



## PhRMA Foundation Value Assessment Initiative Year-End Review 2021

The PhRMA Foundation Value Assessment Initiative promotes advancements in value assessment that inform health care decision making by prioritizing care that is most valuable to patients.

Over the past four years, the PhRMA Foundation has made great strides in advancing innovation in methods in value assessment. The Foundation has championed the integration of patient voices in value assessment research and has funded efforts to broaden conversations around value and ensure that health care decisions are transparent and address the needs of all health care stakeholders, including patients, payers and providers. **In particular, this initiative seeks to prioritize patient centricity and health equity as key pillars of the value assessment framework development process.**

### Table of Contents

<i>PhRMA Foundation Challenge Award</i> .....	2
<i>Health Equity Challenge Award</i> .....	4
<i>2021 Research Awards</i> .....	6
<i>Centers of Excellence</i> .....	7
Patient-Driven Values in Healthcare Evaluation (PAVE) .....	7
Research Consortium for Health Care Value Assessment .....	10
(Value Consortium) .....	10
The Center for Pharmaceutical Value (pValue).....	11
Center for Enhanced Value Assessment (CEVA).....	13
<i>Webinar Series – Advancing Patient Centered Outcomes and Impacts in Value Assessment..</i>	13
<i>Conference Presentations &amp; Workshops</i> .....	15
<i>The PhRMA Foundation Blog &amp; Third-Party Commentaries</i> .....	17
Voices in Value Blog Posts .....	17
Op-eds/Commentaries Highlighting PhRMA Foundation Centers of Excellence .....	18
<i>2020 Year-End Review</i> .....	19

## PhRMA Foundation Challenge Award

The PhRMA Foundation began funding Challenge Awards in 2017. Each year, a pressing question related to value assessment in health care is distributed and researchers are invited to submit proposals in response. In 2020, researchers were asked to respond to the following question:

*What approaches are needed to consistently and reliably incorporate patient-centered outcomes in value assessment for both population- and individual-level health care decision-making?*

This summer, the winning papers were published in a special issue of Value & Outcomes Spotlight. You can read them all [HERE](#).

### **First Place – \$50,000**

[Generalized Risk Adjusted Cost Effectiveness \(GRACE\): Ensuring Patient-Centered Outcomes in Healthcare Decision Making](#)

#### *Award Recipients:*

- Charles E. Phelps, PhD – University of Rochester
- Darius N. Lakdawalla, PhD – University of Southern California School of Pharmacy and Schaeffer Center for Health Policy & Economics

Drs. Phelps and Lakdawalla propose using a novel approach – Generalized Risk-Adjusted Cost-Effectiveness (GRACE) – that aligns the economics of cost-effectiveness analysis with the human circumstances of patients and consider, in particular, how in standard models a given gain in life expectancy is worth less to sicker or more disabled people, because of the approach to weighting. The GRACE model reveals how traditional methods fail to account for disease severity, patient risk-aversion, and other issues and assures that patient preferences, particularly the quintessential measure of untreated health status, reliably and consistently enter value measures used at both population and individual decision-making.

### **Second Place – \$25,000**

[Nudging Health Economists: A Process for Systematic Identification of Patient-Centered Outcomes for Inclusion in Value Assessment](#)

#### *Award Recipients:*

- Joseph Mattingly II, PharmD, MBA, PhD– The University of Maryland School of Pharmacy
- Julia F. Slejko, PhD – The University of Maryland School of Pharmacy
- Elisabeth M. Oehrlein, PhD, MS – The National Health Council
- Eleanor M. Perfetto, PhD, MS – The National Health Council, The University of Maryland School of Pharmacy

The authors aim to provide practical guidance on a process for identifying and presenting patient-centered outcomes in a way that makes it easier to include them in value assessment, thereby “nudging” more economists to choose to include these outcomes in their models and not dismiss them simply as limitations. The process includes forming a multi-stakeholder, patient-centered advisory board, engaging the board in the research agenda, conducting evidence synthesis and qualitative research to ensure viewpoints are not missed, and disseminating findings to multi-stakeholder audiences. A publicly available, centralized database of identified patient-centered value elements should be created to increase the likelihood of their uptake in value assessment.

