National
Priorities
Partnership
*Convened by the*
*National Quality Forum*

# PATIENT & FAMILY ENGAGEMENT CONVENING MEETING
## SYNTHESIS REPORT

MAY 2010

# NATIONAL PRIORITIES PARTNERSHIP

*Convened by the National Quality Forum*

## PATIENT AND FAMILY ENGAGEMENT CONVENING MEETING SYNTHESIS REPORT

*This report presents a high-level synthesis of a meeting conducted as part of the efforts of National Priorities Partnership workgroups. The purpose of this meeting was to identify actions to drive the achievement of the patient experience of care goal of the patient and family engagement priority.*

## I. INTRODUCTION

In its 2008 report, *National Priorities & Goals—Aligning Our Efforts to Transform America's Healthcare*,[1] the National Priorities Partnership (NPP) identified six National Priorities that if addressed would significantly improve the quality of healthcare delivered to Americans. In continued support of improving patient-focused care, NPP selected patient and family engagement as one of the six priority areas, along with three specific goals: increasing the use of patient experience of care measures, improving patient self-management skills, and increasing the use of shared decisionmaking tools.

It is not enough to identify priorities and goals for national action, however. For change to occur, action must follow. To address the goals of each priority area, NPP established workgroups to provide guidance for the development of comprehensive action plans to drive change. In response to this charge, the Patient and Family Engagement Workgroup convened a meeting of key stakeholders on May 21, 2010, in Washington D.C. See Appendix A for a list of meeting participants. The purpose of the workshop was to build a shared knowledge base and identify specific action steps for NPP Partners and others to consider that would have the greatest potential to address the first of three patient and family engagement goals identified in the 2008 NPP report that:

> ***All patients will be asked for feedback on their experience of care, which healthcare organizations and their staff will then use to improve care.***

This report provides a high-level synthesis of this workshop and includes a chart (Appendix B) summarizing the key drivers and high-leverage action steps suggested by workshop participants. It summarizes the powerful arguments in support of the value of capturing patient experience; the strengths and challenges encountered by current survey users; and the potential of health information technology for addressing key issues in survey administration, integration of data sources, and sharing of survey results. The report also highlights findings related to patient and family engagement of other recent NPP workgroup activities and concludes with an update on activities promoting the use of patient-reported measures of care experience that have occurred since the workgroup's inception.

## II. WORKSHOP PROCEEDINGS

The meeting began with a rich discussion, started off by presenter Susan Edgman-Levitan, Executive Director of the Stoeckle Center at Massachusetts General Hospital,[2] about the value of collecting and acting upon data that measure patients' experience of care. She presented compelling findings that illustrate how a positive patient care experience relates to better patient outcomes, improved patient-clinician communication, and greater patient engagement. Such data can:

- identify communication problems that can lead to medical errors or poor outcomes of care;
- identify gaps and fragmentation in the system of which clinicians might not be aware;
- identify elements of patient care experience that need improvement and provide valuable information to guide redesign of care practices; and
- strengthen partnerships between clinicians, patients, and family caregivers in coping with illness or staying healthy.

Participants agreed that a major paradigm shift must occur to change an existing mindset that experience surveys are "nice to do," but are not critical for driving toward high-quality care. Increasing the understanding that patient and family caregiver perspectives are critical indicators of quality is important to effect widespread adoption of experience surveys. Several consumer advocates noted there is also an important role for the consumer advocacy community to play—stressing the importance of patient and family input, and encouraging consumer participation not only in responding to surveys when they are offered, but in shaping quality improvement initiatives via advisory panels, focus groups, etc.

Dale Shaller continued the discussion with an overview of the evolution of patient experience tools, particularly patient surveys such as the Consumer Assessment of Healthcare Providers and Systems (CAHPS) group of surveys developed by the federal Agency for Healthcare Research and Quality (AHRQ) and endorsed by the National Quality Forum (NQF). The CAHPS toolbox now includes patient surveys of experience with health plans, hospitals, medical groups and clinicians, nursing homes, behavioral health services, dialysis facilities, and dental services. The surveys can be tailored to meet specific user needs by adding supplemental questions—about interaction with specialists, for example, or medication management. Widespread use of a standardized tool such as CAHPS is extremely valuable to providers, purchasers, and consumers because it permits valid comparisons of performance, but many view the cost of survey administration and analysis as a major barrier to adoption.

