

# Patient and Family Engagement Resource Compendium



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## EXECUTIVE SUMMARY

By partnering with patients, their families and other caregivers, hospitals can improve the quality and safety of health care,<sup>1,2</sup> reduce costs,<sup>3</sup> increase employee satisfaction<sup>4,5</sup> and improve the patient experience.<sup>6</sup> Carmen et al.<sup>7</sup> define patient and family engagement as “patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system—direct care, organizational design and governance, and policy making—to improve health and health care.” This definition acknowledges that PFE represents a continuum of strategies and interventions that can occur at the bedside, in the board room and in the community. Partnering with patients and families has many cascading benefits related to health care quality, patient activation and elimination of health care disparities. It can transform organizational culture in profound ways.

### HOW TO USE THIS COMPENDIUM:

The Health Research & Educational Trust (HRET) developed this resource compendium to help link PFE concepts and strategies to available resources. This compendium highlights the array of resources that can support hospital efforts to partner with patients and families and provides some recommendations on how the available resources can be used. The website addresses for each resource are hyperlinked from the title, and the titles in the table of contents are bookmarked within the document to ease navigation. The compendium’s topics include:

- » Leadership
- » Assessments
- » Patient and family advisory councils
- » Quality improvement
- » Bedside rounding
- » Nursing bedside shift report
- » Family presence policies
- » Discharge planning

- » Patient activation and health literacy
- » Shared decision-making
- » Health information technology
- » Health care disparities

## GETTING STARTED

Starting a new program or initiative can seem like a daunting task. In a 2013-2014 national survey, 51 percent of hospital chief executive officers reported competing organizational priorities as a significant barrier to effectively engaging patients and families, followed by the time to set up and implement advisory programs.<sup>8</sup> While PFE does require time, resources and leadership, there is a return on the investment, and PFE likely aligns with existing organizational goals and strategic objectives. Below are some resources to help you learn more about PFE implementation strategies and how other organizations have addressed these barriers.

### HOW CAN THESE RESOURCES HELP YOU?

- » Understand the importance of tapping into health care’s key stakeholders by reviewing [Engaging Health Care Users: A Framework for Healthy Individuals and Communities](#).
- » Review the [Patient Experience Case Studies](#) to understand how organizations have implemented their PFE vision.
- » Consider some of the peer-reviewed research in the [Journal of Patient Experience®](#).
- » Connect patient experience/satisfaction scores to PFE using [Achieving an Exceptional Patient and Family Experience of Inpatient Hospital Care](#).
- » Use more comprehensive guides such as [The Patient-Centered Care Improvement Guide](#) and the [Guide to Patient Family Engagement in Quality and Safety](#) to develop specific action plans.

| <b>RESOURCE TITLE</b>  | <b>ORGANIZATION</b>                             | <b>DESCRIPTION</b>   |
|--|---|--|
| <b>Guide to Patient and Family Engagement in Quality and Safety</b>                                | Agency for Healthcare Research & Quality        | This comprehensive guide contains handbooks, sample forms, checklists and PowerPoints and features modules on: 1) Patients and families as advisors 2) Communication to improve quality 3) Nurse bedside shift report and 4) IDEAL discharge planning. |
| <b>Engaging Health Care Users: A Framework for Healthy Individuals and Communities</b>             | American Hospital Association                   | This guide offers a framework for health care user engagement and addresses barriers to involvement; the guide includes short case studies.  |
| <b>Journal of Patient Experience®</b>  | Association for Patient Experience              | The Association for Patient Experience, a non-profit sponsored by Cleveland Clinic, publishes this free peer-reviewed journal.   |
| <b>Patient Experience Case Studies</b>   | Beryl Institute                                 | This website provides over 40 case studies from health care organizations nationwide.  |
| <b>A New Definition of Patient Engagement: What is Engagement and Why is it Important?</b>         | Center for Advancing Health                     | This white paper proposes an “engagement behavior framework,” a qualitative description of the behaviors that individuals must perform to benefit from their care.   |
| <b>Achieving an Exceptional Patient and Family Experience of Inpatient Hospital Care</b>           | Institute for Healthcare Improvement            | Through research and interviews, this white paper identifies primary and secondary drivers of exceptional patient experience as measured by HCAHPS scores.   |
| <b>Advancing the Practice of Patient and Family Centered Care in Hospitals: How to Get Started</b> | Institute for Patient- and Family-Centered Care | This guide outlines how hospitals can begin to partner with patients, providing an assessment tool, checklist and bibliography.  |
| <b>Partnering with Patients and Families: A Guide to Getting Started for Hospitals</b>             | National Partnership for Women & Families       | This fact sheet outlines the key elements and organizational practices of patient-centered care.   |
| <b>The Patient-Centered Care Improvement Guide</b>   | Planetree, The Picker Institute                 | This guide includes strategies for engaging key stakeholders and practical approaches to customize the patient experience.   |

