

**Comparative Effectiveness and Patient-Centered Outcomes Research:
Enhancing Uptake and Use by Patients, Clinicians and Payers
January 26 – 27, 2017
Washington DC**

Conference Summary

Conference Overview

There currently exists significant resources and expertise in the conduct of comparative effectiveness research (CER) and patient-centered outcomes research (PCOR), which has led to steady accumulation of CER/PCOR evidence in the literature. However, there remain opportunities to better integrate CER/PCOR evidence into decision-making. Specifically, there is need to understand the barriers and to design effective strategies to ensure uptake and use of CER/PCOR by clinicians, patients, payers, and policy-makers. To the end, the Pharmaceutical Research and Manufacturers Association (PhRMA) Foundation, together with the Academy for Managed Care Pharmacy (AMCP) held an invitation-only conference on January 26-27, 2017 in Washington, DC. titled *“Comparative Effectiveness and Patient-Centered Outcomes Research: Enhancing Uptake and Use by Patients, Clinicians and Payers.”* The conference was attended by 70 experts and opinion leaders representing clinicians, patients and payers. The aims of the conference were 1) to provide an overview of the existing landscape on strategies to enhance uptake and use of CER/PCOR by patients, clinicians, and payers; 2) identify and discuss the needs and gaps in the uptake and use of CER/PCOR evidence by patients, clinicians, and payers; 3) identify the best methods or approaches to enhance the uptake and use of CER/PCOR evidence by patients, clinicians, and payers; 4) provide an opportunity for networking among attendees; and 5) develop a consensus document or other enduring material that provides benefit beyond the conference by providing a framework for recommendations and tools for training current and future users of CER/PCOR evidence.

About the Participants

A unique aspect of the conference was that it brought together individuals representing clinicians, patients, payers, and pharmaceutical companies. These groups were considered the “users” of CER/PCOR evidence that had the most at stake in the goals of the conference. Moreover, having the different groups represented was thought to better foster understanding of challenges faced by stakeholders, and to encourage greater adoption of successful strategies across user groups. Among the 70 invited participants were individuals from academic organizations, professional associations, healthcare provider groups, insurance companies and other payer organizations, patient advocacy groups, government agencies, research groups, pharmaceutical and biotech manufacturers, and others in the CER/PCOR field. A complete list of participants is provided in the conference program.

Agenda and Discussion

The conference had a full agenda that included presentations by experts in the field and time for breakout discussions and networking. The program started on the afternoon of January 26,

2017 with an introduction and welcome by Eileen Cannon, President of the PhRMA Foundation, and Glen Schumock from the University of Illinois at Chicago. The opening session featured an overview of the history of CER education programs, and the motivation behind the PhRMA Foundation's Centers of Excellence in CER Education, presented by Michael Murray of the Regenstrief Institutes and Purdue University. Following that were three presentations from the PhRMA Foundation-funded CER Centers. First, Beth Devine and Lou Garrison from the University of Washington gave a summary of the activities and accomplishments of the centers at Johns Hopkins University, Harvard, the University of Utah, and the University of Washington. Next, the two most recently funded centers presented: Simon Pickard presented on behalf of the University of Illinois at Chicago, and Eleanor Perfetto presented for the University of Maryland.

The next session provided an opportunity for attendees to hear the latest on funding, major initiatives, and direction of the three major sponsors for CER/PCOR research – the Patient-Centered Outcomes Research Institute (PCORI), the Agency for Healthcare Research and Quality (AHRQ), and the National Institutes of Health (NIH). These presentations were by William Lawrence, Sharon Arnold and David Meyers, and Josephine Briggs, for PCORI, AHRQ, and NIH, respectively. The information presented generated a robust question and answer exchange. Next on the agenda was an equally interactive stakeholder panel, moderated by Scott Smith of the Department of Health and Human Services. The purpose of the panel was to discuss the needs and gaps in the uptake and use of CER/PCOR from the user's perspective. Eleanor Perfetto represented the National Health Council and gave the patient perspective. Caleb Alexander of Johns Hopkins University presented thoughts from the clinician perspective. Soumi Saha of ACMP spoke on the payer's perspective, Murray Ross from Kaiser Permanente presented from the health system perspective, and Julie Locklear from EMD Serono gave the pharmaceutical industry perspective. A set of follow-up questions from the moderator and audience helped explore various aspects of the different perspectives.

The evening of the first day of the conference was highlighted by a networking session, dinner, and keynote address. The networking session gave attendees ample opportunity to connect and share ideas. This session was complimented by other networking opportunities that occurred during breaks and before and after sessions. The keynote speaker was Kavita Patel. Dr. Patel is a nonresident fellow at the Brookings Institute. She has a deep understanding of health issues and policy discussions occurring in the Capitol and shared her insight on CER/PCOR moving forward in the transition between administrations and beyond. The presentation was excellent and prompted a lot of discussion at the dinner tables.

