Innovations in Stakeholder Engagement

Conference Summary
AHRQ Community Forum Project
October 21, 2011

On October 21, 2011, the Agency for Healthcare Research and Quality's (AHRQ's) Community Forum project convened a conference to explore innovative approaches for engaging stakeholders in health care research. AHRQ involves stakeholders—patients, consumers, caregivers, clinicians, researchers, health care payers, and policymakers—in its Effective Health Care (EHC) Program throughout the research process to improve research quality and assure that research is relevant, important, and responsive to users' needs. The goals of this conference were to identify emerging strategies and state-of-the-art methods for engaging stakeholders that will enhance the EHC Program's current stakeholder initiatives, and to provide a forum for a broader discussion of these approaches with others interested in involving stakeholders in health care research.

> **AHRQ's Community Forum, initiated in 2010, seeks to improve and expand public and stakeholder engagement in the Agency's Effective Health Care Program, which conducts and supports comparative effectiveness research.**

In advance of this conference, AHRQ's Community Forum team explored the current field of stakeholder engagement, both within and outside the health care industry. The team conducted a literature review, interviewed key informants, reviewed Web sites, and convened a panel of experts with knowledge and experience in stakeholder engagement. Through this process, the team identified a number of promising approaches, which were featured in the conference.

The conference focused on ways to use social media, such as online communities, and engagement techniques, such as grassroots organizing and collaborative research methods. Representatives of Government Agencies, health care researchers, patient and provider interest groups, technology providers, and health care payers contributed to the discussion. This report describes each featured Web-based and in-person engagement approach discussed during the conference; it concludes with a summary of considerations for implementing strategies to promote collaboration between stakeholders and researchers.

Online Collaborative Platforms

An online collaborative platform is computer software that supports communication and information-sharing between individuals involved in a common task. 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. Users may suggest, comment on, discuss, refine, and vote on ideas via online methods. These platforms promote transparency, participation, and collaboration.

Overview of Types of Online Collaborative Platforms

Chris Haller, Founder and CEO, Urban Interactive Studios

Online collaborative platforms provide an avenue for individuals to find and share information about health-related experiences, participate in online brainstorming, and interact with each other or with health organizations, to make better informed decisions about their own health care or help inform actions of health care entities (e.g., professional societies, Government Agencies). E-patients (people who use the Internet to seek out and share health information) are increasingly interested in having two-way dialogues with health organizations via social media, and organizations are recognizing that social media and social networks can serve as a cost-effective way to solicit consumer input to improve processes. For example, rather than having experts generate ideas for the public, online platforms facilitate crowdsourcing, the process of soliciting input and ideas from groups of individuals to carry out a task, solve a problem, or answer a question.

The following are examples of online platforms:

- *Ideation platforms* allow people to post or share ideas, comment on others' ideas, and rank or vote on ideas. These are typically micro-participation efforts, which allow participants to engage at their own convenience and do not require a significant time commitment.

- *Online dialogue platforms* facilitate two-way conversation and discussion of ideas, as a substitute for face-to-face meetings.

- *Prediction markets* allow users to forecast outcomes of future events and provide a space for users to discuss and bet on the probabilities of those outcomes. They are a means of aggregating information from experts on a given topic. Prediction markets related to health can be used, for example, to estimate future demand for a particular treatment or forecast events related to the spread of a disease. An example is the Iowa Electronic Health Markets, which uses prediction markets as a tool for disease surveillance (http://iehm.uiowa.edu).

- *Online communities* can be open to everyone or restricted to a particular audience. These are discussed in the next section.

- *Mobile Health (mHealth)* is becoming increasingly popular in communities that are not connected to the Internet (e.g., remote areas of Africa), where researchers and local health practitioners have a difficult time aggregating information or understanding what is going on in a community. mHealth uses simple cell phone technology, such as text messaging, to drive community health initiatives. For example, it can be used to help patients adhere to treatment regimens by sending them reminders via text message.

- *Virtual worlds* can provide learning opportunities that are unavailable in the real world. For example, simulations can be used to help people virtually experience what occurs in an emergency or what a newly built environment could look like.

Mr. Haller highlighted a number of critical points in using online platforms:

Recognize stakeholders' time limitations. Give a Minute (giveaminute.info) is a micro-participation effort where individuals can use virtual Post-it® notes to suggest or share ideas. One city used this ideation platform to ask people for ideas about what would encourage them to take public transportation more often. Advertising in public transportation (e.g., subways, buses) encouraged people to provide feedback via their mobile phones. The approach worked well because people could text when they had even a short amount of extra time.