Source: HRET, 2015.

## LEADERSHIP

Leadership is one of the most important drivers of patient-centered care in hospitals and health systems.<sup>9,10</sup> Developing and sustaining patient and family partnerships is a long-term investment and one that requires vision. Senior leaders can connect PFE to the organization's strategic plan and mission, allocate human and financial resources and adjust processes and policies. Executive sponsors can also facilitate organizational culture change by integrating patient-centered care concepts into performance evaluations, employee recruitment, orientation and other operations. Rather than viewing PFE as a separate independent initiative, leaders should consider how it can be integrated into existing initiatives and processes. Below are some resources that can support senior leaders in their pivotal role.

### HOW CAN THESE RESOURCES HELP YOU?

- » Work with the organization's board and the senior leadership team to integrate

PFE into the organization's vision and goals using [A Leadership Resource for Patient and Family Engagement Strategies](#).

- » Identify strategies that will help you accomplish your PFE goals and determine where they occur on the continuum featured in [Patient and Family Engagement: A Framework For Understanding The Elements and Developing Interventions and Policies](#).
- » Understand which PFE strategies have been most effective and where opportunities for innovation exist using [A Roadmap for Patient + Family Engagement in Healthcare](#).
- » Determine how PFE strategies can be integrated into the hospital's existing initiatives from the examples provided in [Partnering with Patients and Families to Design a Patient- and Family-Centered Health System](#).
- » Use the [CAHPS Improvement Guide](#) to aid in evaluating PFE interventions and calculate the hospital's return on investment.

| <b>RESOURCE TITLE</b>  | <b>ORGANIZATION</b>   | <b>DESCRIPTION</b>  |
|--|---|---|
| <b>A Leadership Resource for Patient and Family Engagement Strategies</b>  | American Hospital Association, Institute for Patient- and Family-Centered Care        | This guide will help leaders develop a PFE vision, identify organizational opportunities, develop a plan for specific PFE goals and monitor progress on them.   |
| <b>CAHPS Improvement Guide</b>   | Agency for Healthcare Research and Quality  | This guide offers practical strategies that organizations can use to improve the patient experience and is aimed at health care executives, managers, physicians and other staff who are responsible for measuring performance and improving quality. |
| <b>A Roadmap for Patient + Family Engagement in Healthcare</b>   | American Institutes for Research  | This roadmap outlines specific PFE strategies that are effective, sustainable and scalable and highlights where more innovation is needed.  |
| <b>Here to Stay: What Health Care Leaders Say About Patient Engagement</b>   | Center for Advancing Health   | This paper features the results of a series of interviews exploring both how different health care stakeholders describe “patient engagement” and which strategies the stakeholders use to facilitate engagement.                                     |
| <b>Patient and Family Engagement: A Framework For Understanding The Elements And Developing Interventions And Policies</b> | Health Affairs  | In this journal article, the authors present a framework for engagement activities, proposing that they occur along a continuum at the direct care, organizational design and governance and policy-making levels.                                    |
| <b>Partnering with Patients and Families to Design a Patient- and Family-Centered Health System</b>                        | Institute for Patient- and Family-Centered Care, Institute for Healthcare Improvement | This report provides a set of 11 recommendations addressing the role of payers, foundations, hospital leaders and other stakeholders; short examples and case studies are interspersed.   |
| <b>Patient-Centered Care: What Does it Take?</b>   | The Commonwealth Fund   | Based on leadership interviews, this report identifies seven key factors contributing to patient-centered care at the organization level.   |

