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# **The State of Patient Engagement and Health IT**

August 12, 2014

**“Prepared, engaged patients are a fundamental precursor to high-quality care, lower costs and better health.”**

*Institute of Medicine, Partnering With Patients to Drive Shared Decisions, Better Value and Care Improvement, 2013<sup>1</sup>*

## Executive Summary

Even without universal agreement on “one” definition of patient engagement, two truths are emerging: a patient’s greater engagement in healthcare contributes to improved health outcomes, and information technologies can support engagement. The HIMSS Patient Engagement framework provides a five-milestone roadmap for health providers looking to support patients through the use of IT tools and resources: inform me, engage me, empower me, partner with me, and support my e-Community.<sup>2</sup> Patients want to be engaged in their healthcare decision-making process, and those who are engaged as decision-makers in their care tend to be healthier and have better outcomes.

Financial health related to healthcare costs and types of insurance coverage also influences consumer health behaviors. Consumers and health providers’ financial incentives are beginning to align to foster patient engagement, including movements to provide transparency. Information and communication technologies may be disruptive to providers’ existing infrastructures, sunk investments and workflows. Technology developers and providers keen on health informatics are taking advantage of several strategies to drive interoperability and streamlined communications. The growing use of patient portals, secure messaging (including email), and social media are reducing barriers in communication between providers and patients.

The phrase “patient engagement” means different things to different people and health industry stakeholders. One predominant definition for patient engagement is, “the relationship between patients and healthcare providers working together to promote and support active patient and public involvement in health and healthcare and to strengthen their influence on healthcare decisions, at both the individual and collective levels.”<sup>3</sup>

The Center for Advancing Health offers a health engagement behavior framework based on behavior, defining engagement as “actions people take for their health and to benefit from healthcare.”<sup>4</sup> The Patient Activation Measure (PAM), which classifies patients into one of four increasingly engaged levels, is gaining increasing attention among both U.S. and European health providers.<sup>5,6</sup> The HIMSS Patient Engagement framework provides a five-milestone roadmap for health providers looking to support patients through the use of IT tools and resources: inform me, engage me, empower me, partner with me, and support my e-Community.<sup>7</sup>

The American Hospital Association’s Committee on Research developed a framework for engaging healthcare users that spans a continuum that includes the individual, the healthcare team, the organization, and the larger community, shown in Figure 1. What underpins this framework are information sharing, shared decision making, self-management, and partnerships—all key ingredients for engaging patients.

**FIGURE 1**



Source: AHA COR, 2013

Many other patient and health engagement paradigms have been developed, adding to the lack of a common set of criteria to help gauge “where” patients are on the engagement continuum.

### Emerging learnings in patient engagement

Even without universal agreement on “one” definition of patient engagement, two truths are emerging: a patient’s greater engagement in health care contributes to improved health outcomes, and information technologies can support engagement.

Engagement matters. People actively engaged in their health are more likely to stay healthy and manage their conditions, follow treatment plans, eat right, exercise, and receive health screenings and immunizations.<sup>8</sup> On the other end of the patient engagement spectrum, patients without the skills to manage their healthcare incur costs up to 21% higher than patients who are highly engaged in care.<sup>9</sup> The evidence-base for shared decision-making is growing: it has been linked to fewer hospital admissions and surgeries for sensitive conditions,<sup>10</sup> fewer rehospitalizations,<sup>11</sup> less spending,<sup>12</sup> improved patient safety outcomes,<sup>13</sup> and greater patient satisfaction.<sup>14</sup>

Altarum Institute’s Consumer Engagement measure (ACE), which assesses peoples’ health engagement behavior across several dimensions, found that the most health-engaged people tend to have a healthier BMI, remember to take daily medications, ask about cost, and use cost transparency tools more than least-engaged people.

