

PIPC/AGA Dissemination & Implementation Roundtable Summary Document

On November 6, 2013 the Partnership to Improve Patient Care (**PIPC**) and the American Gastroenterological Association (**AGA**) convened a Roundtable Discussion of patient advocacy and provider organizations to discuss the development of a Dissemination and Implementation Action Plan by the Patient Centered Outcomes Research Institute (**PCORI**). The goal of the Roundtable was to identify and articulate consensus recommendations to guide PCORI as it initiates this next phase of its research agenda.

This document summarizes that discussion and promulgates a set of observations and recommendations that reflect areas where consensus was either achieved or is presumptively achievable among the participating groups (**Appendix A**).

Patient-Centered Dissemination of Research Findings

The roundtable participants clearly articulated a need to disseminate research findings in a fashion that communicates their impact clearly for patients with the studied disorders and their clinicians. The need to discover and subsequently translate the actionable consequences of research findings in meaningful ways that motivate individual patients to act, as opposed to promulgating generic conclusions broadly relevant to the impacted populations, was a recurrent theme of the discussion. The concept was most precisely articulated as the difference between simply informing patients “generically” about research results relevant to their diagnoses and care options, versus educating patients in a manner that motivates them to transform their individual behavior in ways likely to improve their personal health outcomes.

Examples of diseases where research-motivated patient action can have significant, potentially lifesaving impact included (the well-recognized) colorectal and (less appreciated) esophageal cancers. In this latter example it was noted that prophylactic upper endoscopy in (identifiable) potentially higher-risk patients has the potential to be lifesaving. To better advance the critical goal of transforming behaviors, it was suggested that early partnerships between PCORI-funded investigators and the relevant advocacy and provider groups is essential in ensuring researchers understand what questions and information are important to patients and providers, ultimately influencing what and how findings are disseminated and implemented. Conceptually, the investigators could work with organizations representing these critical “consumers” of their study results to identify and evaluate creative approaches to enhancing the impact of their findings. In addition, a more sophisticated understanding of the communications techniques that will facilitate behavioral change is vital. Studies designed to discover the most effective communications vehicles and methods, which will likely vary among different populations and disorders, are vital. The assembled groups at the roundtable have access to the highly-motivated patients and providers necessary to evaluate communications techniques, and articulated the enormous potential of a focused collaboration among these patients, providers, their constituencies, and PCORI.

Use of Biomarkers as Communication Tools

Patients with Barrett’s esophagus (**BE**) and high-grade dysplasia or esophageal adenocarcinoma (**EAC**) and their families commonly complain that their primary care physicians “didn’t listen to their symptoms” or that the patients “had to demand esophagogastroduodenoscopy (**EGD**)” in order to be diagnosed. Thus, it is often only the “squeaky wheel” (a persistent and outspoken patient or family member) that “gets the oil,” *e.g.*, a key diagnostic procedure. This situation clearly needs to be remedied, both to meet patient-centered research needs and to reduce mortality from EAC by achieving earlier diagnosis.

In this context, it was pointed out at the meeting that molecular biomarkers have been studied extensively in BE and EAC patients, though less so in gastroesophageal reflux disease (**GERD**).

Several panel members pointed out the potential to apply biomarker data in a novel way, specifically, as an improved mechanism to communicate cancer risk to patients and providers. Studies designed to establish the predictive value of biomarkers were proposed as important new tools enabling engagement of patients as partners in managing their disease and controlling their destiny.

Use of Registries as Tool for Dissemination

Discussions among the group about how to best engage patients consistently mentioned the use of registries. Many of the participating organizations maintain registries among their respective constituencies. The potential of registries, already established as effective mechanisms to capture information about patients as part of an enhanced “multi-directional” process to disseminate and explain research findings and help patients, families, caregivers and providers understand the implications of new research finding was compelling. The value of disseminating “real time” summaries of research findings, suitable for lay audiences, to registry participants provides value to both patients and the organizations sponsoring the registries. During the discussion, it was noted that registries can also be used as an educational tool to teach patients some basics about what they should expect from a quality clinical encounter—for example, participants stressed the importance of having a thoughtful discussion between patients and their physicians about differential diagnosis. If patients appreciate this interaction as a component of quality care, they will be empowered to ask their physician about the differential diagnosis of their symptoms. This is a mechanism to create the “informed” health care consumers that policymakers consistently seek.

