PIPC and Families USA Roundtable: Summary and Recommendations
August 2014

On June 19, 2014, the Partnership to Improve Patient Care (PIPC) and Families USA co-hosted a roundtable discussion on "Accountability for Patient Engagement in Research and Dissemination." The purpose was to move beyond a discussion of the points of engagement, and focus on who is accountable for patient engagement, and what makes engagement meaningful. It was noted, and agreed by participants, that a goal of patient engagement is real patient empowerment and activation in their health care. A focus of the discussion was implementation of the Patient-Centered Outcomes Research Institute (PCORI), which is creating a precedent for patient engagement practices in research that could be modeled by other entities.

Participants in the roundtable discussion included representatives of PCORI Advisory Panels, members of PIPC, and non-profit organizations representing patients. During introductions, participants described their varied personal experiences with the health care system and with patient and community engagement in research and dissemination. Participants had expertise working with PCORI, the Agency for Healthcare Research and Quality (AHRQ), and the National Institutes of Health (NIH) - some as analysts, others as patient representatives, and others as researchers.

Prioritization of Research

The discussion began by focusing on accountability for engagement in the prioritization of research, with a focus on the activities of PCORI's Advisory Panels in the targeted funding announcement process. The roundtable participants had the opportunity to review the work of Dr. Dan Mullins and the National Health Council related to the points of engagement, as well as the work of PIPC to identify a process for research prioritization. One participant provided the roundtable group with a background on the process utilized by the Institute of Medicine (IOM) in prioritizing 100 comparative effectiveness research (CER) topics for research, as instructed by the American Recovery and Investment Act (ARRA). It was noted that one way PCORI identifies a topic of importance is by reference to its inclusion on the IOM list. The targeted funding

announcement process utilizing advisory panels was described, although it was acknowledged that to date PCORI was mainly funding projects from the broad funding announcement process which is investigator-initiated. The group was also educated on PCORI's recent pragmatic trials initiative, or large simple trials, which were viewed as more representative of the process for prioritizing topics outlined in PCORI's authorizing law.

Topic Solicitation Transparency

This overview of PCORI's work raised the topic of accountability and transparency in the process of soliciting research topics from patients. Participants acknowledged that without patient engagement and the patient voice in the prioritization of research, certain high priority research topics would not be included in the research agenda of AHRQ, NIH, and PCORI. Although the IOM process was perceived as an improvement over other processes for prioritization, some participants raised concerns regarding how accountability for ensuring stakeholder input is achieved. One participant provided the example of a disease that is a leading cause of death being excluded from the IOM's top 100 research priorities for CER because the organization that represents that disease was not aware of the process, and therefore not engaged. As a result, that group has made significant strides to engage with other research entities such as PCORI.

The IOM process was described as the gold standard at the time it was conducted. In the conversation, it was elicited that although those that were engaged had positive experiences with the IOM's process for soliciting topics, there was concern about the transparency of the process for considering those submitted topics to narrow them down to 100 topics. Similarly, advisory panel members described PCORI's process as "collapsing" topics that were alike, then conducting a literature review on those collapsed topics that represented larger groupings. There was some concern that this particular process for narrowing down the topics provided to the advisory panels could be more transparent, so that advisory panel members and the public had a better understanding of the rationale for moving a topic to advisory panel review versus those that were not chosen for further consideration.

Accessibility

Accessibility to opportunities for engagement was a concern for participants. In particular, access and usability of PCORI's web portal for submitting topics was raised as meriting further review. For example, a participating organization described its

activities to make the PCORI web portal usable to its members for submitting topics, underscoring the challenge of being accountable for engaging patients in the topic solicitation process. In this case, the patient organization made itself accountable to its members for providing a template for submitting research questions to the PCORI website. PCORI set up the web portal, but the organization became accountable for making it usable, indicating the value of shared accountability between the research organization and its patient stakeholders for topic solicitation.

Another organization described its work outside PCORI to make public comment opportunities accessible, from webinars to one-on-one phone calls and listening sessions. It was suggested that user-friendly tools for commenting could be provided to community members to prevent them from being overwhelmed by the process.

It was also acknowledged that individual patient advocates not representing groups of patients are often isolated and their voices minimized if they are the sole patient partners or one of very few. Individuals may be chosen as the patient partner despite not having an experience that is directly linked to the engagement activity simply because they have experience in being the "engaged patient." The process of engagement is intimidating and the process itself can be a barrier to engagement of people with certain challenges, such as language barriers or mental illness. Participants have urged research funders to make engagement more broadly accessible to individual patients. They want engagement to be meaningful, diverse, and accessible to both organizations and individual patients.

