The Role of Consumers, Families, and the Community in Patient Safety: Learning from Experience

2008 AHRQ Annual Meeting
Rockville, Maryland
September 8, 2008 ~ 3:00-4:30pm

The Journey

Session Objectives

- Identify the range of roles and responsibilities that consumers, patients/families play in efforts to improve patient safety in the health care environment.
- Describe how your organization currently includes consumers, patients/families in the planning, delivery, and evaluation of patient safety - oriented interventions.

Session Objectives

- Describe how you will plan to introduce the concept to your organization's leadership.
- Identify resources for planning and implementing patient safety programs for consumers, patients/families

Presentation Outline

- Introduction
  (3:00-3:15pm)
  Katherine Crosson, MPH, AHRQ

- Patient/Family Perspective
  (3:15-3:25pm)
  Jim Beveridge, Member, Patient/Family Advisory Council
  Aurora Health Care, Wisconsin

- Range of Roles for Consumers, Patients/Families
  (3:25-3:50pm)
  Cezanne Garcia, MPH
  Institute for Family Centered Care

- Partners in Safety: The Aurora Health Care Journey
  (3:50-4:10pm)
  Kathryn Leonhardt, MD, MPH
  Aurora Health Care, Wisconsin

Introduction

Magnitude of the Problem

- Medical errors result in annual:
  - Deaths of 44,000 – 98,000 hospitalized patients (US)
  - Injuries to approximately 1 million individuals (US)
- Surgical errors cost nearly $1.5 Billion annually
- World-wide recognition of the need to promote patient safety
  - Countries representing 78% of the world's population have pledged to work together to reduce medical errors

    (World Alliance for Patient Safety)

Support for Patient/Family Engagement

Who supports a prominent role for the consumer, patient/family in patient safety?

- Consumer/Patient Organizations
- Government
- Professional Groups/Research Organizations

Consumer/Patient Organizations

- Consumer's Advancing Patient Safety (CAPS)
- National Family Caregiver's Association
- PULSE (Patient Safety Network Counsel)
- International Alliance of Patients' Organizations
- Institute for Family Centered Care

Government

Department of Health and Human Services

- Agency for Healthcare Research and Quality
- Centers for Medicare and Medicaid Services
- Centers for Disease Control
- National Institutes for Health

Institute of Medicine

Academic Institutions

- Patient Safety Curriculums
  - Medical and Nursing Schools
  - Schools of Public Health
  - Allied Health Professionals
- Continuing Education
- Board Certification

Professional Organizations

- National Patient Safety Foundation
- The Joint Commission
- American Hospital Association
- Institute for Healthcare Improvement
- Institute for Family-Centered Care
- World Health Organization / Alliance for Patient Safety

Patient/Family Perspective

Jim Beveridge

Member, Patient/Family Advisory Council

Aurora Health Care, Wisconsin

Range of Roles for Patients and Families

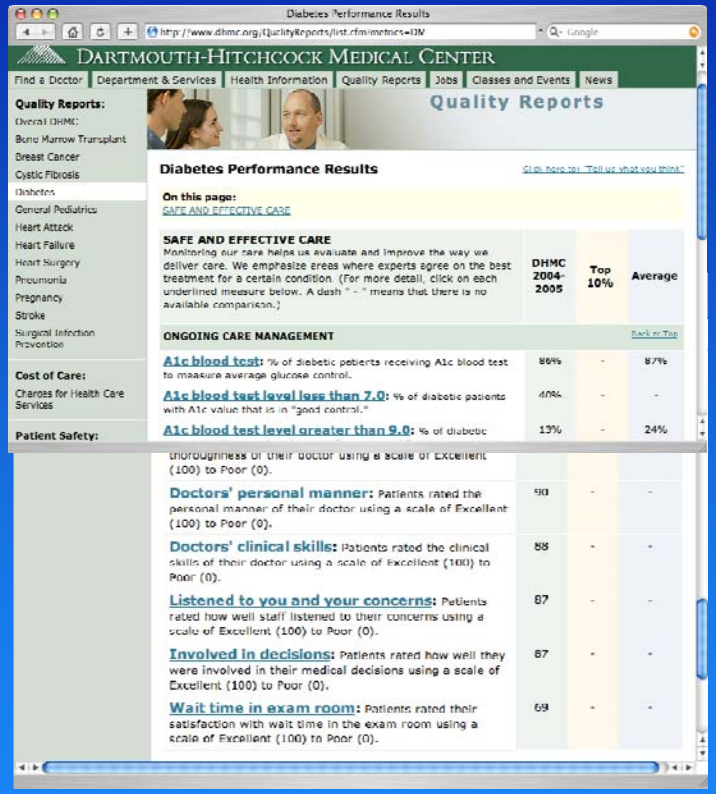
Cezanne Garcia, MPH

Senior Program and Resource Specialist

Institute for Family Centered Care

Patient- and family-centered care is working with, rather than doing to or for.

The Public Reporting of Quality and Satisfaction



- Fostering the partnerships among patients, families, clinicians, and others to encourage constructive dialogue and further improvement when reporting quality data publicly.
- Reductions in mortality associated with intensive public reporting of hospital outcomes.

Keeping Pulse: Learning About the Patient and Family Experience . . .

Focus groups and surveys are not enough!

Hospitals and health systems create a variety of ways for patients and families to serve as advisors and leaders.

Why Involve Patients and Families as Advisors in Safety Initiatives?

- Bring important perspectives about the experience of care
- Insights on how systems really work
- Inspire and energize staff
- Keep staff honest and grounded in reality
- Provide timely feedback and ideas
- Lessen the burden on staff to fix the problems…staff don't have to have all the answers
- Bring connections with the community
- Offer an opportunity to "give back"

Domains of Care to Improve Strategies and Tools for Safer Practices

- **Clinician - Patient and Family Care Interaction**
  - Patient and Family
  - Clinician
- **Clinical Microsystem**
  - Team interaction
  - Access to care
  - Clinical information systems
  - Patient feedback
- **Healthcare Macrosystem**
  - Coordination of care across care settings
  - Public information on practices

Thomas Bodenheimer's Improving Primary Care Strategies and Tools for a Better Practice (2007)

Preparation: Key Steps to Involving Patients and Families on Committees and Councils

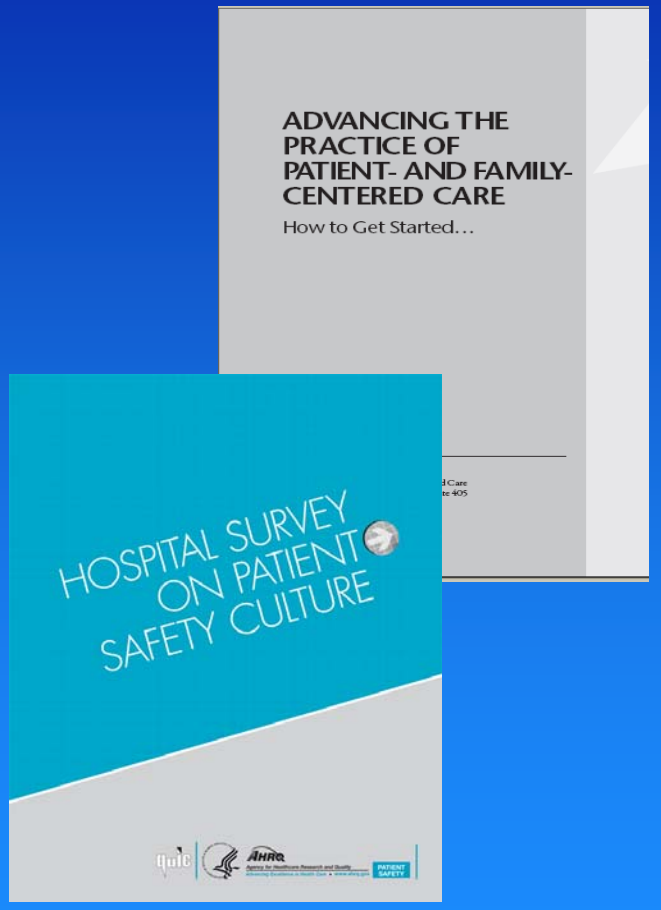
- **Selecting Patient and Family Partners**
  - Two or more
  - Representative of the Ethnic Diversity of Your Patient Population
  - Key Qualities
    - Able to Share Ideas Constructively
    - Speaks Up
- **Operationalizing Transparency with Legal Protections**
  - HIPAA training for volunteers
  - Sign Confidentiality Agreements

