Report to the
Agency for Healthcare Research & Quality
from the
Consumer-Led Workshop to Advance Patient Safety[1]
(October 16-18, 2003, Houston, TX)

Prepared on Behalf of Workshop Participants by Jonathan Peck, Institute for Alternative Futures and Martin Hatlie, Partnership for Patient Safety[2]

Structured Abstract

The purpose for this project was to invite consumers into the lead role in advancing patient safety and create a partnership between consumers and other stakeholders in improving healthcare. The workshop was designed to create the vision, mission, goals, and action steps that can energize a consumer-led change effort. The scope of this change effort is national—including federal, state, and local initiatives—and encompasses reforms for both the healthcare and judicial systems that will improve patient safety. The methods used included appreciative inquiry (AI), storytelling, vision exercises, and open discussion with structured facilitation. Throughout the process, consumer leaders were invited to determine objectives for the workshop and beyond. The results of the workshop included a vision that participants accept as compelling, a mission that clearly defines what an organization needs to do in order to serve the vision, six goals that will take 5 to 10 years to achieve, and sets of action steps that can lead to the goals being reached. The most important result is that participants committed themselves to a sustained effort, which a new organization—Consumers Advancing Patient Safety—will organize. Key words in this report are patient safety, National Consumer-Led Patient Safety Board, Local Consumer-Led Patient Safety Advisory Boards, National Patient Safety Learning/Reporting System, National Patient Safety Awareness Campaign, Just Compensation, and Alternative Routes to Justice for Patients.

I.　Purpose

This report describes the Consumer-Led Workshop to Advance Patient Safety, held at the University of Texas M.D. Anderson Cancer Center, October 16-18, 2003. We are grateful to the Agency for Healthcare Policy and Research (AHRQ) for the support that made this workshop possible, and we offer back the results with enthusiasm and hope.

Most reports, meetings, initiatives, or prescriptions for healthcare reform are formulated by clinicians or other leaders working somewhere on the healthcare delivery side of the fence. Usually very well intentioned, these initiatives almost always are introduced by protective suppositions about what would be better for consumers of healthcare or what it is that consumers want. If included at all in the development of a reform agenda, the voice of the consumer typically is marginalized, most often used to dramatically accentuate the ideas of others or underscore core values. However well meaning, these approaches presume consumers to be unable to appreciate the complexity of modern healthcare, much in the way caring adults might underestimate their children's capacity to address difficult or emotionally troubling aspects of life.

Such an approach fails to take into account that many consumers are intelligent, fully functioning adults who appreciate that we live in an increasingly complex and risky world. We do not all read or comply at the level of a third-grader, even if that is the statistical average. Indeed, at this moment in history, some of us have been trained and work in industries that are significantly *ahead* of healthcare in understanding organizational risk management, systems-based quality improvement, teamwork, and communication in complex, dynamic human

enterprises. Even when we lack such professional training, we usually bring common sense to the equation and an appreciation for gaps in the safety net that busy providers or researchers may not discern. Moreover, consumers who choose to partner are highly motivated to contribute in any way we can. We approach our partnership role with a profound desire to prevent harm.

Motivated by the aspiration to offer our own voice to the national deliberation on healthcare safety and quality improvement, we turned the typical approach to a healthcare workshop on its head. We *started* with consumers --- specifically, experienced patients and lay caregivers --- who see ourselves as constructive partners and change agents. Beginning from this authentically patient-centered reference point, we invited other healthcare stakeholders to engage with us to articulate and carry forward a plan for reform.

The output of this workshop is a **vision**, a **mission**, **goals**, and an **action plan** that outline what consumer change agents, working in partnership with other innovators, believe can be achieved at the national, state, and local levels in the United States (and Scotland)[3] in the first part of the new century. In addition, we contribute the tools of a workshop process that emphasizes honest and deep exchange of experience, high aspirations, and transparency as the basis for partnership among all stakeholders. A notable strength of this model --- and we were delighted to experience this in Houston --- is the relative ease in which the invisible wall that typically separates consumers and providers when we discuss healthcare failures very quickly dissipated. Providers and other system stakeholders were sincerely welcomed to join consumers in tackling this tough subject, and they quickly acclimated to the constructive environment that consumers had established. We did not have to work hard at moving beyond blame, anger, or defensiveness. The design of our process moved us through this often-immobilizing emotional territory.

The authors of this report encourage providers interested in patient safety to use both the content and workshop process outlined herein to fully integrate consumers, patients, and their families into their healthcare communities, *especially* in their efforts to improve safety and quality. The partners who designed and guided the workshop agenda and exercises have an ongoing commitment to continue to advance patient-centered, systems-based initiatives that focus on consumer participation and invite others to join in this work. With this report, we place the workshop content into the public domain, to be used and adapted by all who resonate with the vision for a safe, compassionate, and just healthcare system that underlies it.

The Consumer-Led Workshop to Advance Patient Safety, held on October 16-18 in Houston, Texas, was supported in part by a Small Conference Grant from the Agency for Healthcare Research and Quality (AHRQ). The University of Texas M.D. Anderson Cancer Center helped sponsor the event by donating facilities and staff support. The Institute for Alternative Futures (IAF) and Partnership for Patient Safety (p4ps) also co-sponsored the effort through donated time and services. Other financial and "in-kind" contributors to the event included Atlantic Health System Hospital; Booz Allen Hamilton; Geri Amori/Communicating HealthCare; Healthcare Mediations, Inc.; Leadership by Design, Inc.; Dennis O'Leary, MD; OSF Healthcare System; Partnership for Patient Safety; Paul M. Schyve, MD; and VHA Healthcare Foundation. All the workshop participants contributed their time, energy, and experience.

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[3] 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 in the United States.

II.   Scope

Scope

The deepest motivation to have a consumer-led workshop advance patient safety came from people whose experience in healthcare created both a strong desire to improve care and a clear realization that patients and their families have a vital role. Recent history suggests that, although leaders and innovative stakeholders see the need for change to make the healthcare community more systems-based and patient-centered, change has been slow. The commitment arising from people who have suffered from medical error, who are determined to help prevent future harm and are ready to partner with other innovators, can be a powerful and transformational force.

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*
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> 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*[4] report on errors in medicine was released. However, consumers are not often part of these discussions; hence, as a collective, they are not provided the 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 that 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.

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[4] Kohn LT, Corrigan JM, Donaldson M, eds. *To Err Is Human: Building a Safer Health System,* Washington, DC, National Academy of Sciences, 1999.

III. Methods

Workshop planning was led and guided from the beginning by two consumers[5] who are "frequent flyers" in the healthcare system. IAF hosted an initial planning session with these consumer leaders and their partners.[6] We set about the delicate task of designing a workshop that truly would be consumer led and thus not over-designed or led by consultants. We agreed upon a campfire as the central metaphor for the Consumer-Led Workshop, imagining that consumers who had experienced medical error would initiate the gathering by telling their stories "around a campfire." We then tested and refined the methods that were used for the workshop with the consumer leaders in the planning session.

The methods included an Appreciative Inquiry (AI) interview. The interview seeks to find a positive core in people's experience as a base for building on what works, rather than focusing on the negatives through problem solving.[7] The interview instrument (see Appendix 1) was subsequently distributed to those selected for the workshop, matching consumer advocates with stakeholders. The intent of the interviews was twofold. First, we sought to develop optimism by helping participants discover the positive possibilities that their interview partners could amplify through the AI interview. Second, we intended to form relationships that would create the basis for building partnerships in the workshop. This worked. On the second day of the workshop, the first stakeholder entered the room to join "the campfire" and received a warm embrace from his interview partner. When the larger group of stakeholders joined the campfire, they received a standing ovation as their welcome. Evaluations showed that workshop participants were generally positive about the AI interview; in terms of building a foundation for the partnership that was formed during the workshop, AI proved to be a critical method.

