

**Moving Beyond the Tipping Point to Create a Person-Centered Health-Care System in
America One Patient at a Time**

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Section I: Context

Patient-Centered Care, Engagement and Choice: Easy Win, Hard Sell

“Respect for Autonomy” is the first principle of medical ethics. And individualism is the defining attribute of American culture. In this regard, the concepts of engaging patients in decision-making and choices about their own health care have already won. While these notions have long been a part of the rhetorical fabric of American health care, only recently has engaging and partnering with patients and empowering them with the once protected (or simply non-existent) information and tools to make informed decisions made its way as a strategic pillar of prominent health care strategies in America today. It seems we have entered a time of widespread consensus that ensuring good quality-care—and the positive health outcomes associated with it—is substantially related to whether consumers and patients are able to play a significant role in selecting, managing and evaluating their own care.

Both Federal health care reform strategies such as the Institute of Medicine’s Crossing the Quality Chasm “Ten Rules” for transforming health care in America and the President’s New Freedom Initiative as well as private sector frameworks for health care quality improvement, such as the “Chronic Care Model”, do more than portray patient engagement and choice as mere niceties. Rather, they place these goals squarely in the vital center of defining and ensuring good health care—and at the heart of defining a person-centered health care system.¹⁻³ In this way, recent reform models appear to be falling into step with both public sentiment and the evidence-base, which tell us that partnering with and creating a health care system that gives consumers information to make good choices and is responsive to patients values and preferences is as central to good health outcomes as doing the right test or procedure and is often the explanation for success on this front as well.⁴⁻⁸

Institute of Medicine Crossing the Quality Chasm Strategy Ten Rules for Transforming Health Care in America
Safety: The health system will be set up to prevent and reduce errors. If a mistake occurs, you will be notified and those responsible will apologize.
Beyond Patient Visits: Help will be available by face-to-face encounter, e-mail, telephone, and the Internet.
Cooperation: Your clinicians will coordinate their efforts with each other and with you.
Science: Your care will be based on the best available scientific knowledge.
Individualization: Your clinicians will adapt to meet your needs and preferences.
Control: You are the source of control.
Information: Your medical record is yours to keep.
Anticipation: Efforts will be made to proactively help you restore and maintain your health.
Transparency: You are entitled to know what you wish to know about your care, including information about clinician performance, alternative treatment options and costs of procedures.
Value: Your money and time will be valued, not squandered

By taking patient-centered care, engagement and choice seriously, health care in America is seeking a new maturity that (1) acknowledges the importance of shifting the current balance of power toward partnership and engaging patients and consumers in the design and delivery of health care (2) recognizes the pervasive influence of relationship and communication in the success of all health care encounters and (3) accepts the reality that major improvement is required and embraces the need to continuously articulate, examine, report on and innovate to improve performance on achieving our goals for patient care. Using a patient-centered care line of reasoning the conclusion is that it is not enough to *do* the right thing if what we are interested in are positive health outcomes and establishing a culture of respect and dignity in health care. If we pursue the flavor of patient-centeredness and engagement reflected in prominent initiatives to transform health care in America, health care providers in particular (and the systems that support and influence them) are also called to *be* different. They are called to engage in highly personal tasks to (1) become conscious of and committed to improving their own relationship, communication, advocacy and negotiation skills as well as (2) cooperate in making their performance transparent (if even only to themselves) and (3) proactively shifting relationships with patients and families to one of partnership versus paternalism. To some, this is a lot to ask. To others, it is *the* make-or-break developmental task for health care in America—the failure of which will set us further behind in health outcomes and further ahead in economic burden. On the other hand, while hard-won, success in this area may come as a relief as health care sheds its burdensome mask-of-perfection and enters into the potentially enlivening, co-creative process of patient care suggested by the brand of patient-centered care, engagement and choice currently promoted.

Definition of Patient-Centered Care

While it is always hazardous to suggest a definition for such broad and related yet distinct concepts such as patient-centeredness, engagement and choice, both the IOM “Ten Rules” above and following definition of patient-centeredness, which incorporates the concepts of engagement and choice, are set forth as proxy anchors for this discussion:

Patient-centered health care is health care that establishes a working partnership with patients and their families to ensure decisions are made that respect and honor patients’ wants, needs, and preferences and to ensure that patients have the education and support they need to make informed decisions and act as a central resource in their own health and/or the health of their family.