A concern was raised that there is not a process for the patient community outside the advisory panel members to insert their recommendations directly to the advisory panel. The group was enlightened as to the specific process used within PCORI advisory panels for prioritizing topics, whereby panels are provided with a list of topics, which they then must condense and prioritize.   Some participants felt that this type of process does not allow for any review of non-prioritized topics, which then may limit the overall priorities selected. As a result, such a process could limit accessibility by disenfranchised populations to provide meaningful input into the prioritization activity, especially related to those non-prioritized topics.

Pre-Engagement

Understanding that PCORI solicits topics for advisory panel consideration from the public, a PCORI advisory panel member relayed the need for engagement events to

provide information to attendees in a manner that makes the research process more accessible to them. For example, providing broad information about PCORI is not as useful as providing information on where and how to engage in the process in concrete terms. From this discussion, the value of pre-engagement was highlighted as a means to ensure that broad engagement events are productive and goal-oriented.

Pre-engagement became a theme of the discussion. Participants agreed that the end user of the information should have input up front. Right now, engagement may happen if someone knows someone related to the research organization that highlights the upcoming opportunity. In the context of accountability and PCORI, one participant highlighted that pre-engagement would allow those participating in PCORI advisory panels and others that follow PCORI's work to prepare their constituencies for upcoming opportunities to provide input. It was acknowledged that traditionally the "usual suspects" among the research community are the ones prepared for the funding announcements and input opportunities, and are therefore the first to get access. Community-based participatory research (CBPR) provides a good model for pre-engagement, whereby relationships with community partners are built long before a grant application is submitted.

Organizational Support for Engaging Individuals

The participants discussed the value of engaging organizations. Generally, there was consensus on the need for research funding entities such as PCORI to focus their efforts on engaging organizations or individuals with access to a larger community that they can then bring to the table to provide individual input. As a caveat, it was emphasized that there are large organizations representing diseases and conditions, and there are other organizations such as the Urban League that represent certain ethnic populations, and then there are smaller regional organizations. Entities seeking to prioritize research should be engaging organizations at all levels so that they are bringing to PCORI the views of hard-to-reach populations that require more creative strategies to engage meaningfully. It was emphasized that hard-to-reach populations may be more time-consuming and complex to engage, but they also provide the most potential for valuable input, and there are organizations that know how best to reach them.

It was suggested that PCORI's Ambassador Program could have a stronger organizational focus, in addition to its current individual members. Instead of holding an isolated event in one part of the country, PCORI could be better served by facilitating relationships among organizations. As Ambassadors, organizations could serve as an

advisory group to PCORI to highlight stakeholders that they may not have engaged, such as churches and other faith-based organizations. They could also provide PCORI with insight on how different organizations interact with various populations such as persons with disabilities or a particular disease.

On a more practical note, a participant raised the issue of money and resources that are needed for organizations to be truly engaged in the process of research and dissemination. True accountability will require that entities such as PCORI provide resources to ensure that organizational stakeholders are able to participate in these pre-engagement opportunities. There was wide agreement that accountability for engagement means providing the necessary resources to engaged partners that are being relied upon for pre-engagement of their communities and members. Those participants involved with PCORI's Patient-Powered Research Networks (PPRNs) reiterated that the time and effort involved in that process is costly to grantees, and is a good example of the need for resources to support the level of involvement needed to be meaningful. It was noted that PCORI's Ambassador Program includes complex training modules, and ambassadors are not paid for that time - yet it was acknowledged that paying them could have negative consequences for patient-centeredness as well.

Engagement of Providers and Clinicians

Providers and clinicians were identified as another group that requires better engagement. One participant described the traditional research process from the researcher perspective as: (a) researcher creates an intervention; (b) provider uses intervention; and (c) patient benefits from intervention (and should be happy to have it). Using PCORI as an example, there are now built-in incentives for researchers to engage patients. There is not the same incentive to engage clinicians and providers who can help to determine the practicality or usefulness of the intervention. Engaging providers was viewed as important to capture real world outcomes using real world interventions. It was suggested that engagement of the providers expected to use an intervention be incentivized similarly to patient engagement. Medical advisory teams in some non-profit organizations were described as potential sources of provider and clinician engagement.