The planning meeting also used a method for developing a collective vision that expresses the deeper aspirations a group of people share. The technique involves imagining that one is near the end of life, reflecting on success and communicating that through a letter to a beloved member of the next generation.[8] The letters created by the planning group formed the basis for draft objectives distributed prior to the workshop. Although these were purposefully proposed as a basis for the workshop design, they were kept in draft form so that the workshop participants could change both the objectives and the agenda. Furthermore, one set of objectives was drafted for the workshop itself, and another was drafted for consumer roles in general.

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[5] Roxanne Goeltz is a cancer survivor and the sister of Mike, whom 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 patient safety organizations, have testified before policymaking bodies, and publicly speak about the importance of partnership between providers and consumers in advancing patient safety.

[6] Our consumer leaders were Roxanne Goeltz and Susan Sheridan, and the partnering organizations were Partnership for Patient Safety, Communicating Healthcare, and Leadership By Design.

[7] 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. See www.appreciativeinquiry.cwru.edu for a fuller discussion of the methodology and www.aiconsulting.org for a description of AI used in healthcare conferences.

[8] This technique was created by Roger Fritz of Leadership By Design and has been used with a large variety of organizations and communities by IAF.

Draft Objectives for the Workshop:

- To build a foundation for a movement that empowers consumers with a collective voice to address healthcare with safety for all the first consideration
- To envision the roles through which consumers can help keep healthcare honest and transparent
- To identify practical steps and pathways for consumers to partner in improving the safety of their healthcare
- To fuel the passion and commitment that will sustain enduring efforts to improve safety and prevent medical error

Draft Objectives that Stretch Beyond the Workshop:
- To show stakeholders throughout healthcare that patients and their advocates are an important resource for improving healthcare
- To help imbed the principles of patient safety and patient-centeredness into the culture of healthcare organizations
- To create public recognition for shared responsibility in safe healthcare
- To show how the power of closure and forgiveness can create healthy change for patients, families, and providers with positive benefits for healthcare systems

These objectives were distributed to participants who were selected to attend the workshop, but they were not explicitly discussed or adopted there. Nevertheless, subsequent evaluations from participants and the conveners indicate that the workshop actually did achieve the objectives drafted for the meeting and opened the way for achieving the objectives stretching beyond the workshop.

Recruitment Process

A nationwide call was disseminated asking for applications from:

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 12 consumer participants were evenly split between those who were primarily patients and those who were primarily lay caretakers/care managers. The 16 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.

Recruitment of consumer advocates and stakeholders for this workshop took place through a web-based notification as well as an outreach effort through the various networks that the

planners linked to, extending to patient safety organizations (e.g., the National Patient Safety Foundation) and a wide variety of stakeholder organizations (e.g., The Joint Commission and many healthcare systems leading in patient safety). Each application was reviewed, using selection criteria that included capacity to be a change agent as well as identity in a priority population, as defined by AHRQ. The application forms can be found in Appendix 2 and a list of people selected can be found in Appendix 3. We arranged for each invited stakeholder to call one consumer to conduct the AI interview and sent out an information package that included a draft set of objectives as well as an agenda.

Workshop Planning and Pre-Work

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 it 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.

Workshop Process

The Consumer-Led Workshop to advance patient safety was organized to unfold in two distinct phases over 3 days:

1. On Day One, consumers gathered and, through a facilitated sharing of experiences and stories, envisioned a safe, patient-centered healthcare system of the future, and then articulated 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.

The workshop began with people who had significant experience as healthcare consumers or family members sharing stories. Many were stories of suffering, injury, and death---stories of when systems failed or when caregivers shut down and retreated into denial, subterfuge, or legal maneuvering. Yet, the remarkable courage of survivors and family members also emerged from these stories, as did their abilities to communicate, innovate, and start new, collaborative initiatives based on the lessons they had learned.

After the stories, facilitator Roger Fritz outlined an aspirations model, which revealed how individuals or organizations either act in alignment with their aspirations to shape circumstances or behave as victims of circumstances. In the latter case, people are trapped by guilt, anger,

and fear into a mire of rationalizations, justifications, and explanations that never connect to actions that change the circumstances. Those who can retain an aspiring mind are able to align their behavior with their vision and change their circumstances. With this model in mind, the storytellers were invited to write their letters to the next generation. A small group of people abstracted the following statement from those letters, expressing the consumer activism initiating the workshop.

We are the lifeline for patients, their families, and healers who suffer medical error. We are the consumer advocates who find and partner with healthcare leaders to form communities of concern for excellence and for the person in healthcare. Together, we make safety come forth from the expectation that we the consumers set for healthcare that is compassionate, safe, and honest. Our National Healthcare Safety Board oversees the error reporting system and ensures that medical licensure depends on learning from medical error. Our local Citizen Advisory Boards are partners with those facilities that support healing and restore hope, making them the places where patients want to go. We work with the medical schools to teach the written and unwritten rules that go with you when you are sick. We will not go away. We are the lifeline.

On the second day of the workshop, the consumers met to review and modify this statement and to begin discussing goals. The stakeholders who would be their partners arrived and were briefed in a separate room, where they were given copies of the statement written in italics above. Then the stakeholders were invited "to the campfire" to help shape the vision, mission, and goals that were to emerge from the workshop.

Over the course of ensuing discussions, it was remarkable how thoroughly the division between "consumers" and "stakeholders" disappeared and a partnership emerged. As one partner said, "we are all going to be consumers of care some day, and we are all stakeholders." Thus, the products of the workshop represent the inseparable interests of all who were there and who are determined to make certain that the change they envision extends beyond the workshop. The vision and mission that were adopted show how the initial identity of the consumer activists expanded to include all the stakeholders as partners.

VI.   Results: Vision, Mission, Goals, and Action Steps

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 healthcare community what consumers and providers need to know whenever they interact within healthcare systems.

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***

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 The Joint Commission, Leapfrog, CMS, AHA, state licensing boards, AMA, ANA, AARP, and other consumer groups.

Goal #1: Action Steps

1. Inventory who is 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.

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3. Identify future ongoing funding. Insurance dollars, trial lawyers dollars, licensing fees. Will take up to 1 year.
4. Prepare a blueprint for the board and integration with other organizations. Will take 6 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 months.
8. Identify lobbying mechanism and national champions. Ongoing.

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 exiting 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 five 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 The Joint Commission 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 ensure 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 US 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 an integral part of assessment. This should be an endpoint, not just in credentialing new graduates but in re-credentialing folks who are already out there.
- Develop metrics, including the following: 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: (i) that every person wanders about with their medical history with them, and (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 - **A**bstain, **B**e monogamous, use a **C**ondom)*
- *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:

- *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.

Resources and Next Steps

Participants in the workshop realized that the action steps are rudimentary and require additional planning and refinement, working in partnership with the community of stakeholders. They discussed the resources needed to pursue the articulated goals and came up with a variety of sources, including foundations, government agencies, and companies. Yet, the full

group discussion made clear that the most vital resource would be the ongoing commitment of participants in this workshop and those who they recruit subsequent to the workshop.

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),[9] a non-profit organization, has been activated to carry this work forward.

As one participant wrote afterward:

> *I have come to the belief that healthcare, in general, and organizations individually have a lot to gain by engaging individuals like I met in Houston. My appreciation for the potential untapped resource, which resides in their experiences, interest and passion, is enormous.*

Dissemination of Workshop Results

As mentioned, the Workshop facilitators and participants plan to place the vision, mission, goals, and action plan in the public domain, to be used and adapted by all who resonate with it. This content 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.