**FIGURE 2: Top Three Goals and Concerns for Breast Cancer Decisions**

Condition: Goal	Patient	Provider	P
Keep your breast?	7%	71%	P<0.01
Live as long as possible?	59%	96%	P=0.01
Look natural without clothes	33%	80%	P=0.05
Avoid using prosthesis	33%	0%	P<0.01

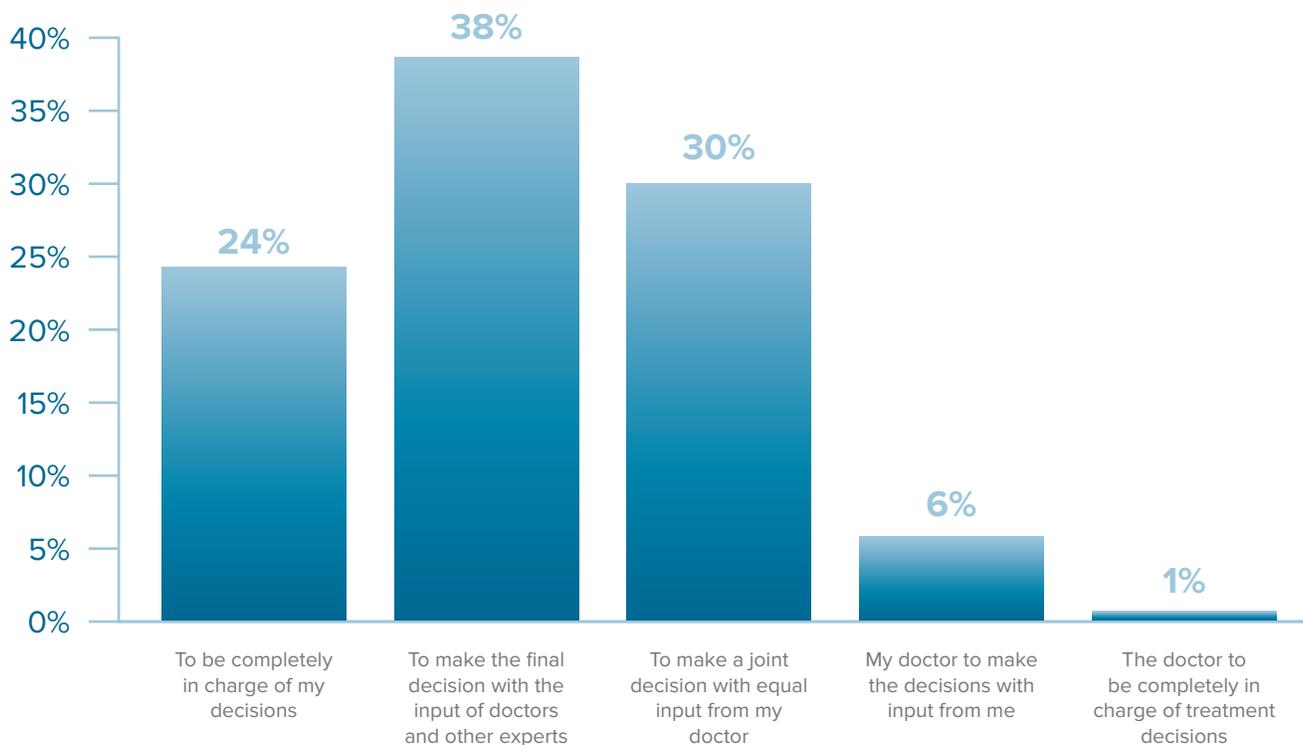
Source: Sepucha KR, Fowler FJ. Measuring Decision Quality: Where We Stand Today. Informed Medical Decisions Foundation, March 2013

Health engagement brings people and their health providers into collaborative decision-making. Figure 2 presents data from a study of patients and providers, illustrating significant differences between breast cancer patients' goals and concerns compared with their doctors.<sup>15</sup> This incongruence could lead to a very different treatment path that overlooks a patient's preference.

