Transforming Patient-Centered Research: Building Partnerships and Promising Models

Workshop Report Prepared by
Institute for Alternative Futures

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Executive Summary

The Patient-Centered Outcomes Research Institute (PCORI) has a unique mission to put patients and those who care for them at the center of healthcare research. It is a tremendous opportunity to bring patients, caregivers, clinicians, providers, researchers, and the entire healthcare community together to answer, through research, the questions that matter most to patients. As part of PCORI's effort to fulfill this mission, we convened 150 individuals from across the country in October 2012 to begin a discussion about how to conduct patient-centered research that includes meaningful roles for patients and other healthcare stakeholders throughout the research process.

> *I returned from the workshop much better educated on PCORI and how patient engagement is paramount to its success.*
>
> Matt Cheung, workshop participant

The workshop included a pre-event exercise that invited participants to share their vision for patient-centered research. What could it look like in the future? How could it effectively put patients at the center of the process, from identifying and prioritizing questions all the way through to disseminating and implementing results? The two-day workshop, "Transforming Patient-Centered Research: Building Partnerships and Promising Models," was held in Washington, D.C., on October 27 and 28 and featured five breakout sessions on topics critical to authentic patient-centered research:

- Identifying and Selecting Research Questions
- Reviewing Research Proposals for Funding
- Matching Patients and Stakeholders with Researchers
- Disseminating Research to the Community
- Evaluating PCORI's Patient and Stakeholder Engagement Programs

Led by PCORI staff and trained facilitators, the sessions created a rich dialogue about engagement. From the event, many networks and connections among the participants were established that continue to generate ideas to enhance research. From the workshop, PCORI received a range of suggestions that we continue to explore, including:

- How to best capture research ideas from patients and other stakeholders
- The concept of "micro-grants" for building partnerships between patients and researchers
- Enhanced patient participation in funded proposals
- Tools for matching researchers with patient partners
- The creation of a PCORI ambassador initiative

Always receptive to community feedback, PCORI is already implementing two of these ideas. A micro-contracts program is under development to support communities in research partnership development activities. PCORI also is exploring an ambassadors program to equip patients and other stakeholders with tools to get more members of their communities involved in research and to serve as a valuable resource for the organization's future programs.

During an evening dinner, participants were invited to organize themselves into affinity groups, and some of the topics that emerged included PCORI advisory panels, disparities in health care, hospital-acquired infections, transparency, caregivers, rare diseases, and clinical trials. A number of these affinity groups are now developing additional networks that will continue to focus on these topics, while

strengthening the community of engaged patients and advocates working on patient-centered outcomes research.

The workshop's agenda was created by a working group of patients, patient organizations , a PCORI board member, and PCORI Methodology Committee members and organized around the following objectives: to build partnerships to make patient-centered outcomes research a reality; to generate ideas and principles for how patient-centered research can be promoted, conducted, and disseminated; to identify and further develop the most promising models of patient engagement that exist today; and to form an enduring community to support these activities on an ongoing basis.

Response to the workshop was overwhelming. PCORI received approximately 350 letters of interest from individuals interested in attending. Many of those unable to attend in person, because of the event's space limitations, participated remotely through the workshop's webcast and through social media. One message from participants was clear: patients are ready to be partners in research—in suggesting and vetting research questions, as members of research teams, and as partners in sharing research results. Indeed, the workshop validated and endorsed the vital role patients and other stakeholders can play in advancing patient-centered research.

A summary of feedback from the five breakout sessions follows.

IDENTIFYING AND SELECTING RESEARCH QUESTIONS

Participants stressed that PCORI must ask the type of questions that patients can address, and then these questions should be vetted and translated (into research questions) as they go through the submission process. In selecting research questions, PCORI should be strategic, avoiding duplicating the work of National Institutes of Health (NIH) and Centers for Disease Control and Prevention (CDC), funding a mix of disease-specific and more general population health and social determinants of health research, and also looking for "low-hanging fruit" that would produce an impact before Congress's evaluation of PCORI seven years from now. Workshop feedback demonstrated that it is critical for PCORI to conduct broad outreach to ensure that all populations are brought into the process, reaching beyond those who self-identify as "patients."

Further, PCORI should leverage the potential of "big data" and should be transparent in all aspects of the process, in particular, updating those who submit questions on where their questions are in the process, much as an online retailer will provide e-mail updates (e.g., "your order has shipped"). This will mitigate disappointment on the part of patients who make the effort to engage and fear their engagement may provide no tangible results.

REVIEWING RESEARCH PROPOSALS FOR FUNDING

Participants stressed that PCORI's processes must be transparent, and that patient-centeredness should hold equal weight with other values in the review process, rather than being another "box that needs to be checked" on research applications. PCORI should empower patient and scientific reviewers through education and training to stand on equal footing with each other. PCORI should be specific and direct in all communications, in particular, by taking time to define terms like "patient engagement" to make clear PCORI's expectations about how patients will be involved throughout the process. Participants recommended that PCORI use lay language and provide guidance for patient statements of support that includes clear terms for the types of tasks patients might undertake during the proposed research process. Most importantly, PCORI should make the review process fun and interesting, addressing the

risk that the format, structure, and content of a conventional review process might overwhelm those coming in from outside the research community.

MATCHING PATIENTS AND STAKEHOLDERS WITH RESEARCHERS

Participants suggested that PCORI establish a clearinghouse—for example, a "Match.com" model—that brings together researchers and patients with common interests, in part by supporting or leveraging networks and collectives that already exist. PCORI should recruit patients into this clearinghouse through diverse means and from a variety of groups, reaching out to those whose voices now go unheard. To support this recruitment, PCORI should create a group of PCORI ambassadors who know PCORI well and can carry PCORI's message to their own networks and organizations. PCORI should also alter its funding to incentivize collaborations among patients and researchers. One key notion identified by participants was to "flip the funding," meaning that if patients are going to be fully engaged in research, then the financial incentives need to be aligned to that goal. PCORI grants could, for example, go to patient organizations or groups rather than researchers to incentivize researchers to work with patients. PCORI could also offer smaller funding opportunities to facilitate collaborations among patients and researchers to develop proposals or to promote a broader culture change around patient-centered outcomes research.

DISSEMINATING RESEARCH TO THE COMMUNITY

Participants encouraged PCORI to develop communication vehicles and channels appropriate to diverse audiences, including disenfranchised patients, using plain language and standard formats. PCORI should learn how non-healthcare entities (e.g., Apple) have created rapid popular acceptance of innovations.

> *We talked about an overlap zone, a shared, common cultural ground that researchers and patients and other stakeholders can join in.*
>
> Lori Frank, PhD,
> Director, PCORI Engagement Research

PCORI should require from grant applicants a dissemination plan that involves patients and knowledgeable PR/marketing experts and that includes quantifiable measures of success. PCORI should build an infrastructure for dissemination that could include: conferences, conversations at barber shops, patient support groups, a national tour, health fairs, brochures, TV or radio public service announcements, graphic novels ("comic books"), and much more. At the same time, PCORI should strengthen dissemination through social networks, mobile apps, and computer games to reach all generations. PCORI should also train patients and researchers on how to do dissemination differently and should recognize that the best people for doing the research are not necessarily the best people to disseminate the results.

EVALUATING PCORI'S PATIENT AND STAKEHOLDER ENGAGEMENT PROGRAMS

PCORI should make evaluating patient engagement a requirement for every research proposal and should evaluate patient engagement at each stage of the research process: topic generation, research design, research implementation, dissemination, and outcomes. This evaluation should include both objective measures (e.g., how many patients were engaged?) and subjective measures (e.g., how satisfied were patients with the engagement process?). Longitudinal measures should be tracked as well, particularly since patients will likely "vote with their feet" by affiliating with research institutions whose patient engagement programs are more effective. PCORI could create a "seal of approval" for those institutions that are conducting "research done differently." Evaluations should incentivize "co-learning" between patients and researchers, not making patients into researchers and vice versa. PCORI

should assess whether patient engagement effectively reduces the time required for research findings to change practice, and, if so, how. More generally, evaluation should capture the meaningfulness, quality, and impact of patient engagement in research.

Participants' ideas on these topics were synthesized the following day in report-outs to the full group, which included members of PCORI's Board of Governors, Methodology Committee, and senior management. PCORI leaders stated that the following workshop outputs will guide their efforts moving forward:

- This workshop demonstrates that patients are ready, equipped, and eager to engage.
- Transparency is critical.
- Information must be tailored to meet patients' needs.
- PCORI's activities must reach out to and be inclusive of all communities.
- Capacity building via training and toolkit development is needed.
- It will be essential to help patients hold their own throughout the research process.
- Flexibility is required in the funding available from PCORI.
- The idea of a "Match.com" model to connect patients and researchers is intriguing.
- No trade-offs can be made between engaging patients and conducting high-quality research.
- This workshop could be the start of a transformation in how research is done.

As with PCORI's leadership and staff, workshop participants committed themselves to this work in the months and years ahead. Recognizing the unique opportunity offered by PCORI, these patients, family caregivers, patient representatives, and other stakeholders formed a community that will expand. As people from all stakeholder groups, communities, ethnicities, and walks of life are brought into the process, PCORI can transform how research is done. This transformation will put patients at the center, and generate the information they need to make the health decisions that are best for them. This is our vision of patient-centered research.

