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Patient-Centered Care 2015: Scenarios, Vision, Goals & Next Steps

By The Institute for Alternative Futures
On behalf of The Picker Institute

The Picker Institute

The Picker Institute, Inc. sponsors research and education in the fields of patient-centered care to support and cooperate with educational institutions, and other interested entities and persons, in fostering a broader understanding of the theoretical and practical implications of approaching healthcare with a focus on the concerns of patients and other health care consumers.

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The Institute for Alternative Futures

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♦   Providing techniques for organizational and social transformation that will instill vision and integrity;
♦   Sharing insights gained from leading-edge futures research with a constantly expanding body of integrated knowledge;
♦   Creating networks of relationships among leaders for more strategic, systemic global and humane decision-making;
♦   Developing practices that sustain organizational success in the present while consciously investing in endeavors that expand opportunities for future generations.

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Executive Summary

Patient-centered care has attracted leaders in visionary healthcare organizations, research institutions and public policy centers who advocate that patients' interests and concerns should be at the center of their own healthcare experience. They have been swimming against a current of forces that push the quality of patient care below such issues as rising healthcare costs, medical liability, staffing shortages, and access to care. In 2004, patient-centered care is rarely the central concern of hospitals, nursing homes or medical practices in the U.S., Canada or Europe. In order to channel the highest aspirations of healthcare leaders, the Picker Institute, a leader in measuring the nature and quality of patient-centered care, commissioned the Institute for Alternative Futures (IAF) to help create a shared vision for patient-centered care. This report is an invitation to help shape such a shared vision.

To begin the process IAF developed ten provocative forecasts and used these in interviews to stimulate the thinking of 50 health care leaders. IAF used the results to create four different scenarios for patient-centered care in 2015:

> ### Scenario 1 -- *Informed Consumers Exercising Their Clout*
> *Remarkable medical advances are available for consumers able to pay. Although almost everyone has access to a basic tier of healthcare, employers have shifted to defined contributions. Anybody can "buy up" through the tiers all the way to concierge care. To attract the more affluent and informed consumers in higher tiers, smart hospitals and medical practices are instituting patient centered system design and inviting patients to actively participate in their health. They tout high scores for patient satisfaction on report cards. A strong patient brand plus a growing product line of technological advances are what sell. Yet patient-centered care is not available to many.*
>
> ### Scenario 2 -- Healthcare Refugees with Nowhere to Turn
> *Americans are stunned when the healthcare system nearly collapses in 2009. Confronted with unrelenting, double-digit healthcare inflation running into an economic recession, employers drop coverage en masse. The government institutes price controls and healthcare spending contracts to 12% of GDP by 2015. This is still more than most countries spend on healthcare, but it hits the poor and middle class hard. The most affluent 10% of Americans who are ready to pay out-of-pocket*

can still get timely, excellent care. The majority wait for routine interventions, preventive treatments, and the poor wait longer. Safety, quality and evidence-based medicine suffer. A crisis of leadership within the healthcare industry and government offers patients nowhere to turn to secure their health and well-being.

Scenario 3 -- Excellent Systems Converge

A convergence of scientific knowledge and information tools with public understanding and acceptance transform U.S. healthcare. The standard of care is high quality, safe treatment based on the latest evidence of effectiveness. Patients understand and expect patient-centered care, and the medical community widely accepts its practices. Patients and their families can effectively master their health with the support and coaching of user friendly, responsive health systems. Patients communicate with their team leader or other appropriate providers to tailor their care to individual health conditions and learning preferences. Patients and physicians use medical technology to identify future health risks and employ aggressive prevention strategies. Healthcare remains the largest sector of the American economy at 16% of GDP, but Americans can clearly see their large investment paying off in significant health gains for everyone.

Scenario 4 -- Collaborators in Health

Because health is everyone's responsibility, health services are structured to apportion accountability and incentives to patients, physicians and other players to make their best contribution to health. Collaboration is the multiplier that transforms limited resources into effective health outcomes. Patients and professionals share responsibility for decisions and practices that foster safety and evidence-based medicine. They thrive in a web of relationships connected by open access to information, coaching and support, and responsive, easy to navigate processes. Patients and healthy individuals succeed with the support of their families, patient peer groups, health professionals, and advanced biomonitoring and information systems. Advances in medical, social and spiritual technologies are tools in their hands to facilitate learning and healing. With the advent of shared accountability, communities have newfound resources for sustaining the health of everyone, and their circle of concern widens to take in poverty and other social problems at the root of poor health.

In February 2004, the Picker Institute convened the Patient-Centered Care Vision Summit. A group of 27 key leaders used these scenarios as input to a shared vision for patient-centered care. In using the scenarios, participants observed that what is most likely is not

the futures they want. The vision statement they proposed for a community of individuals is as follows:

> *Our vision of care is that each of us is in charge of our health. Healthcare providers are there to help us gain the skills and knowledge to enable us to take charge. Each of us gets the care we need, not less and not more.*
>
> *Our care is efficient and respectful of the value of our time. It integrates ethics and compassion with science. Each of us learns from an early age to be healthy throughout our lives. When we are sick, our care reduces fear and aids healing. When we live with chronic disease, our care and our own health practices bring quality to life. Our care at the end of life honors our values. Our caregivers treat us with respect even if we do not know what they know or do not come from the same background.*

Parallel vision statements in this report speak to the commitments that providers should make to their patients and that leaders in the field should make to the public. Common throughout the three statements are themes of respect for each individual, partnerships for health, and placing ethics with compassion hand in hand with science.

The Summit then developed "audacious goals" or "stretch targets". These twelve provide significant opportunities for making patient-centered care the norm and the standard of care. These audacious goals are:

1. **Patients Share in Decision Making.** By 2015, at least 50 percent of patients will participate in shared decision-making processes that lead to a measurable improvement in decision quality. We will have developed, implemented, and responded to an array of measures of "concordance" between healthcare interventions and what people value, first as individuals and then as communities.

2. **Enable Patients to Direct Their Care.** By 2010, 80 percent of patients and families believe they have the knowledge, supports and confidence necessary to direct their own health and healthcare.

3. **Patients Use Performance Data to Choose Supportive Providers.** By 2010, patients will be able to choose their healthcare providers based on comparative performance data that shows how well providers support the patients and their family's role in care.

4. **Measure and Reward Providers for Achieving Patient Empowerment.** By 2010, health professionals and healthcare facilities will be rewarded according to their patients' sense of empowerment and self-efficacy, which will be measured routinely.

5. **Make Patient Perspective a Priority in Policy and Planning.** By 2010, all policy and planning decisions will consider patient perspective first. Patients and/or their families will be present and actively participate in all decision-making bodies.

6. **Adopt IOM's Simple Rules for Healthcare.** By 2015, access, quality and safety will be the organizing principle of every community's healthcare. Communities nationwide will implement IOM's Simple Rules for the 21st Century Healthcare System in every organization, institution and care setting.[1]

7. **Provide Access to Patient-Centered Care Information and Care.** By 2015, everyone will have information and access to patient-centered healthcare and 50 percent will receive their care through a Picker patient-centered care practice.

8. **Include Patient-Centered-Care Tenets in Licensing Requirements.** By 2015, every health professional licensed to practice in the U.S. is competent, agrees with the major tenets of patient-centered care, and is honest in compliance with standards agreed to between the public and the health profession. Healthcare professionals who cannot or will not comply are removed and no longer practice.

9. **Train Healthcare Professionals to Support Patients.** By 2010, all healthcare professionals will receive training in how to support patients and enable them to play an active role in their care.

10. **Promote Joint Contracting for Care and Prevention in Diabetes.** By 2015, all patients with Type 2 Diabetes will "contract" or "sign" a joint care and prevention agreement with their caregivers.

11. **Provide Healthy Living Skills Education.** By 2015, all school-age children will receive education to enhance lifelong skills for living a healthy life.

12. **Anticipate Late Life Care Needs.** By 2015, education will be available to everyone 50 years and older on realistic scenarios regarding health, long-term care, and the end of life through videos, CDs and interactive media.

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1 Institute of Medicine's Simple Rules for the 21st Century Health Care System, "Crossing the Quality Chasm" report. The rules are: Care is based on continuous healing relationships. Care is customized according to patient needs and values. The patient is the source of control. Knowledge is shared and information flows freely. Decision-making is evidence-based. Safety is a system property. Transparency is necessary. Needs are anticipated. Waste is continuously decreased. Cooperation among clinicians is a priority.

These goals are significant insofar as they help motivate and coordinate action. A number of participants publicly committed to take action to help achieve one or more of the audacious goals. Some of the actions that are needed include:

♦ Developing coordinated strategies among patient-centered care stakeholders

♦ Developing a measure of patient self management competency that can be used both to tailor care in the clinic and inform patients so they can choose providers who best empower them to achieve healthy outcomes

♦ Developing decision quality measures and teaching health professionals how to define and value shared decision making

♦ Working for national and international standards to implement the personal health record

The complete list of Next Step actions is included in the report that follows.
To create the future envisioned by healthcare leaders, patients must have the knowledge and confidence to share in making decisions about their care. They should be able to choose the healthcare providers who will support them, and the providers should be rewarded for increasing their patients' sense of empowerment. Once these commitments to audacious goals are fulfilled then, patients will have the care they need, not more and not less.

The participants at the Patient-Centered Care Vision Summit, the Picker Institute, and the Institute for Alternative Futures now invite others working to advance patient-centered care to use the findings in this report to find their own way to the highest ground in patient-centered care. Here is how: Use the scenarios in planning; adopt or adapt the vision statements and if your vision and goals align, join in with the actions taken by others to become advocates for a standard of care that honors patients as partners in their healing.

Introduction

This report summarizes a trip into the future for patient-centered care: a trip into the future that explores both what might happen (plausible futures), and what leaders in the field think should happen (vision, audacious goals and next steps). This is a project of the Picker Institute executed by the Institute for Alternative Futures, in conjunction with leaders in the patient-centered care field.

IAF, a nonprofit futures organization that helps organizations discover and create their preferred future, used ten provocative forecasts to prompt more than 50 healthcare leaders to share their views about the future of patient-centered care. The forecasts address such topics as healthcare technology, the role of health professionals, and the level of health disparities in our society. From the interviews and additional research on patient-centered care, IAF created four scenarios that illustrate how the future might unfold for patient-centered care in the United States[2].

Twenty-seven key leaders in the patient-centered care movement used the scenarios to help them to frame the possibilities for the future. In a two-day summit in Baltimore March 15-16, 2004, these leaders:

♦ Analyzed the scenarios for insights about plausible futures, as well as the future they prefer to create.

♦ Identified the core elements of a 2015 vision describing their preferred future.

♦ Proposed audacious goals on patient empowerment, healthcare system standards, access to patient-centered care, training professionals and targeting specific health challenges.

♦ And committed to specific next steps which they will take, and which we invite the readers of this report to join in taking.

This report will review the definitions of patient-centered care; consider the scenarios and their implications; explore legacies and initiate discussion of a vision for patient-centered care. This discussion needs the perspective of consumers, providers and the leaders of the patient-centered care field. The discussion needs to identify audacious goals for the field,

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[2] The interviewees are listed at the end of the full scenario report in Appendix E.

consider the levers of change required to move forward, and then identify specific next steps.

We invite you to consider the vision and audacious goals; to consider how your vision and goals relate to those in this report. Most important, if your vision and goals align, you can join in or support the specific next steps that the leaders in the field recognize will lead to a future that achieves patient-centered care.

Defining Patient-Centered Care

Patient-centered care is a critical component of healthcare. This project identifies core aspects common to many definitions, but also argues for a broadening of the term "patient". Many people should have care before they have the symptoms that identify them as patients.

The Picker Institute has identified these seven prime aspects of patient-centered care:

1. **Respect for patient's values, preferences and expressed needs.** This dimension is best expressed through the phrase, "Through the Patient's Eyes" and the book of the same title, and leads to shared responsibility and decision-making. [3]

2. **Coordination and integration of care.** This dimension addresses team medicine and giving patients support as they move through different care settings for prevention as well as treatment.

3. **Information, communication and education.** This includes advances in information and social technologies that support patients and providers, as well as the cultural shifts needed for healthy relationships.

4. **Physical comfort.** This dimension addresses individual, institutional and system design (i.e. pain management, hospital design, and type and accessibility of services).

5. **Emotional support.** Empathy and emotional well-being are as important as evidence-based medicine in a holistic approach.

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[3] Gerteis, Margaret, Susan Edgman-Levitan, Jennifer Daley, and Thomas L. Delbanco, editors. *Through the Patient's Eyes.* Picker/Commonwealth Program for Patient-Centered Care, Jossey-Bass, 1993.

