

Developing a *Patient-Centered Complex Care Research Agenda:* Environmental Scan

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Center for Health Care Strategies

Contents

Environmental Scan Overview	2
Environmental Scan Findings	3
Population	3
Intervention.....	5
Comparator	7
Outcomes	9
Timing.....	11
Setting	12
Supporting Patient Engagement in Research	14
Research Design Considerations	17
Considerations for Enacting a Research Agenda	18
Conclusion	20
Appendix. Key Informant Interviewees	20

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Environmental Scan Overview

With funding from the Patient-Centered Outcomes Research Institute (PCORI), the Center for Health Care Strategies (CHCS) led the development of a *Patient-Centered Complex Care Research Agenda*. This project was motivated by the desire to spur more rigorous research and evaluation efforts in complex care, recognizing that its currently limited evidence base and wide programmatic variation have made it difficult to determine what aspects of complex care are most effective and for whom. 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 the amount of money saved through reductions in health care services and not by what matters most to patients. There is much more for complex care to learn about who it helps, why it is helpful, what kind of value it generates, and what it should look like to best support patients' needs and goals.

The *Research Agenda* aims to:

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

As a first step in developing this *Research Agenda*, CHCS conducted an environmental scan including: (1) interviews with various complex care stakeholders; and (2) a literature review to assess the current state of complex care research and identify gaps and opportunities. CHCS interviewed 20 individuals who bring their own perspectives on complex care, including people with lived expertise of complex care, researchers, providers, and organizational leaders (see [Appendix](#) for list of interviewees). In addition, CHCS reviewed more than 40 resources, including peer-reviewed journal articles, reports, thought pieces, and other non-peer reviewed literature.

Applying the PICOTS Research Framework

CHCS used the PICOTS research framework to organize the scan. This framework helps researchers clearly define a research question using the following domains:¹

- **Population** that is studied;
- **Intervention** that is delivered to some patients;
- **Comparator** [intervention] that other patients receive;
- Important patient **Outcomes** that are assessed;
- **Timing** of when outcomes are assessed; and
- Clinical **Setting**.

PICOTS Framework

- P** - Who is studied?
- I** - What is studied?
- C** - What did others receive?
- O** - What happens afterwards?
- T** - When?
- S** - Where?

This framework allowed us to take a more refined look at where research challenges and opportunities exist in the field. These areas frequently overlap (e.g., population could drive which intervention to use), so many findings can apply to multiple areas.

This report summarizes what CHCS learned from the interviews and the literature review. It describes key takeaways and potential research opportunities for each of the PICOTS domains. This scan informed subsequent *Research Agenda* activities and helped CHCS and its partners develop the *Research Agenda*.

Environmental Scan Findings

Population

There is no standard definition of a complex care population. Terms such as “high-need patients,” “high utilizers,” and “people with complex health and social needs” are used throughout the field, but there is wide variation in what they mean. This section explores considerations for defining the complex care population and potential research approaches that could help refine who complex care efforts should focus on.

KEY TAKEAWAYS

- **We refer to the complex care population as if it’s a single group of people who all share the same characteristics, but it’s not.** It’s a set of populations with different needs and experiences in the health care and social service systems.
- **We need a better way to identify complex care populations and what interventions work for whom.** We have some sense of existing subgroups and well-established interventions for these subgroups that are valuable to build on, but the current approach to defining complex populations is too varied and inconsistently applied.
- **It is difficult to disconnect the way we define populations from available data sources and interventions.** Population is a more subjective and fluid concept than we often conceive of it. The population studied is often connected to prior research and therefore is researched again, with a different intervention.
- **There has been progress in identifying and segmenting individuals with complex health and social needs.** The National Academy of Medicine (NAM), for example, conducted a meta-analysis and created a “starter taxonomy” that is used to guide health systems and payers as they integrate medical, behavioral, and social risk factors to classify patients with complex health and social needs.²
- **Valuable work has been done in other fields (e.g., behavioral health, HIV care) to define relevant subpopulations and understand their needs.** Many of these populations have complex health and social needs. Thus, it would be valuable to understand and translate how research from other fields can inform complex care design and implementation efforts.
- **Complex care research should increase its focus on understanding the impact of trauma on people with complex health and social needs.** So much of the complexity we see results from adverse childhood experiences, traumatic experiences throughout one’s lifetime, and intergenerational trauma.³ The complex care field currently does not adequately account for this when understanding who complex populations are or what is driving their needs.

RESEARCH OPPORTUNITIES

Drawing from CHCS' interviews and literature review, research opportunities to better understand who people with complex health and social needs are include:

1. Defining Complex Populations

A 2021 study found wide variations in approaches to defining complex populations. The authors identified six broad domains of population criteria used to identify individuals with complex needs, including:⁴

- Age
- Income
- Health care costs
- Health care utilization
- Health conditions
- Additional subjective criteria such as referrals or screening results

The authors found that criteria from multiple domains were frequently used in combination, and exact specifications were highly variable within each domain. Overall, 90 population definitions were identified, 83 percent include at least one cost- or utilization-based criterion. This study underscores a few central challenges, namely that: (1) there is a lack of clarity and standardization when defining complex populations; and (2) the field over-relies on terms like “high-cost” or “high utilizers” to define complex populations.

The 2017 NAM publication, *Effective Care for High-Need Patients: Opportunities for Improving Outcomes, Value, and Health*, details four key areas to guide effective care: (1) define key characteristics of high-need patients; (2) use a patient categorization scheme — or a taxonomy — to tailor care; (3) deploy promising care models and attributes to better serve this specific patient population; and (4) seek policy-level action to support the spread and scale of evidence-based programs.⁵ A taxonomy that separates a health system's population based on the care they need and the frequency they need it can help determine how to effectively care for that population. Both the literature review and the findings from CHCS' key informant interviews highlighted the need for uniformity in definitions and called for consistency in whom the term “complex care populations” refers to.

