

Recommendations

These recommendations take into consideration testimony originally coded to 14 (Education of Consumers)¹, 20 (Patient Inclusion)², and 30 (Consumer/Patient Advocacy)³, and 27 (Advocacy)⁴ as well as other sources.

- R1. The Michigan Partnership for Safe Health Care, in collaboration with health-care delivery organizations and professionals, insurers, employers and professional associations, should establish an ongoing statewide patient safety awareness and education campaign for health-care consumers and providers to increase health literacy; empower consumers, patients and their families/caregivers and advocates to better assume their roles as partners in the health-care encounter; and to build community support for system approaches and strategies that reward and promote safe, quality care. Specifically, this effort should:
 - R1a. Document consumer concerns and needs for information.
 - R1b. Develop and/or disseminate information, tools, and resources for decision-making about health care and providers and as well as guidelines on their use.
 - R1c. Disseminate information about existing and forthcoming safe care initiatives in Michigan's health-care delivery organizations.
 - R1d. Coordinate educational efforts to consumer/patients with programs targeting clinicians.
 - R1e. Consider developing health-care consumer and patient safety programs for primary and secondary school curricula.
 - R1f. Assess the impact and progress over time of educational programs.
- R2. Health-care practitioners and the organizations in which they work should develop or adopt policies, practices and programs that incorporate the values, needs and preferences of patients and their families in the care process, and that promote open and clear communication between patients/families and health professionals about health issues, treatments, patient safety concerns, and adverse events, should they occur. In particular, health-care delivery organizations should:
 - R2a. Facilitate teamwork and patient advocacy, where patients/families are active members of the team involved in decisions about care.
 - R2b. Offer programs/training to help providers, patients, and families learn effective communication skills.
 - R2c. Offer staff training in cultural competency.
 - R2d. Establish guidelines for disclosing adverse events and medical errors to patients/families and supporting both patients/families and providers in the aftermath.
 - R2e. Support the patient/family role in error prevention by encouraging patients to communicate openly with health-care professionals and staff, and by providing tools and opportunities for patients to comment on safety issues.
 - R2f. Incorporate patient safety training as part of annual staff competency programs.
 - R2g. Adopt patient education materials and communication strategies tailored to varying levels of health literacy, with special attention paid to vulnerable populations, such as those with low literacy, limited English, or cognitive impairment.
 - R2h. Establish guidelines to make available to patients information from the medical record about their health and health care.

- R3. All health-care planning and delivery agencies and organizations should find ways to embed the consumer/patient voice in the structure and process of designing safe care.
 - o R3a. State-level bodies and organizations involved in developing policies or designing systems, facilities, and programs in patient safety should include consumer/patient/family representatives as part of their composition.
 - o R3b. Health-care delivery organizations should appoint consumers/patients as well as representatives of community and employee groups to their boards.
 - o R3c. Health-care delivery organizations and the Partnership should develop consumer/patient advisory councils to provide input on all topics related to the delivery of safe, patient-centered care.
- R4. The Partnership, in conjunction with appropriate state agencies, health-care delivery organizations, professional associations, health-care consumer groups and other concerned parties, should develop a range of alternative pathways to resolve disputes and address grievances when medical errors occur. These alternative pathways should encourage open communication between health-care professionals and their organizations, and patients and their families, and should seek just and equitable redress for aggrieved parties.

Rationale

Finding ways for the voice of health-care consumers, patients and their families/caregivers to become a legitimate and ongoing part of the structure and process of health-care delivery must be at the heart of all efforts to ensure safe care, at the state level and within all health-care delivery organizations and settings.

