Center for Innovation
& Value Research

# Uncovering the True Cost of Healthcare

## Time is Money: Capturing Time Effects of Economic Impacts

Workshop #2 Learning Report

February 2025

*This workshop and report was partially funded through a Patient-Centered Outcomes Research Institute® (PCORI®) Eugene Washington PCORI Engagement Award (#EACB-32695).*

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# Uncovering the True Cost of Healthcare

## Time is Money: Capturing Time Effects of Economic Impacts

## Workshop #2

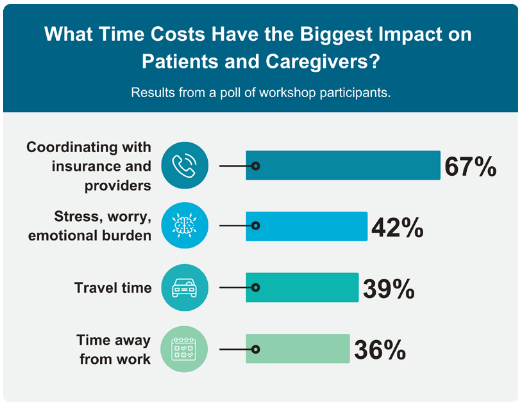
### Plain Language Summary

Patients and caregivers face many economic challenges related to "time costs"—the time spent on activities such as receiving care and navigating the health systems, and time lost, like missing work, school, and family time. Some time costs occur over hours, days, or weeks, while others lasts months or years.

The Center for Innovation & Value Research hosted the second workshop in a six-part series on November 14, 2024. Over 40 people attended the virtual workshop including patients, caregivers, researchers, and others. This workshop focused on exploring what time costs patients and caregivers experience as they manage their health conditions.

Highlights from the workshop included:

- Tina Aswani-Omprakash, CEO of the South Asian IBD Alliance and a patient with Crohn's disease and other serious health conditions, shared her personal story. She described how navigating her conditions has impacted her career, mental and social health, and family.
- Workshop attendees participated in small-group discussions to share their own experiences with time costs. Attendees mentioned examples of **time costs** related to getting and giving care, administrative duties, and self-advocacy. Participants also discussed the **near-term impacts** or immediate effects, such as lost time at work or school, as well as the **ripple effects** or the longer-term impacts, such as feeling isolated and experiencing burnout.
- Beth Gore, CEO of the Oley Foundation, led a discussion panel with Tina and Casey Quinn, Senior Advisor for Patient-Centered Economic Outcomes at the Patient-Centered Outcomes Research Institute (PCORI). They talked about what changes need to happen in our healthcare system for time costs to be captured in research.
- Moving forward, collaboration is essential among researchers, funders, patients, and caregivers to better understand and address time costs. We need to:
  - Listen to the lived experiences of patients and caregivers to identify which time costs matter most and why.
  - Recognize how time costs differ for different people.
  - Measure the quality of time, not just the minutes spent.
  - Realize that time costs can lead to long-term challenges, such as reduced income.


What Time Costs Have the Biggest Impact on Patients and Caregivers?

Results from a poll of workshop participants.

**Uncovering the True Cost of Healthcare** is a Center for Innovation & Value Research (Center) project exploring patient-centered economic impacts. We recognize that patients and caregivers are payers in the U.S. healthcare system and our research and decisions need to reflect that.

Through partnerships with patients, caregivers, researchers, and other decision-makers, we are seeking better ways to understand how healthcare costs affect patients and their families.

## Summary

The Center for Innovation & Value Research (the Center) convened its second virtual workshop—*Time is Money: Capturing Time Effects of Economic Impacts*[1]—on November 14, 2024. This six-part series is part of the project Uncovering the True Cost of Healthcare.[2]

With over 40 participants[3] representing a range of (and often overlapping) perspectives, the workshop explored economic impacts that patients and caregivers experience as time costs defined as the time spent on activities such as receiving care and navigating the health system—and "time lost"—like missing work, school, or family time. Some costs occur over hours, days, or weeks, while others last month or years. The workshop explored what aspects of these time costs are most important to include in research, and how time costs differ by patient and family characteristics.

