

# **Preliminary Report of Consumer-Led Workshop to Advance Patient Safety (October 16-18, 2003, Houston, TX)**

**Prepared on Behalf of Workshop Participants by Facilitators:  
Institute for Alternative Futures  
Partnership for Patient Safety**

## ***I. Introduction***

This draft summary provides a summary of the **vision, mission, goals and actions** created by a working group of consumers and healthcare stakeholders during the Consumer-Led Workshop to Advance Patient Safety. Supported in part by a Small Conference Grant from the Agency for Healthcare Research and Quality, the Workshop was held in conference space donated by The University of Texas M. D. Anderson Cancer Center in Houston, TX on October 16-18, 2003.

Other financial and “in kind” contributors to the event include Atlantic Health System Hospital, Booz Allen Hamilton; Geri Amori/Communicating HealthCare; Healthcare Mediations, Inc.; Institute for Alternative Futures; Leadership by Design, Inc.; Dennis O’Leary, MD; OSF Healthcare System; Partnership for Patient Safety; Paul M. Schyve, MD; VHA Healthcare Foundation. Workshop participants contributed their time, energy and experience.

## ***II. Workshop Products: Vision and Mission***

### **Vision**

***We envision creating a healthcare system that is safe,  
compassionate and just.***

### **Mission**

***To be a champion for patient safety in a new healthcare culture.***

***To be a voice for individuals, families and healers who suffer harm in  
healthcare encounters.***

***To teach the health care community what consumers and providers  
need to know whenever they interact within healthcare systems.***

### **III. Workshop Products: Goals**

- Goal # 1:** *Establish a National Consumer-Led Patient Safety Board*
- Goal #2:** *Create Local Consumer-Led Patient Safety Advisory Boards in Every Community in the United States [and Scotland]\**
- Goal # 3:** *Institute a Non-Punitive National Patient Safety Learning/Reporting System*
- Goal #4:** *Establish a National Education Effort on Patient Safety for Providers and Consumers*
- Goal # 5** *Develop a National Patient Safety Awareness Campaign that Emphasizes Patient and Healthcare Community Partnership with Trust and Open Communication*
- Goal #6:** *Put into Place Systems that Provide Just Compensation and Alternative Routes to Justice for Patients who are Harmed in Interactions with the Healthcare Community*

More detail on these national goals, together with initial ideas/recommendations on action steps, time frames, strategies, metrics, resources and potential partners are captured in Section VIII of this document.

### **IV. Workshop Background**

Development of the Consumer-Led Workshop to Advance Patient Safety was motivated by two fundamental concerns:

1. *Articulations by the Institute of Medicine (IOM) and other policymakers on the importance of making healthcare more safe, systems-based and patient-centered; and*
2. *The absence of a collective voice for consumers interested in sharing their experience and lessons learned as partners with responsibility for contributing to both safe healthcare delivery and policymaking on advancing systems-based, patient-centered care.*

At the policymaking level, most stakeholders in healthcare have been actively discussing patient safety and systems-based improvement strategies since at least late 1999 when the IOM's *Error in Medicine*<sup>#</sup> report was released. However, consumers are not often part of these discussions and, hence, as a collective are not provided the

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\* One non-consumer Workshop participant is a resident of Scotland, and argued that the national goals and actions steps were needed in that country as well as the United States.

<sup>#</sup> Kohn LT, Corrigan JM, Donaldson M, eds. *To Err Is Human: Building a Safer Health System*, Washington, DC, National Academy of Sciences, 1999.

same exposure to safety science and systems-based thinking. When consumers are included in patient safety or quality care improvement discussion, it usually is in an advisory role to organizations or groups led by other stakeholders. Collectively, consumers continue to organize and be heard most often under the rubric of “victims rights” organizations. Important as these organizations’ perspectives are, they do not position consumers as partners who assume responsibility for working with healthcare collaboratively to advance patient safety.

