

**PAVE** PATIENT-DRIVEN  
VALUES *in* HEALTHCARE  
EVALUATION



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. PAVE is a recipient of the PhRMA Foundation's Value Assessment Initiative Centers of Excellence Award.

## Overview

Patient engagement and perspective is critical to any discussion of value, yet unconventional assessment models often fail to fully capture the patient perspective. It is important for the field of value assessment to evolve to more patient-centric models. PAVE is at the forefront of this movement, developing approaches to value assessment that:

- Solicit meaningful input from patients
- Ensure transparency in methods and decisions
- Develop creative solutions to meet the needs of all health care decision makers

To achieve patient-driven value assessment, it is important to work with patient partners from start to finish. This involves calculating multiple value metrics from different perspectives, and highlighting differences in preferences for treatment and their effects.

## Ongoing Activities

- Engage diverse patient communities to identify costs and benefits of treatments that are most important to patients
- Measure patient values and preferences for health-related benefits and risks to incorporate into economic evaluation of treatments
- Test different methodological approaches for patient-driven value assessment in health care interventions and services for individuals
- Perform patient-driven cost-effectiveness analyses using patient-informed value elements
- Educate the patient and research communities on patient-driven value assessment
- Partner with Hispanic community groups to understand patient values that are under-represented in health care evaluation and decision-making

## Website

<https://pharmacy.umaryland.edu/PAVE>

## Key Staff

**Susan dosReis, PhD**

*Director*

[sdosreis@rx.umaryland.edu](mailto:sdosreis@rx.umaryland.edu)

**Julia Slejko, PhD**

*Co-Director*

[jslejko@rx.umaryland.edu](mailto:jslejko@rx.umaryland.edu)

**Wendy Camelo Castillo, MD, MSc, PhD**

*Hispanic Patient Engagement Core Lead*

[wcastillo@rx.umaryland.edu](mailto:wcastillo@rx.umaryland.edu)

**Joey Mattingly, PhD, PharmD, MBA**

*Director of Operations*

[jmattingly@rx.umaryland.edu](mailto:jmattingly@rx.umaryland.edu)

**C. Daniel Mullins, PhD**

*Patient Engagement Core Lead*

[dmullins@rx.umaryland.edu](mailto:dmullins@rx.umaryland.edu)

**Eleanor Perfetto, PhD, MS**

*Education Core Lead*

[eperfetto@rx.umaryland.edu](mailto:eperfetto@rx.umaryland.edu)

## **Videos, Infographics & Webpages**

Video: [PharmacoEconomics Chat: Joseph Mattingly](#)

Video: [Understanding Patient Values in Treatments for Major Depressive Disorders](#)

Video: PhRMA Foundation Centers of Excellence: [Spotlight on PAVE](#)

Video: [What You Need To Know About Hepatitis C](#)

Video: [More Than A Virus: The Impact of Hepatitis C](#)

Infographic: [Patient-Centered Value Assessment: Hepatitis C \(HCV\) treatment](#)

Webpage: [NHC Real World Evidence Classroom](#)

## **Peer-Reviewed Original Research**

Selker H, Cohen T, D'Agostino, Sr. R, Dere W, Nassir Ghaemi S, Honig P, Kaitin K, Kaplan H, Kravitz R, Larholt K, McElwee N, Oye K, Palm M, Perfetto EM, Ramanathan C, Schmid C, Seyfert-Margolis V, Trusheim M, Eichler HG. [A Useful and Sustainable Role for N-of-1 Trials in the Healthcare Ecosystem](#). *Clin Pharmacol Ther*. 2021 Sep 22. DOI: 10.1002/cpt.2425. Epub ahead of print.

