A Patient-Centered Complex Care Research Agenda: Recommendations for Collective Action

September 15, 12:00 – 1:30 pm ET

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Questions?

To submit a question online, please click the Q&A icon located at the bottom of the screen.
Today’s Agenda

- Why a Patient-Centered Complex Care Research Agenda?
- Research Agenda overview
- Panel Discussion
- Questions & Answers
- Concluding Remarks
Goals for Today

Attendees will:

- Understand the need for a Research Agenda that is patient-centered
- Understand the goals of the Research Agenda
- Highlight opportunities to better coordinate research efforts and capture what matters most to patients
- Learn how to incorporate the Research Agenda's recommendations into your work
Meet the Facilitators

Anna Benyo
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Dedicated to strengthening the U.S. health care system to ensure better, more equitable outcomes, particularly for people served by Medicaid.

Together with our partners, our work advances:

- **Effective models for prevention and care delivery** that harness the field’s best thinking and practices to meet critical needs

- **Efficient solutions for policies and programs** that extend the finite resources available to improve the delivery of vital services and ensure that payment is tied to value.

- **Equitable outcomes for people** that improve the overall wellbeing of populations facing the greatest needs and health disparities.
Project Partners

• Funded by the Patient-Centered Outcomes Research Institute (PCORI)

• Collaborators:

- PFCCpartners
- The National Center for Complex Health & Social Needs
- Institute for Healthcare Improvement
Patient-Centered Complex Care Research Agenda: Review of Recommendations
Key Definitions

What is complex care?

• A person-centered approach to care that brings together patients and their families, the community, and the health care system to improve health outcomes and well-being for people with complex health and social needs.

Who are people with complex needs?

• Adults with complex health and social needs whose incomes do not always cover basic living needs such as food, transportation, and housing.
Why a Patient-Centered Complex Care Research Agenda?

- Limited and conflicting research
- Overreliance on cost and utilization measures
- Limited use of patient-centered input on research design or outcomes
- Need for more nuanced evidence
“We have not only lived a journey critical to complex care research but our intersectionality of living in communities as well as intergenerational family dynamics enlighten our understanding of complex care issues.... This depth of introspection may not always be gained from professional practitioners unless they have the lived experience themselves.”

- Suzette Shaw
Research Agenda Patient and Family Advisory Board Member
Developing a Patient-Centered Complex Care Research Agenda

• Environmental scan

• Input from over 100 health care stakeholders, including individuals with lived expertise of complex care, researchers, payers, & health system leaders:
  → Interviews
  → Patient and Family Advisory Board and Research Communities
  → Series of five workgroup sessions
  → Survey of complex care stakeholders
Key Recommendations

1. Meaningfully partner with patients and communities in research

2. Focus on a prioritized set of research questions

3. Measure outcomes in a more consistent and patient-centered way
Recommendation #1: Meaningfully Partner with Patients and Communities in Research

• Engage patients and communities as partners in all stages of research

• Build more patient and community engagement skills

• Use different and new research skills, practices, and design
Recommendation #2: Focus on a Prioritized List of Research Questions

1. What services and approaches are most effective for which patients and why?

2. How can the different people and organizations who provide complex care services effectively coordinate with each other, and how does this affect care?

3. What is the role of a trauma-informed approach in complex care programs?

4. What gaps in services and resources must be addressed to fully meet the needs of individuals with complex health and social needs?

5. What impact does setting have on complex care efforts?
Recommendation #3: Measure Outcomes in a More Consistent and Patient-Centered Way

Five Key Categories of Measurement:

1. Patient-Centeredness
2. Racial and Health Equity
3. Quality of Life
4. Coordination of Care and Systems
5. Cost and Utilization
Implementation Opportunities

• Use recommendations to inform new research
• Engage in collective learning
• Develop a Complex Care Practice-Based Research Network
• Develop a core set of complex care standards and measures
• Support the use of patient-centered research methods
• Apply the existing evidence base
• Pursue research with health care transformation in mind
“Sometimes numbers don’t go down medically, but that doesn’t mean that people are not happy or joyous because they’re getting their needs met.”

- LaKeesha Dumas
Patient and Family Advisory Board Member
PANEL: How to Build A More Patient-Centered Approach to Complex Care Research

Alan Coker
Recovery Support Specialist (retired) and Patient and Family Advisory Board Member

Melissa Golpl
Patient and Family Advisory Board member

Amanda Johnson, MD, MBA
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Doris A. Maldonado Mendez, MEd, GAL, HIS, CCHW, YMHFA
National Latine Community Health Navigator and Patient and Family Advisory Board member

Cara Nikolajski, PhD, MPH
Director of Research Design and Implementation, UPMC Center for High-Value Health Care
Questions?
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Opportunities to Learn More

• National Center for Complex Health and Social Needs Conference
  → Workshop September 21, 4:00 - 5:15 pm PT
  → “Beehive” informational session, September 22, 12:00 - 2:00 pm PT

To view the Research Agenda, visit www.chcs.org/research-agenda
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