At the healthcare service delivery level, consumers who wish to contribute knowledge gained or lessons learned have few non-adversarial avenues for doing so. Particularly after healthcare accidents occur which cause patient harm, constructive communication usually ceases. Consumers are funneled to the legal system for remedies, and their experience and observations are thereafter presented in an adversarial context that most often is not heard or digested into system learning. When consumers file complaints with licensing boards, accreditors or regulatory authorities, these actions are often perceived as threats, not knowledge contributions. Most healthcare organizations don’t have consumer advisory bodies. With a few notable exceptions, those that do are reluctant to use them to discuss medical error or system failure. Assuming that patients and their lay caretakers see things the system doesn’t, it follows that safety will be improved if their learning can be garnered and factored into quality improvement.

## **V. Objectives**

- 1. To articulate the ways in which consumers can contribute to safety and what their roles and responsibilities are as partners in ensuring good healthcare treatment outcomes;*
- 2. To outline the opportunities in the current environment that consumers have to advance patient safety; and identify what is being done, how successfully and by whom;*
- 3. To identify what else can be done, short term and long term (goals and actions); and*
- 4. To make findings and recommendations for post-workshop next steps.*

## **VI. Workshop Planning and Pre-Work**

Workshop planning was led and guided from the beginning by two consumers\* who are “frequent flyers” in the healthcare system.

A nationwide call was disseminated asking for applications from:

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\* Roxanne Goeltz is a cancer survivor and the sister of Mike, who she believes died as the result of healthcare system failure. Susan Sheridan is the widow of Pat and mother of Cal, both of whom suffered serious injuries as the result of medical system failure. Roxanne and Susan each are active in a patient safety organizations, have testified before policymaking bodies, and publicly speak about the importance of partnership between providers and consumers in advancing patient safety.

1. *Consumers interested in partnering to make healthcare safer, who had substantially interacted with healthcare and saw themselves as change agents; and*
2. *Non-consumer healthcare stakeholders interested in partnering with consumers to establish safer and more patient-centered care.*

Applications were encouraged from consumers and non-consumer stakeholders who worked or participated in any healthcare setting, including acute, ambulatory, long-term and home-based care. The goal was to select comparable numbers of consumers and non-consumer stakeholders. Selections were made through a modified Delphi process.

The twelve consumer participants were evenly split between those who were primarily patients and those who were primarily lay caretakers/care-managers. The sixteen non-consumer participants included accreditors, researchers, patient safety officers, risk managers, systems performance/improvement personnel, physicians/physician executives, pharmacists, nurses/nursing executives, healthcare consultants, lawyers, consultants, philanthropists, employers and alternative dispute resolution professionals.

Once selected, mutual telephone interviews between consumer and non-consumer pairs were organized, using an Appreciative Inquiry\* tool built on the following questions:

1. *Describe a time when you were involved in making healthcare really work for you or somebody you know. What made it work?*
2. *In what ways did others (the patient, their family or friends, healthcare providers or others) partner in making it work? Please describe how you and the others figured out how to do what you did.*
3. *Describe an experience where you have succeeded in changing something or accomplished a goal by overcoming obstacles in an inventive way. This can be a healthcare experience, but doesn't have to be.*
4. *What do you expect to share and contribute at the workshop in Houston?*

Interview reports were filed with and reviewed by facilitators before the Workshop.

## **VII. Workshop Design**

The Consumer-Led Workshop to advance patient safety was organized to unfold in two distinct phases over three days:

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\* Appreciative Inquiry (AI) is a technique designed to use participants' past personal and professional successes in problem solving as the basis for developing strategies for addressing future organizational and/or social challenges. AI theory repositions "problems" as opportunities for organizational and personal change, growth and success.

1. On Day One, consumers gathered to meet and, through a facilitated sharing of experiences and stories, envision a safe, patient-centered healthcare system of the future and then articulate a mission for achieving it.
2. On Days Two and Three, consumer participants were joined by non-consumer stakeholders, for continued work in refining vision and mission, the development of goals and actions, and discussion of recommendations and next steps.