### Most patients say they are ready to health-engage

Nine in 10 U.S. adults report wanting to share in healthcare decision making, including 24% who want to be “completely in charge” of their decisions, 38% who wish to make the final decision with input from doctors and experts, and 30% seeking to make a joint decision with equal input from their doctor, shown in Figure 3.<sup>16</sup>

**FIGURE 3: 9 in 10 U.S. Adults (92%) Want to Share Health Decision Making, Spring 2014  
1 in 4 Wants to Be “Completely” In Charge**



Source: Altarum Institute Survey of Consumer Health Care Opinions, Spring 2014

In addition, consumers, caregivers and patients alike are seeking to engage with the health system in the same ways they deal with other facets of daily living. Ninety percent of patients welcome web-based, “self-service” options, such as accessing health information (83%), online scheduling (72%), and refilling prescriptions online (72%). However, nearly one-half of patients are not aware if their health records are available electronically, Accenture found.<sup>17</sup>

Consumer engagement via digital platforms is a work-in-progress, according to Kaveh Safavi, global managing director of Accenture’s health business, who believes the gap between patients and providers will narrow in the next few years. Stage 3 Meaningful Use will, eventually, increase the patient’s ability to self-manage care and access comprehensive data.

“The concept of the patient as a consumer is poorly understood in healthcare,” Safavi says. “Looking forward, these customer-centric models will become an inevitable reality for healthcare, but health systems have a small window of time to leverage them as a differentiator before they become mainstream.”

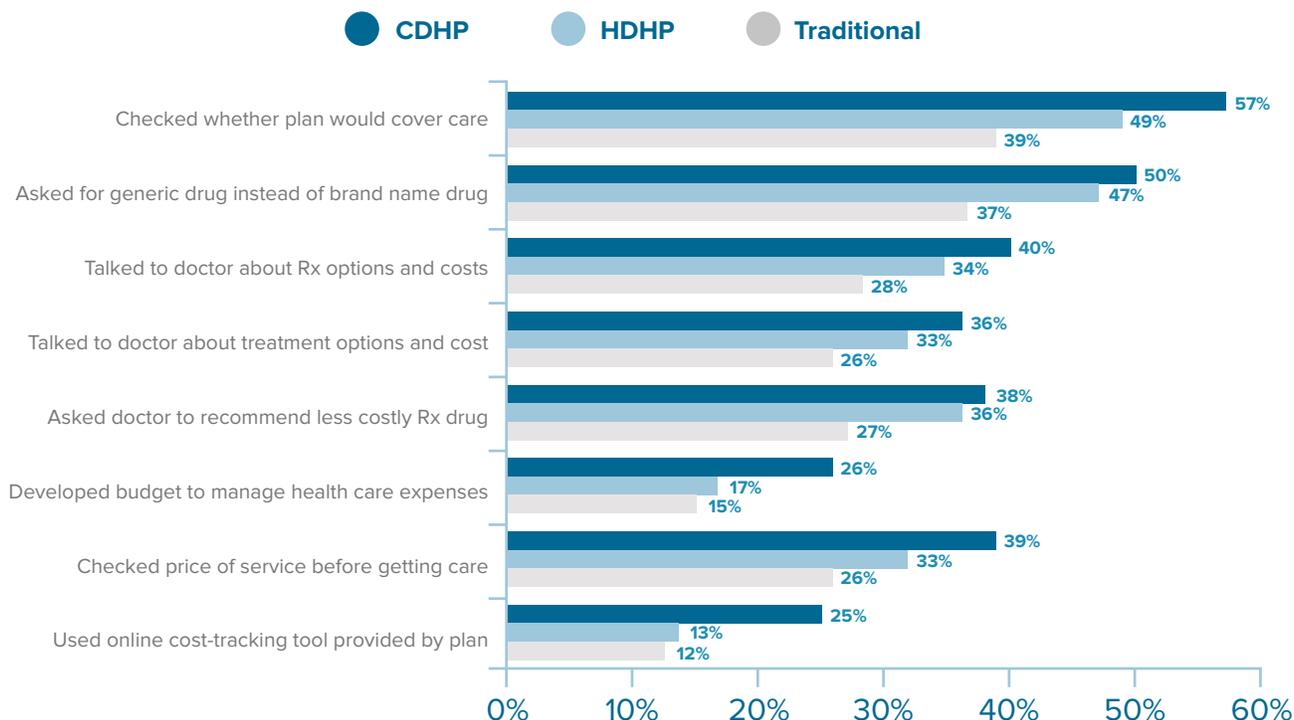
## Changing health financing changes consumers’ and providers’ behavior

Consumers and clinicians are adopting mobile and digital technologies in their lives outside of healthcare, and bringing those personal workflows into health care “life flow.” At the same time, both consumers and providers are dealing with changing healthcare financial arrangements.

