[tiab] OR social network*[tiab] OR facebook OR twitter OR myspace OR blog*[tiab] OR wiki*[tiab]) NOT (editorial[pt] OR letter[pt] OR comment[pt]) Limits Activated: English, Publication Date from 2001 to 2011	18
	Stakeholder*[ti] AND (group process* OR presentation* OR critical appraisal*) NOT (editorial[pt] OR letter[pt] OR comment[pt]) Limits Activated: English, Publication Date from 2001 to 2011	6
	Stakeholder*[ti] AND (“clinical research” OR research process* OR “health research” OR “health services research” OR Health Services Research[majr]) NOT (editorial[pt] OR letter[pt] OR comment[pt]) Limits Activated: English, Publication Date from 2001 to 2011	25
	Stakeholder*[ti] AND health[tiab] AND training[tiab] NOT (editorial[pt] OR letter[pt] OR comment[pt]) Limits Activated: English, Publication Date from 2001 to 2011	7
	Stakeholder*[ti] AND health[tiab] AND (advocacy OR consumer advocacy OR patient advocacy) NOT (editorial[pt] OR letter[pt] OR comment[pt]) Limits Activated: English, Publication Date from 2001 to 2011	2
Total for PubMed		359

Database	Search Statement	Number of Records Downloaded (Duplicates Excluded)
ERIC	Stakeholder* (in Title) AND (engagement OR engage OR engages OR engaged OR engaging OR involve OR involvement OR involved OR participat* OR input OR panel OR panel OR public policy OR public policies) (in Keywords) 2006–2011	58
	Stakeholder* (in Title) AND (technolog* OR “web 2.0” OR “social media” OR “social network” OR “social networking” OR facebook OR twitter OR myspace OR blog* OR wiki*) (in Keywords) 2006–2011	14
	Stakeholder* (in Title) AND Health (in Keywords) AND Training (in Keywords) 2006–2011	2
Total for ERIC		74
EBSCO Academic Search Premier and SocIndex	Stakeholder* (in Title) AND (engagement OR engage OR engages OR engaged OR engaging OR involve OR involvement OR involved OR participat* OR input OR panel OR panel OR “public policy” OR “public policies”) (in Select a field optional) AND “Environmental health” (in Select a field optional) 2006–2011	5

Database	Search Statement	Number of Records Downloaded (Duplicates Excluded)
	Stakeholder* (in Abstract) AND (engagement OR engage OR engages OR engaged OR engaging OR involve OR involvement OR involved OR participat* OR input OR panel OR panel OR "public policy" OR "public policies") (in Select a field optional) AND "Environmental health" (in Select a field optional) 2006–2011	51
	Stakeholder* (in Select a field optional) AND (technolog* OR "web 2.0" OR "social media" OR "social network" OR "social networking" OR facebook OR twitter OR myspace OR blog* OR wiki* OR "group process" OR "group processes" OR presentation* OR "critical appraisal" OR "critical appraisals" OR "clinical research" OR "research process" OR "research processes" OR "health research" OR "health services research" OR training OR advocacy OR "consumer advocacy" OR "patient advocacy") (in Select a field optional) AND "Environmental health" (in Select a field optional) 2006–2011	17
Total for EBSCO		73

Appendix B: Organizations Engaging Stakeholders Identified From Peer-Reviewed Literature, Grey Literature, and Web Sites