2. Understanding How Patients Define Themselves

There is little in the published literature on how patients would define themselves, nor have there been documented complex care research studies that involve patients in research design and implementation in a meaningful way. As Califia Abwoon, case management specialist at Behavioral Health Services in Los Angeles, California noted, “Whenever you come in contact with the client, you need to envision that client as your mother, your brother, your sister, your aunt, your uncle – you need to sit up there, and establish that kind of mindset.”⁶ A patient-centered care model might prioritize social needs over cost or utilization measures or define complex populations in novel ways. The complex care field can benefit by listening to patient experiences and stories about defining complex populations.

3. Addressing Bias in Population Identification Approaches

Communities of color are disproportionately impacted by poverty and social determinants of health due to forces such as structural racism, often resulting in a higher level of complex care needs.⁷ At the same time, some data methods that are routinely used by health systems to identify populations to improve care may perpetuate racial bias.⁸ For example, researchers recently found racial bias in a commonly used data algorithm that assigned Black patients the same level of risk as white patients — when in fact they were sicker than white patients. According to

the authors of this study, “This...bias occurs because the algorithm uses health costs as a proxy for health needs. Less money is spent on Black patients who have the same level of need, and the algorithm thus falsely concludes that Black patients are healthier than equally sick white patients.”⁹ As the field strives to better understand which populations are best served through complex care efforts, it will need to ensure that it is addressing this type of bias within research efforts.

4. Exploring Responders vs Non-Responders

Interviewee Rishi Manchanda, president and CEO at HealthBegins, noted that another potential way to categorize complex populations is to focus research on identifying “responders” and “non-responders” to specific interventions.¹⁰ Exploring a “responder” vs. “non-responder” framework could help gather evidence on what interventions are effective for whom, and provide a roadmap to refine the intervention for the “non-responders.” This framework goes beyond simply publishing what worked and what did not work for a given population, but rather offers insight into what changes might improve intervention effectiveness for specific population subsets.

Intervention

The field of complex care currently uses an array of interventions, most of which are anchored in care management and care coordination. However, there is little standardization among these interventions, making it difficult to understand what features are most effective. The Better Care Playbook¹¹ is a resource center that curates research on complex care interventions, but more needs to be done to build the evidence base in this area.

KEY TAKEAWAYS

- **There is not a standardized set of interventions that comprise complex care.** Interviewees consistently noted that they could not easily identify what intervention worked for whom. While there are some care models that show promise (as reported in the NAM publication and through the growing evidence base documented on the Better Care Playbook), the field could consider coalescing around promising care models and codifying the set of interventions that should be implemented for specific subpopulations.
- **External forces such as payment sources, health care infrastructure, and available community resources can drive which interventions are used, rather than patient need.** This adds to the lack of standardization across interventions since they are driven by a diverse set of external circumstances.
- **Patient-centered perspectives are often missing from intervention design and implementation.** Patient feedback is not routinely considered in research design, implementation, or administration of programs. The complex care field needs to transform research design so that not only is it patient-centered and driven by what patients value, but that patients are involved and inform the research design.
- **Interventions are continuously being reassessed and tweaked toward the goal of quality improvement, which complicates evaluation.** In striving to meet patients’ needs, complex care programs are frequently modifying interventions to improve services for patients. These adjustments may not adhere to strict research protocols, which can create challenges for research studies.

Refining the Field: Lessons from Complex Care Randomized Control Trials

In a 2020 study, the Camden Coalition evaluated its signature case management intervention, the Camden Core Model.¹² From 2014-2017, the Camden Coalition partnered with researchers affiliated with Massachusetts Institute of Technology's Abdul Latif Jameel Poverty Action Lab North America (J-PAL) to conduct a randomized controlled trial (RCT) to evaluate how Camden's approach affects patient hospital readmissions. The study found no difference between the treatment and control groups on hospital readmissions within 180 days. It did, however, find a statistically significant rise in the number of participants receiving food assistance (SNAP benefits).¹³

Interviewees consistently noted that 180 days was an insufficient timeframe for assessing outcomes, especially for such a complex and under-resourced patient population. Further, interviewees noted that the measure (hospital readmissions) had significant limitations given the complexity of the population of focus.

On the other hand, a randomized quality improvement trial conducted at CareMore Health in Memphis, Tennessee, published in 2020, found that its complex care management intervention reduced total medical expenditures by 37 percent and inpatient utilization by 59 percent.¹⁴

As CHCS noted in a blog post reflecting on these results, "Taken together, these studies underscore the imprecision of the term 'complex care,' and the compelling need for the field to sharpen everything from its language to its identification algorithms, intervention approaches, and measurement strategies."¹⁵

RESEARCH OPPORTUNITIES

Drawing from CHCS' interviews and literature review, opportunities to use research to develop more effective interventions for people with complex health and social needs include:

1. *Drawing on Existing Evidence*

There is growing interest from researchers and providers about the need to adapt evidence-based interventions to specific clinical environments. Some relevant interventions with evidence behind them include Housing First and community health worker (CHW) models. Housing First¹⁶ has become a widely considered best practice intervention for people who are experiencing homelessness. According to the Alliance to End Homelessness, Housing First interventions prioritize people obtaining housing before pursuing other goals. This model has a strong research base and shows promise as the intervention that best addresses homelessness.¹⁷

CHW interventions are another promising care model. There is increasing evidence that CHWs play a key role in improving patient self-management of chronic diseases, leading to better patient engagement and health outcomes.^{18,19} But even an evidence-based approach may require adaptation to ensure effectiveness in a new setting. One interviewee, James Schuster, chief medical officer at UPMC Health Plan, shared that when UPMC integrated CHWs in modest size primary care practice (PCP) settings, the CHWs had difficulty engaging with the PCP teams.²⁰ This highlights the need to learn from the evidence base, while making changes as necessary to ensure effectiveness in particular settings.