In the U.S., consumer-driven plans are fast-growing as employers and plan sponsors look to slow the growth of health costs by allocating greater health financial risk to employees. In 2014, 38% of all workers with health insurance were enrolled in a health plan with at least a \$1,000 deductible,<sup>18</sup> and consumers’ enrollment in high-deductible health plans tripled between 2009 and 2014.<sup>19</sup>

Consumers’ health behaviors are influenced by the type of health plan in which they are enrolled, shown in Figure 4. Members in consumer-directed health plans (CDHPs) and high-deductible health plans (HDHPs) tend to be more cost-conscious than people covered by traditional health plans in seeking health services, such as checking whether their plan will cover care, asking for generic instead of brand name prescription drugs, and broaching the subject of costs with their physicians.<sup>20</sup>

**FIGURE 4: Cost-Conscious Decision Making by Type of Health Plan, 2013**



Source: EBR/Greenwald & Associates Consumer Engagement in Healthcare Survey, 2013

Health providers are facing their own transition to value-based payment, where payors are looking to migrate from paying for volume to paying for value taking various forms, including quantifying improved patient outcomes and population health, bundling payments, and paying for performance. This creates another avenue for patient engagement, for health financial engagement that both transparently informs patients of their payment responsibilities and bolsters providers' collection efforts. The more the patient is included in the conversation, the more likely the provider at risk will be able to manage that risk.

## Coming together, patients and providers – enablers for patient engagement

Consumers and health providers' financial incentives are beginning to align to foster patient engagement. Other factors are also coming into play to grow adoption and deepening of patient engagement and motivate patients and providers to collaborate for health.

*Meaningful Use.* Government mandates and financial incentives are motivating providers to allocate more resources toward workflow and technologies to meet Meaningful Use Stage 2, which emphasizes patient engagement. MU Stage 3 will further expand this requirement, motivating provider investment of even greater time and money toward engagement.

*Consumers as a species are morphing into 'homo informaticus.'* Most people consume media across multiple digital platforms, which deliver just-in-time, personalized information to the digital consumer. "Healthcare's new entrants: Who will be the industry's Amazon.com?" asks PwC's Health Research Institute in a report on the new health economy.<sup>21</sup> As phones, tablets and TVs get smarter and more connected, people take on the persona of *Homo Informaticus*, described in EY's report How to copilot the multichannel journal. *Homo informaticus* is the rational consumer smartly using technology to filter information.<sup>22</sup>

*The power of physicians opening notes.* The OpenNotes project published research in the *Annals of Internal Medicine* measuring the impact on doctors and patients of extending patients access to view their doctors' notes over a secure Internet portal.<sup>23</sup> The trial was conducted with Beth Israel Deaconess Medical Center, Geisinger Health System, and Harborview Medical Center (more providers are involved in Open Notes today). The study found that virtually all patients involved wanted to continue to have access to their doctors' notes. A majority of patients agreed that OpenNotes could have many benefits including taking better care of themselves, enhancing understanding of health conditions, remembering care plans, preparing for visits more effectively, feeling more in control of their care, and improving adherence to medication instructions. Most physicians did not experience significant workflow interruptions or loss of practice productivity.

*Mobile platforms enable health engagement.* Mobile apps and self-tracking devices can help patients help themselves. There is huge promise in the advent of mobile when combined with "big data" analytics and quantified-self (i.e., self-tracking) data to provide in-the-moment, real-time, personally-relevant coaching, education, and support. While there is promise, there is also concern in that many mobile apps' policies allow consumer-generated data to "leak" to third party data brokers who track and analyze data for purposes about which consumers are often unaware.<sup>24</sup> Health data legal experts note that these data flows can fall out of the purview of HIPAA. Beyond these potential privacy issues, both consumers and physicians may have "app fatigue," needing support in identifying the most useful apps for specific patients and circumstances.

