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Delivery of Patient Centered Care in the U.S. Health Care System: What is standing in its way?

Authors: Anna D. Sinaiko, Ph.D., Kristoffer Szumigalski, Diana Eastman,
and Ayna T. Chien, M.D.



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Introduction

Patient Centered Care (PCC) in the U.S. health care system will better meet the goals and needs of patients, particularly those who face the greatest obstacles to good health, and improve health equity.¹⁻³ Several initiatives explore how to make the health care system more patient centered, with efforts that develop frameworks to describe processes and elements involved in PCC, or that disseminate case-studies of successful PCC implementations.* However, the effort to make the U.S. health care system more patient centered remains a work in progress.

This paper aims to inform efforts towards making the U.S. health care system more patient centered. It first draws from existing frameworks and definitions of PCC to articulate a comprehensive model for PCC that accounts for the multi-level nature of the health care system and identifies the information about individuals that is necessary for PCC. Second, the major barriers to delivering PCC, according to the peer-reviewed literature, at each level of the health care system are identified. Articulating these barriers can help stakeholders identify where and how to intervene to facilitate delivery of PCC.

Findings presented in the paper have benefited tremendously from input from a panel of experts representing patient, provider, payer, policy, and research stakeholders' perspectives. Together these stakeholders make up Advisory Committee that was assembled to assist with planning and strategy for the Robert Wood Johnson Foundation and AcademyHealth Patient Centered Care Meeting that took place in May 2019.

This paper formed the basis of the discussion at this two-day, invitational meeting in Washington D.C., which was attended by additional representatives from across these stakeholder groups. This paper kicked-off the discussion, but the scope of the meeting discussion was much broader because it is critical to have other sources also inform the transformation of the U.S. health care system to one that is patient centered. Many more voices and perspectives, in particular those of patients from a variety of backgrounds and circumstances, are needed to give a full picture of what is standing in the way of delivering patient centered care.

Part 1: What is Patient Centered Care?

Patient centered health care takes a holistic view of a patient's health, circumstances and well-being in an effort to meet each patient's goals and needs to maintain or improve their health. The individual is at the center of care delivery and the patient's voice is

heard and informs care throughout all interactions with the health care system. More specifically, PCC engages individuals and their family members/caregivers in informed or shared decision-making in partnership with their practitioners; respects patient and family member preferences, values, and cultural and socioeconomic contexts; reflects collaborative, coordinated, and accessible care; and aligns health care system-level incentives with these objectives. PCC was listed as one of six core elements of high-quality care by the Institute of Medicine. Higher quality, patient centered care provided to all individuals is critical to reduce health disparities and achieve health equity. Health equity is defined by the Centers for Disease Control and Prevention as giving everyone the opportunity to attain their full health potential, regardless of social position or other socially determined circumstances.

Although the first efforts to build the principles of PCC in the U.S. health care system began as early as the 1960s,⁴ conceptions of PCC have varied over time.⁵ The definition of PCC in the prior paragraph includes elements most commonly included in description of patient centered care,^{1,6-8} including the definition reported in the Institute of Medicine's 2001 report, *Envisioning the National Health Care Quality*, and the definition adopted during a prior meeting on the topic convened by AcademyHealth and the Robert Wood Johnson Foundation in Spring 2018.⁹

Today, there are several models of PCC. Although there is overlap across these models, the models vary on key dimensions including the role of the patient.¹⁰ For example, we searched for definitions of PCC in papers published between January 1, 2017 – January 31, 2019 on the topic of PCC, most of which involve evaluations of efforts to improve patient centeredness in a specific context. We found 17 papers had explicit definitions for PCC. The definition of PCC articulated by the Institute of Medicine was the only one to be used by more than one paper, but it appeared in only a minority of papers (n=5). Moreover, the definitions of PCC were broad, and often lacked specific descriptions of what PCC includes.

Variation in the vision of PCC has important implications for policy. When interventions to implement PCC derive from different models of PCC, the interventions are not necessarily working towards the same end and the evidence on the interventions' impact is not comparable. In this context, using such findings to inform policy or build patient centeredness is challenging.