Faculty members Tina Aswani-Omprakash, co-founder and CEO of the South Asian IBD Alliance (SAIA); Casey Quinn, Senior Advisor for Patient-Centered Economic Outcomes at the Patient-Centered Outcomes Research Institute (PCORI); and Beth Gore, CEO of the Oley Foundation, shared their experiences and insights through a story share, panel discussion, and closing reflections. Participants and faculty engaged in discussion through small groups, Q&A, and a poll. In this report, we highlight key learnings from the workshop.

> *"There needs to be value and respect for patients' time. If we start doing research, we might be heading in that direction."*
>
> *– Tina Aswani-Omprakash, Workshop Faculty*

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[1] Patient-centered economic impacts are the financial outcomes that patients, family members, and caregivers experience due to health conditions and healthcare treatment. For a full definition and the Framework, see Appendix A.

[2] This project was partially funded through two Patient-Centered Outcomes Research Institute® (PCORI®) Eugene Washington PCORI Engagement Awards (#EASCS-24272 and #EACB-32695).

[3] Refer to Appendix B for a full list of workshop participants.

## Grounding in Lived Experience

To anchor discussions in lived experience, Tina led off the workshop by sharing some of her story living with Crohn's disease and multiple chronic conditions. She described the tremendous economic burdens that her family faced, including her father passing away from the same condition when she was 8 years old, resulting in poverty and lack of health insurance. Her symptoms of joint pain, eye inflammation, and other intestinal issues were dismissed by her pediatrician as growing pains and allergic conjunctivitis.

As a young adult, she had to advocate for herself to get a colonoscopy, given her family history of the disease. Ultimately, Tina was diagnosed at 22 years old. Some of the time costs and impacts that Tina and her family experienced included:

- Waiting months for specialist appointments with gastroenterology, rheumatology, nephrology, hepatology, and ophthalmology.
- Managing scheduling and referrals, travel from a suburb to the city, and wait time before every appointment required significant time investment by Tina and her mother.
- Negotiating with insurance companies on drug coverage and prior authorizations.

Delays in diagnosis and treatment prolonged Tina's poor health, leading to extended economic impacts:

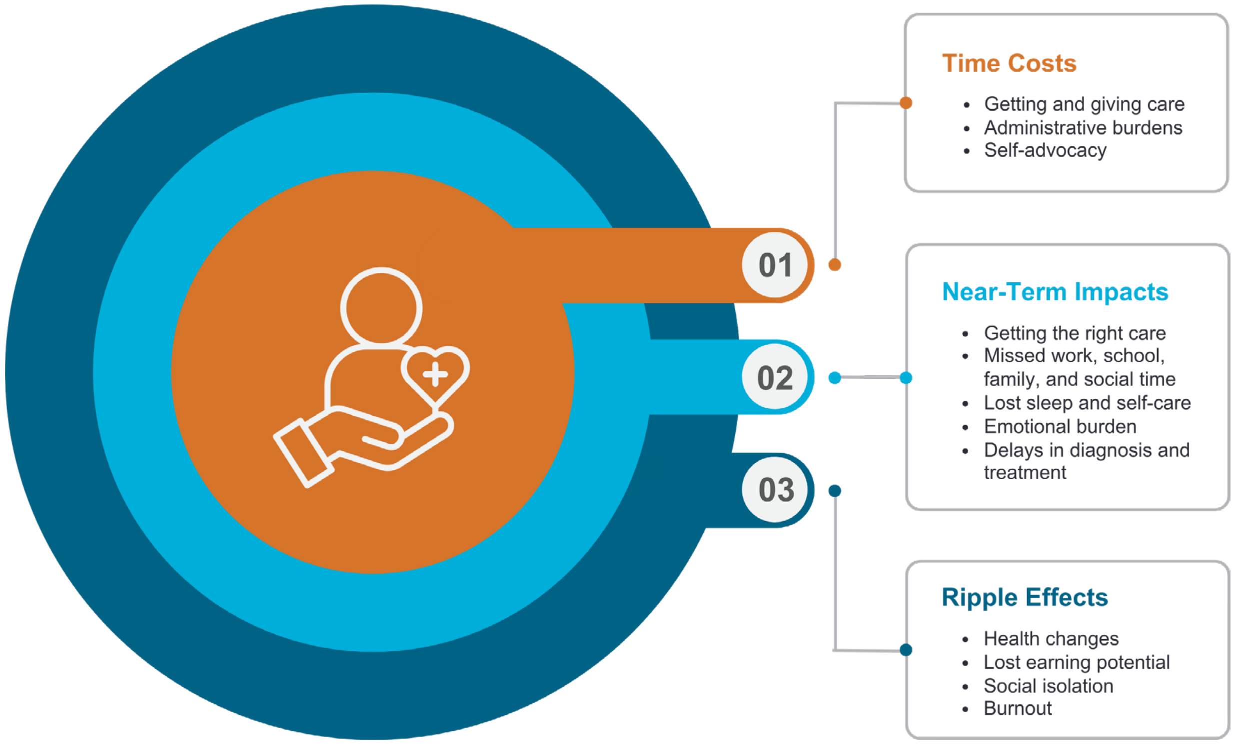
- Tina's inability to work for a longer period
- Costs of maintaining health insurance through COBRA after losing her job
- Mental health struggles due to cultural stigma around illness
- Severe family stress.

