

## The Future of Patient-Centered Care: Scenarios, Visions, and Audacious Goals

CLEMENT BEZOLD, Ph.D.

### ABSTRACT

The U.S. health care system is transforming. It must. Patient-centered care (PCC) is a core quality that the system should include. This article presents the highlights of a project on the future of PCC created for the Picker Institute. As an example of futures work, this project developed four images or stories of what might happen, as well as a vision and audacious goals for what should happen to PCC.

The first and most likely scenario is an increase in patient-centeredness as a function of current trends. However, in the second scenario, health care could become even more stressed and leave PCC behind as it seeks to lower cost without focusing on quality. The third scenario envisions more excellent systems that integrate PCC seamlessly into their work. The fourth scenario sees collaboration and shared responsibility, in association with advanced information tools, thereby enabling PCC to contribute to preventing illness and lowering health care costs.

The scenarios indicate that the patient-centeredness of health care could improve slightly, stall, or advance significantly. The PCC Vision calls for each of us to be in charge of our health, and to get the care we need (not less and not more) in timely, effective, and personal ways consistent with our values. The audacious goals set an agenda with priorities from the PCC community. These include shared decision making by consumers, ensuring health care professionals are trained in supporting active patients, anticipating health and long-term care needs for individuals, adopting the Institute of Medicine's (IOM) simple rules for health care, and making the patient perspective a priority in policy and planning.

Each of us and our organizations are confronted with the challenge of this vision and audacious goals. Health care professionals and provider systems, whether conventional or alternative in nature, face these issues. While complementary and alternative medicine (CAM) providers often get higher marks from consumers for their attention, many CAM modalities are largely provider-determined. Patient-centered care will require more empowerment and activation of patients and consumers.

### INTRODUCTION

**W**hat is the future of patient-centered care (PCC)? What should it be? This article reports on the Picker Institute-sponsored Patient-Centered Care Vision Summit in 2004 that worked to answer these two questions about the future of PCC. The Institute for Alternative Futures (IAF) explored the future by first identifying 10 drivers shaping health care and patient-centered care. Forecasts were devel-

oped for these 10 drivers and used to engage 50 leading health care experts in interviews on the future. Four scenarios or alternative paths for PCC in 2015 were developed and used at a February 2004 Vision Retreat where participants identified their shared image of the best that PCC could be.

Visions are engaging but need to be made real in terms of general descriptions of the future. One way to do so is to identify "stretch targets" or audacious goals that should be

pursued. The Summit participants developed 12 audacious goals and ranked them in order in terms of their importance to the vision of PCC. These goals, presented in this article, serve as a core agenda of priorities to pursue.

To give the rationale for the approach just described, this article first describes the nature of futures work, particularly, “aspirational futures.”

### *Distinctive features of futures work*

The PCC Vision Project is an example of “futures work.” It combines research on what “might be” in the future with statements of what the community involved in the PCC Summit wants to create. Thus, this project combines aspects of research and aspects of planning. It deals with learning and with intention. The particular approach to futures work described is that of “aspirational futures” developed by the IAF.

### *Futures work: Dealing with uncertainty and aspirational futures*

Science tends to seek the truth through formulating hypotheses and testing them. One function of futures research is to develop forecasts or images of the future in the face of uncertainty. These forecasts can only be tested as time unfolds. Thus, there are no “future facts,” since they have not yet occurred. The plausibility of some statements about the future is more supportable than others. For example, demographic forecasts that indicate how many people will be alive in a given year, say 2025, tend to be more likely than forecasts for how healthy those individuals will be in 2025 or how much they will be spending on health care. But the forecasting aspect of futures work is different from conventional science because, in effect, forecasts are assertions. A major part of their value is to allow us to consider implications (e.g. if there are, as the U.S. Bureau of the Census forecasts, 335 million individuals living in the United States in 2025,<sup>1</sup> what are the implications of that size population)? Thus, one major use of futures is to forecast future conditions, often with multiple forecasts or scenarios, and explore the implications, rather than proving the truth.

Futures work has parallels to social science. The functions of the social sciences are to understand, describe, explain, predict, and control. Futures work has similar functions, including aiding in creating better futures with an explicit relationship to values and choices. Creating better futures involves identifying what we want to create in our visions and goals, and relating our choices to those goals, informed by our forecasts or scenarios of what might happen. The “we” can be an individual, an organization, a community, or a nation. Where social science may seek more accurate predictions, futures work seeks effective forecasting in the context of irreducible uncertainty, and in the context of creating the futures we want.

