



Multi-Stakeholder Dialogue on Achieving Patient-Centered Core Impact Sets (PC-CIS)

August 17, 2022
10:00 a.m. – 2:30 p.m. ET
Zoom

10:00 – 10:05 a.m.

Welcome & Introductions

Mr. Rutta and Dr. Escontrías will provide remarks welcoming the audience, give a brief overview of the National Health Council's mission, introduce the co-chairs, and review acknowledgements.

Remarks by:

- Randall Rutta, MA, CEO, National Health Council
- Omar A. Escontrías, DrPH, MPH, Vice President, Research, Education & Programs, National Health Council

10:05 – 10:15 a.m.

Review Dialogue Objectives

Ms. Kennedy and Dr. Valentino will review the day's objectives, agenda, and housekeeping items.

Dialogue Co-chairs:

- Annie Kennedy, Chief of Policy, Advocacy, and Patient Engagement, EveryLife Foundation for Rare Diseases
- Leonard Valentino, MD, President & Chief Executive Officer, National Hemophilia Foundation

10:15 – 10:30 a.m.

PC-CIS Rationale & Expected Uses

Dr. Perfetto will give a high-level review of the Patient-Centered Core Impact Sets Blueprint as an introduction to the day's panels.

Presenter:

- Eleanor Perfetto, PhD, MS, Professor, University of Maryland, School of Pharmacy and Consultant, National Health Council



10:30 – 10:45 a.m.

PC-CIS Use Cases

Ms. Schrandt will discuss the Arthritis Foundation use case. This case was utilized throughout the PC-CIS Blueprint. She will also examine other potential use cases and pilot studies of the Blueprint.

Presenter:

- M. Suz Schrandt, JD, Founder & CEO, ExPPect

10:45 – 10:55 a.m.

Mindfulness Break

Meditation is an act of mindfulness that encourages staying focused on a thought or activity. Participate in a guided 1-minute meditation activity.

10:55 – 11:20 a.m.

PC-CIS Patient-Group Perspectives

The panelists in this session will delve into the PC-CIS Blueprint strengths and challenges from the patient-group perspective. Panelists will highlight how patient groups can be positioned to uptake the Blueprint.

Moderator:

- Omar A. Escontrías, DrPH, MPH, Vice President, Research, Education & Programs, National Health Council

Dialogue Co-Chairs:

- Annie Kennedy, Chief of Policy, Advocacy, and Patient Engagement, EveryLife Foundation for Rare Diseases
- Leonard Valentino, MD, President & Chief Executive Officer, National Hemophilia Foundation

11:20 – 11:30 a.m.

Mindfulness Break

Mindful breathing teaches us to become aware our natural breathing rhythm and flow as we inhale and exhale. Participate in a guided 1-minute breathing activity.

11:30 a.m. – 12:15 p.m.

PC-CIS Other Stakeholder Perspectives

This session will explore the PC-CIS Blueprint strengths and challenges from the industry perspective. Panelists will also share their unique perspectives on leveraging the Blueprint to advance patient engagement efforts.



Moderator:

- M. Suz Schrandt, JD, Founder & CEO, ExPPect

Panelists:

- Michael Thompson, President & CEO, National Alliance of Healthcare Purchaser Coalitions
- Yvette Venable, Vice President of Patient Engagement, Institute for Clinical and Economic Review (ICER)
- Laura Lasiter, PhD, Senior Director, Policy & Research, PhRMA

12:15 –12:45 p.m.

Meal Break

12:45 – 1:30 p.m.

PC-CIS Research Perspectives

The panelists in this session will review the PC-CIS Blueprint advantages and improvements from the data user and research perspective.

Moderator:

- Eleanor Perfetto, PhD, MS, Professor, University of Maryland, School of Pharmacy and Consultant, National Health Council

Panelists:

- Jennifer Bright, MPA, Chief Engagement and Strategy Officer, Innovation & Value Initiative
- George Gondo, MA, Associate Director of Research, National Psoriasis Foundation
- Richard J. Willke, PhD, Chief Science Officer, ISPOR

1:30 – 1:40 p.m.

Mindfulness Break

Stretching is a useful activity that can help improve overall flexibility, neuromuscular coordination, balance, and postural awareness. Participate in a guided 1-minute stretch activity.

1:40 – 2:25 p.m.

Reactor Panel

Speakers in this reactor panel will discuss polling results, identify key themes from the Dialogue sessions, and will provide their views on the Blueprint reactions and discuss future steps.



Moderator:

- Eleanor Perfetto, PhD, MS, Professor, University of Maryland, School of Pharmacy and Consultant, National Health Council

Panelists:

- Jennifer S. Graff, PharmD, Senior Director, Professional Affairs, Academy of Managed Care Pharmacy
- Joey Mattingly, PhD, PharmD, MBA, Associate Professor, Pharmaceutical Health Services Research, University of Maryland, School of Pharmacy
- Melanie Paris, MA, MPH, Senior Director of Education and Strategic Partnerships, American Kidney Fund

2:25 – 2:30 p.m.

Closing Remarks and Next Steps

The Dialogue co-chairs and Dr. Escontrías will give a short wrap-up for the meeting and thank attendees.

Remarks by:

- Annie Kennedy, Chief of Policy, Advocacy, and Patient Engagement, EveryLife Foundation for Rare Diseases
- Leonard Valentino, MD, President & Chief Executive Officer, National Hemophilia Foundation
- Omar A. Escontrías, DrPH, MPH, Vice President, Research, Education & Programs, National Health Council