**Third Place (Tie) – \$5,000**

[Evolution of Precision Medicine: Applying a Population-based Evidence Assessment Repository \(PEAR\) to Achieve Patient-Centered Outcomes at the Point-of-Care](#)

*Award Recipients:*

- Jonathan H. Watanabe, PharmD, PhD – University of California Irvine School of Pharmacy & Pharmaceutical Sciences
- Derjung M. Tarn, MD, PhD – University of California Los Angeles School of Medicine
- Jan D. Hirsch, PhD – University of California Irvine School of Pharmacy & Pharmaceutical Sciences

The authors propose a step-wise framework that shapes goals based on patient values and shared decision-making that is continuously refined by utilizing a population-based evidence assessment repository (PEAR) to achieve person-centered care. The PEAR aims to empower the care team to ensure measurable data-driven treatment decisions that are tailored towards patient needs, characteristics, and wishes.

**Third Place (Tie) – \$5,000**

[Coproduction in Learning Healthcare Systems is the Key to Unlocking True Healthcare Value](#)

*Award Recipient:*

Brandy Fureman, PhD – Epilepsy Foundation, Epilepsy Learning Healthcare System

The author shares her experience using co-production – a process where patients, care partners, and providers work together to design a health system that optimizes the health outcomes that matter most to patients. For example, evaluations of value in epilepsy must look beyond standard clinical endpoints of seizure control and address other outcomes that are important to epilepsy patients such as motor skills, communication, learning, attention and emotional wellbeing.

## Health Equity Challenge Award

The challenges of COVID-19 brought the crucial work of our nation's scientists to the forefront and highlighted the need to address racial inequity in health care. The PhRMA Foundation has established a new Challenge Award focused on finding solutions to racial health disparities. This Challenge Award aims to inspire bold and vital research on how value assessment can better capture evidence regarding diverse populations and drivers of health disparities. Researchers were asked to respond to the following question:

*How can value assessment methods and processes better account for populations that are typically underrepresented in research and drivers of health disparities?*

**The award-winning papers were published this summer in a special issue of the *Journal of Managed Care and Specialty Pharmacy*. Read it [HERE](#).**

### **First Place – \$50,000**

#### **Drivers of Health Disparities and Consequences for COVID-19 Vaccine Choices: Modelling Health Preference Heterogeneity among Underserved Populations**

##### Award Recipients:

- Eline M. van den Broek-Altenburg, PhD, Larner College of Medicine at the University of Vermont
- Jamie S. Benson, BA, Larner College of Medicine at the University of Vermont
- Adam J. Atherly, PhD, Larner College of Medicine at the University of Vermont
- Stephane Hess, PhD, Choice Modelling Centre & Institute for Transport Studies, University of Leeds

New approaches to capture drivers of health disparities and account for underrepresented groups in value assessment methods are warranted. Dr. van den Broek-Altenburg and co-authors conducted an analysis of COVID-19 vaccine preferences among underrepresented populations and explored methodological approaches to incorporate differences in unobserved individual preferences in value assessment. The authors propose the use of discrete distributions and probabilistically segmenting a sample population into different segments, better reflecting the underlying values of individuals in underrepresented populations. The research concludes that health care interventions intended to reduce health disparities that do not reflect the underlying values of individuals in underrepresented populations are unlikely to be successful.

### **Second Place – \$25,000**

#### **Using Latent Class and Quantum Models to Value Equity in Healthcare: A Tale of Two Stories**

##### Award Recipient:

- Surachat Ngorsuraches, PhD – Auburn University

To adequately capture the value of health equity in value assessment, systematic consideration of health equity in decision making is critical. In this research, Dr. Ngorsuraches describes two approaches to empirically address health equity in value assessment by valuing health care attributes with an equity lens. The first approach uses a discrete choice experiment to elicit preferences from individuals on preferences value attributes with a latent class model to derive the value of equity, and the second approach uses a flexible choice model to value health equity. These methodological approaches can be used by value assessors to determine how equity enters the preferences for decision makers.

### **Third Place (Tie) \$5,000 each**

#### **It's Time to Represent: Shifting the paradigm to improve the quality of inputs into value assessment frameworks**

##### Award Recipients:

- Leticia R. Moczygemba, PharmD, PhD – TxCORE, The University of Texas at Austin
- Carolyn M. Brown, PhD – TxCORE, The University of Texas at Austin
- Michael Johnsrud, PhD, RPh – TxCORE, The University of Texas at Austin

To better understand the importance of equity in value frameworks, advancing the racial/ethnicity representation in inputs in value assessment is critical. In this work, Dr. Moczygemba and colleagues propose a two-pronged strategy to increase the diversity of populations that participate in research and address drivers of health disparities to better inform value assessment with the following objectives: 1) Launch a comprehensive national campaign using a community-engaged approach to inform, create buy-in, and generate excitement for participation in research, and 2) Enhance information used in value assessment frameworks by expediting current methodological initiatives to require a minimum set of patient-reported social determinants of health elements to be collected and reported in research, including clinical trials and observational (real world) studies. Through this work, scalable efforts to increase representation of diverse racial/ethnic groups and social determinants of health in value assessment can be attained.