Thus, the first step in this paper is to articulate a comprehensive model for PCC that can guide and inform a path towards making the U.S. health care system more patient-centered. Our model builds on existing frameworks in the literature; in particular we draw from the National Patient Advocate Foundation Roadmap Model and the National Institute on Minority Health and Health

* For examples, see the framework on creating patient and family engaged care from the National Academy of Medicine, an implementation guide for identifying and incorporating patients' needs and goals into primary care, and case-study of the New York Dept of Health and Mental Hygiene. ¹¹¹⁻¹¹³

Figure 1.1 Comprehensive Model of Patient Centered Care and Outcomes

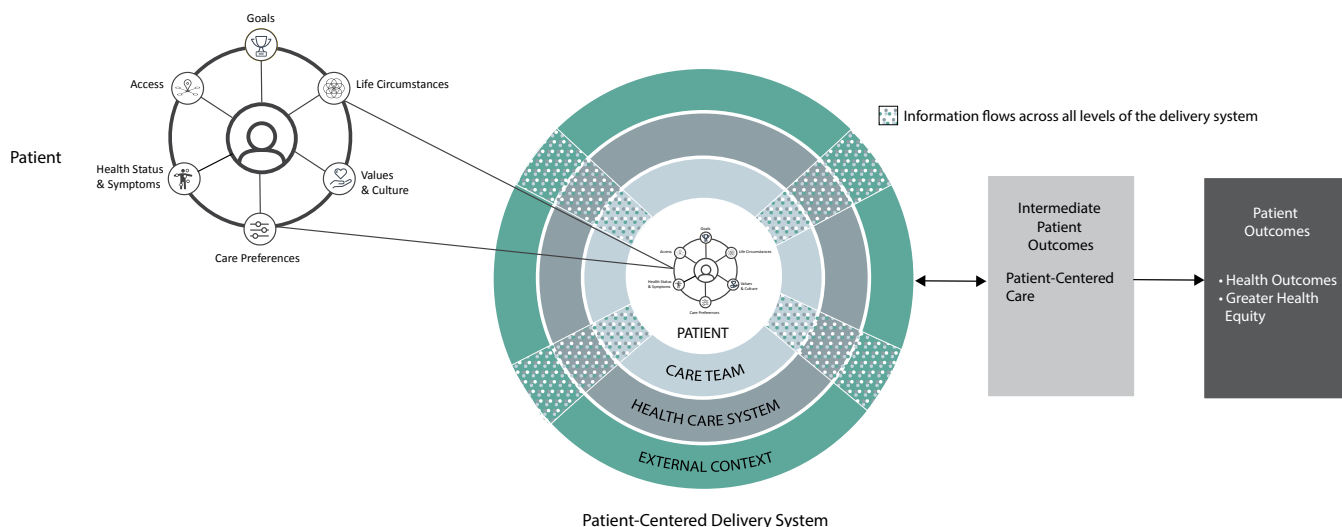
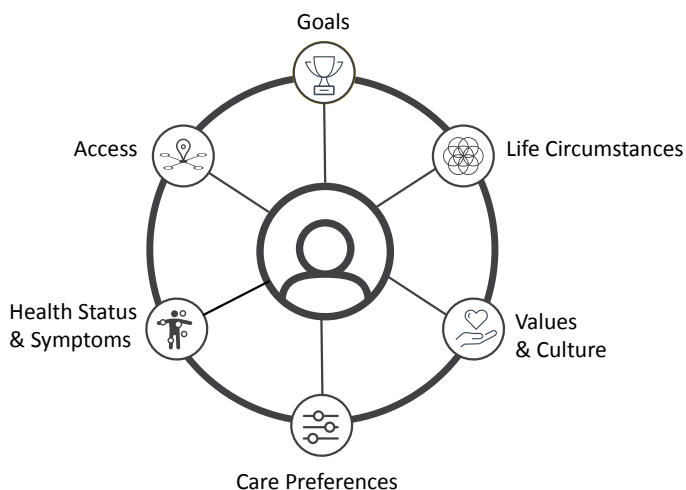


Figure 1.2 Patient Dashboard and Domains



Disparities Research Framework. The contribution in this paper is to make connections across existing frameworks and add to them to account for the multi-level nature of the health care system and to identify the specific information domains about individuals that must inform PCC at each level of the delivery system. Our model also articulates connections across the levels of the delivery system and with external environment, and illustrates the relationships between PCC, health outcomes and health equity. Finally, our model emphasizes the importance of information flow *both* from and to the patient throughout the care delivery system (Figure 1.1).

Patient Context

Meaningful patient engagement with the health care system and having the patient’s voice be heard throughout decision-making is the foundation of PCC. Moreover, patients’ needs are met regardless of where they are and where they are from.

In this context, we have identified six dimensions, which we term domains, that together must be accounted for if care is to be patient centered. Each domain describes a different set of information that needs to be gathered and incorporated into care (Figure 1.2).