2. Addressing the Upstream Dilemma

Many interviewees emphasized the need for complex care to focus on upstream interventions that address root causes and attempt to prevent complex health and/or social needs from developing. As Allison Hamblin, CHCS CEO and president, and Kedar Mate, Institute for Healthcare Improvement (IHI) CEO and president, noted in a 2021 *Health Affairs* blog post, “The best way to avoid the need for complex care down the road is to start identifying risk and building resilience through investments in early childhood. This shift begins with increased understanding across health care of the impacts of adverse childhood experiences and a move to embrace family-centered and multigenerational approaches to care.”²¹

There are significant efforts underway to address structural root causes of poor health upstream, including through community-level interventions.²² At the same time, the complex care field is grappling with how far upstream to shift its focus, as well as the type and timing of interventions that are most useful to long-term health and well-being.

3. Spreading and Scaling interventions

Another area for consideration is scalability of interventions that are demonstrated to be effective and sustainable. Researchers can help the field better understand which interventions should be scaled and spread, and what community characteristics may be important to understand when attempting to do so. As measurement expert Ellen Shultz noted, “Context is key: programs and services should be tailored to communities and therefore can't be plug and play.”²³

4. Improving Technology Infrastructure

Many interviewees noted that weak technology infrastructure, a lack of interoperability, wide variation in program design, and inconsistent measures make it difficult to collect data at a large scale and across systems to get a holistic sense of the impact of an intervention. This contributes to the gaps in the evidence base on what interventions work and for whom. Addressing these challenges would improve the quality of data used in research, and help build a more robust evidence base

Comparator

Within the PICOTS framework, the use of a comparator establishes the baseline against which a given intervention will be assessed. This section explores common comparators in complex care research and discusses the opportunities for comparative effectiveness research (CER) – a research methodology that is well-suited to assess the impact of different approaches to care – to serve as a useful framework for complex care.

KEY TAKEAWAYS

- **More work needs to be done to determine appropriate comparators.** Oftentimes “usual care” is used as the comparator, but that is not necessarily ideal given the complexity of this population. Using alternative complex care interventions as comparators may be more appropriate and beneficial.

Comparative Effectiveness Research

According to the Institute of Medicine, CER is “an approach that compares the benefits and harms of alternative methods to prevent, diagnose, treat and monitor a clinical condition or to improve the delivery or care... It should be conducted using ‘real world’ patients so that results are readily generalizable across populations.”²⁴

- **Randomized controlled trials are the gold standard from a methodological perspective, but can be difficult to fund, implement, and sustain in the complex care field.** While these controlled studies have a rightful place in research, including in evaluating complex care programs, many interviewees noted that they are not an ideal mechanism for evaluating the effectiveness of complex care interventions because they require a highly controlled environment.
- **Given the variation across the field, CER is a valuable framework to build the evidence base.** CER involves comparing two (or more) interventions in clinical practice. This distinguishes CER from other types of clinical research because it can validate a particular intervention and then identify which treatments best meet a certain population’s needs. This may be a particularly ideal research approach to enact a complex care research agenda given the wide variation in programs across the country.

Many interviewees suggested CER will be an important research framework for a complex care research agenda because it supports comparisons of approaches across settings by more transparently identifying population subsets served and specific interventions employed.

RESEARCH OPPORTUNITIES

Drawing from CHCS’ interviews and literature review, following are opportunities to support CER to improve care delivery for people with complex health and social needs:

1. Consider Emerging Evidence

Across the field, researchers are focusing on CER. A team at UPMC is completing a PCORI funded evaluation of a study that compares high-touch, high-tech, and usual care approaches for people with multiple chronic conditions. This study is examining: (1) primary outcomes including patient activation, health status, hospital readmissions; and (2) secondary outcomes including functional status, quality of life, care satisfaction, emergent care, engagement in primary care, and gaps in care.²⁵ These outcome measures reflect a wide range of factors that include patient perspectives, and do not solely focus on cost and utilization measures. This study is an example of the kind of CER that the field of complex care could further explore.

2. Center Patients in CER

Complex care research provides opportunities to include the patient voice, but it is not consistently incorporated. The PCORI Engagement Rubric: Promising Practices for Partnering in Research lays out a framework for centering the patient experience in CER studies through three stages:

- Planning the study;
- Conducting the study; and
- Disseminating the study results.²⁶

For each of these stages, the PCORI rubric outlines suggestions for meaningful patient involvement and patient-researcher partnerships. Such a framework can help move complex care into incorporating patient-centeredness in CER activities.

Outcomes

One way to think about outcomes from the PICOTS perspective is to ask what the desired or expected outcome or objective is of an intervention. In the complex care field, there has been an overreliance on cost and utilization measures to show cost savings as outcomes. This is partly because these measures are often the most readily available data, but also because payers and health systems have traditionally viewed complex care programs as a key area of opportunity to control costs. This section summarizes the concerns with this approach, as well as the broad interest in expanding to include more patient-centered outcome measures.