Patient centered care, as defined here, mediates the achievement of other health care system aims such as patient safety, promptness, effectiveness, efficiency and equity. With patient-centered care consumers have information to make good health care choices. During health care encounters, the door is proactively opened for patients to raise issues, questions and concerns -- issues, questions and concerns that can dramatically improve provider understanding and the effective treatment of patients. Translated to the level of the care system, a practice of patient centered care requires routine assessment of the health needs, values and preferences of the population served and the design of delivery systems according to what is learned. This practice can impact (1) what information is made available to consumers to help them understand the health care system and make good health care choices; (2) what care is made available; (3) where

and when this care is made available; (3) the physical setting for care and (4) strategies for educating and supporting providers to practice care in a way that is responsive to the culture, preferences and unique context of their patients.

Where is the Evidence?

Consumer Choice

The driving hypothesis regarding consumer choice is that giving consumers information to select health plans, hospitals and doctors based on quality as well as cost will drive improvements in health care and outcomes by rewarding high-performers with increased market share and revenues.⁹ To date, there is no evidence that this has yet occurred.¹⁰⁻¹¹ However, while fewer than 30% of consumers report seeing information on quality when making health care choices, there is evidence that consumers want information about quality. There is also evidence that public reporting of this information stimulates efforts to improve care by health care providers.¹²⁻¹⁶ Preliminary studies also suggest that the logic of consumer choice may work better for selecting doctors vs. health plans or hospitals.¹⁷⁻¹⁸ For instance, a study conducted in a Kaiser Permanente health plan showed that when health plan members were given provider-specific information to aid in the selection of a primary provider, these individuals were much more likely to perceive that they did in fact choose their primary provider (78% vs. 22% not receiving information) and to retain their primary provider after one year (93% vs. 69% not receiving information). PacifiCare has had similar findings for health plan members that access and use their provider Quality Index. Most studies conclude that the overall lack of evidence regarding the effective use of health care quality information to aid consumers with health plan or provider choices is largely due to the lack of salience, evaluability and accessibility of this information as well as competition with larger factors that drive patient choice, such as cost and convenience.¹⁹⁻²³

Patient-Centered Care and Engagement

Unlike in the area of consumer choice, there is an accumulating body of evidence on the value of other aspects of patient-centered care such as partnering with patients to support self-care, shared-decision making and overall patient activation.^{4-8, 24} In addition to the obvious face value of patient-centeredness (or family-centeredness in the case of children and other dependent populations), emerging patient engagement strategies can now link their efforts to all manner of positive events such as:

- Improvements in the adherence to medical advice, self-care and health outcomes
- Decreases in negative events requiring hospitalization and emergency room use
- Increases in the provision and consent to needed services (e.g. mammography)
- Prevention of negative events and safety errors
- Reduction in elective health care procedures and treatments and, hence, costs of care
- Increased consumer satisfaction and less decisional conflict
- Changing unhealthy behaviors/adopting healthier lifestyle
- Reduced health-related psychosocial and emotional distress and its often dramatic effects
- Improved self-reported health status (e.g. pain, energy level, ability to do things)
- Improved performance on clinical indicators (e.g. blood pressure, blood sugar levels)

It is important to note that the majority of the evidence applies to people with chronic conditions and has largely focused on the self-care education and support and shared decision making components of patient-centered care. In these cases we find that patient-centered care has significant positive predictive power for a variety of outcomes such as those listed above. That is, with these features in place, a variety of outcomes are more likely. In contrast, the more general aspects of patient-centered care, such as provider communication and trust, more often have a strong negative predictive power. That is, if patient-centered care is not present, it is not likely that other aspects of good care occurred. However, there are many cases where these aspects of patient-centered care are present and good clinical care and outcomes are not. For example, in the area of early childhood preventive and developmental services we find that without family-centered care (defined more generally as respect, listening and cultural sensitivity) it is highly unlikely that parents received recommended anticipatory guidance and parental education. Yet, it is not the case that those reporting positive family-centered care are highly likely to receive recommended care.²⁵

Where are Patients and the Public?

Most consumers report that they would like more information to make choices among health plans, doctors, hospital and other providers. Only 32% report that the current certification and licensing requirements of doctors are very effective in ensuring high quality care. (KFF 2002). Yet, only 2 of 5 believe that there are big differences in the quality of care provided by doctors, specialists and different hospitals. The same number says the ratings by consumers of quality would greatly influence their choice of doctors. (KFF 2002)

While patient-centered care and patient engagement and activation have both been linked to improved health outcomes and reduced health care costs, the majority of patients continue to report significant problems receiving care that is patient-centered (KFF 2002, KFF 2003, EBRI 2002):

- 68% say they are very or extremely concerned about the quality of health care
- 42% say they have personally been involved in a medical error situation
- 72% say that the medical error they experienced was due to doctors not having enough time
- 53% say the problems they experience with quality relate to being treated with dignity
- 75% say the problems they experience with quality relate to being listened to
- 63% say the problems they experience with quality relate to not getting needed information

A wealth of data from numerous public polls and surveys and over 100 consumer and patient focus groups confirm the importance of patient-centered care, engagement and choice to American consumers and patients. These and related findings have led to the incorporation of patient-centered care as a discrete category in national frameworks for quality information.^{13,27-29} Studies demonstrate that consumers describe health care topics within the rubric of patient-centered care as the most tangible aspect of the health care system:

- having systems designed so that they are accessible and convenient
- the communication, respect, trust and caring they experience with providers
- having their unique circumstances and values considered in the diagnosis and treatment of illness
- understanding options and being involved in making medical decisions

- their ability to get the information, education and support they need to care for themselves and prevent and manage their own health
- getting support and follow-up to manage a complex health condition.

