

# Engaging Patients and Families in the Safest Care

*Priority Actions for Health Care Leaders, Clinicians,  
and Policy Makers*



## LEADERS OF HEALTH CARE SYSTEMS

### 1. Establish patient and family engagement as a core value for the organization.

- Create written behavioral values and standards for all clinical and non-clinical staff that speak to: treating the patient and family member with dignity and respect, information sharing, participation in care, and collaboration in improving care.
- Make unlimited visitation policies the standard for all inpatient units, ICUs, and emergency departments.
- Give patients and their proxies full access to their clinical records and personal health information through patient portals, written materials, and options such as OpenNotes<sup>®</sup> and the U.S. Department of Health and Human Services Blue Button<sup>®</sup>.
- Sign the World Innovation Summit for Health “Declaration on Engagement for Global Health” (<http://www.wish-qatar.org/app/media/951>).

### 2. Involve patients and families as equal partners in all organizational activities.

- Establish patient and family advisory councils for all major clinical services and large ambulatory practices.
- Incorporate patient and family advisors into governance board roles, quality and safety committees, and other relevant safety- and research-oriented committees and teams.
- Have patients and family members routinely review all patient-oriented written materials and educational brochures for content, relevance, and clarity.

### 3. Educate and train all personnel to be effective partners.

- Place high priority on creating a learning culture that emphasizes patient safety, models professionalism, enhances collaborative behavior, encourages transparency, and values the individual learner.
- Establish patient/family faculty programs to educate clinicians, staff, and health professional students about the experience of illness and perceptions of safe care.
- Incorporate into all programs training in communication skills that focuses on patient and family partnerships, shared decision making, and disclosure and apology.
- Launch a broad effort to emphasize and promote the development and use of interpersonal skills, leadership, teamwork, and collaboration among faculty and staff.

### 4. Partner with patient advocacy groups and other community resources.

- Participate in the design and implementation of programs that involve the broader community—churches, schools, community organizations, public health entities—to help inform adults and young adults about how to get the care they need, how to use patient safety checklists, and how to choose the right health care system and health care professional.
- Partner with patient advocacy groups to develop community education campaigns to inform people that it is important to understand the purpose of medications, to always question unusual or unexpected tests or medications, and that it is okay to speak up with questions and concerns about anything that happens in the course of receiving care.

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## HEALTH CARE CLINICIANS AND STAFF

### 1. Support patients and families to engage effectively in their own care.

- Routinely involve patients in informed decision making about all diagnostic tests and treatment options, including medications.
- Use strategies such as Ask Me 3<sup>®</sup> and teach-back to overcome health literacy barriers and to ensure that patients truly do understand their condition, what they need to do next, and why it is important to do so.

### 2. Engage patients as partners in safety and care design.

- Invite patients and family members to partner with clinical and administrative staff in quality improvement activities.
- Involve patients and family members as full partners in the design and redesign of clinical workflows and care delivery.

### 3. Support patients and families when things go wrong.

- Create healing environments that include a physical setting and an organizational culture that support patients and families through the stresses imposed by illness, hospitalization, medical visits, healing, and bereavement.

## HEALTH CARE POLICY MAKERS

### 1. Involve patients in all policy-making committees and programs.

- Include patients and family members in safety-related policy-setting groups and committees at all governmental levels and within relevant bodies (e.g., accreditation, certification) in the private sector.
- Train patients and families through initiatives such as the National Breast Cancer Coalition's Project LEAD<sup>®</sup> to prepare them to fully participate in these activities and to advocate on behalf of other patients.

### 2. Develop and implement safety metrics.

- Implement and improve CAHPS (Consumer Assessment of Healthcare Providers and Systems) scores. This measure of patient experience now encompasses the continuum of care and includes many dimensions of the care experience related to improving safety, such as communication, responsiveness of staff to patient concerns, coordination of care, hand hygiene, and shared decision making.
- Implement and improve SOPS (Hospital and Medical Office Surveys of Patient Safety Culture) scores, which measure important attributes of organization culture contributing to patient safety. In many cases, it correlates closely with CAHPS measures.
- Participate in state and federal medical error reporting including measures such as falls, readmission rates, infections, adverse drug events, employee injury rates, and worker's compensation payments.
- Create new measures of patient safety related to diagnostic error, medication reconciliation, care inconsistent with patient preferences, and other key safety issues.

### 3. Engage patients in setting and implementing the research agenda.

- Engage patients and family members as partners to identify effective safe practices, create checklists and practice bundles, and test these innovations.
- Build patient and family input into defining key research questions and into strengthening the evaluations of relationships between patient experience and patient safety across the continuum of care. Suggested research topics for advancing the role of patients and families in ensuring safe care include:
  - Clinical studies that seek to understand the nature and extent of medical errors and the clinical effectiveness of interventions that can prevent or mitigate the extent of harm
  - Research on tools for optimizing the integration of patient preferences into clinical decision making
  - Studies that seek to examine and enhance patient adherence to recommended therapies
  - Research on how to improve communication between patients and their caregivers in ways that enhance the safety and effectiveness of care
  - Research on how to evaluate and support the critical contributions of family caregivers