| RESOURCE TITLE                      | ORGANIZATION        | DESCRIPTION  |
|-------------------------------------|---------------------|--|
| <b>Measuring Patient Experience</b> | The Evidence Centre | This report provides a general overview of the most commonly researched approaches to measuring patient and caregiver experience reported in empirical literature. It summarizes key themes from research about the strengths and weaknesses of various approaches and provides some descriptions of specific tools as examples. |

Source: HRET, 2015.

## ORGANIZATIONAL ASSESSMENTS

Hospitals just starting on this journey may want to conduct an assessment to identify existing strengths and areas of opportunity. Assessments can indicate how the organization's approaches compare to best practice and can help prioritize initiatives and evaluate progress at different levels of the organization. Below are some assessments related to patient- and family-centered care and family presence policies.

## HOW CAN THESE RESOURCES HELP YOU?

- » Assemble a group of stakeholders to complete the [Patient- and Family-Centered Care: A Hospital Self-Assessment Inventory](#) including board quality committee members, senior leaders, managers, front-line staff and patient and family advisors.
- » Determine priorities for change and improvement using the [Patient- and Family-Centered Care Organizational Self-Assessment Tool](#).

| RESOURCE TITLE   | ORGANIZATION   | DESCRIPTION   |
|--|--|---|
| <b>Patient- and Family-Centered Care: A Hospital Self-Assessment Inventory</b> | American Hospital Association, Institute for Patient- and Family-Centered Care | This assessment inventory is designed to help hospital and health system leaders, trustees, medical staff and employees think about how a hospital, department or clinical area operationalizes patient- and family-centered care and determines priorities for change and improvement. |
| <b>Family-Centered Care Assessment</b>   | Family Voices, Inc.  | This tool was developed to measure families' experience of care using psychometric properties and is available via request.   |
| <b>Patient- and Family-Centered Care Organizational Self-Assessment Tool</b>   | Institute for Healthcare Improvement   | This tool assesses a broad range of patient- and family-centered care elements and should help health care professionals determine how their organization is performing.  |
| <b>Are Families Considered Visitors in our Hospital or Unit?</b>               | Institute for Patient- and Family-Centered Care                                | This checklist may be useful in understanding the level of support for current policies and practices regarding family presence and participation and prioritizing action steps.  |

Source: HRET, 2015.



## PATIENT AND FAMILY ADVISORY COUNCIL/COMMITTEE: RESOURCES FOR HOSPITALS

Patient and family advisory councils seek to integrate the perspectives of patients and families into care delivery and the health care environment. Councils build and strengthen partnerships with clinicians and leadership to improve the health care organization. In a 2013-2014 national survey of hospital CEOs, only 21 percent responded that the organization’s PFAC met within the last 12 months.<sup>11</sup> In contrast, the Dana Farber Cancer Institute’s council members attend monthly meetings and contribute an estimated additional 10 to 15 hours per week.<sup>12</sup> The study’s contrast with Dana Farber’s experience suggests a wide variation in the way health care organizations engage their patient and family advisors. The Dana Farber Cancer Institute maintains that their adult and pediatric PFACs are an integral part of organizational decision-making.<sup>13</sup> Over time, patients, families, clinicians and leadership developed a higher level of mutual respect and trust. This redefined relationship helped the organization explore new PFE models.

Hospitals and health systems should develop processes to recruit, orient and support

patient and family advisors and prepare hospital staff to meaningfully engage and partner with them. Below are some resources to help health care organizations create, sustain and advance their PFACs.