CAPS was established to disseminate the output of the workshop on a continuing basis and realize the national goals articulated through its processes. It is anticipated that the national goals and action plan will be refined interactively over time. Additional workshops like the one done in Houston will be held in whatever settings are amenable to aspirational partnership between consumers and other health system and legal system stakeholders dedicated to achieving healthcare systems that is safe, compassionate, and just.

CAPS spokespersons already have presented workshop content, including the national goals, at the QUIC Summit on patient safety in November 2003 (See Appendix 4, testimony of Roxanne J. Goeltz, November 7, 2003). Immediate next steps include building a website (www.patientsafety.org) and a discussion forum as a virtual center for dissemination and refinement of the articulated goals and action steps. To jump start this discussion, this report will be distributed by blast email to more than 2000 leaders[10] in patient safety in early 2004.

Via its regular newsletter, IAF also will disseminate a link to this report. Both p4ps and IAF will link from their websites to the CAPS website to facilitate awareness of and participation in discussion of this report and the goals and action plan developed at the workshop. Workshop facilitators and planners will look for opportunities to present variations on this report at appropriate conferences or small group meetings as well as opportunities to publish content that emerged from the workshop in both peer-reviewed and non-peer-reviewed journals.

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[9] CAPS is an Illinois non-profit corporation, designed by the IRS as a 501c3 research and education organization. Every workshop participant has been invited to serve as a Founding Advisor to CAPS.

[10] The mailing will go to the p4ps list, comprised of persons who have attended the national patient safety symposia convened by p4ps (which also were supported by AHRQ grants in 2001 and 2002) or visited the p4ps website. All persons on the p4ps list have indicated a desire to receive educational materials on patient safety topics by email.

Workshop planners and facilitators also offer to work with AHRQ to assist in any dissemination efforts it may wish to undertake, the goal being to encourage more widespread discussion and solicit additional input into refining the six national goals and the action plan. This would serve as an extension of the dissemination of ideas that occurred at the November 7th QUIC Summit to broader audiences and will jumpstart what CAPS, p4ps, or IAF can achieve on their own. AHRQ dissemination avenues could include information posted to the AHRQ website, public relations activities, and the organization of a web-assisted teleconference focused on consumer partnership.

Evaluation of the Workshop

Nine (33%) of 27 participants returned an evaluation. Responses have been tabulated, and comments/suggestions were captured in Appendix 5.

Workshop participant evaluations suggest that 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 1-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.

One consumer described her experience after the workshop:

> *Personally, my mind has been spinning since I left Houston thinking of the possibilities. I can't wait until I have written material from Houston to start sharing it with current stakeholders I have contact with. I will continue my efforts to push for support systems to be in place for adverse events; support that will go well beyond admission. After attending this workshop, I am more committed to patient safety efforts as well as support services that need to be part of it.*

Conclusion and Recommendations

Because the workshop was convened and led by consumers, its output is authentically patient centered. In designing it, our focus was decidedly not on consumers' or victims' rights but was on the *contributions* consumers can make to healthcare safety and paving non-adversarial pathways for us to do so. The collaboration between consumers and other stakeholders that was achieved underscores that the opportunities to build such non-adversarial pathways are ripe and can be realized.

CAPS has been established to further this approach and, more specifically, the national goals articulated by the collaborative team that gathered at the workshop.

We realize that some of these goals may require legislative or regulatory public policymaking to be fully realized and therefore may not be activities that AHRQ can collaborate on or financially

support. However, all the national goals have research components as initial steps. We recommend that AHRQ consider supporting the following research and dissemination activities.

> **Recommendation A**: *That AHRQ further disseminate this report through a number of additional avenues including information posted to the AHRQ website, public relations activities, and the organization of a web-assisted teleconference focused on consumer partnership and the consumer-led workshop. This would serve as an extension of the dissemination of ideas that occurred at the November 7th summit to broader audiences.*

With respect to Goal 1 (Establishment of a National Patient Safety Board or Authority), one immediate need is for the preparation of an inventory of what organizations at both the state and federal levels, and in both the public and private sectors, are doing to support patient safety research, develop national patient safety policies or guidelines, collect and analyze reports of medical errors or system failures, establish standards, develop curricula for providers, develop information for consumers and coordinate the activities of and/or share information among regulators.

Consumers who are interested in feeding back their experience to healthcare now do not know where to start; accordingly, an inventory of what's being done would serve consumers needs by mapping the landscape. It would also be an important piece of research to be used by policymakers in developing activity blueprints for centralized state or federal patient safety authorities and their integration with other organizations.

> **Recommendation B**: *That AHRQ support the preparation of a thorough inventory of patient safety activities being done at the federal and state levels by both public and private organizations.*

With respect to Goal 2 (Establishment of Local or Regional Patient Safety Advisory Boards), the need was articulated for community-based opportunities for consumers to participate in healthcare organization facility and process design, the development of patient safety information for consumers, the implementation of medication safety and other error-prevention activities in both acute and non-acute treatment settings, designing initiatives that provide feedback and reporting of consumer learning to healthcare stakeholders, and providing input to regulatory and accreditation bodies.

Given the anticipated variation from local community to community, we propose tackling this goal through pilot projects in a small number of locales that self-declare as ready (or that have already started) to include consumers in patient safety coalitions. Results of this pilot study would be evaluated and developed into a model program. Among other objectives, such a model program would advance the national interest in making healthcare more transparent.

> **Recommendation C**: *That AHRQ support at least five regional demonstration initiatives to design and evaluate programs for active consumer participation in the kinds of systems-based medical error prevention activities now being developed within healthcare organizations.*

With respect to Goal 3 (National Patient Safety Reporting/Learning System), the need was articulated for mapping the ways in which consumers can be fully integrated into the national and regional information infrastructure improvement work that is now a priority for

Secretary Thompson and the AHRQ. More specifically, this includes developing multiple avenues for consumers to report to incident and narrative occurrence repositories, educating consumers about their role in contributing to error reporting/learning systems, working to ensure that the information in such repositories is accessible to patients and lay caregivers partnering in their own care (which may involve the integration of consumer friendly search strategies and nomenclature distinct from that used by clinicians), developing evaluation metrics to track the correlations between consumer participation in reporting and outcomes or process improvements, and establishing consumer roles in the development and dissemination of best practices that are formulated based on reported data.

Again, one way to begin is pilot projects, starting with condition-specific reporting targets and collaboration between consumers and healthcare communities that wish to work with consumers to achieve proof of concept, followed by a nationwide roll-out. Another approach is to involve consumers as full partners in the migration of patient safety reporting and learning programs from the large, acute healthcare systems that have led in developing them to smaller hospitals and acute, long-term care and home care environments. Active consumer involvement in statewide or regional reporting can play an integral role in strengthening the continuity of care for patients who access healthcare services in more than one treatment setting.

> ***Recommendation D****: That AHRQ support pilot projects for the collaborative development by consumers and providers of reporting systems designed to track instances of (i) the failure to treat neonatal hyperbilirubinemia and (ii) the failure to effectively document and communicate malignant pathology, analyze the lessons learned, and develop best practices for both clinicians and lay caregivers.*

> ***Recommendation E****: That AHRQ support pilot projects that include consumers in the extension or transfer of patient safety reporting infrastructure from acute care hospitals to less supervised settings, such as ambulatory care, long-term care, and home healthcare, as well as from urban to rural population centers.*

With respect to Goal 4 (Public and Provider Education about Patient Safety), movement forward depends on developing a concerted effort to integrate systems-based and patient-centered thinking into the educational experience of healthcare clinicians, healthcare organization administrators, and consumers. The inventory of patient safety activities discussed above (***Recommendation B***) is a crucial first step in establishing a comprehensive picture of who is developing patient safety curricula for healthcare provider constituencies, both in graduate training and the continuing education and re-credentialing arenas.