Once You've Started: Preparing Patient, Family and Staff Partners

- **Orientation to Safety Initiatives**
  - Orientation/Training
  - Mentors
- **Encourage participatory styles**
  - Offer facilitation training to middle managers and supervisors in PFCC initiatives.
  - Jargon and key concepts resources
- **Reinforce value of patient/family input and concrete suggestions of how this information will influence practice and policy**

Gauge Your Strengths for Partnering with Patients and Families in Getting Your Patient Safety Program Started

- Conduct an environmental scan
  - Priority initiatives
  - Culture assessment
- Develop a high level outline for a program.
- Secure approval to move forward.
- Draft a formal plan with goals, objectives, time lines, and responsibilities.
- Commitment to resources for implementation and evaluation.



Key Readiness Domains to Engage in Patient-and Family-Centered Safety

- Data transparency
- Flexibility around aims and specific changes of improvement project
- Underlying fears and concerns
- Perceived value and purpose of patient and family involvement
- Senior leadership support for patient and family involvement
- Experience with patient and family involvement
- Collaboration and teamwork

5-Year Quality Plan – Operations

Strategy: Safety and quality work is patient- and family-centered

- Work with legal department to establish framework for patient and family advisors serving as team members.
- Educate leaders, front line staff, and families about patient- and family-centered care.
- Establish that patient and family experiences are drivers for quality improvement.
- Board provides leadership for quality and safety.
- Physicians are engaged in patient safety and quality as partners.

5-Year Quality Plan – Prioritizing Key Initiatives

- Process of leadership rounding.
- Patients and families serve on quality teams.
- Family involvement in Rapid Response Team implemented across University Health System.
- Create a patient- and family-centered "model" unit at each hospital.
- Hold an annual physician safety/quality summit.

5-Year Quality Plan – Culture Change

- Patients tell stories at Board meetings.
- Patients and families serve on root cause analysis teams.
- Patients and families share stories at the Medical Executive level.
- Leverage technology to customize and enhance communication with patients and families.
- Expand patient- and family-centered units.

Readiness: Patient and Family Partnerships in Day-to-Day Care

Our Partnership Pledge

At Hopkins, we take a team approach to your safety. We invite you and your family to join us as active members of your care team.

We pledge to

- Coordinate your care
- Explain your care and treatment
- Listen to your questions or concerns
- Ask if you have safety concerns and take steps to address them.
- Ask about your pain often and keep you as comfortable as possible
- Check your identification before any medication, treatment or procedure
- Label all lab samples in your presence
- Clean our hands often

We ask you, or a loved one, to

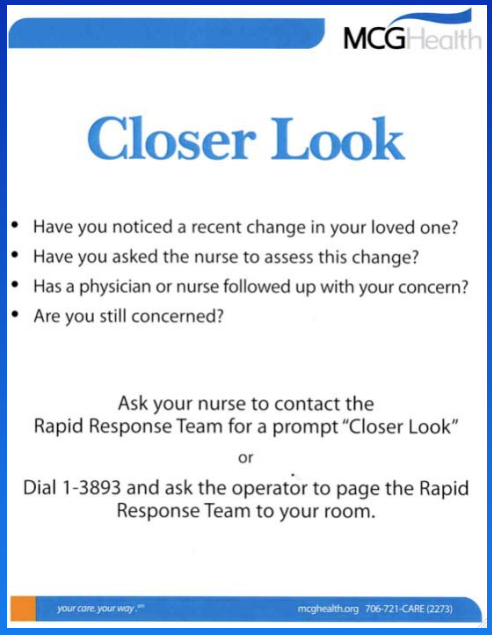
- Ask questions
- Speak up if you are concerned about a test, procedure or medicine
- Check the information on your ID bracelet for accuracy
- Be clear and complete about your medical history, including current medications
- Clean your hands often and remind your visitors to do the same
- Remind us if we do not carry out our pledge to you

We welcome your involvement and feedback. The unit manager is available to hear concerns about your care and safety.

From the doctors, nurses and staff of The Johns Hopkins Hospital

JOHNS HOPKINS MEDICINE
THE JOHNS HOPKINS HOSPITAL

Adoption: Build Strategies to Support Patient and Family Active Roles in Care

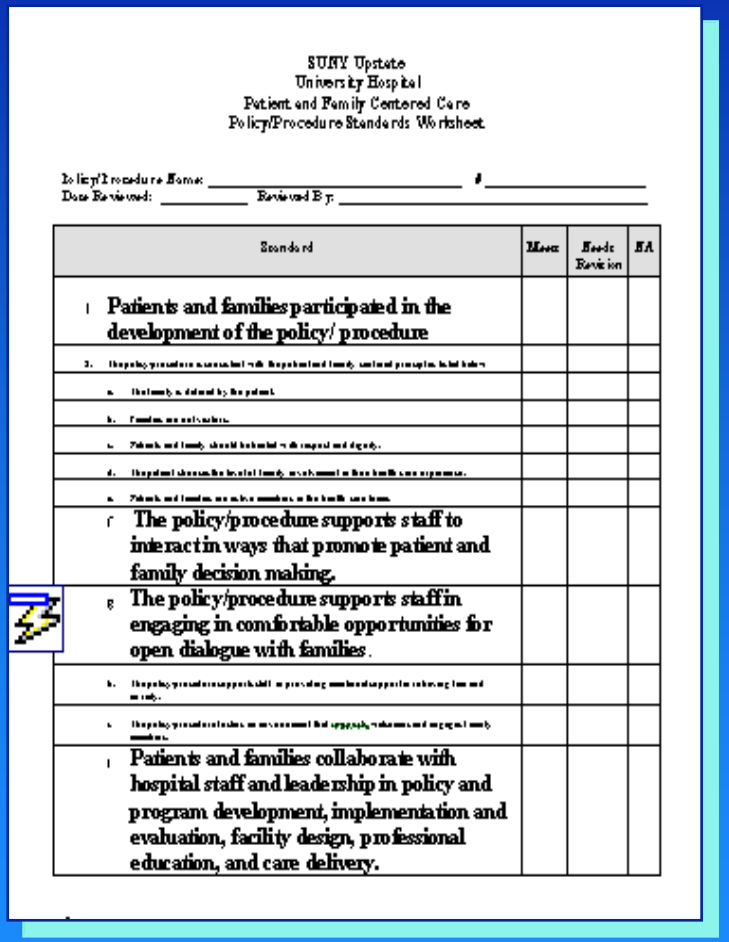


Best Practices Examples of Engaging Patients and Families as Partners

- Defining safety policy
- Developing and supporting evidence-based safety initiatives
- Patient safety-related training of staff and providers
- Designing and testing interventions
- Promoting and disseminating best practices
- Developing safety dashboards

Defining Safety Policy

- University of Washington Medical Center - Advisor membership on safety committees
  - Patient Safety Committee
  - Falls Prevention Committee
  - NICU Quality Leadership Team
- SUNY Upstate Medical University PFCC Policy Development Worksheet - Patients and families participate in policy/procedure development



SUNY Upstate
University Hospital
Patient and Family Centered Care
Policy/Procedure Standards Worksheet

Policy/Procedure Name: _____ #: _____
Date Reviewed: _____ Reviewed By: _____

Standard	Meets	Needs Revision	NA
1 Patients and families participated in the development of the policy/ procedure			
2.			
a.			
b.			
c.			
d.			
e.			
f The policy/procedure supports staff to interact in ways that promote patient and family decision making.			
g The policy/procedure supports staff in engaging in comfortable opportunities for open dialogue with families.			
h.			
i.			
1 Patients and families collaborate with hospital staff and leadership in policy and program development, implementation and evaluation, facility design, professional education, and care delivery.			