> *"When insurance takes forever, you're not getting your medications on time, then your condition gets worse."*
>
> *– Workshop Participant*

## How Time Costs Impact Patients and Caregivers

Throughout the workshop, faculty and participants emphasized that the U.S. healthcare system consistently undervalues patients' and caregivers' time. This often results in long waits for care, cumbersome paperwork, and shifting care coordination tasks onto patients and their families to reduce institutional costs. This work amounts to time costs that patients, caregivers, and their families pay while interacting with the healthcare system.

**Figure 1. Time Costs and Their Impacts for Patients and Families**



**Time Costs**

- Getting and giving care
- Administrative burdens
- Self-advocacy

**Near-Term Impacts**

- Getting the right care
- Missed work, school, family, and social time
- Lost sleep and self-care
- Emotional burden
- Delays in diagnosis and treatment

**Ripple Effects**

- Health changes
- Lost earning potential
- Social isolation
- Burnout

Time costs may seem small, typically measured in hours or days, but they often add up to significant impacts over months or years. Some impacts can be positive – for example, time invested in getting the right care from the right care team can result in health improvements. But many impacts of time costs are negative, often intersecting and compounding into long-term ripple effects.

During the workshop, participants and faculty highlighted examples of time costs and how they impact patients and families, as described in the following pages and illustrated in Figure 1.

> *"The healthcare system does not take patient time seriously."*
>
> *– Casey Quinn, Workshop Faculty*

## Examples of Time Costs and Their Impacts

### 01 Time Costs

Time costs vary widely depending on individuals' unique circumstances, needs, and priorities. Individuals with limited access to care often face particularly steep time costs as they navigate barriers such as provider shortages, longer travel times to reach care, or finding affordable care options when uninsured.

- **Getting and Giving Care:** Spending time meeting with a provider or care team, learning about a condition and self-management, undergoing treatment, providing care to a loved one at home, and self-care activities.
- **Administrative Burdens:** Research, phone calls, consultations, and paperwork necessary to find care, navigate the system, manage insurance, and coordinate among providers.
- **Self-Advocacy:** System errors, fragmentation, discrimination, and lack of respect for patients' and caregivers' time means many people must spend time and energy advocating for themselves or a loved one, including learning how to self-advocate.

### 02 Near-Term Impacts

People managing many responsibilities or demands on their time, whether related to work, family, caregiving, or community, face especially difficult tradeoffs around time costs, which can exaggerate near-term impacts. In contrast, having more social support or greater flexibility in scheduling can dampen the impact of time costs, making it easier to absorb these costs through small changes ("drifts") rather than needing big adjustments ("shifts") in work or lifestyle. People with more serious illness may benefit more from time invested in finding the right care team.

> *"The impact when you find the right specialist and you're getting the care you need, it can feel like a weight is lifted."*
>
> *– Workshop Participant*

- **Finding the Right Care Team:** Feeling heard, getting a diagnosis, getting appropriate treatment, and receiving information to be able to better manage health.

