

**STATE COMMISSION ON PATIENT SAFETY  
ROUND ONE RECOMMENDATIONS  
MAY 26, 2005**

**Category D: Implementing Safety Systems in Health Care Organizations**

Code: Patient Include (20): The submitted testimony recommends inclusion of patients to design specific and individual-level processes of care as it relates to improvements in health care safety.

**Recommendation: D7:**

Health care practitioners and the organizations in which they work, including both ambulatory and non-ambulatory facilities, should develop or adopt policies, practices and programs as part of their patient safety agenda, that incorporate patients' values, needs and preferences in the care process and that promote open and clear communication between patients and providers about health issues, treatments, patient safety concerns, and adverse events, should they occur.<sup>1</sup>

In particular, hospitals, nursing homes and ambulatory care facilities should:

- Encourage teamwork and patient advocacy, where patients are considered active members of the team, are involved in decisions about their care, and become resources to address both patient safety and health care problems<sup>2 3 4</sup>
- Offer training and programs to help providers, patients, and families learn effective communication skills<sup>5</sup>
- Offer training in cultural competency to staff<sup>6</sup>
- Establish guidelines for sharing information on adverse events and outcomes to patients/families and supporting them in the aftermath<sup>7 8</sup>
- 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<sup>9</sup>
- Train and utilize patient representatives for patient safety advocacy, with a specific role of facilitating communication for patients and families following a medical error<sup>10 11</sup>
- Require patient safety training as part of annual staff competency programs<sup>12</sup>
- Join efforts to adopt health care passports for patients, as a way to make information available to patients about their health and health care<sup>13</sup>
- 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<sup>14 15 16</sup>

**Rationale:**

"Patient safety is a huge endeavor. We miss opportunities to add additional safeguards if we fail to include patients and their families in our efforts to improve safety. Until the patient participates in their care, we reinforce the separatist care-giver vs. care-recipient notion of health care. Patients want a safe health care experience and want to help us make sure that happens"<sup>17</sup>

**STATE COMMISSION ON PATIENT SAFETY  
ROUND ONE RECOMMENDATIONS  
MAY 26, 2005**

A clear message comes from both the testimonies and the literature on patient safety: patients and families need and want to be included in decisions about their care; they have a need and a right to be informed of all aspects of their care, including errors, should they occur; they have a role in error prevention; and patients, families and providers alike need help in communicating information to each other to promote safety and quality of care.

Effective communication underlies many concerns. Poor physician-patient communication is considered one of the root causes of medical error.<sup>18</sup> 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 standards<sup>19</sup> and submitted testimony acknowledges it.<sup>20</sup> Patients, however, often feel that physicians don't listen to them or talk over them. As one respondent (a consumer) put it, "I think if doctors were to just listen, listen, they could really do wonders for people.<sup>21</sup> ...if they would sit down and look at you right in your eye and pay attention to what you are saying, they could avoid a lot of these mistakes..."<sup>22</sup> A recent issue of the Patient Safety Advisory, published by Pennsylvania's Patient Safety Authority, reported on studies of physician communication showing that "physicians redirect and interrupt a patient's initial descriptions of their concerns after an average of only 18 to 23.1 seconds."<sup>23</sup> Patients may end up discouraged and give incomplete histories, leaving the clinician with incomplete information and opening a door to potential errors.

Using medical jargon or a level of language inappropriate to the patient's or family's ability to comprehend is another piece of the communication picture. Providers do recognize this problem and express willingness to address it. As one respondent (a provider) summarized it:

"The literature suggests, and a study by the American Medical Association Foundation (Helping Your Patients Understand) demonstrates, that patients frequently lack understanding of medical information provided by physicians and other health care providers. This represents use of medical jargon and other language not comprehended by patients and leads to significant potential and actual medically adverse occurrences....<sup>24</sup> Communication issues contribute to increased patient risk related to this increased complexity.<sup>25</sup> Particularly with patients, with the tendency for healthcare professionals to speak in unfamiliar terminology and with a reticence by patients to tell their care providers that they do not understand.<sup>26</sup> We need to learn how to communicate with our patients from whatever level our provider, whether we're physicians, pharmacists, psychiatrist, psychologist, mid-level providers, we have to learn to communicate. We have to have that [communication] open and available."<sup>27</sup>

Other factors contributing to poor communication, discussed earlier under recommendations addressing education of providers and consumers, are low levels of health literacy; deficiencies in cultural competence among staff; 'cross-cultural dyads', where there are significant differences in the cultural backgrounds of

**STATE COMMISSION ON PATIENT SAFETY  
ROUND ONE RECOMMENDATIONS  
MAY 26, 2005**

providers compared to their patients<sup>28</sup>; and the difficulty that patients may have in being aware of their health status or simply remembering enough details of their health history to be able to report them accurately and in a timely manner. All of these factors make it hard for patients, especially those among vulnerable populations, to be active partners in their own care.