### **Third Place (Tie) \$5,000 each**

#### **Incorporating Health Equity into Value Assessment: Frameworks, Promising Alternatives, and Future directions**

##### Award Recipients:

- Vakaramoko Diaby, PhD – University of Florida
- Askal Ali, PhD – Florida A&M University
- Aram Babcock, PharmD, MS, MBA – University of Florida
- Joseph Fuhr, PhD – University of Florida
- Dejana Braithwaite, PhD – University of Florida

To better understand the value of health equity in value assessment frameworks, exploring methods that value diverse perspectives is critical. In this study, Dr. Diaby and colleagues examine emerging value assessment frameworks in the United States and present examples, where evidence on outcomes and preferences for value do not take into consideration diverse perspectives. The authors identify possible solutions to improve existing value assessment methods and illustrate – using a hypothetical shared decision-making case study – an alternative to current value-assessment frameworks, “equitable multi-criteria decision analysis”, that could be implemented in the context of the value-based assessment of prevention choices for women at high risk of developing breast cancer. These proposed alternatives and solutions can be used by researchers and decision makers to incorporate health equity into value assessment.

## 2021 Research Awards

The PhRMA Foundation launched its Value Assessment Initiative Research Awards in 2018, providing \$100,000 yearly to support three leading national researchers’ work to advance value assessment methods in the United States. The PhRMA Foundation continues to provide Research Awards to organizations and individuals to identify and address challenges in research conducted to assess the value (clinical, humanistic, and economic) of medicines and health care services.

- **Understanding Patient Cost Sharing Thresholds for High and Low Value Care Towards Development of a Value-Based Formulary**

**Diana Brixner**, PhD – The University of Utah, Department of Pediatrics, Division of Clinical Pharmacology

Dr. Brixner’s research aims to estimate patient preferences and willingness-to-pay for a select group of high and low-value medications in an effort to inform the development of value-based formulary (VBF) designs. Her team will conduct a discrete choice experiment (DCE) with 400 patients with Type 2 Diabetes from the University of Utah Health Plans, using a literature review and focus group to identify which attributes of medications are necessary to include in the DCE. Dr. Brixner’s team will then assign a monetary value to patient’s willingness-to-pay for each of the select medications and compare it to their current cost-sharing status and pre-determined value by the University of Utah Health Plans.

- **Measuring the Value of Fear of Contagion in COVID-19 Care**

**Surachat Ngorsuraches**, PhD – Auburn University, Harrison School of Pharmacy, Department of Health Outcomes Research and Policy

Dr. Ngorsuraches seeks to obtain a quantitative measure COVID-19 fear of contagion that can be factored into value assessments of vaccines and therapies that treat this and other diseases. His team plans to conduct a discrete choice experiment to elicit the willingness-to-pay among a sample of 500 adults with and without COVID-19 infection and use the results to determine the relative importance between all study attributes and costs. Dr. Ngorsuraches's work was later part of webinar series hosted by the Illinois State University titled [Covid-19: International Perspectives](#).

- **[Estimating the Value of Diabetes Prevention Programs Using Real-World Data](#)**

**Natalia Olchanski, PhD** – Tufts Medical Center's Center for the Evaluation of Value and Risk in Health, Institute for Clinical Research and Health Policy Studies

Dr. Olchanski aims to use real-world data to estimate the value of diabetes prevention programs. Her team will use data from the National Health and Nutrition Examination Survey to characterize the diabetes risk of individuals referred to or actually receiving diabetes prevention programs care. Dr. Olchanski and colleagues will then use individual-level simulation modeling to estimate the individual- and population- level value of diabetes prevention programs to assess the impact of using real world data on value assessment for diabetes prevention programs.

## **[Centers of Excellence](#)**

The PhRMA Foundation has funded four Centers of Excellence, with each Center receiving a \$500,000 grant spread over three years. The Centers aim to promote development and implementation of innovative research and tools that advance high-quality value assessment and value-driven decision making.