KEY TAKEAWAYS

- **More patient-centered measures are needed to capture well-being, quality of life, trusting relationships, and experience of dignity.** There is widespread agreement that patient-centered research measures are crucial to understanding the impact of complex care efforts. Several good sources to consider drawing on for this include the National Center's Patient Reported Outcome Measures (PROMs) report, Full Frame Initiative's Five Domains of Wellbeing, Well-Being in the Nation Measurement Framework, and CDC's Health Days Index.^{27,28,29}
- **While cost and utilization measures inadequately capture the impact of complex care interventions, they are still important indicators.** Though the field needs to expand the scope of measures, including patient-centered measures, there is still a role for researchers to investigate cost and utilization.
- **It is difficult to separate out intervention and outcomes from broader environmental context and root causes.** This tension raises questions about the purview of complex care and reasonable expectations on outcomes given both upstream factors and environmental conditions.
- **Process measures are valuable and may be better to use than outcome measures in the early stages of programs.** Because it may take many months, if not years, for complex care efforts to have an impact, it may be more realistic to use process measures in the early stages of a complex care program. Understanding the processes that have allowed successful complex care efforts to thrive is just as important as understanding their impacts, particularly when thinking about scaling and replication.
- **Complex care programs have not meaningfully captured health equity measures and rarely report on health equity outcomes.** There are new opportunities to center health equity within complex care research design by recognizing systemic racism and injustice in the health care system and centering the patient's voice and experience.

RESEARCH OPPORTUNITIES

Drawing from CHCS' interviews and literature review, following are opportunities to redefine complex care's focus on outcomes and identify new measures to better assess quality of care and well-being for people with complex health and social needs:

1. Expand Complex Care Outcomes to Include What's Important to Patients

There is significant recognition that the field of complex care should shift from a focus on outcomes that are solely based on cost and utilization to patient-centered measures that focus on quality of care and patient well-being. Jose Figueroa, assistant professor of Health Policy and Management at the Harvard T.H. Chan School of Public Health and assistant professor of medicine at Harvard Medical School, noted that, "Cost and utilization measures say nothing about the quality of care; plus, some people need to have more utilization because it shows they are getting the care they need. Patient experience and satisfaction are all better indicators of quality."³⁰

PROMs are a promising way to gauge individuals' health and well-being in a way that values person-centeredness, a core principle of complex care. Using PROMs, patients report on their own health care needs through tools such as interviews, surveys, or other technologies to obtain this data. A report by the National Center highlights the need for complex care programs to embrace PROMs and outlines implementation strategies.³¹ The need for person-centered data is crucial to understanding how complex care programs work for individuals and what changes patients would make to develop a better health care system that meets their needs.

2. Develop Consensus on Person-Centered Metrics

There is little meaningful, widespread adoption of measures that reflect patient experience, quality of life, well-being, trusting relationships, impact/mitigation of trauma (healing), and independence. That being said, the National Committee for Quality Assurance (NCQA) along with other complex care stakeholders, developed a set of "person-driven outcome measures." Between 2013 – 2020, NCQA and researchers tested these measures and found that patients, providers, and caregivers found value in setting care planning goals and that the overall approach was feasible to implement.³² However, to date there has been no widespread adoption of these new measures.

3. Center Patient Experiences

One key takeaway from the environmental scan is that typical complex care measures do not consider nor capture what is important to patients. Lawrence Lincoln, an interviewee with lived experience, stated that he knows when complex care is working through values such as connectedness and purpose, believing in his own future, and healing.³³ LaKeesha Dumas, consumer engagement coordinator, Multnomah County Mental Health and Addictions Services Division in Oregon, and a person with lived expertise, pointed out that for some people, "...in their quality of life, sometimes numbers don't go down medically, but that doesn't mean they're not happy and joyous because they're getting their needs met over here in another area."³⁴

4. Address Equity

There are equity implications in the fact that the field of complex care most frequently focuses on cost and utilization measures to assess the effectiveness of program approaches. Doing so gives a skewed perspective on the many, overlapping forces contributing to patients' complexity. These include multi-generational poverty, systemic and institutional racism, and lack of access to resources. The health care sector must do a better job of measuring health inequities and holding the health care system — through complex care programs and other efforts — accountable for addressing them.

Timing

Per the PICOTS framework, the concept of timing refers to the period of time over which outcomes are measured in studies. This was one of the most widely discussed issues among CHCS' interviewees, with many agreeing that there are drawbacks to the short timeframes that are currently used to evaluate efforts, and opportunities for research to drive helpful changes to the field by shifting this aspect of the conversation.

KEY TAKEAWAYS

- **The current evaluation timeframe is too short.** The typical research timeframe for assessing outcomes within complex care — 12 months or less — is far too short to expect sustained improvement with a population whose needs are this complex. Shifting to a more longitudinal perspective — both programmatically and in research — is key to better understanding where, how, and for whom complex care efforts are successful.
- **The field must shift from seeing complexity as an acute issue to a chronic one that requires long-term involvement in care in order to improve outcomes.** Research approaches, and timelines in particular, should reflect this shift in turn.
- **Short evaluation timeframes discount the impact of systemic forces and inequities that contribute to complexity.** Forces such as systemic racism, lack of adequate community resources to refer patients to, or long waitlists for behavioral health services all place limitations on complex care's ability to impact patients, and none of these can be addressed in a short period of time.
- **Studies with short evaluation timeframes add value when they focus on process measures.** To get a more accurate picture of outcomes, longer evaluation timeframes are needed. But using process measures can make evaluation periods of less than a year more useful.

Both the literature review and the key informant interviews confirmed that complex care research has traditionally been structured to assess the impact of interventions on a relatively short timeframe. This may be because the field initially developed with a “diagnose and treat” perspective of complexity. As David Labby, health strategy advisor at Health Share of Oregon stated, “Many of us began with the simple notion that if we engaged with individuals with complex needs in an intensely patient-centered way, we could understand what they really need and refer them to appropriate services, which would help stabilize them. After our care management intervention, they would graduate with improved outcomes.”³⁵ As such, many complex care programs are still oriented to provide time-limited, rather than ongoing and longitudinal services. Several interviewees alluded to the fact that the Camden Coalition RCT reinforced their sense that complex care must shift away from this type of “acute care” model and reorient itself to provide care to individuals over a long period of time, with evaluation timeframes changing to match.

