

# A Patient-Centered Complex Care Research Agenda

*A guide to build the complex care evidence base by prioritizing what matters most to people with complex health and social needs.*



**A**lthough complex care is a widely used approach to support people with multiple health and social needs, there is considerable variation across programs, and not enough is known about what works best for which people. More and stronger research is needed to help the field understand the most effective and efficient approaches to complex care. Additionally, most research to date has focused on whether people who receive complex care services visit the emergency department less or have fewer admissions to the hospital, and as a result, cost the health care system less money. This definition of “success” is very different than what patients may find meaningful about complex care, and ignores other important ways that these services may affect people, such as improving quality of life and well-being. To truly understand the impact of complex care and build a stronger evidence base, a more coordinated approach to research is needed. This approach must recognize the value of patients’ experiences and expertise and include them in all parts of the research process.

Recognizing this need, the Center for Health Care Strategies (CHCS) developed the *Patient-Centered Complex Care Research Agenda* with funding from the Patient-Centered Outcomes Research Institute (PCORI). The *Research Agenda* was co-created by more than 100 partners, including individuals with lived expertise of complex care, researchers, providers, and health care system leaders. It is an actionable guide for improving complex care research and building stronger evidence by prioritizing the experiences of people with complex health and social needs.

The *Research Agenda* can help:

- **Guide all complex care stakeholders** in effectively working together to strengthen the field’s evidence base by focusing research on a recommended subset of questions and measurement categories.
- **Inform researchers** in designing research to focus on patients’ priorities and experiences and including patients as valuable research partners; and
- **Support patients** in recognizing how their expertise can be used to strengthen complex care research efforts.

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**“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, Patient and Family Advisory Board member

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## Recommendations: Patient-Centered Research Priorities

The *Research Agenda* outlines three core strategies to build a stronger, more coordinated, and patient-centered complex care evidence base:

1. **Meaningfully partner with patients and communities in research;**
2. **Focus on a prioritized set of research questions;** and
3. **Measure outcomes in a more consistent and patient-centered way.**

Each of these three recommendations represents an opportunity for complex care to be more patient-centered in designing, researching, measuring, and delivering services. They also represent opportunities for complex care stakeholders to grow new skills and partnerships.

### 1. Meaningfully Partner with Patients and Communities in Research

Collaborating with patients and communities in all stages of research — from identifying what to study to figuring out how to use study results — is key to understanding how complex care affects the issues that matter to patients. The *Research Agenda* outlines two opportunities to involve patients in research:



- **Build more patient and community engagement skills.** Collaborating on research projects should be as easy for patients and community members as possible. To support this collaboration, research teams should use strategies such as engaging patients in culturally competent ways; creating project materials and timelines that accommodate patients' needs; using trusted messengers, such as community health workers or peers, to support engagement efforts; using trauma-informed approaches; and compensating patients for their time.
- **Use patient-centered research skills, practices, and design.** An array of research methods can be used to better capture the full range of patient experiences with complex care. Examples include qualitative research, longitudinal research, and community-based participatory research. Health care systems must be trustworthy partners to patients and communities. As such, health care systems should clarify research goals and progress, share data and results, and approach research with the goal of developing long-term relationships.

### 2. Focus on a Prioritized Set of Research Questions

To date, most complex care research has looked at how much money complex care saves and how it changes health care use over a short period of time. This narrow focus means that the field does not yet fully understand who complex care is most effective for, what aspects of it are most impactful, or what other types of value it might create. In order for complex care to be as effective as possible, this *Research Agenda* identifies five critical questions for research to focus on:



- ***What services and approaches are most effective for which patients and why?***
- ***How can the different people and organizations who provide complex care services effectively coordinate with each other, and how does this affect care?***
- ***What is the role of a trauma-informed approach in complex care programs?***
- ***What gaps in services and resources must be addressed to fully meet the needs of individuals with complex needs?***
- ***What impact does setting have on complex care efforts?***

Coordinating research to focus on these questions will help grow the evidence base in more patient-centered and more comparable ways to get a more complete understanding of the impacts of complex care.

### 3. Measure Outcomes in a More Consistent and Patient-Centered Way

Expanding research to measure the impacts of complex care beyond changes in cost and health care utilization is critical to building the evidence base around what matters most to patients. To address this need, the *Research Agenda* identifies five categories of measurement that complex care research should use:



- **Patient-centeredness**
- **Racial and health equity**
- **Quality of life**
- **Coordination of care and systems**
- **Cost and utilization**

More validated patient-centered measures are needed in complex care research, including in these categories. Focusing on developing and collecting data from these measurement categories will provide a more accurate picture of what is working and why, and how complex care impacts patients and other members of the care community, including family caregivers and providers.

### Next Steps: Implementing the Research Agenda

These research priorities provide a roadmap for the complex care field to build the evidence base in ways that will allow it to be more patient-centered, impactful, and efficient. Concrete next steps that complex care stakeholders can take to act on the *Research Agenda* include:

- 1. Use recommendations to inform new research.** Design research using the recommended research questions, categories of measures, and engagement strategies.
- 2. Engage in collective learning.** Create opportunities for different groups of people who are involved in complex care to learn together and build their research skills.
- 3. Develop a *Complex Care Practice-Based Research Network*.** This network can provide an opportunity for complex care stakeholders to work together in a coordinated way to design, analyze, and learn from each other's efforts.
- 4. Develop a core set of complex care standards and measures.** Use a patient-centered approach to define complex care's core research values and establish a set of measures to guide all complex care research.
- 5. Support the use of patient-centered research methods.** Funders, policymakers, and organizational leaders can prioritize investing in research, and support the use of patient-centered research approaches such as community-based participatory research or qualitative research.
- 6. Apply the existing evidence base.** Understand what has worked well in adjacent fields, such as HIV care and housing, and apply those lessons to complex care.
- 7. Pursue research with health care transformation in mind.** Seek to better understand how what works well with complex care can support better care for all patients – not just those with complex health and social needs.

The field of complex care has seen exciting growth over the past decade in better supporting people with an array of complex health and social needs. By focusing on the strategies in the *Research Agenda* and centering patients' experiences as a core value for research, the field will be well-positioned to grow its understanding of how to support patients as impactfully and efficiently as possible in years to come.



## ABOUT THE PATIENT-CENTERED COMPLEX CARE RESEARCH AGENDA

The *Patient-Centered Complex Care Research Agenda* provides a blueprint to guide complex care research aimed at developing a strong patient-centered evidence base. It was developed by the Center for Health Care Strategies and a team of committed partners through support from the Patient-Centered Outcomes Research Institute. The recommendations reflect the expertise of a diverse community of advocates, people with lived experience, system leaders, and researchers, who are actively working to improve the health and well-being of individuals with complex health and social needs. To learn more, visit [www.chcs.org/research-agenda](http://www.chcs.org/research-agenda).



## ABOUT THE CENTER FOR HEALTH CARE STRATEGIES

The Center for Health Care Strategies (CHCS) is a policy design and implementation partner devoted to improving outcomes for people enrolled in Medicaid. We support partners across sectors and disciplines to make more effective, efficient, and equitable care possible for millions of people across the nation. For more information, visit [www.chcs.org](http://www.chcs.org).

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