

### Summary of Studies Evaluating the Efficacy of Patient Involvement as a Safety Improvement Strategy

Question	Study (Year)	Findings/Conclusions
Can patients recognize potential errors?	Kuzel <sup>1</sup> (2004)	Patients were able to identify problematic ambulatory care incidents, many which were linked to specific harms. The incidents included errors of omission and commission and occurred in all phases of primary care.
	Weingart <sup>2</sup> (2005)	Patients were able to retrospectively identify “problems,” “mistakes,” and “injuries” that occurred during hospitalization. Many of these patient-identified events were not captured by the hospital incident reporting system or recorded in the medical record.
Will patients be willing and able to participate in error prevention strategies?	Weingart <sup>3</sup> (2004)	Medical inpatient (or their surrogates) were willing to participate in an intervention designed to decrease adverse drug events. Caregivers found the intervention unobtrusive and beneficial at reducing medication errors. However, patients had a limited capacity to partner with clinicians due to the acuity or severity of their illness or cognitive impairment. Interventions that rely on patient and family participation may be more effective in populations with few comorbid illnesses (e.g. labor and delivery, elective surgery), with reliable family involvement (e.g. pediatrics), and with satisfactory functional status (e.g. ambulatory care).
	Entwistle <sup>4</sup> (2005)	Consumers should be involved in developing safety advisory materials. Distributing safety advisories to patients may not be sufficient to create partnerships; <i>active</i> encouragement and a supportive environment is needed. Rather than rely on patients to remember to act – systems should be designed to enable people to contribute appropriately by default.
	Hibbard <sup>5</sup> (2005)	Engaging patients in safety requires the use of language that is understandable and compelling. <i>Medical errors</i> is a more effective phrase than <i>patient safety</i> for communicating with the public. To have maximum impacts, educational approaches to engage patients should aim to increase both the patient’s sense of self-efficacy and understanding of the effectiveness of the recommended actions.

<sup>1</sup> A.J. Kuzel and others, “Patient Reports of Preventable Problems and Harms in Primary Health Care,” *Annals of Family Medicine* 2, no. 4 (Jul-Aug 2004): 333-40.

<sup>2</sup> S.N. Weingart and others, “What Can Hospitalized Patients Tell Us About Adverse Events? Learning from Patient-Reported Incidents,” *Journal of General Internal Medicine* 20, no. 9 (September 2005): 830-6

<sup>3</sup> S.N. Weingart and others, “Lessons from a Patient Partnership Intervention to Prevent Adverse Drug Events,” *International Journal for Quality in Health Care* 16, no. 6 (June 2004): 499–507

<sup>4</sup> V.A. Entwistle, M.M. Mello and T.A. Brennan, “Advising Patients About Patient Safety: Current Initiatives Risk Shifting Responsibility,” *Joint Commission Journal on Quality and Patient Safety* 31, no. 9 (September 2005): 483-494.

<sup>5</sup> J.H. Hibbard and others, “Can Patients be Part of the Solution? Views on Their Role in Preventing Medical Errors,” *Medical Care Research* 62, no. 5 (Oct. 2005): 601-616.

	Waterman <sup>6</sup> (2006)	Patients are generally comfortable with error prevention, however participation varies according to how comfortable they are with the recommended actions. For example, many feel comfortable asking about the purpose of their medication whereas they are less comfortable questioning caregivers about handwashing practices. Educational interventions to increase patients' comfort with error prevention will be necessary to help them become more engaged.
	Peters <sup>7</sup> (2006)	How much consumers worry about the possibility of a medical error is a strong predictor of whether they will take precautionary actions to prevent errors .An understanding of how worry influences a patient's preventive efforts will help in building communication strategies which will effectively engage them as vigilant partners in care.
Will patient involvement actually reduce errors?	Weingart <sup>8</sup> (2004)	Hospital nurses anecdotally reported that medication errors had been prevented because a medical inpatient or family member identified drug-related problems.
	Pames <sup>9</sup> (2007)	Ambulatory providers reported that in some situations it was patient vigilance (asking questions, seeking solutions) that prevented harm which could have resulted from a medical error.

<sup>6</sup> A.D. Waterman and others, "Brief Report: Hospitalized Patients' Attitudes About and Participation in Error Prevention," *Journal of General Internal Medicine* 21, no. 4 (April 2006): 367-70.

