



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.

September 2022

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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.

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* Rachel Davis Consulting, formerly with CHCS.

Introduction

KEY TAKEAWAYS

- Although complex care is now 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, and how it could work better.
- More and stronger research is needed to help the field understand the most effective and efficient approaches to complex care.
- To date, most research has focused on whether people who receive complex care services visit the emergency department less or are admitted to the hospital less, and therefore cost the health care system less money. Defining “success” in this way ignores many of the other ways that complex care may affect people, including around things that matter most to them, such as their quality of life and well-being.
- To fully understand the impact of complex care and build a stronger evidence base, research must recognize and include the patient experience.
- This *Research Agenda* provides a blueprint to guide future complex care research by proposing that the field focus on:
 1. Meaningfully partnering with patients and communities in research;
 2. Focusing on a prioritized set of research questions; and
 3. Measuring outcomes in a more consistent and patient-centered way.

For more than a decade, complex care programs have grown across the United States. Initially an experimental approach used by a few early adopters, complex care now fills a critical gap in the U.S. health care system.^{1,2} Complex care programs exist throughout the country, serve a wide range of people, and are led by various stakeholders in a range of settings. Several recent efforts exemplify complex care’s maturation. These include: the “*Blueprint for Complex Care*,” which proposed a strategic plan to accelerate the field’s capacity to effectively serve individuals with complex health and social needs; the establishment of “core competencies” (abilities) for frontline complex care providers; and a language guide for clearly communicating about complex care.^{3,4,5} Large-scale policy efforts such as the federal Medicaid Health Homes program and California’s Whole Person Care and Advancing and Innovating Medi-Cal (CalAIM) initiatives also signal that at a state and national level, this work is a growing priority.^{6,7,8}



This growth has led the field to an important crossroads: while it has evolved from an emerging field to an established one, there is little existing high-quality research that highlights what aspects of complex care are most effective and for whom. To support patients as effectively as possible, and ensure that resources are used as efficiently as possible, it is essential to build and strengthen the complex care evidence base.

As part of this effort, it is critical that complex care research focuses on understanding patients' experiences of care, and how complex care services help patients achieve their health and well-being goals. Traditionally, "success" in complex care programs has been defined by reductions in health care costs or services used and not by what matters most to patients. There is much more for complex care to learn about who it helps, what kind of value it generates, and how it can best support patients' needs and goals.

Recognizing this need, the Center for Health Care Strategies (CHCS) developed this *Patient-Centered Complex Care Research Agenda* with funding from the Patient-Centered Outcomes Research Institute (PCORI). This *Research Agenda* provides a blueprint to guide future complex care research aimed at developing a strong patient-centered evidence base. It recommends engaging patients and communities as partners in research to ensure that their perspectives inform all stages of the work. It proposes that complex care stakeholders collectively focus their research on a set of prioritized patient-centered research questions and use more patient-centered methods and measurement domains to assess outcomes.

This patient-centered approach to research will require the field to ask new questions, measure outcomes in different ways, build new skills and relationships, and bring new partners to the table. Ultimately, adopting a patient-centered research focus will more accurately capture complex care's impact, strengthen the field's ability to provide the most effective care possible, and consistently promote patient-centered values.

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Understanding Key Terms

To help readers, key foundational terms are explained below. Additional terms are defined in the [Glossary](#) (page 45).



What is a research agenda?

A research agenda outlines a clear framework, including questions and priorities, to guide future research activities and lead to more impactful findings. This *Research Agenda* identifies areas for future complex care research with a focus on a patient-centered approach.

What is complex care?

Complex care is 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.⁹ It prioritizes patients' health care goals, coordinates care across providers and settings, and links patients with necessary health and social resources.

Who are people with complex needs?

This *Research Agenda* focuses on **adults with complex health and social needs whose incomes do not always cover basic living needs** such as food, transportation, and housing. Health needs include both physical and behavioral conditions, including mental health and substance use challenges. Social needs include stable housing, nutritious food, and transportation, to name a few.

Who are complex care stakeholders?

Within complex care, many terms are used to describe the people who receive services and those who are involved in providing them. This paper uses the following terms to describe complex care stakeholders:

- **Patients:** Individuals who receive and interact with complex care services.¹⁰
- **Community:** Refers to both the geographic area where patients live and work as well the individuals who live and work in the area. Also group(s) of people who share similarities (e.g., the LGBTQ community).
- **Providers:** Licensed clinicians, such as doctors, nurses, or social workers.
- **Care team members:** Individuals who provide complex care services to patients, such as community health workers (CHWs), peers, and case managers. This term also includes health care providers.
- **Family caregivers:** Unpaid individuals who have a personal connection to the patient and support them in meeting their needs through activities like assisting around the home, attending appointments, etc.

Other stakeholders include **health care systems, community-based organizations, health plans, researchers, policymakers, and funders**. Collectively, this group of stakeholders represents a broad care community, with each bringing their own expertise to the field. There are many diverse types of medical providers, patients and communities, and caregivers. The terms highlighted above are used throughout the *Research Agenda* for consistency, and are not meant to detract from the recognition that a diverse range of experiences and identities exist within each of these categories.

Audience Roadmap: Using this Research Agenda

The *Patient-Centered Complex Care Research Agenda* is intended to inform all members of the complex care community, including patients and family caregivers, researchers, health care organizations and community-based organizations (CBOs), and providers as well as health plans, policymakers, and funders. Below are suggestions for how these audiences can use this document.



Patients and their caregivers are the experts about their lives, their needs, and the systems they navigate. Those interested in partnering on research efforts can use this document to:

- Learn more about the complex care research environment.
- Identify how their experience and expertise would benefit complex care research efforts.
- Understand how to engage in research as contributing partners who help shape all aspects of the work, including design, implementation, analysis, and application of the results.

Researchers play an influential role in identifying what works and what doesn't work in complex care. Researchers can use this document to:

- Inform research design to build a more robust and patient-centered complex care evidence base.
- Understand the benefits of taking a patient-centered approach to research.
- Identify concrete strategies and build skills for engaging patients and communities as research partners.

Providers are the frontline of complex care and have valuable perspectives on complex care's impacts. They can use this document to:

- Identify opportunities to shape complex care research efforts.
- Support the development and collection of patient-centered measures.
- Infuse their work with patient-centered principles.

Health care organizations and CBOs provide care to patients, employ providers and other care team members, and often lead or are key partners in complex care research. They can use this document to:

- Prioritize novel approaches to research that grow the complex care evidence base in patient-centered ways.
- Identify opportunities to support staff in growing patient engagement skills.
- Develop partnerships with patients and communities to enhance research efforts and contributions.
- Explore different types of complex care outcomes that can inform decision making about programs.

Health plans, policymakers, and funders set priorities, invest in complex care's growth, and are key drivers of advancing the field. These partners can use this document to:

- Develop new approaches and policies that support patient-centered research.
- Advance new norms for the field, including adopting longer study periods for assessing impact and measuring success in more patient-centered ways.
- Inform future investments in research skills, studies, and collaboration with patients and communities.

The Current State of Complex Care: Research Opportunities and Challenges

While the field of complex care has grown, there is wide variation of what it looks like in practice. Some programs, often based in hospitals and emergency departments, provide treatment for a brief period and support patients in transitioning back into their communities.¹¹ Programs in primary care or behavioral health care settings often provide longer-term services. Most models use team-based care with some combination of nurses, social workers, case/care managers, community health workers (CHWs), and others providing services.

Complex care programs also serve a broad array of individuals.¹² Many programs focus on people who have multiple recent emergency department visits and/or inpatient admissions. Others focus on individuals with specific combinations or numbers of chronic conditions.

The wide range of settings, interventions, team composition, and populations served is both a strength and a weakness of complex care. This variation has allowed complex care practitioners to think creatively, develop innovative approaches to care, and explore how to customize services rather than providing them in a “one-size-fits-all” approach. However, the current evidence base for complex care is limited in part because the wide variation in approaches makes it hard to apply the results from any given study to the broader field.

There are numerous reasons why few high-quality and patient-centered complex care research efforts have been conducted to date and why a rigorous evidence base is missing. These include:

- **Resources:** Conducting high-quality research requires money, time, and expertise, which are often in short supply, particularly for research focused on underserved populations.
- **Skills to engage patients:** Meaningfully engaging patients is an important part of designing and delivering complex care services.¹³ However, the field is still growing its expertise on how to best engage patients, and more training and skills are needed to do this well, including in research.
- **Data:** Both health and social data are needed to fully understand the impact of complex care. The health care sector is still determining what types of social data to capture and how to do so. The need to build technology infrastructure, address data-sharing barriers, and develop patient-centered measures also contribute to this challenge.
- **Perceived value beyond return on investment:** Complex care’s value is often exclusively reduced to its potential to save health care systems money. This focus has heavily skewed complex care research toward assessing its impact solely on cost and utilization. To demonstrate the true value of complex care, research needs to look at a broader array of outcomes, including what matters most to patients.

The Need for a Patient-Centered Research Approach

Complex care strives to meet the self-defined needs of the patients it serves. Yet, although patient-centeredness is a core value of complex care, this focus is rarely reflected in research and evaluation activities. For example, cost and utilization-focused outcome measures reflect the priorities of policymakers, payers, and health care system leaders rather than patients. In addition, to date, most studies have sought to assess these measures over a short period — typically 12 months or less. Many of the challenges that populations served by these programs face, such as lack of housing, histories of trauma, and/or social isolation, are often not solvable in a short time frame. These types of challenges can be further compounded by long-standing environmental and societal factors (e.g., living in communities with little access to behavioral health care, lack of quality education, systemic racism, etc.) that are even more difficult to address quickly. This lack of patient-centeredness in complex care research and evaluation means that the field has little evidence-based insight into the various ways that complex care programs affect outcomes for the people they serve.