Overall, interviewees felt strongly that the current emphasis of short timeframes for research inadequately considers the complexity of this population and the broader racial, health, and socioeconomic inequities that impact their ability to thrive, and unhelpfully contribute to a narrative that this type of work offers “quick fixes.” LaKeesha Dumas stated, “Sometimes there is no ‘better’ in complex care. Sometimes you just have to make patients comfortable,” underscoring both that many patients’ health care needs are so complex that they will never be ready to “graduate,” and that complex care efforts can still have a positive impact on them over time (albeit in ways that are less traditionally defined as “success” in our current health care system).³⁶

RESEARCH OPPORTUNITIES

Drawing from CHCS' interviews and literature review, following are opportunities to rethink the timing to assess the effectiveness of complex care interventions:

1. Extend the Research Timeframe

Because most complex care evaluations to date have focused on outcomes at 12 months or less, the field has little high-quality evidence to help it understand how long interventions must be administered to see sustained impact for a subset of patients. More longitudinal studies are needed to help refine this aspect of complex care. To help inform this, complex care programs can and should also do more to understand patients' perspectives on how long they believe interventions should be offered — this is a place that is ripe for future evaluation efforts.

2. Improve Our Understanding of Trajectory

The field also lacks adequate evidence to understand when in a person's trajectory of risk or complexity is it most impactful to intervene. Many interviewees raised the question of whether complex care efforts should be aimed at treating complexity or preventing it. Future research focused on understanding what interventions at which points in an individuals' risk trajectory are most beneficial should be prioritized and may help guide the field in answering this question.

3. Acknowledge Racial and Health Inequities

As was widely discussed following the Camden Coalition RCT, many of the individuals that complex care programs serve live in communities that experience deep racial and health inequities. It is unrealistic to expect that complex care programs could solve the systemic forces contributing to these inequities in less than a year, and yet studies showing poor outcomes risk contributing to further disinvestment in such programs. Lengthening the timeframe for complex care research could more effectively address these challenges.

Setting

The setting of complex care efforts – both in terms of where programs and interventions are based, and the broader geographic and community context in which patients reside — is an important, albeit understudied, facet of the work. This section explores the research opportunities related to these two dimensions of setting, with interviewees emphasizing that the geographic/community context is an often-overlooked determinant of the impact of complex care efforts.

KEY TAKEAWAYS

- **“Setting” has multiple dimensions in complex care.** This includes:
 - **Where the program/services/interventions are based/delivered** (e.g., hospitals, federally qualified health centers (FQHCs), payor-based, community-based, etc.); and
 - **The geographic/community context** where patients live and complex care programs are situated.
- **Setting has not been a major focus of research to date.** This lack of focus makes it hard to understand how setting affects outcomes.
- **The community where patients live and complex care programs operate is increasingly seen as a critical determinant of how effective complex care efforts can be.** The community context, and its implications for health, well-being, and access to services, needs to be better understood and would benefit from more

research. Factors such as the prevalence and availability of resources — particularly housing, access to nutritious foods, behavioral health treatment, the strength of community institutions, and the degree of trust community members have in health care systems — can have a significant impact on this work.

- **Rural complex care programs need more attention.** It would be helpful to better understand how to tailor models developed in urban areas for rural settings, and to identify innovations emerging directly from rural programs themselves.
- **A CER framework may be a useful way to better understand the role of setting.** Since there is wide variation across programs, a CER framework can refine a comparison between two settings (hospital-based or community-based, for example) to better understand how setting impacts complex care outcomes.

In the literature review, setting is most often discussed in terms of where programs/services/interventions are based, but few, if any, evaluations seem to focus specifically on studying the role that setting plays on outcomes. The Camden Coalition RCT seemed to crystalize for several interviewees that the field must do more to take setting — in the geographic/community sense — into account. Because complex care seeks to holistically address the health and social needs of patients, its success is highly impacted by the availability of community resources such as behavioral health services, social services, specialty medical care, etc. When complex care programs operate in communities with less access to these resources — often lower-income and/or rural communities — this inherently affects their impact. More research is needed to help program implementers understand how to most effectively consider the role of setting, including understanding what impact complex care can reasonably be expected to have under specific community resource constraints.

Interviewees also underscored how critical it is for complex care programs to understand other aspects of the community context that they are operating in — for example, are health care partners perceived as trustworthy? What are the community priorities, and how do complex care efforts support (or undermine) these? What community assets, institutions, or relationships should be leveraged to ensure success?

RESEARCH OPPORTUNITIES

Drawing from CHCS' interviews and literature review, following are opportunities to incorporate community setting into research design to better assess the effectiveness of complex care interventions:

1. Understand Community Assets

The field would benefit from more formally incorporating community assets into the way that programs and services are designed and delivered and assessing the impact of these in evaluations. Rural communities, for example, often have fewer community resources to refer patients to, but often have more trusting relationships between providers and patients. Lower-income communities that may lack ready access to services often rely on community-based institutions such as faith-based organizations to provide supports. Assessing and understanding such community assets would allow complex care programs to form more effective partnerships and maximally leverage community resources to support patients.

2. Use Setting to Better Understand Who to Serve

In reflecting on the role of setting in the Camden Coalition's RCT, David Labby said, "(The field's) segmentation approaches could shift from looking not just at who is high risk for poor health outcomes and cost, but to identifying segments where there is a continuum of clinical and community supports that has a realistic chance of providing long-term stabilization — or where we are willing to invest or partner in creating needed supports."³⁷ Conducting more research about how the presence of community-based resources such as mental health services or supportive

housing programs work in tandem with clinical interventions would help the field get a more refined sense of who complex care can be most impactful for.

3. Leverage a CER Framework

Because there is such a wide variation in terms of where complex care programs/services/interventions are delivered, there is a natural opportunity for a CER framework to further assess the ways in which the setting contributes to impact by comparing similar interventions across different settings.