<sup>7</sup> E. Peters and others, "Why Worry? Worry, Risk Perceptions, and Willingness to Act to Reduce Medical Errors," *Health Psychology* 25, no. 2 (March 2006): 144-52.

<sup>8</sup> S.N. Weingart and others, "Lessons from a Patient Partnership Intervention to Prevent Adverse Drug Events," *International Journal for Quality in Health Care* 16, no. 6 (June 2004): 499-507

<sup>9</sup> B. Pames and others, "Stopping the Error Cascade: A Report on Ameliorators," *Quality and Safety in Health Care* 16, no. 1 (February 2007): 12-16.

## All Patients Are Not Created Equal

- Chronic care vs. episodic care

Patients with chronic conditions (and their families) who know about their condition, what to expect during a treatment episode and feel sufficiently empowered are more apt to speak up when any lapses occur.

Comments from a patient with diabetes: *They sent me home with a blood sugar of 446 and They forgot to give me insulin for high blood sugar.*<sup>10</sup>

While many patients could recognize a problem, some would not because of disability or illness.

- Age and sex variations

One study found that older people, especially older women, worry more about medical errors. The more a person worries about medical errors, the greater likelihood they will take strategic or preventive actions.<sup>11</sup>

Several studies have shown that women more frequently express concerns and negative emotions to their physician than do males.<sup>12</sup>

- National culture variations

When we talk about differences between cultures, we are speaking in generalities, and we must remember not to expect every patient to behave in a manner consistent with those generalizations in every situation. In addition, patients and family members often adapt their behaviors to suit their situations. Predicting a patient's attitudes and behaviors based on their nationality is imprecise, and it's better to learn each patient's beliefs and preferences when possible because they can differ from the national norm.

- Language

English is not the primary language for many patients. This makes using written materials to educate patients about their care or their role in maintaining safety a less effective method of communication. The verbal translation of information from English to another language may compromise the content of patient educational materials.

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<sup>10</sup> Weingart SN et al. Lessons from a patient partnership intervention to prevent adverse drug events *International Journal for Quality in Health Care* 2004; 16(6):499-507

<sup>11</sup> Peters E, Slovic P, Hibbard, JH, Tusler M. Why worry? Worry, risk perceptions, and willingness to act to reduce medical errors. *Health Psychol.* 2006 Mar;25(2):144-52.

<sup>12</sup> Street RL et al. Patient participation in medical consultations: why some patients are more involved than others. *Medical Care* 2005 Oct; 43(10): 960-969

- Literacy

Studies have shown that more educated patients are generally more active participants in their health care experiences.<sup>13 14</sup>

It is estimated that over 90 million adults in America have limited literacy. These individuals can identify words or read simple sentences, but cannot accurately and consistently locate, match and integrate information from newspapers, advertisements or forms. The majority of these individuals are born English-speaking Americans who did not complete high school. Brochures and other written information about the patient's role in patient safety will not be effective for communicating with low literacy patients. In addition, people with low literacy typically do not confide in practitioners that they have difficulties reading or understanding materials. They often feel embarrassed and do not want to be judged poorly.

Written materials about patient safety and the patient's role in reducing errors may need to be supplemented or replaced by verbal discussions and visual aids that illustrate key points. Eliciting questions and feedback from the patient will help practitioners assess their comprehension and engage them as willing participants in their care.

- Health Literacy

Health literacy refers to individual's ability to read, understand and use health care information to make effective health care decisions and follow instructions for treatment.

Patients with limited health literacy skills:

- Have less understanding of instructions
- Have less knowledge of their medical conditions and treatments

Clinicians interacting with patients/families with limited literacy skills:

- May not have the time (or may not take the time) to adequately explain instructions, medical conditions or treatments
- May discount or devalue views of patients or relatives

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<sup>13</sup> Beisecker AE, Beisecker TD. Patient information-seeking behaviors when communicating with doctors. *Med Care.* 1990;28:19–28.

<sup>14</sup> Street RL Jr, Voigt B, Geyer C, et al. Increasing patient involvement in choosing treatment for early breast cancer. *Cancer.* 1995;76:2275–2285.

**Days to a couple hours before your surgery...**

**Review all the information on the Consent Form before you sign it.**

You, or your surrogate, must sign a consent form before any surgery can take place. It should be written in words that you can understand. If you are not sure about anything, ask.