This report captures and lays the groundwork for ideas and recommendations from the workshop. Its intent is to inform PCORI's Board of Governors and staff decision making on best practices and opportunities in engagement. Finally, it will continue to function as a discussion point as PCORI works with all stakeholders in the healthcare community.

PCORI is appreciative of the community's participation and input through this workshop and other forums to date. Feedback on this report, including ideas and suggestions that expand on the five breakout session themes, may be submitted by email to getinvolved@pcori.org. Additional opportunities for engagement can be found through the "Get Involved" section of pcori.org.

Table of Contents

Introduction

What is meaningful—and unprecedented—about the Patient-Centered Outcomes Research Institute is captured in its name. "Patient" refers to those who receive care and advocate as partners in health care that improves quality of life. "Centered" speaks to an inner solid core that is unwavering amidst vicissitudes and to the clear knowledge of one's own true purpose. "Outcomes" refers to tangible changes in the care delivered to people based on truths that will endure, as opposed to "results" that are narrowly defined to fit the timeline or interests of a researcher or other stakeholder. "Research" refers to a noble quest for learning—a search for answers that improve people's lives. "Institute" refers to an enduring entity, conceived and built out of a realization that something new is needed. What is meaningful about PCORI is the very real potential it represents to create "research done differently"—with the patient firmly rooted at the center.

To design this "research done differently," PCORI invited 150 people—of whom three-fourths were patients, caregivers, or patient advocates, and the remaining were other stakeholders (see **Appendix 3**)—to Washington, D.C., for a two-day workshop titled "Transforming Patient-Centered Research: Building Partnerships and Promising Models." The design of the workshop came from a collaboration among PCORI staff members, a volunteer "working group" of patient representatives and other stakeholders (see **Appendix 2**), and the facilitation team: Jonathan Peck and Eric Meade, from the Institute for Alternative Futures, and Martin Hatlie, from Project Patient Care. One key component of this design was an aspirational framing—that is, participants would be asked to envision what successful patient-centered research *could* be in the future, not to dwell on the failings of the past. To facilitate this framing, participants paired up before the workshop to conduct a "pre-work" exercise that elicited their initial thoughts on patient engagement and put them in an aspirational frame of mind. (See **Appendix 4**.)

The workshop's objectives were to build partnerships to make patient-centered outcomes research a reality; to generate ideas and principles for how patient-centered research can be promoted, conducted, and disseminated; to identify and build on the most promising models of patient engagement that exist today; and to form an enduring community to support these activities on an ongoing basis. As PCORI Director of Patient Engagement Sue Sheridan told participants, "This is an invitation to help us build us." And build they did. In a series of interactive and creative discussions, in plenary sessions, and in small groups, participants provided more than 100 ideas (see **Appendix 1**) and offered important principles to guide PCORI's work in the years to come.

To set the stage for these discussions, presenters from four different successful models of patient engagement described their experiences and highlighted the features that made their models successful. These models are briefly described below.

- Maret Felzien and Ned Norman are on the Community Advisory Council of High Plains Research Network (HPRN). The council guides a research network that includes every clinic, physician practice, nursing home, and public health department in a large rural area in eastern Colorado. The Council's nine-year partnership with researchers has reached the point where the Council is fully involved in designing, implementing, and evaluating research studies, as well as in explaining the results in the community. Council members are local people from all walks of life, who go through a research "boot camp" that helps them work "shoulder to shoulder" with researchers to ensure that research is relevant to the community.

- Kris Schulze and Vinod Bhutani from Parents of Infants and Children with Kernicterus (PICK) shared the experience more than a dozen years ago of a small group of parents whose children suffered preventable lifetime brain damage due to severe newborn jaundice. As these parents learned of one another, they converged on a medical symposium in Chicago and formed PICK. Partnering with physicians and organizations such as the Joint Commission, the CDC, and the American Academy of Pediatrics, these parents learned that a simple $1 test can prevent a lifetime of disability. These "moms on a mission" gathered evidence and advocated to change pediatric standards of practice, which have now been implemented across the country. PICK also works to ensure that those with preventable disabilities are given every opportunity to lead as full a life as possible.

- Ben Haywood, CEO of PatientsLikeMe.com, shared how his brother's diagnosis of ALS (Lou Gehrig's Disease) prompted his family to create what has become PatientsLikeMe.com, a website where patients share their stories and exchange information about how their illnesses are affecting their bodies, minds, and lives. The stories and data they submit constitute a new research infrastructure for patients who need answers faster than conventional research can offer. The site's approach to informing patient decisions acknowledges that much evidence is imperfect and exists across a spectrum of quality, as it is aggregated from the real experiences of patients. The goal is to help patients drive their individual care decisions while contributing to aggregated information that drives systemic learning.

- Childlene Brooks, from Maryland's Talbot County, and Janice Bowie, from the Johns Hopkins Bloomberg School of Public Health, presented a collaboration by the Talbot County NAACP, the county health department, and Dr. Bowie to conduct community-based participatory research to better understand the county's pervasive health disparities, particularly among African American residents. Based on needs assessments and asset mapping, the collaboration has applied for grants to address the disparities in cancers and other conditions that make Talbot County less healthy than others in Maryland. The partnership formed from the initiative of community members who have a long-term commitment to build the county's capacity for improving health outcomes.

These presentations showed that successful patient engagement in research is possible and reinforced the positive frame of mind that participants had already explored during the pre-work exercise. Following these presentations, participants divided into small groups, which rotated through the following topics:

1. Identifying and selecting research questions
2. Reviewing research proposals for funding
3. Matching patients and stakeholders with researchers
4. Disseminating research to the community
5. Evaluating PCORI's patient and stakeholder engagement programs

We are experts at understanding our community. We know what people are concerned about, we know what they need and want in our small towns in northeastern Colorado… We also know how information moves through our rural community. We know who moves it. We know who drives it. We have the pulse on northeastern Colorado.

Maret Felzien, Member, High Plains Research Network Community Advisory Council

In the evening, over dinner, many participants organized themselves into affinity groups to focus on: creating advisory panels, social determinants of health, advance directives and hospital-acquired infections, transparency, caregivers, and clinical trials. A number of these groups are developing networks that will continue to focus on these topics, while strengthening the community of engaged patients and advocates working on patient-centered outcomes research.

After all groups had contributed their ideas on each topic (see **Appendix 1**), small group facilitators—drawn from PCORI staff—synthesized key ideas and presented them to the full audience, which included members of PCORI's Board of Governors and executive leadership. When these PCORI leaders were asked to respond to what they had heard, participants were pleased to hear the leaders' enthusiasm about many of the ideas that the workshop had produced, as well as their commitment to pursuing these ideas going forward. It was clear to those who had participated that the workshop had achieved its objectives—to build partnerships, to generate ideas and principles, to develop models, and to form an enduring community. As PCORI Methodology Committee member Clyde Yancey said: "This kind of forum is really novel. It hasn't happened before. So the patient-centeredness, the patient engagement has happened as of this weekend."

Breakout Summaries

Each topic below represents an important component of the patient-centered research process. The input received during the workshop will be used by PCORI staff to develop policy and programmatic recommendations to the PCORI Board of Governors.

IDENTIFYING AND SELECTING RESEARCH QUESTIONS

PCORI is working to develop a transparent and deliberative process that produces patient-centered questions and encourages participation from patients and other stakeholders who are not typically involved in the research process, including underserved populations. Research questions PCORI will address include:

- Assessment of prevention, diagnosis, and treatment options
- Improving healthcare systems
- Communication and dissemination research
- Addressing disparities
- Accelerating patient-centered outcomes, methodological research, and infrastructure

In each area, PCORI seeks patient involvement to identify and select the most important questions. For this purpose, incorporating web and social media tools is a priority for the developing process to allow for broader participation.

In the breakout sessions, which focused on how to improve the PCORI process for identifying and selecting research questions, participants recommended the following.

Ask the type of questions that patients can address. As Ben Hayward of PatientsLikeMe.com had stated earlier in the day, "Patients don't have research questions. They just have questions."

Participants suggested asking patients to answer, “What is your biggest health concern that you don’t know a lot about?” or, “What is your greatest health issue, and what do you need to know about it?” This would be much less intimidating and much more accessible than asking patients to provide research questions as they are typically formulated.

Recognize that some translation needs to occur between patient questions and research questions. The questions a patient might ask (e.g., what should I do?) may be reframed for research. Participants noted the need to take the “me” out of the question, but to leave the “patient” in. However, people will vary in their ability to move their own question along that trajectory. So the research partnerships will depend on mutual understanding. Because research with patient engagement is fairly new, this understanding may be difficult to calibrate, especially in the first few rounds of funding. Participants identified a few potential solutions to this challenge:

- PCORI could create a group to translate questions submitted by patients into questions that can be pursued through scientific research.
- PCORI could create a process that vets and scales the questions as they go through the selection process.
- PCORI could create toolkits, online tutorials (e.g., a YouTube video), and free seminars to teach people how to convert their own questions into research questions. These resources could include examples of questions that could serve as models for others to follow.