- **Missed Work, School, Family, and Social Time:** Performance issues at work or school due to distractions, time away, or stress related to time costs. Often these impacts have financial costs when patients or caregivers must use paid time off or go unpaid due to time costs. Also includes missing important family or social events while feeling ill or managing time costs.
- **Lost Sleep and Self-Care:** Time spent on healthcare tasks or caregiving often means less time for sleep and other self-care activities such as exercise, hobbies, relaxing, and socializing.
- **Stress and Emotional Burden:** Frustration from wasted time, mental fatigue of navigating complex systems, and the emotional ups and downs of self-advocacy. Also includes emotional stress of worrying about financial costs of care, lost work or education time, or lost income.
- **Delays in Diagnosis and Treatment:** Ongoing pain or other symptoms while waiting for care, and not feeling well enough to engage in work, school, family, or social activities.

> *"A time cost of clinical care is the 'recovery' time of any interaction with healthcare – the mental, physical, and emotional exhaustion."*
>
> *– Workshop Participant*

## 03 Ripple Effects

Near-term impacts of time costs frequently compound into ripple effects with long-term consequences for patients, caregivers, and their families. Financial impacts of time costs can be particularly dramatic for individuals with low incomes, as any lost income can have significant long-term ripple effects, including debt or homelessness.

- **Health Changes:** Can be positive or negative, depending on whether patients get timely diagnosis and treatment from the right care team. Positive changes include reduced or better managed symptoms, resolving a condition or slowing disease progression, and better quality of life. Negative changes include complications, disease progression, poor or declining physical or mental health, and ultimately less healthy time to focus on what matters most in one's life.
- **Lost Earning Potential:** May result from delaying or limiting education, career stagnation, early retirement, or cutting back work time (e.g., part-time instead of full-time) due to time costs. Also includes job loss due to absences or performance issues. Losing a job can mean losing health insurance, compounding financial costs. Having a lower income also frequently makes it more difficult to manage time costs.

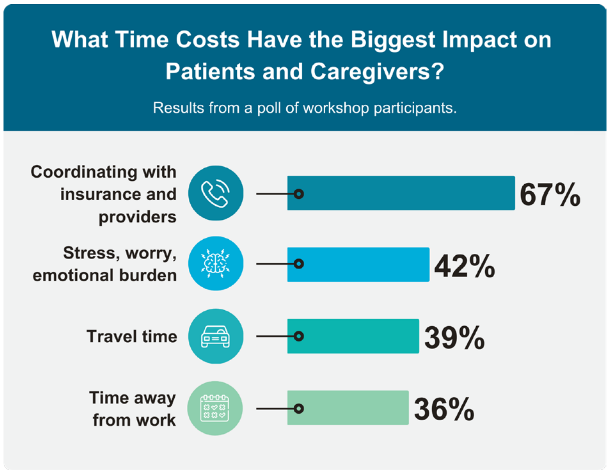
- **Social Isolation:** Over time, missing family time or social activities can lead to strained relationships or social isolation, which may also impact mental health and emotional well-being.
- **Burnout:** Feeling overwhelmed or exhausted by long-term effort to manage time costs, which can undermine resiliency and coping skills for managing other life challenges. When patients experience discrimination, bias, microaggressions, or other harm while receiving care, they may develop anxiety, depression, or other long-term trauma effects, and may delay or avoid seeking care even when needed.

In addition to direct economic impacts such as lost income, lack of respect for patients' and caregivers' time can get in the way of needed care. Providers, too, often face time costs resulting from system fragmentation and inefficiencies, limiting their ability to provide high-quality care. Workshop faculty Beth Gore shared an example of needing nearly 12 hours of preparation, travel, and return to get her son, who uses a wheelchair, to a five-minute doctor's appointment. Conducting the visit via phone, e-mail, or video call would dramatically reduce this time cost for Beth and her son, and potentially make better use of the care team's time, too.

Conversely, when patients and caregivers feel their time is valued, it fosters trust and collaboration with their care team. Patients and providers will both benefit from making time costs and their impacts visible, and ultimately making better use of their time.