6. **Involvement of family and friends.** Care giving includes more than patients and health professionals so that the larger community of caregivers are considered.

7. **Transition and continuity.** Delivery systems provide for caring hand-offs between different providers and phases of care.

During the project—both in the interviews and in the Vision Summit—it was pointed out that patient-centered care will reflect patients' values and engage them as partners in their care. Patients and their families must be involved in decision-making. They need education, information, and coaching to facilitate their informed and full participation. Responsibility and accountability for health should be shared among members of the provider team: payers, patients, families, communities, businesses and governments—essentially all elements of society.

The National Health Council commissioned a review of the many definitions of patient-centered care as part of its Putting Patients First® initiative and concluded with this definition: *Patient-centered care is quality healthcare achieved through a partnership between informed and respected patients and their families, and a coordinated healthcare team.*

There was widespread agreement that patient-centered care is one aspect of appropriate healthcare as defined in the Institute of Medicine's six aims for the healthcare system in IOM 2001 Report, *Crossing the Quality Chasm*[4]:

1. **Safe** – avoiding injuries to patients from the care intended to help them.

2. **Effective** – providing services based on scientific knowledge to all who could benefit, and refraining from providing services to those not likely to benefit.

3. **Patient-centered** – providing care that is respectful of and responsive to individual patient preferences, needs and values, ensuring that patient values guide all clinical decisions.

4. **Timely** – reducing waits and harmful delays for both those who receive and those who give care.

5. **Efficient** – avoiding waste: including waste of equipment, supplies, ideas, and energy.

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[4] *Crossing the Quality Chasm: A New Health System for the 21st Century.* Institute of Medicine, March 2001.

6. **Equitable** – providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status.

Broadening the focus beyond hospitals and beyond treatment to prevention should be part of our vision. The process of caring begins well before anyone becomes a patient. In this context, "patient-centered care" has limits as the banner for this movement. The Vision Summit participants offered various alternative terms, such as consumer or citizen-centered care, or health-centered care. These phrases show the growing awareness that care is evolving to include prevention and the role of community in achieving health.

Given this change coming from within the patient-centered care movement, it is important to consider how the future might evolve and change around patient- centered care in the years ahead. The IAF scenarios explored four alternative paths into the future that help clarify the vision or preferred future for patient- centered care.

Patient-Centered Care 2015: Four Scenarios

Using its aspirational futures methodology[5], IAF created four scenarios for patient-centered care in 2015. Scenarios provide an opportunity for learning and for building commitments. IAF's experience in a wide range of settings shows that what appears likely in the future often precludes what is a preferred or visionary future. A deeper look requires a range of futures that includes surprising successes.

In the first scenario, IAF extrapolated a best guess of the most likely future from current trends in the United States. This scenario illustrates what could happen as the future of patient-centered care unfolds in patterns now familiar within U.S. healthcare. A second scenario explores some of the many things that could go wrong as basic systems fail. Two other scenarios are aspirational and orient to the question: "What would the future look like

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[5] IAF has facilitated many futures projects using this aspirational approach, including such projects as "Healthy People for a Healthy World: The Belmont Vision for Healthcare in America, (http://www.altfutures.com/pubs/belmontvision.pdf), the Military Health System 2025 project for the Department of Defense, and the UK government's Economic and Social Research Agency's study of genomics and social science, (http://www.altfutures.com/esrc.asp).

if a critical mass of stakeholders successfully pursued visionary ends?" One of these scenarios takes an objective, system view of patient-centered care, while the final scenario is a more subjective and humanistic view of the possibilities.

Prior to developing the scenarios, IAF developed a series of "provocative forecasts" on issues such as access and financing, electronic medical records, the role of the physician, equity and disparities. Over 50 leading experts were interviewed (they are listed at the end of the full scenarios in Appendix B below). Using its "aspirational futures" approach and input from these interviews and additional research on trends and forecasts in healthcare, IAF constructed the four patient-centered care scenarios.

Thus for patient-centered care **Scenario 1**, the extrapolative scenario, develops a marketplace view of American medicine. Those with resources and knowledge can secure some degree of patient-centered care because healthcare providers see it as good business. The fortunate and well informed have access to smarter medical technologies and treatments. **Scenario 2** examines what happens to patient-centered care when the healthcare system is near collapse, and most people make do in a world where quality, access, safety, and technological progress are compromised. **Scenario 3** places patients and healthcare professionals in a well-designed and progressive healthcare delivery system, where every component is performing well. **Scenario 4** evolves from the premise that health has become everyone's responsibility, collaboration defines all relationships, and systems and technologies are integrated for mutual accountability.

The scenarios summarized below are in full text with a matrix of scenario forecasts in the **Patient-Centered Care 2015 Scenarios** report in Appendix B.

Scenario 1 - Informed Consumers Exercising Their Clout

Remarkable medical advances are available for consumers able to pay. Although almost everyone has access to a basic tier of healthcare, employers have shifted to defined contributions. Anybody can "buy up" through the tiers all the way to concierge care. To attract the more affluent and informed consumers in higher tiers, smart hospitals and medical practices are instituting patient centered system design and inviting patients to actively participate in their health. They tout high scores for patient satisfaction on report cards. A strong patient brand plus a growing product line of technological advances is what sells.

Smart people with chronic diseases choose providers offering comprehensive and evidence-based management of their illnesses. Providers promise sophisticated biomonitoring,

telemedicine, and targeted therapies for cancer and chronic illnesses. Yet the patient-centered care hyped in medical ads often proves to be less than promised.

Scenario 2 - Healthcare Refugees with Nowhere to Turn

Americans are stunned when the healthcare system finally collapses in 2009. Confronted with unrelenting, double-digit healthcare inflation running into an economic recession, employers dropped coverage en masse. The government institutes price controls and healthcare spending contracts to 12% of GDP by 2015. This is still more than most countries spend on healthcare, but it hits the poor and middle class hard. Desperate patients now simply want to hold onto some form of basic care. Patients feel powerless navigating a system with too few resources to respond to their physical, much less their emotional needs. Delivery of care, even for chronic diseases, is a patchwork of makeshift fixes. The most affluent 10% of Americans who are ready to pay out-of-pocket can still get timely, excellent care. The majority waits for routine interventions, preventive treatments, and the poor wait longer. Safety, quality and evidence-based medicine suffer. The medical technology industry, once the symbol of the nation's scientific prowess, subsists on limited capital and produces only incremental improvements in the face of price cuts. Without a large public market, even the affluent find expected advances slowing down. A crisis of leadership within the healthcare industry and government offers patients nowhere to turn to secure their health and well-being.

Scenario 3 - Excellent Systems Converge

A convergence of scientific knowledge and information tools with public understanding and acceptance transform U.S. healthcare. The standard of care is high quality, safe treatment based on the latest evidence of effectiveness. Patients understand and expect patient-centered care, and the medical community widely accepts its practices. Patients and their families can effectively master their health with the support and coaching of user friendly, responsive health systems. Patients communicate with their team leader or other appropriate providers to tailor their care to individual health conditions and learning preferences. Where no good choices exist for medical conditions, most patients and physicians have good support systems for facing difficult decisions. Patients and physicians use medical technology to identify future health risks and employ aggressive prevention strategies. Targeted therapies are available to cure or control most chronic diseases. Healthcare remains the largest sector of the American economy at 16% of GDP, but Americans can clearly see their large investment paying off in significant health gains for everyone.

Scenario 4 - Collaborators in Health

Because health is everyone's responsibility, health services are structured to apportion accountability and incentives to patients, physicians and other players to make their best contribution to health. Collaboration is the multiplier that transforms limited resources into effective health outcomes. Patients and professionals share responsibility for decisions and practices that foster safety and evidence-based medicine. They thrive in a web of relationships connected by open access to information, coaching and support, and responsive, easy to navigate processes. Most all patients understand and meet their individualized health plan goals. They succeed with the support of their families, patient peer groups, health professionals, and advanced biomonitoring and information systems. Teams of providers organize around their patients to promote prevention and effectively manage chronic illnesses. Advances in medical, social and spiritual technologies are tools in their hands to facilitate learning and healing. With the advent of shared accountability, communities have newfound resources for sustaining the health of everyone, and their circle of concern widens to take in poverty and other social problems at the root of poor health.

Reflecting on Patient-Centered Care in the Scenarios

The Vision Summit participants used the scenarios to reflect on how patient-centered care might evolve. The **Healthcare Refugees** scenario is a dark future that opens the possibility of public revolt against a system that has slammed the door on caring. This cost-focused, competitive world sacrifices quality and safety. Aggressive payers are likely to clamp down much as they did under the HMO model. People anticipating sicknesses are anxious about their well-being and patient advocates would become more strident. The only patient-centered care occurring in this scenario would be in concierge care, which might actually get even better. Caregivers would experience high burnout and low productivity in a system that undervalues them. States and providers squeeze the public out of the decision making process as they collude to keep costs low. The social costs to communities and businesses of this future are very high.

Summit participants noted how easy it would be to slide into the *Healthcare Refugees* future. In truth, many populations, such as immigrants and the poor, experience this future now. Services are limited for most people in states where high malpractice rates are driving away physicians. If the traditional healthcare system fails to meet needs, people may have to go outside the system to create alternatives for care.

The scenarios confront the prevailing American focus on individual rather than community health. Only the fourth scenario explicitly raises the role of communities and families in creating health. Community and culture create health, not the medical system. To create the preferred future for patient-centered care, the Vision Summit participants noted that the United States would have to challenge this bias toward individualism in healthcare. This tension between individual and collective values runs throughout public policy debates, healthcare spending priorities, reimbursement and incentive practices, and the design of insurance benefits.

Access to healthcare will be important to the future of patient-centered care. Each scenario analyzes the degree to which America has addressed access. Although the ***Informed Consumers*** scenario is crafted to be the most likely future, the Vision Summit participants pronounced it too Darwinian to be viewed as a positive scenario. The U.S. government will have to address inequities. However, two representatives from Picker Europe advised against jumping to the conclusion that universal access is a guarantee of patient-centeredness. It is just as difficult to achieve patient-centered care in nations that offer universal care, and many pioneering patient-centered care practices come from the United States despite the lack of universal access to care.

The ***Excellent Systems Converge*** scenario illustrates what can happen when people build upon the best within the current healthcare system and solve problems incrementally through a series of clear transitions. This "visionary systems view" scenario is consistent with prevailing American cultural values. It envisions patients using decision aids and frank conversations to make their own judgments about managing their illnesses. How well these decision-making systems accommodate the needs of the elderly and people with limited capacities will be critical to their acceptance. As good as the decision-making systems might be in this scenario, they could still be paternalistic without the modulating influences described in the fourth scenario, ***Collaborators in Health.***

The Vision Summit participants identified several key requirements that must converge for the **Excellent Systems** scenario to occur. Incentives for physicians and patients must be aligned around patient centeredness. Medical education must prepare physicians to coach their patients in taking responsibility for their health and their interactions with healthcare systems. People will need access to measures that evaluate their medical care experiences. With the advent of the web and other advanced communication technologies, they could even compare their experience with those of people in other communities and countries and decide to go there for care.

Collaborators in Health makes the case that a network of people caring for both patients and their caregivers can lead to prevention and better health outcomes for individuals and communities. An accessible and transparent information and communications infrastructure is essential to connect this network. One working group at the Vision Summit proposed thinking about the work ahead as a series of learning and loving actions. Education curriculum would prepare both patients and providers to work in collaborative ways. New facilitating professions could emerge, such as patient navigators, health counselors, and patient care advisors. Healthcare professionals would learn how to use patient values to measure the quality of medical decisions. People should be rewarded for capturing and sharing information on a number of factors, such as risks, values, costs and outcomes. Healthcare providers could hire only loving employees and informal caregivers could be paid for their services.

Systems of organizing care, like the medical home with its accessible physicians and preventive care, create reminders that the best systems of care could prevail. Incentives such as care management fees, reimbursement for interactions beyond office visits, and disease management can support collaboration among healthcare providers.

In ***Collaborators in Health****,* universal care is achievable because communities discover resources they may now ignore in a less caring system. Healthy lifestyles and behaviors help people discover "less can be more". A new social contract grounded in collaboration could transform medical practice and supersede the need for malpractice reform.

Most Likely Scenario Is Not What We Want

When leaders believe the most likely future is inevitable they may lack the will to take the affirmative actions to create a preferred future. What often compels people to embrace change is seeing how their failure to act could lead to a future they do not want. When they realize that their actions matter, then people can imagine how much better the future could be if they do act. This is the creative power of scenario thinking.