Be strategic and transparent in decisions regarding funding priorities. For this purpose, participants raised the following considerations:

- There is an obvious tension between disease-specific and general populations, between rare disease research and research on the social determinants of health. PCORI will have to work across the expectations of many different groups.
- PCORI should not just fund the research desired by the loudest advocates, and should focus on patient-centered outcomes research with the potential to change how care is delivered.
- PCORI should also avoid funding “me too” studies that offer little clinical value. Similarly, participants encouraged PCORI to avoid duplicating research already being funded by the NIH, the CDC, and other such organizations.
- Congress will evaluate PCORI seven years from now; thus, many participants encouraged PCORI to identify “low-hanging fruit” through which PCORI could demonstrate its value within that short time. These could be areas where there is no data, and any data would be hugely beneficial, or areas where there are specific gaps that could be filled quickly, and where the impact could be demonstrated quickly.
- PCORI may receive questions fitting the following suggested categories:
    - The answer is already known. For these questions, PCORI should find a way to disseminate the existing knowledge to those who need it and also fund research into the obstacles to dissemination.
    - There is some data, but no answers (yet). For these questions, PCORI should try to establish a shared data repository so that answers can be found to fill the knowledge gaps and synthesize evidence to create new knowledge.
    - There is no data. For these questions, PCORI should identify the research questions that would lead to the highest impact for the delivery of care.

Conduct broad outreach to ensure that all populations are brought into the process of identifying and selecting research questions. This outreach should include groups such as clinicians (who could enter

questions alongside their patients), patient advocacy groups, public health departments, research organizations that have patient advisors, and those serving high-disparity populations (schools, community health centers, churches, and other faith-based organizations), as well as less obvious groups such as employers, prison inmates and their providers, service members and veterans, student councils and PTAs, and homeless people. Participants also envisioned training patients to facilitate discussions that would yield research questions.

Reach beyond those who self-identify as patients. For this purpose, participants felt that PCORI's outreach should put "boots on the ground" in communities, as well as at existing meetings of patients and caregivers. This could be done through health fairs; kiosks in stores such as Target, Walmart, and Costco; or in any setting where people feel comfortable. Through this process, PCORI can solicit research questions but, more importantly, visibly demonstrate that PCORI is a true partner. While participants recognized the importance of social media, they also stressed that PCORI should use a *wide array* of approaches—including pen and paper for those who lack access to the Internet or the ability to use it. Participants also proposed having PCORI "ambassadors" within the community, which could include workshop participants themselves.

Leverage the potential of "big data." Doing so includes:

- Using the Centers for Medicare & Medicaid Services (CMS) claims database to find the sickest people, and then identify the research questions that would provide the knowledge they need.
- Mining social media, using algorithms to find the questions already being asked by patients.
- Collecting questions that have been rejected by other funders (CDC, NIH, etc.) to find topics that would be appropriate for PCORI to pursue.
- Creating new online platforms to crowd-source questions, and then allow those questions to be tagged as "already asked," "ineligible," and so forth. This platform could also allow patients to create a "wish list" of research topics or to "like" topics that have been submitted by others.

PCORI must be transparent in all aspects of the process. Despite the great efforts identified above, participants recognized the very real possibility that some who submit questions will be disappointed if their questions do not lead to actual research. For patients and caregivers who have been advocating for patient-centered research for many years, there is a great risk that they will have their hopes dashed if PCORI does not take up a research question they submit or if PCORI somehow mismanages the process.

The best possible antidote to this disappointment is for PCORI to be transparent in all aspects of the process. For example, participants felt strongly that those who submit research question should receive e-mail updates as the question moves through the PCORI process, much as an Amazon.com customer receives a message after an order that says, "Your order has shipped." When a question is rejected, PCORI should be transparent as to the reasons why. Furthermore, PCORI should create a repository for rejected questions so that they can be taken up by other research organizations, funders, or crowd-sourced efforts.

During the meeting, the murals included in this report were created for each topic by the graphic facilitation firm Visual Insight.

REVIEWING RESEARCH PROPOSALS FOR FUNDING

PCORI invites patients and other stakeholders to serve as reviewers for all submitted research proposals. Stakeholder reviewers play an important role in helping PCORI determine which research applications receive funding. PCORI is interested in refining the strategy for recruiting, training, and utilizing patient and stakeholder reviewers to ensure that anyone who is interested in being a reviewer has an opportunity to do so, regardless of prior research or medical experience.

For the initial round of PCORI funding applications, Cycle I, the Institute conducted a merit review of applications through a two-phase process. In Phase I, scientific reviewers established which proposals met rigorous technical standards. In Phase II, scientific reviewers and stakeholders reviewed applications that ranked highest in Phase I, focusing on the potential impact of the research for patients and other decision makers, as well as on the quality of the plan in each proposal for engaging patients and other stakeholders in the research. Of the eight criteria used to evaluate proposals, patient reviewers were asked to score on three criteria that are directly related to patient-centeredness. This stakeholder review was conducted in a face-to-face meeting and discussions that involved both scientific and stakeholder reviewers. These panels of stakeholder and scientific reviewers then assigned criteria and overall scores for each application. It was these final scores that were used in making funding decisions.

With the recent opening of Cycle II, PCORI is considering whether to involve stakeholders in both Phase I

and Phase II, either for Cycle II or future cycles. In the breakout sessions focused on how to improve the PCORI process for reviewing research proposals for funding, participants responded by articulating the following values.

PCORI's processes must reflect transparency. Participants stressed that the following items should be made publicly available: backgrounds of reviewers, proposal review criteria, submitted proposals, and data and findings from funded research. The purpose of such transparency is not just to allow for public scrutiny and oversight; it is also to ensure that the research community "makes better mistakes tomorrow" because all stakeholders are able to learn from one another. In particular, this transparency of research data and findings would support collaboration among researchers, which would help reduce the average of 17 years it now takes for a discovery to move from research to practice.[*]

Patient-centeredness should hold equal weight with other values in the review process. To do this fully requires the following four components:

- Reviewers should give equal weight to the criteria of patient-centeredness and scientific rigor. Historically, there has been a tendency to "check the box" by including patients in the research process at something less than full engagement from idea inception to research dissemination. Instead, submissions should include a paragraph that directly explains how the project is patient-centered and outlines the specific, meaningful, behavioral tasks to be undertaken by patients. Going even further, some participants suggested that PCORI require a patient co-principal investigator on each funded project and that patient-centeredness may be considered as part of rigor rather than as two mutually exclusive criteria that need to be balanced with each other. Another recommendation is to have each proposal's patient engagement plan accompanied by patient letters of support or other means, such as patient videos. Submitters should also include an evaluation of their patient engagement at the end of the project.
- Reviewers should give equal weight to the criteria of meaningfulness and relevance. Here, meaningfulness is defined in terms of outcomes of the highest order for patients, caregivers, and families—for example, not just survival, but quality of life. Relevance includes the likelihood that the research would impact clinical practice and should be informed by the severity and prevalence of the disease or health issue to be addressed. The appropriate measures will need to be developed.
- Patients on review panels should score all eight criteria, not just the three that are directly related to patient-centeredness. Having scientists score all eight criteria while patients score only three criteria conveys a power differential that is out of alignment with PCORI's stated aspiration for true patient engagement. For this purpose, PCORI may need to provide additional training to patient reviewers to enable them to meaningfully score these criteria. Additionally, having them score all eight criteria may raise the bar for submitters to explain their projects in lay language. An alternative option would be to allow all reviewers to decide for themselves (on an individual basis) which criteria they are qualified to score.
- Honoraria and other compensation for patients and scientists (both as reviewers and in the proposed research budgets) should be equal.

[*] Agency for Healthcare Research and Quality, "Closing the Quality Gap," http://www.ahrq.gov/clinic/epc/qgapfact.htm (accessed 12/20/12).

Empower patient and scientific reviewers through education and training to stand on equal footing with each other. One tool for this training might be a mocked up "ideal proposal" that reviewers could look over in advance. In terms of scientific knowledge, participants noted that many potential patient reviewers are already subject matter experts on the diseases with which they have personal experience. This was seen as desirable; in fact, some felt that disease-specific patient organizations should be included in the review process. It was also noted that patients are not the only ones who need education and training about PCORI's "research done differently." Researchers, too, will need to acquire new skills for engaging patients and understanding patient perspectives.

PCORI should be specific and direct in all communications. This includes taking time to define terms like "patient engagement" to make clear PCORI's expectations about how patients will be involved throughout the process. Participants recommended that PCORI use lay language and provide guidance for patient statements of support with clear terms for the types of tasks patients might undertake during the proposed research process. They also stressed that PCORI needs to provide prompt responses and feedback to those who apply for funding.

Last, but not least, participants were clear that **PCORI should make the review process fun and interesting**. For those coming into this process from outside the world of research, there is a risk that the format, structure, and content of the review process could be overwhelming if some effort is not made to make this form of engagement enjoyable for all who participate.