### HOW CAN THESE RESOURCES HELP YOU?

- » Gather feedback from patients and families on new processes with the help of [How to Conduct a “Walkabout” from the Patient and Family Perspective](#), in the absence of patient and family advisors.
- » Understand how to establish and sustain a PFAC using [Patient and Family Advisory Councils: A Hospital Toolkit to Engage Patients](#).
- » After reviewing [Staff Liaison to Patient and Family Advisory Councils and Other Collaborative Endeavors](#), identify someone in your organization who can serve as a staff liaison to the PFAC.

Develop a process to recruit, interview and orient advisors using the [Patient Advisory Council Playbook](#) and [Patient Family Advisory Council: Getting Started Toolkit](#).

| RESOURCE TITLE  | ORGANIZATION  | DESCRIPTION  |
|---|---|--|
| <a href="#">Patient and Family Engagement Newsletters</a> | American Hospital Association/ Health Research & Educational Trust, Institute for Patient- and Family-Centered Care | Through a series of eight issues, these newsletters describe how to develop and sustain a patient and family advisory council. |

| <b>RESOURCE TITLE</b>  | <b>ORGANIZATION</b>                             | <b>DESCRIPTION</b>   |
|--|---|--|
| <b>Guide for Developing a Community-Based Patient Safety Advisory Council</b>              | Agency for Healthcare Research and Quality      | This guide describes how to develop a community-based advisory council and improve patient safety alongside patients, consumers and a variety of professionals from both health care and community organizations.                      |
| <b>PFACs: Where's the Money? The Financial Impact on Hospitals</b>                         | Beryl Institute                                 | This report discusses the results of a national survey and closes with 10 recommendations for action.  |
| <b>Patient Family Advisory Council: Getting Started Toolkit</b>                            | BJC Healthcare                                  | This toolkit describes how to establish a PFAC and provides a sample budget, organizational structure, timeline, agenda, planning checklist, vision statement, marketing materials, advisor application, interview questions and more. |
| <b>Patient and Family Advisory Councils: A Hospital Toolkit to Engage Patients</b>         | Colorado Hospital Association                   | This toolkit explains why hospitals need PFACs and then outlines the steps to create and sustain one.  |
| <b>Creating Patient and Family Advisory Councils</b>                                       | Institute for Patient- and Family-Centered Care | This tool outlines the reasons for establishing a PFAC, the qualities and skills of effective advisors and considerations for the council's structure and governance.  |
| <b>How to Conduct a "Walkabout" from the Patient and Family Perspective</b>                | Institute for Patient- and Family-Centered Care | This tool describes how to conduct a "walkabout" to gain patient and/or family feedback.   |
| <b>Patient and Family Advisory Councils: A Checklist for Getting Started</b>               | Institute for Patient- and Family-Centered Care | This checklist outlines the administrative tasks associated with establishing a PFAC.  |
| <b>Patient and Family Leaders in Paid Positions: Common Challenges-Effective Solutions</b> | Institute for Patient- and Family-Centered Care | This resource discusses the challenges of employing patient and family leaders and offers some solutions.  |
| <b>Patient- and Family-Centered Position Descriptions</b>                                  | Institute for Patient- and Family-Centered Care | This website provides position descriptions of family-centered occupations from a variety of organizations.  |