Another participant identified barriers to engagement of clinicians and providers. In operating a diabetes prevention model, the participant described significant efforts to facilitate referrals to the program. The response is simply that the provider does not have time, and no one in the office is administratively responsible for it. The patients do

not know they are not being referred. And patients will defer to their primary care doctors. Therefore, overcoming barriers to provider engagement should be a priority.

Accountability for Outreach and Feedback

Roundtable participants stressed the need for both outreach and feedback from funding organizations seeking to be accountable for engaging stakeholders. In one example, the implementation of the PCORI Rare Diseases Advisory Panel was criticized for its process of engagement and responsiveness to the concerns raised by some organizations. In terms of accountability, there was a view that PCORI was not sufficiently accountable for outreach to rare diseases groups and concerns raised by them. This experience underscored the concern that accountability for engagement can be undermined by insufficient outreach and responsiveness to organizations that represent the patient populations that potentially benefit from the panel's work.

In a more positive example, a PCORI advisory panel member pointed to the subcommittees that their panel had developed as being responsive to concerns expressed by the panel after the first round of prioritization. These newly created subcommittees are not limited to panel members. There was also a description of the use of work groups to better define the terms in a funding announcement. The process was perceived as greatly improved by the use of these subcommittees and work groups, once they became transparent per the urging of panel members.

Another participant expressed significant concern about the lack of transparency and feedback loop related to decisions that PCORI was making. Other participants shared those concerns. For example, it was not clear how panel chairs and co-chairs were chosen, or how terms were selected for panel members. One panel member described the recurrence of a topic on their list of topics to prioritize that had already been recommended to be shifted to another panel where it was better suited for consideration – with no explanation as to why. More positively, participants having participated in PCORI advisory panels acknowledged it was a welcoming place to provide input.

In wrapping up the discussion related to prioritization, the participants agreed that their recommendations for PCORI should make its work more systematic, and allow PCORI to lean on their patient partners, including organizational stakeholders, to bring efficiency to their processes. The key words to which PCORI should aspire were "efficient," "inclusive," "transparent," and "engaging."

Conduct of Research

The group was provided with an overview of PCORI's Patient and Family Engagement Rubric as an example of PCORI's efforts to make researchers accountable for engaging patients throughout the research process. Participants that had experience as PCORI merit reviewers attested to PCORI's efforts to only fund applications that included patient engagement.

Changing the Culture of Research

It was perceived that traditional researchers were better engaging patients, not because the culture had changed to value patients as research partners, but simply because researchers wanted to get funded. Researchers who support CBPR were an exception, because they have been engaging patients for years and therefore know how to do it well. Anecdotally, it was suggested that there are some traditional researchers that are recognizing the value of patient engagement after they do it successfully. In this changing paradigm, researchers are expected to provide value to the patient partner in exchange for a letter of support. Patient partners want to know how resources are going to be distributed to give them a meaningful role.

Enforcing Engagement Among Researchers

This led to a discussion of the role of the research funder in its oversight of the researcher and patient engagement. As an example, PCORI has begun to use an Engagement Officer to make researchers accountable for meaningful patient engagement.

A participant shared that Thomas Percival, who created the American Medical Association's Bioethic Code of Conduct, dismissed a recommendation that patients should receive unbiased medical information. It was his view that patients should be protected from medical information, a sentiment that is carried on in today's culture of medicine. It was a shared view of the roundtable that this culture, at least among researchers, could change only with the financial incentives being provided to do so by entities like PCORI.

Another participant relayed her organization's experience with a PCORI-funded grant, where her organization provided a support letter but was not meaningfully engaged nor

offered resources to meaningfully engage in the project. In another example, the group was advised of an AHRQ project whereby the topic selection was not transparent, the topic did not reflect a priority for the targeted patients, and the engaged clinicians were so upset about the quality of the report that they sought to not be named as key informants. Per these examples, it was suggested that PCORI should be evaluating accountability with engagement on a project-by-project basis.

PCORI is enforcing engagement better than other funding organizations, and the concept of auditing the engagement with the use of an Engagement Officer is a positive step. It was suggested that this role could be expanded to the use of an Engagement Panel that serves as a review panel determining if engagement is appropriately happening in a project during the research process. It was also strongly supported that if engagement is not happening appropriately, funding should be cut off. It was also suggested that contracts with patient partners can be used to hold researchers accountable for their engagement.