There is strong support among Michigan patient safety stakeholders, as well as national bodies such as the Institute of Medicine, JCAHO, National Quality Forum, National Patient Safety Foundation, and others, for bringing patient-centered care into the patient safety agenda, where the provider-patient relationship is reframed as a partnership with shared decision-making, open communication, and where patients have an active role in the process of care as well as error prevention and safety design.^{5 6 7 8 9 10} Based on both testimony and literature, attention should be focused on strengthening the consumer/patient voice in four main areas: patient safety education; the provider-patient/family relationship; the design and planning of safe care processes; and dispute resolution.

Educating consumers and patients about patient safety is recognized as a key factor in reducing patient harm. Patients who know what they need, can make their preferences known, and play an active role in their care are more likely to experience positive results and be satisfied with the care they received.¹¹ When patients are unable to read, understand and act on information necessary to obtain health care, they are at greater risk for poor outcomes, inappropriate hospitalizations, greater health costs and a higher incidence of medical errors.¹²

Effective communication underlies many concerns. Poor physician-patient communication is considered one of the root causes of medical error.¹³ Patients have a right to know and understand their treatments, the services they receive, and any procedures or medical devices used in their care. JCAHO includes these directives in their standards¹⁴ and submitted testimony acknowledges them.¹⁵ Patients, however, often feel that physicians don't listen to them or talk over them and studies on physician communication have documented this disconnect.^{16 17} Patients may end up discouraged and provide incomplete histories, leaving the clinician with insufficient information and opening a door to errors. Other factors contributing to poor communication include using medical jargon or an inappropriate level of language; cultural competence deficiencies among staff; 'cross-cultural dyads,' where a provider's cultural background is significantly different than that of the patient;¹⁸ and patients who may be unaware

of their health status or have trouble remembering and reporting details accurately and in a timely manner. Closing communication gaps involves addressing these factors, building greater public awareness of patient safety, and, ultimately, working toward a shared vision of the environment in which safe care can unfold, where health care is conducted as a partnership based on trust and open communication.¹⁹

Despite wide acknowledgement of the important role of patients and families in error prevention and early detection,²⁰ it is clear that they cannot carry out this role unless health-care delivery organizations and providers help them understand it, invite them to join in designing safe care policies and programs, and work to create an environment that supports questions and provides specific mechanisms to solicit reports and provide feedback.

Encouraging open and honest dialogue between clinicians and patients when errors occur is a very important part of the communication package. Patients want to know what happened and why, how to manage their care as a result, and how to prevent a similar incident from happening in the future. Families look to their caregivers for comfort and support—and an apology. This level of openness is by far the exception rather than the rule, despite an ethical obligation to disclose and JCAHO's requirement that sentinel events and other unanticipated outcomes of care be reported to patients and their families when appropriate.²¹ While fear of litigation is still the norm in most care settings, there is a growing awareness that open communication can benefit the physician-patient relationship. Some medical centers are encouraging their physicians to disclose errors and apologize and several states have passed legislation protecting physicians from having apologies used against them in the courts.²² Full-disclosure approaches such as "Sorry Works!"²³ and the VA's humanistic risk management are gaining ground. Other alternatives to dispute resolution are being explored through demonstration projects, including the recently introduced Fair and Reliable Medical Justice Act.²⁴ Equally important is the potential that apologies may have a cost benefit by reducing the frequency of litigation and the level of pay-outs.

Evidence for harm reduction

Assessing the impact of patient-centered care on patients and their safety is a difficult task. Evaluations of the effect of patient-centered care on many patient safety outcomes, such as medication errors and other types of errors, patient falls, clinical outcomes, and readmission rates are infrequent, but there are some studies with positive indicators, particularly for patient satisfaction.^{25 26} There is also some evidence that in the ambulatory setting, patient-centered care can "decrease litigation, decrease the likelihood of unnecessary testing, increase patient compliance, and improve outcomes," particularly patient satisfaction.²⁷

The evidence is less clear for acute care settings. Success appears to be measured in large part by the degree to which the patient's voice has been integrated into the infrastructure of the organization.²⁸ A recurring theme is emphasis on sustaining the process, rather than reaching a measurable outcome. As expressed by one of the leading proponents of patient-centered care, "Engaging patients must be a mindset, not a program."²⁹

The experience within the VA system with humanistic risk management and full disclosure in the event of injury or medical error, where patients' interests come first, suggests that this approach may yield positive financial benefits to hospitals by avoiding lawsuit preparation, litigation, court judgments and trial settlements.³⁰ However, the unique characteristics of the VA system, its patients, and the legal status of its providers makes it difficult to generalize the VA experience to other acute care settings.³¹ Other benefits to health-care organizations may be improved public perceptions and increased market share.