Supporting Patient Engagement in Research

An imperative of this project is to ensure that patients are more fully engaged in future complex care research efforts. The below section highlights the benefits of such an approach, as well as key considerations for ensuring that this is done in an effective and empowering manner.

KEY TAKEAWAYS

- **Patients are rarely involved in complex care research except as subjects.** The field is missing out on valuable feedback and insight because of this, and must do a better job to include patients in all stages of research moving forward.
- **Patients should be included in the research process early and often.** It is hard to course correct once research has already begun.
- **Research efforts should seek to understand and align with community priorities where possible.** Doing so will support partnerships in the community and ensure that the research has value beyond the study.
- **Data should be shared with the community.** This supports accountability, builds trust, and ensures bidirectional benefit from the research.
- **There are a variety of existing approaches that complex care should explore to support patient engagement in research.** There are well-established methods that complex care programs could avail themselves of.

The literature review and interviewees confirmed that there are few efforts to incorporate people with lived expertise in complex care research design, implementation, analysis, or dissemination. There was universal and emphatic agreement from interviewees that incorporating patients into the research process would be valuable. Innovators in the field are starting to move in this direction. When describing UPMC's efforts, James Schuster indicated that the health system often uses patients as co-investigators on its studies. Many interviewees acknowledged that while these efforts are commendable and a sign that the field is starting to shift, much more remains to be done.

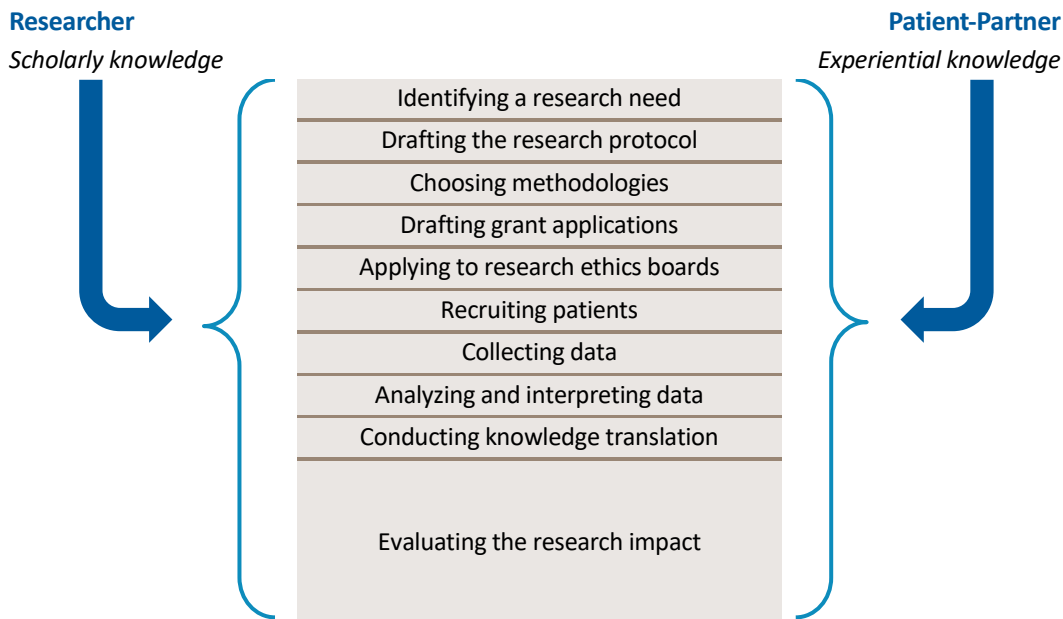
Ellen Schultz, independent consultant, advised that community collaboration should be embedded throughout a research project. She suggested that complex care researchers should, as standard practice, begin the process by asking contributing community members questions such as, "Through this project, what would you want to be able to take with you? What would you want to be able to take to your community? What would you want to take to the health care system that you engage with that would help you?"

The 2015 article, “Patient and Service User Engagement in Research: A Systematic Review and Synthesized Framework,” provides a useful four-component framework for thinking about patient engagement in research:³⁸

1. **Patient initiation** - introducing patients to the research process;
2. **Building reciprocal relationships** - recognizing the equal value and importance patients bring to research teams and acknowledging them as equal partners;
3. **Co-learning** - ensuring that researchers are open to learning from patients, and creating space for them to inform and contribute to meeting agendas and conversations; and
4. **Reassessment and feedback** - continually evaluating and improving team practices, and fostering patient empowerment.

The below exhibit illustrates various research steps where patients’ experiential knowledge could be used to meaningfully inform the research process.³⁹ Formalizing something like this into a “Complex Care Research Checklist” may be worth exploring further.

Exhibit 1. Potential Researcher and Patient Research Contributions



Source: Adapted from *Patients as Research Partners: How to Value Their Perceptions, Contributions and Labor?*⁴⁰

RESEARCH OPPORTUNITIES

Drawing from CHCS’ interviews and literature review, following are opportunities to engage patients and incorporate their perspectives into research design:

1. Build on Existing Frameworks

Within the complex care community, organizations including Maimonides Medical Center, Hennepin County Medical Center, and Commonwealth Care Alliance have used strategies such as community-based participatory research (CBPR, sometimes also referred to as Participatory Action Research), human-centered design, and journey mapping to meaningfully engage patients in complex care research.^{41,42,43} These approaches provide a roadmap for integrating and supporting patient engagement in research, and the lessons learned from these and other sites engaged in this work may be worth drawing on in the future.

2. Promote Community Partnership

Research can provide a key opportunity for complex care to deepen its community partnerships. By involving community members throughout the research process, aligning research efforts with community priorities, and sharing data with the community on a regular basis, complex care researchers can ensure that evaluation efforts support trust-building and partnerships with communities.