Pathway to Resolve Engagement Challenges

In one project, PCORI was praised for sending its own staff to attend external advisory committee discussions to learn first-hand how engagement is happening. It was highlighted that there are PCORI projects where engagement is meaningful, and having an impact on research design, and others where engagement is not working as well. This raised the question of what to do in circumstances where communicating the problem to the investigator does not lead to a solution. It was suggested that PCORI could create a pathway for patients to address shortcomings in the engagement process during the life of a project, so there are concrete, explicit steps to take toward resolving the issue.

It was noted that PCORI's projects are monitored for adherence to milestones, particularly recruitment of participants. When there are problems, the project officers get together and discuss those issues. Patient engagement could be another topic for project officers to monitor, with the aid of the Engagement Officer. Regular contact between the project officers and the patient partners in the research team could provide an additional source of accountability.

Expectations for Patient Co-Investigators

It was further noted that PCORI prefers that patient and stakeholder partners be included on the core research team. In some circumstances, unrealistic expectations can arise if a single patient partner - especially one that may be dealing with health challenges at the time the research is taking place - is expected to participate in all levels of the research with the research team taking on equal amounts of work. Although there was general support for patients being co-investigators, the role of the patient can and should differ on each project. By being a co-investigator, the researcher has a responsibility to the patient. As a consultant, the patient may or may not be invited to provide input. The primary investigator should not fear the consequences if the patient partner is unable to take the same amount of responsibility in the project due to their health or other constraints. The goal is for the patient to have a powerful voice that has weight where it matters.

The Long-Term View of Patient Experience

Although PCORI has plans to evaluate the patient experience in research, it was further suggested that PCORI incorporate a more longitudinal survey of the patient's experience. The experience of a patient in retrospect, after the research is complete, is important to determine whether the patient would partner in research again. For the researcher, the end game is to be published, but for the patient and the community, the end game is the usability and consequence of the research. As an example, it was noted that a goal of the PPRNs is to communicate research results to participants, so they are thinking of the end game at the beginning of the project.

Diversity

The diversity of investigators was also considered a priority. It was suggested that there are disparities among engaged patient partners in research and among investigators. If the primary investigators do not reflect the diversity of the patient population, they are not likely to bring with them the networks that reflect the patient population. Therefore, PCORI should incorporate into its evaluation framework a review of the diversity of its primary investigators. Diversity should be broadly defined to include race, ethnicity, sexual orientation, gender, etc. And the review of diversity should extend from the individual patient partners to the organizational patient partners and the networks that they bring to the project.

Community Engagement in Rigorous Research

PCORI was recognized as funding fewer of the "usual suspects" in the academic research community in each subsequent cycle of funding. Although the first PCORI funding cycle awarded mostly traditional academic institutions, there are more and more awards going to lesser-known entities. There is a myth that strong community engagement and rigorous science are mutually exclusive. Those engaged in CBPR can teach more traditional programs how to do both. Educating patients, community advocates and other community experts on issues related to the science can help stakeholders see that community engagement and good science go hand-in-hand.

Patient Voice in Research Methodology

In terms of research methods, it was suggested that the PCORI Methodology Committee should have a patient voice, particularly to drive more methods on qualitative and observational research. Yet, the role of the patient was largely debated, as patients are not typically statisticians or methodological experts and should not be simply there in a "token" role. The patient role will require clear translation in understandable terms, and an opportunity for the patient to digest the information and provide feedback. A patient can provide great feedback on qualitative methodology in the context of what is reasonable to ask. In mixed methods research, some offer training such as ethics training, after which the community members gets a certificate of completion to take to other projects.

This led to a discussion about whether patients should serve on the Methodology Committee, or whether patients should serve in an advisory capacity. One participant questioned the impact of new methodologies on the potential for dissemination of studies, because a study with rigorous standards may not be usable to patients. Another participant noted there are different kinds of rigor. As an example, the FDA engaged patients in a bi-monthly meeting in their drug development initiative, presenting questions that came from medical reviewers. In the process, patients pushed back to better format the questions so that they would get the answers they were seeking – the researcher defined the statistically important and good study design, and the patients helped them implement it in a way that would get them the answers they were seeking. In that way, it was suggested that several patients should serve in an advisory role, while having a patient voice on the Methodology Committee itself as well.