Adopting a more patient-centered research approach will benefit the field in numerous ways, including by:

- **Expanding the evidence base around impact.** Within traditional health care research, medical providers and researchers are typically seen as the experts, and their academic and professional skills dictate how research is designed. Taking a patient-centered approach to complex care research recognizes patients' unique and valuable expertise that will allow the field to ask new questions, measure different outcomes, and contribute to stronger research results. This will help the field better understand the impacts of complex care and improve the quality of care.
- **Addressing racial and health inequities.** Groups that have been impacted by racial and health inequities, such as people of color, people with low incomes, or people with disabilities, are overly represented in populations with complex needs.¹⁴ At the same time, they are often either excluded from research efforts, or used merely as research subjects and studied by researchers who have little connection to or long-term investment in the community. Including patients in complex care research design and centering research efforts on their experiences will help the field more explicitly understand the impact of potential inequities and how to more effectively address them in complex care programs.
- **Building research skills, quality, and capacity.** By partnering with patients, complex care researchers can enhance their understanding of the lives and experiences of complex populations and build their ability to partner effectively with patients. Partnering with patients can also improve research questions, the methods used to collect data, and interpretation of results. Patients, in turn, have the opportunity to grow additional professional skills and knowledge that can be applied in a variety of settings.

Developing a Patient-Centered Complex Care Research Agenda

KEY TAKEAWAYS

- This *Research Agenda* was created using feedback from over 100 partners, including patients with lived expertise of complex care, researchers, providers, and health care system leaders.
- It recommends the questions, measures, skills, and approaches that complex care research should focus on to better understand how to make complex care as effective as possible.
- Designing research with patients' experiences in mind is key to making sure that the results will be useful. This approach will allow the field to:
 1. Build the evidence base in stronger and more comparable ways.
 2. More fully understand what aspects of complex care work and for whom, and how it affects patients' lives.
 3. Make research more effective by ensuring that studies are directly informed by patients' experiences and needs.
 4. Better understand how racial discrimination and inequities in the way that health care is available to different groups of people impact complex care and can be addressed.

This *Research Agenda* outlines core priorities to guide patient-centered complex care research and highlights opportunities for the field to advance these priorities. Following is background on how the agenda was developed.

Project Activities

The *Research Agenda* was developed through a wide range of activities and conversations and in collaboration with more than 100 stakeholders, including individuals with lived expertise of complex care, researchers, providers, and health care system leaders. The recommendations address their collective priorities for complex care research and what is needed to improve research efforts to reflect what matters most to patients.



ENVIRONMENTAL SCAN

To understand the current state of complex care research and identify opportunities to improve it, CHCS conducted an environmental scan consisting of interviews with 20 subject matter experts, including five with lived expertise of complex care, and a review of more than 40 publications.¹⁵

WORKGROUPS

Between December 2021 and July 2022, CHCS convened five workgroup sessions with patient partners and teams from 10 health care organizations (see [Acknowledgements](#)). Health care organizations were selected based on their national reputation as leaders in complex care, with each organization represented by researchers, providers, and leadership. Workgroups explored the following questions:

1. What should the complex care field be striving to accomplish, and how can research support this?
2. What research questions are most important for complex care to answer?
3. What should complex care measure to understand its impact more comprehensively?
4. What resources, skills, and strategies are needed to build the complex care evidence base in a coordinated and patient-centered way?

The feedback from these conversations was central to the *Research Agenda's* recommendations.

PATIENT PARTNERS

CHCS created two groups to ensure that patient voices were central to building this *Research Agenda*.

The **Patient and Family Advisory Board** (PFAB) consisted of seven members from across the country who have lived expertise of complex care. Led through a collaboration with Patient Family Centered Care Partners (PFCCpartners), this group met monthly to provide overall project guidance, co-design the workgroup meetings, and provide feedback on the *Research Agenda*.

The **Patient and Family Research Community** included nine individuals and family members with lived expertise in complex care who provided feedback on specific aspects of the *Research Agenda* at numerous points throughout the project.

Members of both groups participated in the workgroup sessions and played an instrumental role in developing the *Research Agenda* recommendations.

ORGANIZATIONAL PARTNERS

CHCS partnered with PFCCpartners, the Camden Coalition's National Center for Complex Health and Social Needs, and the Institute for Healthcare Improvement to support this project. In addition to participating in the workgroup sessions, representatives from these organizations met several times to review findings, provide feedback, and inform the *Research Agenda* recommendations.

SURVEY

To ensure that a broad range of complex care stakeholders could weigh in on the *Research Agenda*, CHCS developed a survey to solicit feedback on questions explored by the workgroups. In May 2022, CHCS and the Camden Coalition's National Center for Complex Health and Social Needs distributed the survey in their monthly newsletters, and responses were used to inform this *Research Agenda*.

Collaboration in Action: Partnering with Patients to Develop this Complex Care Research Agenda

Recognizing that meaningfully partnering with patients was a crucial step for developing this *Research Agenda*, CHCS and PFCCpartners recruited patient partners from across the country for this project. Initially, the project set a goal for creating a five-member Patient and Family Advisory Board (PFAB). However, when over 40 individuals applied, it became clear that more avenues for participation were needed. With guidance from PFCCpartners, CHCS expanded the PFAB to seven members and created the Patient and Family Research Community to provide an additional forum for feedback.



Both groups were engaged throughout the project, and involved in:

1. Co-designing project activities, workgroup meeting agendas, and objectives;
2. Implementing a collective vision for what should be included in the *Research Agenda*; and
3. Reviewing materials and drafts of the *Research Agenda*.

One of the first things the groups made clear was that they did not want to be tokenized or give their opinions in a “patient-only” way. Rather, they wanted to be integrated as equals in all discussions. To align with this value, PFAB and Research Community members were included alongside other project participants in every workgroup session. They were never asked to self-identify in discussions, they were mixed into group conversations with other health care organization partners as individuals with subject matter expertise, and credentials were not listed in meeting materials. Similarly, the CHCS team met with PFAB members monthly to get their feedback on each stage of the project and used this guidance to inform the Environmental Scan, the workgroup structures, and the *Research Agenda*.

The impact of this collaboration — on participating stakeholders and on the content of the *Research Agenda* — has been profound. There were clear examples throughout the workgroups where patients’ contributions shaped the research priorities identified by the workgroup. For example, following a panel discussion where PFAB members described the challenges they experienced navigating the health care system, the group came to consensus that “Coordination of Care and Systems” should be one of the prioritized measurement domains.

In follow-up interviews and surveys, health care representatives who participated in the workgroup shared that the collaboration helped them better understand the value of including patients in this type of work. Similarly, patient partners shared that participating in the project felt meaningful on many levels. As Lawrence Lincoln, one of the PFAB members said, “Being included in the process of developing this Research Agenda has, in and of itself, been an important factor in my ongoing care and development. Being a complex care recipient who is now able to contribute to making the systems more informed and effective is yet another example of a positive outcome of this model of complex care research.”

Source: Adapted from *Engaging People with Lived Expertise to Inform Complex Care Research*.¹⁶

Recommendations: Patient-Centered Research Priorities

Based on insights gathered from stakeholders described above, this *Research Agenda* outlines three main strategies to build the complex care evidence base in a patient-centered way:



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

By adopting these recommendations when designing future research studies, complex care research efforts can be more coordinated and help build a stronger evidence base. 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



RECOMMENDATION 1: KEY TAKEAWAYS

- 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 most to patients.
- Complex care needs to do a better job of partnering with patients and communities. It can do this by:
 1. Building more patient and community engagement skills, and
 2. Using patient-centered research skills, practices, and designs.
- Collaborating on research projects should be as easy for patient 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.
- Different ways of designing research can be used to better capture the full range of patients' experiences of complex care. Examples include qualitative research, longitudinal research, and community-based participatory research.
- Health care systems must be trustworthy partners to patients and communities. They should be clear about research goals and progress, share data and results, and approach research with the goal of developing long-term relationships.

The current complex care evidence base provides limited insight into who complex care works best for, what types of interventions are most impactful, and what settings and resources are needed to effectively carry it out. To answer these questions, more needs to be done to understand patients' experience of care. Including patients and communities as meaningful partners in all aspects of the research process is essential to accomplishing this. To do so, this *Research Agenda* suggests two areas for complex care to focus on: (1) **patient and community engagement strategies**; and (2) **patient-centered research skills, practices, and design**.

This section outlines practical strategies to engage patients and communities in research and opportunities to build new research skills, practices, and design to support patient involvement.



There are examples of patients and communities partnering in complex care research in meaningful ways. Community-based participatory research and participatory action research (PAR) for example, are well-established approaches to collaborative research that several complex care programs have used to inform their approach to care (see [Community Care of Brooklyn](#) case study on page 22). This type of meaningful collaboration, however, is not widespread. This may be due to several factors, including a lack of training or familiarity with how to partner with patients or use more patient-centered research designs. This also reflects a broader health care bias to see medical professionals as the experts at the top of the hierarchy, and patients as passive recipients, rather than individuals with their own valuable set of expertise.

Meaningfully involving patients and communities in research is important to ensuring that research reflects what matters most to them. This, in turn, would make research more applicable to the day-to-day experiences of individuals with complex health and social needs. This type of partnership would also be a key step to ensuring that health equity — and specifically as it relates to race and ethnicity — is more deliberately addressed in research. Partnering with patients and communities can also enhance understanding of what types of research questions to ask, what measures to use, and how to interpret and apply the results effectively.