*Demand for transparency in health care.* People enrolled in the growing number of consumer-directed and value-based health insurance plans rely on transparency that serves up health service and product costs, quality, and value propositions. There's evidence, though, that the healthcare marketplace has a long way to go to enable people easy access and streamlined experiences for discovering this information. A July 2014 Associated Press-NORC poll found that Americans do not think information about the quality of health providers is easy to come by, and they don't trust information sources that produce this information.<sup>25</sup> The good news for physicians is that consumers say they would trust word-of-mouth recommendations from doctors far more than provider quality data coming from the government or third parties.

*A cautionary caveat: not all patients trust EHR security.* Patients may have mixed feelings about disclosing personal information to physicians who use an electronic health record. "The perception of the technology may elicit non-disclosure as a privacy-protecting behavior," according to a study characterizing EHRs as a "double-edged sword."<sup>26</sup> Recent research finding a positive relationship between EHRs and quality of care can be tempered by a negative side of EHRs with respect to perceived and real privacy and security risks.<sup>27,28</sup> Patient-provider communication should include explicit conversations regarding EHRs' benefits as well as how clinicians protect patient confidentiality and their use of EHRs.

## Data, data everywhere: where's the integration for patient engagement?

While the transition in health financing from volume-to-value is an enabler for patient engagement, the pace of change will vary by geographic market, as well as by providers' cultures and ability to take on financial risk. Furthermore, in the context of patient engagement, the AHA describes the provider mindset as a "professional culture and norms that intimidate patients in approaching their healthcare providers."<sup>29</sup>

The very promising information and communication technologies that can support patient engagement will be disruptive to many providers' existing information and communication technology infrastructures, sunk investments, and workflows.

In his paper on the growing role of patient-centered care, patient safety advocate Dr. Michael Millenson wrote, "Advances in online health information pose an additional challenge. Individuals can go outside traditional channels for tracking vital signs, sophisticated diagnostic and treatment algorithms, and communities of patients and doctors to help interpret the results. In theory, patient-generated data should interface seamlessly with information from health plans, providers, and others. The next round of federal meaningful use regulations for electronic health records is expected to address patient-generated data, but a smooth-functioning electronic partnership remains years away."<sup>30</sup>

The proliferation of consumer-facing digital health devices for both health/fitness and chronic disease management presents a scenario for consumer "small data" creation populating Big Data sets that may challenge the workflow and capacity of the community physician practice. But the supply side of wearable health tech focused on consumers continues to grow, reaching the apex of Gartner's Hype Cycle in 2014. Hyped or not, the Consumer Electronics Association launched the Health and Fitness Technology Division in May 2014, signalling significant growth in this market segment.<sup>31</sup> Similarly, HIMSS' collaboration with Continua Health Alliance and the mHealth Summit in the Personal Connected Health Alliance, formed in February 2014 to promote consumers' use of digital devices to bolster health.

Technology developers and providers keen on health informatics are taking advantage of several strategies to drive interoperability and more streamlined communications, such as the Direct Project, Fast Healthcare Interoperability Resources, Blue Button +, and open APIs, among them.

Building on open APIs, a wild card that could jump-start the patient engagement IT infrastructure, are platforms that are being designed to collect, organize, and analyze patient-generated data that can then be shared with providers' health records systems. The Summer 2014 announcements from Apple HealthKit (working with Epic Systems and Mayo Clinic); Google Fit (allied with Adidas, Basis, Intel, Polar, Withings, among other fitness trackers); Samsung S Health (partnering with UCSF<sup>32</sup> and, possibly, UnderArmour<sup>33</sup>); and WebMD's Health Target, all have ambitious designs in health. Microsoft, too, may be launching a fitness band in the autumn of 2014.<sup>34</sup> To truly support health engagement, these projects must mesh with the healthcare ecosystem – most especially, providers collaborating with patients.

