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Moving Patient-Centered Care Forward: How Do We Get There?



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Executive Summary

Background

In May 2018, AcademyHealth convened a broad range of health care stakeholders in Washington, D.C., to discuss the topic of patient-centered care, a term that has assumed a prominent place in the health care lexicon in recent decades. Supported by the Robert Wood Johnson Foundation, the meeting sought to assess progress toward a patient-centered health care system – one in which the needs, preferences, and values of patients, their families, and caregivers are at the center of care – and importantly, to identify actionable strategies for moving patient-centered care forward.

Discussion

Meeting participants offered a diverse set of comments about factors that can inhibit or encourage patient-centered care, and identified a number of strategies for strengthening the patient-centeredness of the health care system, now and into the future. Specifically, meeting participants noted the need to:

- Increase the availability of customer service, communications, and cultural competency training to help health system staff learn to elicit information from patients about their lives and preferences for care effectively and respectfully.
- Provide education and training opportunities that help patients, their families, and other caregivers better understand health conditions and treatment options and empower them to advocate for themselves in a complex system – recognizing that not all people will be interested in these opportunities.
- Strengthen the diversity of the health care workforce and engage community-based organizations as partners in care, building patient trust in the process.
- Leverage technology to help improve the coordination and convenience of care without losing sight of patient preferences or the importance of the patient-provider relationship.
- Improve transparency – of care team decisions, of guideline development, of health care costs – to improve trust among all patients and particularly among vulnerable populations who may view the health care enterprise with apprehension and suspicion.
- Prioritize research activities that synthesize existing evidence and explore how promising interventions instituted in one setting can be implemented elsewhere.

In raising these and other ideas, meeting participants emphasized that health care providers – supported by the systems in which they operate – should seek to understand the context of patients' lives and help patients make informed treatment decisions that align with their unique needs, preferences, and goals, as well as those of their families and caregivers. More broadly, several people suggested that user-centered design, an approach to product development that puts the intended user's needs and context at the center of design decisions, is an important lens through which to consider the design and delivery of health care.

Looking Ahead

In the context of a complex and ever-evolving health care system, realizing the promise of patient-centered care is an ongoing imperative, rather than a destination with a clear endpoint. However, collaboration among health care stakeholders, innovative thinking, and actionable strategies like the ones described here can help accelerate progress toward this important aim.

Introduction

Over the past few decades, health care stakeholders have increasingly used the term “patient-centered care” to describe what health care in the United States could or should be. While the term has many definitions and is used to describe an array of activities, several common elements are worth noting, as described in a 2017 article in *NEJM Catalyst*.¹ Namely, patient-centered care:

- takes a holistic view of a patient’s health and well-being;
- engages patients and their family members in informed or shared decision-making;
- respects patient and family member preferences, values, and cultural and socioeconomic backgrounds;
- reflects collaborative, coordinated, and accessible care; and
- aligns health care system-level objectives with patient-centered goals.

Yet, for all the talk of patient-centered care, it can be difficult to discern measurable progress in a health care system that remains complex, fragmented, and expensive. Despite important work by many individuals and organizations in this space, our collective effort to understand, implement, evaluate, pay for, and spread effective strategies for promoting patient-centered care still has a long way to go.

In May 2018, AcademyHealth, with support from the Robert Wood Johnson Foundation, convened more than 70 patients and patient advocates, researchers, clinicians, health care system leaders, health policymakers, and other stakeholders to discuss the path toward patient-centered care. Specifically, the meeting sought to generate actionable solutions – be they policies, tools, research, or other ideas – for making health and health care systems truly focused on the goals and needs of the people they serve, particularly those who face the greatest obstacles to good health.*

The purpose of this report is to summarize key themes from the meeting discussion, with a particular focus on actionable insights of potential interest to health care systems, patient advocacy groups, provider associations, research funders, and a broad range of other entities that have a role to play in helping advance patient-centered care. The following highlights major areas of discussion and related actionable strategies, and does not reflect any particular priority order.