There is a “futures field” of academics and professionals who develop and apply the various approaches to futures work. The futures field is not a mature field or discipline, although it is a global activity, with undergraduate and graduate training programs and a cadre of individuals and organizations providing futures services on six continents. Refereed journals in the field include *Technology Forecasting and Social Change*, *Futures*, *Foresight*, *Futures Research Quarterly*, and the *Journal of Futures Studies*. In addition, there are popular and professional associations, including the World Future Society, the World Futures Studies Federation, and the Association of Professional Futurists. However, the field is neither uniform nor consistent in how “futures work” is developed and pursued.

Thus, the futures field remains more a craft than a science. It is about learning in the face of uncertainty rather than proving the truth. It is about creating better futures by making choices, linked to values, informed by a rich sense of what might happen, resulting in plausible futures or scenarios. Ideally, it is about making wiser choices and creating preferred futures.

There is a rich and growing futures literature in health care. It focuses on a range of topics and levels: the health care system as a whole in the United States<sup>2,3</sup>; visions for the U.S. health system<sup>4</sup>; health futures globally<sup>5</sup>; cancer and the goals that should be pursued in the United States to control cancer<sup>6</sup>; using futures to support health for all<sup>7</sup>; the health professions, such as nursing<sup>8</sup>, primary care,<sup>9,10</sup> and chiropractic.<sup>11</sup> While most of this literature is focused on conventional health care, futures work on various complementary and alternative medicine (CAM) modalities and approaches is growing.<sup>12</sup>

The Picker PCC Vision Project looks at health care in the United States with a particular focus on its patient-centered qualities. The project reported here combined research, as well as vision and goal development, using IAF’s aspirational futures approach.

### *Aspirational futures approach*

In its work in a wide range of settings, including much of the futures literature cited above, IAF has evolved an approach we call “aspirational futures.” It uses scenarios and the related research to make us smarter, and it clarifies what the organization or community involved in the process wants to create. Thus, it deals with plausible and preferred futures. The work of Roger Fritz of Leadership by Design and his “aspirations model” has been significant in IAF’s development of its approach.<sup>13</sup>

IAF’s aspirational approach to futures can be illustrated in the following two figures. Figure 1 is descended from classic strategic planning. A vision leads to the development of strategies based on the organization’s position and its strengths and weaknesses, as well as the opportunities and strengths identified in its environment. Scenarios summarize alternative paths for the strategies.

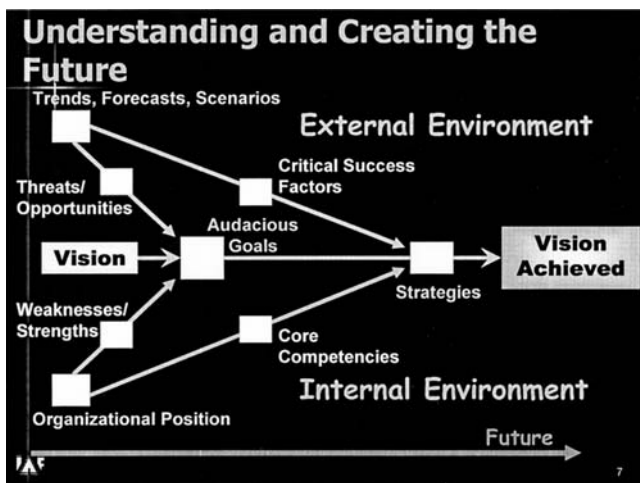


FIG. 1. Role of vision and scenarios in aspirational futures.

Figure 2 separates the likely or plausible futures components from the preferable ones. However, one important enhancement in IAF’s Aspirational Futures approach to scenarios is to include scenarios, in the range of what might happen, that explore what success would look like if a critical mass of stakeholders effectively pursued visionary outcomes.

The PCC Vision Project is the use of a futures approach to enable a community, in this case the Patient-Centered Care Community and, specifically, the Picker Institute, to look at the future, develop the language of a shared vision, and then consider the most important goals to pursue that vision.

*The Picker Patient-Centered Care Summit Project*

The PCC movement is significant in the United States and Europe. It works to ensure that patient interests and concerns are at the center of the patient’s health care experience. In 2004, the Picker Institute, a leader in measuring the nature and quality of patient-centered care, commissioned IAF to convene a Patient-Centered Care Vision Summit and engage key leaders in developing a vision and challenging goals for the field. This request was based on the experience of similar vision projects, particularly the Belmont Vision effort, that in the early 1990s developed a vision for health care in the United States.<sup>14</sup>

*Defining patient-centered care*

The Project began with the Picker Institute definitions of PCC. Picker had begun its research by asking four questions:

- What do patients want?
- What do patients value?