Cook N, Livingstone H, Dickson J, Taylor L, Morgan K, Coombes M, Wortley S, Oehrlein E, Vicente-Edo MJ, Waibel F, Liden B. [Development of an international template to support patient submissions in Health Technology Assessments](#). *Int J Technol Assess Health Care*. 2021 Apr 1;37(1):e50. DOI: 10.1017/S0266462321000167

Oehrlein EM, Luo X, Savone M, Lobban T, Kang A, Lee B, Gale R, Schoch S, Perfetto E. [Engaging Patients in Real-World Evidence: An Atrial Fibrillation Patient Advisory Board Case Example](#). *The Patient*. 2021 Mar;14(2):295-300. DOI: 10.1007/s40271-020-00479-8

Slejko JF, Hong YD, Sullivan JL, Reed RM, dosReis S. [Prioritization and Refinement of Patient-Informed Value Elements as Attributes for Chronic Obstructive Pulmonary Disease Treatment Preferences](#). *The Patient*. 2021;14(5):569-579. DOI: 10.1007/s40271-021-00495-2

dosReis S, Butler B, Caicedo J, Kennedy A, Hong YD, Zhang C, Slejko JF. [Stakeholder-Engaged Derivation of Patient-Informed Value Elements](#). *The Patient*. 2020;13(5):611-621. DOI: 10.1007/s40271-020-00433-8

Mattingly II TJ, Love BL. [Changes in Cost-effectiveness for Chronic Hepatitis C Virus Pharmacotherapy: The Case for Continuous Cost-effectiveness Analyses](#). *Journal of Managed Care & Specialty Pharmacy*. 2020;26(7):879-886. DOI: 10.18553/jmcp.2020.26.7.879.

Mattingly, T.J., Slejko JF, Onukwugha E, Perfetto EM, Kottlilil S, Mullins CD. [Value in Hepatitis C Virus Treatment: A Patient-Centered Cost-Effectiveness Analysis](#). *PharmacoEconomics*. 2019;38(2):233-242. DOI: 10.1007/s40273-019-00864-8

Mattingly II TJ, Slejko JF, Perfetto EM, Kottlilil S, Mullins CD. [What Matters Most for Treatment Decisions in Hepatitis C: Effectiveness, Costs, and Altruism](#). *The Patient*. 2019;12:631-638. DOI: 10.1007/s40271-019-00378-7

## **Journal Reviews and Commentary**

Mattingly II TJ, McQueen RB, Lin PJ. [Contextual considerations and recommendations for estimating the value of Alzheimer's disease therapies](#). *PharmacoEconomics*. 2021;39(10):1101-1107.

Mattingly II TJ, Heil EL. [The Economics of Penicillin Allergy Testing: Still Scratching the Value Surface](#). *Clinical Infectious Diseases*. 2021;72(6):939-941.

Mattingly II TJ, Slejko JF, Oehrlein EM, Perfetto E. [Nudging Health Economists: A Process for Systematic Identification of Patient-Centered Outcomes for Inclusion in Value Assessment](#). *ISPOR's Value & Outcomes Spotlight*. Vol. 7. No. S2. September 2021.

Perfetto, E.M., Schoch, S., Oehrlein, E.M. [Tools for Compensating Patients for Their Patient-Engagement Activities](#). *ISPOR's Value & Outcomes Spotlight*. Vol. 7. No. 3. June, 2021.

McQueen RB, Slejko JF. [Toward Modified Impact Inventory Tables to Facilitate Patient-Centered Value Assessment](#). *PharmacoEconomics*. 2021;39(4):379-382. DOI:/10.1007/s40273-021-01017-6.

Medeiros M, Love TR, Slobogean GP, Sprague S, Perfetto EM, O'Hara NN, Mullins CD. [Patient and stakeholder engagement learnings: PREP-IT as a case study](#). *J Comp Eff Res*. 2021;10(6):439-442. DOI: 10.2217/ce-2020-0266.

Linthicum MT, dosReis S, Slejko JF, Mattingly TJ, Bright JL. [The Importance of Collaboration in Pursuit of Patient-Centered Value Assessment](#). *The Patient*. 2021;14(4):381-384.

Desai B, Mattingly II TJ, van den Broek R, Pham N, Frailer M, Yang J, Perfetto EM. [Peer Review and Transparency in Evidence-Source Selection in Value and Health Technology Assessment](#). *Value in Health*. 2020;23(6):689-696. DOI: 10.1016/j.jval.2020.01.014.