Each domain is defined as follows:

- *Access* conceptualizes the idea that patient access to high-value health and supportive care should be when and how patients need it, thereby allowing for the possibility of non-traditional settings for care delivery.
- *Health Status and Symptoms* includes an individual’s current health status and symptoms, and past clinical and other relevant history (e.g., trauma) that impact overall health status.
- *Goals* for outcomes of care can differ across individuals in terms of functional status, mobility, or other endpoints; incorporating goals are a component of quality of care.¹¹
- *Life Circumstances* captures the idea that health care should account for the context in which the individual lives his or her life, including their sources of family or other support, housing,

health insurance, socioeconomic factors, stage of life, and other relevant circumstances. Life circumstances are often complex, broadly including social determinants of health which are overlapping social structures and economic systems that are responsible for most health inequities.¹² More specifically, interpersonal circumstances (e.g. family circumstances, income/access to resources, domestic violence) or structural trauma (e.g., poverty, racism), are also relevant.³

- *Values and Culture* is about individuals “attitudes, feelings, or circumstances” that reflect distinctive racial, national, religious, linguistic, or cultural heritage.^{13,14}
- *Care Preferences* accounts for a patient’s preferences among services, such as between processes of care and outcomes, or between health care and meeting other needs. Preferences must be “informed”, that is, based on full information. The interaction of patient preferences with the patient’s life circumstances, and how preferences for care change with changes in those circumstances (e.g., access to resources) is important to assess. Without direct information about preferences, clinicians, in general, are unskilled at diagnosing what patients want¹⁵⁻¹⁸ and patients make different decisions and quality of care is better when they are well informed and their preferences are recognized.^{19,20}

Patient Centered Delivery System

In modern medicine, delivery of care occurs across multiple levels. Typically this includes clinicians and non-clinicians within a practice site, separate practice sites and physician organizations within a health system, and different institutions across the delivery system. Yet individuals enter the delivery system from different starting points. Meaningful patient engagement and care reflecting the information domains should be achieved regardless of how or where patients access health care.

The external context in which the delivery system sits also has an impact on the organization and structure of the delivery system. For example, market-level competition affects incentives for both vertical and horizontal integration across providers, community-based resources (e.g., jobs, affordable housing, churches) and neighborhood features (e.g., groceries, pharmacies, crime levels, availability and access to public housing) change the feasible care options for a patient.

These levels are shown as concentric circles in the Figure 1.1, with information flow from and to the patient across all levels. Information from the patient domains affects the delivery of care across the multiple levels of the U.S. health care system in a variety of ways. Table 1.3 describes domains of PCC across the delivery system starting with the broadest level, which interacts with the greatest number of patients, down to the most narrow, which is the individual patient herself.

Part 2: Barriers to Delivery and Implementation of Patient Centered Care

There are several barriers impeding delivery of PCC in the United States. In some cases, these barriers are pervasive, affecting all individuals who encounter the health care system. In others, however, the U.S. health care system meets the needs for some while failing to achieve patient centeredness for subsets of individuals. In these latter cases, there are barriers that impede delivery of patient centered care to specific sub-populations, and interventions must be tailored to these groups.

We identify four barriers. Each barrier, along with some of the gaps in evidence and understanding of how to address them, is described here; additional background and information can be found in the Appendix.

Barrier 1: Missing Information and How to Collect It

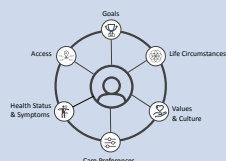
- Understanding the patient context requires information about patients’ access to health care, health status and symptoms, life circumstances, values and culture, goals and care preferences (Figure 1.2). Information collected frequently falls short of that needed to deliver patient centered care.
- The best methods and approaches to collecting the missing information about patients, and how it varies with patient characteristics, illness and acuity, and other factors are not well known, and not included in clinician education/training.
- Currently, information exchange efforts focus primarily on moving clinical health / health status information; there is inadequate focus on the other information domains valuable to patient centeredness.
- Interoperability in information systems would allow for exchange of needed information across providers, including providers within a practice site, across practices within a single health system, across separately owned organizations and increasingly across health care and community or public health organizations. This interoperability remains low.²¹

Barrier 2: Inadequate Trust, Respect, and Trustworthy Exchange of Information

- Patient trust in health care providers and the health care system, and its prerequisite mutual respect, is critical for PCC and for achieving desired health and equity outcomes.²² For example, significant numbers of patients are not adherent to their medication regimens, and understanding of root causes of behavior (e.g., affordability, misalignment with patient preferences, medical mistrust, access) is important.^{23,24}