Drawing on this inventory, a logical next step is the development and piloting of a high-impact project on patient safety designed to teach systems-based thinking, reinforce patient-centered values, and facilitate communication between consumers and providers about the difficult topics of error and accidental injury.

> ***Recommendation F****: That AHRQ support a high-impact, education-dissemination project that includes (i) both top-down and grass-roots buy-in; (ii) strategies for individual, personal investment in the dissemination of educational content, including career-enhancing qualifications, small-group support systems, and high-profile opportunities to showcase content; (iii) curricular materials that use adult education theory specifically adapted for the cultures of the target audiences, including small-group*

learning, small number of concepts per learning session, and personalized feedback; (iv) cutting edge subject matter; and (v) cutting edge technology.

With respect to Goal 5 (Creating National Awareness), as a first step, we propose a nationwide survey of providers' and consumers' awareness of patient safety risks, issues, and concepts. The survey will be used to shape a public awareness campaign and will also serve as a baseline for measuring results of that campaign. In addition, it should inform the development of the high-impact curriculum addressed in ***Recommendation F***.

> ***Recommendation G****: That AHRQ support development and implementation of a baseline survey of consumers and providers on patient safety issues and ideas.*

With respect to Goal 6 (Assuring Just Compensation for Patients Harmed by Health Systems Error), this objective interfaces with the national public policy debate on civil justice reform. We propose as an initial research project a study of consumer attitudes regarding what patients and families want to be told when a medical error or medical accident occurs, what compensation they think should be tendered, what remedial actions they expect at the local provider organization level and the public health level to prevent similar future occurrences, how important an apology is and the impact an apology has on a patient's decision to file a liability claim, and preferences for a jury trial versus litigation alternatives such as mediation or arbitration.

Research of this kind has the potential to better equip policymakers challenged to address periodic tort "crises" with patient-centered data to balance against the selective facts presented by lawyer and physician lobbying groups. As such, it could assist both the legal and medical systems in being more patient centered.

> ***Recommendation H****: That AHRQ support consumer attitude research about preferences regarding communication of facts, means of dispute resolution, remedial action, and magnitude of compensation after the occurrence of preventable adverse events.*

Finally, we realize that the national goals set forth in this report reflect the work product of a relatively small group of individuals. Although the workshop planners tried to recruit participants from diverse populations nationwide, much more can and should be done to test and validate this work product among regionally and culturally diverse groups of engaged consumers and healthcare stakeholders. With this report, we place the workshop process model and tools described herein into the public domain to be used by others interested in contributing to the transformational work that has begun. As part of our ongoing efforts to realize the vision, mission, goals, and actions articulated in the Consumer-led Workshop to Advance Patient Safety, CAPS and IAF also will look for additional opportunities to invite others to the "campfire" to expand and enrich this important discussion of safety, justice, and compassion in healthcare.

> ***Recommendation I****: That AHRQ support other workshops or forums that engage consumers and other healthcare stakeholders in efforts to work together collaboratively to build effective partnership that achieve a safe, just, and compassionate healthcare system.*

VII.   List of Products

1. Appreciative Inquiry Interview Instrument—Appendix 1
2. Workshop Applications—Appendix 2
3. Consumer-Led Workshop Participants—Appendix 3
4. Oral Statement of Roxanne J. Goeltz at AHRQ 2nd National Summit on Patient Safety Research—Appendix 4
5. Evaluation Summary—Appendix 5
6. Summary of Recommendations to AHRQ—Appendix 6

APPENDIX 1

Appreciative Inquiry Interview for Patient Advocates and Healthcare Stakeholders in Patient Safety

Here's what we want from the interviews:

> An appreciative inquiry (AI) seeks a positive core of success that experience offers for us to build upon. We want you to find that positive core to establish the partnership between patient advocates or consumer activists and key leaders who represent other stakeholders in healthcare.

> We would like you to take written notes from the AI interview—capturing what your partner said and emailing it to jpeck@altfutures.com prior to the workshop. We expect to get your interview partner's summary of your remarks as well, and it will help us get a head start before we get to Houston.

Consumer Name_____
Stakeholder Name _____

Directions: Each person takes a few minutes to think about questions 1,2 & 3. Then each person interviews the other for 10 minutes, taking down notes for each of the questions.

Question 1: Describe a time when you were involved in making healthcare really work for you or somebody you know. What made it work?

Question 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.

Question 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.

Question 4: What do you expect to share and contribute at the workshop in Houston?

Directions: After both interviews have been conducted, discuss any lessons or insights that can be drawn to contribute to improving patient safety. Briefly summarize these on the back of this sheet.

Form filled out and notes taken by

_____

Name

Partnership for Patient Safety and Institute for Alternative Futures

Consumer-Led Workshop to Advance Patient Safety
October 16-18, 2003

Application Guide for (Non-Consumer) Stakeholder Participation

Partnership for Patient Safety (p4ps) and the Institute for Alternative Futures (IAF) are convening a group of healthcare consumers and other stakeholders for a workshop that will take a new look at consumers' roles in partnering to ensure patient safety. The workshop will be held in Houston, TX, at The University of Texas M.D. Anderson Cancer Center, from October 16-18, 2003. The meeting is being supported in part by funds granted by the Agency for Healthcare Research and Quality (AHRQ), which does research on patient safety issues. Consumer Planning Committee Co-directors are Roxanne J. Goeltz, Member, National Patient Safety Foundation Patient & Family Advisory Council, and Susan E. Sheridan, President of Parents of Infants and Children with Kernicterus (PICK).

Objectives & Deliverables

Our primary objective is to assist policymakers and healthcare organizations become more patient-centered by better understanding the roles *consumers* play or could play as *partners* in keeping healthcare safe in all healthcare settings. We are particularly interested in learning from consumers who have been *change agents*, so that we can build on their experience and teach others what they learned through their interaction with healthcare. Our ultimate purpose is to improve healthcare.

The workshop has two distinct phases. Beginning on Thursday, October 16, 2003, a group of consumers will convene to share experiences, focusing on their efforts to communicate with healthcare providers about errors or safety concerns. On the afternoon of Friday, October 17, a group of non-consumer stakeholders will join the consumer participants to interactively explore roles and pathways for successful consumer partnership with the healthcare system. The combined group will work together through noon on Saturday, October 18, when the workshop will conclude.

Expected deliverables of the workshop include (1) an environmental analysis of the opportunities for consumer partnership on patient safety issues as well as the gaps and obstacles that stand in the way of successful consumer partnership; (2) an authentically patient-centered vision statement on the role of consumers as partners; and (3) a report that includes an action plan for next steps in establishing pathways between consumers and other key stakeholders for successful partnership activities.

The following criteria will be considered in selecting consumer participants:

1) capacity to be a change agent and work to improve patient safety;
2) ability to articulate their story about their own experience with the healthcare system;
3) commitment to attend the entire conference;
4) whether they are a member of a priority population, as defined by AHRQ[11]; and
5) willingness to be involved in interviewing and being interviewed by other potential meeting participants.

<u>(Non-Consumer) Stakeholder Participants</u>

We look forward to the workshop being an event in which consumers interested in partnering and other stakeholders from the healthcare system ready to effectively partner with such consumers will begin important work in realigning their relationships. Consumers who have experienced medical error or systems failure often move into -- or are distanced by healthcare in a way that produces -- adversarial relationships and behaviors that are not conducive to systems learning or change. Our intention is to identify other pathways for interaction that are more successful in advancing patient safety and optimal treatment outcomes.