3. Avoid Tokenism

In order to ensure equal footing with patients in a research partnership there must be an acknowledgement of the value of contributions made by patients participating in research as well as and sufficient compensation for their contributions.⁴⁴

Without both of these, the authors warn that patients participating in research may feel as if their contributions were not meaningfully considered. The researchers also highlight that recognition of the contributions of patients participating in research can take a variety of forms, and that different patients will have different preferences. Examples of recognition types include financial, personal (e.g., certificate of participation), knowledge (e.g., access to training), academic (e.g., invitations to speakers at scientific conference, co-authorship), or altruistic (e.g., building self-worth).

4. Ensure Representative Research Partners

As the field of complex care moves to more meaningfully involving patients as research partners, it will be important to ensure that the individuals who are engaged are truly representative of the community and patient population. This entails paying attention to factors such as race, gender, socioeconomic status, education levels, health care needs, etc., and making meaningful efforts to recruit patients who have not traditionally been engaged before.

5. Acknowledge Barriers to Equity

Black and Indigenous individuals have experienced historic exploitation in the context of health care research.^{45,46,47,48} This history, combined with factors such as lack of trust of health care institutions and inadequate representation among the research community, contribute to skepticism regarding research among individuals with complex health and social needs.^{49,50} Systemic racism in health care and a lack of representation and diversity among providers perpetuates mistrust. Researchers and health systems alike must acknowledge this context and confirm their dedication to health equity and inclusion, a critical step to building trust and accountability.

Research Design Considerations

The following considerations are based on CHCS' literature review and interviews with patients, researchers, providers, and health system leaders. They point to specific changes researchers and the field can make to ensure a more equitable and sustainable environment for conducting complex care research.

Key Takeaways

- **Research should be designed with implementation in mind.** As such, this research cannot only be done in academic medical centers. Entities such as federally qualified health centers and community-based organizations should also be encouraged to participate in research efforts.
- **Complex care programs need implementation support.** Complex care programs need resources and technical support to put research into practice. Without this, the impact of future research will be limited.
- **Qualitative research and process evaluations have a meaning role to play.** These help capture the nuances of complex care, and patient and provider perspectives on its value and impact.
- **Studies must reflect patients' values or interests.** Research is often driven by what matters to the health care system or funders, and so does not always capture what patients or communities want to understand.
- **RCTs have value, but are not always practical or ideal.** They are particularly helpful for demonstrating cost effectiveness, but can be problematic for ethical reasons, the length of time and amount of financial resources they may require, and ongoing programmatic changes that can occur in the context of quality improvement.
- **There may be useful alternative research structures to use instead of RCTs.** Approaches such as CBPR, pragmatic trials, which prioritize understanding whether an intervention actually works in real life, or mechanism experiments, which test a particular causal mechanism within a policy rather than the policy itself, may provide more generalizable results on a quicker timeframe and with a simpler research design.^{51,52}

Interviewees unanimously acknowledged the need for more refined research and growing the complex care evidence base. But many also stated that more and better evidence is not enough. To enact the findings of future research, complex care practitioners will also need significant capacity building and implementation support. This includes growing the number of researchers focused on complex care, strengthening programs' ability to collect measures, and building their capacities to understand and implement research findings. Many also underscored the importance of ensuring that research is designed with implementation in mind from the start — a perspective that academic medical centers or researchers removed from the broader community context do not always hold front and center.

Particularly when discussing how best to capture what matters most to patients in the research efforts, interviewees advocated for broader use of qualitative research to better capture and measure things that are important to patients and go beyond cost/utilization/disease management. There was also interest in conducting more process evaluations to better understand the mechanics of how successful complex care programs are developed to support scaling — i.e., who was in the room deciding things? How was the community engaged?

Not surprisingly, interviewees also expressed reservations about the role of RCTs in complex care. Many said they are theoretically useful, but not particularly practical given the iterating nature of complex care and the extended timeline they require to conduct. Many preferred using a CER framework to support a faster research timeline.

Amy Finkelstein, J-PAL co-founder and co-scientific director, Jesse Gubb, research manager at J-PAL, and Anna Davis, research scientist investigator at Kaiser Permanente, encouraged the field to consider alternative research design structures such as mechanism experiments to more efficiently home in on the causal mechanisms driving complex care impacts, and/or pragmatic trials to produce more generalizable and applicable findings.

Considerations for Enacting a Research Agenda

Through the interviews and literature review, CHCS assessed potential approaches for carrying out the *Research Agenda*, including through Practice-Based Research Networks (PBRNs). This section summarizes the feedback gleaned on this topic, including interviewees' sense that complex care programs will need robust implementation support to successfully coordinate research efforts.

Key Takeaways

- **There is widespread support for a coordinated research structure such as a PBRN.** Most interviewees were familiar with the concept of PBRNs, and agreed that some type of centralized structure would be a useful mechanism for building the complex care evidence base.
- **A coordinated research structure would ideally be coupled with implementation support and research capacity building.** Doing so will help ensure that organizations have the internal capabilities to conduct research, and then translate findings into programmatic changes.
- **Patients, communities, and frontline complex care staff must be involved in defining the research questions.** These perspectives can provide insight into the direction and design of research efforts. Without a direct connection to complex care priorities and values, researchers or academics may miss an opportunity to coordinate research that meaningfully addresses issues that matter most to people with lived experience of complex care.
- **The field needs mechanisms for capturing SDOH data.** Complex care research would benefit from including these factors into research design because the data would provide a more holistic picture of population needs and program impacts.
- **Data should be shared with the community.** To live up to patient-centered goals, future complex care research efforts, including centralized ones focused on enacting the *Research Agenda*, should include approaches for sharing the data with the community in a transparent and timely fashion to support capacity and trust building.