Many of your questions will be answered by reading the consent form. Here are some good questions to ask in order to better understand your surgery:

1. What is the name of the surgery that will be done?  
\_\_\_\_\_
2. Where or what body part will you be operating on? (Write down if it is the left or right side, if needed.)  
\_\_\_\_\_  
\_\_\_\_\_
3. Are there any alternatives to surgery?  
\_\_\_\_\_  
\_\_\_\_\_
4. What are the risks of this surgery?  
\_\_\_\_\_  
\_\_\_\_\_

5. What is likely to happen if I don't have the surgery?  
\_\_\_\_\_  
\_\_\_\_\_

6. Who is in charge of the surgical team? (Write the name here.)  
\_\_\_\_\_  
\_\_\_\_\_

7. About how long will it take to recover after the surgery?  
\_\_\_\_\_  
\_\_\_\_\_

**The doctor or other member of the surgical team will make a mark with a pen on the part of your body where the surgery will happen. This should be done BEFORE you go into the operating room.**

Some doctors will sign their name or initials. Some doctors will make an "X" or "Yes" mark on the correct body part.



Staff will mark the place to be operated on

Check that the mark does not rub off. It will be very important for the doctors and nurses to see the mark while you are asleep just before the surgery. Tell your doctor or nurse if the mark rubs or washes off before the surgery.

**An hour, or less, before the surgery...**

**While you are still awake, a doctor or nurse will ask you to say your name, your social security number or birth date, and the part of your body that will be operated on.**

Don't be alarmed by these questions; your doctor knows who you are. This is how they make sure they have everything right.



Say your name and SS# and where the operation will be

**Just before the surgery begins...**

**Just before the surgery begins, everyone in the operating room will take a short "time out" and check for the last time that they have the right patient and are doing the right operation on the right body part. You may be asleep for this part.**



"Time out" just before starting the surgery

The doctors and nurses in the VA are taking these important steps to make sure that everything goes as planned for your surgery.

Source: VA National Center for Patient Safety, 2006

**Patient/Family Engagement Self-Assessment**

Are you personally ready to engage patients and family in improving safety?

Instructions: Using the scale to the right, check the response that describes your level of agreement with each of the following items:	Strongly Disagree	Slightly Disagree	Neutral	Slightly Agree	Strongly Agree
1. I believe it is important to engage patients and families in preventing medical errors and adverse events.					
2. I believe that patient and family perspectives and opinions are as important as professionals.					
3. I believe that patients and families bring a safety viewpoint to the care team that no one else can provide.					
4. I consistently let patients/families know that I value their insights about safety.					
5. I work to create an environment in which patients and families feel supported and comfortable speaking up when they have concerns.					
6. I listen respectfully to the safety concerns of patients and their family members.					
7. I clearly state to patients and families what they can do to prevent medical errors and adverse events.					
8. I feel comfortable telling patients and families that caregivers might make a mistake or act unsafely.					
9. I feel comfortable asking patients and families to speak up if they think a caregiver has made a mistake or is acting unsafely.					
10. I know that all patients and family members cannot serve as safeguards in their care and do not place unrealistic expectations on individuals unable to participate in preventing medical errors and adverse events.					

Source: Spath PL and Swain P. "Creating Opportunities for Patient Involvement." Chapter in: *Engaging Patients as Safety Partners: A Guide for Reducing Errors and Improving Satisfaction* (Chicago: Health Forum Inc. 2008).