Meaningfully partnering with patients and communities in complex care research would also create opportunities for more trusting relationships to grow between these groups and health care researchers. Many individuals with complex health and social needs have either had their own negative experiences with health care systems and health care research that have led to mistrust, or come from communities with historical experiences of research and health care abuse, discrimination, and mistreatment.^{17,18,19} Complex care's efforts to become more patient-centered must address these issues of mistrust. Forging meaningful relationships through research would be a major step toward doing so.

This type of collaboration would also benefit the field by allowing complex care stakeholders to grow new skill sets. Complex care professionals and researchers would have the opportunity to gain patient-centered research and relational skills. Similarly, patients and community members would have the opportunity to grow their own research and leadership skills, and further develop relationships with complex care partners.



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.

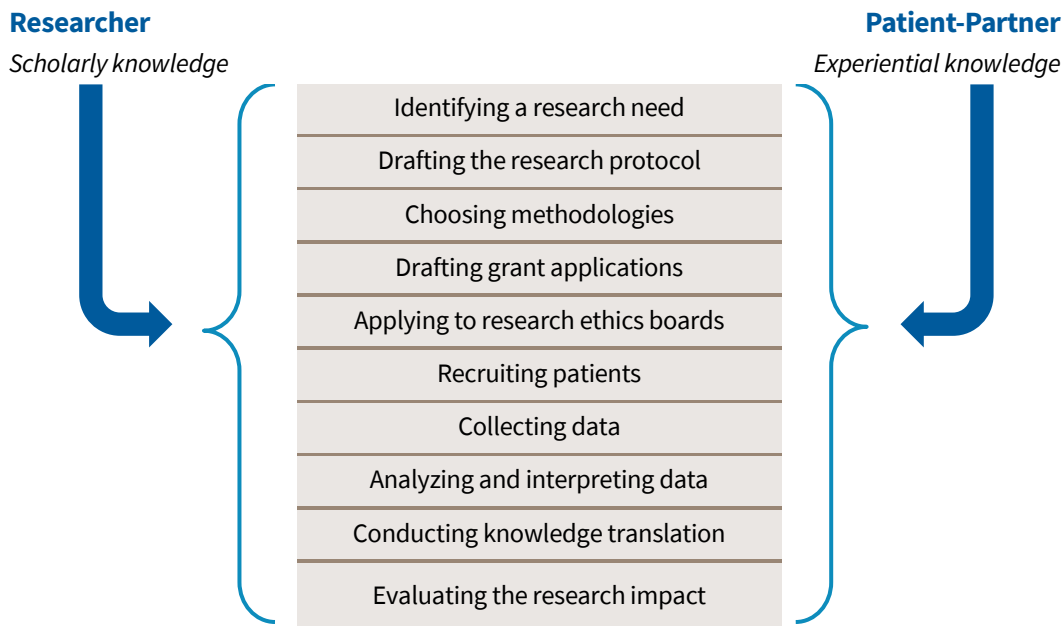
- Suzette Shaw, Patient and Family Advisory Board member

PATIENT AND COMMUNITY ENGAGEMENT STRATEGIES

There are a number of strategies to support meaningful research partnerships with patients and communities. Many of these fall broadly under “engagement strategies,” including:

- Collaborating with patients in all stages of research.** It is important to ensure that patient expertise informs the entire lifespan of a research project. **Exhibit 1** outlines opportunities across the research continuum for where patients’ perspectives can be useful to inform research.²⁰

Exhibit 1. Potential Researcher and Patient Partner Contributions to Research



Source: Adapted from *Patients as Research Partners: How to Value Their Perceptions, Contributions and Labor?*²¹

- Engaging patient partners in culturally competent ways.** In addition to developing flexible and tailored engagement approaches, it is important that research teams engage patient partners in ways that demonstrate understanding of and respect for the various cultures that they come from. Examples of this include ensuring that materials are translated into appropriate languages and hiring translators for meetings as needed, or understanding cultural practices or norms that may inform how certain health behaviors are perceived and discussed. These types of accommodations can benefit all research team stakeholders who come from culturally diverse perspectives, not just patient partners.
- Using trusted messengers and existing structures to support recruitment, engagement, and collaboration.** Care team members such as CHWs are connected to communities and are often trusted in ways that health care system representatives may not be. Including them on research teams can create upfront credibility and forge connections with patients and community members. Existing patient partnership structures with established relationships, such as Patient or Community Advisory Boards, could also be a useful source of patient research partnerships.

- **Co-designing research roles.** In pulling together a collaborative research effort, all stakeholders (not just patient and community partners) should share what skills, strengths, expertise, and interests they have, and how those can be best used throughout a project. Collaboratively designing research roles that put these skills to maximum use and support learning opportunities will foster buy-in, and help all partners better understand the perspectives they represent and the value they bring to the team.
- **Preparing and supporting patients to be successful partners.** Potential strategies include:
 - **Involving more than one patient partner on the research team.** This will ensure that a wider variety of patient perspectives are included, and reduce the burden on individual patients to be the sole representative with lived experience on the team.
 - **Holding orientation sessions for patient partners.** Sessions can help answer their questions and familiarize them with the work and their roles on the project, how their expertise will be used, and other team members involved.
 - **Creating background materials to help patients understand project details.** Materials should use plain and culturally appropriate language and, as necessary, be translated into different languages based on the composition of the community and patient participants.
 - **Checking in with patient partners regularly.** It is important to understand how the participation process is going for them, if they have any questions, or if anything needs to be changed to ensure that they can maximally contribute to the research process.
- **Using trauma-informed practices to engage and support patient partners.** Research team members should be aware of the impact of trauma on individuals and able to recognize its signs and symptoms. They should be equipped to incorporate this sensitivity into interactions to avoid retraumatizing patient partners.²²
- **Providing fair compensation for patients' time and expertise.** It is critical to compensate patient partners for their expertise. This compensation can take many forms, so it is important to have a flexible approach and upfront conversations with patient partners to understand their preferences. Financial compensation is an important way to honor expertise and should be considered for all research partnerships. Financial compensation may have implications, however, for benefits that are tied to income eligibility (e.g., Medicaid, SNAP, housing programs, etc.). In these circumstances, other types of compensation, such as providing access to trainings, inviting individuals to speak at conferences, or offering co-authorship may be of interest to patients.²³
- **Ensuring that research timelines accommodate patient partners.** Certain aspects of research projects can move quickly, and practices that may be normal in these settings, such as providing short lead times for reviewing materials, may create barriers for patients to fully participate. To ensure patient partner engagement, teams should consider scheduling meetings at a frequency and time that works for patient schedules, creating meeting agendas that allow adequate time for interaction, and sharing materials with sufficient advance notice.

- **Using a variety of engagement strategies to ensure access and participation.** Patients with complex health and social needs may have barriers to attending in-person meetings (i.e., jobs that do not permit them to participate during workday hours, lack of transportation or childcare), virtual meetings (i.e., lack of internet or computer access, unfamiliarity with technology platforms, etc.), or even conference calls (i.e., lack of phone access). It is important to design engagement strategies that can accommodate the circumstances and needs of patient partners. For example, patient partners may need or prefer to have materials mailed to them, and those who are unfamiliar with technology platforms such as Zoom may need training on how to use them.

Patients as Experts: Lessons from USC Street Medicine Trojan Trainer Program

The University of Southern California's (USC) Trojan Trainer program²⁴ offers an example of what respecting patient perspectives can look like in complex care, and the benefits for patients and health care professionals. The program builds physician assistant (PA) and medical students' skills by linking them with a mentor who has current lived experience with unsheltered homelessness. It is premised on the idea that students need to learn from experts, and patients have expertise that is highly valuable but not traditionally acknowledged in the medical setting. The year-long program changes the relationship between medical providers and patients by elevating patients' expertise to help transform how medical providers interact with and care for people with complex needs.

Through the program, teams of up to five medical and PA students are assigned to a "trainer" who is an individual experiencing unsheltered homelessness and a patient of the Keck School of Medicine of University of Southern California's Street Medicine Program.²⁵ Trainers meet with students as frequently as once a week and take students through their daily activities, providing context about their lives.

Trainers use their lived experience to: (1) teach medical providers how to be responsive to their needs; (2) improve patient-provider relationships by having providers "walk in the patient's shoes;" and (3) enable providers to learn first-hand the many challenges people with complex health and social needs face.



PATIENT-CENTERED RESEARCH SKILLS, PRACTICES, AND DESIGN

Meaningful patient and community collaboration will require complex care stakeholders to grow patient-centered research skills, implement more patient-centered research practices, and design research in new ways. Strategies include:

- **Building trustworthiness.** As previously referenced, patients and communities often lack trust in health care systems and researchers based on past experiences. To address this mistrust, health care and research stakeholders need to build their credibility. This can be accomplished by:

- **Ensuring that research teams reflect the communities and populations being studied.** In recent years and as part of a broader national conversation around diversity, equity, inclusion, and accessibility (DEIA) many health care institutions have prioritized developing a diverse workforce. These efforts should extend to research, as patient partners should not be the only members of a research team who reflect the racial, ethnic, cultural, or life experiences of the communities studied.

- **Providing upfront clarity about research efforts.** It is important to have clear conversations with communities and patient partners around research goals and explain how research will be conducted and how results will be used. Researchers should create clear expectations for patient and community involvement, including where and how they will be involved, how their feedback will be used, and how they will be kept informed of research efforts.