Consumers often describe these features of health care as what makes up a good health care system. When describing what makes up poor quality care, consumers often refer to failures in patient-centered care. In the absence of patient-centered care, as defined here, patients report experiencing:

- Hurried and unavailable providers
- Use of terms and language that creates a basic and unacknowledged barrier to communication
- Being discouraged from sharing information they view as important to good diagnosis and treatment decisions and adherence to medical advice
- Not understanding their condition, goals for treatment, why medical recommendations were made or how to follow these recommendations
- Not having options presented or discussed and not discussing alternative options that they are considering (e.g. natural therapies) or simply not having these options taken seriously
- Not having medical decisions explained and being discouraged from challenging those decisions even if they suspect a medical error or misapplication of treatment
- The artificial segregation of the emotional and intellectual decisions involved in making health care choices and little consideration of their day to day or cultural context and how that affects their ability to stay healthy and follow medical advice Hard, but important, issues avoided – especially if they are personal, emotional, or spiritual.
- Insensitivity to physical pain, emotional distress and confusion about what is happening
- Unnecessarily uncomfortable, cold or disrespectful physical environment in the carrying out of medical inquiries or procedures

Consumers acknowledge that patient-centered care may take more time during certain health care encounters. However, they frequently share their own anecdotal examples of how patient-centered care can prevent negative health events and save time and need for services overall.

Exhibit A: A Recent Dialogue About Ian (age 7) and Family-Centered Care

N: I heard Ian was in the hospital all last week. How are things going for him and his family now?

C: Truthfully, things are a nightmare. As you know, Ian—who is a treasure and very bright--has had symptoms for several years, including an inability to attend school for long stretches. It took this recent and very scary escalation in symptoms and a week in the hospital for him to be diagnosed. Since his near fatal reaction to a medication error when he was three *{Ian was given penicillin even though he is allergic. The doctor did not read the chart and his mom assumed that the med was not penicillin-based as she told the doctor he was allergic}*, his mom has been gunshy about doctors. She has no information to use to find out who would be good for Ian’s condition and who would be open to helping to coordinate with the school and the 2-3 specialists the hospital doctors say he’ll need. Now that he has this diagnosis no PCP so far will take him in her area—one turned him down only after they drove all the way to the office for an appointment. The specialists he needs in the area do not have appointments for 4 months and none offered to help with an interim plan. All of this even though they have United Health Care and BCBS for Ian. Ian’s mom is alone with him because her husband is four hours away so he can work and keep their health insurance – which they really can not risk losing now. She is in a little pile right now and needs help herself. Ian needs medication ASAP so he can get his condition managed before he starts school and maybe we can take him on a little vacation so he can feel normal again. We can’t do either until he gets care as he is really too

symptomatic to function. Ian's parents are very worried about the meds as few of the choices have been tested for use with children. Anyway, this is too much for her to handle without care coordination or family support/respite. You know the story. She can't even get a babysitter who is trained to handle his issues. With his symptoms Ian is too scared to be alone and the only way she can make calls to arrange things is to put him in front of the TV – which seems to escalate his symptoms. He still hears her talking. We must stay mindful of Ian's growing awareness that he is being “rejected” from school, from PCPs, etc. He needs to have a welcoming and good experience. His mom's stress elicits hesitancy and not help from providers. She needs help so she can take care of herself – she can't exercise, socialize or begin to think about getting a job.

N: I'm so sorry she is having such problems living the microcosm of all that's wrong with health care for children. Do you know “CSHCN Doc”? Though it is far away he might be a candid resource and be able to advocate directly for an appt. with specialists if the hospital records could be sent over. Remember, Ian's condition is a treatable condition in an otherwise (I am sure) handsome, healthy, very capable little boy. The challenge is helping all of those involved in Ian's life, particularly teachers and school staff, to understand this. At some point, it will be important for someone with knowledge and expertise to do a school in-service so they can understand this as a chronic condition, not as misbehavior. You'll have a fight to get that, care coordination and respite care covered by insurance –the three things besides the medication and therapy that are most needed. Let's keep up the fight!