A metaphor guiding the design of the Workshop was the notion of a *campfire*, where people came to compare their life experiences, share their deepest dreams and discuss “big ideas.” Consumer participants began the meeting “at the campfire” and, on Day Two, invited in and introduced the non-consumer stakeholders they had interviewed in the AI pre-work process.

### **VIII. Workshop Products: Goals and Action Steps**

#### **Goal # 1: National Consumer-Led Patient Safety Board**

*Establish a National Consumer-Led Patient Safety Board within 5 years with the following functions:*

- *Development of national policies for patient safety*
- *Repository of medical errors*
- *Coordinate all patient safety activities among all established organizations and regulatory bodies*
- *Research and evaluation of safe practices*
- *Work with state licensing bodies and/or national accreditation organizations to adopt safety policies*
- *Responsible for the regulations for healthcare safe practices*

*The structure of the Board would be to have at least 51% Associates from consumer organizations such as local patient safety networks and other representatives from partner organizations such as JCAHO, Leapfrog, CMS, AHA, State licensing boards, AMA, ANA, AARP, and other consumer groups.*

#### **Goal #1 Action Steps**

1. Inventory who’s doing what. It will take 3 months to do that through email. Could use this Houston Advisory Committee to help.
2. Identify seed grants. Need a half million to \$1 million. Will take 3 months. Consider NIH RO 1 grants.
3. Identify future ongoing funding. Insurance dollars, trial lawyers dollars, licensing fees. Will take up to one year.
4. Prepare a blueprint for the board and integration with other organizations. Will take six months.
5. Incorporate if necessary and charter.
6. Metrics for safety rating – develop them. Will take 1 year.

7. Membership identification for the Board. Will take 6 mos.
8. Identify lobbying mechanism and national champions. On-going.

### **Goal #2: Local Consumer-Led Patient Safety Advisory Boards**

*Create Local Consumer-Led Patient Safety Advisory Boards in every community in the United States [and Scotland] within 10 years to collaborate with the National Patient Safety Advisory Boards. These Local Boards can utilize existing state healthcare associations and will provide advice and consultation to local healthcare providers in areas such as:*

- *Building design*
- *Developing patient safety information for consumers and stakeholders*
- *Error detection and prevention*
- *Gather and disseminate advice based on patient/consumer experience*
- *Provide consultation to provider organization and regulatory agencies*

### **Goal #2 Action Steps**

1. Year One:
  - a. Assess existing networks
  - b. Enlist champions
  - c. Identify state structures and organizations
  - d. Develop the plan
2. Year Two:
  - a. Take plan to “challenge groups”
  - b. Revise plan
  - c. Identify 5 pilot sites
3. Year Three:
  - a. Implement pilot sites
4. Year Four:
  - a. Evaluate pilots
  - b. Revise the plan
  - c. Take the plan to the National Patient Safety Board for promulgation across the nation

### **Goal # 3: National Patient Safety Learning System**

*Institute The National Patient Safety Learning System within 10 years as a positive, non-punitive system with the following components:*

- *a shared learning data repository that includes narrative occurrence reports*
- *searchable information tied to medical nomenclature thesaurus*
- *stories of both solutions and failures*
- *multiple reporting avenues, centralized and nationwide*
- *a broad based dissemination function*

*Metrics will include:*

- *Reporting rates from multiple consumer and provider sources*
- *Evaluating to determine the proportion between reported events to outcomes and the practices/procedures used*
- *Near miss and intervention reporting rates*

*Partners will include:*

- *Professional societies like CAP and AAP*
- *Federal partners like AHRQ, CMS and CDC*
- *National organizations like the National Patient Safety Foundation, National Quality Forum, and Institute for Safe Medication Practices*

### **Goal #3 Action Steps**

1. Start with issue-specific reporting, with smaller scale pilots until we achieve proof of concept
2. Then move to smaller localized, controlled or regional environments, such as a managed care system or a multi-hospital system
3. Then conduct a phased rollout to the national level
4. Then expand to more issues from the initial issue-specific lessons learned. This becomes part of the outreach and marketing of best practices. (This is good model for best practices because it includes consumers.)
5. Once we've established a best practice, based on proof of concept, built with natural partners and piloted, then take to JCAHO as patient safety goal. Then feed it back through professional groups and the education system as mapped out by the Education Working Group Goals [below].