Participants then heard presentations from three survey users: Jim Chase, CEO, Minnesota Community Measurement; Melinda Karp, Director of Strategic Planning and Business Development, Massachusetts Health Quality Partners; and Robert Krughoff, President, Consumer's Checkbook. Mr. Chase talked about the challenges in publicly reporting survey data. "Medical groups," he noted, "want rigorous and exact reporting and consumers want things simple." Ms. Karp reported their experience in Massachusetts with piloting patient care experience at the practice or physician level, including a study to see whether or not the identity of a patient's insurer (commercial compared to Medicaid) is a determining factor in the quality of the care experience; they concluded it is not.

Mr. Krughoff concluded this phase of the meeting by describing his successful project to reduce the cost of survey administration. Working in collaboration with local organizations in three sites—Denver, Kansas City, and Memphis—Mr. Krughoff and his team collaborated with insurers to combine enrollment data, draw the survey sample from the consolidated data, and conduct a single survey. As a result the survey administration process was affordable and each physician received an adequate sample size. The scores, *by physician,* were then publicly reported on the Consumers' Checkbook web site,[3] and the community coalitions' websites linked to those scores. Healthy Memphis Common Table, the sponsor of the Kansas City initiative, also published a special booklet honoring the 98 Memphis physicians who scored above average in the survey and distributed it community-wide. In addition, major insurers in both the Kansas City and Memphis areas are working with lower-performing physicians to improve their performance.

The afternoon discussion included presentations that focused on two other important initiatives in the use of patient experience surveys. Eric Holmboe, Senior Vice President of the American Board of Internal Medicine described developments in the incorporation of patient experience surveys into Maintenance of Certification (MOC) programs. What is particularly exciting about this is that MOC requires that physicians not just conduct an assessment of their practice, but also develop a plan for improvement. He also noted that most of the survey instruments currently available do not supply detailed information about the “why” behind the ratings, so there is a critical need to develop additional tools with the capacity to provide real-time qualitative information to clinicians as well. Sarah Scholle then provided an update on the National Committee for Quality Assurance’s (NCQA’s) efforts to expand requirements for collection of patient experience data in their new criteria for certification of Patient-Centered Medical Homes (PCMH). That survey—PCMH CAHPS—should be available in mid-2011.

The workshop concluded with the effort, led by workgroup chair Debra Ness, to develop consensus on key action steps that could lead to broader use of patient experience measures in improving our health system. These “drivers of change” and associated action steps are discussed in more detail in the next section.

## III. DRIVERS OF CHANGE AND MOVING TOWARD ACTION

### Driver: Consumer Engagement and Knowledge Dissemination

Workshop participants encouraged stakeholders to seek opportunities to build the case for patient experience by increasing public awareness and support, and by underscoring the role that patient experience information can play in driving quality improvement. This approach will require a significant change in professional culture and the relationship between patients and clinicians. It will also require widespread appreciation of the value of patient reported information in improving patient care experience, patient engagement, and ultimately patient outcomes. A part of this paradigm shift must include helping consumers to better understand the role they can play in improving care.

The group highlighted various opportunities, including the importance of involving patients and consumers in practice redesign and implementation of new models of care. Examples included creation of patient and family advisory councils, participation in governance and implementation efforts, strategies for fostering partnerships between patients and staff around quality improvement design, and effective education and presentation of consumer survey results.

### Driver: Public Reporting and Payment

Two key messages relating to payment surfaced during this meeting. First, providers must be incentivized to routinely collect patient experience of care information. This could be accomplished through a number of complementary strategies including public reporting and pay-for-performance initiatives and professional recognition, accreditation, and certification programs. It was emphasized that multi-payer, public-private alignment of these strategies is critical. Some examples of key levers for creating the right incentives include: board certification programs, certification requirements for models of care such as the PCMH and Accountable Care Organization (ACO), and the Centers for Medicare & Medicaid Services (CMS) Physician Quality Reporting and Physician Compare programs.