Any group can assess its understanding of the future for patient-centered care by rating these scenarios as the participants in the Vision Summit did. Simply assign 100 percentage points across the four scenarios to rate their probability. Likewise, distribute another 100 points to rate their preferability.

The figure below identifies the results from the Vision Summit. Participants confirmed Scenario 1 as the most likely future for patient-centered care. In their discussions, they

recognized the tremendous power that current practice and values can have to shape a less desirable future. The inertia of the present system is taking us toward a likely but undesirable future. Participants preferred the third scenario, and even more, the fourth scenario, *Collaborators in Health.*

A tension emerged from this exercise: to what extent do strategies to promote patient-centered care simply make marginal improvements in a healthcare system that needs fundamental change. However, an even larger lesson emerged, reinforcing the purpose of the summit. To achieve a more desirable future than appears likely, we need a shared vision, engaging goals, and strong commitments to action.

Participants then turned toward their shared visions for patient-centered care by considering the greatest legacies they could leave for future generations.

Likelihood v. Preferability of Scenarios

Question	1	2	3	4	5
Likelihood	38.5	26.5	19.6	9.5	5.8
Preferability	9.5	0.8	26.7	49.0	14.0
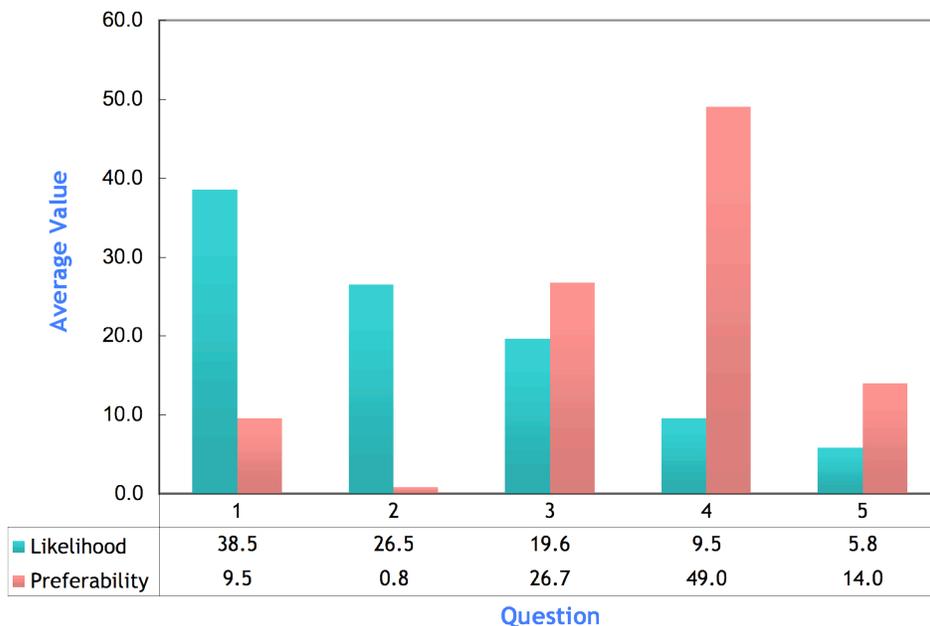
Note: Participants spread 100 points across the scenarios for likelihood and 100 points for preferability. Participants could construct their own scenario, add it to the original four, and award it points. These scenarios primarily blended the original four. The votes for these various fifth scenarios were averaged to create a "none of the above" option. This "none of the above" option, shown as 5 above, garnered 5.8 points for likelihood, and 14 points for preferability This generated insights but reinforces the general lesson that the inertia of existing conditions make scenario 1 the most likely of these options. Conversely, to create more preferred futures shared vision, commitment and effective change is urgently needed.

A Shared Vision for Empowering Patients in Their Care

Visions express people's highest aspirations for what they want to create in the future. They are powerful statements of what people find meaningful and they project shared values into the future. Because visions appeal to the heart, the Institute for Alternative Futures often asks people to explore the legacies that would result from achieving a vision. IAF invited the Vision Summit participants to imagine the year is 2015 and write a letter to a young child (a grandchild or friend's child) describing the most important legacies of patient-centered care, the legacies they are most proud of having been part of creating. Each person's letter touches what he or she values most about the transformative possibilities in patient-centered care. Participants produced moving letters that IAF then used to focus on themes for a shared vision.

IAF gleaned the most compelling language and ideas from these letters to create a composite of elements for a vision statement. The participants provided their reactions at the Vision Summit. Then IAF developed draft statements to which participants gave additional subsequent input. The result is three interrelated vision statements focused on three different audiences:

♦ **The Public** - A statement of what the public will experience in patient-centered care in 2015

♦ **Healthcare providers** - A second statement that invites providers of patient-centered care to serve a shared vision

♦ **Patient-centered care leaders** - A third statement that invites leaders of patient-centered care to serve a shared vision

The Institute of Medicine's three phases of life affirm that patient-centered care will respond effectively to all phases of life and are the model for these vision statements. The core for all three statements is a promise of "the care we need and no less, the care we want and no more". Albert Mulley, MD, Chief of General Medicine at Massachusetts General Hospital authored this eloquent phrase. It promises both access and care defined by personal values. It counters the tendencies of some providers to use their superior knowledge and preferences to deliver care that they want to give irrespective of patient wishes. When challenging situations arise and the right care is difficult to discern, a

patient's values and preferences are honored through shared decision-making. A strong message of personal responsibility runs throughout the vision statements. This sets an expectation that people will seek care that is consistent with informed, responsible choices and behaviors.

A Vision for Patient-Centered Care

Each of us is in charge of our health. Healthcare providers are there to help us gain the skills and knowledge to enable us to take charge. Each of us gets the care we need, not less and not more.

Our care is efficient and respectful of the value of our time. It integrates ethics and compassion with science. Each of us learns from an early age to be healthy throughout our lives. When we are sick, our care reduces fear and aids healing. When we live with chronic disease, our care and our own health practices bring quality to life. Our care at the end of life honors our values. Our caregivers treat us with respect even if we do not know what they know or do not come from the same background.

A Vision of Providers' Commitment to their Patients

Nothing is more important to good health than the care you take of yourself. When we become your partners in this care, our caring will be centered on you. We will be there to support your efforts in maintaining your own health and functioning. You will get the care you need, not less and not more.

We will share our knowledge and skills to inform and involve you in every decision. We will respect you and your time. We will work to simplify your care and minimize waiting. We will teach you at an early age how to care for yourself. When you are sick, we will care for you with competence and warmth to reduce your fears and aid your healing. If you live with chronic disease, we will support you in bringing quality to your life. When you come to the end of your life, you can be confident that ethics and compassion will be hand in hand with science.

Vision for Leaders in Patient-Centered Care

We commit to individuals being in charge of their health. We insist they get the care they need, not less and not more.

We respect others as individuals, irrespective of their background, and we respect the value of their time. We will work to simplify care and minimize waiting. We will help everyone learn at an early age to be healthy throughout life. When a person is sick, we will work to reduce fear and aid healing. If a person has a chronic disease, we will work to improve quality of life. At the end of a person's life, we will ensure that ethics and compassion go hand in hand with science.

What this vision would require

Visions are important for what they prompt us to focus on: in this case, the requirements for healthcare to operate within this vision. At the Vision Summit, Karen Davis, President of the Commonwealth Fund, proposed this list of elements for a patient-centered practice that would be consistent with the vision statements above:

◆ The practice team (MD, RN, others) is available when the patient wants it with same day appointments, same day response to emails and prescriptions filled by email request.

◆ Patients receive reminders when it is time for preventive care, chronic care lab tests or check-ups.

◆ Patients receive all lab/imaging and procedure results promptly.

◆ The practice team coordinates specialty referrals, use of other services, ensures that they happen (e.g., seeing the specialist, filling prescriptions, getting a mammogram/colonoscopy, following through with recommended treatment such as chemotherapy).

◆ Patients train in self-care and have information on clinical guidelines for their condition, health education and treatment plan.

◆ Patients have information on provider quality, costs over course of illness episode/time period, fees, outcomes, other patients' rating of practice, provider qualifications, and philosophy of practice.

◆ Patients have access to their own electronic medical records.

◆ Patients have decision support to understand treatment choices.

◆ Patients are alerted to any deviation in their care from recommended clinical guidelines.

♦ Practice teams receive regular feedback from patients on patient experience with care and monitor patients for adherence to treatment plans.

♦ All of the above are applicable to all medical care settings, including nursing homes.

Visions are more important for what they do than what they say. The participants of the Patient-Centered Care Vision Summit developed this vision and are committed to it. We encourage readers of this report and those who encounter this vision to consider the words and their meaning to you. Consider if you too will accept it. If not this precise vision, what is your vision for patient-centered care? Share that vision and pursue it.

Audacious Goals for Patient-Centered Care

A vision is a statement of what we want in the future. It provides a "north star"-- an important guide for achieving a vision. Another approach is to establish "audacious goals" (originally termed "Big, Hairy Audacious Goals" or BHAGs by Collins and Porras[6]). These goals are "stretch targets". The vision creates a tension between what is now and what should be. The audacious goals identify measures that show progress toward a vision.

Vision Summit participants worked to identify audacious goals to propose for the wider patient-centered care community. Look upon these goals as a menu of important targets for leaders in the field to choose from or to commit to collectively.

We asked participants: In order to achieve a vision of patient-centered care at every stage of life, what goals must healthcare leaders, policy makers, patients and the public share? The Vision Summit participants proposed clear and compelling goals that could be a focal point and catalyst for action for the next ten years. These were collected and after the meeting, participants ranked them. These twelve goals were the most highly ranked:

 Patient Empowerment

1. **Patients Share in Decision Making.** By 2015, at least 50 percent of patients will participate in shared decision-making processes that lead to a measurable

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[6] Collins, Jim and Jerry Porras. **Built to Last, Successful Habits of Visionary Companies.** Harper Business Essentials.

improvement in decision quality. We will have developed, implemented, and responded to an array of measures of "concordance" between healthcare interventions and what people value, first as individuals and then as communities.

2. **Enable Patients to Direct Their Care.** By 2010, 80 percent of patients and families believe they have the knowledge, supports and confidence necessary to direct their own health and healthcare.

3. **Patients Use Performance Data to Choose Supportive Providers.** By 2010, patients will be able to choose their healthcare providers based on comparative performance data that shows how well providers support the patients and their family's role in care.

4. **Measure and Reward Providers for Achieving Patient Empowerment.** By 2010, health professionals and healthcare facilities will be rewarded according to their patients' sense of empowerment and self-efficacy, which will be measured routinely.

Health System Design and Planning

5. **Make Patient Perspective a Priority in Policy and Planning.** By 2010, all policy and planning decisions will consider patient perspective first. Patients and/or their families will be present and actively participate in all decision-making bodies.

6. **Adopt IOM's Simple Rules for Healthcare.** By 2015, access, quality and safety will be the organizing principle of every community's healthcare. Communities nationwide will implement IOM's Simple Rules for the 21st Century Healthcare System in every organization, institution and care setting.[7]

Throughout the Vision Summit, participants shared a strong appreciation for the existing body of work promoting patient-centered care. They honored the shoulders on which they all stand in seeking progress in patient care. Even as participants proposed new steps they might take, they also gave a high priority to fully implementing the recommendations of the Institute for Medicine on access, quality and safety.

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[7] Institute of Medicine's Simple Rules for the 21st Century Health Care System, "Crossing the Quality Chasm" report. The rules are: Care is based on continuous healing relationships. Care is customized according to patient needs and values. The patient is the source of control. Knowledge is shared and information flows freely. Decision making is evidence-based. Safety is a system property. Transparency is necessary. Needs are anticipated. Waste is continuously decreased. Cooperation among clinicians is a priority.

Assure Access

7. **Provide Access to Patient-Centered Care Information and Care.** By 2015, everyone will have information and access to patient-centered healthcare and 50 percent will receive their care through a Picker patient-centered care practice.

Set Standards

8. **Include Patient-Centered-Care Tenets in Licensing Requirements.** By 2015, every health professional licensed to practice in the U.S. is competent, agrees with the major tenets of patient-centered care, and is honest in compliance with standards agreed to between the public and the health profession. Healthcare professionals who cannot or will not comply are removed and no longer practice.

Train Professionals

9. **Train Healthcare Professionals to Support Patients.** By 2010, all healthcare professionals will receive training in how to support patients and enable them to play an active role in their care.