Finally, registries also offer the ability for assessment. Since communications through the registries are bi-directional, there is the potential to assess the outcomes of the rapid dissemination of information using an array of approaches evaluating patient and provider behavior, and ultimately outcomes. Evaluating the potential of registries in the dissemination and implementation effort seemed a productive use of PCORI funding to many of the participants.

In addition to their ability to communicate with patients and educate through registries, portals, and other communication modalities, the advocacy groups noted that they have unique knowledge of what patients want and need from the health care system. Oftentimes this is not what providers--and especially researchers--believe that they need. What worries patients, what they understand, what presentation and delivery styles cause confusion versus those that are potentially helpful (and definitely in some cases) are better known by advocates than researchers. PCORI should require funded projects to access and use this knowledge to enhance the dissemination and implementation of research findings. As with the design of projects and the selection of research questions, early collaboration with the specific advocacy community to determine methods for communicating results and assessing impact should be required actions for PCORI.

Communications Training for Providers

Building upon PCORI's introductory presentation, which identified physicians as the most respected source of information for patients, the roundtable participants spontaneously expanded the roster of respected sources of information to nurses, clinical social workers, and pharmacists. They then suggested that PCORI invest resources in projects intended to enhance provider communications skills among these cohorts. This issue becomes especially compelling in view of the progressively limited time available for physicians and patients to talk, a reality that surfaced often in the conversation. *(Parenthetically, shorter visits were not raised as a criticism of providers; in fact, all acknowledged that providers, especially primary care providers, are under incredible time pressure from multiple obligations from many sources and are not themselves responsible for truncated visits.)*

Studies assessing how to maximize the value of increasingly limited physician resources are essential, as are studies designed to test models intended to enhance the communications effectiveness of the array of non-physician providers increasingly on the front lines of patient interaction. There was a clear consensus that PCORI could have a significant positive impact by funding contracts that supported advocacy and professional organizations in the development and assessment of creative mechanisms to train additional provider groups for effective patient education.

Ensuring Credible and Evidence-Based Dissemination

The groups were very aware of the wide, persistent, and growing availability of “research” that is confusing, not rigorous, often frightening, and therefore potentially harmful for patients. They felt PCORI had an opportunity to help patients identify methodologically sound research that is genuinely meaningful for them and separate this work from irrelevant and poorly conducted studies. The groups are already engaged in this activity for their constituents and the idea of co-branding their efforts with PCORI, especially for PCORI sponsored studies, was intriguing. As a corollary, the attendees noted a lack of information about the management of complex chronic disorders of various types (this was not confined to one disorder, it impacted many of the organizations present and multiple patient groups). Groups envisioned a research agenda addressing this issue as one which PCORI could develop collaboratively and disseminate with a coalition of advocates. This coalition could both generate critical patient-centered research questions and disseminate results. Finally, there was a consensus that the research community needs to work with patient advocates to help identify “where patients are” with respect to their critical concerns. The groups have often been surprised by what their constituents want to know, (in-depth information on FDA guidelines, for example), and they are willing to conduct focus groups to assess patient needs and motivations. Helping advocacy groups convene and conduct these focus panels among their members could be a valuable use of PCORI resources as the data collected can guide the dissemination and implementation allocation decisions of both PCORI and patient groups.

An area that emerged as clearly problematic was the need to assist overburdened primary care practices in the identification of patients with complex chronic disease who need referral, and facilitating these referrals when indicated. The problem of communicating and translating emerging research findings to primary care doctors and their patients was recognized as real and growing. While there was insufficient time to explore solutions, the idea of a “patient journal club” had some resonance as a “top of mind” suggestion. Communication about complex emerging research, its credibility and role in diagnosis and therapy is clearly an area where work is needed and a vital arena for PCORI engagement and collaboration with providers and patient advocates. Primary care doctors and specialists need assistance to ensure they are informed about and fully appreciate the nuances of emerging research findings (including implications on specific patient subpopulations and limitations of the research) at a level consistent with their scope of practice. Patients need adequate translation of evolving research findings in order to become fully empowered participants in developing their care plan and evaluating its implementation. Trials of methodologies to accomplish this translation from bench to bedside, to the generalists and specialists and ultimately to patients, are clearly needed and seem logical foci of emphasis for PCORI’s dissemination and implementation resources.