| <b>RESOURCE TITLE</b>  | <b>ORGANIZATION</b>                              | <b>DESCRIPTION</b>   |
|--|--|--|
| <b>Patients and Families as Advisors in Design Planning</b>  | Institute for Patient- and Family-Centered Care  | This tool lists ways to engage patients and families in the design of new facilities.  |
| <b>Presentations by Patients and Families: Staff Liaison Coordination and Preparation Roles</b>      | Institute for Patient- and Family-Centered Care  | This tool outlines considerations for hospital staff when inviting patients and families to present.   |
| <b>Sharing Personal and Professional Stories</b>   | Institute for Patient- and Family-Centered Care  | This document describes how story sharing can be used as an exercise to develop a common understanding of patient- and family-centered care.   |
| <b>Staff Liaison to Patient and Family Advisory Councils and Other Collaborative Endeavors</b>       | Institute for Patient- and Family-Centered Care  | This document describes the role of the staff liaison to PFACs.  |
| <b>Tips for Group Leaders on Involving Patients and Families on Committees and Task Forces</b>       | Institute for Patient- and Family-Centered Care  | This tip sheet explains how to select advisors, how to prepare and facilitate committee meetings with advisors and how to anticipate illness demands.  |
| <b>Tips for Recruiting Patient and Families to Serve in Advisory Roles</b>                           | Institute for Patient- and Family-Centered Care  | This tool provides tips on how to recruit patient and family advisors.   |
| <b>Patient Advisory Council Playbook</b>   | Kaiser Permanente                                | This comprehensive resource contains samples of PFAC presentations, a communications plan, measures of success, a patient and family advisor application, interview questions, PFAC meeting agendas and meeting minutes. |
| <b>HIPAA Fact Sheet</b>  | National Partnership for Women & Families        | This fact sheet dispels myths regarding HIPAA privacy and security rules and Joint Commission standards as barriers to patient- and family-centered care.  |
| <b>Powerful Partnerships: A Handbook for Families and Providers Working Together to Improve Care</b> | National Institute for Children’s Health Quality | This guide is intended to help both family members and health care professionals who are working together and includes communication tips, patient stories and frequently asked questions.                               |

| RESOURCE TITLE   | ORGANIZATION   | DESCRIPTION   |
|--|--|---|
| <b>Engaging Patients in Improving Ambulatory Care: A Compendium of Tools from Maine, Oregon, and Humboldt County, California</b> | Robert Wood Johnson Foundation/<br>Aligning Forces for Quality | This compendium of resources provides tools that health care organizations in three communities have used. These tools can help organizations recruit, orient and train patients; clarify roles and responsibilities; and put a structure in place to foster ongoing, productive relationships. |

Source: HRET, 2015.

**PATIENT AND FAMILY ADVISORY COUNCILS/COMMITTEES: RESOURCES FOR PATIENTS AND FAMILIES**

As previously mentioned, health care organizations should prepare patients and families to serve on the PFAC. After recruiting and interviewing prospective advisors, many organizations provide an orientation during which they review the council’s history, governance structure, goals and accomplishments. During orientation, hospitals can also provide materials to help support advisors in their role. A few resources that hospitals could consider adapting are provided below.

**HOW CAN THESE RESOURCES HELP YOU?**

- » Share [Tips for How to be an Effective Patient or Family Advisor: A Beginning List](#) and [Sharing Your Story: Tips for Patients and Families](#) with your PFAC and discuss how these resources could be customized to your organization.

| RESOURCE TITLE   | ORGANIZATION                                     | DESCRIPTION  |
|--|--|--|
| <b>Sharing Your Story: Tips for Patients and Families</b>  | Institute for Patient- and Family-Centered Care  | These tips are designed to help patients and families share their story.   |
| <b>Tips for How to be an Effective Patient or Family Advisor: A Beginning List</b>                   | Institute for Patient- and Family-Centered Care  | This list highlights the qualities of effective patient and family advisors.   |
| <b>Powerful Partnerships: A Handbook for Families and Providers Working Together to Improve Care</b> | National Institute for Children’s Health Quality | This guide is intended to help both family members and health care professionals who are working together and includes communication tips, patient stories and frequently asked questions. |

Source: HRET, 2015.

## PARTNERING TO IMPROVE THE QUALITY OF CARE

Many hospitals are accustomed to asking patients for feedback through their PFAC or patient satisfaction surveys. However, health care organizations should also invite patients and family advisors to problem-solve and be part of decision-making at the unit, task force and board level.<sup>14</sup> Organizations partnering with patients and families on quality improvement teams and involving them in governance will be more likely to see a greater return on investment.<sup>15</sup> Below are some resources to help hospitals and health systems integrate patient and family advisors in quality improvement initiatives.