We are particularly interested in stakeholder participants who represent or reflect the views of the following sectors:

- Accrediting organizations
- Allied healthcare providers (including technicians, physician assistants, nurse practitioners, emergency medical personnel, etc.)
- Educators
- Employers who purchase healthcare services
- Foundations with an interest in improving healthcare quality
- Government (including health policymakers, healthcare payors and regulators)
- Healthcare facilities administrators (including acute, ambulatory and long-term care facilities)
- Healthcare facilities executive leaders
- Healthcare facility governing board members
- Law (including plaintiff and defense lawyers, mediators and judges)
- Managed Care
- Medical device manufacturers and distributors
- The medical profession
- Nursing
- Pharmaceutical manufacturers and distributors
- Pharmacy
- The press
- Researchers

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[11] AHRQ defines priority populations as low income groups; racial and ethnic minority groups; women; children; the elderly; individuals with special healthcare needs, including individuals with disabilities and those who need chronic care and end-of-life healthcare; and individuals living in inner-city, rural and frontier areas. CONSUMERS DO NOT HAVE TO BE A MEMBER OF A PRIORITY POPULATION TO PARTICIPATE IN THIS WORKSHOP.

The following criteria will be considered in selecting (non-consumer) stakeholder participants:

1) active involvement in efforts to improve patient safety or healthcare quality;
2) commitment to attend the conference on Friday, October 17 through noon Saturday, October 18;
3) willingness to be involved in interviewing and being interviewed by other potential meeting participants; and
4) willingness to sponsor the workshop by: a) paying your own travel expenses to attend the workshop; b) sponsoring a consumer participant by paying their travel expenses; c) providing a supplemental grant in support of the workshop; or d) providing a grant or in-kind services for follow-up activities, such as hosting meetings or printing and disseminating the findings of the workshop. Sponsors will be acknowledged in the final report on the October Consumer-Led Workshop to Advance Patient Safety.

Application for (Non-Consumer) Stakeholder Participation

Please print

Name_____

Title_____

Organization_____

Address_____

_____

City_____State_____Zip_____

Work Phone_____Fax (if available)_____

Home, Cellular or Alternate Phone (if available)_____

Email_____

1. Can you attend the workshop from October 17 through noon on October 18, 2003? ❑Yes ❑No

2. Do you represent a stakeholder sector, as delineated above? ❑Yes ❑No

    If yes, which one(s)? _____

3. Are you willing to interview and be interviewed by another meeting participant? ❑Yes ❑No

4. Are you interested in sponsoring the October Consumer-Led Workshop? ❑Yes ❑No

    If yes, in what capacity? _____

Please describe the ways in which you or your organization have partnered or are interested in partnering with consumers to keep healthcare safe. Feel free to use additional pages if necessary or to attach materials that illustrate your interest in patient-centered care and patient safety.

APPENDIX 3

Consumer-led Workshop to Advance patient Safety
October 16-18, 2003
Houston, TX

Consumer Participants

Carol A. Armenti
54 Sunrise Boulevard
Toms River, NJ 08753
(H) 732-255-1132
(C) 908-910-3216
carolarmenti@comcast.net

Diana Artemis
3431 Lakeside View Dr.
Falls Church, VA 22041
(H) 703-671-4916
(W) 202-548-5517
diana.t.artemis@baesystems.com

Rebecca DeVivo
3930 N. Wayne #3N
Chicago, IL 60613
(H) 773-755-0398
(W) 312-464-5196
Rebecca_Devivo@ama-assn.org

Roxanne Goeltz
1313 Hillside Lane
Burnsville, MN 55337
(H) 952-898-3096
jdr@frontiernet.net

Gerald R. Goodman, DrPH, CCE
5715 Yarwell
Houston, TX 77096
(H) 713-729-8161
(W) 713-794-2361
ggoodman@twu.edu

Maryella Jansen
2206 Vista Ave. SE
Olympia, WA 98501
(H) 360-352-9436
(W) 360-236-4792
maryella.jansen@doh.wa.gov

Linda K. Kenney
2 Plowshare Ct.
Mansfield, MA 02048
(H) 508-337-9836
LKenney@medicaltrauma.org

Becky Martins
PO Box 273
Warren, ME 04864
(H) 207-273-4321
(W) 207-273-3474
voice4patients@aol.com

Beverley McDonald
2345 Oxford #511
Berkley, MI 48072
(H) 248-548-3049
(F) 248-543-3212
(C) 248-227-1413
bmcdojshe@aol.com

Suzanne Mintz
National Family Caregivers Association
10400 Connecticut Ave., Ste. 500
Kensington, MD 20895
(H) 301-949-3638
(F) 301-942-4930
(W) 301-942-6430
Suzanne@nfcacares.org

Susan Sheridan
202 Sandra St.
Eagle, ID 83616
(H) 208-939-0260
(C) 208-867-3479
psheri9110@aol.com

Judith Winter
PO Box B
Greenbank, WA 98253
(H) 360-222-3202
Winter@whidbey.net

Stakeholder Participants

Howard Cohen, MD
Patient Safety Officer
Saint Francis Medical Center
530 NE Glen Oak Ave.
Peoria, IL 61637
(W) 309-624-9339
Howard.S.Cohen@osfhealthcare.org

Vikki Ann Entwistle
Harkness Fellow In Health Policy
Harvard School of Public Health
677 Huntington Ave., 4th Floor
Department of Health Policy and Mgmt.
Boston, MA 02115
(W) 617-432-6448
(F) 617-432-4494
(H) 617-267-2186
ventwist@hsph.harvard.edu

Suzanne Graham, RN, PhD
Director of Patient Safety
CA Regions of Kaiser Permanente
Kaiser Foundation Health Plan, Inc.
1950 Franklin St., 14th Floor
Oakland, CA 94612
(W) 510-987-4651
suzanne.graham@kp.org

Linda Kosnik
Chief Nursing Officer
Overlook Hospital/
Atlantic Health System
99 Beauvoir Ave.
Summit, NJ 07902
(W) 908-522-2095
Linda.Kosnik@ahsys.org

Tina Maund
Director, Performance Improvement
Overlook Hospital/
Atlantic Health System
99 Beauvoir Ave.
Summit, NJ 07902
(W) 908-522-4912
(F) 908-522-5315
Tina.Maund@ahsys.org

Laura Misuk
Director
VHA Health Foundation
220 E. Las Colinas Blvd.
Irving, TX 75039
(W) 972-830-0224
(F) 972-830-0332
lmisuk@vha.com

Virginia Morrison, JD
Executive Vice President/
Chief Financial Officer
Health Care Mediations, Inc.
405 Redwood Rd.
San Anselmo, CA 94960
(W) 415-456-5038
(F) 415-456-0216
(H) 415-640-0279
gmorrison@HealthCareMediations.com

Sara Olson, RN
Medical Systems Consultant
Quality Focus, Inc.
2965 Ryan Dr. SE
Salem, OR 97309
(W) 541-688-2574
(F) 541-607-5592
(P) 541-718-3948
sarols@earthlink.net

Paul M. Schyve, MD
Senior Vice President
Joint Commission on Accreditation of
Healthcare Organizations (JCAHO)
One Renaissance Blvd.
Oakbrook Terrace, IL 60181
(W) 630-792-5950
(F) 630-792-4650
pschyve@jcaho.org

Patsy Stinchfield, RN
Director
Pediatric Infectious Diseases
Children's Hospitals and Clinics
2525 Chicago Ave. S.
Minneapolis, MN 55404
(W) 651-220-6136
(F) 651-220-7233
patsy.stinchfield@childrenshc.org