Mattingly II TJ, Love BL, Khokhar B. [Real World Cost-of-Illness Evidence in Hepatitis C Virus: A Systematic Review](#). *PharmacoEconomics*. 2020;38(9):927-939.

Mattingly II TJ. [The Economics of Drug Allergy](#). *Current Opinion in Allergy & Clinical Immunology*. 2020;20(4):395-400. DOI: 10.1097/ACI.0000000000000651.

Mattingly II TJ, Shere-Wolfe K. [Clinical and Economic Outcomes Evaluated in Lyme Disease: A Systematic Review](#). *Parasites & Vectors*. 2020;13:34. DOI: 0.1186/s13071-020-04214-y.

Harrington RL, Hanna ML, Oehrlein EM, et al. [Defining Patient Engagement in Research: Results of a Systematic Review and Analysis: Report of the ISPOR Patient-Centered Special Interest Group](#). *Value Health*. 2020;23(6):677-688. DOI:10.1016/j.jval.2020.01.019.

Mattingly II TJ. [Elimination of Hepatitis C Virus Infection in Canada is Achievable, But is the Rest of the World Ready to Join in This Effort?](#) *JAMA Network Open*. 2020;3(5):e204355. DOI:10.1001/jamanetworkopen.2020.

Slejko, J.F., Mattingly, T.J., Mullins C.D., Perfetto E.M., dosReis, S. [The Future of Patient-Driven Healthcare Evaluation: The Patient-Informed Reference Case](#). *Value in Health*. 2019 May;22(5):545-548. DOI: 10.1016/j.jval.2019.02.003.

### **Op-eds, Editorials, Reports & Blog Posts**

dos Reis S, Amill-Rosario A, Slejko J. [Health Technology Assessment: Evidence Generation Methods for Patient-Driven Values](#). *Health Affairs Forefront blog*. March 14, 2022.

National Health Council and National Alliance of Healthcare Purchaser Coalitions. [A Dialogue on Value Assessment that Meets the Needs of Patients and Employers](#). Washington, DC, June 2021.

Oehrlein EM, Perfetto EM, Schoch S, et al. [Patient-Centered Real-World Evidence: Methods Recommendations from an Evidence-Based Consensus Process](#). National Health Council, Washington DC, May 2021.

Perfetto E. [Project Update: Patient-Centered Core Impact Sets \(PC-CIS\)](#). National Health Council, Washington, DC, June 10, 2021.

dosReis, S, Linthicum, M, de Fur Malik, E, Slejko, JF, Xie, R. [Identifying Patient-Driven Value Elements in Major Depressive Disorder](#). Innovation and Value Initiative (IVI) Value Blueprint. May 31, 2021.

dosReis, S. [The Patient Perspective Approach Should Guide Value Assessments of COVID-19 Vaccines](#). *Medium*. May 18, 2021

Mattingly, TJ. [Centering the Patient Perspective in Hepatitis C Treatment Evaluation](#). *Voices in Value*. May 14, 2021

Perfetto E, Kennedy A, Bright J. Contributor: [A Vision for Patient-Centered Core Impact Sets—A Unifying Approach to Patient Centricity](#). *American Journal of Managed Care*. March 10, 2021.

Camelo Castillo, W. [Racial and Ethnic Disparities in Health Care are Found in the Missing Patient Voice](#). *Medium*. November 10, 2020

Mattingly, TJ, McQueen RB. [Using PCORI to Advance Patient-Centered Values](#). *Fierce Healthcare*. November 6, 2019

dosReis, S. [Making the Patient Voice Matter In Value Assessment](#). *Managed Care Magazine*. September 3, 2019.

Mattingly, TJ, Slejko, JF, Peretto, EM, dosReis, S. [Putting Our Guard Down: Engaging Multiple Stakeholders to Define Value in Healthcare](#). *Health Affairs Blog*. January 28, 2019.