C: Thank you N. We'll see if the social worker from the hospital can fax the records to “CSHCN Doc” –the hospital specialists who cared for Ian both went on vacation without writing their final reports on Ian. So, it might be another two weeks – but we can't wait!

Section II: Current Status

Patient Engagement and Choice Strategies: Beyond Tokenism, Toward Improvement

A key sign that our goals for patient-centered care, engagement and choice are moving beyond rhetoric in America is the nature of the policies and strategies being employed to implement these values in both the public and private sectors. Taking a developmental perspective, health care in America has achieved many important developmental milestones on the road to maturity and maximizing its potential. Broadly speaking, the public and private sector policies and strategies to advance patient-centered care, engagement and choice may be categorized into three areas:

1. Helping consumers choose health plans, insurance coverage and doctors
2. Activating patients to share decisions and manage their own care
3. Building public will and advancing evidence-based advocacy

What follows is a short summary of examples of activities in each of these areas. A full discussion on each activity is beyond the purview of this paper.

Efforts to help consumers choose health plans, insurance coverage and doctors

“The amount and nature of risk perceived by the customer during purchase has been recognized as important in defining the customer's information needs and in predicting the acquisition, transmission and processing of information during the decision making process.” Dholakia, 1997

Several notable private sector efforts to engage and empower consumers and patients to choose health care plans and health care providers are underway. Examples include:

1. **Employer-driven consumer-directed health care plans.** Here consumers assume increased financial risk for the selection of their care. Theoretically, this increased financial risk will motivate consumers to seek out and make informed decisions and reduce the unnecessary or discretionary health care expenditures employers no longer want to be at risk for. Some say that it is incumbent upon employers who require consumers to direct their own care in this way to ensure they have good information for making choices. Whether these plans are or ever can really be “consumer-directed” is a topic of substantial debate in the field.
2. **Health plan-driven doctor choice initiatives.** Increasingly, health plans are providing their members with comparative quality information to use when selecting a primary provider. In this way, health plans such as Kaiser Permanente and PacifiCare take the theory of consumer choice “in-house” rather than placing it in the broader market arena. Evaluations to date suggest that this information does influence member decisions and motivates provider efforts to improve.
3. **Accrediting organization-driven performance assessment efforts** such as The National Committee on Quality Assurance and the Joint Committee on Accreditation of Healthcare Organizations. Consumers can use the internet to find out if a health care plan or organization has been accredited by NCQA or JCAHO. Information on individual measures that make up accreditation decisions is not available for public release.
4. **Public and health industry-driven efforts to develop public performance information.** The National Quality Forum, which is largely comprised of health-industry organizations who also play a strong functional role in defining quality measures, is engaged in an extensive process to define quality measures for various health care settings and topics. To date, implementation has not taken place and the NQF does not have authority to require data collection or reporting. The purchaser and consumer members of the NQF have developed a separate organization called The Disclosure Group to ensure a greater focus on purchaser and consumer interests in the specification and implementation of quality measures. While consumer and patient reported information is essential to measuring consumer relevant aspects of quality, the NQF has neither seriously considered nor endorsed any such measures to date.

Public sector efforts include the many activities underway to help Medicare beneficiaries make good health plan and prescription medication card choices as well as those of the Federal Office of Personnel Management and the Veterans Health Administration. Major advances have taken place in Medicare in the area of public information on long term care and home care as well as hospital care. Work is underway to develop a doctor quality measurement effort. Even though Medicaid represents 20% of all of America’s children, currently no requirements for measurement and disclosure of quality and other consumer choice information are in place in Medicaid.

Status: Despite the near heroic efforts of many over the last decade, few people have access to or are able to effectively use available information to assist them in making choices among health plans, doctors, hospitals or other providers. The most widely available quality information is that provided using the National Committee on Quality Assurance’s Health Plan Employer Data and Information Set (HEDIS). HEDIS has the potential to provide 25% of insured persons and 75% of those enrolled in Health Maintenance Organizations with basic

information about health plan quality. Yet, few report seeing or being able to understand or use this information. While not made apparent to consumers, many quality reports are misleading due to the use of “grading on a curve” methods. For example, in a state report on commercial HMOs using HEDIS measures there were 39 times a health plan was given the highest grade possible (a full circle symbol) on the HEDIS chronic condition measures, yet in only 46% of these cases were health plan performance scores at or above 70—the score at which consumers and experts often report comfort in labeling performance as “good”.^{26, 22} HEDIS data can be searched online or purchased. However, health plan level results often conflict with the provider level information set forth by these same health plans, accreditation levels all appear to consumers to be “good” and measurement scoring models often hide real performance, which leaves consumers with information that confuses and diffuses distinctions for making decisions.^{20, 34-35}