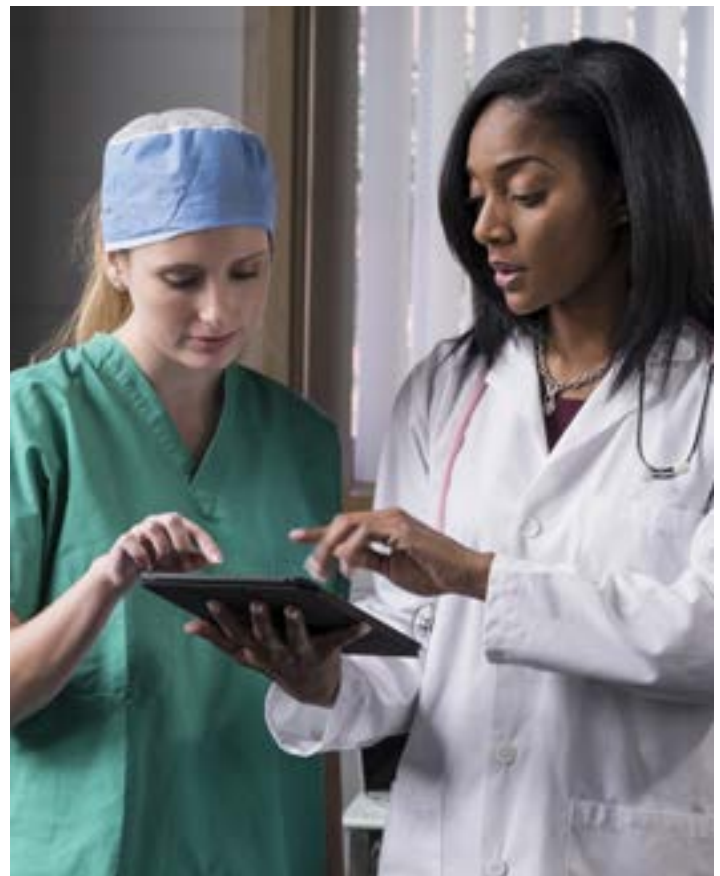
* At the request of meeting participants, Altarum has created an email discussion group focused on the topic of patient engagement and patient-centeredness. If you would like to join this group, please send your request to Lynn.Quincy@Altarum.org.

Strengthen training opportunities for providers, patients, and caregivers

Throughout the day-and-a-half long meeting, participants emphasized the important role that education and training can play in supporting patient-centered care. While most comments focused on customer service, communications, and cultural competency training for health care providers, participants also cited the need for education and training that empowers patients, their families, and/or other caregivers to be informed and engaged partners in the provision of care.

For providers and health system staff

Several meeting participants suggested that health care professionals of all types receive training in basic customer service skills, a critically important skillset that participants observed is sometimes overlooked in health care settings. One participant suggested that everyone working in a provider setting – from the physician to the receptionist to the billing specialist – receive customer service training that includes instruction on how to speak respectfully about difficult issues, including affordability. Others agreed, noting that a patient’s early interactions with receptionists and other frontline staff can set the tone for the entire visit, for better or for worse.





Providers could also benefit from communications training, participants noted, coupled with training to recognize and reduce implicit bias and strengthen understanding of different cultures. Meeting participants provided examples of how providers can lack the skills needed to ask patients and their families about unmet social needs that affect their health; use language that conveys empathy or understanding of patients' lived experiences; or listen effectively and compassionately to patients and their families. Participants suggested that communications and cultural competency training are key for helping providers learn to respectfully and effectively ask questions to learn about their patients' lives and elicit information about patients' needs, preferences, and goals for care. Such training could also help providers identify when and how to invite patients and their families into the decision-making process and how to continue conversations about goals and preferences over time.

In addition to training, participants noted that toolkits and other resources could assist providers in discerning patient preferences, communicating various treatment options and their tradeoffs, and supporting patients in making decisions that align with their preferences. For example, one participant raised the idea of a "preference library" that uses case studies and other resources to help providers understand the rationale for various patient preferences. Other meeting participants described the usefulness of resources that help providers connect their patients with other individuals who have dealt with similar health decisions. Participants suggested further work to understand and utilize resources such as peer-to-peer programs and libraries of videotaped patient experiences, for example, the Database of Individual Patients' Experience of illness (DIPEX).²

For patients and caregivers

Meeting participants emphasized that providers are not the only ones who could benefit from education and training. Rather, opportunities should also be available to patients, their family members, and other caregivers to help them better understand health conditions and treatment options and to empower them to be effective advocates for themselves and their loved ones in a complex and evolving system.