## **[Patient-Driven Values in Healthcare Evaluation \(PAVE\)](#)**

Patient-Driven Values in Healthcare Evaluation (PAVE) is a unique collaboration between the University of Maryland School of Pharmacy, the National Health Council, patient community leaders, and payer and industry leaders. The organization is dedicated to developing and advancing new methods to incorporate the patient perspective into value assessment and value-based decision-making. Through this initiative, PAVE is building a diverse and extensive network of partners to build technical expertise in patient-centered health outcomes research, education, and dissemination.

### **Manuscripts**

1. [A Useful and Sustainable Role for N-of-1 Trials in the Healthcare Ecosystem](#)

Harry P. Selker, Theodora Cohen, Ralph B. D'Agostino, Willard H. Dere, S. Nassir Ghaemi, Peter K. Honig, Kenneth I. Kaitin, Heather C. Kaplan, Richard L. Kravitz, Kay Larholt, Newell E. McElwee, Kenneth A. Oye, Marisha E. Palm, Eleanor Perfetto, Chandra Ramanathan, Christopher H. Schmid, Vicki Seyfert-Margolis, Mark Trusheim, Hans-Georg Eichler

In this article, we review opportunities, stakeholders, issues, and possible approaches that could support general use of N-of-1 trials and deliver benefit to patients and the healthcare enterprise. To assess and expand the benefits of N-of-1 trials, we propose multistakeholder meetings, workshops, and the generation of methods, standards, and platforms that would support wider availability and the value of N-of-1 trials.

2. [Development of an International Template to Support Patient Submissions in Health Technology Assessments](#)

Nigel Cook, Heidi Livingstone, Jennifer Dickson, Louise Taylor, Kate Morgan, Martin Coombes, Sally Wortley, Elisabeth Oehrlein, María José Vicente-Edo, Franz Waibel, Barry Liden

*International Journal of Technological Assessments in Healthcare*

Using experience and feedback from the implementation and use of the Scottish Medicines Consortium's Summary Information for Patient Groups, the authors developed an international template to support patient submissions in Health Technology Assessments

3. [Engaging Patients in Real-World Evidence: An Atrial Fibrillation Patient Advisory Board Case Example](#)

Elisabeth M Oehrlein, Xuemei Luo, Mirko Savone, Trudie Lobban, Amiee Kang, Brian Lee, Rex Gale, Silke Schoch, Eleanor Perfetto

*The Patient*

The Pfizer–Bristol Myers Squibb Alliance partnered with the National Health Council and the Arrhythmia Alliance to engage with people diagnosed with atrial fibrillation to understand patient perspectives and enhance patient centricity to inform future studies using real world evidence.

4. [Tools for Compensating Patients for Their Patient-Engagement Activities](#)

Eleanor Perfetto and Elisabeth Oehrlein

*Value & Outcomes Spotlight*

The goal was to create a toolbox that would guide compensation of patients and patient groups who are involved in patient engagement activities, mostly related to medical product development

5. [Patient and Stakeholder Engagement Learnings: PREP-IT as a Case Study](#)

Michelle Medeiros, T Rosie Love, Gerard P Slobogean, Sheila Sprague, Eleanor M Peretto, Nathan N O'Hara, C Daniel Mullins  
*Journal of Comparative Effectiveness Research*

This commentary presents a case example of patient and stakeholder engagement in a clinical trial and the results of a small stakeholder-experience evaluation.

6. [The Importance of Collaboration in Pursuit of Patient-Centered Value Assessment](#)  
Mark T Linthicum, Susan dosReis, Julia F Slejko, T Joseph Mattingly II, Jennifer L Bright  
*The Patient*

Major advances not only in methods for patient-centered value analyses but also in building a patient-centered research environment are needed. This can be accelerated through coordinated and collaborative efforts.

7. [The Economics of Penicillin Allergy Testing: Still Scratching the Value Surface](#)  
T Joseph Mattingly II, Emily L Heil  
*Clinical Infectious Diseases*

Striving to achieve the “triple aim” (better care for individuals, better care for populations, and lower cost) means looking beyond the safety and efficacy of health interventions to include population health and incorporate aspects of health economics into our assessments.

8. [Prioritization and Refinement of Patient-Informed Value Elements as Attributes for Chronic Obstructive Pulmonary Disease Treatment Preferences.](#)  
Julia F Slejko, Yoon Duk Hong, Jamie L Sullivan, Robert M Reed , Susan dosReis  
*The Patient*

This patient-engaged formative work identified patients with chronic obstructive pulmonary disease key attributes of value-based decision making that underpin benefit-risk trade-offs between physical endurance, treatment side effects, care access, and cost. This study illustrates an iterative process for eliciting and refining a comprehensive list of value elements, resulting in a subgroup of elements important to a specific patient population.