Target Health Challenges

10. **Promote Joint Contracting for Care and Prevention in Diabetes.** By 2015, all patients with Type 2 Diabetes will "contract" or "sign" a joint care and prevention agreement with their caregivers. [8]

Health Education

11. **Provide Healthy Living Skills Education.** By 2015, all school-age children will receive education to enhance lifelong skills for living a healthy life.

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[8] The Center for the Advancement of Genomics (TCAG) and Duke University Medical Center (DUMC) are collaborating to create the first fully integrated, comprehensive practice of genomic-based prospective medicine to generate predictive and prognostic data on specific diseases that can aid both doctors and patients in the earlier detection and better treatment of these illnesses. The collaboration seeks to create a futuristic personalized health plan and medical record including genomic information to predict health risks and outcomes from therapy, which could be the basis for prevention agreements.

Anticipating HealthCare and Long Term Care Needs

12. **Anticipate Late Life Care Needs.** By 2015, education will be available to everyone 50 years and older on realistic scenarios regarding health, long-term care, and the end of life through videos, CDs and interactive media.

Consider these audacious goals. If goals are exciting, they can create the momentum for taking on entrenched practices, priorities that compete, and indifference. These proposed goals challenge the healthcare community to change not just in a few select places but everywhere patients and their families interact with the healthcare system.

Are there goals which you personally, and your organization might commit to pursuing?

Discussing Levers of Change for Patient-Centered Care

After the work on goals, Vision Summit participants considered the levers of change they could operate from several perspectives. One perspective focuses on aspects of current reality that the scenarios highlight. Today only the fortunate will get loving care in the United States. The description of *Healthcare Refugees with Nowhere to Turn* is already the case for many in the United States. Many Americans and newcomers to this land already suffer and die in healthcare settings that devalue their life and well-being.

Today's systems do not support healthcare providers that foster integrated, longitudinal care. In fact, those most committed to patient-centered care are among the most frustrated practitioners. Personal satisfaction with medicine is higher among specialists who perform select procedures and do not approach healthcare in an integrated way with their patients. Reimbursement does not reward caring. Research funding for patient-centered care is puny compared to biomedical science budgets. This reality could become much worse if people do not act. Healthcare can become more costly, less equitable, and much more frustrating for healthcare professionals and patients alike. The costs of neglect are high.

Many of the Vision Summit participants questioned whether significant change could be achieved from within the healthcare system. Maybe what is needed will be as dramatic as

a civil rights movement. Grassroots organizing is easier to do when greater numbers of people grow more frustrated with the current system. About 20 percent of the U.S. population is ripe for mobilization, according to research by the National Health Council. What the patient-centered care movement may need is a blueprint for concerted public action to do as Thomas Jefferson advised and "inform their discretion." Getting more information into the public's hands is essential. Patients need to be able to imagine how their future will be transformed by the outcomes of care.

Change will require risk on everyone's part. Strategic coalitions could break through barriers. The levers of change are multi-leveled. Only a partnership at four levels could bring about a convergence of forces leading to change:

♦ The medical profession needs to make patient-centered care a priority and energize the healthcare infrastructure.

♦ Public activism must generate a cultural shift. Citizens must understand what is at stake, embrace the vision for change, and make an emotional connection to the services that will make a difference in their health.

♦ Businesses need to use market forces and take investment risks that contribute to an excellent system.

♦ Multiple levels of government have to take public policy actions that determine what is locally acceptable and nationally appropriate.

Next Steps to Action

The Vision Summit developed the vision and audacious goals that can bring us to patient-centered care. The audacious goals represent potential stretch targets that stakeholders in the patient-centered care arena can pursue. Participants at the meeting determined they would take positive action toward these goals. A fulsome dialogue within communities can create wider agreement over the goals and support for the actions.

These individuals named below will be taking steps that you can support or collaborate on. Some of these next steps were already planned; others were generated during the meeting. Some have the resources necessary, but welcome additional commitments of support.

Others will require additional financial and organizational support. However, all are being pursued. You can contact the person identified. (For contact information, direct your inquiries to Marsha Rhea, IAF, 703-684-5880 or mrhea@altfutures.com)

Strategies for Advancing the Practice of Patient-Centered Care

Judith Hibbard, PhD, professor of health policy at the University of Oregon, is developing a measure of **patient self-management competency** used in the clinical setting to tailor care. She also is developing measures to **inform patients in choosing providers** who best empower them to achieve healthy outcomes.

Albert Mulley, MD, Chief of General Medicine at Massachusetts General Hospital will develop and teach **decision quality and measures** for health professionals. He will be developing and testing decision quality and **value concordance instruments** and helping to define the business case for shared decision making.

Don Detmer, professor of medical education at the University of Virginia Health System, will be working for national and international standards and implementation of the **personal health record**, including a public education initiative to support the electronic health record. He also will continue working on European policy for "informed patients".

Many other strategies are taking shape. These include developing the **health coach or navigator role**; creating training initiatives and simulations for **medical education and accreditation**; shaping **toolkits and leadership training** for nursing homes, long-term care and end of life care.

Processes for Sharing Information and Best Practices

Randy Carter, vice president of organizational development and strategy for The Planetree Alliance, will **share information** that can be mutually beneficial. He will be sharing the 2015 vision and goals in Planetree meetings and conferences. Likewise, Gail Warden, president emeritus of the Henry Ford Hospital Health System will share the vision and goals from this summit in other conferences and forums, such as the National Quality Forum. Don Detmer plans to share the work at conferences of the Blue Ridge Academic Health Group.

Stephen C. Schoenbaum, MD & MPH, senior vice president at the Commonwealth Fund will work to develop and promote **measures of patient experience** at the physician level.

Surveys to evaluate physicians in the office and hospital are needed. To institutionalize this practice, physicians could do their own surveys and report them "voluntarily" to some central organization; insurers could survey their beneficiaries about their experience, or the surveys could become part of some type of accreditation or board recertification. Some public reporting process should recognize physicians who meet a certain threshold of performance.

Karen Davis, PhD, President of the Commonwealth Fund, will flesh out the practices for patient-centered care by adding **tools, models and innovation case studies** to the Commonwealth Foundation website. She also plans to inform people through speeches she is asked to give.

Angela Coulter, PhD, chief executive for Picker Institute Europe, will **publish articles**, viewpoints and resources on good practice, bad practice or evaluated practice in the international journal she edits. She also is interested in assembling data quantifying patient-centered care with indexes across countries and settings.

Actions to Mobilize the Public and Healthcare Community

The National Health Council has convened a **National Advisory Commission on Patient-Centered Care** chaired by Dr. John Seffrin, CEO of the American Cancer Society. The commission brings together a group of experts and champions of patient-centered care to serve as high level advisers to NHC. The number one priority will be **personal health records/electronic medical records**. A standardized national health information infrastructure would enable patients and their families to be more involved in the delivery of their own healthcare. Marc Boutin, NHC vice president of policy development and advocacy, is coordinating this Commission. Boutin/NHC will provide a **research paper** that identifies the following themes of patient-centered care, which are based on patient outcomes: (1) care over time that involves the patient's family; (2) information that is shared and accessible; and (3) respect for the patient's needs, values and preferences.

NHC also reviewed **available public and proprietary research**, polling data, focus group testing, etc., related to patient-centered care. The NHC research identified four, somewhat overlapping audiences that could be engaged and mobilized on patient-centered care topics. These include: people with chronic diseases and/or disabilities who are already online and view patient-centered care as an empowerment issue; health information seekers who are technologically savvy and involved in self-management; patient advocates who are already primed to communicate that patient-centered care is a means to improve

quality; and members of the general public interested in technology and/or the relationship between the coordination of health care and quality. The Council will next conduct formative research to develop, refine and **select key message concepts about patient-centered care** as a solution to problems that patients and their families face in dealing with the healthcare system.

Nancy Whitelaw, PhD, vice president for research and demonstration for the National Council on Aging, will meet with seniors to get their advice on priorities for patient-centered care. She plans to develop systematic and visible strategies for **understanding what this concept means to older adults** and how to make patient-centered care a reality for them.

Sir Donald Irvine, CBE, MD, FRCGP, Chairman of the Picker Institute Europe, will work to identify a "coalition of the willing" ready to work within medical schools, primary care groups, and hospitals to **imbed patient-centered care values and standards** throughout the system. Picker Europe also will be testing current professional codes of practice against the Picker principles and work to incorporate them in **licensure.** Irvine is also in dialogue with Dr. Foster Limited, a web-based resource for medicine information, to incorporate awareness of patient-centered care.

Among other actions to mobilize the healthcare community are plans to network patients and families interested in **disclosing errors** as an alternative to litigation; to work for a **patient bill of rights** that includes patient-centered care; to keep alive the issue of quality in **nursing homes**; and to revisit **where funders give resources** to create tension on behalf of safety and quality.

The key to creating the preferred future is not to accept current reality. Instead, take informed action aligned with goals informed by your vision of the future you want. The scenarios, vision, audacious goals and action steps are a call to action to the larger community in patient-centered care. IAF invites anyone sharing related interests to network with the leaders who joined to collaborate on creating patient-centered care. Many people believe patients should get the care they need, not less and not more. When they give voice to this shared vision through their actions, they create an echo chamber that can transform the beliefs and practices of health and healing.

Appendix A: Patient-Centered Care Vision Summit Participants

Vision Summit Participants
March 15-16, 2004
Baltimore, MD

The Picker Institute and the Institute for Alternative Futures have the deepest appreciation for everyone who attended the Vision Summit on the Future of Patient-Centered Care and contributed their insights to this report.

Marc M. Boutin, J.D.: Marc Boutin is Vice President for Policy Development and Advocacy at the National Health Council.

Randy Carter: Randy Carter is Vice President for Organizational Development and Strategy at The Planetree Alliance.

Erie Chapman, JD: Erie Chapman is the President and Chief Executive Officer of the Baptist Healing Trust.

Paul D. Cleary, PhD: Dr. Cleary is a Professor of Health Policy at the Harvard Medical School.

Angela Coulter, PhD: Professor Coulter is the Chief Executive for Picker Institute Europe.

Glenna M. Crooks, PhD: Dr. Crooks is the President and Chief Executive Officer of Strategic Health Policy International, Inc.

Karen Davis, PhD: Dr. Davis is the President of the Commonwealth Fund.

Don E. Detmer MD & MA: Dr. Detmer is Professor of Medical Education at the University of Virginia Health System.

Susan Edgman-Levitan, PA: Susan Edgman-Levitan is the Executive Director of the John D. Stoeckle Center for Primary Care Innovation.

Lars Fallberg: Lars Fallberg is the Managing Director of the Picker Institute Scandinavia.

Samuel Fleming: Samuel Fleming is the Chief Executive Officer of Decision Resources.

Rosemary Gibson, PhD: Dr. Gibson is Senior Program Officer of the Health Care Group at the Robert Wood Johnson Foundation.

Lucille Hanscom: Ms. Hanscom is the Administrative Director for the Picker Institute Inc.

Michael Hays: Michael Hays is the President and Chief Executive Officer of the National Research Corporation.

Judith Hibbard, PhD: Dr. Hibbard is a Professor of Health Policy at the University of Oregon.

Sir Donald Irvine, CBE, MD, FRCGP: Sir Donald Irvine is the Chairman of the Picker Institute Europe.

Mary Jane Koren: Mary Jane Koren is a Senior Program Officer at the Commonwealth Fund.

Nancy L. Laite: Mrs. Laite is on the staff of the Picker Institute, Inc.

Albert Mulley, MD: Dr. Mulley is the Chief of General Medicine at Massachusetts General Hospital.

Barbara McNeil, MD & PhD: Dr. McNeil is the founding Head of the Department of Healthcare Policy at Harvard Medical School.

Margaret E. O'Kane: Margaret E. O'Kane is the President of the National Committee for Quality Assurance.

Harvey Picker, Ph.D.: Harvey Picker is the Chairman and Founder of the Picker Institute, Inc.

Jona Raasch: Jona Raasch is the Chief Operating Officer of the National Research Corporation.

Stephen C. Schoenbaum, MD & MPH: Dr. Schoenbaum is a Senior Vice President at the Commonwealth Fund.

Gail Warden: Mr. Gail Warden is the President Emeritus of the Henry Ford Hospital Health System.

J. Mark Waxman: Mr. Waxman is the President and General Council of the Caregroup Healthcare System and board member of the Picker Institute, Inc.

Nancy Whitelaw, PhD: Dr. Whitelaw is Vice President for Research and Demonstration at the National Council on the Aging.

