

Partnering with Patients to Drive Shared Decisions, Better Value, and Care Improvement

In February 2013, the Institute of Medicine's Roundtable on Value & Science-Driven Health Care convened a workshop, gathering patients and experts in areas such as decision science, evidence generation, communication strategies, and health economics to consider the central roles for patients in bringing about progress in all aspects of the U.S. health care system. This Meeting Summary is being released in conjunction with a complete transcript of the event, the Workshop Proceedings. Over the course of 2 days, 31 speakers commented on the importance of patient and caregiver engagement in achieving the best care at lower cost.

The discussions highlighted the critical role and capacity for patients and families to be leaders in informed care decisions, knowledge generation, and value improvement.

Individual workshop participants identified a few overarching themes and messages.

Overarching themes and messages:

- **Culture dominates.** “Culture eats strategy for lunch every time,” as mom-turned-advocate Cristin Lind noted. Thus, improving the quality of the care experience and using limited resources wisely will require significant culture shifts.
- **“Listen first, listen fully.”** That’s what Ekene Obi-Okoye, a premedical intern at the University of California, San Francisco, learned as she supported patients with breast cancer. By listening first and listening fully, patient and caregiver voices are integrated fully into every possible level of decision making—care, system design, and policy making—and the quality of care improves.
- **Patient engagement is a skill, not a trait.** Being an engaged patient and actively engaging patients are not intuitive skills. Patients and clinicians learn these skills over time and through partnership with a supportive care team.
- **Trust matters.** Effectively delivering cost and quality information requires trusted translators who convey information in ways that are easy to understand.
- **Prepared, engaged patients are a fundamental precursor to high-quality care, lower costs, and better health.** Achieving and exceeding these three basic aims of health and health care policy calls for partnering with patients as leaders and drivers of care improvement.

INFORMED, SHARED CARE DECISIONS

A meaningful care experience is when the patient is fully informed and the provider has elicited the patient's preferences and goals.

Evidence strongly indicates that when patients are fully informed and engaged in making decisions about their care, patient satisfaction goes up, results improve, and health care costs go down, stated Gary Langer of Langer Research Associates and a number of other workshop participants. In pursuit of more and higher-quality shared decision making, the first workshop session explored how to increase demand for shared decisions, as well as the changes in infrastructure, culture, and training that would be necessary.

- **Patients want to be partners in their health.** When patients receive clear information about their choices, most want to be an equal decision maker when choosing their care plan, Langer observed in his presentation.
- **Strong and visionary leadership promotes culture change.** The leaders of health care organizations can ensure that shared decision making is part of routine practice by setting the standards, pointed out Grace Lin of the University of California, San Francisco.
- **Training can help patients and clinicians engage in shared decisions.** Informed conversations are facilitated by patients who learn to ask questions and clinicians who learn to listen fully, noted Sherrie H. Kaplan of the University of California, Irvine.



KNOWLEDGE GENERATION

We owe it to ourselves, our families, and society to learn from our experiences—but permission matters.

According to many workshop participants, improvements in reliable capture of data from the care experience will make knowledge generation more timely and clinically useful. But clinical data use requires individual patients not only to make informed choices about privacy and security, but also to be informed stakeholders in the knowledge generation process, remarked Susan Brown Trinidad of the University of Washington. **Building trust and understanding is the foundational element in using health data for evidence development,** added Nancy E. Kass of Johns Hopkins Bloomberg School of Public Health. Clinicians frequently are asked to serve as trusted translators when it comes to discussing privacy, security concerns, and the potential benefits and harms of data sharing, a number of speakers pointed out. When patients and clinicians partner to make data more readily available, this enhances the real-time learning potential and leads to better care.

- **Various incentives promote data sharing.** Evette Ludman of the Group Health Research Institute explained that patients are motivated to share their data by altruism, trust, and clear explanations of impact, risks, and benefits.
- **Effective clinician communication strategies can help.** By facilitating conversations about new evidence development, clinicians can enable patients to advocate for using their health data for care improvement, observed patient advocate Mark Gorman.
- **Patients want to be asked about using their data.** Applying practical and trusted approaches to privacy and consent can address the imperative to draw, in a seamless fashion, on clinical data for scientific advances, Group Health's Ludman continued.
- **Information feedback loops capture and apply lessons learned from the patient experience.** Kenneth D. Mandl, of Children's Hospital Boston, Harvard Medical School, and Harvard-MIT Health Sciences and Technology, noted that bidirectional communication on patient-reported outcomes ensures that data are being used efficiently and effectively.
- **Distributed leadership fosters patient engagement.** When patients are partners in their health and owners of their data, health care quality improves, Genomera Genetic Alliance's Greg Biggers remarked, echoing other speakers.