Second, wider adoption will depend on the establishment of sustainable financing model(s) for the collection of standardized patient experience surveys. Opportunities to reduce cost through centralized survey administration as in the Consumer’s Checkbook model or greater use of health information technology resources should be pursued. Once again, multi-payer, public-private alignment was viewed as critical to success.

### Driver: Accreditation, Certification, and Professional Development

For patient experience surveys to have an impact, healthcare professionals must believe in and acknowledge their value and realize that patient and family insights offer important information to improve quality of care and patient outcomes. Stakeholders must buy into the case for patient experience, and professional associations, practice leaders, and the public must support and reinforce this belief. At a system level, patient experience data should be built into all delivery system models—both traditional models and those emerging as part of healthcare reform initiatives—and results should be evaluated as part of a continuous feedback loop. The use of patient-reported experience measures will be particularly important in monitoring the impact of new care models on individuals with multiple chronic conditions for whom condition-specific quality measures are not adequate. It will also play an essential role in helping to monitor the impact of care models on different populations and to better address disparities. Finally, healthcare professionals must themselves undergo a “cultural shift,” and embrace the importance of continuously seeking patient and family caregiver feedback. This mindset should be embedded early on in medical education and training programs.

In addition to the more formal drivers of accreditation and certification, professional associations and healthcare organizations should offer healthcare professionals practical tools and strategies to improve care based on patient feedback. It should also be recognized that all staff, including direct care workers and support staff, have an impact on how patients and their families experience care, and therefore organizations could adapt or expand service excellence training programs for front-line, office, dietary, housekeeping, and security staff. Additionally, thoughtful reward and recognition programs for all staff—based on patient experience of care data and patient and family comments—can further instill in all employees the importance of their contributions to the welfare and experiences of their patients.

### Driver: Infrastructure Supports

To adequately drive adoption and use of patient experience of care surveys, major infrastructure supports are needed. As new models of healthcare delivery are put into practice, the use of patient and caregiver experience surveys should be integrated from the start as a key way to assess these models, ensure that they are providing better patient care, and provide valuable information to innovate and test new approaches to providing higher quality care at lower cost. Although the correlation between experience scores and high-performing systems has not been established, the need for patient input is critical to designing systems that improve care coordination and optimize patient experience and engagement.

Meeting participants emphasized the importance of strong leadership in creating a culture of patient-centeredness. Such a culture would include review in all senior leadership meetings of patient experience data and feedback along with other important metrics, such as clinical and financial data. Human resource policies should link hiring, orientation, training, staff education, and performance evaluations to quality and safety goals to reinforce this culture, and leadership should be aggressive about managing employees who do not uphold the standards, values, and culture of the organization. Employee surveys should be implemented to identify barriers to culture change and to assess the quality of work life for staff.

## IV. PATIENT EXPERIENCE OF CARE MEASUREMENT GAP ISSUES

Building on the discussion about key interventions and drivers of change, workshop participants identified critical measurement challenges and gaps. In addition to standardized surveys, which may be conducted annually or biannually, there is also a need for tools that provide qualitative, real-time, actionable feedback that can be used rapidly by practitioners to redesign and improve care delivery. Many such tools and resources exist—the CAHPS Improvement Guide,[4] and resources offered by the Institute for Patient- and Family-Centered Care, the Institute for Healthcare Improvement, and Planetree—but further work is needed to develop, test, and disseminate the best tools for different types of practices. These resources are critically important for moving from collecting data to acting on it in order to drive improvement that is meaningful to patients and their families. One practical example discussed was that of a Veterans Affairs (VA) facility that realized through patient comments that their parking situation was creating a hardship, particularly for their patients with breathing difficulties. The addition of a shuttle service resulted in immediate and substantive improvements in patient experience.