Inform stakeholders early. Notify individuals about an upcoming Web site or resource and ask them to subscribe to a mailing list or register their interest in the platform. This early step allows organizers to efficiently notify individuals when the platform is finalized and live.

Ensure equal consideration of user input. Many times, the contributions of those who have responded most recently to a discussion thread or to requests for ideas are more prominently visible than the contributions of those who responded early on. It is important to assure that people who engage at any time within such a process receive equal attention and visibility.

Featured Collaborative Platforms

The National Cancer Institute (NCI) Experience: Using Collaborative Platforms for Communities of Practice—*Lakshmi Grama, Senior Digital Content Strategist, NCI*

NCI has used a variety of Web-based tools to facilitate occasional as well as ongoing interaction with stakeholder communities of practice, defined as groups of people who share a concern, set of problems, or passion about a topic and who deepen their knowledge and expertise in this area through interaction with each other. NCI initiatives that have involved *intermittent* interaction include:

- *National Dialogue on Improving Federal Web Sites*. This Federal initiative, conducted by the General Services Administration (GSA) and Office of Management and Budget (OMB), used Ideascale, a Web-based platform that facilitates crowdsourcing by allowing users to submit, comment, and vote on ideas for improving Federal Web sites. NCI used ideas gathered through this initiative to improve its Web site.

- *Provocative Questions* used a Web site to prompt cancer researchers and patients to propose research questions. The ideas generated through this effort led to the development of a request for applications (RFA).

NCI initiatives that support *ongoing* engagement with communities of practice include:

- *NCI Translational Research Network* (NTRIN, pronounced Enter In) is an invitation-only network that provides a protected environment where translational researchers can find each other, discuss issues, and establish collaborations. It uses Ning, an off-the-shelf platform where users can share documents, ask questions, and hold discussions.

- *United States–Latin America Cancer Research Network* also uses the Ning platform to provide a safe, secure and confidential environment for cancer researchers

throughout Latin America and the United States to discuss specific information about clinical trial protocols.

- *Research to Reality* links cancer control practitioners and researchers to promote collaboration between these groups. The site offers learning opportunities such as cyber seminars and followup conversations, as well as providing a space for discussion on moving research into practice. Drupal, an open-source free content management framework supported by a large community of developers, is used to support the site.

- *AccrualNet* supports successful enrollment of patients in a research study by providing access to existing tools, materials, and published journal articles on clinical trial recruitment; a space to ask questions, share experiences, and post tips and materials; and training opportunities on successful recruitment strategies. To support this network, NCI uses WordPress, a free blogging tool.

Lessons Learned: Online Collaborative Platforms

Focus on the purpose. Communities of practice mobilize around a need and interest, rather than a technology. Technology is simply one tool for sharing knowledge and best practices. For communities of practice to succeed, users must be interested and willing to mobilize around a project or topic, regardless of the technology.

Use seeding to build conversations. The audience will need help to learn about the expectations for discussions and questions on the platform. The "90:9:1" ratio says that 90 percent of individuals coming to the platform want to find information but will not participate or contribute; 9 percent are temporary contributors; and 1 percent are "champions" that keep the dialogue moving forward and make it a success. Reach out to the 1 percent to cultivate ("seed") discussions.

Recognize active contributors. Sustained and engaged community leadership and management are critical. Identify the "champions," show them they are appreciated, and encourage their continued involvement.

Allocate resources for dedicated support staff. Sustaining participation in online communities requires continuous interaction. Project staff should track "hot button" issues related to the topic and of interest to the community, create content and facilitate discussions surrounding these issues, and summarize conversations so participants understand how their discussions promote the broader purpose of the community.

Product Development Challenges

A product development challenge is a contest in which an organization challenges its target audience to submit ideas for or to create products. These products might be, for example, 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). The host organization determines the process for evaluating submissions and selecting winners. Entries may be judged by individuals from the host organization, members of the target audience, a separate entity, or some combination of these. The challenge format can be used to engage

stakeholders at the point of topic identification and in generating creative ideas around dissemination and implementation.