Appendix B: Patient-Centered Care 2015 Scenarios

Vision Summit on Patient-Centered Care
March 15-16, 2004
Baltimore

Patient-Centered Care
2015 Scenarios

IAF | **picker**
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By The Institute for Alternative Futures

On behalf of The Picker Institute

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Setting the Context for a Shared Vision

For more than two decades, leading health organizations, institutions, researchers and public policy advocates have promoted the idea that patients should be at the center of their own healthcare experience. Much has been learned about the principles and practices shaping patient-centered care. While many agree that patients should be the focal point of design and delivery of healthcare, implementation lags. Patient-centered care is not standard practice in hospitals, nursing homes and medical practices in the U.S., Canada or Europe. It is still a visionary goal to be pursued and a set of principles with the power to transform healthcare. The Picker Institute, a leader in advancing the practice of patient-centered care, is asking those who work in this field to commit to a shared vision and take the bold steps to make it the universal standard of care.

The Picker Institute commissioned the Institute for Alternative Futures (IAF) to convene a dialogue among the proponents of patient-centered care to better understand what will be required in the next ten years to achieve full acceptance and implementation. IAF is facilitating a process to define a vision for patient-centered care that could weave the work of multiple advocates and practitioners into a shared outcome. IAF crafted ten provocative forecasts to probe what people believe will be essential to success, and used them in interviewing more than 50 key proponents. From this learning, IAF now offers four scenarios that illustrate how the future might unfold for patient-centered care in U.S. healthcare. While focused on the US, the scenarios suggest relevant priorities and opportunities for countries that provide some form of universal healthcare.

Defining Patient-Centered Care

The Picker Institute's research, information and education, and assessment tools rely upon seven dimensions of patient-centered care:

1. **Respect for patient's values, preferences and expressed needs.** This dimension is best expressed through the phrase, "Through the Patient's Eyes" and the book of the same title, and leads to shared responsibility and decision-making.[1]
2. **Coordination and integration of care.** This dimension addresses team medicine and giving patients support as they move through different care settings for prevention as well as treatment.
3. **Information, communication and education.** This includes advances in information and social technologies that support patients and providers, as well as the cultural shifts needed for healthy relationships.

4. **Physical comfort.** This dimension addresses individual, institutional and system design (i.e. pain management, hospital design, and type and accessibility of services).

5. **Emotional support.** Empathy and emotional well-being are as important as evidence-based medicine in a holistic approach.

6. **Involvement of family and friends.** Care giving is understood to include more than patients and health professionals so that the larger community of care givers are considered.

7. **Transition and continuity.** Delivery systems provide for caring hand-offs between different providers and phases of care.

This will form the basis for our exploration of the future of patient centered care. In our expert interviews, (see Appendix A for a summary) other definitions and dimensions were identified and will be explored in the scenarios.

Several larger healthcare design issues impact any future view, such as the state of access to healthcare in the US, its financing, and the roles of various types of health professionals (physicians, nurses, other providers) and their settings and specializations (hospitalists, other specialists, primary care providers, and care coordinators). These were among the issues explored in the interviews and reflected in various patterns in the scenarios.

As a baseline for what would be ideal for US healthcare, we have been guided by the Institute of Medicine's 2001 Report: *Crossing the Quality Chasm*.[2] Patient-centered care is identified as one of the six "aims" for healthcare:

1. **Safe** - avoiding injuries to patients from the care that is intended to help them.

2. **Effective** - providing services based on scientific knowledge to all who could benefit, and refraining from providing services to those not likely to benefit.

3. **Patient-centered** - providing care that is respectful of and responsive to individual patient preferences, needs and values, ensuring that patient values guide all clinical decisions.

4. **Timely** - reducing waits and sometimes harmful delays for both those who receive and those who give care.

5. **Efficient** - avoiding waste, including waste of equipment, supplies, ideas, and energy.

6. **Equitable** - providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status.

In the same report, IOM provided "Ten Rules for Redesign" of health care that further define patient-centered care.[3]

1. Care is based on continuous healing relationships.

2. Care is customized according to patient needs and values.

3. The patient is the source of control.

4. Knowledge is shared and information flows freely.

5. Decision making is evidence-based.

6. Safety is a system property.

7. Transparency is necessary.

8. Needs are anticipated.

9. Waste is continuously decreased.

10. Cooperation among clinicians is a priority.

IAF Interviews

Given the starting definition of patient-centered care and IAF's review of relevant work on the state and future of the US healthcare system, 10 "provocative forecasts" were prepared for use in the interviews. IAF interviewed leading experts and advocates about the future and used the resulting insights to shape the scenarios. The names of those interviewed and more detail on the results of the interviews is given in Appendix B and C. In reviewing the interviews, four themes emerged as essential to advancing and sustaining patient-centered care over the next 10 years:

- **Healthcare must be designed from the patient's perspective.** This includes health facilities, processes, policies and governance, and clinical encounters.

- **Patients must be empowered to manage their care.** Patients and their families should be involved in decision-making and receive education, information and coaching to facilitate their informed and full participation.

- **Healing relationships are essential to good health outcomes.** Patient-provider relationships can be improved through better communication and empathy.

- **Everyone is accountable for health.** Responsibility and accountability are shared among members of the provider team, payers, patients, families, communities, and governments—essentially all elements of society.

Four Scenario Views of the 2015 Future of Patient-Centered Care

IAF created four scenarios to show how these major themes in patient-centered care might play out in different futures. We have used IAF's approach to creating "aspirational futures".[4] Scenarios should consider a range of future possibilities focused on what is likely, what "might" happen (plausible futures), as well as a range of what is desired or preferred (preferred futures). Using this approach IAF extrapolated a "best guess" of the most likely future for patient-centered care from current trends in the US. This "alpha scenario" illustrates what could happen in the zone of conventional expectation, where the future unfolds in familiar patterns. A second scenario considers some of the many "things that could go wrong". This "beta scenario" takes people into a zone of growing desperation where patients are increasingly placed at risk and basic systems fail. The last two scenarios provide different answers to this question: "What would the future look like if a critical mass of stakeholders successfully pursued visionary ends?" These "delta scenarios" or more aspirational scenarios, each describe the outcomes of different orientations and priorities within the zone of high aspiration: one emphasizes an objective, system view and the other a more subjective, human view.

This set of four scenarios are described briefly below, then in narrative form and finally compared in a table.

1. *"Informed Consumers Exercising Their Clout"*, the extrapolative scenario, develops a marketplace view of American medicine in which those with resources and knowledge can secure some degree of patient-centered care, because healthcare providers see it as good business. The fortunate and well informed also have access to smarter medical technologies and treatments.

2. *"Healthcare Refugees with Nowhere to Turn"* examines what happens to patient-centered care when the healthcare system is near collapse, and most people make do in a world where quality, access, safety, and technological progress are compromised.

3. *"Excellent Systems Converge"* places patients and healthcare professionals in a well-designed and progressive healthcare delivery system, where every component is performing well.

4. *"Collaborators in Health"* evolves from the premise that health has become everyone's responsibility, collaboration defines all relationships, and the systems and technologies are integrated to mutual accountability.

As you read the scenarios, consider these questions:

1. What is the relative likelihood of these four scenarios? What is your sense of the relative preferability of these four scenarios?

2. What are the essential elements of a shared vision for patient-centered care?

3. What audacious goals would inspire people to collaborate in assuring patient-centered care is the norm in 2015?

4. Which changes are achievable with the right action steps?

Scenario 1
Informed Consumers Exercising Their Clout

Summary

Remarkable medical advances are available for consumers able to pay. Although almost everyone has access to a basic tier of healthcare, employers have shifted to defined contributions. Anybody can "buy up" through the tiers all the way to concierge care. To attract the more affluent and informed consumers in higher tiers, smart hospitals and medical practices are instituting patient centered system design and inviting patients to actively participate in their health. They tout high scores for patient satisfaction on report cards. A strong patient brand plus a growing product line of technological advances are what sell. Smart people with chronic diseases choose providers offering comprehensive and evidence-based management of their illnesses. Providers promise sophisticated biomonitoring, telemedicine, and targeted therapies for cancer and chronic illnesses. Yet the patient-centered care hyped in medical ads often proves to be less than promised.

Patient-Centered Care

As patients pay more of their bill, they learn to shop for value and effectiveness using report cards. They are very satisfied with the ease of navigating their healthcare systems. Most understand their illnesses and are engaged in making healthcare decisions and following recommended therapies. Disease management approaches help a growing proportion of people with chronic conditions change their behaviors to reduce acute and expensive problems. Certain factors still undermine the promise of better patient-provider relationships for the majority. The high cost of care continues to squeeze the time professionals can devote to each patient. Shortages of key personnel stress healthcare teams and undermine care coordination. Professionals have yet to embrace a culture of caring that recognizes the importance of interpersonal communications and relationships in the healing process. Those who are poor, careless or unlucky get substandard care.

Care Delivery

With chronic disease, including treatable cancers, responsible for 90% of America's disease burden, disease management and care coordination are the focal point for care delivery. Healthcare providers use biomonitoring, advanced communication technologies, and goal contracting with individual patients to change behavior. Physician practices are still fragmented. Hospitalists, intensivists and a multitude of subspecialists interrupt continuity of care for most hospitalized patients. Professional bias often impedes cooperative teaming with non-physicians. Because most providers continue to be part of small independent groups, this hinders financial incentives for team performance.

Standardized electronic medical records (EMRs) were mandated and now capture 95% of hospital encounters and 65% of outpatient visits, according to a 2015 survey, but there are still critical gaps. Many of the primary care clinics serving the uninsured and under-insured are notoriously overwhelmed by paper. Experts cite paper-based systems serving the poor as a major barrier to reducing medical error. The public is still suspicious of EMRs after seeing major privacy violations, coupled with inadequate discrimination protections. Only a small percentage of people keep their own records or challenge information in EMRs. Many activists advocate opening EMRs to patients and their families and accuse providers of resisting giving patients more power. Opponents of open records cite the additional expense and failure to agree upon standards.

Acceptance of prevention is growing. Health professionals use new understanding of disease processes and advanced biomonitoring capabilities to promote prevention, but Americans are reluctant to accept incentives for healthy behaviors.

Patient Safety

Medical errors have been reduced 75% since 2000. Consumer pressure contributed to improvements in safety and quality. Report cards and information on the latest evidence-based treatments are readily available to the public in easy-to-read formats. Advances in EMRs and the application of pharmacogenomics for effective drug selection have made a huge difference.

Health Technology

Steady advances in biotechnology, nanotechnology, and information technology produce a plethora of new monitoring, diagnostic, and treatment modalities. Professionals like them and consumers demand them, in spite of high costs and variable effectiveness. People with chronic diseases and many others use noninvasive biomonitoring devices, often worn or imbedded in clothing. These devices are effective in helping many elderly retain key life functions until they near death. Their high costs are more than offset by preventing expensive complications. Targeted therapies became available after 2010 for many cancers, diabetes, heart disease, and even Alzheimer's disease. EMRs have improved coordination of disease management, quality, and identification of evidence-based therapies for population subgroups.

Economics

Healthcare remains the economic driver of the economy at $4 trillion annually - 18% of GDP in 2015. Double-digit insurance premium increases forced employers to shift costs onto employees. Defined contribution for basic tier coverage is now the standard - even for Medicaid. Consumers customize their coverage based on their health needs and desired level of risk. The average out-of-pocket cost for employees rises from 14% in 2001 to almost 25% by 2015; for drugs, it rises 24 to 43% and higher for targeted drugs and advanced therapies. A politically driven patchwork of coverage options and tax incentives reduce the numbers of uninsured to 7.8 million (2.5%) in 2015. The poor have only the basic tier of coverage, and effective access remains a problem for tens of millions of people.

Scenario 2
Healthcare Refugees with Nowhere to Turn

Summary

Americans are stunned when the healthcare system finally collapses in 2009. Confronted with unrelenting, double-digit healthcare inflation running into a recession, employers dropped coverage en masse. Governmental price controls are instituted, and healthcare contracts to 12% of GDP by 2015. This is still more than most countries spend on healthcare, but it hits the poor and middle class hard. Desperate patients now simply want to hold onto some form of basic care. Patients feel powerless navigating a system with too few resources to respond to their physical, much less their emotional needs. Delivery of care, even for chronic diseases, is a patchwork of makeshift fixes. The most affluent 10% of Americans who are ready to pay out-of-pocket can still get timely, excellent care. The majority waits for routine interventions and preventive treatments and the poor wait longer. Safety, quality and evidence-based medicine suffer. The medical technology industry, once the symbol of the nation's scientific prowess, subsists on limited capital and produces only incremental improvements in the face of price cuts. Without a large public market, even the affluent find expected advances slowing down. A crisis of leadership within the healthcare industry and government offers patients nowhere to turn to secure their health and well-being.