Table 1.3. Domains of Patient Centered Care Across Levels of the Delivery System

Level	Domains	What Patient Centered Care Looks Like
External Context (e.g., market and environment outside the health care system, at both community/regional level and national level)	Health information technology (HIT)	Health Information Exchange, development of protocols to facilitate exchange of electronic health information (e.g., FHIR)
	Community and public agency linkages	Health care providers and systems establish collaborative partnerships with community-based organizations and resources (e.g., public agencies, faith-based organizations, advocacy groups, mission-based nonprofits)
	Financial incentives	Financial incentives, where they exist (e.g., contracts between payers and provider organizations) are aligned with delivery of patient centered care
	Policy	Legal and regulatory environment that facilitates and does not inhibit patient centered care (e.g., privacy and informed consent, promoting access to medical education for students of diverse backgrounds)
	Insurance design	Health plans designed to increase patient demand for high-value health care and that is consistent with evidence on patient decision-making in health care settings (e.g., standardized plan designs, framing of information, use of rewards vs. penalties)
Health Care System (e.g., both within and across organizations that deliver health care services)	Care coordination	Care team communicates, coordinates referrals, and closes loops with patients, providers and facilities across the health care system
	Culture	Organizations demonstrate their commitment to patient centered care in their mission statement; Leadership and attitudes of senior management promote patient centered model
	Financial incentives	Provider compensation rewards delivery of patient centered care
	Health information technology (HIT)	Organizations provide accessible, user-friendly electronic platforms to enable patient and/or patient support systems multiple channels to make requests, view results, and communicate
	Patient centered measurement	Organizations have systems in place to receive and track patient-reported outcomes and other metrics of PCC (e.g. levels of trust)
	Quality improvement	Organizations track patient centered measures and gaps in care in addition to other clinical quality measures to drive quality improvement and organizational priorities
	Other structural integration	Shared/common agreements for activities (e.g., accessibility, privacy policies)
Care Team	Care coordination	Care team coordinates and tracks all referrals and care transitions, and follows each to completion to ensure loop closure
	Patient centered measurement	Practices receive and track patient-reported outcomes and other metrics of PCC (e.g. levels of trust)
	Patient engagement and care design	Care team meaningfully engages patients and their support systems (to the extent they desire) in the design and implementation of care
	Team staff composition	Care team staffing meets the broad spectrum of patient needs (e.g., nurses, pharmacists, nutritionists, social workers, mental health clinicians, and care coordinators); “virtual” teams are formed with providers in the community if onsite teams are not feasible. Care team composition exhibits racial, ethnic, and cultural diversity
	Tools and programs	Care team uses tools, such as patient decision aids and consumer research summaries, and programs, such as facilitated peer-to-peer support groups, to complement counseling
	“Top of license” work allocation	Care team maximizes the value of health care appointments by enabling each team member to practice at the top of her or his license through the use of protocols and standing orders
	Training	Care team has ongoing training in: patient and family centered care, use of shared decision making tools, communication skills, culturally safe care, and trauma- and violence-informed care
Patient	Access	Patients have access to high-value health and supportive care when and how they need it
	Health status and symptoms	Patient care is responsive to current health status, symptoms, and past clinical and other relevant history (e.g., trauma), where appropriate
	Goals, values and culture, preferences, and life circumstances	Patients make health care decisions with their care team that reflect their goals, values and culture, preferences and the context in which patients live their lives



- Gaps in access to care also result from not being able to meet needs of patients from all race, ethnicity, religious and other cultures, and may impede trust.^{25,26}
- How and when to measure and deliberately build patient trust to improve health care experiences²⁷ and outcomes, especially for vulnerable or disenfranchised populations,²⁸ is not well understood.
- Implementation of legal standards for informed consent also can inhibit patient centeredness.

Barrier 3: Organizational Culture, and Clinicians' Training, Demographics and Beliefs

- Systems, norms, and a range of management mechanisms can increase and decrease specific behaviors. Clinician attitudes and beliefs can be inconsistent with patient centeredness; for example providers who believe they know or can diagnose patient preferences are less likely to use decision aids.
- Provider perceptions of the difficulty and time required to engage patients in clinical decision-making is associated with lower rates of patient engagement.
- There are gaps in understanding and dissemination of best practices in how to navigate encounters where patient preferences for care are in conflict with evidence-based guidelines for treatment.
- Staff training that fails to include domains and activities of patient centered care, most critically to meaningfully engage patients in their care, is another barrier.

Barrier 4: Alignment of Incentives and Other Factors from the External Environment

- The way in which providers are paid creates incentives to over-provide care that is well reimbursed (e.g., face-to-face visits in a fee-for-service payment system) and under-provide care that is not as well reimbursed (e.g., telephone consultations, visits in non-traditional settings). With pure prospective payment (e.g., a global budget, capitation) providers may avoid patients with higher than average expected costs.
- Patient centered care is increasingly delivered in teams, both within health care systems, as well as through referral relationships with other organizations. Payment systems do not adequately compensate this work.

- Growing proportions of individuals and families in the United States experience high costs of health insurance and health care which is a major barrier to access to care.
- Factors outside the U.S. health care system, such as community characteristics, level of coordination and involvement with community, and the legal and regulatory environment can aid or inhibit whether care is patient centered.

Part 3: Where Do We Go from Here?