## Make It Visible: Including Time Costs in Research

Making time costs and their economic impacts visible is an important first step to recognizing and respecting the value of their time. But today, patients' and caregivers' time costs are rarely included in healthcare research or economic analyses. Including time costs in research studies will provide a more holistic assessment of medical treatments and care delivery models, and ultimately provide evidence for how to improve outcomes for patients and their families.


What Time Costs Have the Biggest Impact on Patients and Caregivers?

Results from a poll of workshop participants.

Workshop faculty and participants discussed considerations for beginning to measure time costs and their impacts within research.

## Start with What Matters

Lived experience is essential for understanding what time costs matter most, and why. Workshop participants highlighted time costs with the greatest impacts on patient and caregivers (see figure on page 7), suggesting a starting place for where to focus research on time costs. Researchers can begin to measure time costs through simple steps, like incorporating questions about time costs and their impacts within surveys, focus groups, or interviews. Simply asking, '*What time costs have you experienced?'* and '*Why does that matter to you?'* can spark valuable insights and build momentum for change. Partnering with patents and caregivers to design and conduct research on time costs will ensure a focus on what matters most.

## Explore Differences in Time Costs and Their Impacts

Time costs and their impacts vary by income, insurance, access to care, and many other factors. Being financially poor and time poor (having more demands on one's time or less flexibility in time management) often track together, exacerbating the impact of time costs. In contrast, social support, flexibility, and more financial resources can buffer some effects of time costs. Understanding these differences in time costs and their impacts is important to work toward a more equitable healthcare system.

## Measure More than Minutes

Everyone makes tradeoffs in how to use their time. What is meaningful to one person may feel like a waste of time to another, and what is a manageable time cost for someone in one circumstance may be a significant burden in another. Measuring time costs and their impacts must take into account differences in how patients and caregivers prioritize their time and manage time costs. To understand and measure time costs, we must account for not only the amount of time, but also the quality of time and outcomes from time invested. Ultimately, measuring the value of patients' and caregivers' time must include respecting their values and priorities in making these tradeoffs.

## Account for Ripple Effects

Time costs can result in lost income, and having less income makes it more difficult to manage time costs. Over time, these ripple effects accrue and compound, akin to accumulating debt. It may never be possible to fully disentangle time costs from all their impacts, but exploring feedback loops and accounting for spillover effects is important to understand how small time costs can translate into bigger impacts over time.

## Call to Action

To get a full picture of the value of healthcare treatments and care models, researchers, funders, patients, and caregivers must work together to explore time costs and their impacts.

### Patients, Caregivers, Advocates

- Talk about and document time costs and their impacts.
- Share: Why do time costs matter to you?
- Collaborate with researchers to design studies that explore time costs.

### Researchers

- Incorporate questions about time costs into ongoing research.
- Develop methods and tools to measure time costs and their impacts.
- Partner with patients and caregivers to design studies focused on understanding time costs and their impacts.
- Test methods to reduce double-counting spillover effects of time costs and their impacts.

### Funders

- Listen to patients about what really matters. Include those time costs in research priorities and agendas.
- Fund development of methods and tools to measure time costs and their impacts.
- Prioritize economic analyses and evaluations that include time costs and their impacts.