## Free Online Consumer-Oriented Safety Resources

- National Patient Safety Foundation ([www.npsf.org](http://www.npsf.org))
- Agency for Healthcare Research and Quality ([www.ahrq.gov](http://www.ahrq.gov))
- Institute for Safe Medication Practices ([www.ismp.org](http://www.ismp.org))
- National Council on Patient Information and Education ([www.talkaboutrx.org](http://www.talkaboutrx.org))
- American Academy of Orthopaedic Surgeons (<http://orthoinfo.aaos.org>)
- National Council on Patient Information and Education ([www.talkaboutrx.org](http://www.talkaboutrx.org))
- The Minnesota Alliance for Patient Safety ([www.mhhp.com](http://www.mhhp.com))
- Madison (WI) Patient Safety Collaborative ([www.madisonpatientsafety.org](http://www.madisonpatientsafety.org))
- Ohio Patient Safety Institute ([www.ohiopatientsafety.org](http://www.ohiopatientsafety.org))
- AORN Patient Safety First ([www.patientsafetyfirst.org](http://www.patientsafetyfirst.org))
- My personal health care – sponsored by the American Health Information Management Association (<http://www.myphr.com>)
- Johns Hopkins Hospital Patient Safety Poster ([http://www.hopkinshospital.org/patients/patient\\_safety.html](http://www.hopkinshospital.org/patients/patient_safety.html))
- Patient education materials on hand washing developed by Kaiser Permanente (<http://nursingpathways.kp.org/national/quality/infection/generaltopics/handhygiene/index.html>)
- Society for Healthcare Consumer Advocacy of the AHA. (<http://www.shca-aha.org>)
- Consumers Advancing Patient Safety (<http://www.patientsafety.org>)
- Partners in Quality: Taking an Active Role in Your Health Care – brochure distributed at Albert Einstein Healthcare Network. (<http://www.einstein.edu/aboutus/quality/article9807.html>)
- Hospital Hints – includes safety tips (Developed by the National Institutes on Aging specifically for seniors) (<http://www.niapublications.org/agepages/hospital.asp>)
- *How to Develop a Community-Based Patient Advisory Council*, a toolkit that can assist health care organizations to expand patient safety partnerships with consumers. (<http://patientsafety.org>)

## Consumer-Oriented Video Presentations

- American Society for Healthcare Risk Management online video on steps consumers can take to get involved in their own health care. (<http://www.ashrm.org/ashrm/foundation/emmisafety/Emmi.html>) (flash player required)
- Sentara Healthcare patient safety video (<http://www.sentara.com/Sentara/PatientVisitorInfo/PatientSafety/SafetyTips/>)
- Johns Hopkins Hospital patient safety partnership video ([http://www.hopkinshospital.org/patients/patient\\_safety.html](http://www.hopkinshospital.org/patients/patient_safety.html))
- *Questions are the Answer: Get More Involved in Your Healthcare*, sponsored by the Agency for Healthcare Research and Quality (<http://www.ahrq.gov/questionsaretheanswer/>)
- *Things You Should Know Before Entering The Hospital* is a patient safety video produced by Four Leaf Enterprises, featuring Ben Hollis of public television's Wild Chicago and Wild Illinois. Cost: \$29.95 plus shipping. For ordering information go to: [www.PatientSafetyVideo.com](http://www.PatientSafetyVideo.com); (773) 480-5858. Partnership for Patient Safety has developed a facilitator's guide to accompany the video. This can be downloaded free at: [http://www.p4ps.org/facilitators\\_guide.asp#](http://www.p4ps.org/facilitators_guide.asp#)

**Additional Resources**

- Large list of sources of information for consumers and health care professionals ([www.brownspace.com/safecare.htm](http://www.brownspace.com/safecare.htm))
- Spath PL. *Engaging Patients as Safety Partners: A Guide to Reducing Errors and Improving Satisfaction* (June 2008) Chicago: Health Forum, American Hospital Association
- *Strategies for Leadership: Improving Communication with Patients and Families*. (2003) Chicago: American Hospital Association
- Rundle, A., Carvalho, M., Robinson, M.(eds.) *Cultural Competence in Health Care* (2002) San Francisco: Jossey-Bass.
- Spath, P.L. "Can You Hear Me Now?" *Hospitals & Health Networks*, Dec. 2003 ([www.hospitalconnect.com/hhnmag/](http://www.hospitalconnect.com/hhnmag/))
- Wachter, RM, Shojania, KG. (2004) *Internal Bleeding: The Truth Behind America's Terrifying Epidemic of Medical Mistakes*. New York: RuggedLand Books.
- Delbanco T, Berwick DM, Boufford JI, et al. Health care in a land called PeoplePower: nothing about me without me. *Health Expert* 2001;4:144-150. Available at <http://www.aeqz.de/english/english/literature/pdf/dellbank2001.pdf>. Accessed June 30, 2005.
- The Joint Commission. *Patients as Partners: How to Involve Patients and Families in Their Own Care*, 2006
- Delbanco T, Augello T. When things go wrong: voices of patients and families. Cambridge, MA: CRICO/RMF, 2006 (DVD).
- B. Johnson and others, *Partnering with Patients and Families to Design a Patient and Family-Centered Health Care System*. Bethesda, MD: Institute for Family-Centered Care, 2007.
- A. Coulter and J. Ellins, "Effectiveness of Strategies for Informing, Educating, and Involving Patients," *British Medical Journal* 335, no. 7609 (July 7, 2007): 24-27.