Exhibit B: Current Events: June 14th 2004

Response to finding that low-income seniors are not signing up for Medicare RX cards

AARP Response: “When there are too many choices, information overload and lack of preparation we get consumer confusion and resistance.” (personal communication with John Rother, June 14th 2004)

President Bush’s Response: “Just because it may seem complicated, I think people should not use that as an excuse because there’s good discounts, there’s good savings.” (National Public Radio Morning Edition, June 14 004. <http://www.npr.org/rundowns/rundown.php?prgId=3&prgDate=15-Jun-2004>)

Strategies to activate patients to share decisions and manage their own care

“The greater the degree of participation of the intended audience in the communication process, the earlier the time at which members of the audience will decide to implement the recommended change.” Zaltman and Wallendorf, 1979

Many provider, health plan and industry sponsored efforts to activate consumers and patients to become informed and engaged in their health and health care are underway in America.

Examples of efforts to **encourage providers to proactively engage and activate their patients** include:

1. **The Chronic Care Model:** This model of care is central to most prominent health care quality improvement efforts nationally.³ At the center of this model are productive interactions between providers and patients –which require patients to be informed and activated and provider teams to be prepared and proactive. Recent examples set forth by Don Berwick of how this model can lead to changes in practice include that of a young person with diabetes who was allowed to choose the method of treatment for her diabetes based on her own preferences. While the selected treatment was not that recommended by the provider, the youth was able to implement it thereby making greater strides in improved health outcomes than if the provider insisted on his first line of treatment. Many tools and research is needed to further define and ground the “informed and activated patient” component of the care model.
2. **Decision-support:** Many tools, such as the Healthwise Knowledgebase, are emerging to give providers and others interested in informing and engaging patients with tools to help them learn about and make patient-centered choices among treatment options.²⁴ These tools are largely proprietary and not in the public domain.

3. **Information therapy:** This model likens “information” to prescription medication, suggesting that we need to prescribe information to consumers and patients in the same way that we would prescribe a medication-taking into account dosage, frequency, etc.³⁶

Examples of efforts to **directly encourage consumers and patients to be more active** partners in their health and health care include:

1. **“Take Charge of Your Health Care” Campaigns:** Pfizer’s Ask-Me-3 campaign is a good example of several efforts to encourage and provide support tools for patients to routinely ask doctors questions and break through the intimidation and hesitancy many have in doing so. Ask-Me-3 encourages all patients to ask “what is my main problem”, “what do I need to do” and “why is it important for me to do this”. Another example is the United Health Foundation’s “Take Charge of Your Health Care” campaign. Two examples of their recent consumer advertisements are provided in Exhibit C below. Campaigns such as that sponsored by Governor Huckabee in Arkansas are additional examples of efforts to educate and engage the public. However, this last example also provides lessons on the conflicts policymakers face when encouraging healthier behaviors that may adversely impact certain business sectors. (Exhibit D)

Exhibit C: United Health Foundation Public Activation Campaign: Two Example Advertisements

New York Times Magazine:

The setting: Man sitting naked draped with a gown in an examining room.

The text: “Medical studies indicate most people suffer a 68% hearing loss when naked.”

Oprah Magazine:

The setting: A woman sitting on an examining table obviously bored and mystified by the equipment around her.

The text: “There are 126 schools in the country that teach you how to be a physician but not one for how to be a patient.”

2. **Cycle of Engagement: Family-centered quality improvement:** The Child and Adolescent Health Measurement Initiative promotes a Cycle of Engagement that creates family-centered model of quality improvement driven by family reports of priorities and needs to ensure a personalized agenda and family reported quality of care. The model creates partnership with providers and encourages open dialogue between pediatric clinicians and patients regarding quality goals and status as well as to provides clinicians and families with information from parents about the quality of their child’s care. Efforts to further develop and evaluate this model are underway.
3. **Personal Health Records:** A central activity for engaging and activating patients is to give them access to their own medical records and encourage them to keep a personal health record that can serve as the primary coordinating center for all their health information. They decide who has access to this information, can edit it to reflect their own perceptions and values and so on. The Markle Foundation is leading this effort with others.
4. **Internet Health Information:** Internet based health care information continues to evolve to support consumer and patient self-education and activation. WebMD is a good example of this. In addition to general information, the internet is beginning to be used to provide consumers with tools to self-evaluate the quality of their current health care providers and receive information on how to improve their care. FACCT’s CompareYourCare is an example of this. This tool is in use in several health plans but is not publicly available. No tools such as this have yet led to comparative quality information that can be used to help

consumers choose among providers—which was the original vision for CompareYourCare (e.g. consumers contribute information to a local data base that builds over time to have sufficient sample to begin to profile health care providers in that area).