Dissemination

The roundtable participants were provided an overview of the distribution of funds to disseminate PCORI-funded research, and the work of Mathematica to develop a Dissemination and Implementation Action Plan. It was conveyed that AHRQ is directed to disseminate PCORI-funded research, and part of PCORI's purpose is to better disseminate research.

Advisory Panels on Dissemination

The roundtable determined that an advisory group on dissemination would be an effective strategy to ensure dissemination is meeting the goals of transparency, inclusiveness and accountability on a project-by-project basis so that it is not "one-size-fits-all." As PCORI is working on a strategic initiative to articulate its research in terms of the target populations (i.e. cancer, mental health, pediatrics, diabetes, etc), one could envision advisory panels around each area of research that includes patients, health professionals and researchers to guide the dissemination.

This led to a discussion about who is the accountable entity to create these types of advisory panels and implement other recommendations related to dissemination, whether PCORI or AHRQ, considering AHRQ has significant funding to do dissemination. Although AHRQ constructs effective and literate decision aids, there was significant critique of the quality of the information going into those decisions aids in the status quo, and AHRQ's ability to disseminate those decision aids into the community. Pre-engagement with patient partners was identified as a key component of any successful dissemination strategy, especially for hard-to-reach communities.

Building Capacity of Stakeholders

Co-branding with patient organizations representing the target populations was raised as one option to ensure that findings are tailored and presented in a useable manner. Funding directed to patient organizations could empower and build the capacity of organizations to participate in dissemination.

There should be a role for the patient partners in research in the dissemination process, as well as the role of the broader community of potential patient partners in dissemination. The researcher will have the capability of answering savvy questions about the demographics of the participants in the research. But then there needs to be training for a team of people to go into the community with that information, equipped to answer the detailed questions about the research. For example, in one community a

theater production was used to educate the audience – a creative way to communicate research findings. Soap operas were another example of creative dissemination. It is not one group or one patient, but the engagement of the larger community that is central to the success of dissemination.

It was suggested that the ambassador program could be an outlet for identifying organizational capacity to participate in research and dissemination. Organizations could provide information to PCORI on where they have access to stakeholders, the populations that are part of their communities, where they are located geographically, what other groups they work with closely, etc. PCORI could then access those organizational ambassadors to play roles as intermediaries, disseminators and communicators around research. A researcher may know how to disseminate at the local level, but this kind of ambassador program would allow the researcher to access a broader community of organizations to disseminate nationwide.

Review and Interpretation of Research Results

The group then discussed the distinction of how to disseminate research findings where there was a conclusion on how to improve care, versus a study that was inconclusive or even negative. The focus of dissemination would differ. In one case you would want that information to reach the target populations, in the latter case, the research should be accessible but more as a learning tool for future research. One participant provided an example of where clinical guidelines and quality measures are driving care practices that are in fact creating more danger to the target patient population because the information is not being filtered to patients based on their age and other demographic information needed to make the treatment decision. Another example was provided of studies that conflict, and therefore patients and their caregivers must make care choices based on the information available that is, in fact, inconclusive. Ultimately, we need to provide information to people in a manner that empowers them. Therefore, there is a role for engagement in the review and interpretation of results that is also important to consider.

Engagement in Development of Decision Aids

Transparency was considered to be a key element of the dissemination process that should include an opportunity for stakeholders to comment on how the process will play out at the point of dissemination. The participants discussed the participation of

the researcher in development of a decision aid that included an external review, and ultimately an evaluation of the usefulness of the information being communicated.

The groups advocated for engagement at each stage of the dissemination process, from the development of the decision aid, to its dissemination. This includes having the decision aid tool made available on the website of patient organizations, and the ability of patient partners to translate it appropriately. Experts in health communication should also be part of the development of the decision aid and the strategy for its dissemination.

It was further suggested that AHRQ could host and fund focus groups for patients to test the communications to ensure it is presented in accessible language, prior to finalizing the decision aid. Were PCORI to foster organizational ambassadors, those organizations could also provide a focus group audience to AHRQ so there is certainty that the audience is truly representative of the target population for the information.

Joint Planning

Participants urged that AHRQ and PCORI plan jointly for dissemination so that the work of PCORI in identifying best practices for dissemination are captured in AHRQ's work to disseminate PCORI-funded research findings. It was not clear to the group the current thinking on how the two agencies will divide their work related to dissemination, nor the roles of the researcher versus third parties in the development of decision aids and their dissemination. Nevertheless, the participants clearly sought a role for the researcher, providers, patient partners in research, experts in health communication and the broader community of patient partners representing the target population of the research.