Featured Product Development Challenge

American Medical Association (AMA) App Challenge and AMA Idealab—*Bob Hicks, Business Development Process Director, AMA; Brian Eaggleston, Physician Outreach and Retention Manager, AMA*

The AMA App Challenge, completed in October 2011, invited U.S.-licensed physicians, residents, fellows, and medical students to submit ideas for smartphone applications (apps) to help them in their daily practices. The prize included $5,000, conceptual credit on the app, and an opportunity to present the idea to the AMA House of Delegates. The AMA developed a micro-site for the challenge that accepted submissions and also served as the voting platform. Both members and nonmembers could submit ideas, but only members could vote on a winner from among the 10 finalists. Through the challenge, the AMA hoped to engage members and nonmembers, bring positive attention to the AMA, and support the development of an app that fit the organization's mission to promote the art and science of medicine and the betterment of public health.

Lessons Learned: AMA App Challenge

Identify drivers for participation. Rather than being driven by the monetary prizes, stakeholders were motivated by the desire for recognition from their colleagues as well as the acknowledgment that they were meeting an important need for physicians. In constructing and publicizing the challenge, the AMA emphasized the significance of the challenge to stakeholders and offered prizes that would provide winners with the visibility and recognition that they valued.

Consider stakeholder needs when selecting a timeframe. The AMA recognized physicians' and students' busy schedules when deciding upon the duration of the submission and voting phases of the contest. In determining the length of time for accepting submissions (3 months) and voting (6 weeks), they selected timeframes that were short enough to hold stakeholders' interest and create a sense of urgency to participate, but also recognized the limited time their audience could be expected to devote to the contest.

Leverage existing resources. The AMA managed a limited budget and short timeframe for marketing by leveraging existing resources and partnerships for publicity and emphasizing Web-based opportunities over print media. To give the idea generation concept a farther reach than simply the app challenge, the organization launched a micro-site (AMAidealab.org) separate from the AMA site that it can use to host future idea generation activities. The AMA promoted the challenge through e-newsletters, e-mail campaigns, AMA publications, and meetings held or attended by the AMA. Numerous health care Web publications and blogs with a technology focus featured the challenge. Also, social media Web sites such as Twitter and Facebook, as well as YouTube, were used to post information and videos about the challenge.

Assure consistency in presentation of ideas. The AMA took two steps to ensure that voting was focused on the value of the ideas submitted, and not on the authors' ability to "mock-up" their concepts. First, a professional artist was hired to create mock-ups of each of the 10 App

Challenge finalist ideas, ensuring uniformity in the quality of the entries' appearance. Second, the Web site where voters viewed the apps displayed the finalists in a random order that regenerated each time the screen was refreshed.

Online Communities

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. Online collaborative platforms, described earlier, provide the software around which online communities can be built.

Much like an in-person community, online communities assemble individuals with shared interests to generate dialogue on a variety of issues. An online community can serve as a cost-effective way for institutions to identify how to deliver enhanced services, by soliciting stakeholder input in a manner that is less resource intensive than in-person techniques. It also can allow service providers to better understand their user base by getting ideas directly from the communities (e.g., polling, sampling) or indirectly (e.g., usage statistics). In the field of health care, online communities can be used for sharing health experiences and health care data, conducting online focus groups, organizing a particular audience (e.g., a society of consumers or health care professionals), or disseminating findings and research products.

Featured Online Communities

Within3: Online Communities—Health Care Professionals—*Atul Shah, Senior Vice President, Strategic Client Development, Within3*

Online communities for health care professionals (HCPs) facilitate peer-to-peer knowledge exchange by providing secure environments in which health care professionals can post about ideas or issues that they find important and discuss these with other clinicians. Clinicians value interactions with colleagues as a way of staying up to date. Online communities offer an alternative means of interaction in an environment where pressures on clinicians' time limit their opportunities for reading journals, attending seminars, and discussing with colleagues. Institutions use online communities to announce upcoming meetings, generate discussion on policy and health care issues, form networks and workgroups, provide education and credits, and facilitate the exchange of materials and resources.

Lessons Learned: Health Care Professional Online Communities

Recognize health care professionals' distinct needs. Social media for health care professionals differs from consumer social media in that these communities want content that is more technical. They want high-quality content that is clinically relevant and scientifically based. Health care professionals prefer a forum that allows them to interact with and learn from their colleagues. Online communities can respond by creating timely and trusted content and also by allowing community members to produce content and react to user-generated content.

Reach out to thought leaders to generate discussion. Respected opinion leaders can be a key source of content and also can drive conversations. It may be necessary to reach out to these

individuals offline to encourage them to "seed" discussions and facilitate more dynamic dialogue.