While gathering facility- or practice-level data is important, it is also necessary to use surveys and feedback measures at the individual physician level. This is the point of contact most central to patient experience, engagement, and outcomes, and therefore surveys done only at the group level may obscure individual provider performance and relegate entire groups of patients to poor quality care. Workshop participants also discussed the need for survey customization, and the need for both generic and tailored patient experience tools (e.g., for patients with specific or multiple chronic conditions). They advocated for measurement that captures and stratifies data by gender and life-stage, as well as data that illuminates issues inherent to disadvantaged populations to allow for tailored, culturally-sensitive interventions.

## V. IMPLICATIONS FOR HEALTH INFORMATION TECHNOLOGY AND DATA COLLECTION

Many of the action steps recommended by workshop participants will require the collection and aggregation of data to facilitate quality improvement, to encourage and enable value-based purchasing, and to provide meaningful information to consumers. Participants explored the implications of health information technology (HIT), how technology can facilitate the collection and use of patient reported data, and how meaningful use criteria required under the American Recovery and Reinvestment Act of 2009 could promote collection of patient experience data. Participants strongly advocated for the inclusion of patient feedback metrics as part of meaningful use requirements.

## VI. PATIENT AND FAMILY ENGAGEMENT AS A CROSS-CUTTING PRIORITY FOR NPP

In the first half of 2010, NPP's Population Health, Safety, and Care Coordination Workgroups reinforced the importance of patient and family/caregiver engagement across the priority areas. At each of their respective meetings, participants repeatedly recognized the centrality of consumers to achieving optimal health and quality healthcare, whether as active contributors to their own personal health, or as recipients of care once they have accessed the health system.

### NPP Population Health Workshop

On February 17-18, 2010, the NPP Population Health workgroup convened a workshop to address its three goal areas around the delivery of effective preventive services, adoption of healthy lifestyle behaviors, and national use of a community index of health. It was widely recognized that patients must be actively engaged to understand the benefits of appropriate preventive services, but also to recognize the importance of healthy living by getting proper nutrition and exercise, and by avoiding risky behaviors such as smoking and alcohol/substance abuse. Recognizing the consumer's critical role in self-management, communication emerged as a prominent theme—particularly in regards to messaging around healthy lifestyle behaviors—as well as the need for consumers to have access to appropriate resources to successfully advocate for their health and change behavior.

### NPP Safety Workshop

On July 28-29, 2010, the NPP Safety Workgroup convened a workshop to address safety issues in the perioperative care environment. The current and potential role of patients and their families or caregivers was central to the discussion, with the acknowledgment that patients and families are the only "team members" always present through an episode of care. Participants highlighted the need for patients to be actively informed and engaged in their care, both as recipients of critical information who must share in decisionmaking, and as key informants regarding their preferences for and experiences of care. Participants advocated for fuller integration of the patient into the care team, and emphasized the importance of sensitivity to cultural influences and health literacy levels.

### NPP Care Coordination Workshop

On September 1-2, 2010, the NPP Care Coordination Workgroup held a workshop to address barriers and drivers to reducing hospital readmissions. As with the Safety meeting, a key theme of the discussions was that “care coordination” is not the same as “coordinated care,” and that ultimately good coordination is in the eye of the recipient of care. Ultimately, the patient’s and family’s experience of care is the most important determinant of whether care is delivered in a safe, timely manner that is concordant with the patient’s needs and preferences. What is expected of staff according to the organization’s policies and procedures is important to address, but the patient’s experience should be paramount in this process.

### NPP Palliative Care and End-of-Life Care Workshop

On November 2, 2010, the NPP Palliative Care and End-of-Life Care Workgroup held its convening to address barriers to access to high-quality palliative care and hospice care services. One of the key drivers of change identified was that of informed consumer decisionmaking, which is dependent on a consistent and accurate definition of palliative care; appropriate communication to the general public through education and public reporting; and shared decisionmaking between the patient and healthcare provider to match treatment to patient goals and preferences.

