Center for Innovation
& Value Research

Summary

2025

6th Annual Methods Summit

Exploring Patient-Centered Value Research from Definition to Dissemination

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The Center for Innovation & Value Research is a 501(c)(3) tax-exempt, non-profit research organization dedicated to advancing the science and improving the practice of health technology assessment through development of novel methods and the creation and application of enhanced health technology assessment models to support local decision-making needs in healthcare.

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OVERVIEW

On March 19, 2025, the Center for Innovation & Value Research (Center) convened its 6th Annual Methods Summit, a pivotal event uniting diverse perspectives and industry leaders to chart the course for the future of patient-centered value research. With over 313 registrants for this year's hybrid event, the Summit served as a collaborative and inclusive forum, allowing stakeholders to explore the full spectrum of patient-centered value research—from defining value and engaging patients to implementing and adapting research strategies based on real-time data.

As part of its ongoing efforts to refine patient-centered research methodologies, the Center held an open comment period on its **Blueprint for Patient-Centered Value Research**. Participants were encouraged to consider how they could apply the Blueprint in their own work and collaborate with the Center to drive meaningful impact.

THEMES

- Many participants hold multiple roles—patients, caregivers, researchers, funders, and payers—highlighting the interconnected nature of patient-centered research.
- Being a "patient" is only one aspect of a person's identity. Research must acknowledge and honor the complexity of individuals' lives.
- Power dynamics between patients and researchers must be recognized, ensuring that patients are valued as equal partners in research.
- Research findings must be actively shared with the right communities to maximize their impact.

RECOMMENDATIONS AND INSIGHTS

PANEL 1: BEYOND THE METRICS: DEFINING PATIENT-CENTERED VALUE RESEARCH

This panel explored foundational principles of patient-centered value research, how different stakeholders perceive patient value, and the importance of ensuring that collected data is actionable, relevant, and mutually beneficial to patients and researchers alike.

- The **"why" behind data collection** needs to be clearly communicated to patients, as well as ways they can potentially benefit in real time from data collection.
- Making sure that not only patients understand the value of collecting this data, but also other stakeholders (e.g., healthcare providers in varied healthcare settings) also recognize the value and multiple potential uses of collecting this data.
- Importance of closing the loop with patients instead of merely extracting data, leading to greater trust and accountability.
- HTA bodies, payers, and regulators are increasingly interested in patient-experience data, but there is a need for better **frameworks to interpret and apply these insights**.
- **Storytelling** can serve as a powerful tool for demonstrating value.

> **It's never too early to start conversations with patients.**
>
> — Magdelena Harrington

SPEAKERS

Carissa Doran, PhD, MPA, BSN
Northwell Health

Magdalena Harrington, PhD
Pfizer

Asia Williams, MPH
National Academy of Medicine

PANEL 2: FROM PARTICIPANTS TO PARTNERS: PATIENTS AS CO-CREATORS IN RESEARCH

This panel highlighted the shift from traditional patient involvement to a more collaborative, co-creation model, where patients actively contribute to research design and decision-making.

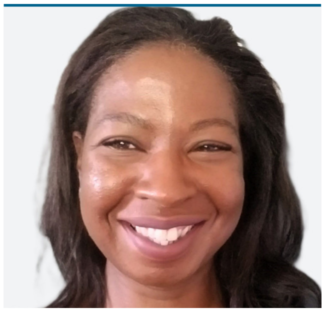
> **Clinical research has to fit into patients' lives.**
>
> — Richie Kahn

- Partnering with patients from the outset helps define the **right research questions** and ensures studies address real-world needs.
- While patient-centered research considers patients holistically, methodologies must be adapted to reflect the **diversity** of patient experiences.
- Research must be **integrated into patients' live**s—it should not be more burdensome than the treatment itself.
- A key consideration remains: How can research be leveraged to improve access to care?

SPEAKERS

Beth Gore, PhD
Oley Foundation

Richie Kahn, MPH
Canary Advisors



Brandy Farrar, PhD, MS
American Institutes for Research

PANEL 3: THE POWER OF PATIENT DATA: LEVERAGING ARTIFICIAL INTELLIGENCE (AI) TO ADDRESS EVIDENCE GAPS IN RARE DISEASE

This panel explored how AI can transform rare disease research, diagnosis, and patient advocacy by addressing critical evidence gaps.

- Four key elements for leveraging AI in rare disease research—AI saves **time** by accelerating data processing, reduces **energy burden** by operation without fatigue, is **free from human**

biases and limitations (though it requires careful management to avoid errors), and enhances **accessibility** by making information widely available.

- Tackling Rare Disease Challenges: AI helps address limited sample sizes and high heterogeneity in rare diseases by synthesizing data across sources, through inclusion of patients' voices, validation and transparency are essential.
  - Don't assume that lack of evidence means there are no existing impacts.
- Pitfalls and concerns about AI's role in rare disease research and patient care:
  - Data Governance and Privacy: The increasing use of AI tools like ChatGPT could break down silos and democratize access to information but also raises concerns about how personal medical information might be shared or misused.
  - Algorithm Validation: AI systems must be thoroughly validated (and re-validated over time) to ensure their decision-making is logical and accurate.
  - Ethical Considerations: Data privacy, algorithm reliability, and human oversight must guide AI's use to ensure it empowers rather than replaces human decision-making.
  - Patient-Centricity and Human Oversight: AI should support, not replace, human decision-making. Keeping a "human in the loop" ensures meaningful, purpose-driven healthcare that reflects individual needs.
- AI as a Catalyst for Change: From diagnosis to patient support, AI holds immense potential, but success depends on responsible implementation that keeps patients at the center.

