

## PATIENT CARE PROGRAM

### *Engaging Patients and Families in a Supportive Healthcare System*

Established in 2000, the Gordon and Betty Moore Foundation is dedicated to advancing environmental conservation, scientific research, and patient care, as well as helping to improve the quality of life in the San Francisco Bay Area. The new Patient Care Program marks the Foundation's enduring commitment to healthcare and aims to achieve, in collaboration with others, a fundamentally better approach to care that improves quality and safety, reduces costs, and ensures dignity and respect to both patients and those who serve them.

#### ***The Foundation's Approach to Addressing Important Problems***

The Foundation employs a targeted approach to philanthropy; one that emphasizes achieving measurable outcomes and having an enduring impact. Based on its core values—impact, integrity, disciplined approach, and collaboration—the Foundation defines the desired philanthropic results and develops a strategy for achieving those outcomes (a “theory of change”) while working with other like-minded organizations, adaptively managing as conditions change, and investing substantial resources as progress is made over the long term.

#### ***The Problem***

Through its research, the Foundation identified four aspects of healthcare in the United States that need significant improvement. Everyone recognizes the first two areas: 1) quality and safety; and 2) the cost of healthcare. The Foundation believes that just as important are: 3) dignity and respect for patients, families, and the healthcare professionals who serve them; and 4) approaches to improving healthcare that can achieve both sustained results and scale across the United States.

Data show that despite vigorous efforts to improve healthcare in the U.S., avoidable medical errors cause up to 98,000 deaths in the U.S. every year, and serious preventable complications affect even more people.<sup>1</sup> Approximately 30% of all healthcare costs are the direct result of poor quality care.<sup>2</sup> In a survey, 49% of ill adults reported that their doctor does not present them with treatment choices or ask their opinion,<sup>3</sup> and 26% of hospitalized patients report that clinicians fail to explain medications prior to giving them.<sup>4</sup> Moreover, patients report a loss of dignity and respect when interacting with the healthcare system, with 43% of survey respondents reporting that their physicians did not always listen carefully, explain things, show respect, or spend enough time with them during office visits.<sup>5</sup> Finally, rarely do improvement efforts achieve both sustained results and widespread adoption.<sup>6</sup>

<sup>1</sup> *To Err is Human: Building a Safer Health System*, Institute of Medicine, November 1999.

<sup>2</sup> “Reducing the Costs of Poor-Quality Healthcare through Responsible Purchasing Leadership.” *Midwest Business Group on Health* (2002): n. pag. Print.

<sup>3</sup> 2005 Commonwealth Fund International Health Policy Survey of Sicker Adults

<sup>4</sup> California, 2009 data as reported on [hospitalcompare.hhs.gov](http://hospitalcompare.hhs.gov)

<sup>5</sup> 2008 Commonwealth Fund National Scorecard on U.S. Health System Performance.

<sup>6</sup> Pronovost, P. “A Road Map for Improving the Performance of Performance Measures.” *Health Affairs* (2011): vol. 30 no. 4 569-573. Print.

Substantially improving each area is extremely important; however, recognizing how each is connected to the other, and addressing them as a whole is perhaps even more important. For example, when complications occur, patients are harmed and costs increase; when patients are neither informed nor involved in key decisions (hence, disrespected), inappropriate care can follow, resulting in unnecessary costs as well as a loss of dignity and respect. The Foundation believes that patients should never suffer from a preventable harm, e.g., avoidable infection, and that preventable harm includes the loss of dignity and respect, e.g., avoidable fear and anxiety.

### ***The Conclusion***

The Foundation has been working with healthcare researchers, practitioners, policy makers, patients and families, and others to understand and acknowledge the achievements of many individuals and organizations in the field of healthcare quality improvement. Moreover, the Foundation has also researched improvement opportunities from other fields and industries, e.g., engineering and telecommunications.

The Foundation concluded ***that improvements in patient care will be more significant, efficient, and durable by focusing on and meaningfully engaging patients and families in their own healthcare within a supportive healthcare delivery system.***

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### ***The Foundation's Patient Care Program***

The Patient Care Program is based on a robust theory of how certain actions will result in the desired outcomes, a theory that is grounded in research and explicitly advocates for focusing on and meaningfully engaging patients and families in their own healthcare within a supportive healthcare delivery system.

The two critical elements of this theory are: (1) focusing on the *continual* meaningful engagement of patients and families in their own healthcare and (2) reconfiguring healthcare teams, processes, and technology as a cohesive “systems approach” to ensure that the healthcare delivery system and the healthcare professionals providing care support engagement to prevent harm, reduce complications, and ensure dignity and respect for patients and families. In this way, the Foundation believes that quality and safety will improve, and costs will decrease.

The Program will also use dissemination science, which provides rigorous approaches to replicate solutions that work rapidly and effectively, to ensure as many patients as possible benefit from the advances.