- What helps or hinders their ability to manage their health problems?
- What aspects of care are most important to them and their families?

The Picker Institute research to answer these questions led to three key findings:

- Discrepancies exist between patient satisfaction scores and the patients’ own account of their actual care experiences.
- Quality was being measured from an institutional perspective rather than through the eyes of the patient.
- Based upon Picker Research, seven dimensions of care define quality through the patients eyes.

These seven prime dimensions of patient-centered care are:

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.<sup>15</sup>
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).

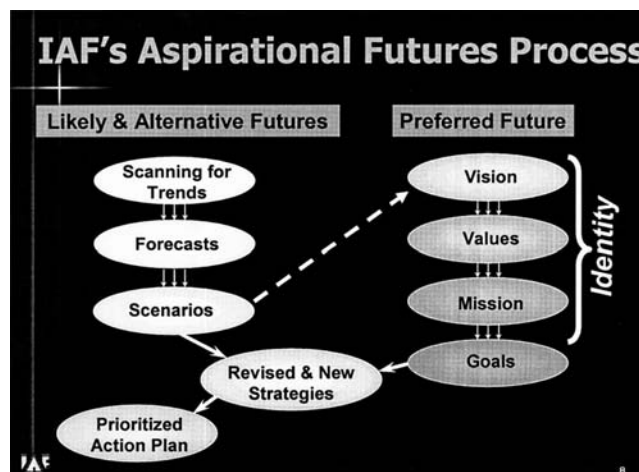


FIG. 2. Institute for Alternative Futures’ (IAF; Alexandria, VA) aspirational futures process.

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. Caregiving 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 PCC must 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.

Other definitions of PCC are in the community. One important definition is from the National Health Council (NHC). The NHC commissioned a review of the many definitions of PCC as part of its national Putting Patients First® initiative and concluded with this definition: “Patient-centered care is quality health care achieved through a partnership between informed and respected patients and their families, and a coordinated health care team.”<sup>16</sup>

There was widespread agreement that PCC is one aspect of appropriate healthcare. This was reflected in the Institute of Medicine's (IOM) six aims for the health care system in IOM 2001 Report, *Crossing the Quality Chasm*<sup>17</sup>:

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

PCC historically arose in hospitals. Its focus now is broadening beyond hospitals and beyond treatment to prevention. Some of the experts interviewed and attendees at the PCC Vision Summit felt that the process of caring begins well before anyone becomes a patient. In this context,

the term “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 reflect the growing awareness that care should include prevention and consider the role of community in achieving health.

### *Expert interviews*

IAF interviewed 50 health care experts and leaders to get their reaction to a series of forecasts and scenarios about the future of health care and the role of PCC. Each interviewee was given forecasts to spur discussion about potential futures and how they might be reached. IAF has found this a useful way to get experts to speculate about changes in areas they are familiar with, as well as changes that might not be part of their normal thinking.

The forecasts focused on 10 topics:

1. Effective health care teams
2. Payment based on outcomes
3. Basic tier of care for all defined by public processes
4. National licensure of health professionals
5. Report cards on local health care providers
6. Biomonitoring enhanced comprehensive health information
7. Health coaching information supported by NGOs
8. Health care teams common for Dx and Rx decisions
9. Kinder, gentler medical curriculum
10. Health disparities lessened by focus on health care and broader determinants

For a description of the forecasts and the reactions from the experts, see the full report.<sup>18</sup>

During the Vision Summit in March 2004 in Baltimore, these leaders used four scenarios to explore alternative paths for PCC. Participants developed language describing their 2015 vision for PCC and audacious goals that would achieve that vision. In July, the vision and goals were presented at the Picker Symposium, a public event and one of the largest in the United States on the topic. Participants at the Picker Symposium used audience-response technology to rank the 12 audacious goals, which are listed below in the audience's rank order.

IAF developed Scenarios for Patient-Centered Care in 2015 as part of the project. These are presented in summary here. The complete versions of the scenarios, vision, goals, and next steps are described in the full project report available at the Picker Institute website: <http://www.pickerinstitute.org/> or at IAF's website: [www.altfutures.com](http://www.altfutures.com).

