AGENDA
Day 1 - Nov 2, 2022

11:00 - 1:00  Registration

12:00 - 1:00  Lunch

1:00 - 1:45  Welcome and Introductions
Rebekah Angove, PhD, Executive Vice President, Research and Evaluation, Patient Advocate Foundation

1:45 - 2:45  Experts by Experience: A Panel Discussion
Mary Mukira, Manager of Grassroots Advocacy, National Patient Advocate Foundation (moderator)
Sharon Alexander, Expert by Experience, Patient Insight Institute
Lisa Hamlett, Expert by Experience, Patient Insight Institute
Jacquelyn Lambert-Davis, RN, DNP, Expert by Experience, Patient Insight Institute
Michael McNear, Expert by Experience, Patient Insight Institute

In this opening session, hear directly from patients and caregivers as they pull from their lived experiences and share why the patient perspective is critically important to research and policy. They will also share why they’ve chosen to be involved specifically in Patient-Centered Outcomes Research (PCOR).

2:45 - 3:00  Break

3:00 - 4:15  Insight Gathering: Identifying What Matters Most to Patients
Part 2
Rebekah Angove, PhD, Executive Vice President, Research and Evaluation, Patient Advocate Foundation

Building off the Pre-Patient Insight Congress virtual workshop, this session will focus on identifying the outcomes that matter most to both patients and caregivers as it relates to navigating their healthcare, financial well-being and quality of life.
AGENDA

Day 1 - Nov 2, 2022

4:15 - 4:45  
Policy Pathways: Taking the Leap from Experience to Action

Rebecca Kirch, Executive Vice President, Policy and Programs, National Patient Advocate Foundation

Stuart Portman, MPH, Senior Health Policy Advisory, U.S. Senate Committee on Finance, Ranking Member Mike Crapo (R-ID)

Becky Shipp, Principal, Becky Shipp Consulting, LLC

This brief panel discussion will feature reactions to the data, analysis and conclusions from earlier sessions with an emphasis on how the lived experience of patients and caregivers can inform specific policy pathways that advance person-centered needs navigation services.

4:45 - 5:00  
End of Day Wrap-up and Next Steps

Rebekah Angove, PhD, Executive Vice President, Research and Evaluation, Patient Advocate Foundation

5:00 - 6:00  
Networking Reception

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Day 2 - Nov 3, 2022

7:00 - 9:00  
Breakfast

9:00 - 10:00  
Words Matter: How Language Shapes Patient Experiences

Rebekah Angove, PhD, Executive Vice President, Research and Evaluation, Patient Advocate Foundation

This conversation will focus on how jargon, acronyms and other “research- and policy-speak” can be a barrier to making research, healthcare, and health policies more person-centered.
AGENDA
Day 2 - Nov 3, 2022

10:00 - 11:00
Elevating Patient Experiences for Actionable Policy Change

Melissa Beauchemin, PhD, RN, Assistant Professor, Columbia University School of Nursing

Nicole Braccio, PharmD, Policy Director, National Patient Advocate Foundation

Kathleen Gallagher, MPH, Vice President, Health Services Research, Patient Advocate Foundation

Laurie McWright, Deputy Director or the Seamless Care Models Group, Center for Medicare and Medicaid Innovation, Center for Medicare & Medicaid Services

Stephanie Stinson, Patient Advocate, Crohn’s and Colitis Foundation

The healthcare outcomes most beneficial to people in their everyday lives may not always be reflected in academic or clinical research. People's lived experiences are important to improve health equity and reduce disparities. This session will be a safe space for patients, researchers, and policy experts to learn from each other about the research outcomes that matter to all of us and are actionable for policymakers.

11:00 - 12:30
Rapid Poster Walk

This inaugural rapid poster walk will showcase research projects that amplify the under-represented patient voice. Researchers from across the US are sharing their work on social needs navigation, patient-centered research, engagement science and more. Participants will have the opportunity to interact with all the researchers in small, proctored groups.

12:30 - 1:30
Lunch

1:30 - 3:00
Breakout Discussions: Identifying Research Topics that Matter to Patients

This facilitated breakout discussion will focus on prioritizing research topics that align with the patient-reported outcomes identified in the “insight gathering” session from Day 1.

3:00 - 3:30
Break
AGENDA
Day 2 - Nov 3, 2022

3:30 - 5:00  
Can We Talk About Patient Engagement in Research? Building Communication Skills and Connections for Patients and Researchers

Melissa Williams, MPH, Director of Grassroots Advocacy and Partnerships, National Patient Advocate Foundation

Patients and caregivers want to be a part of all aspects of research. This session will focus on highlighting the challenges that both patients and researchers experience when participating / designing research projects, and ways to potentially shift the current research paradigm. Participants will also help create a new resource for patients and caregivers to build confidence in advisory roles.

5:00 - 6:00  
Networking Reception
Posters will remain on display for participants to re-visit.

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Day 3 - Nov 4, 2022

7:00 - 9:00  
Breakfast

9:30 - 10:00  
Overview of Grassroots Advocacy Program and Presentation of Donna Guinn Outstanding Volunteer Award

Melissa Williams, MPH, Director of Grassroots Advocacy and Partnerships, National Patient Advocate Foundation
10:00 - 10:45

**Health Needs Navigation Initiative: Where We’re Headed**

*Nicole Braccio, PharmD, Policy Director, National Patient Advocate Foundation*

*Melissa Williams, MPH, Director of Grassroots Advocacy and Partnerships, National Patient Advocate Foundation*

The Patient Insight Institute aims to design research that represents all patients and their diverse lived experiences and compels policymakers to enact change. This session will outline the data needed to move policy and how we are positioning the Health Needs Navigation initiative to be successful and sustainable no matter the political climate.

10:45 - 11:00

**Break**

11:00 - 12:15

**Patient-Led Community Action and Grassroots Organizing**

*Wanda Clevenger, BSN, BCPA, WE Bridge the Gaps, Inc*

*Toni Kay Mangskau, Advocate and Healthcare Worker*

*Jamie Stokley, CEO and Founder of Helping Harvest Foundation, Inc.*

*Brittany Sullivan, Advocate and Project Manager, Public Affairs at Stride*

*Mary Mukira, Manager of Grassroots Advocacy, National Patient Advocate Foundation*

In the final session, a panel of NPAF volunteers will share their passion for grassroots advocacy and how they’re using NPAF campaigns to advocate for healthcare improvements in their communities. Participants will then have an opportunity to brainstorm their own community initiatives / organizing ideas and get feedback on its execution.