It is the goal of numerous stakeholders that patients are at the center of health care, yet substantial barriers keep patients from their central position. In the spring of 2018, the Robert Wood Johnson Foundation partnered with AcademyHealth to hold the first of two conferences to identify **actionable strategies** for making health and health care systems truly focused on the goals and needs of the people they serve.

In May 2019, to continue efforts towards making the U.S. health care system more patient centered, AcademyHealth partnered with the Robert Wood Johnson Foundation to host second meeting. Providers, patient advocates and patients, as well as policymakers, researchers, health plans, health system representatives and other stakeholders discuss the evidence on strategies, models and interventions. Discussion was focused on the four areas identified as barriers to PCC in the peer-reviewed literature: (1) understanding the patient context: important information & how to collect it; (2) building trust & mutual respect between patients and providers in the health care system; (3) aligning incentives with patient-centered care; and (4) creating a culture of medicine that delivers patient-centered care.

The meeting discussion extended far beyond these four topics, and we hope that evidence can continue to inform the way to address the barriers to patient centered care identified above. The meeting discussion also highlighted the importance of elevating patient experience and patient stories as evidence that can inform improvements to care delivery. Identifying what works, what hasn't and the gaps in our knowledge of how to deliver patient centered care is the next frontier in making the U.S. health care system patient centered. Working as partners with patients and families to inform and co-design these efforts will be critical to our success.

Appendix: Additional Detail on the Barriers to Delivery and Implementation of Patient Centered Care

Barrier 1: Missing Information and How to Collect It

What information is missing?

Understanding the patient context requires information about patients' access to health care, health status and symptoms, life circumstances, values and culture, goals and care preferences (Figure 1.1). However, health care providers regularly lack this information.

Least frequently missing (because it is the easiest for clinicians to observe) is a patient's current health state. The patient's clinical history may be available depending on health information exchange functionality within a clinician's health system, patients' longevity within the system, or patients' own access to their personal electronic health information. In many cases critical information about health history is missing.

Information needed in the five other domain areas frequently falls short of that needed to deliver patient centered care. Despite some efforts to encourage collection of social determinants of health and other factors about a patient's life circumstances,²⁹ information on these domains are not frequently captured or stored in a standardized way,³⁰ nor is it clear that such information will be used to the benefit of PCC given that the health care system has its own history of segregation and discrimination.³¹ Patient preferences about the degree to which they would like to engage in a wide variety of difficult conversations (e.g. cost-of-care, end-of-life) are not elicited, despite such preferences being rather strong.³²⁻³⁴ There remains a paucity of effective collection of goals of care and informed care preferences from patients, throughout the care process¹⁹ and at the end of life.^{11,35}

Gaps in understanding how and when to collect this missing information?

There are key unanswered questions about the best methods and approaches to collecting the missing information about patients, and how it varies with patient characteristics, illness and acuity, and other factors. These questions include who on the clinical team, whether physician, other clinician or nurse, other clinical team member, is best suited to engage with patients to collect information about life circumstances, needs, goals and preferences? When should that person engage the patient and when should engagement not be with the patient but be with another family member or support person? How exactly should clinicians discuss difficult topics and how can cultural competency training support these efforts? Can decision support tools, or scripts help these efforts?

Stakeholders are beginning to recognize that information exchange interventions will need to differ depending on intervention goals.^{36,37} One barrier that reduces information exchange between patient families and providers is cultural.³⁸ While families from low-income backgrounds generally have high levels of interest in cost conversations,³⁹⁻⁴⁶ minority groups may need to be approached in a way that acknowledges embarrassment, fear of compromised care quality, and frank medical mistrust (i.e., lack of belief in the credibility and reliability of physicians' or institutions' words and actions that may stem from racial, ethnic, and gender bias among providers).^{47-49,39,40,50-53} Non-English speakers often struggle with language barriers when it comes to understanding insurance terms or in communicating with providers. There is inconsistent use among providers of interpreter or other similar resources. Moreover, non-English speakers often don't ask for resources, even when available, for fear of prejudice against immigrants.¹⁹

For example, for quality and cost information to be meaningful to consumers, it needs to reflect consumer priorities and be presented in a way that makes it accessible and understandable. Increased education can help individuals and families incorporate this information into choices. It also needs to reflect what we know about how patients make decisions, including susceptibility to decision-making errors due to systematic biases. For example, one of the most intuitive and common ways to describe risk is through probability, however, evidence from psychology and behavioral economics reveals that people often do not correctly interpret probability correctly.^{54,55} Framing and wording of treatment options could also affect patient choices.⁵⁶ Measuring patient activation levels would help health providers target time and resources to patients.⁵⁷ We can maximize the value of doctor's appointments for less-activated patients by using specially trained medical assistants, such as health coaches, to meet the patient prior to their appointment to help them formulate their self-care questions for the clinician.¹⁹

A few efforts to fill these gaps include shared decision making, serious illness conversations, and cost-of-care conversations. Shared decision-making enshrines the central role of the patient in health care decisions. It uses decision aids and one-on-one conversations to give patients information about the benefits and risks of her potential options and include them in clinical decisions. Simply using the decision aid or other SDM interventions may not be sufficient. Doctors implement decision aids very differently: some engage the patient's perspective in decision-making while others support the case for their own recommended course of care.⁵⁸ Likewise, some patient-doctor cost conversations costs may not meet patient needs.