## HOW CAN THESE RESOURCES HELP YOU?

- » Determine some of the roles that patient and family advisors can play in your organization using [Partnering to Improve Quality and Safety: A Framework for Working with Patient and Family Advisors](#).
- » Prepare staff members who will be working with patients on quality improvement using the toolkit provided in [Patient Engagement in Redesigning Care](#).

| RESOURCE TITLE   | ORGANIZATION                                    | DESCRIPTION   |
|--|---|---|
| <b>Evidence Boost: A Review of Research Highlighting How Patient Engagement Contributes To Improved Care</b> | Canadian Foundation for Healthcare Improvement  | This brief provides a context and summary of research findings on case studies of patient engagement for health system improvement in four countries.   |
| <b>Pandemic Planning and Patient- and Family-Centered Care</b>   | Institute for Patient- and Family-Centered Care | This resource provides a set of guidelines that reflect the core concepts of patient- and family-centered care when developing a pandemic plan.   |
| <b>Partnering with Patients and Families to Enhance Safety and Quality: A Mini Toolkit</b>                   | Institute for Patient- and Family-Centered Care | This toolkit provide resources that will support efforts to partner with patients and families in quality and safety and includes: a patient and family advisor sample application form; tips for involving patients and families in committees and task forces; and recommendations for integrating patient- and family-centered concepts into rapid response teams. |
| <b>Safety Is Personal: Partnering with Patients and Families for the Safest Care</b>                         | National Patient Safety Foundation              | This report assesses the current landscape of patient partnerships to improve safety, distills the barriers to engagement and makes policy and practice recommendations for health care leaders, clinicians, staff and policymakers.  |

|   |   |  |
|---|---|--|
| <b>Partnering to Improve Quality and Safety: A Framework for Working with Patient and Family Advisors</b> | Symposium for Leaders in Healthcare Quality       | This guide presents a framework for working with patient and family advisors on quality and safety initiatives.  |
| <b>Patient Engagement in Redesigning Care</b>   | University of Wisconsin Health Innovation Program | This toolkit contains a patient engagement toolkit, a resource for hospital staff partnering with patient and family advisors on quality improvement initiatives, and a welcome packet for patient and family partners. The University of Wisconsin recommends that organizations customize these materials to match their specific goals, processes and PFE strategies. |

Source: HRET, 2015.

## ENGAGING PATIENTS AND FAMILIES DURING THE HOSPITAL STAY

Health care is becoming increasingly complex and specialized. As a result, hospitalized patients interact with many different clinicians on a daily basis. Effective communication is a key part of keeping patients safe, informed and more engaged in their care. Multidisciplinary bedside rounding, nursing bedside shift report, family presence policies and discharge planning are all effective ways to engage patients and families during the hospital stay.

Multidisciplinary rounding can facilitate nurse-physician communication and teamwork, increase patient and family satisfaction, and increase family involvement and understanding.<sup>16,17</sup> Despite time being a perceived barrier to multidisciplinary rounding, a survey of 256 pediatric hospitalists in the U.S. and Canada found that respondents did not report an increase in rounding duration.<sup>18</sup> Time is also perceived a barrier to nursing’s bedside change-of-shift report; however, Tidwell et al. found that bedside shift report led to a \$13,000 decrease in overtime costs and improved patient, family and staff satisfaction.<sup>19</sup>

Clinicians have the opportunity to increase patient and family members’ knowledge and skills while they are in the hospital. Welcoming family presence policies also encourage family members to participate in their loved ones’ care and discharge planning. Discharge planning aims to reduce hospital length of stay, prevent unplanned readmission to hospital and improve the coordination of services following discharge from hospital. Discharge planning should begin well before the patient is actually discharged.<sup>20</sup> Evidence suggests that hospital discharge planning is more effective if there is interdisciplinary communication, open communication between health care workers and family, family education and ongoing support after discharge.<sup>21</sup> Below are some resources to help you implement or optimize these PFE practices in your organization.

### HOW CAN THESE RESOURCES HELP YOU?

- » Develop a plan to implement the steps in the [Re-engineered Discharge Toolkit](#) for a specific patient population, service or unit.
- » Customize the [Discharge Preparation Checklist and Care Transition Plan](#) to your organization and integrate it into your admissions process.