### *Patient-centered care 2015: Four scenarios*

Four scenarios for patient-centered care in 2015 were developed for The Picker Institute in order to create a shared vision for patient-centered care. IAF used its aspirational fu-

tures methodology<sup>4,14,19</sup> to create the scenarios to enable a deeper look at what patient-centered care might be like in 2015. The first scenario demonstrates the most likely future of PCC, taking into account current U.S. health care trends. The second scenario explores some of the possibilities that may occur if the current system fails. The last two scenarios were created to represent what the system might look like if visionary thought was integrated into the system. A summary of these scenarios follows.

#### *Scenario 1—**informed consumers exercising their clout***

Medical advances are available to consumers who can afford them. While almost everyone has access to a basic tier of health care, employers have shifted to defined contributions. Consumers move up the tiers all the way to concierge care by paying money. Smart hospitals and medical practices are implementing PCC and engaging patients to actively participate in their health care. They receive high scores for patient satisfaction. A strong patient brand plus a growing product line of technological advances is, financially, the most lucrative. Smart people with chronic diseases choose providers offering evidence-based management of their illnesses. Providers, for competitive edge, are guaranteeing sophisticated technologies. Yet, the PCC praised in medical ads is often inadequate. Because of the marketplace view of medicine, only those of means are receiving PCC.

#### *Scenario 2—**health care refugees with nowhere to turn***

There is astonishment among Americans when the health care system almost collapses in 2009. Due to double-digit health care inflation and economic recession, most employers drop coverage. The government steps in setting price controls and health care spending contracts to 12% of the GDP by 2015, which hits the poor and middle class the hardest. The lack of resources to meet physical and emotional needs within the system makes patients feel powerless. Quality, access, safety, and technological progress force patients to make do with makeshift fixes, even for chronic diseases. The most affluent 10% who can pay out of pocket can still receive timely, excellent care. The majority has to wait while the poor wait even longer. Caregivers experience high burnout and low productivity since they are undervalued. The medical technology industry, once known for its highly credible scientific research, now makes only small improvements due to price cuts. This is felt even by the affluent. There is no leadership within the health care industry, and the government has not picked up the slack creating nowhere for patients to turn to secure their health and well-being, resulting in the possibility of revolt against a system so uncaring. There are high social costs to communities and businesses.

#### *Scenario 3—**excellent systems converge***

U.S. health care is transformed through scientific knowledge and information tools, as well as the public's understanding and acceptance. Patients and health care professionals exist within a system that is well designed and progressive. The standard of care is high-quality, safe treatment based on latest evidence of effectiveness while patients understand and expect patient-centered care from a willing medical community. Patients communicate with a team leader or other appropriate providers to receive individualized care based on health conditions and learning preferences. Medical technology is used by patients and physicians to identify future health risks and employ aggressive prevention strategies. While health care is still the largest sector of the American economy at 16% of GDP, Americans are satisfied to see their investment paying off as everyone receives significant health gains.

#### *Scenario 4—**collaborators in health***

Since health care 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. Patients and professionals are connected in a web of responsive, easy-to-navigate processes where most all patients understand and meet their individualized health plan goals. They have support from families, patient peer groups, health professionals, and advanced bi-monitoring and information systems. Providers promote prevention and effective management of chronic illnesses. Advances in medical, social and spiritual technologies aid in the delivery of health care services. Communities have newfound resources for sustaining the health of everyone with the advent of shared accountability and are able to focus on social issues affecting health.

#### *Estimating the likelihood and preferability of the scenarios*

How likely and how preferable are these scenarios? These are relevant questions to stimulate thinking and learning and clarify our choices. To determine the likelihood and preferability of these scenarios, a simple rating was used. One hundred (100) percentage points were assigned across the four scenarios to rate their probability, as well as another 100 points to rate their preferability. Participants confirmed Scenario 1 as the most likely future for patient-centered care while they preferred the third scenario, and even more, the fourth scenario, Collaborators in Health. This is a typical response in this type of scenario polling. It illustrates the existential situation of most fields; namely, the current major trends moving toward the most likely future will not take us to the futures we want. It takes vision and commitment to create better futures.

### *A vision and audacious goals for patient-centered care*

During the summit in March 2004 in Baltimore, leaders used these four scenarios to set up their discussion of a 2015 vision and audacious goals for the field. A vision is a shared statement of the future that the authors/owners of that vision are committed to creating. Given a vision, audacious goals are the stretch targets that will make the vision real.