Gail O. VanZyl
Director - Risk, Regulatory and Health
Information Services
Catholic Healthcare West
350 W. Thomas Rd.
Phoenix, AZ 85013
(W) 602-406-4939
(F) 602-406-6394
gvanzyl@chw.edu

Adam Welsh
Associate
Booz Allen Hamilton
1101 Wooten Parkway
Rockville, MD 20852
(W) 240-314-5649
(H) 508-397-1384
welsh_adam@bah.com

John Whittington, MD
Patient Safety Officer
OSF Healthcare System
800 NE Glen Oak Ave.
Peoria, IL 61603
(W) 309-655-4846
(F) 309-655-6869
John.Whittington@osfhealthcare.org

Kenneth C. Wilson, MD, MS
Henry Ford Health System
One Ford Place, 5a25
Detroit, MI 48202
(W) 313-874-6978
(C) 812-736-3442
(H) 248-305-7163
kwilson2@hfhs.org

Peter K. Wong, PhD, MS, MBA, RPh
Vice President
Clinical Effectiveness & Performance
Improvement
Good Samaritan Hospital
2222 Philadelphia Dr.
Dayton, OH 45406
(W) 937-276-8259
(F) 937-341-8689
(H) 937-430-5218
pwong@shp-dayton.org

Facilitators/Staff

Geri Amori, PhD
Principal
Communicating Healthcare
105 Covington Lane
Shelburne, VT 05482
(W) 802-985-5458
(F) 802-985-5557
itzamori@earthlink.net

Mitchell L. Dvorak, MS
Associate Director
Partnership for Patient Safety (p4ps)
One W. Superior Street, Suite 2410
Chicago, IL 60610
(W) 312-274-9695
(F) 312-274-9696
mdvorak@p4ps.org

Jason M. Etchegaray, PhD
Systems Improvement Specialist
M. D. Anderson Cancer Center
1515 Holcombe Blvd., Box 141
Houston, TX 77030
(W) 713-745-1357
(F) 713-745-4437
(H) 281-293-0175
jasonetchegaray@yahoo.com

Roger Fritz
Executive Director
Leadership by Design
Interco Corporate Tower
101 S. Hanley Road, Suite 1340
St. Louis, MO 63105-3435
(W) 314-721-1143 ext. 13
(F) 314-721-1172
rfritz@leadershipbydesign.com

Martin J. Hatlie, JD
President
Partnership for Patient Safety (p4ps)
One W. Superior Street, Suite 2410
Chicago, IL 60610
(W) 312-274-9695
(F) 312-274-9696
mhatlie@p4ps.org

Jonathan C. Peck, MA
Vice President
Institute for Alternative Futrues
100 N. Pitt Street, Suite 235
Alexandria, VA 22314
(W) 703-684-5880
(F) 703-684-0640
jpeck@altfutures.com

William Rowley, MD
Senior Futurist
Institute for Alternative Futures
100 N. Pitt Street, Suite 235
Alexandria, VA 22314
(W) 703-684-5880
(F) 703-684-0640
browley@altfutures.com

Debora Simmons, RN, MSN, CCRN, CCNS
Sr. Clinical Quality Improvement Analyst
M.D. Anderson Cancer Center,
The University of Texas
1515 Holcombe Blvd.
Houston, TX 77030-4009
(W) 713-792-9524
dsimmons@mdanderson.org

APPENDIX 4

Oral Statement of Roxanne J. Goeltz
AHRQ 2nd National Summit on Patient Safety Research
(November 7, 2003, Arlington, VA)

Thank your for giving me the opportunity to speak to you today.

My brother Mike died of medical error on September 22, 1999, one and a half months before the IOM report came out stating 98,000 people a year die of medical errors in hospitals alone. I am an air traffic controller; in my field that would equate to crashing an airliner with 250 people in it every day.

Mikes death was an incredible learning experience for me. As a family, we take part of the responsibility for Mike's death. We left him alone and should have been there to speak for him when he could not. Before his death, I did not have a clue what the term medical error meant or that such a thing existed. But, in Mike's memory, I tried to learn as much as I could. What I know now is that needless harm is coming to too many people who enter the healthcare system and that every day families continue to be devastated as mine was.

But, as big as the problem is, I have hope. My hope is nurtured by wonderful, dedicated people I've met in the healthcare community who are acknowledging how risky healthcare is and are trying to make a difference. It also comes from a growing number of watchful, knowledgeable consumers who are finding one another and joining our collective voices,

…so that we can be heard

…so, that we can feedback to the system what we've learned

…so that we can help in the prevention of errors

…so that we can partner with healers who authentically want to *First, do no harm*, and together create a healthcare system that truly is safe, compassionate and just.

Those three concepts -- safety, compassion, and justice -- are the core issues that a group of people honed in on as our core values when we gathered in a 3-day workshop last month at the University of Texas M.D. Anderson Cancer Center in Houston. I'd like to spend a few minutes telling you about that experience.

First, it was designed to be consumer led and to create an opportunity for us to be at the center stage of discussion. So often, consumers who care about safety find themselves assigned roles that I'll describe as marginalized. We're invited into other organizations for a meeting, or we're asked to be advisors, or one or two of us are asked to bring the consumer perspective to a mission or plan that already has been set up by others. We share our story but then that is the extent of our contribution. I am grateful to be able to share my story; stories are valuable, and there is a lot to be learned from them, but we have so much more to offer. I can't tell you the number of discussions I've participated in to discuss medical error reporting for which the thought of consumers contributing to the reporting system is "way out there." I'm asked what I think, or even what I need, but much less often what I can do or how I can contribute, not as a victim, but as a change agent. There's a big difference between a sympathetic victim and a motivated change agent, and I ask you to think about that.

In my travels through the world of patient safety, I had the good fortune to meet Sue Sheridan, a woman who has suffered great loss and tragedy in our healthcare system and who opened this summit with compassion and intelligence not anger and

revenge. We are of like mind about the need to create a real consumer voice that is at the table as more than just a sympathetic reminder of the impact of medical error. And together, we gathered resources and developed this Workshop idea that began with consumers and *then* invited other stakeholders in to join and help us figure out how to be effective partners in care.

The second thing I want to say is "thank you."

Without a grant from AHRQ and the willingness of M.D. Anderson Cancer Center to graciously host us, the gathering could not have happened. Our facilitators included the Partnership for Patient Safety, which really was our coach, and the Institute for Alternative Futures, which challenged us to open ourselves to possibility and the envisioning of big goals. On the first night of the workshop, we consumers met and imagined our gathering place to be not the conference room that it was but a campfire, where we shared our most life-challenging experiences, our biggest accomplishments, and our most profound hopes for the future of healthcare.

Working together our diverse group invented our own Utopia. Then, on the 2nd day, we invited in an equal-sized group of health system stakeholders to ground us in reality but also help us devise the roadmap to Utopia. Prior to the workshop, the consumers and stakeholders used an instrument based on Appreciative Inquiry to interview each other. Appreciative Inquiry focuses on examining past personal and organizational successes as the basis for problem solving. It worked well for us. In a very short time at the workshop, both consumers and stakeholders were working together from our deeper identities as change agents and compassionate problem solvers. I must say that it was a wonderful experience.

The third thing I want to briefly cover is our work product.

To begin with, our joint vision was for a healthcare system that is safe, compassionate, and just. Preventing medical errors is not the only goal. Treating families respectfully and with integrity and compassion -- even when there has been a bad outcome and there is a fear of litigation -- is equally important. And, at the risk of oversimplifying, our concern with justice had much more to do with ensuring that families damaged by a bad outcome were fairly compensated than it was with having hospitals blamed or clinicians punished. There was a lot of dissatisfaction with the tort system as our only remedy.