- » Develop a protocol for multidisciplinary rounding using [Applying Patient and Family-Centered Concepts to Bedside Rounds](#) and test it on one shift.
- » Test and evaluate changes to bedside report with one patient using [ISHAPED Patient-Centered Approach to Nurse](#)

**[Shift Change Bedside Report.](#)**

- » Provide education and support to staff using [Implementing a Family Presence Policy: Education Activities for Frontline Staff and Clinicians](#) when transitioning to a more welcoming family presence policy.

| RESOURCE TITLE  | ORGANIZATION                               | DESCRIPTION   |
|---|--|---|
| <b>Comprehensive Unit-based Safety Program (CUSP) Toolkit: Patient and Family Engagement Module</b> | Agency for Healthcare Research and Quality | This module focuses on making sure patients and their family members understand what is happening during the patient’s hospital stay. They should be welcomed as active participants in the patient’s care and prepared for discharge. It includes facilitator notes, a PowerPoint and video all addressing the characteristics of an engaged advisor, effective patient and family communication and IDEAL Discharge Planning. |
| <b>Re-engineered Discharge Toolkit</b>  | Agency for Healthcare Research and Quality | This comprehensive toolkit includes case studies, six tools and step-by-step instructions to improve the discharge process and reduce readmissions.   |
| <b>Transitioning Newborns From NICU to Home: A Resource Toolkit</b>                                 | Agency for Healthcare Research and Quality | This toolkit includes resources for hospitals that wish to improve safety when newborns transition home from their neonatal intensive care unit by creating a Health Coach Program.   |
| <b>Independent Living Assessment</b>  | Boston University, Philips Lifeline        | This assessment was developed by a team of investigators from the Health and Disability Research Institute at the Boston University School of Public Health for seniors to guide their independent living decisions; the results can start a dialogue between seniors, their families and health care providers.  |
| <b>Discharge Planning Checklist</b>   | Centers for Medicare & Medicaid Services   | This checklist for patients preparing to leave a hospital or other health care setting asks patients to answer more than a dozen questions and collects information on medications and upcoming appointments.   |

| RESOURCE TITLE  | ORGANIZATION   | DESCRIPTION   |
|---|--|---|
| <p><b>Engaged Patients Campaign checklists related to:</b></p> <ul style="list-style-type: none"> <li>» <a href="#">Patient and Family Rounding Summary</a></li> <li>» <a href="#">Preparing for Discharge</a></li> <li>» <a href="#">Home Care After Surgery</a></li> <li>» <a href="#">Outpatient SBAR Communication Guide</a></li> <li>» <a href="#">Ten Ways to Be Prepared at a Doctor’s Visit</a></li> <li>» <a href="#">Choosing a Doctor</a></li> </ul> | <p>Empowered Patient Coalition</p>   | <p>The guides and checklists are designed to help patients and families document conversations during rounding and prepare as patients transition to another care environment. The campaign’s resources are available through a free membership.</p>  |
| <p><b>ISHAPED Patient-Centered Approach to Nurse Shift Change Bedside Report</b></p>  | <p>Institute for Healthcare Improvement, The Picker Institute, Inova Health System</p> | <p>These tools are designed to help make bedside shift report more patient- and family-centered.</p>  |
| <p><b>Same Page Transitional Care Resources for Patients and Care Partners</b></p>  | <p>Institute for Healthcare Improvement, The Picker Institute, Planetree, Inc.</p>     | <p>These resources and tools were developed for patients and their caregivers or care partners to use when planning for care or during a stay in a hospital or skilled nursing facility. The tools include surveys to fill out before and after a patient’s stay as well as specific resources designed to support care partners.</p> |
| <p><b>Applying Patient and Family-Centered Concepts to Bedside Pediatric Rounds</b></p>   | <p>Institute for Patient- and Family-Centered Care</p>                                 | <p>This tool provides guidelines and scripting for conducting rounds while providing respect and support for children and their families.</p>   |
| <p><b>Applying Patient and Family-Centered Concepts to Bedside Rounds</b></p>   | <p>Institute for Patient- and Family-Centered Care</p>                                 | <p>This tool provides guidelines and scripting for bedside rounds, addressing the language and tone of communication and privacy.</p>   |
| <p><b>Applying Patient and Family-Centered Concepts to Bedside Rounds in Newborn Intensive Care</b></p>   | <p>Institute for Patient- and Family-Centered Care</p>                                 | <p>This tool provides guidelines and scripting for bedside rounds in newborn intensive care.</p>  |