There was a critique of the existing dissemination programs at AHRQ that rely heavily on the "usual suspects," and a strong will for AHRQ to use PCOR Trust fund dollars differently than their comparative effectiveness program so that it better engages the target communities.

Conclusion

In conclusion, the group discussed that engagement practices led by PCORI in this changing culture of research was being watched not only in the context of the broader health system, but also internationally. As an evolving process, the roundtable

participants expressed hope that PCORI would be responsive to the recommendations of the group, per the list outlined below.

Recommendations to PCORI:

Prioritization

- **Shared Accountability**: There should be shared accountability between research funders and its patient stakeholders for topic solicitation. The research funder could provide user-friendly tools that organizational stakeholders can share with community members to prevent them from being overwhelmed by the comment process.
- **Pre-Engagement:** Pre-engagement should be incorporated into the process of prioritization and community engagement. Broadly, pre-engagement with community leaders can ensure that broad engagement events are productive and goal-oriented. Pre-engagement would allow those participating in PCORI advisory panels and others that closely follow PCORI's work to prepare their constituencies for upcoming opportunities to provide input. Community-based participatory research (CBPR) provides a good model for pre-engagement, whereby relationships with community partners are built long before a grant application is submitted. Ultimately, the end user of the information being generated should have input up front.
- **Broad Engagement**: Entities seeking to prioritize research should be engaging organizations at all levels, from disease specific organizations to those focused on disparities populations. In doing so, entities such as PCORI would be reaching hard-to-reach populations that require more creative strategies to engage meaningfully.
- **Organizational Ambassador Program**: For example, PCORI's Ambassador Program should have a stronger organizational focus to facilitate like-minded organizations coming together in setting priorities for the populations that they serve.
- **Resources to Support Patient Partners**: Accountability for engagement will require providing the necessary resources to engaged partners that are being relied upon for pre-engagement of their communities and members.
- **Engage Providers and Clinicians**: The provider community should be equally incentivized to engage throughout the research process, starting with prioritization, as providers will be expected to use, or not use, the studied interventions.

- **Respond to Feedback**: To be truly accountable for engagement, the views of patients and providers must not only be solicited, but responded to in a timely manner.
- **Systematic Engagement to Build Efficiency**: Research funders, particularly PCORI, should make their work more systematic. This will require providing opportunities for organizational stakeholders to bring efficiency to their processes by taking the tools developed by research funders for engagement to their communities, and being provided resources to do so effectively.

Conduct of Research

- **Project-by-Project Reviews**: PCORI should be evaluating researchers' accountability with engagement in the conduct of research on a project-by-project basis.
- **Engagement Oversight by Officer and Panel**: The role of an Engagement Officer, as implemented by PCORI, should be expanded to the use of an Engagement Panel that serves as a review panel determining if engagement is appropriately happening in a project during the research process. For example, patient engagement could be another topic for the funder's project officers to monitor in a formalized review panel that includes the participation of the Engagement Officer.
- **Consequences for Not Engaging**: If a researcher is not being accountable for engagement of stakeholders as described in their contract with the funder, funding should be cut off.
- **Contracts**: Contracts between the researcher and the engaged stakeholders should be used to hold researchers accountable for that engagement.
- **Pathway to Resolve Engagement Challenges**: Research funders such as PCORI should develop a pathway for patients to address shortcomings in the engagement process during the life of a project, so there are concrete explicit steps to take toward resolving the issues that emerge.
- **Differing Roles of Patients as Co-Investigators**: Patient partners can and should be co-investigators. Yet, the role of the patient can and should differ on each project. The effectiveness of the engagement experience should be judged from the perspective of the engaged patient partners.
- **Diversity**: Research funders should evaluate the diversity of their funded primary investigators. Diversity should be broadly defined to include race, ethnicity, sexual orientation, gender, etc. The review of diversity should extend to patient

partners, from the individual patient partners to the organizational patient partners and the networks that they bring to the project.

