

Planetree Affiliate Member Conference Call

Developing a Consumer Voice in
Patient Safety:
Co-Creating a Safer Health System

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Today, our objectives are to...

- Describe Consumers Advancing Patient Safety or CAPS, a 501(c)(3) organization dedicated to embodying effective patient-provider partnerships and explain why it was established
- Introduce the Appreciative Inquiry methodology used to develop CAPS, now being used by World Health Organization (WHO) Patients For Patient Safety initiative
- Review CAPS goals, values and current activities

What is CAPS?

- Partnership model
- Formational workshop organized and led by consumers in partnership with other stakeholders
- Facilitated by futurists
- Established by an AHRQ funded workshop in October 2003 and many smaller financial and in-kind contributions

Building CAPS –

The methodology:

What motivated us?

- IOM recommendation that healthcare be patient-centered and systems-based
- Absence of a collective voice of consumers on what it means to be patient-centered
- Concern that consumers are not being included in discussions of systems-based improvements and are not climbing that learning curve
- Concern that consumers who experience system failure see our primary role as victims/adversaries
- Belief that consumers see things the system doesn't that can contribute to improvement

What methods did we use to plan the workshop?

- Planning Committee was chaired by consumers
- Designed for equal numbers of consumer and “other stakeholder” participants
- Recruited consumers who saw themselves as change agents and had accomplished something in their lives as part of a team
- Recruited stakeholders who were ready to partner with consumers
- Organized pre-Workshop phone interviews between consumers and stakeholders using an *Appreciative Inquiry* process

What is Appreciative Inquiry and how did it work?

- AI = form of organizational study that highlights and builds upon what a human system does well, not its “problems”
- Based on the belief that we can create what we imagine when we open our minds and our social processes to dialogue among all invested in the work of a human system
- Assumes that interventions into organizations are fateful, and that the energy of a community moves in the direction of the questions first asked; ergo inquiry into what has worked well will move a community toward a positive future
- We began by probing each person’s past accomplishments and the strengths each person brought to the team
- Worked well because it established common ground and mutual respect before consumers and providers even met

Stories are Central to AI.

Their impact is in the
images of success they
create and foster.

What AI questions did we ask?

- Describe a time when you were involved in making healthcare really work for you or somebody you know. What made it work? **[Success Question]**
- 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. **[Partnership Question]**
- 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. **[Change agent question]**
- What do you Expect to Share at the Workshop in Houston?

The Vision that inspires CAPS

We envision a partnership between consumers and providers to create global healthcare systems that are safe, compassionate and just.



CAPS Mission

- **Advocacy:** To be a champion for patient safety in a new healthcare culture
- **Partnership:** To be a voice for individuals, families and healers who wish to prevent harm in healthcare encounters through partnership and collaboration
- **Education:** To teach the healthcare community what consumers and providers need to know whenever they interact within healthcare systems

CAPS Goals

- 1) Establish national consumer-led patient safety boards
- 2) Create local consumer-led patient safety advisory boards in every community
- 3) Institute a non-punitive patient safety learning/reporting systems
- 4) Establish an education effort on patient safety for providers and consumers
- 5) Develop a patient safety awareness campaign that emphasizes patient and healthcare community partnership with trust and open communication
- 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

Principles, Values & Beliefs that guide CAPS work/partnerships

- **Commitment to the Truth**
- **Open and Honest Communication**
- **Partnership and Collaboration**
- **Empathy and Compassion**
- **Challenging and Courageous Change Agents**
- **Diversity and Creative Tension**
- **Transformation of Anger to Action**
- **Accountability and Forgiveness**
- **Appreciation and Positive-Mindedness**
- **System-Oriented and Patient-Centered**

CAPS Update – Does the partnership approach work?

We think so:

- CAPS works internationally to develop **Patients for Patient Safety**, part of the **World Health Organization** World Alliance for Patient Safety dedicated to finding and developing consumer/provider/policymaker partnerships around the globe.
- We've produced a consumer engagement toolkit for **AHRQ**, modeled on our international work that is downloadable at www.patientsafety.org
- We've partnered with **Aurora Health Care** and **Midwest Airlines** on an AHRQ grant to build patient partnership council at the community level focused on medication reconciliation in rural Wisconsin
- We're partnering with **Northwestern University** and **Chicago Public Libraries** to pilot a education program for library users & librarians
- We're voicing the consumer/provider partnership perspective in a regular column in ***Patient Safety & Quality Healthcare***
- We're working with **The Joint Commission** and **Common Good** to encourage litigation alternatives fair for both providers & consumers
- We're advising **Joint Commission**, **National Quality Forum**, **AHRQ**, **National Transitions of Care Coalition**, **Minnesota Alliance for Patient Safety**, and others on patient engagement issues and consumer-centered care.