The concept of a health care passport was proposed as a way to address some of the information gap.<sup>29</sup> Because patients would own these passports and have access to the information on them, the passports would serve to educate patients about their health and care, in addition to being used as an information sharing tool between health care providers and settings. Ideally they would link with electronic medical records, but not be dependent on the EMR system in any given care setting, and could travel with patients when they go on vacation or move from one state to another.

Patients and families have a role in error prevention and early detection.<sup>30</sup> This is fairly widely acknowledged, but it is also clear that they cannot carry out this role unless the health care delivery organization and providers assist them in understanding what this role is, and especially by creating an environment that supports their questions and offers specific mechanisms to solicit and receive information and provide feedback.

One very important part of the communication package is encouraging open and honest dialogue between practitioners and patients when an adverse event occurs. Patients want to know what happened and why, how to manage their care as a result, and, by sharing lessons learned, 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 the Joint Commission's requirement in its accreditation standards that sentinel events and other unanticipated outcomes of care be reported to patients and their families when appropriate.<sup>31</sup> But there are increasing calls for change and signs that opinion may be shifting. In a recent JCAHO report on medical liability and patient injury, the authors note that while fear of litigation is still the norm in most health care delivery settings, there is a growing awareness that open communication “has the potential to heal, rather than harm, the physician-patient relationship”. Equally important is the potential that apologies may have a cost benefit by reducing the frequency of litigation and the level of pay-outs. The report notes that some medical centers and 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.<sup>32</sup>

**STATE COMMISSION ON PATIENT SAFETY  
ROUND ONE RECOMMENDATIONS  
MAY 26, 2005**

**Evidence/information on comparable initiatives being carried out in other states:**

National level. Reframing the provider-patient relationship as a partnership with shared decision-making and open communication has strong support from the IOM, JCAHO, the National Quality Forum, and the National Patient Safety Foundation (NPSF). Including patients in safety design and the process of care is part of the IOM principles for the design of safety systems in health care organizations.<sup>33</sup> In *Crossing the Quality Chasm*, patients are encouraged to adopt a shared decision-making process with their physicians,<sup>34</sup> and in its most recent report, the IOM recommended that “patient safety programs...invite the participation of patients and their families and be responsive to their inquiries.”<sup>35</sup> The philosophy underlies several of the ten high priority strategic areas for action in its consensus statement on patient safety.<sup>36</sup> And it is one of the cornerstones of the NPSF’s National Agenda for Action on patients and families in patient safety.<sup>37</sup>

A number of national-level organizations sponsor educational activities, materials and strategies to support patients and families—as well as health care organizations and professionals—in efforts to engage patients more actively in their care and safety, including the NPSF, the Agency for Healthcare Research and Quality, the Institute for Safe Medication Practice, the Institute for Family-Centered Care, and JCAHO.<sup>38 39</sup>

State Level. At the state-level, there is a ground-swell of support for the shift towards patient-centered care, with many reports to be found of projects and initiatives sponsored by state patient safety centers, consumer coalitions, hospitals and other health care delivery organizations. Organizations represented by the MH&SC and this panel are active in this area. 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.<sup>40</sup> A recurring theme is emphasis on sustaining the process, rather than reaching a measurable outcome. As one presenter put it during a patient safety conference in Wisconsin last year, “Engaging patients must be a mindset, not a program.”<sup>41</sup> Evaluations of efforts on the usually studied outcomes such as the incidence of errors, use of service, costs, patient satisfaction and health status are infrequent, but there are some studies with positive indicators.<sup>42</sup>

**STATE COMMISSION ON PATIENT SAFETY  
ROUND ONE RECOMMENDATIONS  
MAY 26, 2005**

**Pros:**

- Holds great potential for improving safety and quality of care, patient satisfaction
- Michigan would join a national movement in progress, lending momentum and support to efforts already underway in the state
- Availability of many tools, strategies and examples of successful efforts for health care organizations to use, build on
- Strategies and tools not necessarily expensive – just need to be used

**Barriers:**

- Depends highly on implementation of measures to instill a culture of safety within health care settings – patients cannot be partners if organizations are not willing to listen
- Relies in turn on measures such as legislative action on peer protection, a necessary precursor to disclosure or open discussion of errors and adverse events
- Resistance from health care personnel, who may feel challenged, threatened, fear lawsuits, believe that involving patients will take more time
- Caregivers will need new skills and training
- Involves disruption of the status quo, especially in the physician-patient relationship; progress will likely be slow
- Outcomes difficult to define, measure