Assessment

Advantages

- Consumers and patients who are educated and involved in their care are more likely to have better health outcomes and be more satisfied with their care.
- Many tools, strategies and examples of successful efforts that involve patients and families in their care are available for Michigan health-care organizations to build on. Many do not require extensive resources, only the willingness and resolve to carry through with implementation.
- There is some evidence of financial benefits to health-care organizations that engage in disclosure of medical errors to patients.
- Michigan will join the forefront of a national movement to incorporate patient-centered care into the patient safety agenda, lending momentum and support to efforts already underway in the state.

Barriers

- Changing provider/organizational mindsets: Efforts in this area may be met with resistance from health-care personnel, who may be reluctant to share information and treat patients as partners; feel challenged, threatened, and fear lawsuits; or believe that involving patients will take more time. Yet patients cannot be partners if providers/organizations are not willing to listen. Success with building patient-centered care depends on success in building a culture of safety within health-care settings. Both depend on strong support from leadership in adopting these philosophies, implementing tools at all levels of an organization, and staying the course over time.
- Changing consumer/patient mindsets and habits: Efforts may be met with reluctance or discomfort with taking an active role in their care. Cultural barriers and low levels of health literacy for certain population groups also present barriers.
- A greater role for consumers/patients in error prevention as well as progress on alternate means of dispute resolution or injury compensation both rely on the success of measures to safeguard data—measures which are necessary precursors to disclosure or open discussion of errors and adverse events.³²
- Changing mentalities about medical errors: Moving from blame to shared vision will not be easy.
- Change will be slow, with outcomes difficult to define and measure.

Additional comments and concerns

- To avoid duplication and to leverage work underway or accomplished elsewhere, it will be important to coordinate state-level strategies, in consumer education for example, with similar activities at the national level.

Implementation

Further research

- The process and effects of patient-centered care on patient outcomes and safety are poorly understood. Outcomes of particular interest include medication errors, the incidence and severity of falls, clinical outcomes, readmission rates, and risk management. Studies are needed in all health-care settings—ambulatory, acute, and long-term care facilities as well as home care.³³

- Further research is needed to examine the relationship between health disparities and patient safety.³⁴

Legislation and/or administrative rules

- A greater role for consumers/patients in error prevention as well as progress on alternate means of dispute resolution or injury compensation rely on the success of measures—legislative and other—related to safeguarding data. These measures are logical and necessary precursors to disclosure or open discussion of errors and adverse events.³⁵
- As alternate options to litigation are explored to resolve disputes around medical error, one possibility is a hospital/medical grievance commission, patterned after the Attorneys Grievance Commission.³⁶

Resources

- No specific requests for resources were made.

Incentives

- Public and private third-party payers, health plans, purchasers and others should design financial incentives, such as pay-for-performance, as well as non-financial incentives, such as a public recognition program, to reward high-performing providers and encourage Michigan citizens to use the best providers and treatments.³⁷
- The Partnership should consider using similar non-financial incentives (e.g. public recognition awards) to reward health-care organizations that succeed in bringing the consumer/patient voice into their structure and processes in meaningful ways.

Specific steps and target dates

Following adoption of these recommendations, the following steps will take place.

