# *The race for the care: A vision for patient-centered care*

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*"We have been chasing the cure, rather than the care."*

*—Ellen L Stovall,*
*survivor of three bouts with cancer*

What does it truly mean to have a patient-centered approach to care? As a clinician, I can tell you confidently that most of my colleagues tend to get defensive amid talk of the need to adopt a patient-centric approach to care. "Of course, we're focused on the patient!" seems to be the most common reaction. Many simply assume that because care is essentially imparted onto a patient, everything we do, naturally, is patient-centric.

This cannot be farther from the truth. Care today, in many ways, is application-centric, siloed, fragmented and uncoordinated. Electronic medical records (EMRs) have been embraced—in great spirits—to ease care processes, but by design are built mostly to aid transactional activities related to care, such as documentation and billing.

But where is the patient in all of this? Is a system designed to help document our attempts to cure the patient, and help bill for the associated services, really the best we can do? Perhaps the problem is bigger than just the EMR. Perhaps our frequently paternalistic, and often heroic, approaches to care have been cherished, celebrated and incentivized for far too long. Perhaps we need to rethink care in a big way.

## Rising above the silos

One imperative for a patient-centric approach to care is to be able to view the full patient record and obtain a more holistic view of the patient. The full patient story, as many of us are starting to find out, does not live in any one clinical information silo. As we moved from paper-based charts to the EMR, we realized that more information about the patient resides well beyond the EMR. The same is true for radiology. As we moved from film to filmless, we learned that the core systems we use in radiology, such as picture archiving and communication systems (PACS) and radiology information systems (RIS), store limited information about the patient. Making intelligent decisions around the care we are imparting onto our patients requires context, and this really is derived from weaving together multiple data points across disparate clinical information systems. The longitudinal patient record, which may begin to tell the "patient story," resides above the silos. In getting to this "complete picture," we encounter the many challenges of interoperability across the very systems we continue to implement.

The argument is not for clinicians to leave their current clinical information systems and seek something else. Rather, the rationale here is that for us to function in a more patient-centric manner, we need to bring more robust patient context mined from various clinical information siloes, such as EMRs and PACS, as well as

Laboratory Information Systems (LIS), Hospital Information Systems (HIS) and even Health Information Exchanges (HIE), and make all of it accessible and relevant at the point of care.

What we need is a redesign of care processes and methodologies.

## Interoperability

The Office of the National Coordinator (ONC), in its White Paper outlining a "10-Year Vision to Achieve an Interoperable Health IT Infrastructure," states that achieving the goal will be possible only with a strong, flexible health IT ecosystem that can appropriately support transparency and decision-making, reduce redundancy, inform payment reform and help to transform care into a model that enhances access and truly addresses health beyond the confines of the health care system. The ONC goes on to say that "such an infrastructure will support more efficient and effective systems, scientific advancement, and lead to a continuously improving health system that empowers individuals, customizes treatment, and accelerates cure of disease."

While these are lofty goals, interoperability that is conducive to patient-centric care should go further, not just to accelerate the curing of disease, but also to encourage wellness.

We cannot attain true interoperability without first ensuring "operability." We just celebrated the decade of interoperability in health IT. The goal of meaningful interoperability among health information systems perhaps may never be reached without a more disciplined embrace of standards and a better alignment of incentives. Often, clinical information systems tend to be proprietary and 'closed,' although the trend seems to be toward adopting what is perceived as a more "open" approach to data exchange across systems. Newer advances to standards-based approaches, such as the HL7 FHIR[1] standard, provide a promising implementation framework that combines web technologies with HL7's existing offerings.

The Medicare and Medicaid EHR incentive programs provide financial incentives for the "meaningful use" of certified EHR technology. Interoperability and the enablement of easier data exchange between applications can only allow for a more patient-centric approach to care;

one that promises better quality and improved outcomes.

## Is radiology ready?

For decades now, radiology has been debating the virtues of "PACS-driven" versus "RIS-driven" workflows. Indeed, we often have separate worklists for 3D imaging, and perhaps others for voice recognition and transcription systems. The reality, however, is that what we really need is a "patient-driven" workflow. We have been, in many ways, treating patients "one film at a time" for decades. This image-centric culture in radiology needs to give way to a more patient-centric approach to care. Providing true value as imagers calls for fuller context around the images we are expected to look at, so we are able to get a more holistic view of the patient. This is where technology can truly help. Technology needs to provide a more longitudinal view of the patient in the context of the patient's presenting symptoms or other reason for the examination.

A core focus on workflow is critical to enabling behavior that encourages collaborative care across care teams. Radiology can help guide optimal patient and referring-provider decision-making by promoting and utilizing evidence-based recommendations on radiologic procedures. Value must be linked directly to superior outcomes, improved quality, and better satisfaction per dollar spent. We need more data transparency, including around utilization data, appropriateness and costs. This calls for a more end-to-end approach to designing systems that can measure, quantify and present actionable information at the point of care, such that we can influence value-based behavior.

Beyond context, better workflows and a more tightly aligned collaborative care process, we can also do much to demystify the role of radiology to our patients. Much of radiology already has very few touchpoints with patients. This has to change. Radiologists should play a key role in patient education, and they should not be afraid to step outside the reading room to speak to patients where relevant. Radiologists should also actively participate in tumor boards and care decisions. Radiology is integral to almost every care process, but patients do not really comprehend the role of this specialty in their care. We

need to work towards better patient awareness of radiology services, to the specifics of radiology procedures as they pertains to patients, and better reports that make more sense to laymen.