Studies that rely on patient recall tend to estimate a lower proportion of cost discussions than studies that directly observe those visits,³² suggesting that even when cost discussions do take place, they sometimes do not hold much salience for the subjects.

Health Information Exchange

In the modern day, patients interact with multiple health care providers throughout their lives. Sometimes they see different providers within the same organization. Other times they see an array of specialists, spread out through multiple organizations. Clinicians also change as patients transition through a distinct health event (e.g., an inpatient admission for dehydration).

A central challenge with making the U.S. health care system patient centered is how to appropriately collect, share, and exchange the needed information across providers, including providers within a practice site, across practices within a single health system, across separately owned organizations and increasingly across health care and community or public health organizations.

Evidence suggests within some organizations information exchange happens informally. For example, one study that looked at nursing home dynamics found that workers often exchanged information on patient preferences and other clinical information, verbally and informally. Nursing home staff cited time and access to electronic records as barriers to more formal methods of info exchange.³⁸ Many patient centered medical homes use Excel or other manual tools for basic information exchange.⁵⁹ Some information exchange happens through the patients themselves, with doctors sometimes completely reliant on the patient bringing up and sharing information about visits with other providers.^{60,61} Relying on only these mechanisms risks incomplete information exchange. Moreover, they are not scalable.

Electronic health records introduce the possibility of electronic information exchange and this is a policy priority at the Federal level.⁶² Calls for information-sharing have occurred not only across health care settings within a system (e.g., inpatient vs outpatient)⁶³ but also across hospitals and health care systems. Such interoperability remains low,²¹ which impedes care coordination with hospitals and specialists physicians outside a practice (e.g., the so-called “medical neighborhood”).⁶⁴

We close this section with a brief mention of information exchange capabilities. First, information exchange efforts cannot remain focused simply on moving information between hospitals, but should broaden to ensuring that the information is valuable to clinical decisions²¹ or patient centeredness.⁶⁰ Lack of consensus about how to measure and represent data on social determinants of health in the electronic medical record is an additional barrier to information exchange of information.³¹

Barrier 2: Inadequate Trust, Respect, and Trustworthy Exchange of Information

Patient trust in health care providers and the health care system, and its prerequisite mutual respect, may be critical for PCC and for achieving desired health outcomes.²² For example, significant numbers of patients are not adherent to their medication regimens, and understanding of root causes of non-adherence (e.g., affordability, misalignment with patient preferences, medical mistrust) and the role of access to care in exacerbating non-adherence is not well understood.^{23,24} Gaps in access to care also result from not being able to meet needs of patients from all race, ethnicity, religious and other cultures, and may impede trust.^{25,26}

Although the concept of trust and its measurement in medical relationships has gained prominence,^{65,66} trust in institutions and professions has been the focus of a variety of disciplines (e.g., political science, sociology). Further, multiple definitions of trust exist.²² A core sentiment in all definitions of trust is the belief in the goodwill of others—and importantly, that others have the ability to act in the best interest of a third party.²² Respect, correspondingly, is a foundational piece to trusting relationships.^{67,68} Trust is a “state” that can change (as opposed to a “trait” that is somewhat immutable),⁶⁶ and trust is different from seemingly related but distinct constructs (e.g., patient satisfaction).⁶⁹

The more patients trust, the more they seek medical care when needed, adhere to recommended treatments, or are satisfied with health care experiences.⁷⁰ While studies associate greater patient trust with better health outcomes, more work is needed to understand how to deliberately build patient trust to improve health care experiences²⁷ and outcomes, especially for vulnerable or disenfranchised populations.²⁸ Patients from vulnerable backgrounds experience challenges in many areas of their lives that may impact their health and the nature of their interactions with the health care system; thus, finding ways to augment respect and trust may present valuable intervention targets to address health disparities.²⁸ While communication within the patient-doctor dyad affects patient trust in important ways,⁶⁸ other aspects of the health care delivery process may be equally or more important for establishing or building trust.⁷¹ With the growing acceptance of team-oriented health care delivery the consensus view increasingly includes the patient as members of such teams. Thus, concepts of how to build patient trust may similarly need to expand beyond the patient-doctor dyad to include all care team members.⁶⁸ For example, more attention needs to be paid to team composition (i.e., whether the team has the right “mix” of expertise and experience within its members), especially when the team may need to adapt in order to appropriately address patients’ needs.^{72,73} After member composition is established, one can evaluate the team’s dynamics (i.e.,

the degree to which members develop a shared understanding of patient goals, can articulate one another's roles and responsibilities, and are able to resolve conflicts).^{72,73}