## **Conference Presentations**

### *Podium Presentations:*

dosReis S, Amill-Rosario A, Ali C, Elongé E, Xie R, Chapman R, Slejko JF. A Discrete Choice Experiment of Patient-Informed Preferences for Major Depressive Disorder Treatment. On-Demand Podium Session (P55 abstract) ISPOR 2022. May 10, 2022.

dosReis, S., Bozzi, L., Butler, B., Xie, R.Z., Chapman, R.H., Bright, J., Malik, E., Slejko, J.F. Patient-Informed Value Elements Influencing Preferences for the Treatment of Major Depressive Disorder Among Adults. Society for Medical Decision Making (SMDM) Virtual Annual Meeting. October 18, 2021.

Peretto EM. Considering the Full Range of Outcomes in PCORI-Funded Research. PCORI Virtual Annual Meeting. October 4, 2021.

Hong YD, Zhang C, Slejko JF, dosReis S. Eliciting Value Elements for a Patient-Driven Value Assessment. *Value in Health*. May 2019;22(Suppl. 2):S37.

### *Poster Presentations:*

Ali C, Mattingly TJ 2nd, Slejko JF, dosReis S. Informing a Conceptual Framework for a Patient-Centered Value Assessment of Emerging Therapies for Mild/Moderate COVID-19. (PCR80 abstract) ISPOR 2022. May 17, 2022.

Amill-Rosario A, Jegede A, Slejko JF, dosReis S. Patient-Informed Value Assessment of Telehealth Care Services: Conceptualization to Implementation. (MT15 abstract). ISPOR 2022. May 17, 2022.

Nasroodin S, Nguyen K, Namvar T, Xie R, Chapman R, Slejko JF, dosReis S. Evidence for a Patient-Informed Approach to Value Assessment of Major Depressive Disorder Treatments. (PCR65 abstract) ISPOR 2022. May 16, 2022.

Pathan U, Oh J, dosReis S, Slejko JF. Patient-Provider Communication and Health-Related Quality of Life Among Individuals with Chronic Obstructive Pulmonary Disease in the US. (PCR68 abstract) ISPOR 2022. May 16, 2022.

dosReis S, Xie R, Regnante J, Neslusan C, Malik E, Bright J. Strategies to Include Underrepresented Patient Populations in Patient-Centered Research. Virtual ISPOR Europe 2021. Dec. 2, 2021.

Slejko JF, Mattingly TJ, Wilson A, Xie RZ, Chapman RH, dosReis S. Identification of Model Attributes for Patient-Centered Value Assessment of Treatments for Major Depressive Disorder (MDD). Society for Medical Decision Making (SMDM) Virtual Annual Meeting. October 20, 2021.

Slejko JF, Hong YD, Bozzi L, dosReis S. Eliciting Patient Informed Value Elements for Economic Evaluation of COPD Treatment. Respiratory Effectiveness Group (REG) Virtual Summit. March 18-20, 2021

Slejko JF, Hong YD, Bozzi LM, dosReis S. A Patient-Informed Approach to Develop a Discrete Choice Experiment for COPD Treatment. Virtual ISPOR 2020. May 18-22, 2020. *Value in Health*. 2020;23:S360.

Slejko JF, Gray C, Hong YD, Rueda JD, Zhang C, dosReis S. Aligning COPD Outcomes with Patient-Informed Value Element Domains for Use in Economic Evaluations. *Value in Health*. 2019;22(Suppl. 2):S351.

Gray C, Slejko JF. Identifying COPD Patient-Informed Value Elements in Economic Evaluations: A Systematic Review. *Value in Health*. 2019;22(Suppl. 2):S361.

### *Workshops/Issue Panels:*

Grabner, M, dosReis S, Gangan N. Best Practices for Causal Study Designs Using Real-World Data. ([Workshop 18](#)) ISPOR 2022. May 17, 2022.

Chapman R, Kou TD, Oehrlein E, Trusheim M. How Can a Robust Real-World Data Infrastructure Advance a More Patient-Centered Approach to Drug Development and Value Assessment? ([IP4](#)) ISPOR 2022. May 16, 2022.