Ensure an appropriate level of security. Communities for health care professionals are centered around trust, identity, and ongoing relationships. Health care professionals prefer secure communities that allow them to know that the colleagues with whom they are interacting have the academic or clinical background necessary to lend credibility to their opinions. Closed communities also assure health care professionals that any issues or concerns they share about patient care will not be taken out of context or used in a way that would violate their privacy.

Allow multiple means of access. Online communities allow clinicians 24/7 access and mobile access to accommodate their busy schedules. Many clinicians use more than one technology to retrieve information; therefore efforts should expand past the Web into other channels, such as mobile phones and tablets.

Investigate potential legal issues. Organizers of online communities for health care professionals should involve a legal team early in the process to understand any regulatory and compliance issues. These may include Health Insurance Portability and Accountability Act (HIPAA) and Stark regulations for hospitals and issues related to off-label use and adverse events of medications, as well as discoverability, privacy and confidentiality.

Avoid appearing promotional. Health care professionals are less willing to trust and participate in sites that seem to promote a certain technology or treatment, or the interests of a particular entity (e.g., pharmaceutical industry, insurance companies) either through advertising, marketing, or written content.

Cultivate a community. Communities require ongoing planning and execution of content. Organizers should have staff and resources dedicated to maintaining up-to-date content, facilitating discussion and user interaction, and tracking user interests.

PatientsLikeMe: Online Communities—Patients/Consumers—*Dave Clifford, Public Health and Governmental Affairs, PatientsLikeMe*

PatientsLikeMe is an online health-data-sharing platform and online community where patients with different diseases and conditions share experiences and learn from one another to improve their own care. By contributing their own personal health data, community members are able to create a database of patient-reported outcomes that reflects the real-world course of disease. PatientsLikeMe currently has more than 100,000 users contributing data on more than 500 health conditions. As an online community, PatientsLikeMe members communicate with each other through forum discussions, private messages, and profile comments. Community members can also browse symptom and treatment reports and evaluations. On a personal level, members can develop their own profile charts to monitor the effects of their treatments and track discussion items to raise with their doctors on "Doctor Visit Sheets." Finally, from a research perspective, PatientsLikeMe has developed a survey tool as well as provided clinical trial recruitment, both of which can be useful to researchers.

Lessons Learned: Consumer Communities

User-friendliness is a key design aspect. Technology is important, but it is not the main consideration. Understanding the user experience and social context is essential to design. A

complex user process (e.g., multiple sign-ons) may reduce participation. Users also may need training to understand all the functionalities of a site and use them correctly.

Allow community members to share and generate content. Members want to be able to view information about other patients' experiences and share and discuss their own experiences. Information-sharing can allow patients to be better informed about what to expect from their condition and also to receive social support from other members.

Online communities can serve as robust data sources. Online communities can be more than simply places for users to interact. They also can serve as a means of collecting patient-reported outcomes measures and other data to improve patient care. Allowing users to access data about topics on the site (e.g., adherence, cost, side effects of a particular drug) can make communication among users more powerful.

Share information collected through the site with its users. Sharing findings that result from their contributions to the site helps users understand the purpose of their involvement. When an article about PatientsLikeMe was published in *Nature Biotechnology*, it was made open access and available free of charge at http://www.nature.com/nbt/journal/v29/n5/full/nbt.1837.html.

Grassroots Community Organizing

Grassroots community organizing takes 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. Examples include community events (e.g., town hall meetings, health fairs), involving the local press, community-based ad campaigns, and reaching out to advocacy programs within a target community to leverage existing relationships.

Featured Grassroots Efforts

Environmental Protection Agency (EPA), Office of Solid Waste and Emergency Response (OSWER): Community Engagement Initiative—*Ellen Manges, Senior Advisor, EPA OSWER, Lead of Community Engagement Initiative*

The EPA's OSWER handles all waste management and cleanup programs in the Agency, including the Superfund and Emergency Management Programs, which deal with the most serious environmental programs and cleanup programs. The Community Engagement Initiative (CEI) helps affected communities participate in Government decisions on land cleanup, emergency preparedness and response, and the management of hazardous substances and waste.

As part of these efforts, the EPA developed a 16-item Action Plan under CEI to help communities meaningfully participate in Government decisions. Many communities lack the resources, knowledge, or education to participate in a complicated process, and OSWER makes a particular effort to target historically under-represented, remote, and/or at-risk communities that need assistance in locating resources and participating in engagement activities. Previous efforts to engage community members included public meetings, publicity through newspaper articles, and making reports available at the local library. However, OSWER's current administration emphasizes identifying successful ways to deliver information to these communities, as well as making information available.