Day 2 was focused primarily on strategies to improve uptake and use of CER/PCOR. The morning session was kicked-off by a comprehensive presentation on the evidence around dissemination and uptake of CER/PCOR. Elaine Morrato, from the University of Colorado, and Nilay Shah, from the Mayo Clinic, shared their understanding of key frameworks for dissemination and implementation, but also the findings of recent studies of the update of CER in practice. Next were presentations by Ernest Law, of the University of Illinois at Chicago, and Jennifer Graff from the National Pharmaceutical Council. Both presented results of surveys on

key issues around uptake and use of CER/PCOR. Dr. Law presented the results of a pre-conference survey that was sent to those registered for this conference. Dr. Graff presented the results of a survey conducted by her organization of its members.

The morning session continued with breakout group discussions. There were three breakout groups organized by user type which included 1) clinicians, 2) patients, and 3) payers. Each group was asked to take into consideration the pre-conference survey results, and other presentations and discussions at the conference, and then identify the top barriers to CER/PCOR uptake and use relevant to their group. The breakout groups also discussed effective strategies to improve the use of CER/PCOR. The group discussions were lively. Following the breakout sessions the entire audience reconvened and heard summaries from representatives of each group.

During lunch on day 2 there was a presentation by Barry Blumenfeld of RTI international. Dr. Blumenfeld presented the concept of a learning network for improving dissemination of CER/PCOR-based clinical decision support. His presentation was followed by the final session, which focused on the future of CER/PCOR education and use of CER/PCOR evidence in practice. The first presentation was by Diana Brixner of the University of Utah and president-elect of AMCP. Diana provided unique insights from the perspective of AMCP on this topic. The next presentation was by Bill Galanter, of the University of Illinois at Chicago. Dr. Galanter focused on clinical decision support systems as a means to implement CER evidence, and provided his experience and insights on that. Finally, Lou Garrison of the University of Washington, and current president of the International Society of Pharmacoeconomics and Outcomes Research (ISPOR) presented his thoughts and those of ISPOR. The conference concluded with a summary and wrap-up of by Glen Schumock of the University of Illinois at Chicago.

Outcomes and Recommendations

The collective discussion and recommendations from the conference focused on the needs and gaps in the uptake and use of CER/PCOR evidence by patients, clinicians, and payers; and the best methods or approaches to enhance the uptake and use of CER/PCOR evidence by patients, clinicians, and payers. The outcomes of the three groups – clinicians, patients, and payers – are summarized below.

1. **Clinicians:** The clinician group felt that lack of time on the part of clinicians to effectively look-up and use CER/PCOR was a major barrier. They also identified other barriers common to implementation science (i.e., not just specific to CER/PCOR) that are important – like knowledge, attitudes, beliefs, and self-efficacy. The low quality of CER/PCOR studies was identified as a major barrier to its use, as was the lack of evidence in many clinical areas/indications. Strategies discussed included incorporating CER/PCOR into clinical decision support systems and other tools that make it part of routine activities in care.

2. **Patients:** The patient group suggested that greater understanding is needed of what matters most to patients as it relates to their treatment, and to align CER/PCOR research with that. CER/PCOR research needs to be translated in a way that can be accessed by patients and

disseminated to platforms that patients use. The language used to discuss CER/PCOR evidence needs to be understandable to patients. The group suggested that a resource be created that summarizes CER/PCOR evidence in lay terms and is publically available, and resides where patients currently go to get information. Last, we should find ways to help patients reconcile fragmented information and adoption of CER/PCOR across the different providers with whom they interact.

3. **Payers:** The key barriers to uptake and use of CER/PCOR from the payer perspective are timeliness of the availability of results of CER/PCOR studies (e.g., not available when decisions are being made) and the robustness of the data (not directly transferable to the payer's population, or too many gaps in the research evidence available). Lack of resources on CER/PCOR, and lack of education on how to use CER/PCOR data are also barriers. Last, the clinical nuances that are important in decision-making don't get incorporated into CER/PCOR evidence. Strategies proposed included better organization and coordination of CER/PCOR evidence (perhaps incorporating it into existing registries), education programs – especially for regulators, the availability of high quality summaries for CER/PCOR data that can be presented to decision-makers, and the need for a CER/PCOR trained person on formulary committees.

Conference Evaluation and Next Steps

There appeared to be consensus that the conference was successful. In fact, conference organizers received a number of positive comments including both about the content and the opportunity for networking and interaction. A post-conference questionnaire will be distributed to seek a more formal evaluation. In addition, conference organizers are developing a comprehensive report of the findings of the conference. It is intended that this report may form the basis of an article or articles for publication, and that other articles may be developed from the material and/or discussions from the conference. The report and/or articles will provide enduring material and a framework for recommendations and tools for training current and future users of CER/PCOR evidence.