How should trust be measured? The available medical literature tends to evaluate trust from the patients' perspective. It looks at their encounters with doctors or the views patients have of health care as an institution, which includes multiple levels of health care delivery.^{66,67,69,74} More recent attention to understanding trust from the doctors' perspective has suggested that doctors' trust in patients may have meaningful impacts on patient behaviors.⁷⁵ This literature indicates a relationship between trust and patients' attitudes and health behaviors. While some investigators have developed validated instruments for assessing patient trust in patient-doctor dyads,⁷⁶⁻⁷⁹ and recently recommendations to build trust between patients, organizations and their care teams were made by the American Board of Internal Medicine Foundation Forum,⁸⁰ to our knowledge, no broadly accepted measure of patient trust levels exists within the context of patient care teams.⁸¹

Informed consent is another form of regulation that is, on its face, patient centered, as it is intended to assure that providers "disclose the information necessary for patients to make informed choices and to provide a cause of action when physicians fail to carry out this duty."⁸² Moreover, both the courts and medical ethics codes explicitly describe informed consent in terms of patient autonomy.⁸³ However, implementation matters. Legal standards of informed consent are not conducive too, and may inhibit patient centeredness. About half of U.S. states employ a "reasonable patient standard," which requires patient to be informed of any risk that a "reasonable patient" would consider material to their treatment decision and actually place the patient at the center of informed consent.^{84,85} Informed consent documents tend to be focused on reducing the hospital's litigation risk, and are written in dense legalese. Patients are often asked to sign the documents just before the start of the procedure—which may not allow adequate time to digest any information.⁸⁴ Numerous studies have documented that despite signing informed consent forms, patients often do not understand and/or hold mistaken beliefs about the procedure for which they had become "informed."⁸³ Even the way patients are referred to the process of informed consent may also inhibit patient centeredness: providers often refer to the process as of "consenting" patients, not "informing" them.⁸² Finally, the courts have created extremely high burdens to meet the standards for successful recovery under an informed consent tort.⁸³

The above describes the modal informed consent process. Some states are pursuing efforts to make informed consent processes more patient centered. For example, Washington allows shared-decision making to serve as an alternative to traditional informed consent methods.⁸⁴ In addition, several other states, including Connecticut, Minnesota, Maine, New Jersey, and Oklahoma regulators are considering similar approaches.⁸³

Barrier 3: Organizational Culture, and Clinicians' Training, Demographics and Beliefs

The organizational culture of the delivery system itself can also be a barrier to delivery of patient centered care. Systems, norms, and a range of management mechanisms can increase and decrease specific behaviors. Has the organization – which includes senior management down to the front-line clinicians and other practice staff – adopted a mission to deliver PCC? Do the clinicians hold attitudes and beliefs consistent with patient centeredness? Is staff training consistent with domains and activities of patient centered care, most critically to meaningfully engage patients in their care?

A large body evidence in this area comes from studies of shared decision-making. In some cases, doctors may believe that they excel at diagnosing patient preferences. A study of patients with breast cancer shows that this may not be the case: doctor in this study thought that 71 percent of patients with breast cancer would rank keeping their breast as a top priority, yet the actual figure reported by patients was 7 percent.¹⁵ Similarly, doctors believe that 96 percent of breast cancer patients considering chemotherapy would rank living as long as possible a top priority, yet the actual figure is 59 percent.¹⁵ Provider attitudes can interfere with use of decision aids when they believe a patient is already on the right track.⁸⁶ A study examining use of decision aids by surgeons with patients who had early stage breast cancer found greater use among those who had a mentor who used decision aids.⁸⁷

Doctors cite lack of time as another obstacle to using decision aids or implementing shared decision making interventions,^{87,88} however it may actually be the perception of time for these activities that is the barrier. Evidence suggests that decision aids lengthen visit times by an average of a few minutes.⁸⁹ An analysis of videotaped physician-patient visits found that the average conversation about patient costs of care was 68 seconds.⁹⁰ Taken together, this suggests that it's the perception that such efforts will use a lot of time that matters, even though in reality they often don't.¹⁸

An additional need is training for clinicians about how to navigate encounters where patient preferences for care are in conflict with evidence-based guidelines for treatment.