MATCHING PATIENTS AND STAKEHOLDERS WITH RESEARCHERS

Collaboration between patients, caregivers, and researchers is an important aspect of patient-centered research. PCORI is committed to advancing this collaboration. PCORI funding announcements include a requirement that researchers engage patients and stakeholders as meaningful partners in their research teams.

Accordingly, PCORI asked workshop participants to brainstorm ideas for helping interested patients and stakeholders connect with researchers. By engaging patients and stakeholders in identifying innovative strategies to match patients and stakeholders with researchers, PCORI will play a lead role in developing patient-centered outcomes research (PCOR).

During the breakout sessions, participants suggested the matchmaking ideas listed below. Participants expressed the hope that they would be developed for use both by researchers funded by PCORI and by those funded through other sources.

Establish a clearinghouse that brings together researchers and patients with common interests or support those that already exist. Networks like this exist among researchers, but (a) there is insufficient collaboration (often because of researchers' competition for funding) and (b) patients are not involved. One form that this clearinghouse could take would be similar to the dating website Match.com. PCORI should find this, build it, or fund it.

Leverage networks and collectives of patients and researchers that already exist. Wherever researchers gather, patients should be invited to participate. In doing so, the opportunity for serendipitous connections will emerge. Take advantage of "sticky" relationships built on foundations of trust that have already been laid. Participants noted that some research groups already do this (e.g., Susan G. Komen for the Cure, the Parkinson's disease community, and the cystic fibrosis community). Participants also encouraged PCORI to review the following models: Researchmatch.org at Vanderbilt University, Clinicaltrials.com, PatientsLikeMe.com, the P4Medicine Community at Ohio State University, practice-based research networks (PBRNs) supported by Agency for Healthcare Research and Quality (AHRQ), and the Quantified Self movement.

Recruit patients from a variety of settings and groups. Patients should be recruited into this clearinghouse through a variety of means, including: disease groups; community outreach; hospital-based support groups or advisory councils; patient referrals; churches and other faith-based organizations; hospital outreach efforts; community immersion programs for hospital staff; and a technique called "seeding," in which researchers identify persons with the desired characteristics and then ask people to use their networks to find people with the same characteristics.

This recruitment should extend mindfully to those who are unlikely to be heard now, but may have ideas and experiences that can inform research. Examples include persons who are not digitally connected or cannot travel (e.g., to Washington, D.C.) for meetings. One option would be to locate information kiosks in places where specific populations are known to go. One such innovative approach is the Canadian Patient Safety Institute's "Research on Tap" program, which engages pub patrons in discussions about the process, outcomes, and importance of research. Recruitment efforts would be

enhanced by sharing research results to show patients the value and importance of their engagement.

Additionally, recruitment and training of patients could be enhanced by having a group of PCORI ambassadors. These ambassadors could be trained to know PCORI well, would agree to carry the "research done differently" message forward through their networks, and could have access to a toll-free number that they could use to contact PCORI staff. Many participants at the workshop expressed an interest in serving in this ambassador role. PCORI could recruit additional ambassadors using the "seeding" technique described above.

Provide training to patients and researchers for the patient-centered research process. The clearinghouse described above (e.g., the Match.com model) will not be successful unless the expectations that stakeholders have of one another can be articulated and met. It is said that expectations, if not clearly articulated and within a person's capability to meet, are just premeditated resentments. Given the legacy of poor communication and collaboration between researchers and patients, great pains should be taken to prevent these resentments from developing. Training is essential both to create a culture of collaboration and to establish a shared vocabulary for all stakeholders to use.

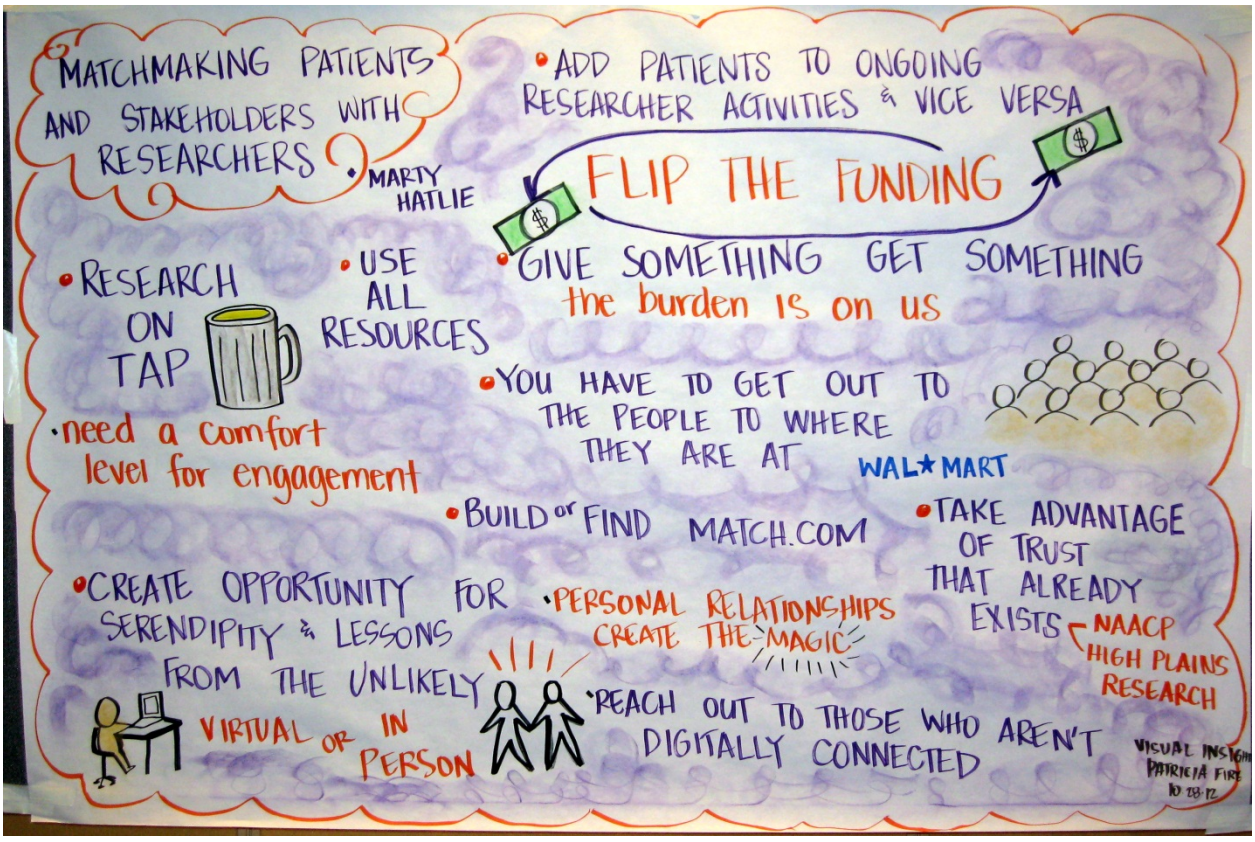
To facilitate training, participants recommended developing "toolkits" to help patients and researchers meet the expectations of PCORI, each other, and other stakeholders. These toolkits should help all stakeholders get ready to participate in the research process. The toolkits should address the roles and responsibilities of the various stakeholders, the competencies needed, and the skills in team building and collaboration. Toolkits should be guided by the principles of trust and respect. Some participants noted that such toolkits already exist, and examples could easily be found through an environmental scan.

Alter funding to incentivize collaborations among patients and researchers. One key notion identified by participants was to "flip the funding," meaning that if patients are going to be real partners in research (rather than just a "checked box" on a proposal submission), then the financial incentives will need to change accordingly. PCORI grants could, for example, go to patient organizations or groups rather than researchers to incentivize researchers to work with patients.

Offer smaller grants to facilitate collaborations among patients and researchers to develop proposals. PCORI could, for example, offer "micro-funding" opportunities—for example, a $10,000 development grant to bring a community together to develop a research project, as was done by the High Plains Research Network in Colorado (as presented in the morning plenary session). This funding could also be used to support learning communities that train patients and researchers or foster dialogue between them—for example, using online meetings, regional stakeholder advisory committees, and roundtable discussions.

This kind of "micro-funding" would also be useful for incentivizing connectors such as clinicians, hospitals, and health system navigators to connect their patients with researchers either directly or via a clearinghouse. Given the extent to which clinicians and hospitals are currently overburdened, these connections would be more likely to occur if a financial incentive was offered.

Give something, get something. PatientsLikeMe aligns all its organizational activity with this reciprocity principle and recommends PCORI use it as a fundamental guideline for all of its matchmaking efforts.



DISSEMINATING RESEARCH TO THE COMMUNITY

The Affordable Care Act's language used for establishing PCORI specifically stipulates disseminating PCORI's research findings to physicians, healthcare providers, patients, payers, vendors of health information, and appropriate professional associations through the Office of Communication and Knowledge Transfer at AHRQ. Successfully disseminating research means having an impact on practice and patient outcomes. The role of patient engagement is vital to that success. This success may depend on centering the communication on the different audiences and meeting their requirements for accepting evidence. Audience differences and other barriers to the translation of research may account for much of the resistance to changing practices in the face of evidence from research. It is clear that improving dissemination will be key to PCORI success, but many unknowns must be addressed. This is an important area for patient engagement, which could lead to new techniques for translating research into improved outcomes.