**Exhibit D: Current Events: June 14th 2004
Governor of Arkansas Promotes Healthy Eating and Weight Loss**

A strong message: Using himself as an example, Governor Huckabee is leading a very personal public education initiative urging Arkansians to lose weight and get fit. He admits that the biggest issues for him were lack of education about nutrition and lack of support and motivation.

A mixed message: When pressed, Governor Huckabee comes out against fast food labeling of the nutritional value of their food saying there should be “no grease police”. He explains that “American’s are such an independent group of people...even if it is to the liberty to choose stupid things...McDonalds’ did not make me fat, I made myself fat...One of the things people have to stop doing is blaming other people for their condition.” (National Public Radio Morning Edition, June 14 2004, <http://www.npr.org/rundowns/rundown.php?prgId=3&prgDate=15-Jun-2004>)

Status: Despite consumer concerns and efforts to engage patients, still today relatively few are activated and engaged. That is to say, few believe an active role in making treatment decisions and managing their own health care is critical to their health and/or have the confidence and knowledge to take action or stay the course in managing their health and health care under stress.²³⁻²⁶ Still, thanks to the internet, many more consumers than ever are obtaining and using information and tools to learn about and improve their own health.³¹⁻³³

Efforts to build public will and advance evidence-based advocacy

“Low-knowledge buyers are influenced by price frames. High-knowledge buyers are influenced by outcome frames.” Smith and Wortzel, 1997

Several efforts seek to educate the public about health care quality and the need for consumer and patient engagement. Goals for these efforts include generating public demand for health care quality information and policy changes required to advance patient-centered care, engagement and choice. Activities in this category include:

1. **National health care quality reports.** The Congress has mandated that the Agency for

Healthcare Research and Quality produce yearly reports on health care quality and health care disparities in America. In addition, the Institute of Medicine and private organizations such as The Commonwealth

The image shows a slide titled "National Healthcare Quality Report Framework" with the subtitle "Components of Health Care Quality". It features a table with "Health care needs" on the y-axis and "Effectiveness", "Safety", "Timeliness", and "Patient centeredness" on the x-axis. The y-axis categories are "Staying healthy", "Getting better", "Living with illness or disability", and "End of life care". The table is currently empty. Below the table, there are three bullet points: "Equity is a component of health care quality that applies to all cells in the matrix", "Resource generation is another component discussed in the National Healthcare Report", and "The first NHQR is due to Congress in 2003". At the bottom, there are logos for SAMHSA, HRSA, CDC, and CMS.

Health care needs	Effectiveness	Safety	Timeliness	Patient centeredness
Staying healthy				
Getting better				
Living with illness or disability				
End of life care				

- Equity is a component of health care quality that applies to all cells in the matrix
- Resource generation is another component discussed in the National Healthcare Report
- The first NHQR is due to Congress in 2003

Fund continue to develop and issue reports on health care quality and reform. With varying success, these efforts are designed to raise public awareness and stimulate change. When the Institute of Medicine “To Err is Human” report was released it garnered tremendous public attention and raised the level of awareness and activity to address patient safety problems in America. A Kaiser Family Foundation poll found that 51% of the public said they followed the safety errors story very or somewhat closely. This and similar efforts are good examples of the power of communicating information to effect change

2. **Providing access and supporting advocacy use of publicly collected data.** The public and private sector spends hundreds of millions of dollars each year collecting information on the health of Americans and the quality of care they receive. Yet few have the skills or knowledge to access and use this data. A small wave of efforts is emerging to allow the public and advocates easy access in using this information that are directed at the public and consumer advocacy organization. An example includes the Children and Youth With Special Health Care Needs Data Resource Center (DRC). The online DRC is accompanied by in-person evidence-based advocacy trainings (www.cshcndata.org).

Section III: Next steps for advancing patient engagement and choice

The current trend to take our commitment to patient-centered care, engagement and choice beyond the tipping point is preceded by the decades-long efforts of many tireless advocates, researchers and innovative providers and policymakers – many of whom were “converted” by personal experiences of pain and loss inescapably linked to health care’s failures in patient-centeredness, engagement and choice. These leaders continuously remind us that patient-centered care, engagement and choice, like all other aims for transforming health care in America, will not sink below the surface of innovation to become a part of the firm foundation of health care in America until and unless these goals and the values they represent are embedded in the perspectives, policies and practices of patients, providers, purchasers and policymakers. The most rate-limiting barriers to ensuring that the required will, knowledge, information and incentives are in place at each level of the health care system to advance patient-centered care and choice are (1) the culture of medicine (2) health care financing and incentives and (3) the information infrastructure. Virtually all proponents of patient engagement and choice acknowledge that creating a truly person-centered health care system will involve:

1. fundamental changes in perspectives and practices of both patients and providers alike – patients must want to be engaged and make choices, be given real and timely mechanisms and providers need to proactively encourage and assist them in doing so.
2. many counter-culture changes in the design and operation of care settings and health care organizations such as providing non-visit based care and personal health record options and integrating into the process of care and management of organizations the collection and dissemination of the performance and educational information needed to support patients’ provider choice and treatment decision-making
3. bold and politically risky shifts in the policy and regulatory environment in which health care operates in America such as requirements for public reporting of health care performance information and rewarding based on patient engagement and choice related performance.