- **Sharing research findings with patients and communities.** Data should not just be available to researchers — it can also be a vital asset to communities. Data can provide new insights into community needs or trends and can inform community-led efforts to address these needs.

- **Building long-term relationships with communities.** It is not uncommon for researchers to “parachute” into communities to conduct research, and leave once the research efforts have concluded. This can leave communities feeling used and hesitant to participate in research efforts. Designing research efforts that prioritize developing and maintaining relationships with communities, and focus on developing community skills and capacity even after research studies have concluded are key to building institutions’ credibility.

- **Using research designs and methods that more fully capture the patient experience.**

There are a number of research approaches that have the potential to center patient experiences, including:

- **Qualitative research.** Unlike quantitative research, which focuses on numerical data, qualitative research collects non-numerical information from sources such as interviews and focus groups. Much of what complex care seeks to accomplish — for example, treating patients with dignity or making it easier to navigate health care systems — can be difficult to quantify.



Being included in this process has, in and of itself, been an important factor in my ongoing care and development. Being a complex care recipient who is now able to contribute to making the systems more informed and effective is yet another example of a positive outcome of this model of complex care research.

- Lawrence Lincoln, Patient and Family Advisory Board member

While quantitative research is critical to complex care research, conducting qualitative research will build a fuller, more nuanced understanding of how patients experience complex care.

- **Longitudinal research.** The challenges that many individuals with complex health and social needs face can be influenced by a variety of factors, including environment, past experiences of trauma, and systemic oppression. Addressing these factors within a short time frame may be unrealistic, and yet a typical complex care research time frame is 12 months or less. If patients need complex care supports for several years to stabilize to the point where their health improves, this lack of longitudinal research may be underestimating, among other things, the amount of savings the field is generating. Studies that have a longer time frame for assessing outcomes — ones that do so over years, rather than months — are rare but are likely necessary for truly understanding the impact of complex care.
- **Community based participatory research.** This is a collaborative approach to research that “equitably involves all partners in the research process and recognizes the unique strengths that each brings.”²⁶ Research topics are chosen for their importance to the community, community members are involved in all steps of the research process, and research is designed to produce actions to improve health outcomes.²⁷
- **Comparative effectiveness research.** This type of research compares the effectiveness of two or more interventions to better understand what approach(es) work best to meet a certain population’s needs. Given the wide variation in complex care programs across the country, this type of research design may be useful to identify which approaches are most effective for specific sub-populations.
- **Implementation evaluations.** Rather than evaluating outcomes, this type of research focuses on understanding how a program or intervention is implemented. This approach may be particularly useful for evaluating complex care programs that are in their early stages, where it may be unrealistic to see significant changes in patient outcomes. Focusing instead on understanding the implementation process — especially in programs that show success — can help the field better understand how to design effective complex care approaches.
- **Using research to study patient strengths.** Individuals with complex needs are often remarkably resilient and resourceful. Designing research that focuses on the strategies that patients use to address their challenges could help the field expand its sense of what impacts complex care has, better understand how patients define “success,” identify conditions or behaviors that contribute to this success, and shed light on how to modify care delivery to best support this population. Positive deviance research could be one method to support this. This approach recognizes that there are often individuals in at risk settings who have developed uncommon but beneficial practices and experience better outcomes than their peers. Positive deviance research seeks to understand what these behaviors are and why they are useful.²⁸

- **Taking complex care realities into consideration when designing and conducting research.** People with complex health and social needs are impacted by social determinants of health and experience high rates of trauma and health and racial inequities. Complex care recognizes that these forces can significantly influence individuals' health and their ability to manage it, and yet few of the field's research efforts to date have focused explicitly on these issues. Researchers themselves may not fully grasp how these forces play out in people's lives. For example, it can take a patient an entire day to get to a doctor's appointment using public transportation, or patients are often asked to repeat their stories over and over again with new providers, which can be retraumatizing. Designing studies that focus on the realities of patients' lives and are sensitive to patients' needs will help ensure that research is accurately studying patients' experiences. Designing research with this patient lens can also help patient partners and research participants feel more supported throughout the research process.
- **Making research more accessible by using plain language.** Research is often written in academic language that is difficult for patients and non-researchers to understand. Using plain language to explain research results will help ensure that a broader number of individuals can understand and engage with the research. For example, in addition to publishing research in academic journals, research teams can complement these efforts by also writing pieces that use a narrative or story-telling approach to explain results. This type of approach may appeal to other audiences as well, such as policymakers and funders, and is an example of the ways that patient-centered research practices can provide numerous benefits.

By focusing on engaging patients and communities in research, building health care partners' patient-centered skills, and designing research to better focus on patients' experiences, complex care research can take important strides toward building a more patient-centered complex care evidence base. These approaches will also support the development of a research workforce that is more familiar with patient-centered concepts, and provide a more trusting foundation for ongoing research collaboration with patients and communities.

Patient Engagement Resources

Following is a sampling of resources to support successful patient engagement and collaboration throughout the research process.

- **Building Effective Multi-Stakeholder Research Teams** – These resources from PCORI support multi-stakeholder research teams in working together more effectively.²⁹
- **Patient Engagement Toolkit** – This toolkit from Kaiser Permanente Center for Health Research supports researchers who want to engage with patients in conducting research.³⁰
- **GRID Toolkit** – This resource created by Tulane University School of Public Health and Tropical Medicine offers equity-centered and creative approaches for authentic engagement in research.³¹

Centering the Community: Community Care of Brooklyn’s Participatory Action Research Studies

Beginning in 2016, Community Care of Brooklyn (CCB) launched a series of PAR projects to address the health disparities in some of the most racially, ethnically, and socially diverse neighborhoods in Brooklyn, New York. To date, the initiative has completed three geographic community-based projects, as well as projects focused on COVID testing and vaccination, mental health awareness, and affordable, safe, and healthy housing. CCB, a coordinated care program led by Maimonides Medical Center and involving hundreds of community organizations and providers, used PAR to equitably involve relevant partners in identifying community challenges and developing solutions. These partners include local residents, community stakeholders — such as labor unions, community-based organizations, and elected officials — and researchers. CCB also selected a PAR approach because of its potential to develop leadership and research skills within participating members of the community.



Each of the projects trained youth and students from the community to lead research focused on how Brooklyn residents perceive their health, the health of their community, and what types of changes they believed would benefit their neighborhoods. The researchers used their knowledge as residents and/or students to conduct the initial inventory of community assets, challenges, and potential solutions. The community-based researchers generated the questions, administered surveys and conducted interviews, analyzed, and published the data. Each project published a report of recommendations for the community.³²

The three PAR community-based projects generated an understanding of how residents of defined Brooklyn neighborhoods perceive their own physical health and the health of their community. By recruiting over 150 high school, college, and graduate students, the PAR team focused on the importance of community organizing. As part of the community, the researchers were able to build trust with their subjects and received a higher than anticipated response. The resulting recommendations gathered include: (1) promoting racial equity and addressing structural racism; (2) advocating for the financial health of community-based organizations; (3) strengthening the civic infrastructure through joint planning; and (4) continuing to involve community members in ways exemplified in the PAR projects. PAR projects in Brooklyn have already led multi-sector partners across health and social systems to incorporate these recommendations in funding and policy decisions.

2. Focus on a Prioritized Set of Research Questions



RECOMMENDATION 2: KEY TAKEAWAYS

- The *Research Agenda* identifies five high-priority questions for complex care research to focus on to strengthen its impact and improve care:
 1. *What services and approaches are most effective for which patients and why?*
 2. *How can the different people and organizations that 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?*
- Coordinating research to focus on these questions will grow the evidence base in more patient-centered, and more comparable ways to get a more complete understanding of the impacts of complex care.

Currently, most complex care research is focused on answering questions related to how much money complex care saves, and how it changes health care utilization (most frequently, how emergency department visits and inpatient admissions either increase or decrease) 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. More needs to be done to answer these questions, and using a patient-centered lens is critical to doing so effectively.

The following section highlights research questions that were identified as “high priority” by the various stakeholders who helped develop this *Research Agenda*. The *Research Agenda* recommends that future complex care research efforts consistently focus on one or more of these questions to enable comparisons, build the evidence base in areas prioritized by patients, and allow the complex care field to get an accelerated, more nuanced, and more holistic understanding of its impacts.



HIGH-PRIORITY RESEARCH QUESTIONS

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

Complex care can look very different from one program or setting to another. This can make it hard to broadly apply complex care research results and understand what aspects are working and for whom. More research is needed to understand:

- *What are different groups of complex care patients?*
- *What types of services best support the needs of distinct groups?; and*
- *What factors contribute to these services being more or less effective for certain populations?*

Individuals with complex health and social needs are not all the same. For example, a middle-aged man who lives in a major city, is on 10 medications to manage conditions including diabetes and high blood pressure, and sees five providers for his health care has very different needs than a woman in her 20s who has relatively few physical health issues, but has schizophrenia, is an active substance user, is experiencing homelessness, and lives in a rural area with few behavioral health and housing services. To account for this diversity, a “one size fits all” approach to complex care is not feasible. Admirably, the field has prioritized ensuring that local settings and population needs influence how services are designed and offered. However, a more nuanced approach to research is needed to better understand who complex care can most effectively serve.

It is also important to explore what factors contribute to services being successful for certain populations. For example, an evaluation of the Camden Coalition’s care management intervention sparked important conversations about what impact complex care efforts can have in areas that lack community resources, such as housing, mental health services, and substance use treatment.^{33,34} Understanding these conditions is a key question for complex care to explore, as it may mean that certain types of interventions may be successful in some communities but not others.