Developing and Supporting Evidence-based Safety Initiatives

- Improve Care by Public Posting of Quality Data
- Translate new Patient Safety Goals

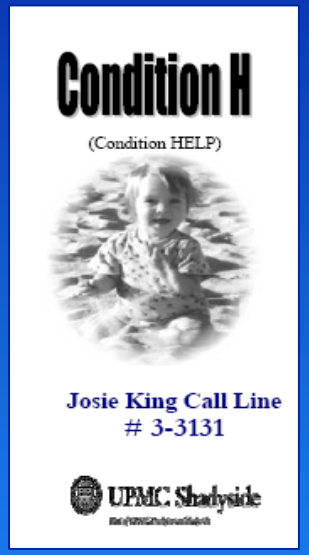
- Participate in National and Regional Collaboratives
- Partner with Patients and Families in Patient Liaison Safety Rounds
- Engage in Priority Safety Initiatives: Hand Hygiene

Translate new Patient Safety Goals

Rapid Response Team (RRT): Transforming Clinician-Only Activation to Family Activation

- Condition H
  - Parents can alert a similar team who will come and assess the situation.
- Family-Activated RRT
  - Over 50 Hospitals
    - N.C. Children's Hospital in Chapel Hill
    - Cincinnati Children's
    - Shands Jackson Medical Center
    - Yale-New Haven Hospital

UPMC
University of Pittsburgh Medical Center

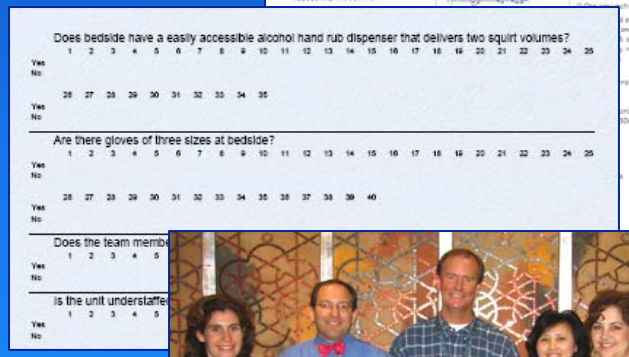


National Patient Safety Foundation®
2007 Socius Award
North Carolina Children's Hospital

Developing evidence-based programs/resources

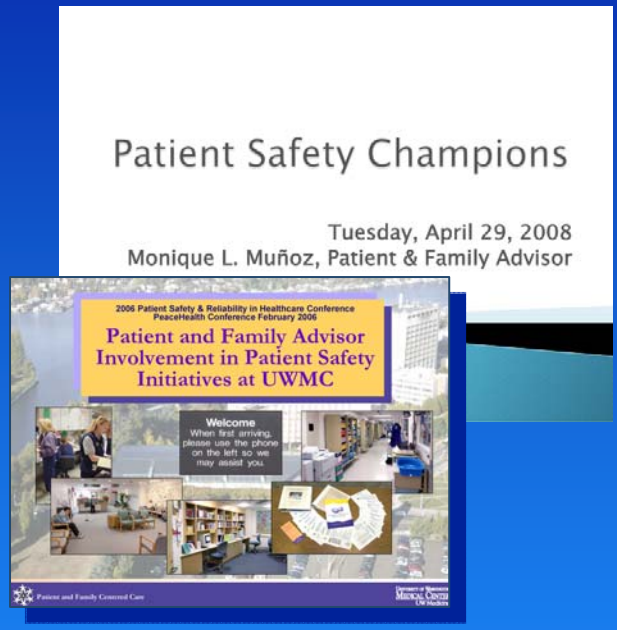
Involving Patient and Family Advisors in Learning-Based Collaboratives

- Vermont Oxford Network
  - Monitoring to Excellence: Quality Indicators
  - Safety Audits: Infection Control
  - Central Line Bundle
- Build Safety Dashboard
- Benefits
  - Increased credibility
  - Transparency
  - Momentum at stages of inertia
  - Advisors are best messengers
  - Power of stories



Training Staff and Providers

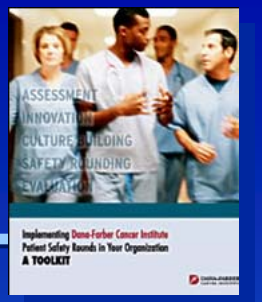
- Patients and Families as Co-Leaders
  - Facilitator
  - Content Expert
  - Faculty



- Keys to Success
  - High level of involvement
  - Related work/educational experience valuable
  - Engage experienced, effective advisor
  - Advisable that level of involvement may necessitate hiring as staff/consultants

Designing and testing interventions

Patient Safety Rounds



Traditional Staff-Led Patient Safety Rounds

- Interdisciplinary Team
- Ask questions that probe about safety
- Effectively identifies:
  - Adverse events
  - Near-miss occurrences
  - Design ideas for systemic interventions to effect change

Patient and Family Safety Liaisons Rounds

- Focus of Patient/Family Liaison: patient feedback on safety concerns
- Patient and Family Advisors involved in designing program

Developing Interventions: Educational Tools and Learning Aids

Growth in Patient and Family Resources that Identifies Roles for Patients/Families to Avert Errors

- Partner with patients and families as co-authors/reviewers
- Include safety standards/descriptions of what health care providers are doing to help ensure patient safety
- Standardized safety messages for patient and family education materials
- Importance of health literacy

Advising Patients About Patient Safety: Current Initiatives Risk Shifting Responsibility, Entwistle, Mello, Brennan, *Journal on Quality and Patient Safety, (Sept 2005)*

Transforming Culture

- Why before how. Philosophy is important, identify core values.
- Remain focused and start small and plan long term.
- Measure what matters. Don't get consumed with minutiae. Identify key benchmarks for success.
- Leadership actions/behaviors are key to develop culture, reinforce norms and allocate resources.
- Embrace patient safety culture shift: there is no doing without mistakes. Learn from it – intentionally move from shame and blame to openness and learning.
- Engage stories to make lessons more personal and powerful.

Quality is more than technical quality.

The patient's and family's experience can be a driver for quality improvement.

Change OF a System, Not Change IN a System

- Migrating patient and family involvement in improvement and transforming the care experience from an exception to an expectation.

- Paradigm shift: patient and families in an entirely new position within our operational and care structures.

"To wait for all the evidence is to finally recognize it through a competitor's product."