Health Care Organizations in Peer-Reviewed Articles Reviewed	
Organization	Purpose (From the Organization’s Web Site)
American University of Beirut with 9 Middle Eastern countries	To identify the top five research priorities for health financing, human resources for health, and the role of the nonstate sector for the next 3 to 5 years
Canadian Institutes of Health Research (Canada)	To create new health knowledge and to translate that knowledge from the research setting into real-world applications
Cochrane Collaboration (UK)	To help health care providers, policymakers, patients, their advocates, and carers make well-informed decisions about human health care by preparing, updating, and promoting the accessibility of Cochrane Reviews
Community partner organization working with ex-sex workers (Canada)	To gain knowledge of the off-street population involved in selling sex services; to identify ways to make service and program delivery more effective and accessible, an outcome similar to Denner and colleagues’ (1999) finding that investigation of service usage patterns among existing and potential clientele is one of the benefits accrued by programs involved in community–academic collaborations; and to reflect on its programs and service clientele with research evidence that confirms the value of the organization to the local community
Environmental Health Research Division within the First Nations and Inuit Health Branch of Health Canada (Canada)	To conduct, coordinate, and fund contaminants-related research in collaboration with the Assembly of First Nations, First Nations and Inuit Health Branch (FNIHB) regions, and the Department of Indian Affairs and Northern Development
Institute for Work & Health (Canada)	To conduct and share research that protects and improves the health of working people and is valued by policymakers, workers and workplaces, clinicians, and health and safety professionals
James Lind Alliance (JLA)	To bring patients and clinicians together in “Working Partnerships” to identify and prioritize the unanswered questions that they agree are most important
National Cancer Institute (NCI)	Part of NIH: To support and coordinate research projects conducted by universities, hospitals, research foundations, and businesses throughout this country and abroad, through research grants and cooperative agreements
National Institute for Health and Clinical Excellence (NICE)	To provide guidance, set quality standards, and manage a national database to improve people’s health and prevent and treat ill health, and to provide recommendations to the United Kingdom’s NHS
National Institutes of Mental Health–funded Interventions and Practice Research Infrastructure Programs	To foster an active, synergistic partnership between mental health researchers and community-based, clinical/services staff, clinicians and patients/clients to (a) advance our knowledge about developing research infrastructure in community settings and the establishment of collaborative

Health Care Organizations in Peer-Reviewed Articles Reviewed	
Organization	Purpose (From the Organization's Web Site)
	partnerships; (b) identify and incorporate those factors (e.g., organizational, sociocultural, interpersonal) in community settings that may be associated with quality care and optimal outcomes for patients and clients; and (c) plan, test, and implement services research interventions (treatment, rehabilitative, and preventive) in community settings
Research evaluation and training partnership between the University of Hawaii and the Hawaii Department of Health	To provide leadership on systems of care research and evaluation, create service-learning opportunities in behavioral health research and evaluation, and provide leadership and support for scientific literacy and data-driven decisionmaking within Hawaii's Child and Adolescent Mental Health Division (CAMHD) and across other child-serving agencies

Non-Health Care Organizations From Articles Reviewed	
Organization	Description/Purpose
Boston School Yard Initiative	To transform Boston's schoolyards from barren asphalt lots into dynamic centers for recreation, learning, and community life
Environmental Protection Agency (EPA)	<p>To protect human health and the environment. To ensure that</p> <ul style="list-style-type: none"> • All Americans are protected from significant risks to human health and the environment where they live, learn, and work • National efforts to reduce environmental risk are based on the best available scientific information • Federal laws protecting human health and the environment are enforced fairly and effectively • Environmental protection is an integral consideration in U.S. policies concerning natural resources, human health, economic growth, energy, transportation, agriculture, industry, and international trade, and these factors are similarly considered in establishing environmental policy • All parts of society—communities; individuals; businesses; and State, local, and tribal governments—have access to accurate information sufficient to effectively participate in managing human health and environmental risks • Environmental protection contributes to making our communities and ecosystems diverse, sustainable; and economically productive
Flemish Centre of Expertise for Environment and Health (Belgium)	For each sub-field and each discipline to produce the necessary relevant data and for the monitoring activities and R&D to restrict challenges to what is essential; to provide the decisionmakers with the necessary and appropriate information so that they can talk in a well-informed way and, whenever requested, argue choices and decisions, transparent to

Non-Health Care Organizations From Articles Reviewed	
Organization	Description/Purpose
	stakeholders and society
Thematic Network on Air Pollution and Health (Europe)	To create a widely supported basis for public health policy related to improving air quality in Europe, and regulatory needs to achieve that goal