A few participants noted that understanding how the human body works is key for understanding the trajectory of a disease and its impact on health. These participants observed that there is often a presumption on the part of providers that patients know their bodies very well, when in fact this may not be the case. Participants suggested explicitly asking patients what they understand about their condition and experimenting with innovative ways to help patients gain a general understanding of the biology of their conditions, for example, via tablets made available in provider waiting rooms.

The way in which health care services are delivered, when, and by whom should be grounded first and foremost in patient and family preferences, rather than trying to force the latest and greatest approach on everyone.

Participants also described the need for communications and self-advocacy training that helps patients, their families, and other caregivers effectively assert themselves in interactions with providers and other professionals across the health care system. Some participants suggested that this type of training – to empower patients and their advocates to speak up, ask questions, share concerns – is one small but important step in addressing the power imbalance that so often characterizes patient-provider relationships. Providers and the systems in which they operate have a big role to play in changing the culture of these relationships, but education and training that helps strengthen patient voices can help, too.

In offering these comments, participants noted that the type and severity of a patient's health condition has important implications for the appropriateness, timing, and delivery of patient education. Someone who has just received a life-threatening or life-changing diagnosis, for example, is in a very different position from someone who has been managing a chronic condition for several years. Patient education efforts should reflect these differences and, importantly, respect individual patient and family preferences.

More broadly, some meeting participants cautioned against establishing unrealistic expectations about the level of knowledge and skill that patients can or should bring to health care encounters, especially when they are facing a critical health issue. In addition, participants noted that while making training opportunities available to patients, families, and caregivers is important, training alone will not fix system-level policies and practices that undermine patient-centered care. These participants emphasized health care systems' responsibility to create cultures that support and empower all patients, regardless of their level of training.

Improve the diversity of the health care workforce

Several participants noted that improving the diversity of the health care workforce is crucial for ensuring that patients of all backgrounds and preferences can access health care professionals with whom they feel most comfortable. Participants noted that age, race, gender, and medical condition are just some of the factors that can influence who a patient feels most comfortable speaking with about his or her care. Some patients may prefer to see a provider of the same gender or race, for example, while others may feel more at ease interacting with a nurse compared to a physician. Participants suggested that eliciting information from patients about their provider preferences and pairing them with health care professionals who reflect those preferences are important steps toward establishing trusted patient-provider relationships.

Meeting participants acknowledged that recruiting and retaining a diverse health care workforce is a continuing effort that will take time. In the short term, participants reiterated the importance of matching patients and providers according to patients' preferences and providing training that helps providers understand how to respectfully work with patients of different ages, races, ethnicities, socioeconomic backgrounds, and other factors.

Engage community members as partners in patient care

Participants agreed: Patient-centered care entails much more than an interaction between a patient and a physician alone. Rather, there are many individuals and entities on the clinical care team (e.g., nurses, pharmacists), on the non-clinical care team (e.g., financial counselors), in a patient's life (e.g., family members, caregivers), and in the community (e.g., social service organizations, the local YMCA) that contribute to a patient's health and well-being and may be engaged as partners in providing patient-centered care.

User-Centered Design: A Promising Approach in Health Care?

In considering ways in which the health care system can be made more patient-centered, several meeting participants surfaced an idea that generated broad support among the group: applying the principles of user-centered design to the health care system.