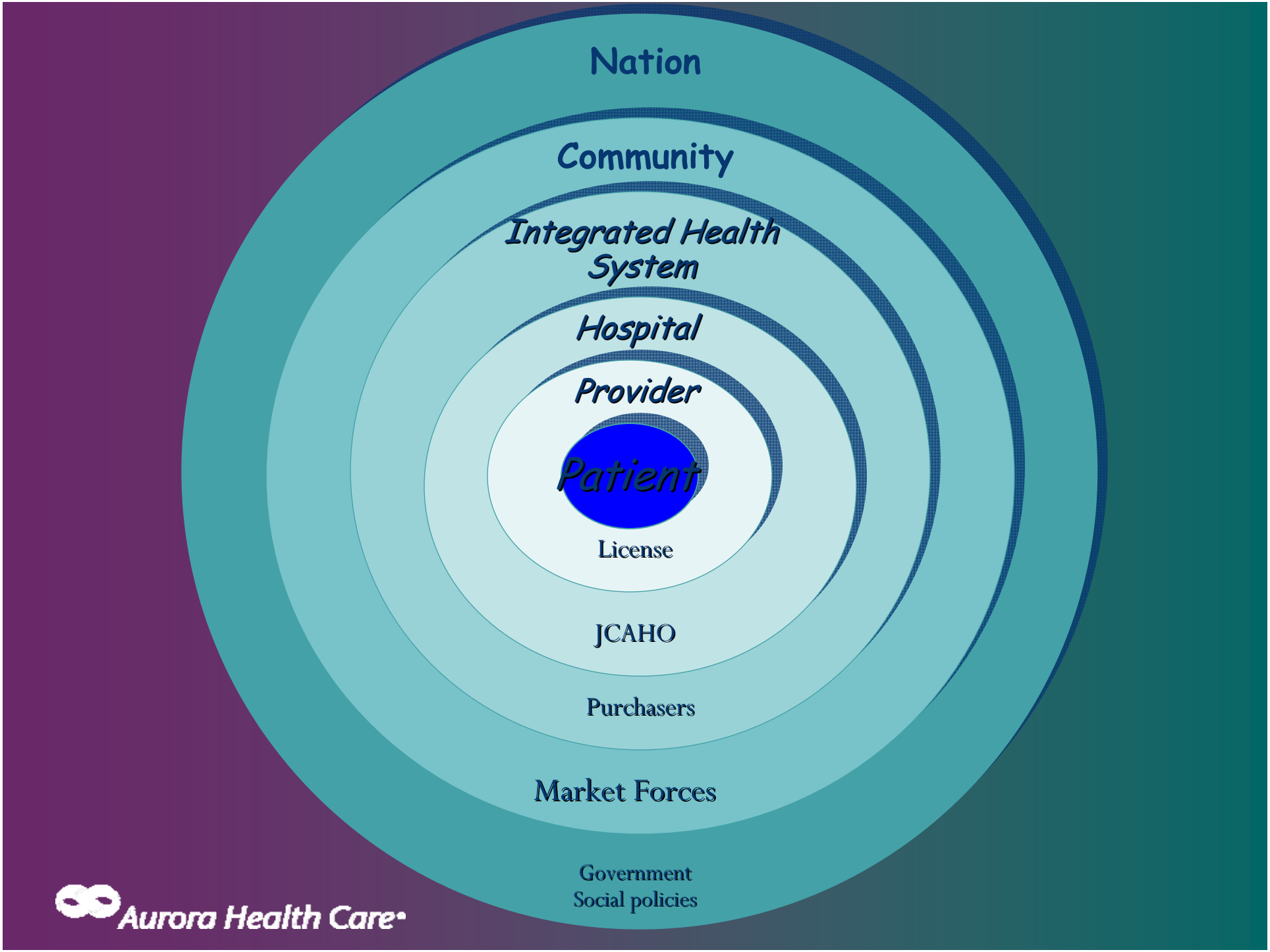
~David Whyte

Partners in Safety:
The Aurora Health Care Journey

Kathryn Leonhardt, MD, MPH

Patient Safety Officer

Aurora Health Care®



Aurora Health Care

Partners in Safety: Research

- Theory: Engaging consumers at the community level will improve safety
  - Patient-centered care
  - Community-based participatory research (CBPR)
- Goals/objectives:
  - Establish a ***community-based*** patient:provider advisory council
  - Identify and implement interventions to ***improve medication safety*** through out the community
- Partners
  - Consumers Advancing Patient Safety
  - Midwest Airlines
  - AHRQ grant support, 2005-2007

Partners in Safety

Walworth County Patient Safety Council

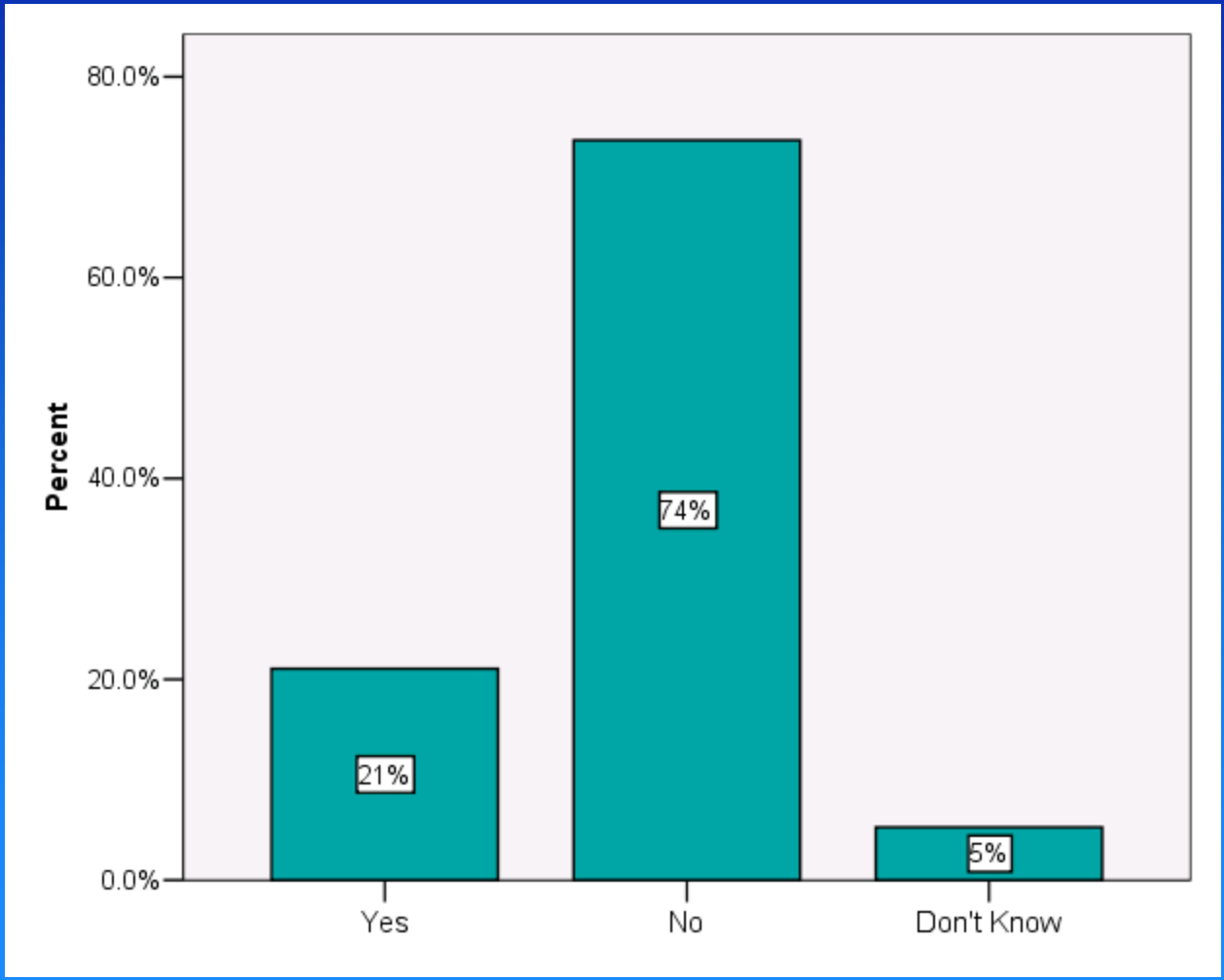
- 11 Patients/Caregivers and 12 Healthcare Providers
  - Patients, doctors, nurses, retail pharmacist, parish nurse, Medicare benefits specialist, social worker
- 5 Aurora Clinics and 4 Aurora retail pharmacies

Identifying the Problem: Formative Research

Q: How do you create an accurate medication list for patients 55 years and older in the outpatient setting?