To fill the need for providers looking to "prescribe" digital health devices for patient health engagement, several projects launched in the past year could curate digital health tools for physicians and patients. IMS Health created the AppScript store for doctors to use in accessing mobile health apps, based on functionality, peer (clinician) and patient reviews. Quantified Care set up an online marketplace for clinicians and consumers to locate, in the company's words, "evidence-based mobile apps and devices."<sup>35</sup> The vision of the company, as explained by the editor of Medgadget, would be for a physician to "prescribe a pill and a smartphone-based blood pressure cuff, and it will show you how well the medication is working, and whether the patient is improving their health."<sup>36</sup>

## Make it easier for patients to engage

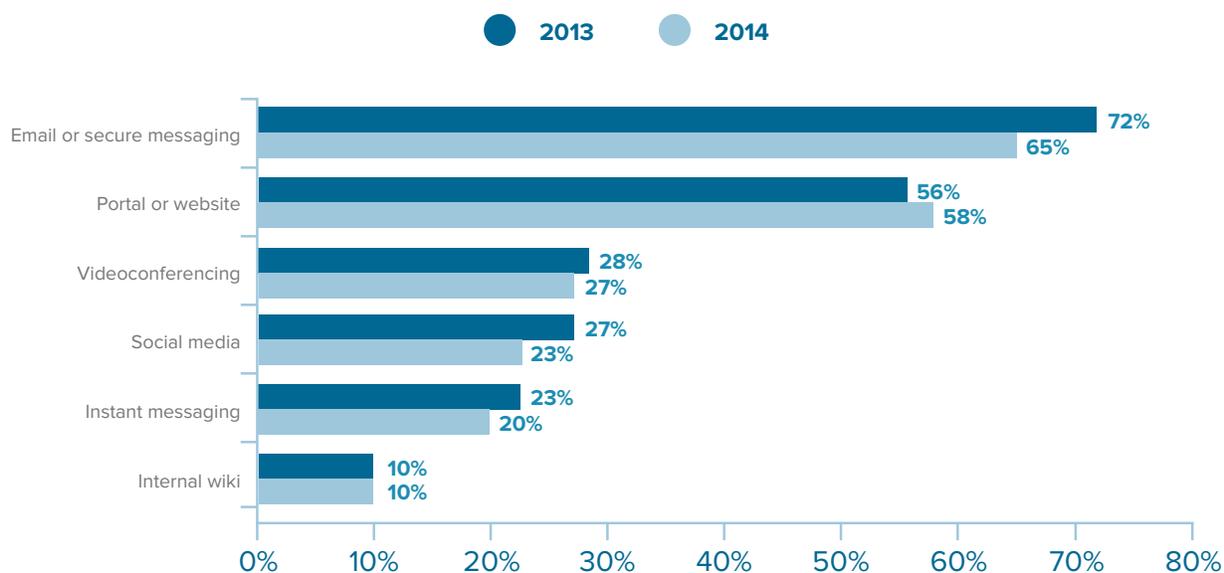
Effective patient engagement technology is not about what people should do, but how to make it easier to do the right thing. For too many patients, and particularly for those people managing multiple conditions, healthcare access is a hassle with different slices of personal data stored with different providers and payers and no "easy button" to press to get a comprehensive view of their health journey.

**What are you doing to build patient engagement bridges using health IT?** Join the HIMSS Connected Patient Community today to share your success stories, lessons learned, and best practices:

<http://www.himss.org/connectedpatient>

The growing use of patient portals, secure messaging (including email), and social media are reducing barriers in communication between providers and patients. Trends for these and other tools for patient collaboration are shown in Figure 5. Dr. Peter Kilbridge, senior director of research at the Advisory Board, has found that, “when I ask [IT teams] what they think of when I say ‘patient engagement,’ they say patient portals.” Dr. Kilbridge warns that IT would do better to focus on the continuum of patient care and communications versus “back into” technology tools that support it. In other words, providers seeking to full engage patients will need to do more than depend on a patient portal or website to meet peoples’ needs along their unique patient journeys.<sup>37</sup>

**FIGURE 5: What the Doctor Ordered: Tools for Patient Collaboration**



Source: InformationWeek Healthcare Priorities Survey, July 2013

*Patients will be engaged when engagement is personally meaningful, trusted, easy and convenient.* This will require health enterprises to think like consumer marketers. A patient is an “N” of 1: with unique demographics, values, clinical indications, genetics, and personal preferences.