### **Goal #4: Education for Patient Safety**

*Educate: 1) every person qualifying or graduating as a healthcare provider with the knowledge and skills that enable them to communicate effectively within healthcare teams and with patients and families within the next 10 years to assure that providers have the vision that healthcare is safe, compassionate and just, and; 2) every person coming into contact with healthcare services through information and support appropriate to their individual needs that helps them interact effectively with providers at every stage in the course of their healthcare journey. Within 10 years every person in the U.S. should have the opportunity to gain "just in time" knowledge and skills to enable them to engage effectively with the healthcare system.*

### **Goal #4 Action Steps:**

*Actions Focused on Healthcare Providers:*

- Identify accreditation bodies, individual certifying boards and educational institutions and make an inventory of who reaches whom.
- Organize the players, including accrediting bodies, professional licensing and certifying boards, and educational institutions. Our role is to lobby these groups for inclusion of the vision and mission in education curricula, and to provide input on design and development of the metrics.

- Ensure that effective communication is an integral part of training in healthcare, effective within teams and in meeting communication needs of patients, and it's an integral part of assessment. This should be an endpoint not just in credentialing new graduates, but re-credentialing folks who are already out there.
- Develop metrics, including: that a high proportion of providers pass communication competency tests and that patient experience surveys reflect good performance on key communication criteria.

#### *Actions Focused on Consumers*

- Provide input into standards setting about patient needs for information and support. All patient information materials will be designed with patients to ensure they meet patient needs.
- Lobby for a centralized system for generating patient information materials and training people who produce them, based on our vision and mission. Consumers/patients will be involved in training the trainers.
- Use our mission and vision to coordinate with existing organizations that create and disseminate medical information to patients and consumers.
- Advocate for every hospital to have an advisory board in place within 5 years
- Articulate goals that: (i) that every person wanders about with their medical history with them, (ii) that all patient information has been designed with and meets the needs of patients.
- Assist in establishing patient/family advocacy boards that have responsibility for regulating, customizing and disseminating the information distributed to patients in that organization, and train people to serve effectively on those boards.

### **Goal # 5 National Patient Safety Awareness**

*Develop national awareness of the importance of patient safety that emphasizes patient and healthcare community (HCC) partnership with trust and open communication by 2009. We will know we have met this goal when:*

- *Americans recognize a slogan/catch phrase that promotes patient safety (Examples: "Stop, drop and roll"; "ABC" AIDS prevention campaign in Africa - Abstain, Be monogamous, use a Condom)*
- *All HCCs support the effort by using a common curriculum around patient safety*
- *There is a common language/vernacular of patient safety*
- *Key points/concepts in patient safety are clearly defined and easily understood*
- *Patients feel comfortable speaking up; they know their medications; they know their treatment plan; they actively participate and question things in their HCCs that do not seem right*
- *Patients are able to verify their own personal information (e.g., their medical records)*
- *HCC providers encourage questions and participation*
- *Consumers participate at all levels of HCC service decisions; it is considered outrageous not to have a consumer involved.*

### **Goal #5 Action Steps**

1. By 2004, we will:
  - a. Perform a baseline survey of consumers and HCC providers regarding their awareness of patient safety principles/concepts. This will begin with regional pilots. We will get financial, verbal and organizational support by enlisting healthcare financing sources and the advertisers, e.g., AHRQ and the Ad Council.
  - b. Define patient safety principles that will be used for baseline survey of awareness. We will go to the research community to develop the survey.
  - c. Secure financing. This will take a multimillion-dollar investment. One place for support is the CDC's National Center for Health Statistics.
2. In 2005, develop a patient safety awareness campaign based on survey results and using a variety of mediums to reach all Americans.
3. By 2007, resurvey Americans to assess effectiveness of the campaign, with the goal of documenting a 50% increase in awareness of the slogan.
4. In 2008, retarget the awareness campaign and refine it as necessary.
5. In 2009, have 90% of Americans recognize the slogan and the principles of the campaign.