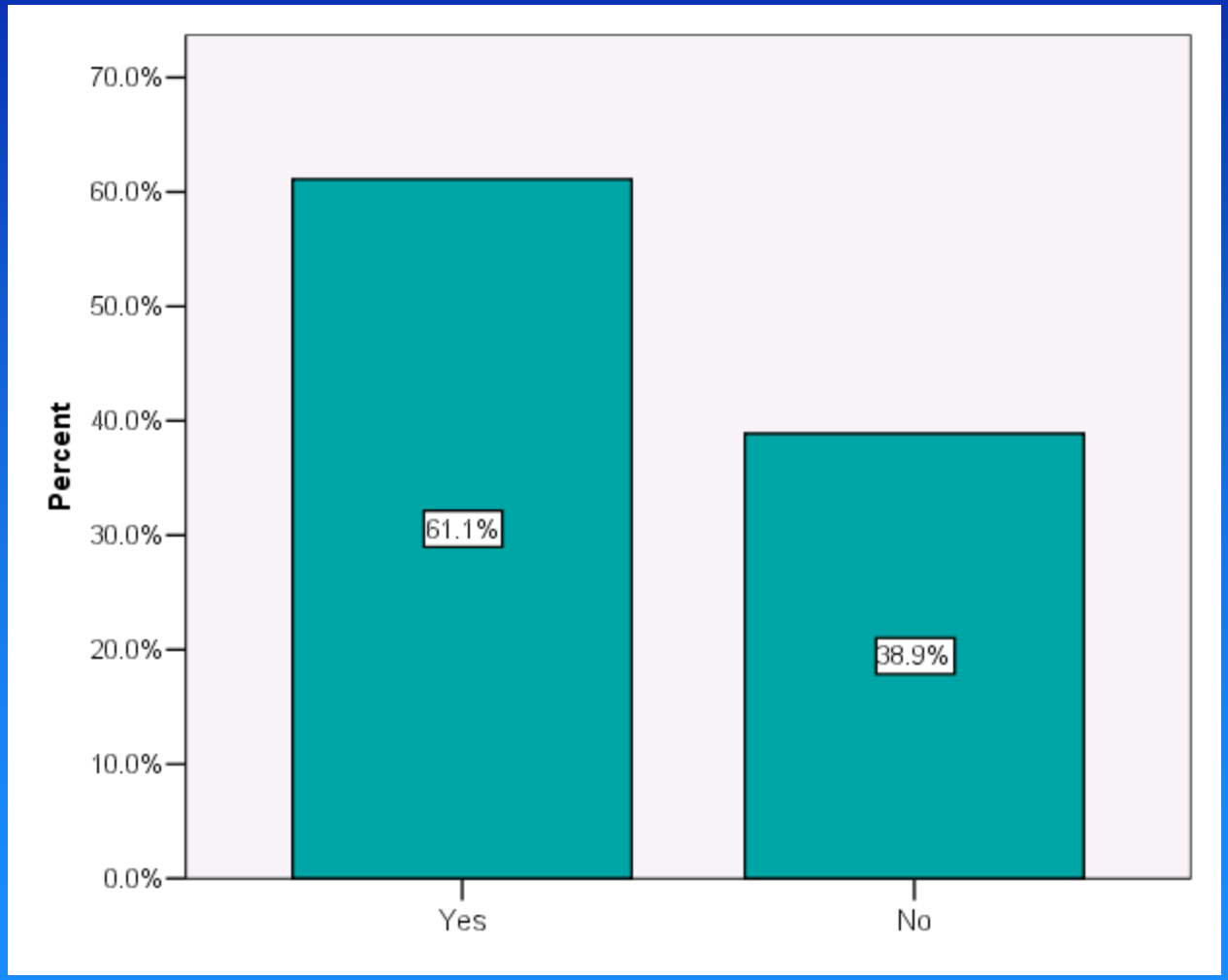
- (2) Focus groups: 22 patient participants
- Patient Interviews (n=21)
- Provider Interviews (n=21)
- Literature review on accurate medication lists in the outpatient setting

Identifying the Problem: Patient Perspective



Q: Does your physician ask you to bring in your medicines to your appointment for review?

Identifying the Problem: Provider Perspective



Q: Are your patients asked to bring in their current medications or list at each visit?

Developing Interventions: Engaging the Community

- Create the tools
  - Evaluations provided by 300 community members
- Enlist the consumers in the community
  - Active role of Advisory Council members
  - Use existing community programs and organizations
- Educate and disseminate