In summary, the roundtable participants, representing both patient and provider communities impacted by an array of gastrointestinal disorders, are confident that the recommendations below reflect their collective thinking:

- Bulleted Summary List Below-

- The dissemination of research findings is not merely educational; it includes the ultimate goal of changing individual behavior. This requires an understanding of what patients want and need to know in order to motivate behavioral change. Patient advocacy groups can help PCORI identify and evaluate these motivational factors.
- Early focused partnerships between PCORI-funded investigators and patient advocacy and provider groups can generate creative ideas about how investigators can maximize the impact of their findings on health outcomes **and should be** part of PCORI-funded research.
- Studies designed to evaluate the impact of varying communications approaches targeted to different groups should be a component of the PCORI research agenda. The groups in attendance have access to highly motivated patients and providers who both want and are positioned to effectively collaborate with PCORI and its funded investigators to identify and craft effective communications techniques.
- A plan to effectively communicate research findings to patients needs to be designed into each study from the beginning, and PCORI-funded investigators should be required to initiate outreach and collaborate with relevant patient advocacy groups to identify the targets, nature, and goals of these communications as early as possible.
- The potential of Registries to facilitate dissemination and implementation efforts is profound and multifaceted. They offer opportunities for communication of study results and empowerment of patients through education. Additionally there is the potential of bi-directional communication...patients connected through Registries can provide meaningful feedback about the impact of dissemination techniques on their behavior. This is an ideal way to evaluate what works and a valuable approach for PCORI. The groups felt that communication among them and PCORI about ongoing and planned information technology (including Registry-focused) strategies is critical to assuring that their communities' collective experiences are appropriately leveraged.
- The advocacy groups and professional societies are often in a better position than researchers to apply for certain grants. They know “where patients are” in their thinking, what worries them and what questions they want answered. PCORI should formalize a process of early outreach to these groups to identify research questions and approaches.
- Appreciating the time pressure on physicians (especially primary care), PCORI should undertake research on enhancing the communications skills of a broader set of providers, specifically nurses, clinical social workers, other caregivers (including family members) and pharmacists. The impact of enhancing the skills of these providers on dissemination and implementation should be a goal of the research program.

- The groups felt that multiple evolving dissemination venues often confront patients with insufficiently vetted, confusing, inaccurate and often frightening information. Collaboration with PCORI, perhaps “co-branding” efforts to promulgate accurate information, was suggested. Additionally, a need to develop broadly relevant information to help patients and caregivers manage chronic diseases (of all types) surfaced as a clear need. Finally, the idea of working with PCORI to create patient focus groups that provide continuing real-time feedback about patient concerns and the impact of dissemination and implementation efforts resonated positively with the group.
- The groups collectively identified that referral of complex patients to the appropriate sub-specialist was often delayed, and that primary care doctors, non-physician providers and patients needed help in facilitating these indicated referrals. Materials should be developed, specific for each group, to address this challenge. Collaborative efforts, inclusive of all the above stakeholders, were considered a proper target of PCORI resources.

We submit this summary to PCORI with the hope that our suggestions will be valuable and reiterate our enthusiasm to continue this dialogue and ultimately take collective action.

Appendix A

Participating Organizations Signing the Summary and Recommendations:

American College of Gastroenterology
American Gastroenterological Association
American Society for Gastrointestinal Endoscopy
Caring Ambassadors Program, Inc.
Crohn’s & Colitis Foundation of America
Esophageal Cancer Action Network
Fight Colorectal Cancer
Hepatitis B Foundation
Hepatitis Foundation International
IBD Support Foundation
International Foundation for Functional GI Disorders
National Foundation for Celiac Awareness
National Pancreas Foundation
National Viral Hepatitis Roundtable
North American Society for Pediatric Gastroenterology Hepatology and Nutrition
Partnership to Improve Patient Care
United Ostomy Associations of America