Patient-Centered Care

With the deterioration of the healthcare sector - price controls, declines in manpower support, and inadequate information infrastructure - many health professionals in 2015 find patient-centered care irrelevant. There are strong emotional and financial incentives for doctors to reduce their time with patients and avoid responsibility for continuity of disease management. Patients with a survivalist mentality manage more of their health themselves, as assertiveness is no match against the health system bureaucracy. Patients and their families despair of ever finding someone to turn to for understanding and assistance. Discouraged providers project their anger and frustration onto patients. The fractured system hinders collaboration between specialties and further stresses poor relationships.

Care Delivery

Demoralized personnel do not have the energy to bring the pieces together for collaborative management and continuity of effort in treating chronic diseases. Healthcare providers struggle to summon the energy and ingenuity to rally around even the most desperate cases. Those enrolled in a solid vertical system such as Kaiser, the Veterans Health System or military are lucky to have providers that can collaborate within coherent management systems and budgets. The uninsured rely on

emergency care in a crisis, while the wealthy pay out of pocket for high quality concierge care. Prevention is abandoned as a health strategy.

Patient Safety

Safety, quality, and evidence-based therapies are slowly becoming accepted practice, despite a lot of politics, finger pointing, and professional resistance. Medical errors have been reduced by 10%, but there is little momentum for more improvement. With the multitude of other challenges, governmental and citizen pressure for safety has withered. The few remaining nonprofit advocacy groups are focused on those few health systems capable of improvement.

Health Technology

Only the affluent have access to advanced technology, and the low volume of sales has significantly dampened investment and slowed new product development. Biomonitoring has proven cost effective in managing complex chronic diseases. Developmental setbacks and regulatory delays allow few targeted drugs for specific diseases to reach the market. Highly restricted formularies permit only a few patients meeting special criteria to have access to them. While many hospitals use a basic electronic medical record, most provider groups do not, making continuity of care difficult.

Economics

Unrelenting double-digit healthcare inflation forced employers to drop coverage en masse in 2006. Governments responded to pressures from a huge number of uninsured middle class voters with a "play or pay" mandate requiring employers to provide a basic tier of coverage. Uncontrollable costs for Medicare and Medicaid also provoked price controls. Health plans were forced to cut costs through eliminating many jobs, infrastructure reductions, and draconian methods to restrict services. This upheaval had a significant ripple effect as healthcare spending dropped from a high of 15% of GDP in 2005 to 12% in 2015. Pharmaceutical and technology companies lost market value. Thirty percent of health plans disappeared through consolidations or bankruptcies. Doctors experienced a cumulative 9% decline in income and many took early retirement. This caused access problems in many locations. There are still over 60 million uninsured, and those fortunate enough to have mandated coverage are mostly dissatisfied with their benefits and quality of service.

Scenario 3
Excellent Systems Converge

Summary

A convergence of scientific knowledge and information tools with public understanding and acceptance transform U.S. healthcare. The standard of care is high quality, safe treatment based on the latest evidence of effectiveness. Patients understand and expect patient-centered care, and the medical community widely accepts its practices. Patients and their families can effectively master their health with the support and coaching of user friendly, responsive health systems. Patients communicate with their team leader or other appropriate providers to tailor their care to individual health conditions and learning preferences. Where no good choices exist for medical conditions, most patients and physicians have good support systems for facing difficult decisions. Patients and physicians use medical technology to identify future health risks and employ aggressive prevention strategies. When chronic diseases are diagnosed, targeted therapies are available to cure or control many of them. Healthcare remains the largest sector of the American economy at 16% of GDP, but Americans can clearly see their large investment paying off in significant health gains for everyone.

Patient-Centered Care

Healthcare purchasers organized a comprehensive education and change management campaign after 2004 in an effort to get the public and medical community to embrace the concepts and responsibilities of patient-centered care. Health plans, advocacy groups, and even school systems now inform and prepare citizens for their roles in taking responsibility for their own health and interaction with care systems. To support healthy patient-provider relationships, the curriculum for professional schools and medical residencies emphasize communication and related skills. These skills are rigorously evaluated for continual improvement. The science of decision making now provides rigorous measures for decision quality that are used for both medical education and public report cards.

Care delivery is now designed to provide easy access to services that respect patients' needs and expectations. A national effort assured the quality, effectiveness, and confidentiality of interactive web sites. Individuals now can get information on the web tailored to their culture, learning style, capabilities and needs. They use "health coaching" software to monitor their health and health systems. Easy access to their healthcare team is provided through high-speed Internet connections and interactive video conferencing for questions and support. This coaching reinforces healthy behaviors and effective adherence to disease management protocols for those with or at risk of chronic disease. When patients face difficult decisions about treatment options, they use decision aids and frank conversations to come to their own judgments about how to live their lives while managing their illness.

Care Delivery

Healthcare team members use contact management software, advanced clinical protocols, electronic medical records and telemed video consults to create highly responsive processes. These support systems both coordinate and coach the nurse practitioners, primary care physicians, specialist physicians, and alternative medicine providers who make up each patient's healthcare team. Frequent communication, education, and coaching bring patients and their families fully into care management. Appropriate resources, communications technology and culturally sensitive design of services ensure all Americans regardless of their finances, geographic location or individual situation can get high quality care consistent with their unique needs. Performance measures indicate high levels of patient satisfaction. By 2015, the system has instilled a strong sense of individual responsibility for one's health. The majority of Americans feel comfortable with their new role in mastering their own health. Comprehensive risk assessment, preventive measures, and coordinated management of chronic diseases flow together in a user friendly and seamless manner.

Patient Safety

Patient safety is a collaborative effort among health systems, providers, patients, families, and citizens. Everyone is focused on ways to achieve successful outcomes, rather than dwell on blame. Leaders advocate for systems engineering and rational solutions to "design out error". Mistakes still happen, but people work hard to prevent error. When failures occur, compensation is swift and fair. Patients largely take safe care for granted, but systems still vigilantly monitor practices, and accreditation bodies enforce transparency. Medical errors in 2015 are reduced 85% below the rate reported in the year 2000.

Health Technology

Incredible advances in technology are rationally applied in a coordinated way to manage the continuum of health and ensure high quality of life. When people learn they have a potential health problem or a new diagnosis, they receive immediate help. Disease management starts with sophisticated monitoring of the environment to identify and reduce risk factors. All Americans can have their genome, proteome, metabolome, environment and emotional factors assessed to forecast future risk of developing disease, as well as the likely success and side effects of specific regimens and pharmaceuticals. People are willing to contribute their medical information, including genotype and phenotype data into medical research. Treatment regimens, and prevention approaches (including chemoprevention) are individually tailored on the basis of the enhanced (though still not perfect) predictiveness of these multiple factors. Numerous targeted therapies are available, and pharmacogenomics is used to rationally select the best therapy for an individual's disease situation. Artificial and cultured organs and minimally invasive procedures are used on those who developed disease complications before new therapies were available. The traditionally high level of morbidity present in the last 10 years of life has been significantly reduced and compressed into the last few months of life for most people.

Economics

Healthcare costs grow to about 16% of the economy (still about one third higher than other countries with leading health care systems). Americans value this significant contribution to the quality of life and well being of the whole country. Demanding consumers and payers hold the free enterprise delivery system to high standards. Healthcare is still primarily a benefit of employment with employees bearing a larger share of the cost. Insurance is designed to help employees make smart choices to gain the best predictable health outcomes. Primary care clinics are playing a larger role in providing basic services, including biomonitoring and predictive assessments, to most poor and underserved populations. A cultural shift to prevention has been effective - people are healthier and require less tertiary care. Programs are in place to insure all Americans have access to comprehensive and affordable care.

Scenario 4
Collaborators in Health

Summary

Because health is everyone's responsibility, health services are structured to apportion accountability and incentives to patients, physicians and other players to make their best contribution to health. Collaboration is the multiplier transforming limited resources into effective health outcomes. Patients and professionals share responsibility for decisions and practices that foster safety and evidence-based medicine. They thrive in a web of relationships connected by open access to information, coaching and support, and responsive, easy to navigate processes. Most all patients understand and meet their individualized health plan goals. They succeed with the support of their families, patient peer groups, health professionals, and advanced biomonitoring and information systems. Teams of providers organize around their patients to promote prevention and effectively manage chronic illnesses. Advances in medical, social and spiritual technologies are tools in their hands to facilitate learning and healing. With the advent of shared accountability, communities have newfound resources for sustaining the health of everyone, and their circle of concern is widening to take in poverty and other social problems at the root of poor health.

Patient-Centered Care

In the time-starved environment of the managed care era, physicians needed proof that collaboration among providers, patients and their families would make a difference. Conventional scientific and business wisdom had marginalized its significance. Controlled studies in 2007 found focusing on provider-patient relationships produced better outcomes and more patient and provider satisfaction at reduced costs. Then researchers showed statistical improvement in the immune system and many other positive effects on the genome, protein synthesis and cell durability. Social science research added insight into health, happiness, and the effectiveness of institutions and society as a whole.

From this research, the critical elements of effective patient care were identified and promoted within organizations, communities and nations. The new wisdom advocated healing relationships and explicitly honoring patient values in determining treatment plans. Institutions, payment systems and medical education made patients the focal point in healthcare. Every architectural form, process and practice in healthcare was examined through the prism of healing. The positive experiences of early practitioners encouraged others to enthusiastically apply this new learning to all aspects of patient care after 2010.

The lines between consumer, patient, family member and provider have since blurred as their new roles include a little of each. Everyone is now on a team with some responsibility for individual, organizational and societal health. Patient-centered care has evolved to include "community centered care" with the realization that poverty, the environment, and other societal issues affect individual and community-wide well-being. Policies and budgets now link healthcare outcomes to employment, housing, transportation and criminal justice systems within communities. Successful healthy community projects have fostered a variety of best practices producing remarkable results.

Care Delivery

The delivery system is a caring system that recognizes health as wholeness for individuals and communities. Effective prevention and management of chronic diseases requires addressing issues at the family, workplace and community level, as well as the individual patient's physical, emotional and spiritual dimensions. Strong values and relationships unite people in care models of common purpose for healthy outcomes. In many communities, churches, hospitals and employers work closely together with families and neighbors to care for patients in crisis. People check in regularly with their virtual group of health buddies for moral support and shared learning from their common life experience. A next generation Internet sustains this web of local and virtual community. Although the number of physicians has not increased, patients are satisfied with the attention they receive through increased access online, other members of the healthcare team, and streamlined processes. Healthcare professionals report high levels of job satisfaction and enjoy the intrinsic rewards of being honored and valued as healers. A range of feedback mechanisms monitor and reward health gains through incentives ranging from reduced premiums to added vacation time at work.

Patient Safety

A cultural shift from blame to cooperation led to better systems for preventing medical error and promoting safe, evidence-based, quality care. After 2005, clinical information systems became popular. These systems use decision-support software, natural language processing and predictive modeling to improve safety. Patients and other members of their team enjoy strong relationships and common goals that make transparency and quality easier to achieve. Citizen boards at the community level work to assure patients and their families are active partners in promoting safe medical care.   Data show a 90% reduction in medical errors since the 1990s. Evidence-based standards for care are universally understood and widely followed. Care is customized to the individual and may include evidence-supported options now found to be safe and effective from what once was called "alternative medicine". Patient satisfaction is consistently very high.

Health Technology

In this era of dawning awareness that health is a more powerful idea than simply defeating disease and disability, researchers and practitioners are integrating advances in medical, social and spiritual technologies. Medical researchers are pursuing prevention at the molecular level and developing targeted therapies for important chronic diseases facing society. Readily available pharmacogenomics

permits selection of the most appropriate therapies for each individual. Easy-to-use biomonitoring devices make continuous monitoring of personal health and interventions feasible and affordable. Inexpensive sensors blanket the environment to detect any changes that could harm or improve community health. Social researchers and health educators have joined with religious and spiritual leaders to create and refine disciplines that empower people to live integrated and meaningful lives that embrace health and accept death.

Personal health records with smart agents and advanced communications technologies are universal within the health system. Thanks to wise government support, features such as speech recognition, computerized reminders and neural-network based survival models are widely adopted. These information gathering and communication systems have been adapted to encourage self and community management of health.

Health plans offer biomarkers, predictive models and simulations to create individual plans for their beneficiaries. These predictive models use data from patients everywhere to continuously advance outcomes research that updates and advances individual health plans. Effective expert systems monitor patient compliance and communication with healthcare providers. Physicians and other health professionals are effectively linked as a team for each patient and share the rewards for successful outcomes. Most people self manage their diseases and measure their progress through comparisons with peer groups having similar conditions.