Oehrlein, E, Burcu M, Mahendraratnam Lederer N, Rivera D. Getting Real with Real World Evidence for Regulatory Decision Making: Where Are We Going? ([OB7](#)). ISPOR 2022. May 17, 2022.

dosReis S, Slejko J, Chapman R, Frank L. [Novel Approaches to Identify and Quantify Patient Input for Health Technology Assessment \(HTA\)](#) Virtual ISPOR Europe 2021. December 2, 2021.

Introduction to Patient Engagement in Medical Product Research. Martin Nguyen A, McBurney R, Oehrlein EM, Schrandt S, ISPOR Short Course. October 20-21, 2021.

RWE Perspectives: Diversity in Data, Devices and Patient Populations. Siami S, Aguel F, Oehrlein E, Peiris V, Salama M, NEST RWE<sup>2</sup>. September 21, 2021.

Putting Patients At The Heart: Resources and Good Practice For Patient Involvement in HTA. Oehrlein E, HTAi Annual Meeting. June 20, 2021.

Patient Participation At The Organizational Level in HTA. Discussion Leaders: Berglas S, Livingstone H, Oehrlein E, Coombs M, Nabarette H, HTAi Annual Meeting. June 20, 2021.

Measuring Relative Value: Advancing Patient-Centered Methods in Value Assessment. Kamal-Bahl S, McQueen B, Slejko JF, Neumann PJ, Academy Health Annual Research Meeting. June 16, 2021.

Addressing Health Inequity in The U.S.: How Can Value Assessment (VA) Contribute to More Equitable Healthcare Resource Allocation? Discussion Leaders: dosReis S, Garrison LP, Kowal S, Xie R, Virtual ISPOR 2021 (Pre-Release/On-Demand).

Advancing Employer Engagement on Value Assessment. Oehrlein EM, Rehayem M, Westrich K, Bright J, Virtual ISPOR 2021.

Qualitative and Quantitative Applications of Incorporating the Patient Voice into Value Assessments. Oehrlein EM, McQueen R, Whittington M, Slejko J, Virtual ISPOR 2021 Workshop.

An Analytic Approach to Incorporating Patient Preferences into Value Elements for Economic Evaluation. dosReis S, Slejko JF, Lakdawalla DN, Willke RJ. ISPOR 2019 Workshop.

### **Invited Seminars and Webinars**

dosReis S (Panel). Community Congress Access Sub-Group on Use of Value Assessments and Implementation of Value Based/Alternative Payment Arrangements in Cell & Gene Therapies. [EveryLife Foundation](#). March 15, 2022.

Amill-Rosario A, Butler B, Caicedo J, Dexter J. [Digital Health & Health Equity. NHC/PAVE Digital Health Webinar Series](#). February 25, 2022.

Camelo W, Dobes A. [mHealth & Examples of Patient Community Engagement. NHC/PAVE Digital Health Webinar Series](#). February 18, 2022.

Coder M, Clay I. [mHealth, Digital Health, Digital Therapeutics: Terminology & Current Landscape Webinar. NHC/PAVE Digital Health Webinar Series](#). February 11, 2022.

Mattingly TJ 2<sup>nd</sup>, et al. Expert Perspective panel in Value Assessment. Arthritis Healthcare Forum [The Arthritis Foundation](#) <sup>®</sup>. December 7, 2021.

Julia Slejko, PhD (PAVE), R. Brett McQueen, PhD (pValue), Peter Neumann, ScD (CEVA), Jennifer Bright, MPA (IVI), Annie Kennedy (EveryLife Foundation for Rare Diseases), LaTasha H. Lee, PhD, MPH (National Minority Quality Forum), Kenneth “Kenny” Mendez (Asthma and Allergy Foundation of America).

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

PhRMA Foundation webinar series on Advancing Patient-Centered Outcomes and Impacts in Value Assessment.  
November 12, 2021.

Susan dosReis, Julia Slejko, Alejandro Amill-Rosario.