During the breakout sessions on disseminating research to the community, participants made clear that, to meet the challenge of "dissemination done differently," PCORI needs to do the following.

Develop communication vehicles and channels appropriate to diverse audiences, including disenfranchised patients. PCORI can develop a branded communication approach with summaries in plain language, standard formats, and targeted efforts to reach disenfranchised patients so they, too, benefit from research done differently. Because today successful dissemination of healthcare research is

the exception rather than the rule, PCORI will need to learn how other non-healthcare entities (e.g., Apple) have created rapid popular acceptance of something new. Companies learn from the market, which, for PCORI, means learning from diverse patients. PCORI must require transparency in dissemination to build trust in research.

Require a dissemination plan from grant recipients. PCORI can accelerate its learning by requiring from researchers receiving grants a dissemination plan that involves patients and knowledgeable PR/marketing experts and includes quantifiable measures of success. By designing dissemination and health literacy promotion into research protocols, PCORI can lead grantees to target key audiences and plan appropriate channels and vehicles to assure that results matter in the real world of patients and providers.

Build an infrastructure for continuous learning. Over time, the research partners can become an infrastructure for continuous learning as different networks reach into doctors' offices, professional conferences, barber shops, patient support groups, English as Second Language (ESL) programs, and even elementary schools. This infrastructure can convey research findings through vehicles such as low-technology brochures, PCORI postcards, TV and radio public service announcements, as well as pictorial "graphic novels" with multi-lingual appeal. Yet, it should also move through social network media, Wikipedia, cell phone apps, and computer games so that dissemination extends effectively to future generations. To assure research accelerates learning, it must reach the point of decision making, such as through decision support tools in a physician office. Feedback loops can assure the continuous learning.

PCORI can take initial steps toward this dissemination infrastructure by creating public recognition of the Institute in communities across the country so that the expectation for research dissemination grows. By strengthening networks of stakeholders that already organize patient interests, PCORI can create a national tour with local events that include health fairs, town halls, and community forums with clinicians, patients, and researchers. These can be tied to local and regional media promotions, such as "medical minutes," that can create recognition for both PCORI and stakeholder partners in dissemination.

The networks of patient stakeholders can strengthen the integration of dissemination with research. Local mentors, such as community health workers and neighborhood mavens, can be trusted sources of health knowledge who are also open to learning and disseminating new findings. PCORI can strategically recruit specific networkers who reach into Medicaid, Veterans Affairs, immigrant, and working poor populations. Even politicians can be recruited to disseminate PCORI research as they benefit from constituent service and improve their policy acumen, which can also help the Institute win further support for its work.

Train patients and researchers on how to do dissemination differently. For both patient stakeholders and researchers learning how patient engagement extends into dissemination, PCORI can develop training and protocols that support continuous improvement through innovation. Scientists need to learn how simple language works to communicate in diverse cultures through stories and popular articles. Patient advocates need to address innumeracy so they learn how probabilities define both the interpretation and limits of research. Both groups need to learn how they best engage in forums where each has roles they are as yet unaccustomed to play. PCORI can help by creating new requirements, such as dissemination formats, joint presentations with patients and researchers, and explicit identification of cultural ambassadors to diverse audiences.

EVALUATING PCORI'S PATIENT AND STAKEHOLDER ENGAGEMENT PROGRAMS

Evaluating the quality of PCORI's patient and stakeholder engagement efforts is critical to the organization's success. We need patients and those who care for them to be effectively engaged and feel a genuine sense of ownership in PCORI's work. PCORI would like to expand mechanisms for receiving feedback on its patient and stakeholder engagement programs so the programs are responsive to those they are meant to serve. In addition to establishing those channels for feedback and evaluation, it is important that we define success in engagement and assess our efforts to date.

During the breakout sessions on this topic, participants recommended the following.

Make evaluating patient engagement a requirement for every research proposal. Some participants asked whether it is possible to have good research that does not also have good patient engagement. While this may be possible with research as it is typically conducted, where patient engagement may simply be an add-on to an established research process, for PCORI's "research done differently," it may be impossible to have good research that does not include good patient engagement.

Evaluate patient engagement for each phase of the research process. Participants identified five phases of the research process, as well as questions to ask for evaluating each project's patient

engagement at each of these phases:

- Topic generation phase
  - Has the question come from the patient community or the research community?
- Research design phase
  - To what degree is there diversity in patient representation? For example, large patient groups, small patient groups, individuals. (Ethnic diversity is addressed elsewhere in the review process.)
  - How many patients were involved at each phase of the research (including modification of the research design, if applicable), and how effective was the engagement process?
- Research implementation/process phase
  - Were patients paid? Was there pay parity among team members?
  - Were patients co-principal investigators on the research project or co-authors on published findings?
- Dissemination phase
  - What is the quality of communications and iterative feedback among the various partners? The language should be accessible, which could be evaluated in part by the summary provided when the results are published.
- Outcomes phase
  - Did practice change? If so, how quickly did it change?
  - What kind and what amount of learning took place among members of the research team?
  - Did patient perceptions of research change based on the patient engagement that took place throughout the process? This could be measured using a "pre-test/post-test" approach where patients respond to the same set of questions at the beginning and end of the project.

Include objective as well as subjective measures in evaluating patient engagement. While the evaluation points discussed above are largely objective (e.g., how many patients were engaged at each phase?), participants identified some important subjective measures that should be captured in the evaluation. For example, how satisfied do patients feel with the engagement processes? Do they really feel engaged and empowered? Also, participants suggested tracking longitudinal measures, because people will "vote with their feet." If a certain research institution is having difficulty with recruitment and retention of patients to engage with them, then it suggests that their patient engagement processes are insufficient. On the other hand, superior performance on these longitudinal measures, coupled with favorable ratings across the other areas identified above, could make a research institution eligible for a "seal of approval" that PCORI could develop. Creating such a "seal of approval" would really require PCORI to lay out what successful "research done differently" looks like, so that they could reward it when it occurs.

Themes from the evaluation session address the following place, time, language, and evaluation criteria.

Establish an overlap zone (place). The key in this zone is to get a common cultural understanding while establishing clear roles and expectations. We are not trying to make patients into researchers or vice versa, but there is more overlap in understanding that is possible and that can be evaluated with ongoing engagement. The key is co-learning through which we train the trainers and inform the informers.

Remodel the infrastructure (place). If research were a building, we would redesign the structure to:

a) Evaluate how widely an engagement—and/or the intervention it was related to—spreads to other groups, other practices, other regions.
b) Evaluate by changes made to organizational charts, changes to requirements for funding from other agencies; will all such agencies require patient engagement eventually?
c) Evaluate changes to the research/medical curricula to assess whether or not there are more educational opportunities for patient researchers. This is a change that should come and is coming.

Accelerate the uptake of research findings (time). If patient engagement is effective, does it reduce the time it takes for research findings to change practices? What is required to accelerate this uptake through dissemination engagement strategies? What are the evaluation criteria and strategies for social media, as well as traditional biomedical literature that have associated metrics? Patients may have dissemination requirements along with researchers.

Find the baseline for longitudinal and embedded evaluation (time). What is the status at the beginning of the whole process, and how does it change at each point along the way—six months, one year, and three years later? What changes for the research team, the research topic, the research community, and the patient community?

Use widely accessible language in study materials for patients and other stakeholders. All communities are acknowledged for having their own language and jargon, so bi-directional clarity is the goal. Who prepares the lay summaries, and are patients involved?

Get at meaningfulness, quality, and impact of patient engagement in research. Indicators can be found by asking: were patients paid as partners in research? Are patients co-authors on publications/dissemination? What is the impact factor—for researchers, patients, and the engagement itself? How widely is the research cited, copied, and used?

Create a type of "Good Housekeeping seal of approval" for research engagement. A rating scale could show the impact of engagement across: research prioritization, research study design, implementation of the study, dissemination, and outcomes of the study.

The key principles for evaluation include: transparency, empathy, infrastructure change, adaptation, and learning—including from negative studies or from poor engagement. Ongoing assessment is valuable for continual learning.

Response from PCORI Leadership

Following the creation of PCORI through the Affordable Care Act of 2010, the U.S. Government Accountability Office (GAO) recruited members of the PCORI Board of Governors. The members include representatives from the patient, research, and other communities. PCORI's vision today is the work of this board, which continues to work passionately and deliberately to make PCORI a success. Several members of the Board of Governors attended the Patient Engagement workshop. Along with PCORI's senior management, they joined the various breakout conversations and attended the presentations of participants' ideas and principles on the following day.

> *What we're saying is that we need to engage patients to make sure that the questions we're asking are important questions, and we have to do high quality research. I think people will be making life decisions based upon the work that we're producing, so we need to hold ourselves accountable for producing high quality rigorous work.*
>
> Anne Beal, MD, MPH,
> PCORI Chief Operating Officer

Members of PCORI's Board of Governors, Methodology Committee, and senior management responded to these presentations, stating that the following workshop outputs and insights will guide their efforts moving forward:

- **This workshop demonstrates that patients are ready, equipped, and eager to engage.** The patients and patient representatives (often family caregivers) who were selected to participate offered ideas and preferences as users of care that were noticeably distinct from those offered

by other stakeholders. Many have shown perseverance in the face of great personal challenges, and they brought infectious energy and hope for change to the event. In many cases, their experiences have forged views that are not readily heard. Researchers need to understand and appreciate these important perspectives. Wherever patients convene, researchers should be there as well. And vice versa.