Simply put, user-centered design is an approach to designing products and services that puts the intended user and his or her needs at the center of the design process.⁵ Designers seek to understand the user's context and needs, use this information to develop solutions, and evaluate and refine those solutions as part of an iterative, multidisciplinary process. Part of what sets user-centered design apart from other design approaches is its commitment to "designing and developing a product from the perspective of how it will be understood and used by [a] user rather than making users adapt their behaviors to use a product."⁶

Meeting participants suggested using principles of user-centered design, not just in the development of patient-focused platforms and tools, but as a framework for designing and delivering health care services more broadly. For example, just as understanding a user's environment is crucial in the development of a new product, participants emphasized that understanding the broader context of a patient's life is integral to providing patient-centered care. Race, ethnicity, gender, socioeconomic status, and cultural background are among the many factors that shape a patient's needs, preferences, and goals regarding his or her care, participants noted. Failure to elicit this information from patients and their families and consider it as part of treatment decisions can result in recommendations that are simply unrealistic for patients to act upon – e.g., prescribing an expensive prescription that is outside a patient's budget, or suggesting a patient get some exercise by walking around her neighborhood located in a high-crime area.

By eliciting information from patients about their health and the broader context of their lives, providers can avoid making these and other inappropriate recommendations that can erode patient trust.

A number of participants reflected on ways in which health care systems do or do not engage with members of local communities and the implications for patient-centered care. Participants noted that making formal connections with trusted individuals and organizations in the community is a way for health care systems to better understand the needs and values of the communities they serve and use that understanding to inform the care delivered in their facilities. These community partnerships can also be critically important in helping to build trust among populations that have been marginalized and even mistreated by the medical establishment over the years.

Trust between patients and providers is of utmost importance, yet it takes time to build and can be easily broken.

Meeting participants identified practices that can undermine or enhance relationships between health care systems and local communities. In an example of the former, some participants described a tendency among some provider organizations to set the agendas for community advisory boards and other forms of community engagement, rather than empowering community members to determine their own priorities. Alternatively, some participants described innovative efforts to bring health system leaders into communities to expose them to social factors affecting local residents' health and to help build empathy for the lived experiences of community members. Some of these immersive experiences included shadowing residents of a food desert (i.e., an area lacking grocery stores and other providers of healthy foods) as they make decisions about what to feed their families and making one's way from where residents live to where they work via poor transportation options.

Keep patients at the center of innovations in service delivery

Another area of significant discussion focused on opportunities and challenges for using innovative care delivery models – including new technologies – to make health care more coordinated, convenient, and responsive to patient and provider needs and constraints.

Meeting participants identified a number of strategies that health care systems are employing or could employ to improve the care delivery process for both patients and providers. These included:

- Co-location of physical and mental health care services as well as social services;
- E-consults with specialists during primary care visits, which improve communication among the care team and save patients a trip to another doctor's office;
- Use of e-consults to help remote family members participate in their loved ones' in-person visits;
- Use of health clinics on wheels to bring providers out into the community, particularly in dispersed and rural settings; and
- The return of traditional house calls as a means of helping providers understand the broader context of their patients' lives, including their family life, housing situation, and day-to-day routines.

In addition, some participants suggested looking to innovative payment and delivery models like direct primary care³ and One Medical,⁴ in which patients pay a membership or retainer fee to access a broad range of primary care services. Specifically, meeting participants described the need to understand how these models work, the value proposition they provide for patients, providers, and payers, and whether these models can serve low-income communities effectively.

In surfacing these examples, meeting participants raised several key points. First, participants emphasized that trusted relationships between patients and their providers are integral to patient-centered care. Discussions about how best to incorporate technology or other innovations in care delivery should not lose sight of the importance of the patient-provider relationship. In addition, in keeping with earlier comments, participants stressed that patients come to medical encounters with very different needs, preferences, and goals. The way in which health care services are delivered, when, and by whom should be grounded first and foremost in patient and family preferences, rather than trying to force the latest and greatest approach on everyone.

Along these lines, participants suggested that technology has incredible potential for improving the coordination and convenience of care, but it is not a one-size-fits-all solution. Some patients will embrace e-visits, online scheduling, and other electronic encounters, participants noted, but some people may lack the skills, knowledge, or resources needed to utilize these tools effectively, while others may simply prefer face-to-face interaction. In addition, greater reliance on technology can have unintended consequences, such as increasing use of low-value services, exacerbating health disparities or stereotypes, and diminishing job satisfaction among health care professionals who find fulfillment in in-person interactions with patients.