- **Longitudinal Survey of Patient Partner Experience**: Research funders should incorporate a longitudinal survey of the patient's experience after the research project is completed to determine whether the patient would partner in research again, and whether the research was usable and had consequence for the patient partner and the community they represent.
- **Patient Voice on Methodology Committee**: The patient voice should be included in the development of methodological standards for research. The PCORI Methodology Committee itself should include patient representatives, and a panel of patients should have the opportunity to serve in an advisory role to the Methodology Committee.

Dissemination

- **Differentiation from Status Quo**: AHRQ should use PCOR Trust fund dollars to test dissemination strategies that differ from their comparative effectiveness program so that they address the patient-centered principles outlined in its statutory guidance and to better engage the communities that benefit from the information provided.
- **Health Communication Scholars**: Health communication scholars should be better engaged in the dissemination process, from the development of decision aids through their dissemination.
- **Dissemination Advisory Groups**: Dissemination advisory groups should be used to ensure dissemination is meeting the goals of transparency, inclusiveness and accountability on a project-by-project basis so that it is not "one size fits all." For example, as PCORI is working on a strategic initiative to articulate its research in terms of the target populations (i.e. cancer, mental health, pediatrics, diabetes, etc), it was recommended that PCORI and/or AHRQ develop advisory panels around each area of research that includes patients, health professionals and researchers to guide the dissemination.
- **Pre-Engagement**: Pre-engagement with patient partners at the early stages of research was identified as a key component of any successful dissemination strategy, especially for hard-to-reach communities, to generate the demand for the information that will facilitate its dissemination and use.
- **Co-Branding**: In disseminating decision aids, there should be co-branding opportunities for patient organizations representing the target populations to ensure that findings are tailored and presented in a useable manner. Patient

partners should be able to not only make decision aids available on their websites, but also be able to translate those decision aids appropriately.

- **Capacity-Building**: Capacity-building in the community should be a component of the dissemination strategy. Patient organizations should have access to resources and funding to be empowered to participate in dissemination.
- **Review and Interpretation of Results**: In order to provide information to people in a manner that empowers them, patient partners should be engaged in the review and interpretation of results of research.
- **Organizational Ambassador Program**: An ambassador program such as that created by PCORI should be an outlet for identifying organizational capacity to participate in research and dissemination. For example, organizational members of PCORI's Ambassador Program could provide information to PCORI on where they have access to stakeholders, the populations that are part of their communities, where they are located geographically, what other groups they work with closely, etc. PCORI could then access those organizational ambassadors to play roles as intermediaries, disseminators and communicators around research.
- **Decision Aids**: The researcher, patient partners, providers and health communication experts should be engaged in the development of decision aids.
- **Focus Groups**: Entities that fund dissemination should host and fund focus groups related to dissemination. For example, AHRQ should host and fund focus groups for patients to test decision aids to ensure they are presented in accessible language, prior to their finalization. Were PCORI to foster organizational ambassadors, those organizations could also provide a focus group audience to AHRQ so there is certainty that the representation of patients truly representative of the target population for the information.
- **Joint Planning**: AHRQ and PCORI should plan jointly for dissemination so that the work of PCORI in identifying best practices for dissemination are captured in AHRQ's work to disseminate PCORI-funded research findings.

The participants in this roundtable discussion concluded that the recommendations above should be considered by research funders and those engaged in dissemination of research broadly. Nevertheless, the discussion centered around the work of PCORI and AHRQ, and the recommendations are most directly applicable to their work. The roundtable participants are excited and supportive of the efforts underway to make research and dissemination more patient-centered. These recommendations are provided to further the thinking about patient engagement, so that it truly empowers and activates patients in their health decisions. We would urge PCORI and AHRQ to

formally respond in writing to our recommendations so that we are assured that they were fully considered.

In closing, we appreciate this opportunity to share our views and recommendations to the research and dissemination community.

Signed:

Alfiee M. Breland-Noble, Ph.D., MHSc., Consultant to team on Diversity and Disparities, Georgetown University Medical Center

Angela Ostrom and Beatriz Duque Long, Epilepsy Foundation

Brandon Leonard (on behalf of participant Lauren Canestrini), Men's Health Network

Caitlin Morris, Families USA

Cynthia Bens, Alliance for Aging Research

Grant Jones, Center for African American Health

James Romano, Patient Services, Inc.

Jamie Lamson Sullivan, COPD Foundation

Lisa Rossignol, The New Mexico Disability Story

Priscilla Huang, Asian Pacific Islander American Health Forum

Sara van Geertruyden, Partnership to Improve Patient Care