9. [Toward Modified Impact Inventory Tables to Facilitate Patient-Centered Value Assessment](#)  
R. Brett McQueen and Julia F. Slejko  
*Pharmacoeconomics*

To consistently incorporate patient-centeredness in value assessment, we propose modifying the generic impact inventory table with disease-specific applications using a two-step process that engages patients and cross-disciplinary collaborations.

## Op-ed, Editorials & Reports

10. [PCORI's Expanded Mandate Creates New Opportunities for Value Assessment Research](#)

T. Joseph Mattingly II

*American Journal of Accountable Care*

The recent reauthorization of the Patient-Centered Outcomes Research Institute (PCORI) comes with an expanded mandate to study the economic impacts of treatments presenting new opportunities for the value assessment research community.

11. [Identifying Patient-Driven Value Elements in Major Depressive Disorder](#)

Susan dosReis, Mark Linthicum, Erica de Fur Malik, Julia Slejko, Richard Xie

*Innovation and Value Initiative (IVI) Value Blueprint*

Application of the PAVE Patient-Driven Value Element Framework to individuals with major depressive disorder (MDD) is a promising first step of a patient-centric approach to value assessment.

12. [A Vision for Patient-Centered Core Impact Sets—A Unifying Approach to Patient Centricity](#)

Eleanor M. Perfetto, Annie Kennedy, Jennifer Bright

*American Journal of Managed Care*

The authors, from the National Health Council, the EveryLife Foundation for Rare Diseases, and the Innovation and Value Initiative, unveil a project to develop a blueprint for creating patient-centered core impact sets.

## Research Consortium for Health Care Value Assessment (Value Consortium)

The Research Consortium for Health Care Value Assessment (Value Consortium) — a partnership between Altarum and VBID Health — promotes the pursuit of value in health care delivery within the U.S. by identifying high- and low-value clinical services, tracking the use of such services, and helping to ensure that consumer and patient preferences are incorporated into the health care decision-making process.

## Research Publications & Concept Papers

1. [Barriers to Our Understanding of Low-Value and High-Value Care](#)

*Value Consortium, Concept Paper*

This paper discusses the challenges of using claims data as a comprehensive data source for measuring low-value and high-value care by illustrating three approaches the authors call the additive, indicator, and comparative approaches. The discussion focuses on the claims data required by each approach, the challenges in using the data for measuring value, and offers suggestions to create a more comprehensive dataset that can provide researchers and policymakers with timely and accurate information.

2. [Similarities and Differences Between States with Varying Rates of Low-Value Care: A Qualitative Review](#)

*Value Consortium, Research Brief*

This analysis examines the characteristics of states with high and low prevalence of low-value care in an effort to identify the key drivers of low-value care. The findings are expected to stimulate further discussion about where additional research is needed to study specific connections between health care access, patient characteristics, state policies and the use of low-value care.

3. [Advancing Health Equity by Increasing Access to High-Value Care](#)

*Value Consortium, Concept Paper*

The authors argue that that the burdens of low-value care may be especially high for currently underserved populations, and that efforts to increase access to care and advance health equity will be most effective when done with attention to promoting high value and minimizing low-value care.

## The Center for Pharmaceutical Value (pValue)

Pharmaceutical Value (pValue) – headquartered within the University of Colorado’s Anschutz Medical Campus – aims to apply and test novel methods for value assessment that encourage stakeholder engagement and promote value-based decision making.

### Published Manuscripts

1. [Contextual Considerations and Recommendations for Estimating the Value of Alzheimer’s Disease Therapies](#)

T Joseph Mattingly II, R Brett McQueen, Pei-Jung Lin  
*PharmacoEconomics*

The regulatory approval of the disease-modifying agent aducanumab has brought more attention to the complexity of the diagnosis, evaluation, and treatment of AD and the difficult decisions payers and policy makers will face over the next few years as innovation continues in this space. This article focuses on AD-specific data gaps and

measurement challenges and provides guidance for evidence generation to facilitate better value assessments for future AD treatments.