### ***Engaging Patients and Families***

Patients and their families are an unrealized, unique resource of important information, vital perspectives, and valuable partnerships for healthcare. For instance, almost all patients believe that they have the knowledge and confidence to play an active role in their own healthcare even when under stress of their medical condition.<sup>7</sup> When “activated,” patients have improved health outcomes

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<sup>7</sup> Hibbard, Judith H., and Peter J. Cunningham. “How Engaged Are Consumers in Their Health.” *Health System Change* Publication no. 8: n.p., 2008. Print.

across a variety of medical conditions.<sup>8</sup> A patient participation study endorsed by the World Health Organization World Alliance for Patient Safety found that 98% of the patients in a hospital setting thought that hospitals should educate them about error prevention. A Cochrane review of 86 clinical trials found the use of patient decision aids led to increased knowledge, more accurate risk perceptions, a greater number of decisions consistent with patients' values, a reduced level of internal decisional conflict for patients, and fewer patients remaining passive or undecided about their own healthcare.

Many healthcare professionals and organizations are developing the concept and practice of patient-centered care, and the Foundation's Patient Care Program seeks to build on that important work. The Foundation believes that healthcare must move from *presuming* that patients and families are engaged to *ensuring* that the healthcare system is *continually* engaging patients and their families in decision-making, setting expectations and achieving desired outcomes, designing and implementing better care models, and advocating for higher quality, safer, affordable, and respectful healthcare.

To do so means understanding that patients and their families and the healthcare system are vital partners, inextricably interdependent and linked. Only through working together can problems be fundamentally addressed and robust solutions created that are durable and respectful to all.

Through its research, the Foundation believes that an integrated effort to engage clinicians and patients simultaneously in partnership has not been previously attempted within the context of a supportive, designed approach. The Foundation seeks to make this approach a practical, widespread means to improve healthcare. For example, patients and their families who are engaged in their own healthcare will, among other activities:

- Work as recognized partners with the healthcare team;
- Participate as fully-informed partners in shared decision-making with their healthcare professionals;
- Equip themselves with the knowledge and skills to manage, when desired and appropriate, their own healthcare; and
- Understand their role and the valuable contribution they can make in ensuring safe, cost-effective, respectful, and, above all, high-quality healthcare.

To be supportive of patients and families, healthcare delivery needs to be redesigned to integrate multiple elements—information technology and decision support, medical technology, interprofessional team-based care, practices based on evidence, systems engineering and continual learning—such that all the different parts work together in an integrated, interdependent, coherent whole that supports continual engagement of patients and families. However, patients and families must be part of the redesign so that the delivery system not only meets the needs of the clinicians in providing the highest levels of quality and safety but also ensures that the care is delivered in a way that enhances the respect and dignity of patients and families and those who serve them.

### ***A Systems Approach to Improving Care***

The component parts of how to solve a problem are best understood in the context of their relationships with each other and with other systems, rather than in isolation and in silos. A “systems approach” means understanding how things—e.g., people, process, structure, and

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<sup>8</sup> Greene J. and Hibbard, Judith H., “Why does Patient Activation Matter? An Examination of the Relationships between Patient Activation and Health-related Outcomes.” *Journal of General Internal Medicine*. 2012;27(5):520-6.

technology—influence each other; identifying their integration and interdependencies; and creating the means to optimize across all the elements that build a coherent, high-performing system designed to reliably, efficiently achieve the desired outcomes.

The automobile industry provides a good analogy in explaining how a “designed” systems approach is better. Safety is part of the basic design of a good automobile and its many systems, e.g., electrical, cooling, fuel supply, braking, etc. The systems approach for a car informs the driver how much gas is in the tank, the air pressure level of the tires, if the car needs oil, what the engine temperature is, whether seats belts are fastened, and if the parking brake is on. All of these components interact interdependently to ensure a safe car for the driver and passengers. The driver does not have to check on each of these items personally; the system does it automatically, reliably, and provides information in a timely, user-friendly fashion that highlights the actions needed to ensure safety. The driver knows how, when, and where to be involved—whether to put more air in the tires or release the brake—because easy-to-understand, accurate information is available and presented on the car’s dashboard. Caring for patients deserves at least this much support.

The Foundation’s Patient Care Program aims to bring this level of system design to healthcare. For example, the Program seeks means to harness the power of health information technology and decision support to provide actionable, timely information to those who need it, when they need it. This enhanced communication will lead to faster, better decisions by the whole care team that includes patients and families.

One of the key components of the integrated design would be the creation of a data display unit—the “clinical dashboard”—for clinicians as well as a comparable display for patients and families. To recover from illness or surgery and avoid harm of complications and errors, each patient may need to receive hundreds of timely interventions each day. Yet, such vital interventions usually depend on the memory and dedicated efforts of individual nurses and doctors.