“Not all patients are the same, so there are many different ways to engage them, depending on a patient’s skills and interests,” an Issue Brief on engaging patients from Robert Wood Johnson Foundation (RWJF) noted in March 2014.<sup>38</sup> RWJF’s Aligning Forces for Quality (AF4Q) project assessed healthcare quality in 16 communities, identified three factors that improved quality and value in healthcare, all of which speak to patient engagement: (1) encouraging collaboration among patients can help them learn to better manage their own health; (2) by making their practices transparent, providers involving patients in quality improvement efforts can generate insights and improve processes; and, (3) engaging patients to influence health systems or policy takes time and resources, but is critical for changing the culture of healthcare.<sup>39</sup>

This culture change celebrates the partnership between person and provider, and respects the knowledge that patients bring to the table. The Institute of Medicine’s Roundtable on Value & Science-Driven Health Care concluded that prepared, engaged patients are a fundamental precursor to high-quality care, lower costs, and better health.<sup>40</sup> Health information technology will play a transformational role in supporting this cultural change and building bridges between people and providers. Health providers and patients, consumers, caregivers, and alike, should partner to build those bridges and cross the chasm for shared decision-making.

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- <sup>1</sup> Institute of Medicine. Partnering With Patients to Drive Shared Decisions, Better Value and Care Improvement. Workshop Proceedings. Washington, DC: National Academies Press, 2013
- <sup>2</sup> HIMSS Foundation and National eHealth Collaborative. Patient Engagement Framework. Accessed at: <http://www.himss.org/ResourceLibrary/genResourceDetailPDF.aspx?ItemNumber=28305>
- <sup>3</sup> Coulter A. Engaging patients in healthcare. New York (NY): McGraw-Hill Education; 2011, p 10
- <sup>4</sup> Center for Advancing Health. A new definition patient engagement: what is engagement and why is it important? Washington (DC): CFAH; 2010
- <sup>5</sup> <http://www.insigniahealth.com/solutions/patient-activation-measure>
- <sup>6</sup> Hibbard JH, Gillbert H. Supporting people to manage their health: An introduction to patient activation. The King's Fund, May 2014
- <sup>7</sup> HIMSS Foundation and National eHealth Collaborative. Patient Engagement Framework. Accessed at: <http://www.himss.org/ResourceLibrary/genResourceDetailPDF.aspx?ItemNumber=28305>
- <sup>8</sup> Hibbard JH and Cuningham PJ. Research Brief No. 8: How Engaged Are Consumers in Their Health and Health Care, and Why Does It Matter? Washington: Center for Studying Health System Change, 2008
- <sup>9</sup> James J. Health Policy Brief: Patient Engagement. Health Affairs, February 14, 2013
- <sup>10</sup> Veroff D, Marr A and Wennberg DE. Enhanced Support for Shared Decision Making Reduced Costs of Care for Patients with Preference-Sensitive Conditions. Health Affairs, 32(2):285-93, 2013
- <sup>11</sup> Mitchell SE et al. Patient Activation and 3-Day Post-Discharge Hospital Utilization. Journal of General Internal Medicine, 29(2):349-55, 2014
- <sup>12</sup> Hibbard JH, Greene J, Overton V. Patients with Lower Activation Associated with Higher Costs; Delivery Systems Should Know their Patients' 'Scores.' Health Affairs, 32(2):216-22, 2013
- <sup>13</sup> Weingart SN. Patient Engagement and Patient Safety. Agency for Healthcare Research and Quality, Perspectives on Safety, February 2013. Accessed at: <http://webmm.ahrq.gov/perspective.aspx?perspectiveID=136>
- <sup>14</sup> Brimmer K. New technologies, hospital strategies promote patient engagement. Healthcare Finance News, June 2, 2014
- <sup>15</sup> Sepucha KR, Fowler FJ. Measuring Decision Quality: Where We Stand Today. Informed Medical Decisions Foundation, March 2013
- <sup>16</sup> Lynch W, Perosino K, Slover M. Altarum Institute Survey of Consumer Health Care Opinions. Spring 2014
- <sup>17</sup> Accenture. Is healthcare self-service enough to satisfy patients? The Accenture Connected Health Pulse Survey, 2012
- <sup>18</sup> The Kaiser Family Foundation & Health Research and Educational Trust. Employer Health Benefits, 2013 Annual Survey
- <sup>19</sup> PwC, Health Research Institute. Medical cost trend: Behind the numbers 2015, June 2014
- <sup>20</sup> Employee Benefit Research Institute. Consumer Engagement Among HAS and HRA Enrollees: Findings from the 2013 EBRI/Greenwald & Associates Consumer Engagement in Health Care Survey, Notes, June 2014, Vol. 35, No. 6