- Within 9 months, the Michigan Partnership for Safe Health Care will convene the first of a series of summits of health-care stakeholders to assess current involvement of consumers/patients/families in the state and identify a core set of activities designed to accomplish the recommendations set forth above.
- Within 12 months, the Partnership will conduct an inventory of consumer/patient/family involvement programs and strategies, focusing in particular on those that have proven successful.
- Within 18 months, the Partnership will develop and promote a Web site containing information about, and links to, these successful programs and strategies. The site will include educational materials applicable for consumers/patients/families, health-care professionals, and health-care organizations.
- Within 24 months, the Partnership will begin implementing a public awareness campaign building on the successful models identified during the inventory process.

Testimony overview

Summary

The patient-centered care recommendations are based on 31 recommendations submitted under the codes of Education of Consumers, Patient Include, Consumer/Patient Advocacy, and Advocacy by a total of 27 informants representing consumers (10), professional organizations (6), providers (2), employers (1), insurers (2), educators (1), hospitals (2), and private health-care organizations (3).

Key findings

Education of Consumers:

- Agreement across stakeholders on the need for more open communication between patients and providers and from health-care organizations to the public about the safety efforts they are engaged in and how they are doing.
- Part of an educational campaign should be building knowledge among consumers, patients, and their families about their role in patient safety.
- Need to work with caregivers as well as patients, employees as well as providers and clinicians, across all care settings.
- Education campaigns need to be an ongoing process, not one-time shots.
- Educating consumers is seen as key component of patient safety.
- Low levels of health literacy are a significant problem and can contribute to errors.

Patient Inclusion:

- Patients and families need and want to be included in decisions about their own care.
- Patient and families have a need and a right to be informed of all aspects of their care, including errors, should they occur.
- Patients and families have an important role to play in error prevention.
- Patients, families and providers alike need help in communicating information to each other to promote safety and quality of care.

Consumer/Patient Advocacy and Advocacy

- The role of patients and families in decisions about care in general and patient safety in particular is often unrecognized and marginalized.^{38 39 40}
- Patients are often assumed to be—and treated as—passive victims of errors, rather than active partners “capable of understanding and contributing to risk management, quality improvement and communication activities.”^{41 42}
- Consumers, patients and their families are angry and disappointed at the lack of support—and especially the lack of accountability—by providers and hospital administrators when medical errors occur.^{43 44}
- Patients and their families are frustrated at the lack of alternate pathways for conflict resolution, other than litigation, when errors do occur, and they are bewildered as well as frustrated with the variability in compensation.⁴⁵

Review Panel Round One

Scoring summary

In Round One, the Review Panel was asked to score each recommendation area on a scale of 1 to 5, where 5=extremely viable, 4=very viable, 3=somewhat viable, 2=potentially viable with changes, and 1=not viable for this project. Average scores for relevant recommendations considered in Round One:

- Education of Consumers: 3.4 (range 2-5)
- Patient Inclusion: 4.1 (range 4-5)
- Consumer/Patient Advocacy: 4.2 (range 3-5)

Notes

Suggestions and concerns raised by Review Panel members after Round One have been addressed in the Round Two presentation.

Education of Consumers:

- An evaluation component was added to the set of aims and tasks for the education effort.
- Patients' caregivers and advocates were added to the language of the recommendation.
- Several panel members felt that to effect change it was important to link patient and consumer education with provider education, by conducting simultaneous efforts or programs, for example. This was addressed by adding an item to the set of aims and tasks for the education effort under R1. It should also be kept in mind that provider education is covered under another set of recommendations (see M: Professional Education).
- To address the concern with building the health literacy of future generations, an item on developing curricula for primary and secondary schools was added.