WHO World Alliance for Patient Safety

Patients for Patient Safety

Patients for Patient Safety: The Champions



Patients for Patient Safety: London Declaration

We, Patients for Patient Safety, envision a different world in which healthcare errors are not harming people. We are partners in the effort to prevent all avoidable harm in healthcare. Risk and uncertainty are constant companions. So we come together in dialogue, participating in care with providers. We unite our strength as advocates for care without harm in the developing as well as the developed world.

We are committed to spread the word from person to person, town to town, country to country. There is a right to safe healthcare and we will not let the current culture of error and denial, continue. We call for honesty, openness and transparency. We will make the reduction of healthcare errors a basic human right that preserves life around the world.

We, Patients for Patient Safety, will be the voice for all people, but especially those who are now unheard. Together as partners, we will collaborate in:

- Devising and promoting programs for patient safety and patient empowerment.
- Developing and driving a constructive dialogue with all partners concerned with patient safety.
- Establishing systems for reporting and dealing with healthcare harm on a worldwide basis.
- Defining best practices in dealing with healthcare harm of all kinds and promoting those practices throughout the world.

In honor of those who have died, those left disabled, our loved ones today and the world's children yet to be born, we will strive for excellence, so that all involved in healthcare are as safe as possible as soon as possible. This is our pledge of partnership.

January 17, 2006

Consumer engagement...

Where do we start?

- **Careful Recruitment** -- Not all consumers are ready to partner
- **Mutual Respect** -- Partners respect one another and are honest about the challenges they face
- **Honesty & Trust Building** -- A crucial first step is medically honest communication & awareness building about the risk of both human error & system failure
- **Active Listening** – What can consumers teach us.
 - And do we have the same values?

Successful partnerships improve healthcare outcomes

- Opportunities for consumers to **participate** in achieving safer care should be offered wherever possible. Evidence shows **better outcomes** when patients “have a job” in managing their:
 - Asthma
 - Diabetes
 - HIV
 - Use of anti-coagulants
 - Management of depression
- Promising approaches in patient safety (so far) include:
 - Orthopedic Surgery’s “**Sign Your Site**” campaign
 - **Infection control** campaigns that prompt patients and families to remind providers about hand washing

Ultimate benefits of consumer/provider partnerships

- If **medical honesty**, more aware & better educated consumers
- If a **shared mental model** of healthcare risk, more robust provider/community relations and trust
- If more engaged consumers, **more opportunities to prevent harm**
- If better treatment outcomes, **more opportunities to reduce litigation exposure**
- If consumers **engaged in reporting** errors, **more feedback** to healthcare organizations and public health bodies

Consumers Advancing Patient Safety – How do we work?

- We share information and resources with other patient safety and consumer groups
- We partner with other organizations interested in achieving our goals
- We offer resources on the web

The power of partnership in healthcare:

A hopeful approach forward

“Mrs. Sheridan, I am the guy who stood up at the HCA PRMI Congress VIII and promised you we'd change our hospital rules within one week to include universal bilirubin screening at Conroe Regional Medical Center. Well, we did it. All babies will be screened at about 24 hours, and plotted on the nomogram, with followup from that as needed. We have empowered nurses to order bilirubins on babies without a doctor's order (or, technically, with our department's standing order). To my knowledge, we have been lucky so far. However, how can you know for sure? Maybe there's a baby or two minimally affected whose problem hasn't been figured out to be kernicterus.

Would you tell Cal about this? And realize that if you hadn't come to the Congress, it wouldn't have been done.”

**...8/25/03 email from Gerald L Bullock, MD,JD,FACOG,
Chairman, Department of Ob/Gyn/Pedi, Conroe Regional
Medical Center, Conroe, TX, to CAPS Co-founder
Susan Sheridan, mother of Cal Sheridan, who
experienced kernicterus as a newborn**

www.patientsafety.org



**Consumers Advancing
Patient Safety**