Other factors that might affect complex care’s impact include health and racial inequities and experiences of trauma. Little research has been conducted that focuses on assessing how these factors contribute to complex care outcomes, but they are important to understand. Similarly, more research is needed to understand whether there are specific points in time for patients when certain services are most impactful. For example, do patients benefit more from care coordination services right after an inpatient admission? Would providing complex care services to someone who is socially isolated protect him or her from developing more complex health needs in the future? Does engaging someone into complex care at an earlier stage of illness help stabilize and empower them to have healthier lives in ways that providing services to those whose conditions are more advanced cannot?

Research should also include a focus on the impact that complex care has on family members, including the children of individuals with complex health and social needs, and caregivers. Patients do not exist in a vacuum. Their health and well-being impacts those around them, and can also affect the health and well-being of their family members (including their children) and caregivers. Providing complex care services to patients may have “spill over” benefits for these family members and

caregivers, and could be another way that complex care generates value. Broadening the question of who complex care affects to include family members and caregivers would allow the field to more fully assess this.

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

One of the defining features of complex care is that it aims to improve the coordination of care for individuals with complex health and social needs. Unsurprisingly, it can be challenging to coordinate across a wide range of partners — a frequent refrain in complex care is that patients often need someone to “coordinate the coordinators.” Duplicative, uncoordinated, and siloed efforts across the complex care ecosystem can lead to inefficient use of resources, and this issue is just as important to understand as gaps in care. Exploring how strong coordination occurs across all stakeholders involved in caring for patients can shed valuable light on how to effectively coordinate care.

Care coordination is needed across a wide range of stakeholders, each of whom bring their own unique set of coordination challenges. These include:

- **Patients, families, and caregivers.** Even though complex care is designed to serve individuals, patients are ironically often left out of many decision-making aspects of their own care. Many individuals with complex health and social needs also have involved family members and/or caregivers, who can similarly be sidelined. Coordination challenges within this group can be driven by a number of factors, including a lack of patient-centeredness on the part of care teams; barriers to accessing technology that facilitates communication (i.e., patient portals, telehealth platforms, etc.); lack of trust between patients and providers; and the complexity of managing multiple treatment recommendations across various provider relationships.
- **Providers and care team members.** It is not unusual for individuals with complex health and social needs to have several different medical and behavioral health providers and care team members (some or all of whom may work for different health care organizations) including multiple case managers. Because of this, care can often feel fragmented, with each point of contact only holding their own slice of patients’ stories, rather than the complete picture. As a result, patients can experience significant logistical burden when navigating their health care needs. For example, they may need to meticulously monitor and bring their medical information to appointments if providers do not have the most current information related to the patients’ care. Similarly, patients may need to repeat their stories over and over again to multiple providers (sometimes even within the same practice or system). This is not only frustrating and time-consuming, but can also cause emotional harm if patients are asked to repeatedly recount traumatic experiences.

Coordinating care at this level can further be complicated by the fact that health care systems use a wide range of information technology (IT) and electronic health record systems, and have numerous legal and technical barriers to sharing information. Data sharing is sometimes limited even within a health care organization, meaning that providers who work for the same

organization are not always guaranteed to have access to the same information. This adds another layer of difficulty for providers and other staff who ideally need to see the full picture of patients' health status and needs.

- **Community partners.** Many complex care efforts entail collaborations between health care and CBOs to effectively address patients' needs. These partnerships ensure that a broader range of health and social services are offered to patients, but coordinating across these organizations can be challenging. This is especially true around data sharing, as differences in IT systems and privacy issues create barriers to sharing patient data across partners (sometimes even for those working in the same health care system).

There are also cultural differences that can make it challenging for health care organizations and CBOs to coordinate care. This can include different approaches to providing team-based care, different levels of familiarity, level of comfort with and access to technology, and communication expectations, among others. An additional factor that contributes to care coordination dynamics is the financial relationship between health care organizations and CBOs. Historically, CBOs often receive little (if any) financial support for these types of partnerships. Efforts by Medicaid programs in New York, California, and Massachusetts point to a growing recognition that community partners must play a lead role in caring for patients and be compensated for this work, but the field is still in the early stages of determining how to make these partnerships financially equitable.^{35,36,37} Creating more formal and equitable financial relationships with CBOs will likely have important implications for coordination, and is worth studying further.

- **Cross-sector partners.** Individuals who experience complex health and social needs often touch multiple systems beyond health care. A 2017 study conducted by researchers in Hennepin County, Minnesota, explored how Medicaid expansion enrollees used public sector services including health care, housing, criminal justice, and human services. The results showed that nearly 80 percent of individuals received services in sectors beyond health care.³⁸

While this study looked at the Medicaid expansion population writ large, the subset of individuals who interface with multiple systems clearly have both health and social needs and represent the types of patients that complex care programs often strive to serve. The Hennepin study helps highlight why it is critical for complex care efforts to include collaboration and coordination with adjacent sectors such as housing, human/social services, and the criminal justice system.

Coordinating across sectors is challenging for many reasons. Funding can be a significant obstacle to cross-sector coordination, as systems often have little financial incentive to coordinate with each other. Similarly, privacy and/or data-sharing policies may constrain the degree to which entities can share or coordinate with each other.

Focusing research on better understanding the impact of this type of coordination and partnership, as well as how to build it, is key to ensuring that patients receive more seamless, less burdensome, and more effective care. It will also help ensure that resources across partners are used more efficiently and in ways that amplify each other's efforts, rather than duplicate them.

3. What is the role of a trauma-informed approach in complex care programs, and how can it be effectively implemented in complex care settings?

Over the past decade, the health care field has increasingly recognized how trauma can affect the health outcomes of all individuals, not just those with complex health and social needs. Not only does trauma contribute to individuals developing complex health and social needs, but for some individuals, past experiences of trauma can make them more vulnerable to experiencing future trauma. For example, there is evidence suggesting that women who experience homelessness are more likely to have experienced abuse in childhood than adult women who are stably housed.^{39,40,41,42}

In response, trauma-informed care (TIC) acknowledges the impact that trauma can have on individuals' health, behavior, and relationships, and incorporates this understanding into the way that health care systems are designed and how providers interface with patients. TIC seeks to:

- Realize the widespread impact of trauma and understand paths for recovery;
- Recognize the signs of symptoms of trauma in patients, families, and staff;
- Integrate knowledge about trauma into policies, procedures, and practices; and
- Actively avoid re-traumatization.⁴³

Providing trauma-informed care has become a core component of complex care given the high rates of trauma experienced by individuals with complex health and social needs.⁴⁴ TIC is designed to better support both patients and providers. A history of trauma can contribute to people feeling triggered and/or unsafe in certain environments, including health care settings, and sometimes lead them to behave in ways that traditionally have been deemed by health care professionals as “aggressive” or “non-compliant.” These types of interactions can be challenging and draining for health care providers, too. TIC offers an opportunity to improve these relationships and interactions, and thereby make the workplace less stressful.

While there is a growing body of evidence and research focused on the impact of trauma on individuals, more research is needed to understand how incorporating TIC into complex care affects patient outcomes and provider satisfaction. Similarly, from an implementation perspective, more research that explores how to best integrate TIC into complex care efforts would be useful. Because TIC is already considered a cornerstone of complex care, this research will help ensure that it is being included in complex care programs in the most impactful way possible.

What Is Trauma and How Does It Affect Health?

Trauma is caused by “exposure to an incident or series of events that are emotionally disturbing or threatening with lasting adverse effects on (an) individual’s functioning and mental, physical, social, emotional and/or spiritual well-being.”⁴⁵ Research such as the original CDC-Kaiser Permanente adverse childhood experiences (ACEs) study shows a clear connection between experiencing trauma and poor health outcomes later in life.^{46,47,48}



Experiences that may be traumatic include physical, sexual, and emotional abuse; childhood neglect; living with a family member with mental health or substance use disorder; sudden, unexplained separation from a loved one; poverty; racism, discrimination, and oppression; and/or violence in the community, war, or terrorism. Many individuals have traumatizing experiences with the health care system, or can have previous experiences of trauma triggered in health care settings.

While people of all backgrounds and ages experience trauma, rates are higher for certain populations, including those who identify as Black, Latino, or multiracial; people with less than a high-school education; people with low income or who are unemployed or unable to work; and people who identify as gay, lesbian, or bisexual. In short, people whose backgrounds or experiences are disproportionately represented within complex populations are more likely to experience trauma.⁴⁹ There is also increasing recognition of trauma caused by experiences of racism — either directly or through exposure to structural racism. This type of trauma can result from living in unsafe communities; having less access to high-quality food, education, housing, or health care; and limited economic opportunities.

Source: Adapted from the *Trauma Informed Care Implementation Resource Center*.⁵⁰

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

While it is important to understand which components of complex care contribute to success, it is equally important to explore what is missing from complex care that could make it more impactful for patients. Complex care programs often exist in resource-strapped settings, and have limited resources themselves. Many programs have become adept at maximizing available resources. While this approach is commendable, it also means that there may be key gaps in how services are designed or provided. These gaps affect all members of the care community, not just patients. Limited resources, for example, can affect providers and care team members by influencing things like caseload numbers, the amount of time they are able to spend with patients, whether they have access to relevant trainings, etc. This, in turn, impacts their well-being, affecting how well care team members can care for their patients and contributing to burnout. Gaps in services and resources can be due to a variety of factors, including:

- **Limited financing.** A lack of financial resources can force complex care programs to make difficult decisions about which types of services and resources are provided, and which are not.