**Additional comments:**

- Will need to be considered together with recommendations relating to consumer education and consumer advocacy (forthcoming)

**Implementation steps:** TBD

**Cost:** TBD

**Implementation Target Date:** TBD

**Grade:**

**Endnotes**

---

<sup>1</sup> Compiled from 14 recommendations coded 20 in 13 testimonies

<sup>2</sup> Testimony 303B

<sup>3</sup> Testimony 104O

<sup>4</sup> Testimonies 104O and 403O

<sup>5</sup> Testimonies 204B and 407O

<sup>6</sup> Testimony 904B

<sup>7</sup> Missouri Commission on Patient Safety (2004). Report presented to Governor Bob Holden, July.

**STATE COMMISSION ON PATIENT SAFETY  
ROUND ONE RECOMMENDATIONS  
MAY 26, 2005**

---

<sup>8</sup> Joint Commission on Accreditation of Healthcare Organizations (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](http://www.jcaho.org/about+us/public+policy+initiatives/medical_liability.pdf)

<sup>9</sup> Testimony 827W

<sup>10</sup> Missouri Commission on Patient Safety, op. cit.

<sup>11</sup> 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*. Retrieved 4.18.05 at <http://www.npsf.org/html>

<sup>12</sup> Testimony 827W

<sup>13</sup> Testimony 903O

<sup>14</sup> Institute of Medicine (2004). *Patient safety: achieving a new standard of care*. Washington, DC: National Academy Press.

<sup>15</sup> Lucas BM and Flowers MA (2004). "Health literacy and patient safety: Implications for health care professionals." Presented at the 2004 Michigan Health and Safety Coalition Conference, *Improving patient safety through innovation and action*. Dearborn, MI: April 14-15, 2004.

<sup>16</sup> Testimony 904B

<sup>17</sup> Spath PL (2004). *IOM's six aims: Patient-centered*, Presented at the WHA Quality and Safety Forum, October 19, 2004.

<sup>18</sup> Kohn LT, Corrigan JM & Donaldson M (eds). (2000). *To err is human: Building a safer health system*. Washington, DC: National Academy Press.

<sup>19</sup> Spath, op. cit.

<sup>20</sup> Testimony 807B

<sup>21</sup> Testimony 407O:95-97

<sup>22</sup> Testimony 407O:160-163

<sup>23</sup> "When patients speak—Collaboration in patient safety" (2005). In *Patient Safety Advisory*, Vol.2, No.1, March, p 4. Retrieved 5/05 from

[http://www.psa.state.pa.us/psa/lib/psa/advisories/march\\_2005\\_advisory\\_v2\\_n1.pdf](http://www.psa.state.pa.us/psa/lib/psa/advisories/march_2005_advisory_v2_n1.pdf)

<sup>24</sup> Testimony 204W:110-115

<sup>25</sup> Testimony 204B:W42-43

<sup>26</sup> Testimony 204B:W45-47

<sup>27</sup> Testimony 204B:110-114

<sup>28</sup> Testimonies 904B and 905O

<sup>29</sup> Testimony 903O

<sup>30</sup> Institute of Medicine (2004), op. cit.

<sup>31</sup> JCAHO, op. cit., p.9.

<sup>32</sup> JCAHO, op. cit., p.10.

<sup>33</sup> Kohn, Corrigan, & Donaldson, op. cit.

<sup>34</sup> Institute of Medicine (2001). *Crossing the quality chasm: A new health system for the 21<sup>st</sup> century*. Washington, DC: National Academy Press.

<sup>35</sup> Institute of Medicine (2004), op cit.

<sup>36</sup> Kizer KW (2001). *Patient safety: A call to action*. Washington, D.C.: The National Forum for Health Care Quality Measurement and Reporting. Retrieved 4.18.05 from <http://www.qualityforum.org>.

<sup>37</sup> National Patient Safety Foundation, Patient and Family Advisory Council (2003), op cit.

<sup>38</sup> Institute of Medicine, (2004), op cit. p.190; and.

<sup>39</sup> 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, 2004.

<sup>40</sup> This was the central focus of B. Johnson's presentation at the 2004 Michigan Health and Safety Coalition Conference.

<sup>41</sup> Spath PL (2004). "IOM's Six Aims: Patient Centered." Presented at the WHA Quality & Safety Forum, October 19, 2004.

<sup>42</sup> Johnson B (2004), op cit.