Economics

As individuals' health status improved and society redirected its health priorities, medical inflation moderated. But it was engaged consumers taking responsibility for their own health and expenditures that held health sector waste in check. In 2015 14% of GDP goes to healthcare (down from 15% 10 years ago). Every American has access to comprehensive healthcare by law through a variety of private sector options. Payments for service reward continuity of relationships and active patient participation. The reimbursement system accounts for individual patient risk and required services. Payment flows to the provider accepting leadership and accountability for coordinating a patient's health strategy with allocation formulas to reward all team members based on level of effort. There are financial incentives for both providers and patients if health gains are achieved, and communities find that having a healthy citizenry is an economic and social good.

Picker Patient-Centered Care Scenarios
Scenario Elements Matrix

Component	"Alpha"	"Beta"	"Delta 1"	"Delta 2"
General	Informed Consumers	Healthcare Refugees	Systems Excellence	Compassionate Collaborations
Scenario Focus	Technology advances & cost control	Failing healthcare system	Rational system design that works	Quantum leap in thinking about health
Patient Centered Care	PCC a competitive strategy	PCC sacrificed due to more pressing problems	Excellent PCC, but lacking passion for the relationship	Empowering relationships highly valued; community centered care too
Design from patient's perspective	Facilities & processes but not governance or encounters	None except for concierge care	Facilities, processes, governance & encounters designed from patient perspective	All aspects with best design of encounters; beyond patient to include community
Empowering patients to manage care	Patient access to information and coaching	Not a focus - limited access to info; no system support	Excellent information and support for patients & families	Peer groups, patients & families well informed to lead in care improvements
Healing relationships	Moderate emphasis; can shop for it	Minimal emphasis; only rich can obtain	Present, not strongly embraced	Passionately embraced
Decision making	Driven by provider & payer values	Payer - cost reduction driven	Scientifically evaluated, Patient empowered; Patient values recognized	Also help patient discover deeper values for decision
Accountability	Moderately accepted	All parties avoid	All parties accept	Even society accepts
Fairness & equity	Unimportant	Denied	Addressed	Encompassed

Component	"Alpha"	"Beta"	"Delta 1"	"Delta 2"
Care Delivery				
Focus on prevention & chronic disease	Disease management focus; prevention increasing	Poor	Designed into system	Core in relationships between peer groups, patients & providers
Collaborative teams	Turf resistance limits effectiveness	Fragmented, poor collaborations	Collaborative teams; good communication	Collaborative teams; Superb relationships
Satisfaction	High for the fortunate few	Patient and provider dissatisfaction high	High satisfaction in excellent healing environment	High satisfaction and communal well being
Patient Safety				
Decrease in medical errors since 2000	75%	10%	85%	90%
Participants	Providers under consumer pressure	Providers of best organizations	Patients, families, providers and citizens all active players	Patients, families, providers and citizens all active players
Health Technology				
Acceptance	Available; used by those with good coverage	Limited availability; limited funding for use	Available & appropriately used by all	Balanced use - not to prolong life
EMR (percent with EMR)	95% of hospitals, 65% of offices; few patients have access	40% - incompatibility; patients do not have access to EMR	100% - patients use their EMR with minimal constraints	100% - Personal health record - smart agent coaches self-managed care; most allow anonymous data mining for research
Biomonitoring	Plentiful; focused on care, not prevention; limited access for poor	Slow development; available for rich	Focused on chronic care & prevention	Focused on chronic care, prevention, equity & other social ends
Advanced therapies	Plentiful; available with controls; poor do not have access	Limited and available for rich	Focused R&D for chronic diseases; widely available	Focused R&D for chronic diseases; widely available

Component	"Alpha"	"Beta"	"Delta 1"	"Delta 2"
Economics				
Percent of GDP	18%	12%	16%	14%
Coverage	Defined contribution; tiered coverage; can customize plan benefits (affects cost)	"Play or pay;" cost controls; many uninsured	Universal access; society values health expenditures	Universal access; budget also includes community wide outcomes; effective health reduces cost
Compensation incentives for outcomes	None	None	Reward purchase of PCC supporting technologies	Reward non-visit care, service satisfaction & health gains

Appendix C
An Evolving Definition and Practice: Patient-Centered Care

Patient-centered care is a concept in transition. When the Picker Institute joined with the Commonwealth Foundation to research the patient experience, it began with analyzing and interpreting the experiences patients have with hospitals.[5] The principles and practices of patient-centered care have been extended to other settings, such as nursing homes, ambulatory care, and physician's offices.

Writing in 2002, Angela Coulter, Ph.D., chief executive of Picker Europe, recaps the history of the concept and proposes that more is at stake than the setting. Patient-centered care must now include a culture change for clinicians and patients, starting with patients' rights to make autonomous decisions.[6]

The Institute for Healthcare Improvement helped operationalize the concept through its seven challenges to healthcare teams.[7] The challenges include giving medical records to patients and putting care protocols in their hands. To achieve greater commitment between patients and their primary care physicians, the Institute recommended testing the Foundation for Accountability Agreement to Share Knowledge with ten patients and enrolling 200 patients in "How's Your Health," an online health status questionnaire. Patients and families should be co-chairs of redesign teams. There should be open visiting in intensive care units, emergency departments, and recovery rooms. The seventh challenge was to implement shared decision-making processes for conditions such as prostatic hypertrophy and breast cancer.

In an aspiring scenario of what healthcare could become in a utopian land called PeoplePower, a five-day seminar in 2000 of 64 people from 29 countries used the guiding principle of "nothing about me without me". They envisioned informed and shared decision-making, mutual commitments to quality and health outcomes, and patient partnership in governance.[8]

The Foundation for Accountability advocated a future healthcare system that is person-centered.[9] It would have these four dimensions:

* Health: The system will help most people understand, be responsible for, and be able to take care of their own health to the maximum degree possible.
* Healthcare: The system will make available the most effective professional and institutional resources to assist people when they can no longer manage their own health without help. The system will embrace and promote the principles of 'patient-centeredness;–self care, personalization, transparency, redesign, quality, justice and control.
* Financing: Every individual and organization–from the patient to the medical school to Medicare-will accept responsibility to use expensive resources appropriately and efficiently.

♦ Citizenship: Society will embrace an explicit consensus of our responsibilities to each other-and the limits of that responsibility.

The concept has now evolved to recognize that health begins in prevention and self care. Well before people become patients, they need to be actively involved in promoting their own health and practicing self-care. Once they are patients, they need to enter this relationship as informed and responsible partners. Working through how patient-centered care should evolve to assure all this and much more happens to make healthcare and patients more responsible will be critical work over the next 10 years.

Appendix D
Interviews Summary

Forecast 1: Healthcare becomes more effective at improving health status despite declines due to chronic diseases in the aging U.S. population of 2015. Healthcare plans retain most of their beneficiaries and use individual risk assessments to guide expenditures. Healthcare providers work effectively as teams to help improve their patients' quality of life. Patients have incentives to meet health goals that they determine with their healthcare team.

A good number of respondents applauded the premise of patient responsibility in this forecast, but some questioned the utility of financial incentives as motivators. Individualized and changing incentives would work better. The public would never accept sanctions as negative incentives. A few people challenged whether patient self-management is realistic, especially for those who cannot be partners in their own care. Yet there has been very little assessment of patient ability to make good decisions, nor how well providers enable improvements in decision making. There was interest in how individual risk assessments would work and how individuals would set health goals. Some direct intervention pilots for chronic disease are now underway, but this is a newly emerging area.

A number of those directly working in patient-centered care are taking the next logical step in this movement and are moving towards shared decision making (See the work of Angela Coulter, John Wennberg, Al Mulley and Richard Rockefeller). What should be addressed is decision making in a tough medical situation like breast or prostrate cancer. Research into how decisions are made in healthcare shows there are distinct challenges to be met across a taxonomy of decisions (e.g., where choices all carry undesirable tradeoffs or where medical evidence is lacking.) The question is not are we doing the right things right. It is whether we are doing the right things, or the wrong things right. Current reality has answers all over the map. A better future reality could bring patients into an initial determination of what defines "right" for their particular circumstance so that the "goodness" of decisions is directed by their values rather than those of a provider or payer system.

Several contradictory comments on the idea that healthcare plans would retain their beneficiaries show intelligent and informed people disagree about what could happen. Would they screen for the patients they want? Are the healthy people the only ones changing plans because they can? Knowing how the healthcare plans would react to change will be important.

People liked team care as an ideal, although several observed this is not what is taught now.

Forecast 2: *In 2015, less than 5% of the American public uses fee-for-service payments, while traditional managed care coverage has dropped to 25% of covered lives. The great majority of Americans pay for their healthcare through the Improving Individual Outcomes (IIO) system, which provides incentives for care coordination that prove especially effective for the population with multiple chronic diseases and/or risk factors for conditions that are expensive to treat.*

Paying for outcomes and care coordination was particularly appealing, though there were some questions about how this could be done. Information systems will provide more specific data about technical performance and the ability to predict outcomes based on adherence to standards of process performance will likely improve. Achieving effective disease management by 2015 also seems plausible to many, though some recognize that care coordination, especially for people with multiple chronic diseases, goes beyond what most providers offer now. Payments linked to quality and standards of performance are likely to appear as employers and thought leaders advocate for it.

Where people disagreed was in the mechanics of this forecast. Currently 85% of health plans are fee-for-service, according to one interview. Would a new payment system be financially feasible or too utopian for our American heritage? Would we ever move back to proposals for population-based care? Could we get more cost-shifting and denied access? Could this idea work without a single payer system? It would take an extraordinary level of uninsured to move the country to universal coverage.

Building budgets up from individual risk assessments would be an extreme change in risk adjustment. How would we account for extreme variations in preference-sensitive care? This forecast doesn't note that public choices, not private ones, are what put people at greatest risk.

Forecast 3: *In 2015 an independent commission determines the basic tier of comprehensive benefits for all Americans based on evidence of effective treatment and global budget projections. Continuous online polling provides public input. Congress makes a final determination on the proposed benefits through an up or down vote with no amendments allowed, to limit the influence of special interests.*

People wanted to discuss the feasibility of having a basic tier of comprehensive benefits and what that tier would include. Anything like universal coverage struck some people as unlikely, although it happened in Medicare and Social Security. Would boomers insist on "near-death" care or support changing lifestyles? The states and insurance companies could determine the benefit tiers. Allocations could be made on a geographic basis by strengthening the responsibilities of states through health departments and quality improvement organizations. From a public health perspective, the first tier could be community intervention, followed by individual level prevention, individualized care by professionals, and then ending with more high tech and hospital-based care.

Those who commented on the continuous online polling and Congressional up or down vote either thought it was strange or liked the political mechanism. There would be a need to educate the public to participate in the dialogue and constantly update their knowledge.

Forecast 4: Between 2005 and 2010 a national licensure system supersedes state boards, which were unable to effectively discipline professionals or accommodate telemedicine. A national consumer movement arose to address medical error, creating a National Patient Safety Board to guide healthcare systems change and tort reform. National and local boards operate in tandem in 2015, with majority representation of consumers at both levels. These boards help drive changes in education, accreditation and revocation of licenses to practice.

National licensure is desirable, but people expected it would be hard to achieve. As an alternative, linking databases would help. Other countries have unified licensing. Duties and standards are becoming imbedded in licensure. People seldom believe it is their physicians who have the problem unless they've experienced a terrible event.

American medicine needs to learn how to disclose errors. Patient errors should be treated like an emergency with mandatory reporting and expedient follow-up. Would a centralized commission with patients serving on it actually improve safety? Patients aren't neutral either. Safety can be achieved through policies and procedures to reduce errors. Another way to transform medicine would be to include patients in the ownership and organization of hospitals.

Forecast 5: The quality of the patient-provider relationship has improved by 2015 thanks to higher levels of trust and better communications. Consumers routinely access report cards prior to choosing healthcare providers. These report cards provide vital feedback to all caregivers, showing both the technical competence scores and the quality reflected in their interaction with patients.

Greater transparency is coming to medicine to support informed choice in consumer-driven healthcare, but report cards may not be the vehicle. Consumers do not value or use report cards. In part, this is because they do not contain the information consumers really want. They are more interested in patient experience metrics and practice characteristics than clinical practice information. To be effective, report cards would need to be simple and useable, like the Zagat's travel and restaurant guides. Eventually global standards for report cards could evolve. There could also be disease specific report cards at the population level.

Other factors that would improve trust recommended in the interviews included: better patient understanding of medical error, breaking down inefficiencies in the delivery of care, compensating for email encounters, patients assessing team care, and becoming fully informed patients. Is this picture of high trust levels feasible by 2015? One person said no, and another said perhaps for the top tier of patients.