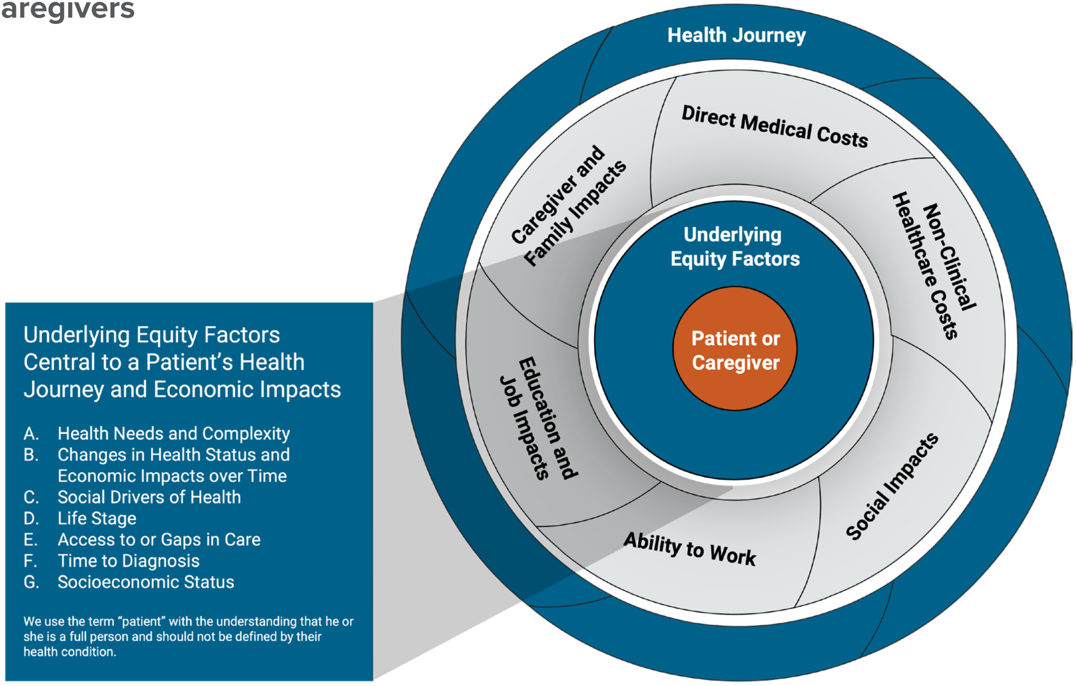
This workshop underscored the often-overlooked dimension of time costs within the healthcare system. Ignoring time costs of patients and their families is ignoring the full costs of care. To truly grasp the comprehensive burden of disease, and adopt a patient-centered approach to care, it is imperative that we begin to systematically measure these time costs. This involves not only quantifying the hours spent in appointments, on self-advocacy, and on caregiving, but also delving deeper, through qualitative research, into the short- and long-term impacts on patients' lives, their careers, their relationships, and their overall well-being. By asking patients the right questions and actively listening to their experiences, we can gain a more holistic understanding of the true cost of illness. Only then can we develop truly patient-centered interventions and policies that effectively address these challenges.

# Appendix A: Overview of Patient-Centered Economic Impacts

Patient-centered economic impacts are the financial outcomes that patients[4], family members, and caregivers experience due to health conditions and healthcare treatment. In 2023, the Center and AcademyHealth partnered with stakeholders to produce A Research Framework to Understand the Full Range of Economic Impacts on Patients and Caregivers. The framework helps us understand what we mean by "patient-centered economic impacts," or the costs associated with seeking healthcare like time spent going to the hospital for a health emergency, medicine, travel to doctors' appointments, or taking care of family members. Six main areas of patient-centered economic impacts identified include: 1) Direct Medical Costs, 2) Healthcare Related Costs, 3) Impacts on Caregivers and Families, 4) Social Impacts, 5) Ability to Work, and 6) Education or Job Impacts.

Patients and caregivers must be at the center of understanding economic impacts – which are often overlapping, complex, and difficult to measure. Further, underlying factors – health complexity, social drivers of health, time to diagnosis, and others influence the experience of these economic impacts.

**Figure A1. An Interactive Framework to Understand Economic Impacts on Patients and Caregivers**



Underlying Equity Factors Central to a Patient's Health Journey and Economic Impacts

A. Health Needs and Complexity
B. Changes in Health Status and Economic Impacts over Time
C. Social Drivers of Health
D. Life Stage
E. Access to or Gaps in Care
F. Time to Diagnosis
G. Socioeconomic Status

We use the term "patient" with the understanding that he or she is a full person and should not be defined by their health condition.

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[4] The Center uses the term "patient" to refer to a person who has had an encounter with the healthcare system and has lived expertise in the healthcare system. We do not suggest that a person is their disease or that it is a person's only area of experience or expertise. We use this term in recognition of their lived experiences and the importance of this experience to improving the healthcare system.