## Free the data

Patients are often left to fend for themselves bteween care episodes. However, this engaged, empowered and connected generation of consumers is perhaps one of the biggest dynamics that can be leveraged to enable "patient-centricity" in the care we offer. A wealth of information exists in patient-provided data, data from patient-portals, from apps, and from connected devices and wearable technologies. The lines between mHealth and traditional brick-and-mortar health care are blurring quickly. It is critical for the healthcare industry to capitalize on this dynamic by ensuring that we are able to free the patients' data from the clinical information systems and make it available to them in actionable ways so we can make them even more engaged in their care. Cloud-enabled image exchanges can allow for easier sharing of imaging studies and reports between patients and their providers. Mobility, done right, could greatly complement existing workflows and improve care quality, access and clinical care coordination, as well as vastly improve consumer engagement in their own health care.

## Incentivizing patient-centric care

Historically, physicians have not been held financially accountable for the health of their patients and outcomes of their treatments. The massive movement from volume-based care to value-based care, exemplified by the development of accountable care organizations (ACOs) and patient-centered medical homes (PCMH), demonstrates that incentive-based patient-centric care models work. These initiatives have the potential to remake healthcare delivery, incentivizing physicians and healthcare providers of all types—hospitals, clinics, long-term care facilities and others—to work together to improve outcomes and generate shared savings.

A survey of U.S. physicians[2] found that physicians expect about 50% of their compensation in 10 years to be value-based; they are aware that the shift to VBC is happening and inevitable.

Patient satisfaction is not just a noble goal; it could also affect reimbursement. The Hospital Consumer Assessment of Healthcare Provid-ers and Systems (HCAHPS) survey is the first national, standardized and publicly reported survey of patient perspectives of hospital care. In October 2012, Medicare began rewarding the best-performing hospitals with bonuses,[3] directly tying patient satisfaction to reimbursement.

A report by the National Committee for Quality Assurance (NCQA) suggests that PCMHs are transforming primary care practices, focusing on patients themselves and their healthcare needs.[4] They also are serving as the foundation for a healthcare system that gives more value by achieving the "triple aim" of better care quality, better patient experience and lower costs. A growing body of evidence shows that PCMHs bring many benefits, including better overall patient-centered care, better quality, improved patient experience, care continuity and disease prevention.

## Informed, shared decision making

Informed, shared decision making is perhaps the pinnacle of patient-centered care. This concept was introduced in the landmark Institute of Medicine (IOM) report *Crossing the Quality Chasm*[5] as one of the fundamental approaches to improving the quality of U.S. health care. The IOM defined patient-centered care as "care that is respectful of and responsive to individual patient preferences, needs, and values" and that ensures "that patient values guide all clinical decisions." This definition highlights the importance of clinicians and patients working together to produce the best outcomes possible.

Achieving a state of informed, shared decision making entails building good clinician-patient relationships so that information is appropriately shared and patients are supported to deliberate and express their preferences and views during the decision-making process, and care pathways are then optimized and personalized to the patient.

Typical "quality" metrics of process and outcome (like matching treatment to diagnosis) sometimes drive overtreatment and inflate costs. However, matching more personalized treatment to patient goals may help keep costs down, drive optimal utilization of care services, and improve overall outcomes and patient satisfaction.

## Comparative effectiveness research

Perhaps Ellen L Stovall was right; maybe we have been chasing the cure, rather than the care.

Ellen, I reckon, knows a few things about care. She is not just a three-time cancer survivor and an advocate for more than 30 years for improving cancer care in America. She is also the former president and CEO of the National Coalition for Cancer Survivorship. Ellen believes that the words "patient-centered" are used to make people feel good.[6] She instead advocates comparative effectiveness research (CER) – a more fact-based approach to personalized care versus soft, feel-good words. CER is the direct comparison of healthcare interventions to determine which work best for which patients and which pose the greatest benefits and dangers.

The Institute of Medicine explains that the purpose of CER is to assist consumers, clinicians, purchasers and policymakers in making informed decisions that improve health care at both the individual and population levels. In essence, the idea is to focus on the patient, using data. Novel idea, one would say. Often the best ideas are the "apparent" ones. All too often, the information necessary to inform medical decisions for our patients is incomplete or unavailable, resulting in more than half of the treatments delivered today lacking clear evidence of effectiveness.[7] CER is particularly important in the age of personalized approaches to making decisions, such as decisions about cancer treatments incorporating phenotypic and genotypic data on the patient. This, coupled with informed decision making and empathy, is the real start to a truly patient-centric approach to care.

Doing what is in the patient's best interest takes more than just words. Healthcare reform will eventually pit the goal of expanding health insurance coverage against strong pressure to reduce the growth in healthcare costs. In a compelling piece published in *The New England Journal of Medicine*,[8] authors Alvin Mushlin and Hassan Ghomrawi argue that unless we are willing to allow our health care to be driven solely by financial and regulatory incentives, CER should become an important part of the equation.

The broader goal of patient-centered health care is to empower patients to become active participants in their care. This calls for rethinking the entire care paradigm. How often, as care providers who have been tasked to cure our patients, do we really care about the complete patient experience, and what really matters most to them? From ordering the right studies for our patients, to performing the right reads and engaging in the appropriate consultations with our colleagues—all under the assumption that we are doing what is best for our patients—how often do we have the time to think about the full patient experience? Patients, who come to interact with care providers at perhaps the more vulnerable times of their lives, also have to grapple with the unfortunate complexities of getting access to care: scheduling, parking, navigating through the system, and speaking with nurses, physicians and technologists—not to mention wrestling with care decisions and understanding daunting reports and instructions. All while trying to get better.

It is critical, then, to put ourselves in their shoes and to redesign the care experience around the patients. The imperative is upon us to design systems that enable the very basic elements of patient-centered care: the free flow of data, a team approach to care, better communication, and care that is personal and empathic.

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