*“Emerging Health Technology Assessment Methods and Evidence Generation on Patient-Driven Values in Healthcare Services”.*  
Enhancing Health Care Value Through Data, Measurement and Evaluation of Services and Procedures.  
Research Consortium for Health Care Value Assessment. November 3, 2021

Eleanor Perfetto, PhD (PAVE/NHC)

*“Value Based Care: Look Ahead Roundtable”*

Virtual presentation, Cancer Support Community.  
October 14, 2021.

Elisabeth Oehrlein, PhD (PAVE/NHC), Lori Frank, PhD (RAND Corporation), Louis P. Garrison, Jr., PhD (University of Washington), Charlene Son Rigby (RARE-X), Bari Talente (National Multiple Sclerosis Society), Sean Tunis, MD, MSc (Rubix Health), Ashley Valentine, MRes, MPH (Sick Cells).

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

PhRMA Foundation webinar series on Advancing Patient-Centered Outcomes and Impacts in Value Assessment.  
September 17, 2021.

Julia Slejko, PhD (PAVE)

*‘Patient-Centered Value Assessment’*

Virtual Seminar, University of Oxford Health Economics Research Centre (HERC).  
September 15, 2021

Elisabeth Oehrlein, PhD (PAVE/NHC)

BIO Patient Advocacy Coffee Chat on Value Assessment.  
September 8, 2021.

Eleanor Perfetto, PhD (PAVE/NHC), Elisabeth Oehrlein, PhD (PAVE/NHC)

*“What Are Patient-Centered Outcomes and Why Aren’t All Health Outcomes Considered “Patient Centered?””*

National Health Council.  
August 11, 2021.

Rachele Hendricks-Sturup, DHSc (Duke-Margolis Center for Health Policy), Elisabeth Oehrlein, PhD (PAVE/NHC), Mehmet Burcu, PhD (Merck & Co.).

*“Patient-Centered Real-World Evidence: Consensus Recommendations & Use Cases”*

National Health Council.  
July 30, 2021.

Julia Slejko, PhD (PAVE)

*“Eliciting, Prioritizing and Quantifying Value Elements for COPD”*

Virtual Seminar, University of Illinois Chicago Population Health Sciences Program and Breathe Chicago Center.  
June 17, 2021.

Susan dosReis, PhD (PAVE), Jennifer Bright, MPA (IVI), Yvette Venable (ICER).

Value Assessment and Women. Society for Women’s Health Research.  
Virtual Policy Council Meeting.  
June 3, 2020.

Susan dosReis, PhD (PAVE), George Miller, PhD (RC-HCVA), Jon Campbell, PhD (pValue), Peter Neumann, ScD (CEVA)

Moderator: Sachin Kamal-Bahl, PhD (COVIA Health Solutions)

*“Grant Recipients Highlight New Approaches to Value Assessment”*

The Next Generation of Value Assessment: Including the Patients Voice Series by PhRMA Foundation & National Health Council.  
November 12, 2019, Washington, D.C.

Lisa Bo Feng, DrPH (Cystic Fibrosis Foundation), Susan dosReis, PhD (PAVE), Josh Seidman, PhD (Avalere Health), David Steinhorn, MD (Children's National Medical Center)

Moderator: Jennifer Bright, MPA (Momentum Health Strategies)

*"Navigating the Frontiers of Innovation and Value: The Value of the Patients Voice"*

Alliance for Health Policy 2019 Solving Health Signature Series.

November 6, 2019, Washington, D.C.

Julia Slejko, PhD (PAVE), Jamie Sullivan (COPD Foundation)

Moderator: Eleanor Perfetto, PhD (PAVE)

*"Partners' Perspectives on the Value of a Patient-Researcher Partnership"*

National Health Council 2019 Science of Patient Engagement Symposium.

October 28-29, 2019. Washington, D.C.

Julia Slejko, PhD (PAVE)

*"Value Assessments and the Role of the Patient Voice"*

COPD Foundation IMPACT COPD Workshop.

June 18, 2019, Washington, D.C.