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> **We don't have the luxury of time. It feels like impatience, but it's not. It's urgency.**
>
> — Sarita Edwards

SPEAKERS

Sarita Edwards, MHA
E.WE Foundation

Harsha K. Rajasimha, PhD, MS
Jeeva Clinical Trials, Inc

Simu Thomas, PhD
Alexion AstraZeneca Rare Disease

PANEL 4: TURNING DATA INTO ACTION: COMMUNICATING RESEARCH TO DRIVE HEALTHCARE CHANGE

This panel highlighted the critical role of effective communication in translating research findings into meaningful improvements in patient care. Panelists shared strategies and real-world examples of conveying research to diverse audiences.

> **Knowledge on its own doesn’t change health.**
>
> — Jessica Johnson

- Effective Communication of Research: Successful communication ensures that research findings lead to tangible improvements in patient care by making data accessible, understandable, and actionable for different audiences, centering the “so what” for patients.
- Tailoring Messages for Diverse Audiences: Panelists emphasized the importance of adapting research findings for various stakeholders, including patients (by asking patients about the best ways to disseminate findings), healthcare providers, policymakers, and the public, ensuring the message is accessible and resonates with each group.
- Real-World Examples of Dissemination: Sharing strategies such as patient co-authorship, using multiple formats (e.g., infographics, fact sheets) and accessible venues (e.g., open access publishing), and partnering with media outlets to amplify and repeatedly message research findings and reach wider communities.
- Feedback Loops and Continuous Engagement: Ongoing engagement ensures research findings are not only disseminated but also used to inform future healthcare practices and policies.

SPEAKERS

Kimberly Westrich, MA
National Pharmaceutical Council

Jessica Johnson, MPH
National Eczema Foundation

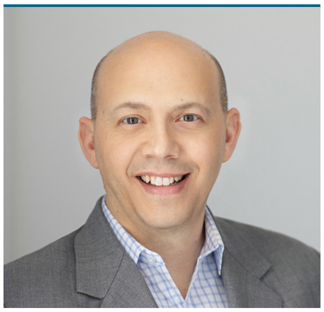
Bridget Doherty, MPH, MS
Johnson & Johnson Innovative Medicine

CLOSING REFLECTION

- Early and Continuous Engagement: Research efforts must prioritize early relationship-building and sustained post-study engagement. Funding agencies should allocate resources for these phases, ensuring meaningful patient and stakeholder involvement.
- Communication and Trust: Overcoming skepticism about research requires clear, transparent, and accessible information.
- Sustainability and Long-Term Impact: Research efforts must not be one-time exercises. Establishing ongoing partnerships and ensuring community involvement beyond individual projects is critical for lasting trust and impact.
- Celebration and Acknowledgment: Recognizing and celebrating research milestones fosters motivation, strengthens partnerships, and reinforces the value of continued collaboration.

SPEAKERS

C. Daniel Mullins, PhD
University of Maryland



Jason Spangler, MD, MPH, FACPM
Center for Innovation & Value Research

LOOKING AHEAD

The 6th Annual Methods Summit reaffirmed the need for a patient-centered, inclusive, and sustainable value research approach. Moving forward, the Center remains committed to fostering meaningful partnerships and advancing methodologies that put patients at the core of decision-making. The final call is clear—**let's work together to turn these discussions into lasting change.**

> **No matter how good the evidence, if we can't afford it, it doesn't matter.**
>
> —C. Daniel Mullins

APPENDIX

MEETING WORKSHEET

The Center's Methods Summit continues to bridge the gap between theory and practice by exploring concrete steps to advance Patient-Centered Value Research. This worksheet allows you to capture comments, questions, and recommendations throughout the sessions. Your input is important as we develop the meeting summary and look towards our future work— we encourage you to use this worksheet to foster meaningful discussions. Thank you for your engagement and for completing and returning this worksheet.

Session One – Defining Patient-Centered Value Research: How can we define and measure patient-centered value in healthcare research to ensure it remains meaningful and actionable?

Session Two – From Participants to Partners: Patients as Co-Creators in Research: As we reflect on the most effective ways to engage patients as meaningful partners in research, how can these approaches be more widely adopted?

Session Three – Execution & Monitoring: Leveraging AI in Rare Disease Research: How can AI-driven research maintain a patient-centered focus while addressing evidence gaps in rare diseases?

Session Four – From Research to Real-World Impact: Leveraging Research Insights in the Final Stages of Value Research: How can we effectively translate research insights into real-world impact through strategic dissemination, implementation frameworks, and best practices?

Wrap-up Session – What key takeaways from today's discussions should shape the future of patient-centered value research?

Key Terms and Definitions

Term	Definition
Health Technology Assessment (HTA)	HTA is a process of looking at new medical treatments, devices, or procedures to see if they are safe, work well, and are worth the cost. It helps doctors and health systems decide which treatments should be offered to patients.
Patient-Centered HTA	This approach focuses on making sure that the needs and experiences of patients are at the center of the decision-making process. It ensures that new treatments or technologies help improve the quality of life and health outcomes for patients.
Patient-Centered Value Research	Patient-centered value research is a collaborative partnership between researchers and stakeholders, particularly patients, to ensure that every stage of the research process—from design to dissemination—is shaped by experiences, needs, and preferences of those most impacted, aligning priorities and outcomes to generate meaningful and actionable insights.

Feedback and Future Topics

We value your input! Please use this space to share any general feedback about the Methods Summit, including what worked well and what could be improved. Additionally, let us know if there are specific topics or methodologies you'd like to see covered in future summits.

Thank you!

Please return completed worksheets to the Center at the end of the event. Virtual attendees may send the worksheet to info@valueresearch.org.

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Learn more on the Center website.