There was broad agreement across interviewees that a centralized approach to coordinating complex care research would be useful to the field. In order for such an effort to be successful, many of the individuals we spoke to underscored that it must be coupled with implementation support to help organizations effectively design and carry out the research efforts, as well as understand how to translate the results into new care approaches. Clemens Hong, director of community programs at the Los Angeles County Department of Health Services, stated, "Research and operations are on two sides of a fence. We need to sit on that fence or have people on the two sides of it working really closely together."⁵³

Echoing themes mentioned in other sections, when reflecting on a structure such as a PBRN, some interviewees emphasized that it will be important for patients and communities to be included in developing and designing the research questions that ultimately get studied through the PBRN. Rishi Manchanda also emphasized that front-line staff should be included in designing the research questions to ensure that what's being studied truly connects to the types of information that complex care practitioners need to best support patients.⁵⁴

Research Opportunities

COLLECT SDOH DATA

In order for future complex care research efforts to be maximally useful, the field must make progress on collecting SDOH data, ideally within organizations' electronic health record systems. Insufficient data collection can hamper researchers' abilities to factor in the full range of experiences of people with complex health and social needs. SDOH data provides a more complete picture of a patient's daily life including issues around housing instability, stress, lack of access to substance use treatment, or food insecurity. Collecting SDOH data would enable complex care researchers, organizations, and health systems to better understand factors that influence clinical outcomes—and ultimately design programs to improve care for patients.

UNDERSTAND PBRN FUNDAMENTALS

There is a useful body of literature around PBRNs that the field should study further if, in fact, this structure is recommended by the workgroups to enact the *Research Agenda*. A 2013 paper, "Pediatric Collaborative Improvement Networks: Background and Overview," highlights the following as key components of a PBRN:⁵⁵

1. Common aim to improve care;
2. National multicenter prospective collaborative improvement efforts;
3. Reducing unnecessary variation by identifying, adopting and testing best practices;
4. Shared, valid, high-quality, real-time data;
5. Infrastructure support to apply improvement science; and
6. Public sharing of outcomes to identify best practices.

Understanding these fundamentals and identifying additional competencies that the field and complex care organizations would need to build to enact these, will be an important initial step in going in this direction.

An Agency for Healthcare Research and Quality scan found that 96 out of 173 registered PBRNs focused on "vulnerable populations." Of the 173 PBRNs, 84 involved collaboration with FQHCs, highlighting the key role that these community-based organizations play in such research efforts.⁵⁶ Additionally, 34 percent of the PBRNs focused on vulnerable populations engaged an active community advisory boards comprised of patient and family representatives. A subset of the PBRNs identified in this report, including the Institute for Family Health Research Network,⁵⁷ which used a PBRN structure to study the perception of stress and its impact on low-income communities through focus groups, may be useful for the field to explore further.

START SMALL

Rishi Manchanda suggested that the field consider developing a "Practice Advisory Board" comprised of an initial group of complex care practices that could help test out a PBRN-type structure. This group could provide insights into what elements of the structure were working, where and what kinds of additional specific supports are needed to carry out the research, what types of hypotheses should be tested out through this structure, etc. He emphasized the importance of having the hypotheses for the research efforts be generated at the practice level by front-line staff and patients, rather than by researchers/academics who are so far removed from the work that they are misaligned with the priorities and realities of patients and complex care programs.⁵⁸

Conclusion

Within each of the PICOTS domains, admirable work has been done to date by complex care stakeholders to assess complex care's impacts. The findings of this Environmental Scan highlight that many additional opportunities exist for research to strengthen the field, ranging from getting a more refined understanding of populations, to lengthening research timelines, to using patient-centered research designs. In combination with the *Patient-Centered Complex Care Research Agenda*, CHCS hopes that this document will provide a useful roadmap for complex care stakeholders to contribute to strengthening the field's evidence base and improving its ability to provide high-quality and impactful care.

Appendix. Key Informant Interviewees

NAME	TITLE	ORGANIZATION	LOCATION
Califia Abwoon	Case Management Specialist	Behavioral Health Services	California
Toyin Ajayi	President, Chief Health Officer	Cityblock	New York
Karen Boudreau	Senior Vice President, Enterprise Care Management and Coordination	Providence Health System	Washington
Anna Davis	Research Scientist Investigator	Kaiser Permanente	California
LaKeesha Dumas	Consumer Engagement Coordinator	Multnomah County- Mental Health and Addictions Services Division	Oregon
Jose Figueroa	Assistant Professor of Health Policy and Management	Harvard T.H. Chan School of Public Health	Massachusetts
Amy Finkelstein	Scientific Director	Abdul Latif Jameel Poverty Action Lab- MIT	Massachusetts
Clemens Hong	Acting Director, Community Programs	Los Angeles Department of Health Services	California
Tracy Johnson	Medicaid Director	Colorado Medicaid	Colorado
Melinda Karp	Executive Director	Center to Advance Consumer Partnership	Massachusetts
Parinda Khatri	Chief Clinical Officer	Cherokee Health System	North Carolina
David Labby	Health Strategy Advisory	Health Share of Oregon	Oregon
Lawrence Lincoln	Patient representative		California
John Loughnane	Former Chief of Innovation	Commonwealth Care Alliance	Massachusetts
Rishi Manchanda	President and CEO	Health Begins	California
Ellen Schultz	Consultant	Ellen Schultz Consulting, LLC	Illinois
Aleea Shaw	Program Manager, Integrated Behavioral Health	Colorado Coalition for the Homeless	Colorado
James Schuster	Chief Medical Officer	UPMC Health Plan	Pennsylvania
Janice Tufte	PCORI Ambassador	PCORI	Washington
Dorothy Winningham	Patient & Family Advocate	PFCCpartners	Virginia

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