Medication Lists : 16,000

Medication Bags : 7,300

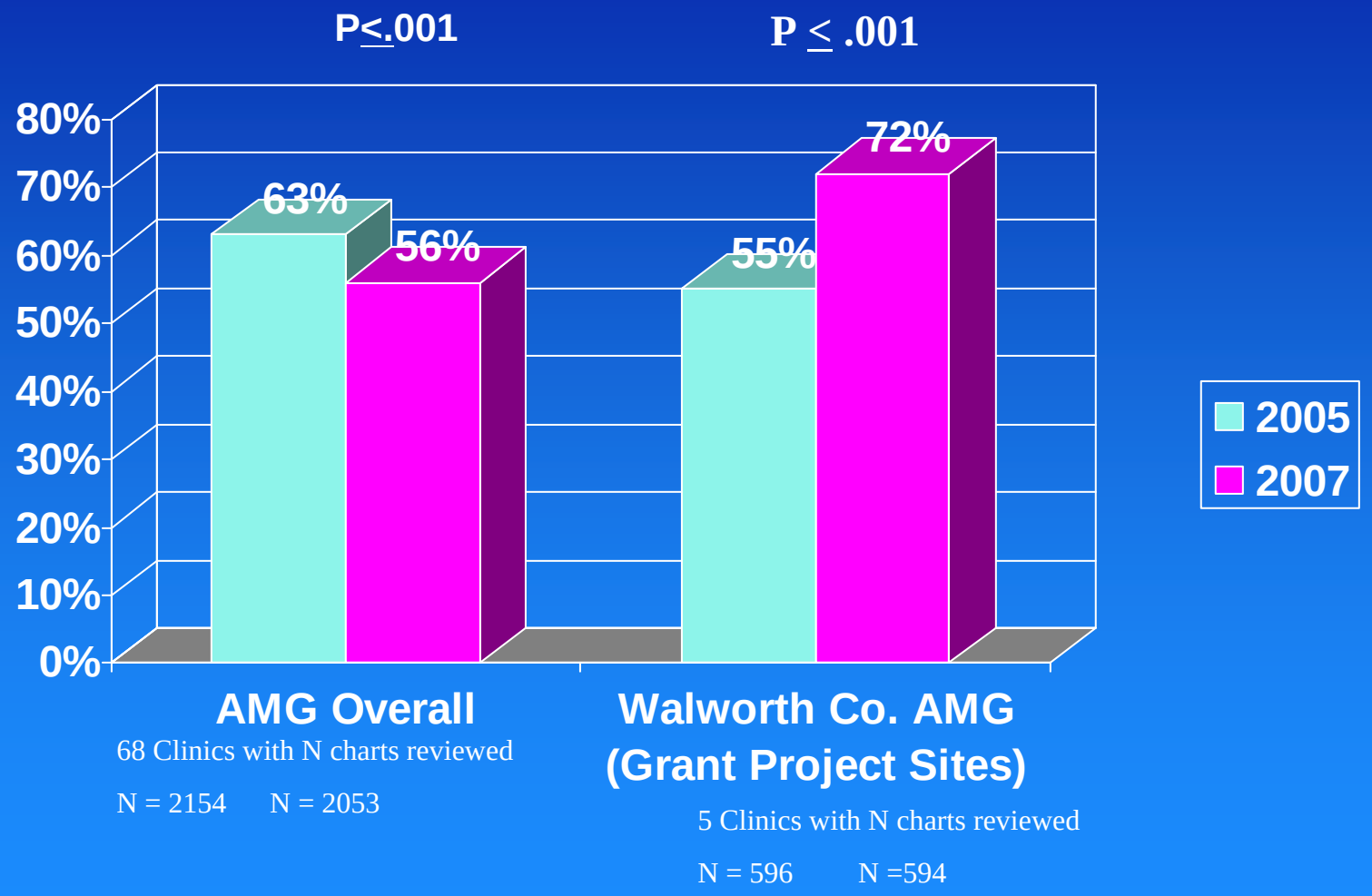
Community Education programs: 80+

Patient and Community Participants: 2,300

Developing Interventions:
Provider Interventions

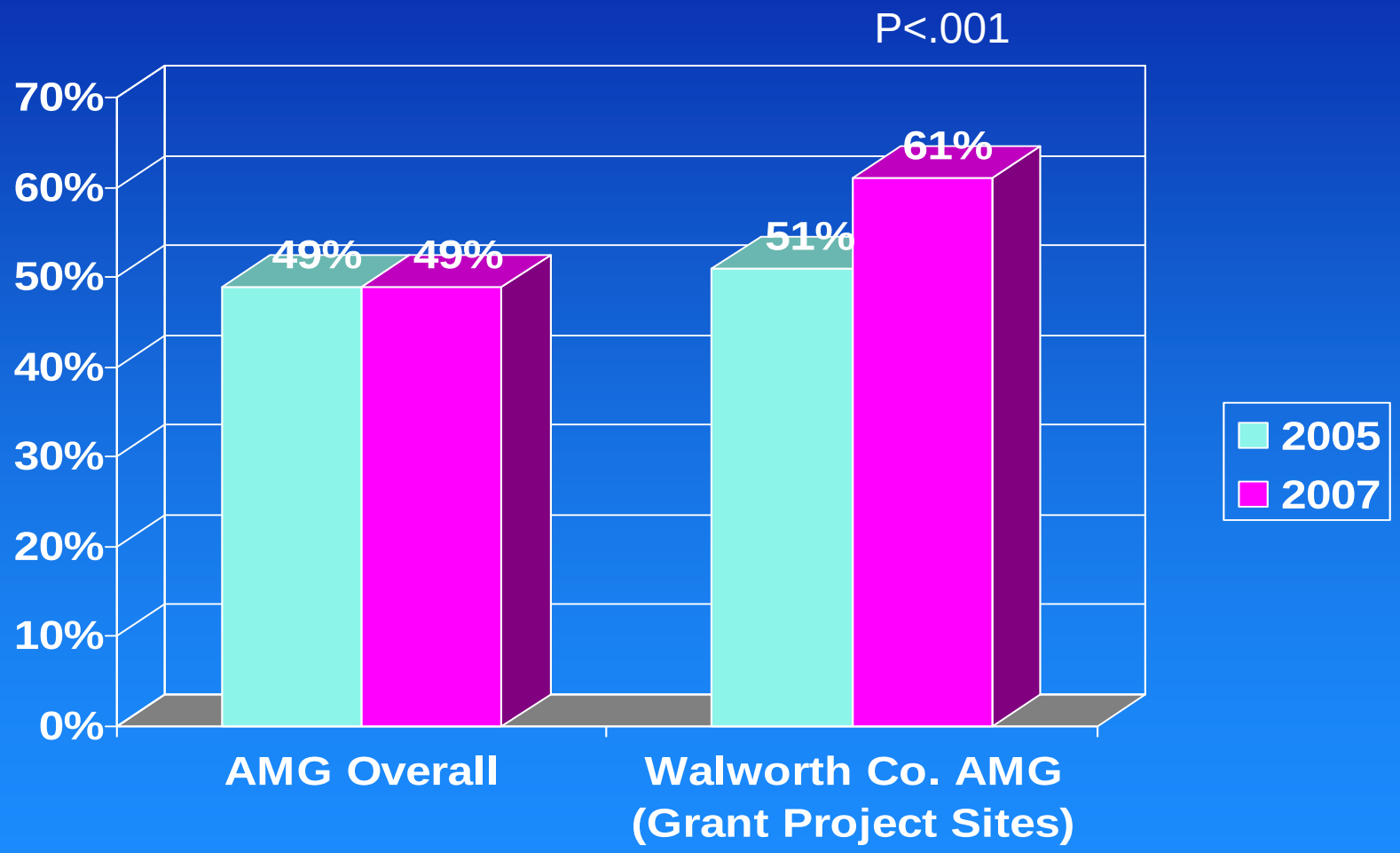
- Clinic Flow Analysis
  - Best practices identified
    - Reminder call/letter to patient; dictation process
  - Defined staff roles and responsibilities
- Forms revised
  - Standardization
- Education and training
  - Outside Speakers
  - Physician engagement through targeted data feedback

Measuring the Results:
Accurate Medication List



Accurate clinic medication list defined as: the clinic medication list contains the same list of prescription medications as the patient's list/bag of prescription medications