## VII. THE PATH FORWARD

The key drivers and associated actions, measure gap areas, and implications for HIT presented in this report are offered as a starting point to increase the uptake of patient experience of care measures. It is hoped that any stakeholder group can evaluate its potential to contribute to NPP’s patient and family engagement goals, and where possible, take specific and immediate action. The path forward includes further drilling down on what steps need to be taken—and by whom—and identifying those who are already leading by example both individually and in partnership with others.

Evidence is mounting that NPP members and other stakeholders appreciate the value of capturing patient experience of care. Since the workgroup’s inception several important action steps have occurred.

- The Patient Protection and Affordable Care Act contains multiple provisions requiring use of patient experience measures, including evaluations of new models of care, the development and adoption of new quality measures, the design of quality incentive payments in the Medicare program, and public reporting of performance information.

- NCQA's proposed standards for Accountable Care Organizations (ACOs), released for public comment in October 2010, identified patient experience as one of the three dimensions for evaluating an ACO's performance and included patient experience surveys as a data source.
- National consumer, labor, and employer organizations, commenting in August 2010 on the CMS proposed 2011 Medicare physician fee schedule, urged that the list of measures used in the Physician Quality Reporting Initiative (PQRI) include a requirement that eligible providers conduct patient experience surveys if there is an NQF endorsed survey available for that provider.
- The final "meaningful use" health information technology regulations, published by the Department of Health and Human Services (HHS) in August 2010, require hospital and physician information technology (IT) systems funded under the Health Information Technology for Economic and Clinical Health (HITECH) Act to incorporate race, sex, and language preference information in all patient records. This will facilitate stratification of survey results, or oversampling of certain patient populations, in order to identify disparities in experience of care.
- The special subcommittee of the AHRQ National Advisory Committee, convened in October to advise the Secretary of HHS on a core set of measures of care for adults enrolled in state Medicaid programs included the CAHPS health plan survey tool in its recommended list.

As stakeholders in the health system continue to emphasize the need to incorporate measures of patient and family experience, NPP workgroup activities have continually reinforced that information on patient and family experience serves not only as an important outcome measure, but that it is an equally important input to guide system design and improvement efforts. Patient experience lays the groundwork for the fullest engagement of the patient and family, not just in providing feedback, but in being activated patients fully engaged in making healthcare decisions as equal members of the healthcare team. For the health system to meet the goal of being truly patient-centered the integration of patients and families must go beyond mere lip service—stakeholder groups need to recognize that patient and family experience is the ultimate reflection of how the health system is performing to meet the needs of those it serves.

## NOTES

1. National Priorities Partnership, *National Priorities and Goals: Aligning Our Efforts to Transform America's Healthcare*, Washington, DC: National Quality Forum; 2008.
2. All meeting presentations are available at www.qualityforum.org/WorkArea/linkit.aspx?LinkIdentifier=id&ItemID=26464.
3. Consumers' Checkbook, www.checkbook.org. Last accessed January 2011.
4. The CAHPS Improvement Guide, www.cahps.ahrq.gov/qiguide/default.aspx. Last accessed January 2011.

# APPENDIX A
# NATIONAL PRIORITIES PARTNERSHIP

## PATIENT AND FAMILY ENGAGEMENT
## CONVENING MEETING ATTENDEES
## MAY 21, 2010

# NATIONAL PRIORITIES PARTNERSHIP
*Convened by the National Quality Forum*

## PATIENT AND FAMILY ENGAGEMENT CONVENING MEETING

### INVITED PARTICIPANTS

**Debra Ness (Co-Chair)**
National Partnership for Women & Families, Washington, DC

**Christine Bechtel**
National Partnership for Women & Families, Washington, DC

**Jim Chase**
Minnesota Community Measurement, Minneapolis, MN

**Christine Crofton**
Agency for Healthcare Research and Quality, Rockville, MD

**Susan Edgman-Levitan**
John D Stoeckle Center for Primary Care Innovation, Boston, MA

**Elizabeth Goldstein**
Centers for Medicare & Medicaid Services, Baltimore, MD

**Eric Holmboe**
American Board of Internal Medicine (ABIM) Foundation, Philadelphia, PA

**Tracy Jacobs**
Institute for Healthcare Improvement, Cambridge, MA

**Melinda Karp**
Massachusetts Health Quality Partners, Watertown, MA

**Paul Kaye**
Hudson River HealthCare, Inc., Peekskill, NY

**Ann Kempski**
Service Employees International Union, Washington, DC

**Robert Krughoff**
Consumers' Checkbook, Washington, DC

**Stephen Lawless**
Nemours, Wilmington, DE

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Consumers Advancing Patient Safety, Alexandria, VA