Health Care Organizations and Initiatives From Grey Literature and Web Sites Reviewed		
Organization	Web Site	Purpose
2011 AMA App Challenge	http://www.amaidealab.org	To help patients through a challenge uniting physicians nationwide to work on the most important professional and public health issues
Alliance Health Network	http://www.alliancehealth.org	Technology-driven company that creates and hosts condition-specific online health networks
Cancer Voices Australia	http://www.cancervoicesaustralia.org.au	National network to provide a forum for people in Australia affected by cancer
Cancer Voices New South Wales (NSW)	http://www.cancervoices.org.au	To provide a consumer voice in cancer issues, offering broad, informed views at local, state, and national levels
Clinical Trials Cooperative Group Program	http://www.cancer.gov/cancertopics/factsheet/NCI/clinical-trials-cooperative-group	To identify important questions in cancer research and to design clinical trials to answer these questions
Cochrane Consumer Network (CCNet)	http://consumers.cochrane.org/healthcare-users-and-evidence	To provide consumer input into developing Cochrane systematic reviews of best evidence in health care and in utilizing this evidence

Health Care Organizations and Initiatives From Grey Literature and Web Sites Reviewed		
Organization	Web Site	Purpose
Congressionally Directed Medical Research Programs (Department of Defense)	http://cdmrp.army.mil/	To incorporate stakeholders in all aspects of the research funding process by convening stakeholder meetings consisting of scientists, clinicians, and consumers. Stakeholders are asked to identify and design programs to fill research gaps as part of a two-tier competitive grants review process.
Consumers Health Forum of Australia (CHF)	http://www.chf.org.au	Umbrella organization of state “peak” health consumer organizations and networks dedicated to particular health conditions and objectives
Consumers United for Evidence-Based Healthcare (CUE)	http://us.cochrane.org/consumers-united-evidence-based-healthcare-cue	National coalition of health and consumer advocacy organizations
DiabetesMine	http://www.diabetesmine.com/designcontest	Online competition to encourage creative new tools for improving life with diabetes
Healthtalkonline	http://www.healthtalkonline.org	Web site/online library of stories of health and illness (interviews, videos, etc.) and information on conditions, treatment choices, and support
Healthymagination	http://www.healthymagination.com/projects	To continuously develop innovations that reduce costs, increase access, and improve quality and efficiency around the world
INVOLVE	http://www.invo.org.uk	To support greater public involvement in NHS, public health, and social care research

Health Care Organizations and Initiatives From Grey Literature and Web Sites Reviewed		
Organization	Web Site	Purpose
InvoNET	http://www.invo.org.uk/invoNET.asp	Facilitated by INVOLVE: Network of people working to build evidence, knowledge, and learning about public involvement in NHS, public health, and social care research
James Lind Alliance (JLA)	http://www.lindalliance.org	To bring patients and clinicians together in “Working Partnerships” to identify and prioritize the unanswered questions that they agree are most important
Love/Avon Army of Women	http://www.armyofwomen.org	Online community & virtual matching service to connect women willing to participate in breast cancer studies with the researchers who need them
National Institute for Health Research (NIHR)	http://www.nihr.ac.uk/Pages/default.aspx	To improve the health and wealth of the nation through research
PatientsLikeMe	http://Patientslikeme.com	Online health data sharing forum where patients with different conditions share experiences and learn from one another about improving their own care
People in Research	http://www.peopleinresearch.org	To provide the public with information on opportunities to get involved in clinical research
Provocative Questions (PQ)	http://provocativequestions.nci.nih.gov/meetings	To identify perplexing problems in order to drive progress against cancer