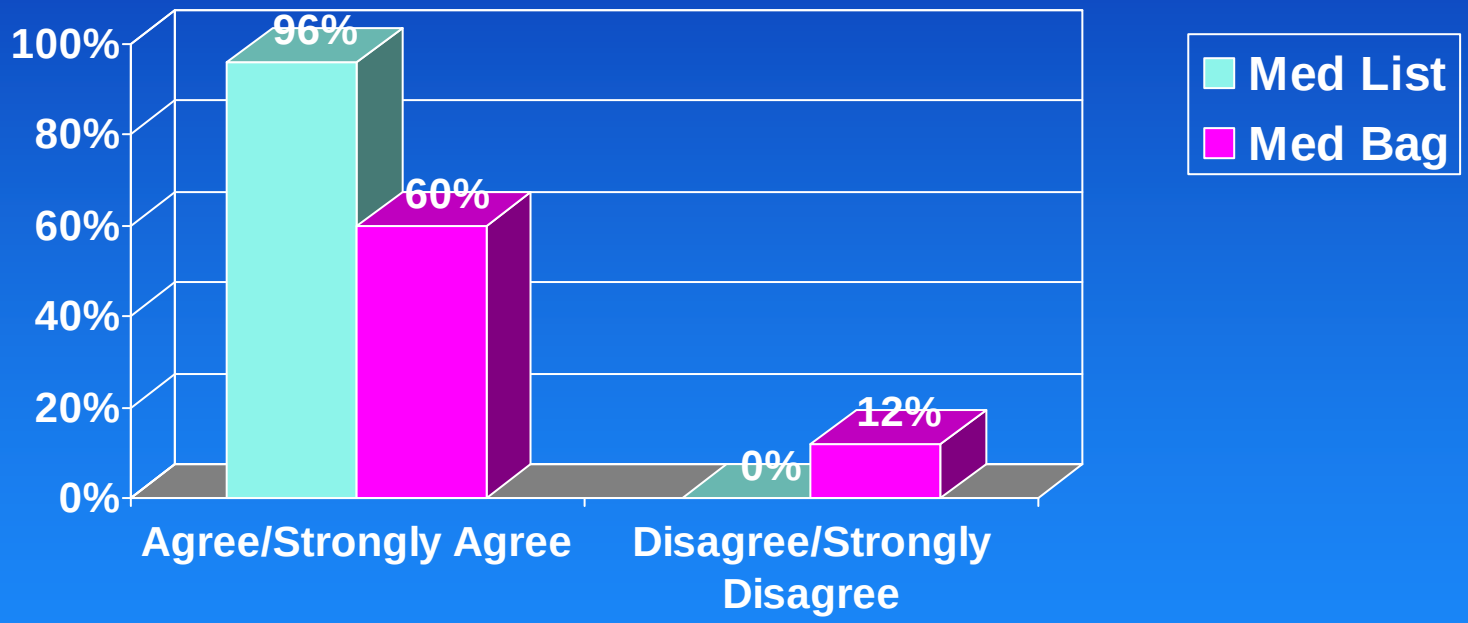
Measuring the Results:
Patient use of Medication Lists



2007: 31% used Partners in Safety list

Measuring the Results:
Provider perspective

The medication list/medication bag helped facilitate communication between you and your patients



Survey response rate 57% (52/92)

Partners in Safety
Dissemination and Replication

Integrating 'partners in safety' into organizational goals :

a. Patient-centered care
b. Patient safety
c. Regulatory requirements
d. Patient loyalty
e. Staff retention
f. Financial goals and incentives
g. Health promotion and education
h. Community engagement

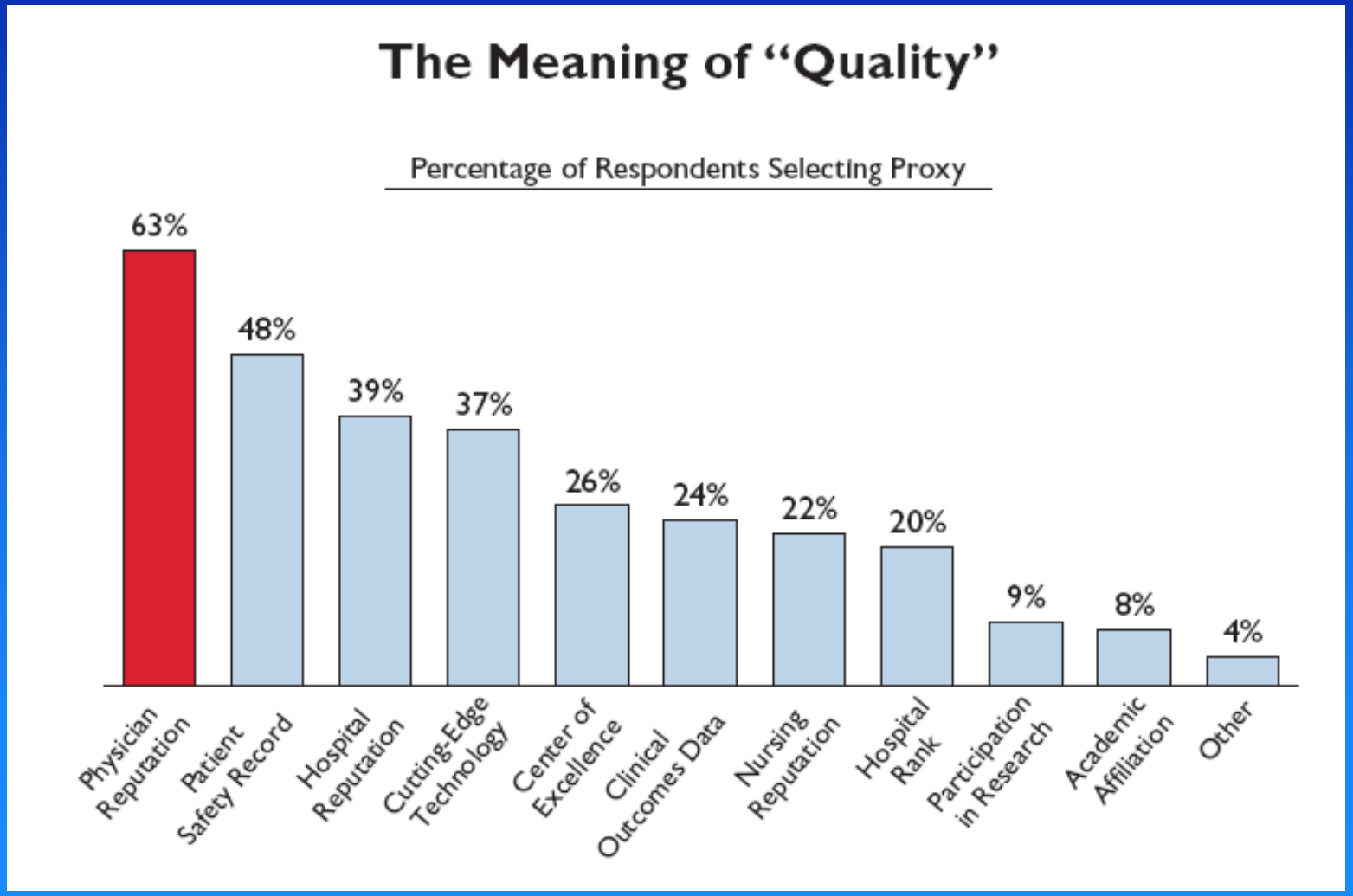
Partners in Safety
Dissemination and Replication

- Leadership support is the necessary (but not sufficient) first step
  - Patient safety is part of the organization's mission
  - Strategic plan built around 'patient at the center'
  - Board committee meetings begin with patient safety story

Partners in Safety
Dissemination and Replication

- Patient-Centered Care
  - Planetree philosophy
- Patient safety
  - Organizational structure and function
- Regulatory Requirements
  - Medication Reconciliation (TJC)
    - Patient survey questions regarding medication safety
  - NPSG #13: Patient involvement in own care for safety (TJC)
    - Patient/family educated/engaged in hand hygiene, fall prevention, RRT activation

Partners in Safety
Dissemination and Replication



The Advisory Board Co., 2007
"Drivers of Consumer Choice"

Partners in Safety
Dissemination and Replication

Behaviors that foster patient loyalty

Outcome of loyal patients

•Safety: Made patient feel safe from medical errors
- Didn't act bothered when asked for something
- Were decisive and confident
- Were proud to be working at the hospital
- Did not say negative things about other staff
- Were cohesive as a team
- Explained things well

Professionalism/ Clinical Excellence

- Were not condescending
- Responded to patient's needs quickly
- Were decisive and confident
- It was easy to do business with the hospital
- Listened carefully to me
- Treated me with kindness
- Asked about my emotional well being
- Helped me to bathroom when needed
- Showed compassion by using touch
- Managed my pain