Lessons Learned: EPA

Simplify and explain scientific information. The science related to the issues can be complex and difficult to communicate to individuals and communities. Consider simplifying with plain language and visual aids (e.g., color coding).

Reach out to minority, remote, and at-risk communities. A disadvantaged community may have difficulty engaging in a technical process. Make an effort to reach out to these communities and provide the necessary assistance for promoting their involvement.

Allow for multiple perspectives. It is not necessary to come to consensus. Different stakeholders have different ideas about issues, and many issues are emotional. Ensuring that everyone participates is more important than coming to agreement, as it allows the ultimate decisionmakers to consider all points of view.

Make technical assistance available to the communities. Consider using technical advisors to assist the community in developing a community involvement plan, understanding the issue at hand, and helping the community advocate for themselves in the process. One option to consider is using a grant approach to allow communities to compete for access to technical assistance resources.

Include all parts of the community. Create opportunities for input from all community members, not just from stakeholders with vested interests, knowledge, or resources. Seek out the economically disadvantaged or environmental justice communities, as they may not be aware of meetings or other activities. Strive to help all community members understand that they have an opportunity to participate and the benefits of becoming involved.

Develop a process to allow all community members to meaningfully participate. Spend time to interview and understand community members. Provide assistance in setting up a community advisory group with local government and/or other interested community members. Partner with local institutions when possible. Promote community involvement plans and make sure plans are effective and can be used over the course of the entire project.

Make decisions transparent and accessible. Tell people when you don't know something and when you might know it. Conduct decisionmaking in a way that communities can trust and make information accessible to them as early in the process as possible.

Provide training to both employees that work with communities and community members themselves. Create a training program for all key personnel involved in engagement activities that informs employees of when, how, and why to engage communities and build trust. Create job training programs for community members (e.g., train community members to participate in a hazardous waste cleanup activity).

Create an online community engagement network. Bring together people who work with communities in an online/interactive way to increase awareness, both within the agency and externally (e.g., among practitioners and researchers).

Consider innovative technologies. Consider using Web sites and text messages to help communities understand information, but remember that some communities may not have access to these technologies.

High Plains Research Network (HPRN)—*Ned Norman, rancher, farmer, founding member of the Community Advisory Council of HPRN; Sergio Sanchez, business owner, member of the Community Advisory Council of HPRN*

HPRN is a practice-based research network of rural hospitals, clinics, and clinicians that works with a community advisory council of farmers, ranchers, school teachers, and other community members to improve medical care in rural Colorado. HPRN has conducted research on a host of topics, including cardiac care and palliative care, medical mistakes, colon cancer prevention, asthma, and the impact of underinsurance on access to care.

HPRN's goal is to translate the best scientific evidence into everyday clinical practice to provide high-quality rural health care. The network's Community Advisory Council (CAC) plays a major role in these goals by helping to inform and guide HPRN's research and ensure that the information returns to and improves the quality of health care in individual rural communities. The CAC is made up of an ethnically diverse group of community members with varying educational and socioeconomic backgrounds, who provide a perspective that may differ from that of health care professionals or researchers. CAC support has led to the successful implementation of health care initiatives, including an effort to encourage screening for colon cancer and another to improve asthma care in clinics, schools, and communities.

Lessons Learned: HPRN

Build on energy within the community. Community members are often motivated by the prospect of helping their community. Build on this energy to facilitate the design of interventions that best meet community needs. Providing feedback to the community members about how their involvement has made a difference will reinforce their interest in being involved in decisions that affect them.

Minimal training is required. Provide 1-day, topic-specific training sessions where providers can train community members on a condition. The community members are already experts on the needs of their community.

Participants are not health care providers. The goal of most campaigns is not to advise the community on health care but to trigger conversations with providers.

Community advisory councils have built trust and rapport with the community. Community advisory councils can be successful in communities even when there is a level of distrust of researchers. Consider using local community members when distributing materials or giving talks at community venues (churches, rotary clubs, etc.). Partner researchers or clinicians with a community member; the researcher or clinician can provide medical information while the involvement of the community member encourages others to trust and listen to the talk.