Health Care Organizations and Initiatives From Grey Literature and Web Sites Reviewed		
Organization	Web Site	Purpose
Research to Reality (R2R)	http://researchto reality.cancer.gov	An online community of practice that links cancer control practitioners with researchers, to provide opportunities for discussion, learning, and enhanced collaboration on moving research into practice
RxFacts.org	http://www.rxfacts.org	To provide physicians with an evidence-based, noncommercial source of the latest findings about the drugs they prescribe
Sermo, Inc.	http://www.sermo.com	Online physician community where members collaborate to improve patient care
The Research Acceleration and Innovation Network (TRAIN) Central Station	http://www.fastercures.org/train/about	To create opportunities for medical research innovators to discuss and tackle the challenges that cut across diseases
UK Clinical Research Collaboration (UKCRC)	http://www.ukcrc.org	A UK-wide environment that facilitates and promotes high-quality clinical research for the benefit of patients

Non-Health Care Organizations and Initiatives From Grey Literature Reviewed		
Organization	Web Site	Purpose
Center for New Media and Citizen Engagement	http://www.gsa.gov/portal/content/140445	To make it easier for the Government to constructively engage with the public
ChemicalRight2Know.org	http://www.chemicalright2know.org/content/learn-more-about-site	To vet (EPA TRI) analyses, share success stories and best practices, and collaborate on solving community chemical-related problems
Collaborize™	http://www.democrasoft.com/about/democrasoft-team.html	To facilitate a vision of online “social networking with purpose”

Non-Health Care Organizations and Initiatives From Grey Literature Reviewed		
Organization	Web Site	Purpose
EngagE stakeholder management tools	http://www.pmlink360.com	To help companies manage stakeholder interaction, increase efficiency, and streamline communications to keep projects on time, on budget, and in-compliance
European Alliance for CSR	http://www.csreurope.org	To serve as a political umbrella for mobilizing the resources of large and small European companies and their stakeholders
Harlem Children’s Zone, Inc.	http://www.hcz.org/about-us/history	To help children in a sustained way, starting as early in their lives as possible, and to create a critical mass of adults around them who understand what it takes to help children succeed
HowTo.gov	http://www.howto.gov	To help Government workers deliver a better customer experience to citizens
IdeaScale	http://www.ideascale.com	To provide an online idea management tool developed for organizations seeking to obtain input from stakeholders/community members
National Charette Institute	http://www.charretteinstitute.org	To provide instruction on the NCI Charette System™, a holistic, collaborative community-planning process that “harnesses the talents and energies of all interested parties to create and support a feasible plan that represents transformative community change”
Office of Citizen Services (OCS)	http://www.gsa.gov/portal/content/141629	To ensure that the public has a unified experience when accessing Government information from the Web/print/phone
Office of Innovative Technologies (OIT)	http://www.gsa.gov/portal/content/154165	To help agencies deliver services to citizens, and to work on IT initiatives that advance the President’s tech agenda
Open Government Dialogue	http://opengov.ideascale.com	To solicit public input in crafting recommendations on open Government
Red Lodge Clearinghouse (RLCH)	http://www.rlch.org/content/about-us	To provide a “one-stop shop for interested citizens to learn, discuss, and participate in environmental policy decisions affecting western communities”

Non-Health Care Organizations and Initiatives From Grey Literature Reviewed		
Organization	Web Site	Purpose
Science & Entertainment Exchange	http://www.scienceandentertainmentexchange.org	To help bring the reality of cutting-edge science to creative and engaging storylines
Trusted Advisory Network (TAN) Program of Hewlett-Packard (HP)	http://www.hp.com/hpinfo/globalcitizenship/commitment/advisory.html	To provide HP the ability to understand stakeholder perspectives and respond to their needs
The National Coalition for Dialogue & Deliberation (NCDD)	http://www.thataway.org	To help members solve today's toughest problems through honest dialogue, quality deliberation, and collaborative action
Urban Interactive Studio LLC: Engaging Cities	http://engagingcities.com/post/329239497/about-engagingcities	To track urban planning 2.0, observing and experimenting with innovative planning processes
Urban Research and Outreach/Engagement Center (UROC)	http://uroc.umn.edu/about/index.html	To advance learning, improve quality of life, and discover breakthrough solutions to critical problems