Patient Inclusion:

- Panel members were very keen on this recommendation. Specific feedback included:
 - o "A very important recommendation, crucial to include consumer of care."
 - o "Support of this [recommendation] will go a long way in helping to change [the] mindset of health professionals."
 - o "Patient advocacy and patient involvement in making care safe is crucial. This approach I believe holds great promise and is relatively inexpensive compared to other recommendations. Would help [the] 'balance process' in the hospital-physician-patient triad."
- Most panel members also felt strongly about avoiding prescriptive language on what specific programs or strategies organizations should adopt. Accordingly, two items from Round One were removed; one called for health-care organizations to designate patient advocates and another called for the adoption of health-care passports.
- Patients' families were added to the language of the recommendation.

Consumer/Patient Advocacy:

- There was consensus among panel members that consumers need to be represented in advisory councils and on boards of all health-care organizations, not just non-profit hospitals.
- Embedding patients/consumers in the running of health-care organizations was supported, although it will be important to think about how to do this. Some patients don't have the wherewithal; maybe use former patients; how to get them up to speed and keep them will need attention.
- Panel members felt strongly that alternate pathways to dispute resolution need to be found, but also that it was unclear how this would come about, whether it would involve carrots or sticks and who would wield them. Some also felt that the development of alternate pathways should be separate from current investigative, regulatory and disciplinary actions; others emphasized that this recommendation shouldn't become an obstacle to moving forward with other recommendations.

Endnotes

- ¹ Code 14 (Education of Consumers) was used to identify testimony recommending the development and implementation of programs and materials to educate consumers on a variety of topics related to patient safety.
- ² Code 20 (Patient Inclusion) was used to identify testimony recommending the inclusion of patients to design specific and individual-level processes of care as it relates to improvements in health-care safety.
- ³ Code 30 (Consumer/Patient Advocacy) was used to identify testimony recommending the inclusion of advocates for consumer/patient preferences and values in patient safety issue discussions aimed at general improvement of patient safety in a system or geographic area (e.g., specific hospital, region, or state).
- ⁴ Code 27 (Advocacy) was used to identify testimony recommending the undertaking of acts in a formal manner (e.g. lobbying) to influence public opinion and societal attitudes or to bring about changes in legislation, administrative rules and regulations, and/or policy at all levels (governmental, community, or institutional).
- ⁵ JCAHO (2005). "Facts about the 2006 national patient safety goals." Washington, DC: JCAHO. Retrieved 7.23.05 from http://www.jcaho.org/accredited+organizations/patient+safety/06_npsg/06_facts.htm.
- ⁶ Kohn LT, Corrigan JM and Donaldson M (eds.) (2000). *To err is human: Building a safer health system*. Washington, DC: National Academy Press.
- ⁷ Institute of Medicine (2001). *Crossing the quality chasm: A new health system for the 21st century*. Washington, DC: National Academy Press.
- ⁸ Institute of Medicine (2004). *Patient safety: achieving a new standard of care*. Washington, DC: National Academy Press.
- ⁹ Kizer KW (2001). Patient safety: A call to action. Washington, DC: The National Forum for Health Care Quality Measurement and Reporting. Retrieved 4.18.05 from <http://www.qualityforum.org>.
- ¹⁰ National Patient Safety Foundation, Patient and Family Advisory Council (2003). *National agenda for action: Patients and families in patient safety, nothing about me, without me. Executive summary*. Washington, DC: The National Patient Safety Foundation. Retrieved 4.18.05 from <http://www.npsf.org/html>.
- ¹¹ JCAHO (2005). *Health care at the crossroads: Strategies for improving the medical liability system and preventing patient injury. Executive summary*. Washington, DC: JCAHO. Retrieved 4.18.05 from http://www.jcaho.org/about+us/public+policy+initiatives/medical_liability.pdf.
- ¹² Flowers M and Lucas BM (2005). "Health literacy: Challenges and solutions". Presented at the 2005 Michigan Health and Safety Coalition Conference, *Strategies to save lives: Patient safety initiatives that make an impact*. Dearborn, MI: April 7-8, 2005.
- ¹³ Kohn LT, Corrigan JM and Donaldson M (eds.) (2000). *To err is human: Building a safer health system*. Washington, DC: National Academy Press.
- ¹⁴ Spath PL (2004). IOM's six aims: Patient-centered, Presented at the WHA Quality and Safety Forum, Oct. 19.
- ¹⁵ Testimony 807B
- ¹⁶ Testimony 407O:95-97
- ¹⁷ "When patients speak—Collaboration in patient safety" (2005). In *Patient Safety Advisory*, Vol.2, No.1, March, p 4. Retrieved 7.28.05 from http://www.psa.state.pa.us/psa/lib/psa/advisories/march_2005_advisory_v2_n1.pdf.
- ¹⁸ Testimonies 904B and 905O
- ¹⁹ Consumers Advancing Patient Safety (CAPS), *2004 Annual Report*, Retrieved 4.17.05 from <http://www.patientsafety.org/>.
- ²⁰ Institute of Medicine (2004), op cit..
- ²¹ JCAHO (2005). *Health care at the crossroads: Strategies for improving the medical liability system and preventing patient injury. Executive Summary*. Retrieved 4.18.05 from http://www.jcaho.org/about+us/public+policy+initiatives/medical_liability.pdf
- ²² JCAHO, *ibid.*, p. 10.
- ²³ For more information on "Sorry Works!", see The Sorry Works Coalition at www.sorryworks.com. Referenced in Wojcieszak D (2005). Standards, audits, and saying I'm sorry: An engineer's family proposes solutions. *Patient Safety & Quality Healthcare*, May/June. Retrieved 7.16.05 from <http://www.psqh.com/mayjun05/consumers.html>.
- ²⁴ Baucus M (2005). "Baucus bill seeks to streamline medical malpractice claims." Press release issued June 29, 2005. Retrieved on 7.16.05 from <http://baucus.senate.gov/newsroom/details.cfm?view=062905-medical>.
- ²⁵ Johnson B (2004). "Developing and sustaining patient and family Involvement in safety." Presented at the 2004 Michigan Health and Safety Coalition Conference, *Improving patient safety through innovation and action*. Dearborn, MI: April 14-15.
- ²⁶ "JCAHO Proposal for patient-centered care brings concept to mainstream healthcare settings" (2005). *The Risk Management Reporter*, 24(3); June, 1-8.

