



New Webinar/Workshop Series!

Advancing Patient-Centered Outcomes and Impacts in Value Assessment *Understanding Research Needs to Prioritize Patients in Comparative Clinical and Economic Assessments*

The PhRMA Foundation has launched new efforts to promote and provide more attention to patient-centered outcomes in research and value assessment in 2021, beginning with a virtual series this fall. Two webinars and one workshop will be held, with the theme “Advancing Patient-Centered Outcomes and Impacts in Value Assessment: Understanding Research Needs to Prioritize Patients in Comparative Clinical and Economic Assessments.” Each of the three events will explore a different aspect patient-centered outcomes and impacts.

Dates and Topics

Webinar 1: Friday, September 17, 2021, 12:00 – 1:15 PM ET

Topic: “History and Current Landscape of Patient-Centricity and Patient-Centered Outcomes/Impacts in Value Assessment”

Webinar 2: Friday, November 12, 2021, 12:00 – 1:30 PM ET

Topic: “Spotlight on Current and Emerging Approaches and Methods to Enhance Patient-Centricity and Inclusive Patient Engagement in Value Assessment”

Workshop: Friday, December 10, 2021, 11:00 AM – 1:00 PM ET

Topic: “Looking Forward: Opportunities Towards a Collaborative Research Agenda for Patient-Centered Evidence Generation and Broad Impact Beyond Current Models”

Background

A high-functioning healthcare system—defined in terms of both efficient care delivery and insurance coverage—should aim to deliver care that produces outcomes and impacts that matter most to patients and society (e.g., mobility, social functioning, ability to work, caregiver burden, or equity). This aim of targeting benefits most meaningful to patients should apply to how we measure the value of treatments and services.

Yet, increasing focus on patient-centeredness in value assessment has revealed gaps between what patients report is most important to them and endpoints typically measured in regulatory approval studies. The gap between endpoints typically measured in the regulatory approval process and outcomes that matter most to patients threatens the accuracy and viability of value and health technology assessments (V/HTA).

Evidence-generation on outcomes and impacts most meaningful to patients has significantly increased over recent years, due to efforts from organizations such as the Patient-Centered Outcomes Research Institute (PCORI). In patient-centered outcomes research, the focus is on outcomes collected in the real-world and more pragmatic clinical trials. At the same time, a stronger focus on health equity and the importance of inclusive patient engagement has modernized health services research. Despite these efforts, inconsistent and incomplete capture and use of outcomes and impacts most meaningful to patients in V/HTA suggests greater research investment is needed to understand both the range of relevant outcomes and differences in patient preferences.

Making progress will require identifying and measuring priority outcomes and impacts most meaningful to patients, while balancing the limitations and opportunities posed by pre-market and real-world evidence-generation. This strategy requires multi-disciplinary and multi-stakeholder engagement to achieve a patient-centered and inclusive standard in value assessment to inform individual and population decision-making.

Objective

To move forward towards a multi-stakeholder approach to enhance patient-centricity in value assessment, this workshop series has the following objectives:

- **Raise awareness** of the gaps in the capture and use of patient-centered outcomes and impacts in value assessment from a variety of key stakeholder perspectives
- **Share and exchange approaches and methods** in current practice to enhance patient-centricity and inclusive patient engagement in value assessment
- **Identify opportunities** towards a collaborative research agenda to prioritize patient-centered outcomes and inclusive patient engagement in value assessment

Output of Conference Series

- Summary of conference proceedings
- Series of articles/blogs on conference findings (co-authored by planning committee, attendees)
- Options for future projects, research opportunities

Agenda

Webinar 1: Friday, September 17, 2021, 12:00 – 1:15 PM ET

Topic: “History and Current Landscape of Patient-Centricity and Patient-Centered Outcomes/Impacts in Value Assessment”

Take Away: Webinar attendees will gain a broad range of perspectives about gaps to advancing patient-centered outcomes/impacts and inclusivity in value assessment from a multi-stakeholder perspective.

Presenter

Elisabeth M. Oehrlein, PhD, MS, Assistant Vice President, Research and Programs at the National Health Council, will share the historical approach to identifying concepts and developing/validating outcomes measures; the current landscape; and how this relates to QALYs (quality-adjusted life years).

Panelists

Lori Frank, PhD, Senior Scientist, RAND Corporation

Louis P. Garrison, Jr., PhD, Professor Emeritus, The Comparative Health Outcomes, Policy, and Economics (CHOICE) Institute, Department of Pharmacy, University of Washington

Charlene Son Rigby, Chief Executive Officer, RARE-X

Bari Talente, Executive Vice President, Advocacy & Healthcare Access, National Multiple Sclerosis Society (Moderator)

Sean Tunis, MD, MSc, Principal, Rubix Health

Ashley Valentine, MRes, MPH, Co-Founder and President, Sick Cells

The PhRMA Foundation welcomes questions from the audience. You will have the opportunity to submit your questions before the webinar as well as during the webinar.

You may register for Webinar 1 [HERE](#).

Webinar 2: Friday, November 12, 2021, 12:00 – 1:30 PM

Topic: “Spotlight on Current and Emerging Approaches and Methods to Enhance Patient-Centricity and Inclusive Patient Engagement in Value Assessment”

Take Away: Webinar attendees will gain a deeper understanding of real-world approaches toward advancing patient-centricity and inclusivity in value assessment, as presented by the PhRMA Foundation’s Centers of Excellence and the Innovation and Value Initiative (IVI). The webinar will include a conversation with patient advocates.

Presenters

Julia Slejko, PhD, Associate Professor, University of Maryland School of Pharmacy - PAVE (Patient-Driven Values in Healthcare)

R. Brett McQueen, PhD, Assistant Professor, University of Colorado Skaggs School of Pharmacy and Pharmaceutical Sciences - pValue (Pharmaceutical Value)

Peter Neumann, ScD, Director, Center for the Evaluation of Value and Risk in Health at the Institute for Clinical Research and Health Policy Studies at Tufts Medical Center, Professor of Medicine, Tufts University School of Medicine - CEVA (Center for Enhanced Value Assessment)

Jennifer Bright, MPA, Executive Director - IVI (Innovation and Value Initiative)

Patient Advocates

Annie Kennedy, Chief of Policy and Advocacy, EveryLife Foundation for Rare Diseases

LaTasha H. Lee, PhD, MPH, Vice President, Clinical and Social Research and Development, National Minority Quality Forum

Kenneth “Kenny” Mendez, CEO and President, Asthma and Allergy Foundation of America (Moderator)

The PhRMA Foundation welcomes questions from the audience. You will have the opportunity to submit your questions before the webinar as well as during the webinar.

You may register for Webinar 2 [HERE](#).

Workshop: Friday, December 10, 2021, 11:00 AM – 1:00 PM ET

Topic: “Looking Forward: Opportunities Towards a Collaborative Research Agenda for Patient-Centered Evidence Generation and Broad Impact Beyond Current Models” **Take Away:** Breakout groups will identify opportunities to develop and implement a patient-centered outcomes/impacts and inclusive research agenda with broad impacts beyond any particular value-based model specification.

Details and registration for this interactive Workshop will be available after Webinar 2. [Please save the date.](#)

All questions can be sent to foundation@phrma.org

You may register for Webinars 1 and/or 2 by clicking [HERE](#).