The clinical dashboard will provide faster and more accurate data analysis, help in decision-making and improve a clinician’s awareness of what has, is, and might happen with the patient’s medical condition. More specifically, the dashboard will:

- Reduce variability in clinical practice based on best care practices, assuring consistent results;
- Integrate data from a variety of sources and present it in one user-friendly display, to help clinicians be better informed, more efficient, and not suffer from the confusion and delays caused by numerous individual displays from multiple medical devices and data points; and
- Customize the clinical decision-making process to the patient’s conditions and wishes and enhance patient care through predictive analysis, which is the ability to make accurate predictions about future events based on historical patterns.

In addition, the sustained creation of a culture of continuous learning and accountability created by this designed systems approach to healthcare will ensure both sustained use of current best practices and faster adaptation to new clinical knowledge.

The Foundation believes that patients should not have to rely on the heroism of individual healthcare professionals working in frequently chaotic environments. A robust systems approach will help all healthcare professionals achieve better results by eliminating, as much as possible, human error, while also ensuring timely feedback and the opportunity for continuous learning and improvement. This approach will not replace the art of medicine or the science of experience,

professional intuition, or collegial relationships. It will however provide a means by which everyone can be most effective, efficient, and valued.

For example, in the 2003 effort led by Dr. Peter Pronovost, the Keystone Initiative implemented a checklist system in the intensive care units (ICUs) of Michigan hospitals to help physicians prevent central line-associated blood stream infections, an often fatal but preventable complication. In the first three months of the project, the infection rate in these ICUs decreased by 66%. In the first eighteen months, the “system” saved 1,500 lives and reduced costs by \$100 million. The checklist system was a “designed approach” that enhanced the work of healthcare professionals, and the favorable results were sustained for more than three years. The intervention has now been spread across the U.S. to 47 states with a 50% reduction in infection rates, and is now being implemented in Europe. This work was based on a designed system to address a single preventable complication, incorporating many elements for sustained improvement disseminated at scale.

The Patient Care Program is expanding on Pronovost’s work, which demonstrated that while good care depends on excellent healthcare professionals, it cannot be dependent on them only. A systems approach can help ensure consistently high quality and safety. It will improve on prior efforts by bringing together professions that once operated in silos—e.g. medicine, nursing, engineering, information technology, and private business—and creating partnerships to build a designed, integrated approach to eliminate all preventable complications and optimize healthcare. And the approach and resultant outcomes are enhanced by engaging patients and families.

Beginning in the acute care setting, but then expanding across and between care settings, the Patient Care Program aspires to do the same with integrated design that will not only reliably provide safe, high-quality healthcare that will be less costly, but also fully support the continual engagement of patients and families.

### ***The New Patient Care***

The following scenario reflects the Patient Care Program’s new vision for healthcare.

A patient develops an infection following surgery, requiring antibiotics, mechanical ventilation, and medications. He is immediately transferred to the ICU where the care team meets with him and his family to understand him as a person and not simply a medical condition. This helps alleviate his fears and reduce his stress level. The family, upon learning that they are welcome in his room at any time, feels that the care team is treating their loved one and them with respect and dignity.

The ICU physician hands the patient and family a digital e-tablet and explains that the display shows all of the interventions the patient should receive to not only heal, but also avoid any complications such as pneumonia, when the multiple interventions should be performed, whether they have been done, and any risks for harm he might develop. The e-tablet also allows the family to easily communicate with the rest of the care team. In addition, there is a digital “menu” of patient care activities in which the family can participate if they wish. Upon review, the patient’s wife expresses her desire to help by regularly assessing her husband’s cognitive state using an easily administered test, determining his muscle strength, and when he is ready, assisting him in sitting, walking, and simple exercises as part of preventing weakness while in the ICU. She has now become part of the care team.

Seeing that the clinical dashboard is predicting the patient to be at high risk for a blood clot, the physician orders blood thinners. During afternoon rounds, the ICU care team reviews the display to

evaluate whether they performed all of the required interventions. They observe a performance shortfall, investigate, and correct it immediately. Nothing is left to “memory.”

Before implementation of the approach advocated by the Patient Care Program, this patient might have developed delirium, generalized muscle weakness and other complications, and died. But because he received all the prescribed interventions, was helped by his family, and was part of a designed system of care, he recovered. Furthermore, tens of thousands of dollars were saved because he did not suffer complications or an unnecessarily prolonged stay in the ICU.

### ***An Invitation to Collaboration***

The Foundation gratefully acknowledges the tremendous achievements and ongoing work of many individuals and organizations in the field of quality improvement and health services research. The Foundation looks forward to collaborating with like-minded institutions, including other foundations, non-profits, for-profit corporations, and government agencies, to ensure higher quality, safer, affordable, and respectful healthcare.