The mission we articulated had three major objectives:

A) to be a champion for patient safety in a new healthcare culture,

B) to be a voice for individuals, families, and healers who suffer harm in healthcare encounters, and

C) to teach the healthcare community what consumers and providers need to know whenever they interact within healthcare systems.

How will we achieve these objectives? Well, we set six goals for ourselves to reach over the next 5-10 years. They are:

Goal # 1: Establish a National Consumer-Led Patient Safety Board. One of the things that consumers cannot accept is that there is no body or organization in this country in charge of safety in healthcare. If we or our loved ones are injured on the highways, or in the air, or by a product, there's a place to go for gathering information and focal point for implementing change. As a professional air traffic controller, I will tell

you that it is crazy that there is no centralized safety authority in this country. We will not

be credible as a country that takes patient safety seriously until we do.

Goal #2: Create Local Consumer-Led Patient Safety Advisory Boards in Every

Community in the United States…and Scotland. As you can see, we had a native of

Scotland in our group. No matter where you live, we thought that the safety net could be

stronger if there were local patient-centered safety groups that expand the interaction

and learning between the system and the consumers they treat. The Massachusetts

Coalition to Prevent Medical Error is a good prototype for building local or regional

communities, and we would build on that model.

Goal # 3: Institute a Non-Punitive National Patient Safety Learning/

Reporting System. Just as a national board is crucial, so is a national information-

gathering system that focuses on lessons learned and also success stories about what

works to improve safety. AHRQ's work in disseminating information is one prototype,

but again much more needs to be done, and it needs to be done in a context where

there is some centralized coordination of data reporting in and out. Secretary

Thompson's leadership in developing a common reporting format for all agencies within

the Department of Health and Human Services, again, is a promising model and

something to build on.

Goal #4: Establish a National Education Effort on Patient Safety for

Providers and Consumers. There's a huge gulf between consumers and the system in

understanding safety science, the needs of consumers when bad outcomes occur, and

the role of consumers in prevention. This gulf needs to be closed through community education.

Goal # 5: Develop a National Patient Safety Awareness Campaign that Emphasizes Patient and Healthcare Community Partnership with Trust and Open Communication. Before education can really happen, the ignorance and denial about the extent of the public health challenge we face must be overcome. Healthcare is far from being as safe as we can make it, and blaming people or the organizations in which mistakes are made as the legal system does is not an effective approach. Healthcare -- like the rest of the world -- is inherently risky, and we all have to be mindful and watchful. That's the message.

Finally, 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. As I mentioned previously, a lot of our discussion of justice focused on fair compensation when injuries happen. By fair, we do not mean a lottery ticket, nor are we satisfied with the prevailing risk management attitude in which avoiding lawsuits trumps honesty or disclosure. Money is not the only form of compensation desired. Clearly, legal reform is a big discussion. Our general view is that it also must become more patient or client centered, just as the dialogue on healthcare reform aspires to be.

We also began outlining the action steps needed to reach each of these goals in 5 to 10 years. More detail on those proposed action steps are in the report in your Summit notebooks.

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 called 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) and a listserv or other discussion forum as a virtual center for dissemination and further refinement of the articulated goals and action steps. We plan to coordinate steps that will be taken around the country as well as in Washington DC.

We're here to help make the system safer through cooperation, and we're not going away. Although I have not talked about it today, I am a cancer survivor and a frequent user of healthcare, so I'm not going away. On behalf of you as healthcare consumers, my family, myself and all the silent voices that cannot share their stories thank you for listening to me today.

APPENDIX 5

Following is the summary of the returned evaluation forms from the Consumer-led Workshop to Advance Patient Safety, October 16-18, 2003, in Houston, TX. Of the 27 consumer and stakeholder participants, nine evaluations (n=4 consumer and n=5 stakeholder) were returned, for a 33% response rate. The evaluation form asked the consumers and stakeholders to respond to a series of seven questions that asked them to evaluate their experience as a participant in the Workshop.

Respondents rated the following questions on a scale of 1 to 5, with 1 indicating they strongly agree and 5 indicating they strongly disagree.

1.   **The dialogue and exchange of ideas over the course of the Workshop had value for me.**

Ratings	# of Response
1	7
2	2
3	0
4	0
5	0
Mean	1.2

N = 9

2.   **The Appreciative Inquiry interview I was asked to do before arriving in Houston was helpful in preparing for the Workshop.**

Ratings	# of Response
1	4
2	2
3	2
4	0
5	0
No response	1
Mean	1.8

N=8

3. **Starting the meeting around a consumer-only "campfire" was appropriate for this kind of meeting.**

Consumers		Stakeholders	
Ratings	**# of Response**	**Ratings**	**# of Response**
1	3	1	1
2	1	2	1
3	0	3	1
4	0	4	1
5	0	5	1
Mean	1.3	**Mean**	3

N=4   N=5

4. **One of the challenges for facilitators is to honor everyone's contribution, yet keep things moving along. With that in mind, the sessions were:**

Ratings	# of Response
Too long	1
Appropriate	7
Too short	1

N=9

5. **The products of this Workshop (including the Vision, Mission, and Goal formulations) met my expectations.**

Ratings	# of Response
1	5
2	3
3	1
4	0
5	0
Mean	1.6

N=9

6. **How will you use the energy/passion/aspirations/vision articulated during the course of the Workshop in your work?**

The content of the Houston workshop document is in some ways duplicative of NPSF's PFAC Agenda. PFAC members had the energy, the passion, the aspirations and a vision, but without the commitment, leadership and resources to move the agenda forward the council's momentum evaporated.

The Houston workshop brought together a group of stakeholders who developed a vision, with proposals to achieve the vision. Now, there's the need to fine tune, and the need for action. At the close of the conference, I was not sure of the next steps. The

conference goals were met. But it was also clear that there was a need for an umbrella organization to unite stakeholders. I'm a visual person so here's what I visualize. Right now (comparing making a quilt to achieving patient safety) there's lots of "patches" in patient safety around the country. They're all different and scattered. Until you have the common thread (i.e., umbrella organization) you'll never complete the quilt.

In its current format I have not been widely effective in gaining interest in the CAPS document. You'll need to develop formulated action steps, to get "buy in." Essential is to get CAPS web site up, and a brochure to market CAPS agenda - opposed to multiple pages to distribute. It's easier to get people to quick scan a brochure, than to ask them to read several pages. Positive responses: "That the "outside" consumer initiative has the greatest potential as a change agent in patient safety - and that it's long overdue." "CAPS has limitless potential" - and that comes from a plaintiff attorney!

I'm counting on CAPS to be a valuable resource to assist the folks in Maine. Maintain the momentum, that's key. If you need help, ask.

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It provides an important lens through which I will frame my work.

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Continue to look for opportunities and projects to demonstrate the mission and vision that was articulated by this group. Look forward to hearing more.

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I have already started to share with my colleagues. We are attempting to start our own patient/member advisory board and what I learned at this meeting and the contacts that I made will be very helpful.

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There is a dormant group in Houston, The Texas Forum on Patent Safety, that could be revived as an association of advocacy groups in Texas. At least that's where I'll start. Otherwise, I will continue to write articles and present papers for the journals that reach healthcare educations on the need to integrate patient safety throughout our curriculum in the same manner our accreditation requirements say we must do for ethics and law. I also plan to submit such a requirement for inclusion in the accreditation requirements for healthcare administration programs. I just finished a 2-year term as a fellow with that accreditation association (ACEHSA) and am well versed on how they work.

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I have come to the belief that healthcare, in general and organizations individually have a lot to gain by engaging individuals like I met in Houston. My appreciation for the potential untapped resource, which resides in their experiences, interest and passion, is enormous. I plan to meet with Beverley McDonald to learn more about what already exists in the southeastern Michigan area as relates to this initiative. I am engaging

others at Henry Ford that may also share an interest in exploring how HFHS can move forward to partner with consumers around furthering the aims of patient safety.