Forecast 6: Consumer health information in 2015 relies on computers that communicate more fully with humans and are interconnected through a vast global network to billions of information sources, including products and devices transmitting data continuously. People

typically use biosensors with feedback monitors, tactile input devices, wearable displays, avatars and haptic interfaces* for 24X7 communications with their computers.

Some expect patients to reject such technologies and push back implementation. Others went beyond the forecast to talk about other tools that are needed, such as smart cards with patient information and decision aids for sharing decision making and tracking outcomes. Every step of the healthcare process would be surrounded by information that is available for decision-making by patients, families, and line staff. Greater efficiency would be possible in everything from line staff using handheld devices to patients being alerted about waiting times. Time for quality could come back into the system through the use of technology.

While someone described this forecast as "pretty far out", one physician we interviewed takes the idea out even further. He sees even physical exams displaced by video electronic interactions and doctor consults outsourced to other countries. The Internet also creates the possibility of communities of patients forming. They could displace physicians, especially in helping manage chronic disease.

Forecast 7: *In 2015 the primary sources for trusted health knowledge are non-governmental organizations (NGOs) that work with academic centers, governments and the private sector. This knowledge is often delivered through health coaches, who teach and help shape healthy behaviors.*

There was almost no agreement on this forecast: patient groups are the most trusted and believable sources; consumers look to commercial organizations; government sources seem more reliable; libraries are the key source for immigrant populations; and pharma companies are better at changing behavior. More focused information is needed, especially for cancer patients. People need to be able to use their personal health record in an integrated way with web-based information on individual providers and chronic care management programs. One visionary imagined people making global comparisons about standards of treatment and medical practice through the Internet.

Forecast 8: *In 2015 the roles of physicians have changed. Teams of providers (physicians, pharmacists, nurses and care coordinators) work with patients and family members to make most diagnostic and treatment decisions. A core of "proceduralist-physicians" handle most medical interventions.*

The idea that physician roles will change is widely accepted. All boards of specialties are requiring interpersonal skills testing. The team members listed above will all be working to the maximum of their

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* Haptics means "of or relating to the sense of touch; tactile (see http://haptic.mech.nwu.edu/ for both definition and descriptions of haptic technologies). Examples of haptic interfaces with computers include devices that vibrate, change temperature or shape to provide information through senses other than sight.

capabilities and there will be new team members not yet imagined. Shifts in roles could occur, such as nurse practitioners and pharmacists assuming the gateway role now played by primary care physicians. The future trend toward hospitalists and proceduralists suggests many MDs would become more like consultants, but this would not eliminate the need for patient communication skills. The team coordinator may become less important if coordination is built into the system.

Some changes in role are inevitable. This is the first year when more women than men are med school students. There remains a need for sufficient minority physicians to assure equity for these populations. Information technologies will change practice. Video consults and other information system tools will let the patient feel in charge, but they may not have access to the full record.

Forecast 9: *Medical education adopted a "kinder, gentler" curriculum by 2015 to incorporate the new emphasis on integrating many disciplines into coordinated team care. Younger doctors receive much of their training through simulations and expect to improve their practice throughout their careers by using a combination of information systems and group decision processes.*

People disagreed about how difficult it will be to get healthcare improvement into the curriculum. People want both the humanities and science to be taught; at least one interviewee said the curriculum design has already gone too far in this direction. Maybe in 10 years medical schools will concentrate on the evaluative sciences as much as biomedical sciences. Medical schools do not teach teamwork, prevention and health promotion. Simulations have great potential. The greatest challenge to teaching patient-centered care is in residency when excessive duty hours work against quality care.

Forecast 10: *Poor and less educated populations still have lower health status and pay more of their incomes for medical services, but the gap has diminished. Most communities seek to address the inequality of health outcomes through education and social services more than through medical intervention. Community health clinics have grown to play a larger role in delivering basic services to assure the poor have access to appropriate care.*

While addressing health outcome disparities is critical, people we interviewed are not hopeful about this forecast. Most people believed the gap would widen as the middle class pays more. Community health clinics are often run by nurses and pressed for resources. Perhaps physicians and retired physicians will volunteer to deliver basic services in community health clinics. The poor and less educated populations should have access to computers, group treatment, and other appropriate tools. What may be needed is a stronger public health delivery system akin to the Veterans Administration and the military health system.

Relying on lifestyle interventions can be seen as second-rate solutions because America does not have a coherent policy on health prevention. Other community organizations should be integrated into a continuum of care and prevention. To deliver health, the system must address the environment people live in and the disadvantages they may have inherited.

Appendix E
Interview List

The Institute for Alternative Futures has the deepest appreciation for everyone who contributed to our interviews on the future of patient-centered care. The following are great minds in the field of healthcare and their insights were indispensable to the preparation of this report. With that in mind, the Institute for Alternative Futures would like to thank:

Paul B. Batalden, MD: Dr. Batalden is the Director of the Health Care Improvement & Leadership Development Center for the Evaluative Clinical Sciences at Dartmouth Medical School.

Donald M. Berwick, MD: Dr. Berwick is the President and Chief Executive Officer of the Institute for Healthcare Improvement.

Maureen A. Bisognano: Maureen Bisognano is the Executive Vice President and Chief Operating Officer of the Institute for Healthcare Improvement.

Erie Chapman, JD: Erie Chapman is the President and Chief Executive Officer of the Baptist Healing Hospital Trust.

Paul Cleary, PhD: Dr. Cleary is a Professor of Health Policy at the Harvard Medical School.

Janet M. Corrigan, PhD: Dr. Corrigan is the Director of the Board on Health Care Studies at the Institute of Medicine.

Angela Coulter, PhD: Professor Coulter is the Chief Executive for Picker Institute Europe.

Glenna M. Crooks, PhD: Dr. Crooks is the president and Chief Executive Officer of Strategic Health Policy International, Inc.

Karen Davis, PhD: Dr. Davis is the President of the Commonwealth Fund.

Suzanne Delbanco, PhD: Dr. Suzanne Delbanco is the Executive Director of the Leapfrog Group.

Thomas Delbanco, MD: Dr. Thomas Delbanco is a professor of medicine at Harvard Medical School.

F. Daniel Duffy, MD: Dr. Duffy is the Executive Vice President of the American Board of Internal Medicine.

Susan Edgman-Levitan, PA: Susan Edgman-Levitan is the Executive Director of the John D. Stoeckle Center for Primary Care Innovation.

Paul Ellwood, MD: Paul Ellwood is the President and Chief Executive Officer of the Jackson Hole Group & Interstudy.

Rose Marie Fagan: Rose Marie Fagan is the Executive Director of the Pioneer Network.

Lars Fallberg: Lars Fallberg is the Managing Director of the Picker Institute Scandinavia.

Samuel Fleming: Samuel Fleming is the Chief Operating Officer of Decision Resources.

Susan B. Frampton PhD: Dr. Frampton is the Executive Director of Planetree.

Atul Gawande, MD & MPH: Dr. Gawande is an accomplished author and surgical resident at Bingham and Women's Hospital in Boston.

Rosemary Gibson, PhD: Dr. Gibson is Senior Program Officer of the Health Care Group at the Robert Wood Johnson Foundation.

Paul Ginsburg: Paul Ginsburg is the President of the Center for Studying Health System Change.

Jessie Gruman PhD: Dr. Gruman is the President and Executive Director of the Center for the Advancement of Health.

Michael Hays: Michael Hays is the President and Chief Executive Officer of the National Research Corporation.

Judith Hibbard, PhD: Dr. Hibbard is a Professor of Health Policy at the University of Oregon.

Elma Heidemann: Elma Heidemann is the Executive Director of the Canadian Counsel on Health Services Accreditation.

Sir Donald Irvine, CBE, MD, FRCGP: Sir Donald Irvine is the Chairman of the Picker Institute Europe.

Mary Ann Kehoe: Mary Ann Kehoe is Executive Director of Good Shepard Services, Ltd.

Mary Jane Koren: Mary Jane Koren is a Senior Program Officer at the Commonwealth Fund.

Ed Krupat, PhD: Dr. Krupat is the Director of the Health Psychology Department at the Massachusetts College of Pharmacy and Health Sciences.

David J. Lansky, PhD: Dr. Lansky is the President of the Foundation for Accountability.

Mack Lipkin Jr., MD: Dr. Lipkin, Jr. is a Professor of Medicine and Director of the Division of Primary Care Internal Medicine at New York University.

Albert Mulley, MD: Dr. Mulley is the Chief of General Medicine at Massachusetts General Hospital.

Rebecca Martins: Rebecca Martins is a tireless advocate for a safer healthcare system for the people of Maine.

Barbara McNeil, MD & PhD: Dr. McNeil is the founding Head of the Department of Healthcare Policy at Harvard Medical School.

Margaret E. O'Kane: Margaret E. O'Kane is the President of the National Committee for Quality Assurance.

Barbara Paul, MD: Dr. Paul serves as a Medical Officer to the Center for Medicare Management at the Centers for Medicare and Medicaid Services.

L. Gregory Pawlson, MPH & MD: Dr. Pawlson is the Executive Vice President for the National Committee for Quality Assurance.

Harvey Picker, Ph.D.: Harvey Picker is the Chairman and Founder of the Picker Institute, Inc.

Jona Raasch: Jona Raasch is the Chief Operating Officer of the National Research Corporation.

Roy J. Romanow QC: Roy Romanow is a former Commissioner on the Future of Healthcare in Canada.

Debra Roter, MD: Dr. Roter is a Professor at the Bloomberg School of Public Health.

Stephen C. Schoenbaum, MD & MPH: Dr. Schoenbaum is a Senior Vice President at the Commonwealth Fund.

Susan E. Sheridan: Susan Sheridan is the President of the Parents of Infants and Children with Kernicterus.

Steve Shields: Steve Shields is the Executive Director of the Meadowlark Hills continuing care retirement community.

Gail Warden: Mr. Gail Warden is the President Emeritus of the Henry Ford Hospital Health System.

John H. Wasson, MD: Dr. Wasson is a Professor of Community and Family Medicine at Dartmouth Medical School.

J. Mark Waxman: Mr. Waxman is the President and General Counsel of the Caregroup Healthcare System and board member of the Picker Institute, Inc.

Myrl Weinberg CAE: Myrl Weinberg is the President of the National Health Council.

John E. Wennberg, MD & MPH: Dr. Wennberg is a Professor of Epidemiology at Dartmouth Medical School.

Nancy Whitelaw, PhD: Dr. Whitelaw is Vice President for Research and Demonstration at the National Council on the Aging.

Footnotes

[1] Gerteis, Margaret, Susan Edgman-Levitan, Jennifer Daley, and Thomas L. Delbanco, editors. *Through the Patient's Eyes.* Picker/Commonwealth Program for Patient-Centered Care, Jossey-Bass, 1993.

[2] *Crossing the Quality Chasm: A New Health System for the 21st Century.* Institute of Medicine, March 2001.

[3] *Crossing the Quality Chasm, ibid*.

[4] IAF has facilitated many futures projects using this aspirational approach, including such projects as "Healthy People for a Healthy World: The Belmont Vision for Healthcare in America, (http://www.altfutures.com/pubs/belmontvision.pdf), the Military Health System 2025 project for the Department of Defense, and the UK government's Economic and Social Research Agency's study of genomics and social science, (http://www.altfutures.com/esrc.asp).

[5] Gervais, Margaret, Susan Edgman-Levitan, Jennifer Daley, and Thomas L. Delbanco, editors. *Through the Patient's Eyes: Understanding and Promoting Patient-Centered Care.* Sponsored by the Picker/Commonwealth Program for Patient-Centered Care. Jossey-Bass, 1993.

[6] Coulter, Angela, Ph.D. *The Autonomous Patient: Ending paternalism in medical care.* Sponsored by The Nuffield Trust, 2002.

[7] *The Courage to Change: Responding to Im-Patient Voices: Seven Challenges for Your Team.* Institute for Healthcare Improvement, Plenary Presentation, IHI National Forum on Quality Improvement in Healthcare, December 4, 2003.

[8] Delbanco, Thomas, MD, Donald M. Berwick, MD, Jo Ivey Boufford MD, S. Edgman-Levitan PA et al. *Healthcare in a land called PeoplePower: nothing about me without me.* Blackwell Science Ltd, 2001 *Health Expectations*, 4, pp. 144-150.

[9] *Innovators and Visionaries: Strategies for Creating a Person-Centered Health System.* Foundation for Accountability, September 2003, www.facct.org