> *It's wonderful to think not only of PCORI as a funder, but PCORI as a model.*
>
> Harlan Weisman, MD,
> Member, PCORI Board of Governors

- **Transparency is critical.** In all of the breakout topics, transparency was underscored as a critical value for PCORI to uphold in everything it does. There should be an open process and open feedback so that patient and stakeholder perspectives can be incorporated into how PCORI operates. This transparency will help create buy-in for the processes of "research done differently." Transparency will also create trust in research findings that will help to mitigate the disappointment that many patients and patient representatives will likely feel if their specific research topics are not addressed.

- **Information must be tailored to meet patients' needs.** Research should help patients and their families make good decisions in an environment where the system is continuously learning. New research must be presented with sensitivity to the various knowledge levels of different patient constituencies. Research is not stagnant; rather, every partner in the process can be learning on an ongoing basis from the knowledge level they hold.

- **PCORI's activities must reach out to and be inclusive of all communities.** Outreach needs to include vulnerable and marginalized populations, including those who do not self-identify as patients. For example, while social media should be an important channel for this outreach, one size does *not* fit all. PCORI must also use alternative channels for reaching the many Americans who lack access to Internet technology or the capacity to use it effectively.

- **Capacity building via training and toolkit development is needed.** For research to be done differently, researchers need training and tools to help them identify the needs and expectations of other stakeholders, especially patients. Training also will be needed to help other stakeholders, particularly patients, so they can engage effectively in all aspects of PCOR.

> *We're going to use the feedback that we're getting today to make changes to the work that we're doing. As you heard Joe Selby say, in many ways what we've heard is quite validating, but we also got a number of new ideas. So know that this is not falling on deaf ears but, in fact, we're very studiously taking notes and listening to what's being said. So we'll definitely incorporate what's going to be part of how we do our work going forward.*
>
> Grayson Norquist, MD, MSPH,
> Member, PCORI Board of Governors

- **It will be essential to help patients hold their own throughout the research process.** Parity in compensation (e.g., honoraria for review panel participants) and leveling knowledge are both ways to level power differentials that will reinforce the centrality of the patient.

- **Flexibility is required in the funding available from PCORI.** Many on the board and staff like the idea of using small contracts to build the capacity to change the culture around patient-centered research. The ability to use small grants that support an infrastructure of engaged patients can enable research done differently.

- **The idea of a "Match.com" model to connect patients and researchers is intriguing.** Participants and board members alike saw that innovative ideas from the online world can connect patients and researchers while drawing from successful platforms that match people socially.

- **No trade-offs can be made between engaging patients and conducting high-quality research.** PCORI must do both together. People will make life decisions based on the work that PCORI funds, so it must be rigorous. At the same time, the questions PCORI is asking also have to be relevant and meaningful to patients. PCORI can lead in assuring that high quality in research is defined as necessarily including patient engagement.

- **This workshop could be the start of a transformation in how research is done.** PCORI has the opportunity to demonstrate a new patient-centered outcomes research model and then disseminate it throughout the research establishment. For this to happen, it will be critical that the patients who participated at the workshop amplify what was done during the workshop after they have returned to their communities. If everyone can commit to do that, then we can make this transformation happen within the next five to seven years.

> *We need you to help us magnify what you have done and what you have suggested over the last couple days with your neighbors, with your family, with your friends, with your communities across the United States… So one of the things that we now know is that in order to increase the number of applications that really have serious patient engagement involved, we have to implement a lot of the ideas that you all have shared with us this weekend.*
>
> Steven Lipstein, MHA, Vice Chair,
> PCORI Board of Governors

Conclusion

This workshop was an affirmation that patient engagement offers a way for research to be done differently with a community of active creative partners that includes patients, family caregivers, and activists, as well as scientists and other stakeholders. Communities form around either place or shared commitment, and the workshop in Washington, D.C., offered both. The commitment people spoke to was a shared set of values, beliefs, and principles for patient-centered outcomes research.

The first principle is that research be truly patient centered. This principle means the patient and family caregivers are truly respected as legitimate partners in research. All stakeholders have to respect both the needs and the assets that patients, their families, and communities bring to comparative

effectiveness research. The 350 people who applied to attend, 150 participants who braved the hurricane to join the workshop, and 450 people who gave up much of their weekend to join the webinar attest to the need patients feel to speak to research and be heard. The outpouring of ideas at each of the research touch points shows the creativity that is a vital asset for PCOR done differently. The affirmation of the workshop coming from researchers and the other stakeholders who joined the patients demonstrated the respect that patients, family caregivers, and advocates have gained through their participation as partners in PCOR.

> *This was a very affirmative meeting for those of us who have been saying that it was time to engage patients more profoundly in all aspects of the research process. If you sat here for this last day and a half, you come away convinced that you were absolutely right, that the patient community is ready and equipped and insightful, and that for everybody who's here, they bring the message that there are lots of other organizations and millions of other patients out there ready to be engaged.*
>
> Joe Selby, MD, MPH,
> PCORI Executive Director

The second principle is transparency. This principle means that, when interests diverge or conflict, there is an ethical obligation to be clear and honest. Knowledge is power and, as PCOR brings new knowledge into health care, the responsibility will grow to share and transfer this power for the larger public interest. Patients coming into research with less knowledge than other stakeholders can gain the larger benefits promised by PCORI through a fierce adherence to the principle that information is made appropriately available in a timely and understandable fashion.

The third principle is reciprocity. Everybody gives something and everybody gets something in the learning system that PCOR helps establish. The successful models of patient-researcher partnerships have demonstrated that this learning offers a creative, fun experience for a serious purpose: to ease suffering and improve health. Researchers will gain empathy and creativity from their partnership, and patients will gain a rigorous understanding of what is known that can help when making decisions about healthcare options.

In the end, the shared interest in PCORI's success is an expression of hope that the changes coming to health care will be guided by a new collaboration that is open to new partners with innovative ideas and a fierce commitment to change. The promising models and partnerships demonstrated in the workshop show that patient engagement works. What follows afterward can define the future for patient-centered outcomes research.

Appendix 1

In the October 27-28, 2012, workshop, participants rotated through five breakout topics representing various phases of the research process. Participants contributed their ideas for each phase on how to make partnerships with patients most effective. Following is a list of their ideas, organized by topic.

IDENTIFYING AND SELECTING RESEARCH QUESTIONS

1. The process must involve communities in defining their own problems and expressing their own concerns, in contrast to having health professionals being the experts and deciding what those problems are.
2. Use crowd-sourcing as a tool to generate research topics, but be mindful of the digital divide and, therefore, consider going in person to common public places (e.g., convenience stores) to start a dialogue and get questions.
3. Consider using challenge prizes to elicit questions.
4. To solicit research questions, approach and develop relationships with a great variety of groups and organizations, including community health advisory boards; public health institutions, such as state public health departments, CDC, and immunization clinics; the sickest patients, as well as individuals who are not patients, to identify questions for preventative care; employers; those who are serving underserved communities; hospitals, churches, and schools; and members of the prison populations, homeless people, and veterans.
5. Ask the question ("What should PCORI study?") in multiple ways. For example, "What is your biggest health concern that you don't know a lot about?" Another question to ask would be, "If you could go back, what would you have liked to know, and what did we miss?" to identify interventions that we are not exploring. To practicing physicians, the question may be, "In your practice, what is the biggest problem you're seeing?"
6. Consider starting out broad with a question like, "Can you tell us what we should be researching?" and then, step-by-step, asking the submitter to make his or her proposed question as targeted or specific as possible.
7. Go for big data. Look at the data sources—which may include message boards, health information technology systems, and patient boards—that are already used, and mine them to see what questions are being asked by patients.
8. Be systematic about gathering questions and develop mechanisms for it such as, for example, registries.
9. Clearly define terms, criteria, and expectations for applicants. For example, does the term "impact" refer to the severity of a given health issue or its prevalence? How do you define "patients"? Some of the in-treatment patients who would be helpful to researchers have a hard time even getting out of bed. Be specific and direct in communications and in requirements.