VALUE

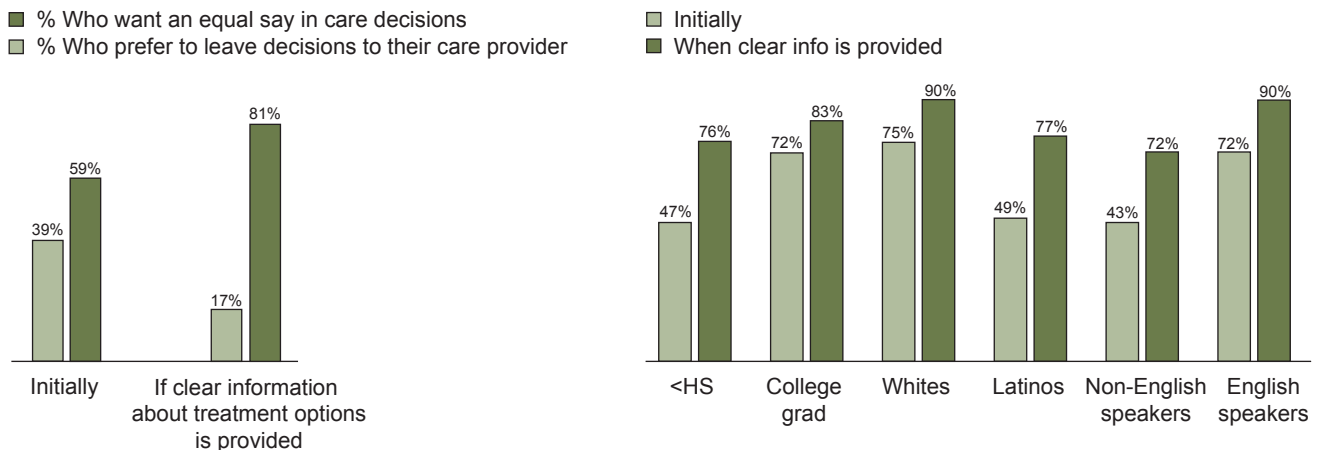
Dollars are a likely proxy for quality in every industry except health care.

- **Patients look for choices they can understand easily and immediately.** Cost and quality information is more useful to patients when it is readily available, transparent, and presented in a meaningful way, stated John Santa of *Consumer Reports* Health Ratings Center.
- **Incentive feedback loops are a dynamic part of the care process.** Multiple panel members expressed support for making quality information transparent in order for the system to learn and improve.
- **Patients choose care tailored to their individual preferences.** Patients primarily care about choosing the care that is right for them given their individual circumstances, although concern about out-of-pocket costs is also increasing, Tresa Udem of PerryUdem observed.
- **Paying for health care is a social decision.** Although many health care choices are made individually, we pay for them communally, explained Marge Ginsburg of the Center for Healthcare Decisions. Given this, patients increasingly want to weigh in on the incentive structures and trade-offs that affect them, she continued.

If patients recognize and expect high-quality, efficient health care, providers will respond, a number of workshop speakers noted. **Since normal market forces are not at work, health care is unlike other industries in that cost is not a proxy for quality**, explained Judith H. Hibbard of the University of Oregon. Indeed, presenting value information in isolation is not effective in helping patients make good decisions; information about quality must be included as well. Thus, patients and families need better access to cost and quality information, provided by a trusted source, to support informed decision making, Hibbard continued. Bringing transparency to cost and quality at the system level necessitates changes in the culture and infrastructure of collecting and communicating this information.

In an efficient health care system, care choices are democratized and based on the best evidence, J. Michael McGinnis of the Institute of Medicine summarized. Though the infrastructure and cultural changes necessary to transform the patient role are significant, empowering patients to become partners in—rather than customers of—the health care system is a critical step on the road to achieving the best care at lower cost, McGinnis continued.

FIGURES: Patients want shared decision making, with up to 81% saying they want an equal say in their care decisions (left). Although some patients were less willing to participate in shared decision making, the gap between patients of varying educational levels and language abilities largely disappeared when they were provided clear and understandable information (right).



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