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**Lee Partridge**
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**Joachim Roski**
Brookings, Washington, DC

**Eileen Scheye**
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**Sarah Scholle**
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**Christy Woods**
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# NATIONAL PRIORITIES PARTNERSHIP

## *Convened by the National Quality Forum*

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# APPENDIX B
# NATIONAL PRIORITIES PARTNERSHIP

# PATIENT AND FAMILY ENGAGEMENT ACTION PLAN

# National Priorities Partnership
# Patient Family Engagement Action Plan

| | Drivers | | | | |
|---|---|---|---|---|---|
| | ***Consumer Engagement and Knowledge Dissemination*** | ***Public Reporting and Payment*** | ***Accreditation, Certification, and Professional Development*** | ***Infrastructure Supports*** | ***Performance Measurement*** |
| **Recommended Actions** | Increase awareness of patients and families of value of responding to patient experience surveys and using publicly reported information.<br>Involve patients and families in survey design and testing, and in development of other measures and mechanisms for providing feedback on patient experience of care.<br>Engage patients in governance structures, patient/family advisory councils, and other opportunities to shape care delivery and practice redesign.<br>Educate all stakeholders to value of capturing patient experience by sharing of evidence that patient care experience and patient/family engagement are critical to successful health outcomes. | Offer financial incentives (pay-for-performance, “tiering”, etc.) for providers to use, report, and meet performance benchmarks on patient experience measures.<br>Establish sustainable financing model(s) for clinician-level patient experience measurement and reporting activities.<br>Include patient experience as essential component of all public reporting on quality performance. | Embed patient experience in medical education and training programs.<br>Incorporate measures of patient experience and patient engagement in professional maintenance of certification programs.<br>Build patient experience into requirements for recognition of traditional and new models of care such as medical/ healthcare homes, accountable care organizations, and others.<br>Expand service excellence training programs for all provider front-line staff, including office staff, dietary, housekeeping, and security staff.<br>Develop thoughtful reward and recognition programs for staff based on patient experience data. | Require use of patient experience measures for accountability (assessment, reporting, and payment) of all new models of care.<br>Offer providers technical assistance in care redesign.<br>Ensure availability of tools and measures for both accountability and quality improvement.<br>Integrate patient feedback metrics as part of meaningful use requirements. | Maximize opportunities for multiple uses of data collected at a single point in time.<br>Develop and expand use of electronic data collection to support use of patient experience and engagement measures for quality improvement, accountability, and clinical decision support.<br>Ensure collection of data that allows identification of disparities among different populations.<br>Expand range of patient experience measures available, including both standardized surveys and tools for providing real time, qualitative patient feedback. |
| **Implementers** | »Consumer advocacy organizations<br>»Research community<br>»Providers and clinicians<br>»Professional associations and practice leaders<br>»Patients, consumers, and consumer advocacy organizations | »Public and private payers, including plans and employers<br>»Labor organizations<br>»Consumer advocacy organizations<br>»Provider organizations<br>»Federal, state, and local government agencies<br>»Community collaboratives | »Medical education community<br>»Accreditation/certification bodies<br>»Public- and private-sector payers and purchasers, including the Centers for Medicare & Medicaid Services (CMS)<br>»Consumer advocacy organizations | »Clinicians and provider organizations<br>»Health plans<br>»Consumer advocacy organizations<br>»Labor organizations<br>»Quality Improvement Organizations<br>»Research community<br>»Health information technology community | »Measure developers<br>»Research community<br>»Health information technology community<br>»Public- and private-sector payers and purchasers, including CMS<br>»Consumer advocacy organizations |