Buy-in from providers was also an essential ingredient for success in implementing changed work processes in the office and investments in the practice (financial and technical) for practices that were transforming from traditional models to Patient Centered Medical Homes.⁹¹ For practices that were part of larger systems, support by the parent entity and alignment with other initiatives were facilitators.⁶⁴

Most of the evidence in this section comes from large health systems and academic medical centers. How these findings generalize to other settings is unknown.

Barrier 4: Alignment of Incentives and Other Factors from the External Environment

Provider Payment and Misaligned Financial Incentives

The way that health care providers are paid has important implications for how care is delivered, and many elements of current payment contracts are potential barriers to the delivery of patient centered care. Delivery of care consistent with the domains in described above would pay providers for a face-to-face visit when it is the best choice for a patient (vis a vis telephone, email). However, payment contracts cannot be written in this way. Moreover, under fee-for-service payment, still a prevailing form of physician payment, a provider is only paid for visits and is not paid for telephone or email consultations. This creates incentives for providers to encourage face-to-face visits. Other concerns with the current fee-for-service system is that the predominant clinician reimbursement is for one-on-one patient visits, which is a disincentive for group visits. In addition, the fee-for-service system rewards volume (i.e. higher numbers of visits over a period of time) and thus providers are disincentivized from taking time to collect information across all domains in the patient dashboard. Misalignment of incentives occurs with pure prospective payment (e.g., a global budget, capitation) as well, where providers may avoid patients with higher than average expected costs that are not recognized by the payment system or by risk adjustment.

Patient centered care is increasingly delivered in teams, both within health care systems, as well as through referral relationships with other organizations. Payment systems do not adequately compensate this work. For example, a health system may have a goal of preventing readmissions. The work for an individual physician is not necessarily preventing readmissions, but rather ensuring high-risk patients are identified for nurse care managers. If that work is critical, physicians should be compensated for the time it takes to perform such aspects of care, which may not be remunerated under a fee-for-service system or rewarded under salary, but are integral to the benefit the health of the patient.

Efforts to improve alignment of provider payment with desired outcomes, including patient reported outcomes and other measures of PCC, are ongoing (e.g. value-based purchasing). Direct payments for investment in patient centered care, similar to payments supporting delivery system transformation into patient centered medical homes, is another possibility. However, there is a poor understanding of how to do this well, and what forms of

payment would create incentives and provide funding for investments in delivering patient centered care.

Affordability

Access to high-value health and supportive care in the place and time that individuals need it is one of the key domains in patient centered care. Growing proportions of individuals and families in the United States have high costs of care which inhibit this access. Health insurance coverage increases health care utilization, and improves disease treatment and outcomes, self-reported health, mortality, and financial security.⁹² Yet, in 2018, the proportion of the United States without health insurance was 10.2 percent, representing an increase over the prior year for the first time since the implementation of the Affordable Care Act, and the high cost of health insurance coverage is the most common barrier to individuals obtaining health insurance.⁹³

Even among those with health insurance, out-of-pocket cost is an important barrier to care. High-deductible health plans (HDHPs) have been promoted with the belief that activated patients facing greater financial responsibility for health care costs would seek cost and quality information, reduce discretionary care, and use higher value providers, which would then improve quality, reduce costs, and facilitate expanded insurance coverage through lower premiums. However, as health plans have increasingly included annual deductibles of at least \$1,000 per individual and \$2,000 per family,⁹⁴ the evidence finds they have not let to patient choosing lower price and/or higher value care.⁹⁵ Instead, increased cost-sharing and HDHPs have been associated with reduced use of both appropriate and inappropriate care, delayed and foregone care, financial burden, and exacerbated health care disparities.^{96–99}

Increased release of health care price information about providers and services has been one attempted solution to help patients manage their health care costs. Several states, many employers, and most large commercial payers have launched web-based price transparency tools, the best of which present personalized estimates of OOP costs.^{100,101} Such tools have tended to be suited to services where there's time for patients to plan care choose providers or medical situations that are relatively straightforward (e.g., childbirth, knee replacements). Despite the reported interest in OOP cost information from patients on surveys,^{34,102,103} very few patients look at or use the sophisticated, web-based patient-facing price transparency tools made available through employers or payers to choose providers.^{104–106} Available price transparency tools have not led to lower health care spending.^{105,107}

Non-Health Care Settings

Because factors outside the U.S. health care system impact the delivery of care, they also have the potential to aid or inhibit whether care is patient centered.^{91,108} Features of the external environment include community characteristics, level of coordination and

involvement with community, and the legal and regulatory environment. One area that has received considerable focus is around privacy protections. Patients value data privacy of their data.¹⁰⁹ However efforts to protect that privacy are criticized as both too onerous¹¹⁰ and yet not comprehensive enough so as to include new initiatives that allow patients to go online and download a copy of their health information for themselves or to share with others (e.g., MyHealthEData, Blue Button, and patient-facing APIs under 21st Century Cures).

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