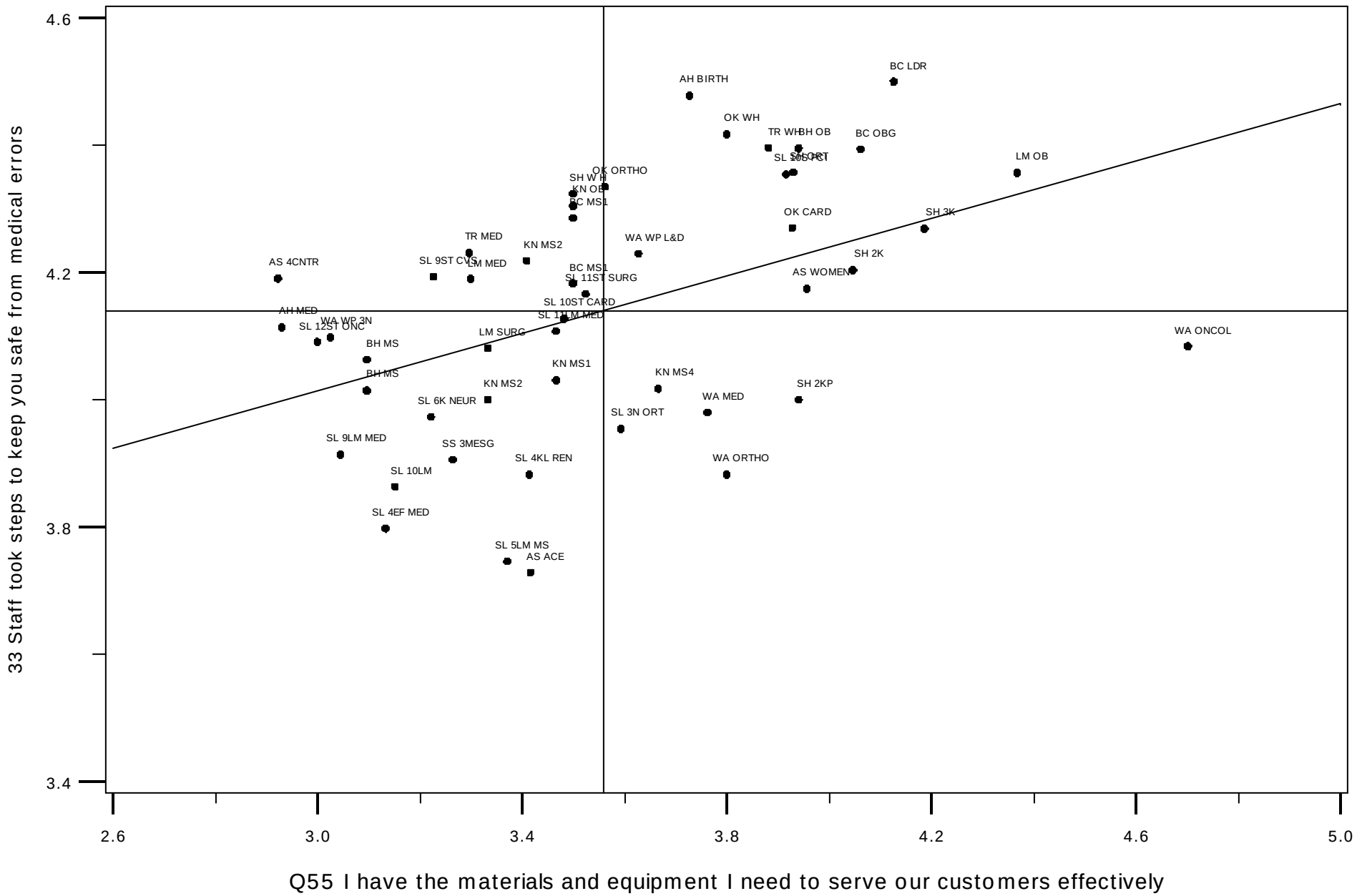
Patient Centered Experience

Loyalty

- Higher rating of quality of care
- Trust in doctors, nurses and staff
- Say good things about hospital
- Would recommend hospital
- Make extra effort to use hospital
- Switch PCP to use hospital
- Pay more per month for insurance to use
- Greater number of referrals to hospital
- More users of hospital in household

Aurora Health Care InPatient Satisfaction and Employee Pulse Survey Oct 2007

Y-Axis Patient Satisfation, X-Axis Employee Pulse, r=0.458 , p<=0.005



Partners in Safety
Dissemination and Replication

2008 Patient Safety Goals
Care Management Impact Score

Aurora Health Care

Medication Safety						
Improve medication management (TJC) – HOSPITAL	Measure: Patient leaves the hospital with a complete list of their medications Methodology: HCAHPS Survey July, Aug, Sept.	95 -100%	90 – 94%%	85 - 89%	< 85%	Hospitals
Improve medication management (TJC) – HOSPITAL	Measure: Complete medication reconciliation form within 48 hrs of admission Methodology: WHA CheckPoint chart reviews	96 and > (WI Benchmark)	90 – 95	85 – 89	< 85	Hospitals
Improve medication management (TJC) – CLINIC	Measure: Accurate medication list on the clinic chart Methodology: Patient interviews	80%	65 – 79%	50 – 64%	< 50%	AMG
Patient-Centered Care						
Increase the level of patient participation in quality/safety projects (Aurora Long Term Strategy) – HOSPITAL, CLINIC, AVNA, RETAIL PHARMACY	Measure: Patients participate in quality/safety projects Methodology: Number of projects with patient involvement	1 project per hospital 1 project - AMG 1 project – AVNA 1 project – Retail Pharmacy	-	-	0 projects	Hospitals AMG AVNA Retail Pharmacy

Partners in Safety
Dissemination and Replication

- Health promotion
  - Medical Home model in clinics
  - Patient-centered care: patient empowerment
- Community Engagement
  - Community programs through out Wisconsin

Partners in Safety
Lessons Learned

- Redefine- *and redesign*- the health care provider role
  - Patient-centered care is a collaborative relationship
  - Workflow and delivery systems will need to be modified
- Apply scientific rigor to your efforts
  - Evaluate, quantify, systems analysis, and measure
- Engage your community
  - Patient safety is a public health concern
- Align with your strategic goals
- Apply lessons from other fields: behavioral economics; marketing.

Remember: the patient is at the center of all we do

Resource Primer

Engaging Patients and Families in Patient Safety: A Primer
2008 AHRQ Annual Meeting-September 9, 2008

Classic Patient Safety Texts

- *Institute of Medicine Quality Chasm Series*
  - *To Err is Human: Building Safer Healthcare Systems (1999)*
  - *Patient Safety: Achieving a New Standard of Care* (2004)
  - *Keeping Patients Safe: Transforming the Work Environment of Nurses* (2004)
  - *Preventing Medication Errors* (2006)

- *Engaging Patients as Safety Partners* (2008) Spath PL, ed.

- *Partnering with Patients to Prevent Medical Errors* (2006) American Hospital Association

- *The Patient's Guide to Preventing Medical Errors* (2004) Karin Berntsen

- *The Patient Safety Handbook* (2004) Barbara Youngberg and Martin Hatlie

Key Sources for Tools, Techniques, Best Practices:
What Did the Doctor Say? Improving Health Literacy to Protect Patient Safety (2007) The Joint Commission

- American Hospital Association (http://www.aha.org)
- Consumers Advancing Patient Safety (http://www.patientsafety.org)
- Federal Government
  - Agency for Healthcare Research and Quality (http://www.ahrq.gov)
  - Veteran's Administration (http://www.va.gov)
- Institute for Family-Centered Care (http://www.familycenteredcare.org)
- National Patient Safety Foundation (http://www.npsf.org)
- World Alliance for Patient Safety (http://www.who.int)

Questions & Answers

Thanks!