²⁷ “JCAHO, *ibid.*.”

²⁸ Johnson, *op cit.*

²⁹ Spath, *op cit.*

³⁰ Kraman SS, Hamm G (1999). Risk management: Extreme honesty may be the best policy. *Ann Intern Med* 131(12), December 21, 963-967.

³¹ Mazor DM, Simon SR, Gurwitz JH (2004). Communicating with patients about medical errors: A review of the literature. *Arch Intern Med* 164;1690-1697.

³² See also recommendations to Safeguard Data & Sources (Code J).

³³ “JCAHO Proposal for patient-centered care brings concept to mainstream healthcare settings.” (2005). *The Risk Management Reporter*, 24(3); June 2005, 1-8.; and Vincent CA, Coulter A (2002). Patient safety: what about the patient? *Qual Saf Health Care* 11:76-80, retrieved 5.30.05 at <http://www.qhc.bmjournals.com>

³⁴ Testimony 905O:13-25

³⁵ See also recommendations to Safeguard Data & Sources (Code J).

³⁶ Testimony 401O:41-43

³⁷ Testimony 501W;59-61, 131-133, 140-142

³⁸ Testimony 403O

³⁹ Testimony 405O

⁴⁰ Amori G, Spath PL (2004). “Strategies for bringing patients into the patient safety process”. Presented at the WHA Quality and Safety Forum, October 19.

⁴¹ Testimony 403W

⁴² Spath PL (2003). “Can you hear me now?” *Hospitals and Health Networks* 77(12), December.

⁴³ Testimony 401O

⁴⁴ Testimony 403W

⁴⁵ Testimony 401O