The Institute for Healthcare Improvement would say that change requires will, ideas and effective strategies to execute those ideas.³⁸ The Crossing the Quality Chasm strategy for

transforming health care in America urges that achieving our patient-centered reform aims requires change at four levels: (1) the level of the patient-provider; (2) within care settings; (3) within organization and (4) in the environment, policies and regulations.¹ While these frameworks apply here, the following areas are set forth as a focus of next steps for continuing to foster the needed changes to further patient-centered care, engagement and choice. Critical steps that are dependent upon major shifts in national policy are not emphasized in the interest of empowering immediate action while awaiting these unpredictable shifts.

Addressing Cultural Dissonance: Consumers and Patients

Recent polls show that 57% of Americans agree that major changes are needed and 23% agree that there is so much wrong with it that we need to completely rebuild it. (KFF 2002) Yet very few patients qualify as being activated using standardized methods for assessing this quality.⁶ This dissonance between wanting to see improvements and yet not interacting with the system as an activated consumer and patient must be addressed. Like the maturing of the health care system, consumers and patients must also mature from a passive and dependent model to a partnership model. Conflicts around not trusting the system but not wanting to disrupt current relationships with providers are common. For instance, a 2003 Kaiser Family Foundation polls shows that 89% of Americans agree that doctors should be required to tell patients if a preventable medical error occurred. Yet, only 37% trust that their doctor would tell them if a mistake was made. It is a fine line between activating patients and consumers and undermining the often central patient-provider relationship. Activation efforts that blame the system serve to support a dependent model of reform—suggesting that “they” could fix it if “they” wanted to—and you are not a part of the problem. Therefore it is important that new efforts not pretend or blame medicine for not having all the answers—rather they should make it clear that it doesn’t. Patient acknowledgement of this is as critical as it is for doctors. It is important to note that activation is especially important for consumers without viable “exit” option. In these cases, patients must be willing to “voice” their concerns and advocate for improvements yet few patients are comfortable voicing dissatisfaction to health care providers.³⁰ This is especially prominent for certain cultural groups and, ironically, those with few other options who are worried that voicing dissatisfaction will lead to a worsening of their care.

Addressing Cultural Dissonance: Physicians

“I will not be ashamed to say ‘I know not’ is the fourth affirmation of the modern-day Hippocratic Oath. Yet, it is worth noting at the outset that while health care providers are growing more comfortable with recent trends to expose the need for change, the push to engage and involve patients has not emerged from the health care sector. This should not surprise us. To effectively engage patients, we must provide them with good information about their choices and be prepared to yield to patient decisions that may not reflect the values or choices of health care providers. In essence, provision of such information and yielding of control serve to shift the balance of power in American health care to create a true partnership with patients. In this case, the very individualism we count on to drive consumer and patient activation, works against the goal to create more partnership oriented health care whereby providers are willing to expose flaws, share power and collaborate with each other on behalf of patients. Individualism and competition have fueled innovation in health care and now we are asking for collaboration and partnership, creating a cultural dissonance that must be addressed. We must acknowledge that

while many aspects of patient-centered care and engagement take the form of concrete actions that anyone can employ, many are only effective if the individual providers involved genuinely care for and have skills to effectively engage, educate and communicate with their patients. At some point, patient-centered care can not be demanded, it must be first learned and then offered.

Addressing Cultural Schizophrenia: Purchasers

As agents of consumer and patients, purchasers have enormous power to stimulate person-centered system changes that ensure patients are engaged, have information and can make meaningful choices. Yet, for the most part inherent conflicts have prevented them from doing so. While seemingly in their best interest to do so, few purchasers use their power to provide incentives and rewards for positive change. Purchasers need strategic and technical support and information demonstrating the costs and benefits of providing information to consumers and employees. Recent efforts of The Disclosure Group may help to pave the way for more bold efforts by purchasers.