Community advisory councils are more than focus groups. Focus groups are often held for a short period of time (1–2 hours.) In contrast, community advisory councils are deeply involved in the process and provide recurring, systematic input throughout the research process.

Involve community advisory councils to raise awareness of specific issues. Community advisory councils can help draft effective messages for raising awareness and generating dialogue about specific issues affecting a community, as they are experts in what can catch the community's attention. Empower community members by designating leaders within smaller

communities—e.g., within a football team, school, junior college, or club—and letting them customize messages and interventions.

Promote interaction between community members. Develop materials that encourage community members to interact with each other. Examples include simple cards with messages that can be passed among community members to generate discussion about an issue, e.g., in the grocery store or on the sidewalk. These cards also can motivate community members to call their clinics to receive small prizes (e.g., coffee mugs), while simultaneously creating buzz around the issue. Simple but catchy slogans are conversation starters.

Tailor materials to your target audience. Develop materials that spark interest with a specific audience. For example, a younger group might respond to the message "Asthma doesn't have to stop you from playing baseball. Talk to your doctor today."

Continuously nurture the network. A grassroots community advisory council must be nurtured continuously so that participants are available when projects arise and do not have to be recruited for each new project. The value of the network is particularly high in rural areas, where information dissemination is more challenging.

Foster a sense of respect, value contribution and loyalty, and promote work that is fun, challenging, and purposeful. A successful community advisory council respects and values every member of the community and encourages ongoing commitment to the council and community. Members are given work that is fun but also challenging and purposeful. Members may appreciate the opportunity to carry out tasks that encourage them to think through complicated issues.

Collaborative Research

Collaborative research, or participatory action research, aims to bring together an organization and stakeholders or service recipients to collaborate in the design and conduct of all phases of the research process. Collaborative research efforts establish relationships with organizations and participants to facilitate collaboration, engage participants early in the process, work to understand the needs of the service recipients, and develop resources and materials to support participants' involvement in research.

Featured Collaborative Research Efforts

Substance Abuse and Mental Health Services Administration (SAMHSA), Children's Mental Health Initiative (CMHI)—*Ingrid Goldstrom, Director of the CMHI Evaluation, SAMHSA*

CMHI provides funds to promote transformation of the mental health system that serves children and youth diagnosed with serious emotional disturbances and their families by coordinating care with other child-serving agencies, such as education, primary care, child welfare, and juvenile justice. CMHI created Youth Advisors Driving Action (YADA), an advisory group of youth that provides input and guidance to national evaluation efforts. Youth are involved in specification and design of research questions, data collection and analysis, and research dissemination. CMHI work is based on the premise that a participatory action research strategy brings researchers and

stakeholders (in this case, youth) together to collaborate in all phases of the research process, rather than just interjecting stakeholders at different steps of the process.

Lessons Learned: CMHI

Engage consumers in designing research questions. Consumers are in the best position to identify research gaps. Ask people what helps them in their recovery and design research questions that are directed at these needs. Consumers can refine and review procedures to help eliminate jargon, use respectful and appropriate language, and identify cultural and linguistic issues to consider.

Involve consumers in data collection and the interpretation of results. Use consumers to interview other consumers. The participants may feel more comfortable sharing personal details with someone to whom they can relate during the interview. Consumers also can help with recruitment. When interpreting results, consumers can provide context that help explain the results of data analysis.

Involve consumers in dissemination/utilization of research results. Consumers can provide input on how to apply research findings to their communities and can help disseminate information within the community. Allow consumers the opportunity to contribute personal stories of recovery to presentations to draw a wider audience and add a personal touch to research findings.

Gather feedback at each step of the research process. Many stakeholders are involved in this iterative process, and it is important to continuously gather feedback. This gives insight into how the process is going each step of the way, while also building trust among stakeholders.

Provide compensation to consumers. Offer fair and reasonable compensation, including cash advances, child care, adult supports for youth, and travel support. Consumers provide knowledge and expertise, and this should be compensated. Schedule meetings for times when stakeholders are available.

Engaging consumers is a "win win." The organization can learn directly from the youth about what they find important, and the youth can gain skills that can facilitate their recovery and empowerment.