2. [Patient and Payer Preferences for Additional Value Criteria](#)

Ivett Jakab, Melanie D. Whittington, Elizabeth Franklin, Susan Raiola, Jonathan D. Campbell, Zoltán Kaló, R. Brett McQueen  
*Frontiers in Pharmacology*

The objective of this study was to engage two key stakeholders; patients and payers to elicit and rank the importance of additional value criteria, potentially assessed in Multiple Criteria Decision Analysis (MCDA).

3. [Criteria and Scoring Functions Used in the Value Assessment of Rare Disease Therapies: A Systematic Literature Review of Multi-Criteria Decision Analysis Tools and Value Frameworks](#)

Tamás Zelei, Nicholas D. Mendola, Baher Elezbawy, Bertalan Németh, Jonathan D. Campbell  
*PharmacoEconomics*

In this study, pValue researchers reviewed multi-criteria decision analysis (MCDA) and value framework articles to investigate the criteria and scoring functions applied in these studies.

4. [Toward Modified Impact Inventory Tables to Facilitate Patient-Centered Value Assessment](#)

R. Brett McQueen, Julia F. Slejko  
*PharmacoEconomics*

To consistently incorporate patient-centeredness in value assessment, we propose modifying the generic impact inventory table with disease-specific applications using a two-step process that engages patients and cross-disciplinary collaborations.

5. [Stakeholder Perception of Pharmaceutical Value: A Multicriteria Decision-Analysis \(MCDA\) Educational Case Study for Value Assessment in the United States](#)

*Under Review*

6. [Deriving Patient Experience Value Elements in Rare Disease: A Case Study in Neuromyelitis Optica Spectrum Disorder \(NMOSD\)](#)

*Under Review*

## Center for Enhanced Value Assessment (CEVA)

The Center for Enhanced Value Assessment (CEVA) – headquartered within the Center for the Evaluation of Value and Risk in Health (CEVR) at Tufts Medical Center – aims to explore the incorporation of non-traditional elements of value into cost-effective analyses.

### Published Manuscripts

1. [Toward Better Data Dashboards for US Drug Value Assessments](#)

Peter Neumann

*Value in Health*

Dr. Neumann explores the use of data dashboards to convey information about a drug's value, including collapsing dimensions of value to a visual representation.

2. [The history and future of the “ISPOR Value Flower”: Addressing limitations of conventional cost-effectiveness analysis](#)

*Under Review*

3. [The Impact of Broader Value Elements on Cost-Effectiveness Analysis: Two Case Studies](#)

*Under Review*

## Webinar Series – Advancing Patient Centered Outcomes and Impacts in Value Assessment

Beginning in the Fall, the PhRMA Foundation launched a three-part webinar series aiming to expose existing gaps in the current use of patient-centered outcomes (PCOs) in value assessment research, share and exchange approaches to enhancing patient-centricity and patient engagement in value models, and – ultimately – identify future opportunities for collaborative and inclusive research in this field.

### **1. History and Current Landscape of Patient-Centricity and Patient-Centered Outcomes/Impacts in Value Assessment**

September 17, 2021

This webinar featured a broad range of perspectives about gaps to advancing patient-centered outcomes/impacts and inclusivity in value assessment from a multi-stakeholder perspective.

[Executive Summary](#)

[Recorded Webinar](#)

### Presenters & Panelists:

- **Elisabeth M. Oehrlein, PhD, MS**, Assistant Vice President, Research and Programs at the National Health Council
- **Lori Frank, PhD**, Senior Scientist, RAND Corporation and President, ISOQOL
- **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, Esq.**, 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

## **2. Spotlight on Current and Emerging Approaches and Methods to Enhance Patient-Centricity and Inclusive Patient Engagement in Value Assessment**

November 12, 2021

Featuring presentations by PhRMA Foundation's Centers of Excellence and the Innovation and Value Initiative (IVI), this webinar sought to provide attendees with a deeper understanding of real-world approaches toward advancing patient-focus and inclusivity in value assessment. A conversation with patient advocates followed the discussion.

[Executive Summary](#)

[Recorded Webinar](#)

### Presenters & Panelists:

- **Rick Chapman, PhD**, Chief Science Officer, IVI (The Innovation Value Initiative)
- **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
- **R. Brett McQueen, PhD**, Assistant Professor, University of Colorado Skaggs School of Pharmacy and Pharmaceutical Sciences - pValue (Pharmaceutical Value)
- **Kenneth "Kenny" Mendez**, CEO and President, Asthma and Allergy Foundation of America (Moderator)
- **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)
- **Elisabeth M. Oehrlein, PhD, MS**, Assistant Vice President, Research and Programs at the National Health Council
- **Julia Slejko, PhD**, Associate Professor, University of Maryland School of Pharmacy - PAVE (Patient-Driven Values in Healthcare)

### 3. Looking Forward: Opportunities Towards a Collaborative Research Agenda for Patient-Centered Evidence Generation and Broad Impact Beyond Current Models

December 10, 2021

This webinar featured two panel discussions to 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.