# Appendix B: Workshop Attendees

We are deeply appreciative of the insights and candor of the individuals who participated in this workshop. We are proud to include a wide range of experts in the field. The project is guided by a diverse Steering Committee and Community Advisory Board of patients, caregivers, researchers, payers, industry experts, and other stakeholders who provide insights, guidance, and co-leadership throughout the project. Individuals with an asterisk "*" by their name are current members of the advisory committees for this project.

### Center for Innovation & Value Research Team

- Ushma Patel
- Ellen Schultz
- Erica Malik
- Melanie Ridley
- Tiffany Huth
- Jessica Brown
- Smita Sanwardeker
- Michelle Cheng
- Dominique Seo
- Xanthia Lam

### Workshop Faculty

- **Tina Aswani-Omprakash, MPH** is a multi-award-winning women's health advocate based out of New York City. Tina pivoted from Wall Street to a path of impactful change in healthcare after her own Crohn's disease diagnosis and life-saving ostomy surgery. She is the founder of *Own Your Crohn's* blog and social media advocacy platform and co-founder and CEO of the *South Asian IBD Alliance (SAIA)*, a patient-clinician led non-profit organization working to improve education and awareness in the growing South Asian IBD community.
- **Beth Gore, PhD** is a national patient safety advocate, author, and speaker. She is the CEO of the Oley Foundation, a home nutrition therapy community and advocacy group. In addition to representing patients through patient associations, serving on boards, and through national committees and task forces, Beth is a mother of six children who are adopted with special needs, including a son who lives with a central line for lifetime nutrition support.
- **Casey Quinn, PhD** is Senior Advisor for Patient-Centered Economic Outcomes at the Patient-Centered Outcomes Research Institute, also known as PCORI. He supports efforts to capture data on the full range of clinical and patient-centered outcomes as part of PCORI-funded research. This includes potential burdens and economic impacts that patients and their families experience.

**Participants**

- Naila Ararawi, Hashemite University
- Madhura Balasubramaniam, South Asian IBD Alliance
- Kim Beall, Nutritional Therapy for IBD
- Jamal Brown, Trustee of Community Advisory Committee and Ambassador for Camden Coalition*
- Karen Carey, Cystic Fibrosis Foundation
- Shailesh Chavan, Ingenious Global Health
- Jennifer Contreras, Takeda Pharmaceuticals
- Mabel Crescioni, PCORI
- Tosin David, Qlarant
- Brian Dawson, PA Rare Disease Advisory Council and the Sumaira Foundation*
- Hannah Dolhai, Cystic Fibrosis Research Institute
- Elena Elkin, Mailman School of Public Health, Columbia University
- Dalya Ferguson, McGovern Medical School at UTHealth Houston
- William Finke, ForHealth Consulting
- Christine Freund*
- Meghan Gallagher
- Tracey Giambertone, Oley Foundation
- Nohora (Nora) Gutierrez, iConquerMS
- Michael Hager, RAI Impact Equity Labs, Inc.
- Lakisha Harris, Hydrocephalus Association
- Elham Heidari, UMass Medicine
- Chiayun Hsu, University of Maryland School of Pharmacy
- Terri Ipsen, Beryl Institute
- Swapna Kakani, Swapna Kakani Consulting
- Shabina Khan, CAPriCORN/PCORI
- Stacey Kowal, Genentech
- Allison Loiselle, National Eczema Association
- Zach Lynkiewicz, HIV + Hepatitis Policy Institute
- Abigale Miller, Med Ink Consulting
- Kevin Moore, RAI Impact Equity Labs, Inc.
- Caroline Pardo, Integrated Action Science
- Mary Reed, Kaiser Permanente Division of Research*
- Mahsa Salsabili, UMass
- Adam L. Scheffler
- Andrea Taylor, Oley Foundation
- Patrick Teo, Tan Tock Seng Hospital
- Shana Traina, Janssen
- Milan Velkov, Helios Kliniken Schwerin
- Bola Williams, Boston Scientific
- Dorothy Winningham, WinnBeHealthy LLC*
- Pin Xiang, Boehringer Ingelheim
- Man Wah Yeung, Public Health Agency of Canada

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