- **Lack of community resources.** Complex care services are often offered in settings that lack the resources that many individuals with complex health and social needs require (e.g., behavioral health services, housing supports, etc.). This can limit programs' abilities to provide patients with the full range of necessary services and resources.
- **Policy constraints.** Like all health care interventions, complex care programs must operate within local, state, and federal policy environments. Complex care efforts that are tied to public benefits such as Medicaid can be limited by program guidelines (at both federal and state levels) around who can be served and the types of services that are permitted to be offered. Similarly, non-Medicaid expansion states may be more limited in terms of the types of complex care programs and services they are able to initiate or link to due to gaps in who is eligible for Medicaid.
- **Missing partnerships.** Because complex care serves individuals with both health and social needs, partnerships across both sectors are often a core part of complex care efforts. For example, health care-based complex care programs may partner with a number of CBOs (either formally or informally) to meet the social needs of patients. Community-led complex care efforts often involve strong partnerships with medical practices and systems. Gaps in services and resources may therefore reflect the need for these entities to forge more and/or new partnerships.

To ensure that research efforts are not limited to exploring solely what researchers think is missing, it is critical to partner with patients to understand their actual experiences of gaps in care. Comparative effectiveness research may be a useful framework to use with this question, since it is designed to identify differences between approaches and understand how these affect outcomes. Gaining a better understanding of what service gaps exist can help shed light on what components are needed for complex care to be impactful, and highlight where additional resources, partnerships, and investments are needed.

5. What impact does “setting” have on complex care efforts?

The setting in which complex care efforts take place can strongly influence what care looks like. It likely also influences how effective complex care efforts are, but little research to date has focused on exploring this aspect of complex care.

Within complex care, the term “setting” is used in a variety of ways, including:

- **The physical location where services are provided.** There is no one standard place where this occurs. Some complex care programs are run out of hospitals or clinics, while others are based in the community. Still others offer a combination of these locations. More research is needed to understand how these features impact patients. For example, how does setting affect how much or how little patients access and engage with services? Does receiving complex care services in the same location as medical providers and specialists make a meaningful difference in receiving necessary care? What effect does setting have on patients' overall level of comfort and emotional experience of care?

- **The geographic context of complex care efforts.** Complex care programs exist in a wide range of geographic settings, each with their own unique traits. Complex care programs based in urban areas are often (although not always) in communities that have more health and social safety net resources than those in more rural communities. Individuals in these settings often have more access to public transit, which can potentially help them access care. Complex care programs based in rural settings have unique assets, too, including the benefit of working with providers who are often deeply familiar with patients and who have established trusting relationships with them. Similarly, they may have more formal collaborations with civic and faith-based organizations that can play an important role in providing social and emotional supports.⁵¹ Gaining a more nuanced understanding of what aspects of setting influence outcomes can help the field better understand which pieces of complex care programs can be reproduced regardless of location, and which need to be customized based on geographic needs.
- **Community characteristics.** Another dimension of setting is related to the assets that communities have, and the forces that historically and currently may shape patient experiences. It is reasonable to expect that complex care programs based in environments where healthy food, affordable housing, and physical and behavioral health care are more readily available may be more successful than complex care programs based in locations where this is not the case, but few, if any studies, to date have explored this question. Social factors such as school quality, levels of community violence, or access to greenspace, may also have an influence on complex care outcomes. Relatedly, factors that contribute to racial and health inequities, such as redlining, mass incarceration, and disinvestment in public institutions, among others, should also be considered. Building more evidence in this area would allow the complex care field to better understand what types of supportive resources are necessary to best meet patients' needs, which could further guide decisions around partnerships, investments in new community resources, and who best to serve where.
- **Who is leading and/or paying for complex care efforts.** In this context, "setting" refers to where decision-making and financial power resides. Complex care programs can be led by a variety of entities, including health care institutions, CBOs, and health plans. Similarly, funding can come from a variety of sources, including through health care institutions; philanthropic grants; government sources; CBOs; payers (including Medicaid); or combinations of these. Funding sources can affect how complex care programs are structured, who is eligible to receive services, what types of services are offered, what types of data and technology are used to support efforts, what types of staff provide care, and how long programs exist, among others.

Focusing future research efforts on these prioritized questions will help the field build its understanding of how, why, and for whom complex care is effective. These questions are central to understanding what approaches are necessary to best support effective patient care and can help the field ensure that patients' perspectives guide how services are designed and delivered.

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



RECOMMENDATION 3: KEY TAKEAWAYS

- Expanding research to measure 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.
- The people involved in developing this Research Agenda identified five categories of measurement that complex care should use to more fully understand complex care's impact:
 1. *Patient-centeredness*
 2. *Racial and health equity*
 3. *Quality of life*
 4. *Coordination of care and systems*
 5. *Cost and utilization*
- More validated patient-centered measures are needed in complex care research, including in these categories.
- Developing and collecting data from these measurement categories will provide a more accurate picture of what is working and why.
- These categories of measures will provide a broader sense of the value that complex care offers to patients and other members of the care community, including family caregivers, and providers.

As previously noted, most complex care research has traditionally focused on understanding whether complex care reduces spending and avoidable health care utilization. While it is understandable that health care systems, payers, and policymakers are interested in the potential for complex care to save money, these outcomes are not what matter most to patients. The focus on cost and utilization is also driven by the fact that these data are the easiest to gather from existing datasets. There are significant gaps in other measurement areas, often making it difficult to easily assess more patient-centered measures. This lack of patient-centeredness in the way that complex care's impact is measured means that there are key gaps in the field's understanding of the type of value it is generating, particularly regarding what is important to patients.



To more accurately understand the impact of complex care efforts, the field must begin using a more patient-centered set of measures to assess outcomes. There have been important efforts to expand the way that complex care outcomes are measured, reflected in recent publications from the National Academy of Medicine; Institute for Healthcare Improvement; CHCS; National Quality Forum; National Committee for Quality Assurance; National Center for Complex Health and Social Needs and others in the field.^{52, 53,54,55,56}

Using more patient-centered outcomes will provide the field with important opportunities to redefine how value is discussed and include outcomes related to individual and community well-being, for example. It also offers an opportunity to study how complex care addresses racial and health disparities more explicitly, and explore how complex care affects providers' experience of work.

Each of the five measurement categories proposed in the *Research Agenda* has some degree of existing measures or tools that reflect their focus, but unlike cost and utilization, there are few validated measures to capture these concepts. Because of this, the field must invest in developing and testing patient-centered measures in these areas. Developing and using these measurement categories, also known as domains, provides an exciting opportunity to understand the impact of complex care more fully.



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

What is a Measurement Domain?

Measures are specific markers that researchers use to assess the impact of an intervention. For example, if a researcher wants to know if a program is helping patients better manage diabetes, they may use blood sugar levels (HbA1c) as a measure of whether patients' diabetes got better or worse over time.

Whereas measures are specific pieces of data, a **measurement domain** is a broad category of measurement. Within a measurement domain, there can be many different types of measures.

This *Research Agenda* focuses on proposed measurement domains as opposed to measures, in part because there are few validated measures that have been developed that specifically apply to the needs of individuals receiving complex care services.



RECOMMENDED MEASUREMENT DOMAINS

1. Patient-Centeredness

To build a field that is more patient-centered, complex care must do more to measure the concept of patient-centeredness. This domain encompasses the degree to which:

- Patients are included in the design of and decisions associated with their care.
- Patients' holistic needs, values, preferences, goals, and priorities are identified and addressed.
- Patient-reported outcome measures are used to assess health and functional status.
- Trauma-informed care principles are included in complex care efforts, including assessing for ACEs and appropriately incorporating results into care.
- Patients feel empowered, treated with dignity, listened to, etc.
- Patients have trust in their providers and care team.
- Patients experience “follow through” in their care.

Examples of Patient-Centeredness Measures

- **ACEs Questionnaire** tool assesses an adult population for childhood experiences of trauma.⁵⁷
- **Patient Activation Measure** is a quantifiable scale to determine how engaged patients are in their own care.⁵⁸
- **Patient Experience of Psychiatric Care as Measured by the Inpatient Consumer Survey** evaluates people's satisfaction with inpatient psychiatric care using factors that are important to the people who receive the care — for example, dignity, rights, and empowerment, among other factors.⁵⁹



Patient-Reported Outcome Measures

Within complex care, there is widespread agreement that the field needs to expand its definition of value beyond cost and utilization and include patient-centered measures that focus on quality of care and patient well-being. Patient-centered measures are not widely adopted, in part because few validated measures exist. To accelerate efforts to build the complex care evidence base and ensure patient-centeredness while doing so, complex care programs would benefit from adopting a standard set of core measures to assess their efforts.



Patient-Reported Outcome Measures (PROMS) are increasingly valued among health care providers and researchers. Using PROMS, individuals assess their own health care needs and sense of well-being with tools such as interviews, surveys, or other technologies to obtain this data. Unlike outcome measures that rely on objective data from tracking diagnostic testing, for example, patients might be asked to gauge their general health, ability to complete various activities, mood, level of fatigue, quality of sleep, and pain.