In a related line of discussion, meeting participants suggested there is significant work to be done to leverage electronic health records (EHRs) effectively to promote team-based care as well as transparency, convenience, and coordination more generally. For example, participants noted that EHRs have significant untapped potential as a means of collecting, organizing, and sharing data relevant to social determinants that affect a patient's life. This technology is also a potentially important tool in helping providers make referrals to social services as social needs are identified during the clinical encounter. Some participants also suggested EHRs could be better utilized to provide information to providers and patients about the cost of various medications and procedures.

Any new approach to delivering care will not go far unless there is a means and an incentive to pay for it.

Reflecting on telemedicine more broadly, participants observed that many technology platforms remain expensive, difficult to use, and generally “clunky” for some health care providers, who require support in rolling out these systems and integrating them into the office workflow. Some participants suggested that, rather than layering technology on top of the existing, historically siloed health care system, technology should be used to transform the way care is delivered. Another issue, participants noted, is that some provider organizations are implementing EHRs and other technology platforms on their own to maintain a competitive advantage.

Rather, participants described the need to find a way to bring these organizations together and have conversations at the policy level that result in greater interoperability and standardization.

Finally, participants acknowledged that any new approach to delivering care will not go far unless there is a means and an incentive to pay for it. Payment structures take time to evolve, participants noted, and significant work is needed to understand whether and how innovative approaches to care that are good for patients and providers are also good for the bottom line.

Improve the transparency of care and costs

Meeting participants agreed that lack of transparency across the health care system erodes patient trust and presents a significant barrier to advancing patient-centered care.

Aspects of the clinical encounter can contribute to this issue. As one participant noted, certain provider behaviors, such as typing notes that are out of a patient's view or holding conversations about a patient's care just outside the exam room door, can exacerbate concerns among patients, and especially among vulnerable populations who may enter health care interactions with suspicion. Participants suggested that sharing clinical notes – through platforms such as OpenNotes⁷ or simply turning around the computer screen – and including patients in care team conversations are potential strategies for addressing those concerns and building trust.

Addressing the Complexity of Insurance

As some meeting participants observed, the complexity and expense of health insurance can undermine efforts to achieve patient-centered care, resulting in significant numbers of people who do not have coverage or do not understand the coverage they have.

Participants suggested that standardizing health insurance benefits could have several positive consequences, including reducing risk segmentation in the marketplace. Simpler benefit designs spread risk better, leading to less variation in premiums and less entry and exit of health plans from the marketplace. Meeting participants also noted that fewer, simpler plans require less administration, freeing up funds that could be channeled into lowering costs for consumers or providing expanded coverage or benefits.

Clinical guidelines also suffer from a lack of transparency, according to some meeting participants, who suggested that the process for developing these guidelines be made more clear and inviting to patients. Engaging patients and their families in the guideline development process is important for ensuring that guidelines reflect variability in patients' context, preferences, and goals, participants noted. One person suggested that health care organizations may be able to follow guidelines more effectively when those guidelines incorporate what patients say they want and need.

Participants emphasized that lack of accessible information about the cost of health care services is a major challenge for both patients and providers. As one participant put it, you can't have true patient centeredness without also having easily accessible cost of care information. Participants described the need for strategies that enable providers to work with patients to navigate cost information, factor this information into treatment decisions, and address the stress and other emotional and psychological effects that patients and their families can experience when making decisions about high-cost care and how to pay for it.

Invest in implementation research

Meeting participants shared diverse – and sometimes conflicting – perspectives about the current state of the evidence on patient-centered care and how best to focus future research activities on this topic. Specifically, the discussion reflected differences between some participants who pointed to important outstanding questions in need of further study, and other participants who

expressed frustration that the research enterprise tends to prioritize new research over activities that help make effective use of evidence that already exists. Where the group found some consensus was in their support of implementation research as an important area of work moving forward.

Over the course of the meeting, participants identified a number of areas where further research is needed to understand and improve various dimensions of patient-centered care. For example, participants described the need to better understand the barriers that inhibit patients' engagement in clinical encounters and to identify effective strategies for inviting patients and caregivers of various cultural and socioeconomic backgrounds into conversations about needs, goals, and preferences. Others suggested that despite significant work in recent decades, there remains a dearth of rigorous research and evaluations demonstrating that resources expended to improve patient-centeredness are beneficial to an organization's bottom line or improve other outcomes of interest to health care delivery system leaders.