The Information Infrastructure: Form Follows Function

Patient engagement and choice strategies require the continuous provision of relevant and timely information to patients and consumers. Yet, the current health care information infrastructure was not designed to track and report on the quality and outcomes of health care –information that consumers want and that is essential to a patient-centered vision for health care reform. In addition, current information systems do not set a place at the table for patients and consumers themselves—who are the best source of some of the most information for understanding needs, outcomes and understanding the effectiveness of care. Nearly all of the strategies summarized here posit that consumer and patient information is the enabling feature for patient engagement and choice – without information engagement and choice remain hallow promises and empty ideals. Efforts to shape information systems to function as a continuous source of consumer and patient relevant information are critical—especially those seeking to put in place a minimum universal electronic medical record and personal health records that ensure integration of information about patient care and health across the range of providers and systems in which they receive care.

Section IV: Issues for Discussion

Three areas lend themselves to immediate action regardless of whether supportive policies and regulations to advance patient-centered care and consumer engagement and choice are implemented in America. Specifically, we can do a great deal now to:

1. Achieve patient-centered quality measurement and reporting
2. Achieve patient-centered health benefits and system design
3. Continue to activate and engage the public and patients

Discussion Question #1: For each of the areas listed above, what is your perspective regarding the degree to which current efforts reflect true partnership with patients and the public. How important is continued effort to achieve partnership? Consider the “continuum of partnership model” set forth in Exhibit E below.

Exhibit E: Assessing Efforts Along the “Continuum of Partnership”

Patient engagement and choice strategies may be characterized along a “continuum of partnership” to indicate the degree to which they reflect values of true partnership and empowerment. There are three levels:

1. **Nonparticipation**

Therapy: patient is passive; attempt to “cure” without active involvement of those who are the target of this curing

Manipulation: patient is “educated” to support the goals or ends of providers vs. to ensure alignment with their own values and preferences

2. **Tokenism:**

Placation: communication, while seemingly sincere, is primarily directed at avoiding patient aggravation and lack of cooperation with goals and values of providers/professionals

Consultation: providers consult with patients on actions/issues but make and impose/insist on the final decision

Informing: patient are informed of choices and options and implications but not asked about their preferences or values or to agree with provider decisions

3. **Shared Power:**

Patient control: decision making is fully delegated to patients

Partnership: providers/professionals and patients/consumers are empowered in an equal relationship, each considering and benefiting from the values, knowledge and perspective of the other.

Discussion Question #2: Private and public sector sponsored social marketing consumer activation efforts are increasingly common. Is this a good idea? If so, how should these efforts be targeted, what should be the tone and who should sponsor these efforts? What do we hope to gain and how will we know if we are successful? Consider:

Target: Should efforts target all consumers equally or those who are most involved, most knowledgeable, most needy?

Timing: Should consumers be activated before the health care quality data they need to evaluate their options is more readily available and other concrete actions (beyond “ask your doctor”) can be suggested?

Tone: Given that we know that perceived risk is predictive of consumers’ situational and enduring involvement in choosing a product, should these efforts be fear-based?

Tactics: Who should sponsor these efforts – the profession? consumer groups? Should top down or bottom up efforts be advocated?

Discussion Question #3: Is it time for more innovative efforts to speed up the trajectory we are on for getting locally relevant quality information to consumers and building capacity of health care providers to partner with and provide care that is patient-centered. Consider the following:

1. **Neighborhood Health Watch** –once a year local communities sponsor a community health care quality assessment of local providers and health system and publish aggregate results in the local paper. Disaggregated results are used in more private forums.
2. **360 Performance Reviews--** providers are rewarded if they engage in 360 assessments with their patients. They would need to ensure that a certain proportion of their patients contribute to standardized, independently sponsored online, telephone or mail-in surveys about their

care which could be used to produce aggregate level local reports. In turn, patients are evaluated by providers and this information is also shared in aggregate form. Doctors and patients have a set time (perhaps via group visits) when they review their individual results with each other and discuss ways to improve.

3. **Quality Days**: The government or disease specific associations (e.g. The American Lung Association) could sponsor an Asthma Quality Day (like the Great American Smokeout). On this day as many people with asthma as possible go online and assess their care, leading to a full report the following day in the public media.
4. **Sensitivity Training**: For example, every medical resident are assigned to shadow and live for a week with a family of a child with a special health care need and practices are rewarded by their own certification bodies if they sponsor and show responsiveness to practice specific patient advisory groups—the membership of which rotates on a yearly basis.
5. **Partnership or A.S.K (Agreement to Share Knowledge) Agreements**: Here, patients are given tools to develop proactive “contracts” with providers to ensure sharing of knowledge and partnership. A model ASK agreement has been developed by FACCT and a model Partnership Agreement has been developed by the Child and Adolescent Health Measurement Initiative. Further development and pilot testing is needed but family groups have shown great enthusiasm for this idea. In some way, providers willing to develop such agreements is a sign of patient-centeredness in itself.

Why wouldn't we consider ideas such as these? Do we apply different standards to doctors than to patients when it comes to acceptable measurement error levels?

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