10. Consider creating sample submitted applications.
11. For patients, many questions are intertwined with questions about housing, education, accessibility, and job coaching. Integrate a life course perspective to evaluate what questions are priorities for research funding.
12. Develop a toolkit (and a YouTube video) to help patients and their families, providers, and organizations solicit and submit questions.
13. Consider creating a committee or group that addresses questions asked by laypersons and help translate their questions into research language. Relatedly, consider listing research question in multiple "languages" (research question versus layperson, i.e., more accessible question).
14. From a provider standpoint, how do we get patients to change their lifestyle to improve health, when their lifestyle is culturally based?
15. Consider grouping questions into two divisions: one being for topics and another group for methodology-related questions.
16. Manage expectations by making it clear what exactly the research question selection or prioritization criteria are so people do not get frustrated. Make the selection process transparent, by giving direct feedback to submitters about what is being done with their ideas and making the deliberations about the questions transparent to the public. This includes letting people know at what state the question is (e.g., under consideration) and what the next steps will be, as well as explaining why a particular question was or was not funded.
17. Consider providing sample questions and research projects to serve as good models for answering other questions.
18. Favor research questions that can be answered in a seven-year term to start with the "low-hanging fruit," so to speak.
19. Have a retention policy for questions that do not have the research necessary to answer the question. Explain what gets put into such a "parking lot" and how long questions stay there before they are entirely removed, if ever. Relatedly, provide or point to a pathway for the unfunded questions so that they can find a match with a researcher or patient.
20. Check databases and sources like AHRQ for information on failed attempts or negative results before selecting a question for PCORI funding.
21. Coordinate the selection of questions such that there is no unnecessary overlap with other funding agents, though questions that get selected may build on or fill in the gaps.
22. Take care to select disease-specific questions, as well as questions pertaining to the larger population.
23. Selected questions should reflect the reality and complexity of living with health conditions, including managing multiple comorbidities and the impact of a disease not just on a (pediatric) patient but also on his or her family.

24. Leverage existing institutions, such as churches, to make contact with their members.
25. Be strategic in the selection of research topics. It should capture a mix of questions related to specific diseases and general health and wellbeing.
26. Use a mass media campaign to spread the word about PCORI and solicit questions.
27. Vet the questions as they go through the submission process.
28. Go where the groups with high health disparities are already meeting. Have "boots on the ground" at those meetings.
29. Partner with clinicians and medical students.
30. Use existing needs assessment data and literature.
31. Mine questions already being asked on social media.
32. Tap into the pool of organizations that already have patient advisors.

REVIEWING RESEARCH PROPOSALS FOR FUNDING

33. Patient-researcher partnerships must be meaningful. Applicant researchers who do not meaningfully engage and partner with patients should not get funded. PCORI-funded projects must completely and integrally entwine patients with the research that is going on in their community.
34. Communicate that the patient reviewer's voice is valuable and, as smart as patients are, train them to properly evaluate proposals and provide strong, productive feedback. Furthermore, patients may not necessarily get to always evaluate studies that are directly related to their expertise (e.g., a diabetic patient may be asked to review a breast cancer-related study), but should still be able to comment on the proposed research method and process as it relates to patient involvement and experience.
35. Instead of having patient reviewers cross areas of expertise (e.g., see diabetic patient example above), consider having members of relevant patient-led advocacy groups who are, in fact, experts in the subject area of the study to be evaluated, participate in the review.
36. In some cases, studies may be scientifically rigorous but not sufficiently patient-centered. Patient-centeredness should hold equal weight with other values in the review process.
37. Train researchers in how to effectively engage patients and their families throughout the process.
38. Ensure diversity among patient reviewers—including organizational and sectoral affiliations, as well as along factors such as ethnicity, education, and income—and share the characteristics of the entire review panel with the public.
39. Indicate *families* as an audience of interest for impact.
40. Insert the word "meaningful"; that is, research must be relevant and *meaningful* to patients. For

example, the outcome of the study may be "survival," but have that framed in a way that speaks to the quality of life, its meaning for the patient. However, be sure not to define it too narrowly. For example, restoring the ability to swallow can be just as meaningful for patients as restoring speech.

41. Evaluate applications for their ability to be implemented into the payment system, that is, feasibility and practice impact.

42. Evaluate adoption by the patient community. For example, it is not simply about getting a drug to market, but rather getting patients to use it.

43. Provide prompt feedback to applicants during and after the review cycle. Likewise, provide opportunities for reviewers to directly ask questions to applicants, if necessary.

44. Allow patient reviewers to score on all eight criteria, rather than a selected few.

45. Consider requiring or scoring higher applications that involve community members as co-principal investigators, even co-authors.

46. Make sure that the required patient engagement plan is sufficiently specific. Applicants should specify meaningful, behavioral tasks for patients that are verifiable (e.g., we will have patient do task X and participate in meeting Y).

47. Consider having patients write the patient engagement plan—and have access to assistance with that task, if necessary—and be able to speak to it. Relatedly, allow non-traditional methods, such as videos, to convey patient engagement, rather than accepting only written letters of support.

48. If there are honoraria in the budget for patients involved in the proposed study, they should be equal for patients and researchers.

MATCHING PATIENTS AND STAKEHOLDERS WITH RESEARCHERS

49. Online communities and clinical research platforms such as PatientsLikeMe.com can help patients turn their stories into quantitative data. This particular platform started eight years ago and has 160,000 patients across a thousand different diseases; it has published 25 papers in peer review journals in the last five years. Platforms like PatientsLikeMe.com counter the skepticism that currently exists about the validity of the patient's experience in research. They also facilitate a process in which outcomes, measures, and understanding help patients drive their own individual care and allow researchers to aggregate and utilize patient perspectives.

50. To incentivize and facilitate patient-researcher partnerships, we need to change the clinician- or researcher-centric paradigm. There are many organizations that fund research, but currently none or few of them channel it through the consumer, patient, or community. We can give a voice to patients by making them the center of the funding sources.

51. Start a clearinghouse for researchers with identified interests and patients with common interests. Then bring the two together. Networks exist among researchers, but there is not as much

collaboration as we need.

52. Identify patients interested in research by inviting them to symposia like this one; wherever researchers gather, patients should be invited to participate. Patients can sometimes be found through disease communities, but not every patient or patient advocate belongs to such a group. Patients who are interested can help identify other patients in their communities, virtual or real. However, symposia will not be accessible to patients unless language is used that is understood by non-researchers or patient advocates are taught the terms they need to know. Symposia can be small or big.

53. Establish a "Match.com" function. Start with collectives of patients and researchers that already exist and mine data as law and privacy concerns permit. Furthermore, PCORI could rank or facilitate ranking by users as dating sites do.

54. Engage PhD students to help with the research. That way we have new researchers who are familiar with the needs of people and patients.

55. Incentivize collaboration. Connectors such as physicians, hospitals, and navigators can be incentivized to connect their patients with researchers or via a clearinghouse. There are models for this.

56. Flip the funding. If patients are going to be real partners in research—more than the checked box on an application or the contributor of a letter of support—their roles need to be compensated. Micro-funding opportunities, for example, could provide great benefit.

57. Share results to incentivize patients. Results of research will help patients understand the value and importance of research. The Canadian Patient Safety Institute "Research on Tap" program is an example of going out to pubs and engaging patrons in discussions about the importance of research, how research works, and results.

58. Ensure matchmaking includes outreach to those who are not digitally connected or cannot come to Washington for meetings. Consider conducting community outreach through indigent health programs, Federally Qualified Health Centers (FQHCs), and other "sticky" community health providers. Another alternative could be info kiosks; for example, the University of Massachusetts does this and provides info on "conquering disease."

59. Train and screen participants. A Match.com-like model will not work unless the expectations that stakeholders have of one another can be met. This will require training, which should address collaboration, language, and culture and utilize multi-modal approaches (e.g., web-based for some, place-based for others).

60. PCORI should fund learning communities to train and foster dialogue. This could be virtual, using WebEx type technology. PCORI could facilitate regional stakeholder advisory committees and local or regional roundtable discussions.

61. Train community leaders as PCORI ambassadors. PCORI should go to where the people are. Options for finding ambassadors include: reaching out to rare-disease groups; reaching out from

Washington to where communities meet; using patient and family advisory councils to reach patients physically and virtually; and call for ambassadors, including establishing a toll-free number for them to use to connect to PCORI staff, and train them. Use "seeding" techniques, which are a well-known mechanism for recruiting patient participants in research: identify core of ambassadors with characteristics PCORI wants, then ask them to use their networks to find similar persons.

62. Include patient stakeholders in activities to develop training materials for researchers. This is the best way to keep training patient-centered.

63. PCORI should develop training and "toolkits" that will help researchers meet the expectations of PCORI, patients, and other stakeholders. Training toolkits for patient advocates are also needed. Toolkits for researchers should include who stakeholders are, their roles and responsibilities, competencies needed, and teambuilding. Toolkits for patient advocates should include what it means to participate in research. Toolkits should be guided by "trust" and "respect" principles.

DISSEMINATING RESEARCH TO THE COMMUNITY

64. Publicly publish studies and results so that other researchers can build on them. Let researchers know that what they are going to submit, study, and publish is all going to be public.

65. Have researchers or PCORI provide patient-friendly descriptions of studies that are selected for PCORI funding.

66. Information should also be made available in pictorial form, as well as written, for less widely spoken languages whenever possible.

67. Develop computer games that disseminate research results while engaging patients that are typically outside the PCOR arena.

68. Work PCORI research into TV programs and stories; target Oprah, Univision, and other shows that address key audiences. Seek celebrity disseminators.

69. Use radio programs that poorer communities tune into for information, including call-in shows that have a popular following.

70. Use "mental model techniques" to assess reasoning and thinking approaches that may create gaps in how people respond to research dissemination.