- <sup>21</sup> PwC. Healthcare's new entrants: Who will be the industry's Amazon.com? Health Research Institute, April 2014
- <sup>22</sup> EY. Consumers on board: how to copilot the multichannel journey, 2014
- <sup>23</sup> Delbanco T, Walker J, Bell SK, Darer JD, Elmore JG, Farag N, Feldman HJ, Mejilla R, Ngo L, Ralston JD, Ross SE, Trivedi N, Vodicka E, Leveille SG. Inviting Patients to Read Their Doctors' Notes: A Quasi-experimental Study and a Look Ahead. *Annals of Internal Medicine*. 2012;157(7):461-470
- <sup>24</sup> Sarasohn-Kahn J. Here's Looking at You: How Personal Health Information is Being Tracked and Used. California HealthCare Foundation, July 2013
- <sup>25</sup> Associated Press-NORC Center for Public Affairs Research. Finding Quality Doctors: How Americans Evaluate Provider Quality in The United States. July 2014
- <sup>26</sup> Campos-Castillo C, Anthony DL. The doubled-edged sword of electronic health records: implications for patient disclosure. *Journal of the American Medical Informatics Association*. Online First: 31 July 2014
- <sup>27</sup> Blumenthal D. Launching HITECH. *New England Journal of Medicine*. 2010;362:382-5
- <sup>28</sup> Technology PsCoAoSa. Report to the President Realizing the Full Potential of Health Information Technology to Improve Healthcare for Americans: The Path Forward., 2010
- <sup>29</sup> American Hospital Association (AHA). Engaging Health Care Users: A Framework for Healthy Individuals and Communities. January 2013
- <sup>30</sup> Millenson ML. Paradigm, Not Pill: The New Role of Patient-Centered Care. National Institute for Health Care Management Foundation. February 2014
- <sup>31</sup> Consumer Electronics Association. CEA Announces Formation of Health and Fitness Technology Division. Press release, May 1, 2014
- <sup>32</sup> Bole K. Samsung, UCSF Partner to Accelerate New Innovations in Preventive Health Technology. Pair Will Work to Validate Promising New Sensors and Analytics for Next-Generation Digital Health Solutions, UCSF press release, February 21, 2014
- <sup>33</sup> Sun L. Will Samsung Partner With Under Armour to Beat Apple and Nike? *Motley Fool*, July 20, 2014
- <sup>34</sup> Mayton J. Samsung, Apple, Microsoft face off in the wearable tech war. *Tech Times*, May 30, 2014
- <sup>35</sup> Schiller B. A Mobile Health Care Marketplace That Curates The Best Technologies. *Fast.Co Exist*, July 21, 2014
- <sup>36</sup> Ibid.
- <sup>37</sup> Murphy C. Patient Engagement. *InformationWeek*, July 2013. Based on InformationWeek's Healthcare IT Priorities survey of 363 providers in 2012 and 337 providers in 2013
- <sup>38</sup> Robert Wood Johnson Foundation. What We're Learning: Engaging Patients Improves Health and Health Care, Quality Field Notes, Issue Brief, Number 3, March 2014
- <sup>39</sup> Ibid.
- <sup>40</sup> Institute of Medicine. Partnering with Patients to Drive Shared Decisions, Better Value, and Care Improvement. Meeting Summary, August 2013