[Executive Summary](#)

[Recorded Webinar](#)

**Patient-Centered Outcomes Panel** discussed a key challenge in patient centered outcomes research- the lack of data available to measure PCOs.

Panelists:

- **Jennifer Bright, MPA**, Executive Director, Innovation and Value Initiative (moderator)
- **Lori Frank, PhD**, Senior Scientist, RAND Corporation and President, ISOQOL
- **Eddie Lee, PharmD**, Head, US Health Economics and Outcomes Research Strategy, UCB, Inc.
- **Charlene Son Rigby**, Chief Executive Officer, RARE-X

**Health Equity and Value Assessment Panel** discussed how value assessment research can capture and communicate differences in outcomes and preferences that impact diverse and underrepresented populations.

Panelists:

- **Terri M. Booker, Esq**, Board Member, Sick Cells Board Member
- **Stacey Kowal, MSc**, Principal Researcher, Health Policy and Systems Research Team, Genentech
- **Eberechukwu Onukwugha, MS, PhD**, Associate Professor, University of Maryland School of Pharmacy
- **Bari Talente, Esq.**, Executive Vice President, Advocacy & Healthcare Access, National Multiple Sclerosis Society (Moderator)

## Conference Presentations

### ISPOR 2021 – May 2021

1. [Qualitative and Quantitative Applications of Incorporating the Patient Voice into Value Assessments](#)

Elisabeth M. Oehrlein, Robert Brett McQueen, Julia F. Slejko, Melanie D Whittington  
*Workshop*

2. [Addressing Health Inequity in the U.S.: How Can Value Assessment \(VA\) Contribute to More Equitable Healthcare Resource Allocation?](#)

Susan DosReis, PhD, Louis P. Garrison, Stacey Kowal, Richard Xie  
*Workshop*

3. [The impact of Social and Novel Elements on Cost-Effectiveness Analysis: Two Case Studies](#)

Ma S, Olchanski N, Cohen JT, Ollendorf D, Neumann P, Kim D  
*Podium*

### **Academy Health Annual Research Meeting – June 2021**

1. [Measuring Relative Value: Advancing Patient-Centered Methods in Value Assessment](#)

Peter Neumann, R. Brett McQueen, Julia F. Slejko  
*Presentation*

2. [The Effect of Unobserved Preferences and Race on Vaccination Hesitancy for COVID-19 Vaccines: Implications for Health Disparities](#)

Eline van den Broek-Altenburg, Jamie Benson, Adam Atherly, Stephane Hess  
*Presentation*

### **Society for Medical Decision-Making Meeting – October 2021**

Health Equity Challenge Award winners panel  
[Recorded Session](#)

#### Panelists:

- **Eberechukwu Onukwughu, MS, PhD**, Associate Professor, University of Maryland School of Pharmacy (Moderator)
- **Eline van den Broek-Altenburg, PhD, MSc**, Assistant Professor of Radiology and Vice-Chair of Population Health Science, University of Vermont Medical Center
- **Surachat Ngorsuraches, PhD**, Associate Professor of Health Outcomes Research and Policy, Harrison School of Pharmacy, Auburn University
- **Karaoke “Karam” Diaby, PhD, MSc**, Assistant Professor in the Department of Pharmaceutical Outcomes and Policy, College of Pharmacy, University of Florida
- **Leticia R. Moczygemba, PharmD, PhD**, Associate Professor in the Health Outcomes and Pharmacy Practice Division at the University of Texas College of Pharmacy (at Austin)

## The PhRMA Foundation Blog & Third-Party Commentaries

In October 2019, the PhRMA Foundation launched a blog, *Voices in Value*, to share perspectives from the value assessment research community and give readers an in-depth look at ongoing efforts to redefine conventional approaches to measuring health care value.

### Voices in Value Blog Posts

1. [Towards Better Data Dashboards for Cost-Effectiveness Analyses](#)

Peter J. Neumann

*PhRMA Foundation, Voices in Value*

Dr. Neumann argues that health care decision making should be informed by well-designed drug value dashboards containing various metrics – conventional cost per QALY ratios as well as measures of a drug’s impact on clinical and patient-centric outcomes, and on budgetary and distributional consequences – that convey the value of drugs along different dimensions.