#### *Patient-centered care vision*

Our vision of care is that each of us is in charge of our health. Health care 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.

#### *An image of the vision in practice*

Visions are important for what they prompt us to focus on. In this case, they are the requirements for health care 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 e-mails, and prescriptions filled by e-mail 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.

#### *Audacious goals for patient-centered care*

At the Vision Summit participants, they identified a dozen "audacious goals" they thought would be most important to achieve their PCC vision. The approach to developing audacious goals used by IAF is based on the work of Collins and Porras in their book *Built to Last*.<sup>20</sup> After the audacious goals were established, they were presented to the 2004 Picker Symposium. Participants at the Symposium were asked to consider the scenarios, vision, and goals, then to rank the relative importance of the goals.

Thus, the list of audacious goals below represents a significant statement of priorities for action from the PCC community. The top 12 goals for the field identified through the PCC Summit and ranked at the 2004 Picker Symposium are:

1. *Participation in shared decision making*—By 2015, at least 50% of patients will participate in shared decision-making processes that lead to measured improvement in decision quality. We will have developed, implemented, and responded to an array of measures of "concordance" between health care interventions and what people value, first as individuals and then as communities.

2. *Train Health care professionals to support patients*—By 2010, all health care professionals will receive training in how to support patients to play an active role in their care.

3. *Anticipating care scenarios/needs*—By 2015, education will be available to everyone 50 years of age and older on realistic scenarios regarding health, long-term care, and the end of life through videos, CDs, and interactive media.

4. *Adopt IOM's simple rules for healthcare*—By 2015, every community's health care will be organized around access, quality, and safety. Communities nationwide will implement IOM's Simple Rules for the 21st Century Health-care System in every organization, institution, and care setting. Simple Rules: 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.<sup>17</sup>

5. *Make patient perspective a priority in policy and planning*—By 2010, a patient perspective will be considered first

in all policy and planning decisions. Patients and/or their families will be present and actively participate in all decision-making bodies.

6. *Enable patients to direct their care*—By 2010, 80% of patients and families believe they have the knowledge, support, and confidence necessary to effectively direct their own health and health care.

7. *Access to patient-centered care information and care*—By 2015, everyone will have information and access to patient-centered health care, and 50% will receive their care through a Picker patient-centered care practice.

8. *Licensing requirements for patient-centered-care*—By 2015, every health professional licensed to practice in the United States 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. Those who cannot or will not comply are removed from practice.

9. *Measure and reward providers for achieving patient empowerment*. By 2010, health professionals and health care facilities will be rewarded according to their patients' sense of empowerment and self-efficacy, which will be measured routinely.

10. *Patients' use performance data to choose supportive providers*. By 2010, patients will be able to choose their health care providers based on comparative performance data showing how well providers support the patients and their family's role in care.

11. *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.

### Next steps

In addition to the audacious goals, the summit participants identified key next steps. These included supporting Judith Hibbard's development of surveys to assess and reinforce patient self-management capacity or activation, national and international standards for the implementation of the personal health record by Don Detmer,<sup>21</sup> Angela Coulter's work on indices of PCC across countries and care settings,<sup>22</sup> the National Health Council campaign for “Putting Patients First” and mobilizing for PCC,<sup>16</sup> and Al Mulley in developing medical school course materials to teach PCC to medical students.<sup>23</sup>

## CONCLUSIONS

The U.S. health care system is transforming. It must. PCC is a core quality that the system should include. The scenarios indicate that the patient-centeredness of health care could improve slightly, stall, or advance significantly. The PCC vision calls for each of us to be in charge of our health,

and to get the care we need, not less and not more, in timely, effective, and personal ways consistent with our values. The audacious goals set an agenda with priorities from the PCC community. These include shared decision making by consumers, ensuring health care professionals are trained in supporting active patients, anticipating health and long-term care needs for individuals, adopting IOM's simple rules for health care, and making the patient perspective a priority in policy and planning.

Each of us and our organizations are confronted with the challenge of this vision and audacious goals. Health care professionals and provider systems, whether conventional or alternative, face these issues. While CAM providers often get higher marks from consumers for their attention, many CAM modalities are largely provider-determined. Patient-centered care will require more empowerment and activation of patients and consumers.

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Address correspondence to:

*Clement Bezold, Ph.D.  
Institute for Alternative Futures  
100 North Pitt Street, Suite 235  
Alexandria, VA 22314*

*E-mail: cbezold@altfutures.com*