James Lind Alliance (JLA) and invoNET—*Ela Pathak-Sen, Director, Commotion*

The JLA, based in the United Kingdom, supports priority setting partnerships that bring together patients, caregivers, and clinicians to identify uncertainties about the effects of treatments and assign priorities for the importance of addressing these uncertainties through research. The organization developed a guidebook describing its approach to establishing priority setting partnerships. JLA works closely with the UK Database of Uncertainties about the Effects of Treatments (UK DUETS). This database lists all uncertainties about a disease treatment or intervention that cannot be resolved by reviewing reliable systematic reviews of existing research. Examples of treatment uncertainties that were identified as research priorities by patients, caregivers, and clinicians include the role of complementary therapies in asthma management and the effects of physiotherapy and surgery as treatments for osteoarthritis of the knee. Entities that wish to establish priority setting partnerships can use the database to understand the uncertainties surrounding a particular topic.

InvoNET is a UK-based network of individuals working to build evidence, knowledge, and learning about public involvement in health research. The organization is funded by the UK's National Institute for Health Research (NIHR); its primary role is to develop an evidence base for public involvement in health research. The invoNET library houses a large research collection, most of which is peer-reviewed, that examines the nature, extent, and impact of public involvement in research. As a result of invoNET's work, organizations that apply for public funding from NIHR are required to include a section on public involvement demonstrating that their research has public support. Another impact of invoNET's work is that patient groups often access the research in their library to encourage health organizations to better involve and consult with them. InvoNET also provides research support related to public involvement in health research to the National Institute for Health and Clinical Excellence (NICE), a UK national body that makes clinical recommendations to the National Health Service and develops clinical quality standards and guidelines about treatments, medications, and procedures.

Lessons Learned: JLA and invoNET

Address patient-defined outcomes. Decisionmaking should be informed by outcomes and preferences that are important to the patients or caregivers. For example, although clinical research indicated that the amount of psoriasis most affected patients' quality of life, patients were most concerned with the location of the psoriasis. In another instance, a review of the evidence showed little difference in effectiveness between older, less expensive antipsychotics and newer, costlier ones; however, patients indicated that the side effect profiles associated with the drugs were crucial to their adherence to treatment regimens.

Create materials directed at patients. To support public understanding and acceptance of guidelines or other materials that influence clinical practices, develop accompanying materials for the public that translate the guidelines into language that is understood by the broader public.

Explain decisions to stakeholders. When decisions about guidelines or clinical recommendations differ from advice received from patients and caregivers, explain why the recommendation differs from their input so they understand that their input was considered.

Recognize opportunities for stakeholder groups to work together. In areas where evidence is uncertain, bringing together small groups of clinicians and consumers to collaboratively discuss what is and is not known can help inform each group's key questions and concerns. Consider patients as experts on their own diseases and empower them to work with clinicians to identify research priorities.

Provide researchers with evidence-based methods to involve patients and the public in their research. Providing research into patient and public involvement in research ensures that researchers can undertake evidence-based approaches to public involvement.

Summary

At the conference, presenters outlined specific findings for activities and approaches to support collaboration between stakeholders and researchers in AHRQ's EHC program. Key themes that emerged for consideration include:

- Recognize that technology supports engagement, but technology alone does not ensure engagement. Stakeholders should recognize a need and purpose for their involvement, and organizers should identify what motivates stakeholders to participate.

- Leverage consumers' growing use of social media to find and share health information. Online platforms and communities can serve as an effective and efficient way to identify stakeholder needs, obtain their input to assist decisionmaking, and engage them in problemsolving to benefit a larger stakeholder community.

- Allocate dedicated resources and staff to make sure that content is accurate, relevant, and up to date.

- Nurture the community by dedicating staff to assist in promoting participant interaction and summarizing the results of their participation.

- Proactively reach out to stakeholders, rather than expecting them to seek out a particular resource.

- Acknowledge that different stakeholder groups have distinct needs, and organizers must understand and meet those needs for the stakeholders to feel comfortable participating.

- Provide a forum for users to develop content themselves and discuss user-generated content with their peers. Users are interested in having two-way dialogues, as opposed to viewing static content.

- Assist the development of discussions through seeding, where specific individuals (e.g., designated staff, thought leaders, highly engaged members) are asked to foster discussion surrounding a particular topic.

- When conveying a complex or technical message, use language that is appropriate for a broad audience to increase public understanding and acceptance of the message.

- Promote transparency throughout the entire process of engaging stakeholders. When a decision is made that differs from stakeholder preferences, include an explanation of the process and conclusion.

- Develop processes that allow all community members, including disadvantaged members, to meaningfully participate.

- Provide training with the purpose of informing stakeholders' participation in activities such as discussion, data analysis, and evaluation.