2. [What Low-Value Care Means for Health Equity](#)

Beth Beaudin-Seiler and Ani Turner

*PhRMA Foundation, Voices in Value*

Dr. Beaudin-Seiler and Ani Turner discuss how low-value care can impose serious burdens on patients in the form of potential harm, unnecessary costs, and wasted resources that could be better used elsewhere.

3. [The Patient Perspective Approach Should Guide Value Assessments of COVID-19 Vaccines](#)

Susan dosReis

*Medium*

Dr. dosReis outlines PAVE’s framework for valuing treatments that centers the patient perspective – and how this approach can be applied to the evaluation of COVID-19 treatments and vaccines.

4. [Centering the Patient Perspective in Hepatitis C Treatment Evaluation](#)

Joey Mattingly

*PhRMA Foundation, Voices in Value*

Dr. Mattingly discusses a recent research project of his where his team developed a novel economic model to assess the value of Direct Acting Antivirals (DAAs) to treat Hepatitis C that incorporated two new patient-informed treatment outcomes – infected life-years and workdays missed. This model found that the use of DAAs

resulted in better outcomes at a cost below historic QALY thresholds used to assess treatment value.

5. [How MCDA Can Drive Better Value Assessment](#)

Brett McQueen

*PhRMA Foundation, Voices in Value*

Dr. McQueen provides a brief introduction to multi-criteria decision analysis (MCDA) and discusses how pValue is using it to improve value assessment methods.

6. [The Voices in Value Year in Review 2020](#)

PhRMA Foundation Staff

*PhRMA Foundation, Voices in Value*

The PhRMA Foundation reflects on the highlights of 2020.

## Op-eds/Commentaries Highlighting PhRMA Foundation Centers of Excellence

### [Inclusion in Health Technology Assessments: The First Step Toward Equity](#)

Lori Frank and Thomas W. Concannon

*Health Affairs*

In this blog post, the RAND Corporation's Lori Frank and Thomas W. Concannon discuss how traditional health technology assessments do not align with goals to support health equity and highlight meaningful patient engagement as the way forward.

### [Reducing Low-Value Care Starts by Understanding its Drivers](#)

Allison Oakes

*MedCity News*

In this commentary, researcher Allison Oakes discusses how, with the right tools, stakeholders can work together to re-align incentives and transform our healthcare delivery system into one that prioritizes value, eliminates waste and leads to better overall patient outcomes.

### [Value Assessment That Puts Patients at the Forefront](#)

Linda Bohannon and Elizabeth Franklin

*Value & Outcomes Spotlight*

Linda Bohannon of Cancer Support Community introduces the Foundation's four Centers of Excellence and provides an overview of their current projects and respective approaches to improving the field of value assessment.

## [National Health Council and Tufts Medical Center Launch New Collaboration on Patient-Centered Value Assessment](#)

National Health Council Blog Post

The National Health Council, in partnership with Tufts Medical Center, is beginning a new project to develop good-practice recommendations to assist researchers in developing more patient-centered value assessments. This project is part of a collaboration between two PhRMA Foundation Centers of Excellence: Patient-Driven Values in Healthcare Evaluation (PAVE) and Tufts Center for Enhanced Value Assessment (CEVA). The groups will be using the PICOTS framework to provide recommendations on how the following elements of value can be defined and measured based on patient experience and using available data resources: patient population, intervention and comparator(s), outcomes of interest, time horizon of interventions and accompanying changes in health, and the setting in which care is delivered.

To learn more about the PICOTS framework, please see the [accompanying infographic](#) from the National Health Council.

###

About the PhRMA Foundation For 56 years, the PhRMA Foundation has been helping to build a larger pool of highly trained, top quality scientists to meet the growing needs of scientific and academic institutions, government, and the research-intensive pharmaceutical industry. To advance this mission, the PhRMA Foundation has awarded more than \$100 million in competitive research fellowships and grants since its founding.

The Foundation's emphasis on evidence-based research that determines the true value of medicines is supported by its Value Assessment Initiative. To date, the Foundation has awarded more than \$4.6 million to support a variety of research projects to help advance this goal, including the establishment of four national Centers of Excellence in Value Assessment.

To learn more, please visit [www.phrmafoundation.org](http://www.phrmafoundation.org)

To read the PhRMA Foundation's 2020 Year-End Review, please click [HERE](#).