As the field considers the use of PROMs, it could draw on a number of resources, including:

- **Measuring What Matters Most to Older Adults** is a set of person-driven outcome measures developed by the National Committee for Quality Assurance (NCQA).⁶⁰ Between 2013-2020, NCQA and researchers developed and tested these quality outcome measures and learned that patients, providers, and caregivers found value in setting care planning goals and that the overall measurement approach was feasible to implement.
- **Person-Centered Implementation of Patient-Reported Outcome Measures in Complex Care Programs** is a report from the National Center for Complex Health and Social Needs that includes a summary of validated PROMs currently in use in complex care programs.⁶¹ These include the PHQ-9, Functional Mobility Assessment, PROMIS 29, among others.
- **The CDC's Healthy Days Measures** is a set of questions from the CDC that asks respondents about their physical health, mental health, and any limitations they have on daily activities including, self-care, work, or recreation.⁶²

2. Racial and Health Equity

Forces such as structural racism and discrimination dramatically affect the health of people of color and other marginalized groups — populations that disproportionately experience complex health and social needs.⁶³ Complex care programs often implicitly focus on addressing these equity issues as part of a holistic approach to care. As a next step, the complex care field must make this focus more explicit. This domain involves:

- Collecting, stratifying, and analyzing data by demographic factors.
- Measuring and analyzing how different, intersecting aspects of marginalized identity — e.g., race, ethnicity, gender, sexual orientation, socio-economic status, etc. — interact with each other to influence health outcomes.
- Including geographic and/or community-level data that provide additional insight into the historical and social forces of racism and inequity (e.g., home ownership rates, school quality and attendance, prevalence of grocery stores, crime levels, etc.) and their impact on outcomes.^{64,65}
- Measuring concepts such as the degree of cultural competency that providers and care team members have and their familiarity with/exposure to concepts such as DEIA, racial and health equity, and structural racism.
- Assessing the degree to which complex care team members reflect the racial, ethnic, and cultural makeup of the patient population and community, and using these data to guide improvements.
- Understanding patients' sense of whether they experience bias or discrimination in their care.

Example of Racial and Health Equity Measures

- The **National Committee for Quality Assurance** has begun requiring stratification by race and ethnicity in its health plan quality measure set, the Healthcare Effectiveness Data and Information Set (HEDIS), to hold plans accountable for addressing disparities in care and outcomes among patient populations.⁶⁶
- **Stress of Immigration Survey** (SOIS) is a screening tool used to assess immigration-related stress.⁶⁷



3. Quality of Life

Much of what complex care strives to achieve is rooted in improving the overall quality of individuals' lives. This can result in difficult-to-quantify outcomes such as reconnecting patients with family members, building patients' sense of self-efficacy, or reducing stress, for example. Capturing data on these types of outcomes would shed light on the more nuanced impacts of complex care programs for both patients and providers. This domain encompasses measures of:

- Well-being.
- Stability, such as housing, employment, sense of safety and security, etc.
- Impacts on caregivers and the families and children of complex care patients.
- Social connections and relationships.
- Access to health resources.
- Provider quality of life, such as levels of burnout, staff turnover, and job satisfaction.

Examples of Quality of Life Measures

- **Quality of Life Scale** is a tool for measuring quality of life across patient groups and cultures.⁶⁸
- **CAHPS Experience of Care and Health Outcomes Survey** asks health plan members about their experiences with behavioral health care and services.⁶⁹



4. Coordination of Care and Systems

One of complex care's main goals is to better coordinate care for patients across many providers and systems. Measuring this concept is vital for gaining a better understanding of where gaps exist and what work needs to be done to address them. This domain encompasses:

- Patients' experience of navigating systems of care.
- Appropriate sharing of care plans and related information with patients, families, and caregivers and across team members to support continuity of care.
- Care team and provider communication, including with social care providers and other sectors to address the full range of health and social needs.
- Trust among partnering organizations and feeling that they have what is needed to support effective coordination.
- Provider and systems' responsiveness, such as length of time to connect with a patient after an emergency department visit, wait times for behavioral health appointments, etc.
- Adequacy of IT systems and data-sharing policies.

Examples of Care and Systems Coordination Measures

- **Care Coordination Quality Measure for Primary Care** is a survey of adult patients' experiences with care coordination in primary care settings.⁷⁰
- **Consumer Assessment of Healthcare Providers and Systems** surveys assess patient experience with health care services delivered in different settings and for specific conditions.⁷¹



5. Cost and Utilization

Cost and utilization are the most commonly used measures to assess complex care's efficacy. While these measures do not provide a full picture of complex care's impact and should not be the *only* measures used in complex care research, they do offer value, particularly for interventions and programs that are well-established (as opposed to in their early stages). As a measurement domain, focus on these measures should be expanded to encompass:

- Traditional measures that ideally would decrease, such as emergency department visits, inpatient admissions and readmissions, length of stay, and total health care costs.
- Indicators that may reflect more improved care such as number of primary care and specialty care visits, mental health and/or substance use disorder treatment visits, etc.
- Costs and savings generated to sectors beyond health care, including jail systems, housing, children and family services, and other social services.
- Utilization related to health-related social needs (e.g., medical respite days, food bank visits, etc.).
- Costs to patients, including time, money, and tradeoffs (e.g., are patients paying for medical care instead of food, or missing health care appointments to retain their jobs?)?

Examples of Cost and Utilization Measures

- **Total Cost of Care Population-based PMPM Index.** The total cost of care is a measure of the total cost of treating a population over a set time frame expressed as a risk adjusted per member per month (PMPM).⁷²
- **Total Resource Use Population-based PMPM Index.** The total resource use measure is similar to the total cost of care measure except costs are replaced with a value that measures resource consumption.⁷³



The Path Forward: Implementing the Research Agenda

KEY TAKEAWAYS

- There are several ways that this Research Agenda’s recommendations can be acted on to move the complex care field forward, including:
 1. Designing future research with the recommended research questions, categories of measures, and engagement strategies in mind.
 2. Creating opportunities for different groups of people who are involved in complex care to learn from each other and collectively test new strategies.
 3. Developing a “Complex Care Practice-Based Research Network” to support coordinated research efforts and more quickly grow the evidence base.
 4. Defining complex care’s core research values and developing agreed-upon standards for what to measure to ensure a consistent approach across research efforts.
 5. Supporting patient-centered research approaches, such as community based participatory research or longitudinal studies.
 6. Understanding what has worked well in other fields, such as HIV and housing, and apply those lessons to complex care.
 7. Designing research to understand how what works well with complex care can support better care for all patients — not just those with complex health and social needs.

Collectively, the above research priorities provide a roadmap for the complex care field to conduct research and grow the evidence base in more patient-centered, impactful, and efficient ways. They speak to the opportunity for the field to: (1) partner with patients more meaningfully in all aspects of research; (2) build research skill sets to support this type of partnership; (3) ask questions that more fully explore the patient experience of care and factors that contribute to complex care’s impact; and (4) measure complex care outcomes to effectively capture the value to patients beyond financial benefits to the health care system. Advancing these priorities can and must be done in both individual and collective ways. Following are opportunities for the complex care field to advance patient-centered approaches to research as highlighted in this *Research Agenda*.



1. USE RECOMMENDATIONS TO INFORM NEW RESEARCH

At an individual level, researchers and organizations can advance the *Research Agenda's* priorities by including them in their research efforts moving forward. This includes focusing new research studies on one or more of the prioritized research questions included in this *Research Agenda*, and/or exploring outcomes drawing from the recommended measurement domains. Similarly, institutions that conduct research, such as academic medical centers, CBOs, or other types of health care organizations, should consider developing more patient engagement opportunities in research and training staff in patient-centered research skills. Doing so will create a shared foundation for research efforts and build the evidence base by allowing results to be more easily compared across studies.

2. ENGAGE IN COLLECTIVE LEARNING AND TESTING

To conduct more patient-centered research and grow the patient-centered evidence base, more opportunities are needed to support patients, communities, researchers, and health care partners in building the necessary skills and partnerships, and test out new approaches. Opportunities to advance these types of collective learning efforts could include:

- **A Complex Care Research Innovation Lab** for patients, researchers, and other partners to:
 - Build their patient-centered complex care research and collaboration skills through trainings, peer-to-peer discussions, and access to experts;
 - Receive technical support for designing and implementing patient-centered research through methods such as community-based participatory research, qualitative research, etc.;
 - Strengthen their abilities to translate research and evidence into practice in ways that support patients and communities; and
 - Test out models for multi-site studies to help the field understand what is needed to do collective, patient-centered research from an infrastructure and oversight perspective.
- **Complex Care Research Practicums** that offer trainings to cohorts of complex care stakeholders, and engage patient partners to co-develop and co-deliver the content. Topics could include:
 - Patient-centered research skills;
 - Incorporating a DEIA lens in research;
 - Implementing research findings; and
 - Using research to support communities.

3. DEVELOP A COMPLEX CARE PRACTICE-BASED RESEARCH NETWORK

There are numerous reasons why there have been few multi-site complex care research efforts to date. These include the wide variation in complex care programs and approaches, a lack of robust evaluation funding, and a lack of infrastructure to support data sharing and analysis. However, multi-site research efforts are a key strategy for quickly growing the evidence base. Addressing these challenges and supporting more and broader research coordination is essential to enacting this *Research Agenda*. To advance this goal, the field could explore developing a *Complex Care Practice-Based Research Network* (PBRN). A PBRN is a group of entities that collaborate to jointly research and

analyze shared research questions. There are numerous existing PBRNs, including ones focused on primary care and oral health.^{74,75} Developing a PBRN focused on complex care would create an opportunity for stakeholders from around the country to partner on specific research questions, share data, work with data experts to analyze their findings, and collectively explore how to put findings into practice. This type of approach would provide complex care with a valuable way to rapidly build the evidence base, but also requires intensive infrastructure and would likely be a longer-term endeavor. To develop a PBRN, stakeholders could begin with a concrete exploration of what would be needed to develop a collaborative research network, and then pilot the model with a small number of sites.