Technology can help improve coordination and convenience, but will not be a useful or appealing tool for all patients at all times.

However, some participants pushed back on the notion of prioritizing new research, suggesting there is a lot to be done to make existing research more useful and used. For example, participants suggested investing in systematic reviews and other efforts that assess the scope and strength of existing evidence on topics relevant to patient-centered care and communicate that evidence to various stakeholders. Some participants emphasized this communications component, describing the need for clear, concise, and engaging infographics, briefs, and other resources that communicate existing research and its implications for patients, providers, C-suite executives, and others.

Where participants found some agreement was on the topic of implementation research, an area of work that participants described as critically important but perhaps underutilized to date. One participant observed that there is a lot of research on how to develop patient-centered programs and tools, but less so on how to adapt and implement these initiatives. He and others cited the need for greater investment in research that helps identify how to take patient-centered care practices that have shown promise in one setting and implement them in another setting. Along these lines, some participants suggested developing case studies that examine

how hospitals or other providers are implementing patient-centered care models, what components of these models work and why, and how these models might be implemented elsewhere. In addition, one participant noted that it is important to examine how interventions become normalized over time and how organizations can keep the “bungee cord of culture” from pulling everything back to where it used to be.

Finally, a handful of participants described changes to the broader research enterprise that could help facilitate useful research relevant to patient-centered care. In particular, one participant noted that highly competitive funding environments put pressure on researchers to present perfect research plans, which in turn affects the topics that researchers choose to study. This participant suggested providing greater opportunities for “pragmatic studies” that address important outstanding questions using the best available methods, even if those methods are imperfect.

Looking ahead

While there is no silver bullet for realizing a patient-centered health care system, the rich set of ideas offered by meeting participants suggests promising ways forward.

In their comments, participants noted that training, tools, and other support can help providers, patients, and family members respectfully surface important information about a patient’s life and preferences for care, and incorporate this information into treatment decisions. Trust between patients and providers is of utmost importance, yet it takes time to build and can be easily broken. Engaging community partners can be an effective way for health care systems to build trust—so too can ensuring that the health care workforce reflects the diversity of communities served and understands the realities of their patients’ lived experiences. Innovative service delivery models, sometimes aided by technology, have incredible potential to transform care for the better, but only if there are incentives to pay for them. Moreover, technology can help improve coordination and convenience, but will not be a useful or appealing tool for all patients at all times. Research activities remain an important area of work moving forward, particularly those activities that synthesize existing evidence and identify how interventions that are effective in one setting can be implemented elsewhere.

It is worth noting that other stakeholders who were not part of the meeting could add to the diversity of ideas raised. Insurers, social service organizations, provider associations, state and local policymakers, and others can play an important role in advancing patient-centered care, and their perspectives should be part of future discussions on this topic.

As the meeting discussion suggested, conversations about achieving patient-centered care elicit both frustrations about progress to-date and a recognition that, in a complex and ever-evolving health care system, realizing the promise of patient-centered care remains a significant work in progress with no clear endpoint. However, collaboration among a broad range of stakeholders; innovative ideas, research, and technology; and a genuine respect for and commitment to patients and their families are some of the strategies that can help move us forward.

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About AcademyHealth

AcademyHealth is a leading national organization serving the fields of health services and policy research and the professionals who produce and use this important work. Together with our members, we offer programs and services that support the development and use of rigorous, relevant, and timely evidence to increase the quality, accessibility, and value of health care, to reduce disparities, and to improve health. A trusted broker of information, AcademyHealth brings stakeholders together to address the current and future needs of an evolving health system, inform health policy, and translate evidence into action. For additional publications and resources, visit www.academyhealth.org.

Endnotes

1. NEJM Catalyst. What Is Patient-Centered Care? Published January 1, 2017. Available from <https://catalyst.nejm.org/what-is-patient-centered-care/>.
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