### **Goal #6: Just Compensation**

*Put into place a set of systems providing alternative routes to justice that flexibly respond to consumer's needs after patients are harmed. These systems will require appropriate compensation, which includes non-monetary items that might be important to consumers. The prevention of harm is a primary interest in meeting this goal of just compensation within the next 10 years. Metrics for progress toward this goal include:*

- *An increase in complaints handled outside of litigation*
- *Increase in redesign processes demonstrating success in safer processes.*
- *Decrease in lawsuits*
- *Survey/measures of the degree to which consumers feel needs were met*
- *Existence of in-house conflict resolution systems in healthcare organizations*
- *Existence of schedule of standardized payouts for injuries*
- *Existence of healthcare facility-based review boards, including consumers*

### **Goal #6 Action Steps**

1. Identify key partners and stakeholders to bring into the planning process.
2. Design a process employing hospital-based review boards with consumer membership, standardized payouts for injuries and expectations for discussing injuries with the patients/families and planning safety improvements.
3. Design in-house systems for addressing patient harm early (pre-claim) and directly.

4. Design proposals for adjusting legal practices so that consumer interests other than money are routinely discussed, confidentiality agreements are reconsidered, and penalties are increased for failing to disclose errors.
5. Bring together a group of leaders to address implementing those designs and barriers to them.
6. Pilot test these measures.
7. Promote them at a national level.

## ***IX. Observations and Next Steps***

Workshop participant evaluations suggest the two-phase structure for the Workshop worked very well overall; it provided the opportunity to consumer participants to express their collective voice and establish themselves as leaders in the community that assembled. It did require that the non-consumer stakeholders catch up on Day Two, which was facilitated by a one-hour orientation prior to their joining the consumers in late morning. The AI pre-work process also served to underscore our partnership focus and help all participants establish common ground prior to meeting one another. Once the group entirely assembled on Day Two, we were surprised at how effectively the line between consumers and non-consumers evaporated. All participants appeared to engage their deeper identity as partner and change agent quite quickly, including those consumers who had expressed anger with the healthcare system on Day One.

While there was a high degree of apparent agreement on vision, mission, goals and actions steps, it should be understood that they are not consensus statements. Neither participants nor the organizations they work for were asked to endorse this work product. Moreover, participants realized that the action steps are rudimentary and require further planning and refinement working in partnership with the community of stakeholders. Accordingly, this work product should be understood as a discussion agenda to be placed in the public domain, widely disseminated throughout the health care community, and used by all organizations and individuals who respond to it.

There was substantial agreement among Workshop participants that our vision, mission and goals comprised a “big, worthy agenda”. The desire for a collective voice through which consumers can be heard on the issue of healthcare safety and serve as a patient-centered resource for reform initiatives call for the establishment of an organization that will work to realize it. Consumers Advancing Patient Safety (CAPS), a non-profit organization, has been activated to carry this work forward. Immediate next steps include building a website ([www.patientsafety.org](http://www.patientsafety.org)) and a listserv or other discussion forum as a virtual center for dissemination and further refinement of the articulated goals and action steps.

The Consumer-Led Workshop to Advance Patient Safety’s vision, mission, goals and action steps already have been circulated to all Workshop participants, who have been encouraged to share them with people they know and engage new partners who can commit to work on this big, worthy, authentically patient-centered and systems-based agenda.