A Complex Care PBRN: Implementation Considerations and Opportunities

A Complex Care PBRN would bring together entities to jointly research and analyze shared research questions pertinent to improving complex care. The key components of a PBRN include:⁷⁶

- Common aim to improve care;
- National research efforts across multiple sites;
- Sites that identify, test, and adopt best practices;
- Shared valid, high-quality, real-time data;
- The ability and infrastructure to make real-time improvements; and
- Public sharing of outcomes to disseminate best practices.



While PBRNs hold exciting promise to accelerate complex care research efforts, in order to implement this approach the field would need to consider how to:

- Develop sufficient infrastructure support to effectively stand up PBRNs broadly;
- Foster partnerships among organizations to coordinate research activities and secure funding;
- Address varied technology capabilities across complex care programs and practices;
- Develop payment models to support building and sustaining the infrastructure; and
- Harness the skills, competencies, and capacities within complex care programs to support practices that perform research and collect and share data.

PBRNs can serve as a valuable tool to advance health equity. Gathering data from diverse communities of patients across the country can uncover opportunities to address equity by identifying disparities among a range of clinical practice settings.⁷⁷ Following are key opportunities for PBRNs to address health equity:

- Through direct relationships with practices that serve diverse communities, PBRNs provide an opportunity to investigate the impacts of race, ethnicity, and social determinants on health.
- PBRNs can serve as a laboratory for studying interventions to address health equity issues, particularly those that are well suited to delivery in primary care settings.
- Because of the real-time nature of PBRNs, practices can notify researchers regarding important health equity issues. The real-time data is an opportunity to investigate and confirm health equity concerns.⁷⁸

PBRNs are a promising approach because they go beyond a single research project to capture what works in actual clinical settings. Complex care programs could benefit from this type of coordinated, real-time learning structure.

4. DEVELOP A CORE SET OF COMPLEX CARE STANDARDS AND MEASURES

To collectively move forward with patient-centered research efforts, the field would benefit from developing agreed-upon standards to support consistency and comparability across complex care research efforts. As next steps, this *Research Agenda* recommends:

- **Collectively defining and codifying complex care’s core research values.** Reorienting complex care research so that it embodies patient-centered principles will require commitment and diligence. Using this *Research Agenda* as a starting point, the field would benefit from creating an agreed-upon set of core research values that explicitly address how, for example: (1) patients and communities should be engaged and supported; (2) the goals that complex care research should seek to achieve; and (3) the ethical standards that complex care holds itself to. Developing these standards with patient-centeredness in mind would provide a valuable “North Star” for the field, grounding it in patient-centered values, and helping hold itself accountable to them.
- **Creating, testing, and adopting a “core set” of complex care measures.** As previously mentioned, one of the main barriers to measuring outcomes in more patient-centered ways is the lack of validated patient-centered measures and tools. A collective effort to address these gaps is key to ensuring successful patient-centered complex care research. Developing a recommended core set of complex care measures that includes a focus on patient-centeredness would provide stakeholders with a standardized framework for research efforts to draw on when designing studies, and would accelerate the development of the evidence base by growing it, at a minimum, on a specific set of prioritized measures. This work could involve collaborations with measurement organizations such as the National Quality Forum; federal entities such as the Centers for Medicare & Medicaid Services; and philanthropic partners interested in complex care, research, and/or patient-centered approaches to care.

5. SUPPORT PATIENT-CENTERED RESEARCH

Robust research efforts can require intensive investments of time and resources. To advance the field as proposed in this *Research Agenda*, more investment is needed, including by policymakers, payers, health system leaders and the philanthropic community. From a financial perspective, it will be imperative to fund more patient-centered complex care research and for health care systems to invest in further developing their staff’s patient engagement and research skills. These investments will be key to growing support to pursue different types of research than have been prioritized to date (e.g., qualitative research, community-based participatory research, longitudinal studies, etc.), and legitimizing the value that these different approaches and data have.

6. EXPLORE AND APPLY THE EXISTING EVIDENCE BASE

One of the most immediate opportunities for complex care to ground its practices in proven approaches is by better understanding the existing evidence base in overlapping, adjacent, or relevant areas. For example, there is a large body of evidence related to CHWs and the Housing First approach (an approach that prioritizes giving people experiencing homelessness permanent shelter with no

prerequisites such as sobriety or participating in substance use treatment).^{79,80} Similarly, the field of HIV has fine-tuned its care management model over the last few decades, and works with many of the same patients and challenges as complex care. A coordinated exploration of existing evidence that could be applied to complex care would be a valuable step and allow complex care stakeholders to draw from an evidence-based playbook, rather than reinventing the wheel.

7. DESIGN AND APPLY RESEARCH WITH HEALTH CARE TRANSFORMATION IN MIND

While complex care has many unique aspects to it, many of the challenges it seeks to address are applicable to broader populations. So, too, are the values it advances. There are many people who do not meet this *Research Agenda's* definition of “complex populations,” but who nevertheless have complicated experiences navigating the health care system, do not receive patient-centered care, and have their health care impacted by their social circumstances. Complex care, therefore, has a valuable opportunity to use its insights to inform larger efforts to improve health care. Because of this, complex care research efforts should identify opportunities to yield generalizable insights about what comprehensive and effective patient care for all individuals should look like, and generate results that support broader health care transformation efforts.

Conclusion

The field of complex care has seen exciting growth over the past decade, and is recognized as a valuable resource to support people with an array of complex health and social needs. As with any reputable field, complex care needs high quality evidence to inform its efforts and justify ongoing investments in the work. More high-quality research and evidence is needed to help complex care stakeholders understand how best to meet the needs of patients. The field has a unique opportunity to commit to building this evidence base in a patient-centered way. This will expand the dialogue regarding complex care's value beyond the ways in which it reduces avoidable costs and utilization, and scientifically ground it in a more holistic way that also includes what matters most to patients and communities. This *Patient-Centered Complex Care Research Agenda* outlines a series of recommendations, including collaboration skills and strategies, research questions, and measurement domains, to support the field in accomplishing this goal. Stakeholders in the field can use this guide in a variety of ways to advance the quality and value of complex care research. In particular, 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 research partners** in designing research to focus on patient priorities and experiences, and including patients as research partners; and
- **Support patients** in recognizing how their expertise can be used to strengthen complex care research efforts.

By collectively focusing on these strategies 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.

Glossary

This glossary contains definitions of terms that are used in this *Research Agenda* and that may not be familiar to all readers.

Core competencies, or core abilities, refer to the knowledge, skills, and attitudes that members of teams or individual providers need when working with people with complex needs.⁸¹

Cultural competency is the ability to understand, appreciate and respectfully interact with people from cultures or belief systems different from one's own

Disinvestment is purposeful withdrawal of investment from communities, meaning developers and builders no longer spend their money to improve neighborhoods, businesses, or shared spaces in the community.

Diversity, Equity, Inclusion and Accessibility (DEIA) refers to four concepts that are key to engaging and supporting individuals from diverse background in all aspects of health care, as follows:

- **Diversity** is the practice of including a broad range of communities, identities, races, ethnicities, backgrounds, abilities, cultures, and beliefs.
- **Equity** is the consistent and systematic, fair, just and impartial treatment of all individuals.
- **Inclusion** is the recognition, appreciation and use of the talents and skills of individuals of all backgrounds.
- **Accessibility** is the practice of designing all aspects of programs, services, and care so that all people, including those with disabilities, can fully and independently use them.⁸²

Health plans are organizations that provide insurance or health care coverage to individuals. Other terms that are used to describe these organizations include “managed care organizations,” or “managed care plans.”

Inpatient admissions refer to patient stays in a hospital. A patient is classified as inpatient as soon as they are formally admitted into the hospital. This occurs when physicians determine that more care is needed than could be provided in an outpatient setting (the emergency room or primary care, for example.) These visits can last for several days and are typically costly.

Outcomes refer to how an intervention affected the patient; outcomes can be positive, negative, or neutral.

Patient-centered (also referred to “person-centered”) refers to approaches that organize care first and foremost around the individual’s specific health needs and wishes. These drive how health care decisions are made and how quality is measured. Patients are partners with their health care providers, and providers treat patients not only from a clinical perspective, but also from an emotional, mental, spiritual, social, and financial perspective.⁸³

Patient partner refers to patients who are actively collaborating with health care systems, research teams, or others on complex care research efforts.

Payers are organizations in the health care industry — such as health plans, Medicare, and Medicaid — that set the prices for service, collect payments, process invoices (referred to as claims in health care), and pay health care providers.

Redlining is a discriminatory practice in which services are withheld from potential customers who live in neighborhoods classified as 'hazardous' to investment. Traditionally, the practice has been used in neighborhoods that have significant numbers of racial and ethnic minorities, and low-income residents. An example of redlining is when banks do not provide mortgages to individuals because of the type of neighborhood they live in. The practice can perpetuate the challenges facing these neighborhoods, contributing to a cycle of disinvestment and poverty.

Scale refers to taking a successful practice (in this context, an intervention or program) and expanding it so that it can reach more people.

Structural racism is a form of racism that is embedded in the laws and regulations of a society or an organization. It can be seen in areas such as criminal justice, employment, housing, health care, education, and political representation. Also known as institutional racism or systemic racism.

Stratify is to arrange or classify. In the health care context, it refers to the practice of identifying particular groups of patients.

Trauma-informed care shifts the focus from “*What’s wrong with you?*” to “*What happened to you?*” A trauma-informed approach to care acknowledges that health care organizations and care teams need to have a complete picture of a patient’s life situation — past and present — to provide effective health care services with a healing orientation.

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