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Given that my job is primarily in the area of education, I am constantly thinking about how to incorporate principals of patient safety, patient-centered care, and partnership into the process. Work from this workshop will help to inform my long-term goals professionally, as well as my day-to-day professional and personal interactions with patients and professionals interacting in the healthcare system.

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I'm not sure yet, but I plan to develop a workgroup within the Michigan Health & Safety Coalition to explore a piloting of meaningful patient/family advisory councils in a couple of hospitals; to get some visibility on the new push at their annual conference in April; and to recruit and train/orient some consumers who will put their shoulders to this wheel.

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Personally, my mind has been spinning since I left Houston thinking of the possibilities. I can't wait until I have written material from Houston to start sharing it with current stakeholders I have contact with. I will continue my efforts to push for support systems to be in place for adverse events; support that will go well beyond admission. After attending this workshop I am more committed to patient safety efforts as well as support services that need to be part of it.

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7. **Please add any other thoughts or comments regarding this workshop.**

Logistically, I was pretty beat after the conference. The first day of the conference, I was up 21 hours. Meals were served late, and the healthiest beverage - water - was not always available. My glucose levels were way out of whack. The second day of the conference, when stakeholders were brought together before lunch was served, I was thinking .... I think I can, I think I can - like the little engine that could. I think I'm going to be able to get out of my chair to get a plate of food. But, also thinking it's a good thing that there's compassionate clinicians sitting all around me, just in case I can't. Sticking to a meal schedule is important.

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With reference to question 5 and my answer here, the interaction, and goals and objectives were excellent. However, the workshop ending was very frustrating for me. Basically, the last 30 minutes went nowhere, with suggestions of list servers and such not up to the intensity of the effort of the previous 2 days. I guess I wanted something tangible to hold onto. Even an organization name, such as the one that was ready to go, would have been something tangible. Granted, it was as they say a skeleton that needed flesh and life, but it was something.

I'm from the old school. If you have a group of people who have a common idea and goal, and want to work toward that goal, then start by identifying short-term things that need to be done a ask who is going to do them. But don't let them out of the room without some personal do-able commitment, something real to do to keep the momentum going. As it is, I am not sure where to jump next. We don't have a continuing working group to serve as a focal point to further the workshop goals, at least not that I can tell. I want such a group.

I also have to say that the impact of consumer action in patient safety is needed right now. With due respect for the JCAHO (although I didn't show such respect in my comments on Saturday) and others who have tried, providers in general just don't get it, or don't care. If we have to call something an "accident" because providers think the word "error" is too oppressive, then we have a problem. Those same people wouldn't agree to call a laceration a "booboo". If you want to get ghoulish, then how about a counter showing how many patients are dying from medical errors every day/hour/ whatever you want. Then a 5- or 10-year time frame for positive action looks a little too generous.

Talk is cheap. I am willing to work on what has been suggested, to identify groups that are doing what now, of those, who is willing to join in an alliance of advocacy groups working in the name of patient safety, and, if the interest is real and the cooperation on some initial goals is real, then that group becomes the Board as key consumer representatives who get membership by virtue of their effort. Everything else can follow from that.

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I understand the thinking behind having the consumer group start the night before we joined them. However, is it possible that such an approach may increase the real and perceived barriers between these "groups" of people? In any case, I think that the entire group seemed to develop considerable connectedness during the meeting.

I also am interested in what specific plans have been suggested to continue the dialogue, both for the participants and the nation as a whole, which began in Texas.

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I think overall the workshop produced many good goals and thoughts. If you were to do it again, I would make the following suggestions:

1. Use information that has already been developed (e.g., the National Agenda for Patients and Families). Although the discussion process is important, a lot of the ground that was covered has already been discussed and/or pursued in other places, and the resultant feeling for me was some reinvention of the proverbial wheel. I think we may have been able to get a little further if we'd started closer to where others have left off, rather than at the beginning. Background materials (brief ones!), along with the interviews, may have been helpful given the various backgrounds and levels of patient safety knowledge.

2. Be very clear and transparent about the goals of the workshop, and discuss them in the beginning. I think there was a lot of confusion over how the products of the workshop would be used, and what commitment was expected from participants. Although this was partly clarified toward the end, it may have been helpful to begin with a discussion of the possible outcomes. Similarly, although I think it was helpful for consumers to meet by themselves for the first day and begin to guide the strategic plan, there could have been a clearer focus on partnership earlier on, which may have prevented some backtracking when meeting with the stakeholders.

Again, I thought it was a great workshop with wonderful and dedicated participants and staff. These are just things that I would suggest if you were going to do it again. It was a great experience for me, and I hope to see the work continue to grow.

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It was a very good beginning and I'm grateful that consumers and staff who put it together got the ball rolling. I probably have some ideas about how this might be done better but – off the top of my head – I think we maybe needed one more half-day. It seems to me we got a little jammed at the end. Even though I had to get back to Detroit and missed the very end, as I looked at what we had yet to do, I thought it was almost impossible to do it as thoughtfully as we needed to.

The pre-conference call was important in the sense of merging the two groups and introductions, but mine was not too helpful. We may have had a little language difficulty over the telephone. I would stay with this model another time.

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APPENDIX 6

<u>Summary of Recommendations to AHRQ</u>

<u>Recommendation A</u>: That AHRQ further dissemination through a number of additional avenues including information posted to the AHRQ website, public relations activities and the organization of a web-assisted teleconference focused on consumer partnership and the consumer-led workshop. This would serve as an extension of the dissemination of ideas that occurred at the November 7th summit to broader audiences.

<u>Recommendation B</u>: That AHRQ support the preparation of a thorough inventory of patient safety activities being done at the federal and state levels by both public and private organizations.

<u>Recommendation C</u>: That AHRQ support at least five regional demonstration initiatives to design and evaluate programs for active consumer participation in the kinds of systems-based medical error prevention activities now being developed within healthcare organizations.

<u>Recommendation D</u>: That AHRQ support pilot projects for the collaborative development by consumers and providers of reporting systems designed to track instances of (i) the failure to treat neonatal hyperbilirubinemia and (ii) the failure to effectively document and communicate malignant pathology, analyze the lessons learned and develop best practices for both clinicians and lay caregivers.

<u>Recommendation E</u>: That AHRQ support pilot projects that include consumers in the extension or transfer of patient safety reporting infrastructure from acute care hospitals to less supervised settings, such as ambulatory care, long-term care, and home healthcare, as well as from urban to rural population centers.

<u>Recommendation F</u>: That AHRQ support a high-impact, education-dissemination project that includes (i) both top-down and grass-roots buy-in; (ii) strategies for individual, personal investment in the dissemination of educational content, including career-enhancing qualifications, small-group support systems, and high-profile opportunities to showcase content; (iii) curricular materials that use adult education theory specifically adapted for the cultures of the target audiences, including small-group learning, small number of concepts per learning session, and personalized feedback; (iv) cutting edge subject matter; and (v) cutting edge technology.

<u>Recommendation G</u>: That AHRQ support development and implementation of a baseline survey of consumers and providers on patient safety issues and ideas.

<u>Recommendation H</u>: That AHRQ support consumer attitude research about preferences regarding communication of facts, means of dispute resolution, remedial action, and magnitude of compensation after the occurrence of preventable adverse events.

<u>Recommendation I</u>: That AHRQ support other workshops or forums that engage consumers and other healthcare stakeholders in efforts to work together collaboratively to build effective partnership that achieve a safe, just, and compassionate healthcare system.