71. Study CDC 9-11 Smallpox Vaccinations plan for dissemination lessons.

72. Recognize underserved and diverse patients, honor them, and really represent the needs and hopes of their participation in research.

73. Consider incentives through "pay for feedback" programs targeted to hard-to-reach populations.

74. The goal should be both to change health outcomes and to change the capacity of people who are making medical decisions.

75. Encourage patients, caregivers, or patient representatives to join editorial boards of national journals such as *The New England Journal of Medicine* or *The Lancet*.

76. Collect patient and researcher testimonials to say how the research has helped, and report on it.

77. Develop PCORI algorithm search engines as free aps for PCOR. Consider a searchable PCORI database with a layperson model.

78. Develop patient portals that provide two-way sharing so that research and dissemination are tied together.

79. Be strategic about spreading the word, including partnerships, outreach, people, and organizations, as well as reach out to people who did not attend this PCORI workshop.

80. Identify "alpha disseminators" and bring them together in forum dedicated to improving dissemination practices.

81. There are questions that have been asked and answered that have not been effectively disseminated. PCORI could help with disseminating such already existing information. Similarly, PCORI could do a great service by conducting an audit of what is already known and published. For example, there are a lot of guidelines; PCORI could create a central infrastructure to help connect those dots for meaningful use. Furthermore, there is good research that simply needs to be translated into plain language. PCORI should also consider addressing innumeracy, because not all clinicians are competent at interpreting probabilities with patients.

82. In dissemination, be mindful of the digital divide. Consider research liaisons who access ideas circulating in communities and disseminate those ideas on social media. Another idea is to personally go to where the people are, that is, show up at community events to share information.

83. Consider conducting a national tour or conducting similar workshops around the country. PCORI can use existing networks that extend into communities to partner on health fairs, town hall meetings, medical minute programs, and other community forums with clinicians and patients.

84. Ask researchers to create knowledge briefs (e.g., patient-focused policy briefs) that can be disseminated via social media platforms, the PCORI website, and elsewhere.

85. Along with written materials, consider facilitating the development of "health coaches" who can empower patients to ask questions, helping them prepare for speaking with their physicians and asking all the questions they need to in the limited time they are given.

86. Conduct a media blitz, as well as maintain ongoing relations with entities such as National Public Radio (NPR).

87. Take a marketing approach and plan dissemination as part of all research grants. Identify what groups benefit most from the information and where they tend to get their information; then build the dissemination strategy based on that. This may include dissemination via television (e.g., "Medical Minute" and short videos that can be played in waiting rooms), pamphlets, periodical inserts, women's magazines, mentors, support groups, and getting out in the community in person.

88. Reach out to non-healthcare industries for communications and dissemination strategies (e.g., how does Apple get the word out on a new product?).

89. Favor funding projects with research protocols that include a large web of providers, rather than a single institution. This is because clinicians have their own network of people they talk with, and, if clinicians are involved in the research, they will be interested and able to reach out to more people.

90. Consider disseminating via:
    a. Big advertising companies that offer affordable services for good causes
    b. State healthcare authority (e.g., Medicaid Children's Health Insurance Program)
    c. Hospital-based, condition-based classes
    d. Corporations that put out data to state health organizations
    e. Literacy organizations to reach immigrants trying to learn English
    f. Pharmacists
    g. Libraries
    h. Accountable care organizations
    i. Patient portals
    j. Radio (many underserved communities use radio to access community content, Q&A with call-ins)
    k. Graphic novels or comic books (which are a rapidly growing trend for public communications) that can be distributed via doctors' offices
    l. Celebrities (especially those with conditions, who get involved in research, to help publicize what's going on)
    m. Disease-based conferences
    n. Politicians

91. Provide a directory of plain-language summaries.

92. Ensure that there are standing members of plain-language editorial boards.

93. Put researchers' stories online to model behavior and show how reaching out to patients makes a difference.

94. Recognize where laws and policies (e.g., FDA) conflict with PCORI dissemination goals and develop collaborations to amend or modify.

95. Help researchers develop communication strategies and materials (e.g., talking points, guide journalism) and define their target audience.

96. Build health literacy strategies into the research. Doing so can be difficult with some research designs (e.g., early signs in neurological disorders), but personal digital assistant–type technology and video could help track responses to information and assess dissemination effect. PCORI can give feedback and language tools that patients can bring to their doctor later on. Build friendly, useful tools/outputs into the research as an incentive to participate.

97. Consider developing a patient-peer-reviewed PCORI medical journal. This journal could be one that is half clinician and half patient from content production through editorial to prevent spin and keep the profession "on track." Negative results should also be reported in some form (e.g., a "journal of negative results").

98. Moderate an online, consumer-driven forum (moderated for fact, not for opinion) with a research-based moderator who can give legitimacy to the discussion.

99. Work with key health professionals (nurse practitioners, social workers, etc.) to become disseminators and tie into CME, CEU, and even pay-for-performance programs.

100. The Association of Cancer Online Resources (ACOR) combines online research with patient experiences. PCORI could moderate this, organize it by condition, and bring researchers and patients into the same venue for feedback and uptake.

101. Expect researchers to provide a very brief (e.g., 90-second) summary of findings in one or more formats (e.g., video) that PCORI can use for dissemination.

102. Consider having researchers and patients co-present project findings and papers. Relatedly, get patient stakeholders to comment on the final report or paper, building it into the way the paper is published.

103. There is a lack of trust between patients and providers. Putting the patient's comments alongside the doctor's findings would help to rebuild that trust.

104. Not everyone is "average." When disseminating, make clear the limitations of the research.

105. Set the expectation that all research can be boiled down and summarized in a useable way, similar to nutrition labels. Have a standard reporting language, format, and release schedule. Develop a standard PCORI format for abstracts.

EVALUATING PCORI'S PATIENT AND STAKEHOLDER ENGAGEMENT PROGRAMS

106. Research should be fun. The process should be fun, challenging, mentally stimulating, and affect the health of our community at large so we keep coming back.

107. Ask applicants to include room for evaluating their patient engagement process after the conclusion of the study, as part of the results. Besides the health information findings, applicants should build in an evaluation of how well the proposed patient engagement process worked out during the conducting of the study.

108. Researchers can track the impact of their idea and publication based on the number of times it gets cited by others. Similarly, PCORI could determine the level of success of a dissemination plan, in part, based on the number of lay press talks about the research.

109. Consider having patient engagement evaluated six to 12 months after the study.

110. Ask the stakeholders what they think has changed because of their involvement.

111. Evaluate the level of diversity among the project participants.

112. Consider linking evaluation to the funding of a project. In venture capital, for example, there is a first round after which an idea may get to a second round. Similarly, PCORI could break the total project funding into installments to incentivize quality and patient engagement (e.g., if you get these results, then you get this chunk of money, and if you get this level of engagement, you get the next chunk of money).

113. Questions to ask to evaluate patient engagement:
    a. Was there a successful outcome and patient engagement? These two need to be evaluated together. (If patient engagement was poor, then that would not count as patient-centered.)
    b. Are people voting with their feet?
    c. Where did the idea come from? Did the idea come out of collaboration?
    d. How quickly is feedback getting into research cycle? How effective was feedback cycle, and how do you quantify that?

114. Evaluation should include both subjective measures of quality of engagement (e.g., satisfaction of patients) and objective measures (e.g., how many patients were involved, and at what stages were they involved?).

115. Another question to ask is whether a given PCORI-funded project has been picked up by other, applicable research groups.

116. Consider developing a PCORI "Good Housekeeping seal of approval" with five buckets to apply such a seal of approval.

Appendix 2—Working Group Members

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Appendix 3—List of Participants

First Name	Last Name	Affiliation	City and State
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Appendix 4—Pre-Work Exercise

See Following Pages

What Brings Us Here?

A Pre-Workshop Exercise for the Oct. 26-28 PCORI Patient Engagement Workshop

"Transforming Patient-Centered Research: Building Partnerships and Promising Models

Please use this worksheet to answer six questions for the PCORI pre-workshop exercise. We encourage you to speak with your exercise partner and submit your responses as soon as possible, and no later than **Monday, October 22**, so that we can review them to enrich the workshop's discussions. If you have any problems completing this form, please contact us at getinvolved@pcori.org.

Before getting started, please provide the following information:

Your Name: _____

Exercise Partner's Name: _____

Responses from this exercise will be provided to PCORI staff and its advisors who are planning the workshop. Some responses will be shared at the workshop to enrich the discussion. May we identify you as the source of your responses? It will help workshop participants and PCORI's broader stakeholder community make a human connection with the responses and show the rich diversity of our participants.

- You may identify me as the source of my responses at the workshop.

  Yes ◯ *No* ◯

  If you select 'No,' any responses you submitted will be treated anonymously, if used during the workshop.

Before your call with your exercise partner, please answer the following questions:

1. What personally excites me about patients being more involved in patient-centered research?

2. What is the biggest hope I have for patient-centered research?

3. What can I offer fellow participants at the PCORI Patient Engagement workshop?

4. What do I hope to take with me as I leave the workshop?

On the Call:

5. What feedback did my partner have for me?

6. What can I say to my partner that builds upon his or her ideas, feeling, or hopes?

Submit via email pcori