| <b>RESOURCE TITLE</b>   | <b>ORGANIZATION</b>  | <b>DESCRIPTION</b>   |
|---|--|--|
| <b>Changing Hospital Visiting Policies and Practices: Supporting Family Presence and Participation</b>  | Institute for Patient- and Family-Centered Care            | The Institute for Patient- and Family-Centered Care working group developed this set of guidelines with respect to changing hospital “visiting” policies and practices, providing specific comments on visitation rights and the format, style and language used in policies and procedures. |
| <b>Implementing a Family Presence Policy: Educational Activities for Frontline Staff and Clinicians</b> | Institute for Patient- and Family-Centered Care            | This facilitator’s resource provides educational activities for front-line hospital staff, helping them to understand the benefits of patient engagement and family presence and key steps to initiate partnerships.   |
| <b>The Surgical Experience: Initial Questions to Ask</b>  | Institute for Patient- and Family-Centered Care            | This tool asks a series of questions to clinicians and hospital staff about the surgical experience.   |
| <b>Post Discharge Tool</b>  | National Patient Safety Foundation                         | The tool was written by health care professionals to help patients follow their care plan.   |
| <b>Discharge Preparation Checklist and Care Transition Plan</b>   | Robert Wood Johnson Foundation                             | This tool provides a checklist of tasks that should be completed before leaving the hospital and documents any follow-up appointments.   |
| <b>How to Avoid Being Readmitted to the Hospital</b>  | Robert Wood Johnson Foundation                             | This tool explains why some readmissions occur and provides tips for patients to help avoid them.  |
| <b>Project BOOST® Implementation Toolkit</b>  | Society of Hospital Medicine                               | This toolkit is designed to function as a workbook consecutively moving through tasks designed to optimize care transitions. While much of the toolkit is publicly available, some tools can only be accessed by program participants.   |
| <b>Making the Transition to Nursing Bedside Shift Reports</b>   | The Joint Commission Journal on Quality and Patient Safety | This article reviews the transition to nursing bedside shift report in a Midwestern academic medical center.   |
| <b>Teach Back Toolkit</b>   | The Picker Institute, Des Moines University                | This toolkit describes teach-back and its effectiveness as an intervention with patients and families; it is accompanied by a video and self-assessment questions.   |

| RESOURCE TITLE   | ORGANIZATION                                      | DESCRIPTION  |
|--|---|--|
| <b>Next Step in Care: Guides and Toolkit for Health Care Providers</b> | United Hospital Fund                              | Next Step in Care has specific guides and a toolkit for health care providers to help them understand the family caregiver perspective. These guides address the following topics: HIPAA, needs assessment, discharge planning, community-based services and medication management.  |
| <b>Next Step in Care: Guides for Caregivers</b>                        | United Hospital Fund                              | 29 guides and checklists for family caregivers available in English, Spanish, Chinese and Russian including A Family Caregiver’s Guide to Care Coordination.   |
| <b>Coordinated-Transitional Care Toolkit</b>                           | University of Wisconsin Health Innovation Program | This toolkit was developed to help hospital systems that serve populations with high rates of patient dispersion, cognitive impairment and vulnerability improve care coordination and post-discharge outcomes such as reduced medication discrepancies. The toolkit outlines a low-resource, telephone-based protocol designed to reduce 30-day rehospitalizations and to improve care transitions during the early post-hospital period. |
| <b>Family-Centered Rounds Toolkit</b>                                  | University of Wisconsin Health Innovation Program | This toolkit seeks to improve family engagement during family-centered rounds; it includes a checklist and associated training curriculum.   |

Source: HRET, 2015.

## HEALTH LITERACY: RESOURCES FOR PROVIDERS

Health literacy is “the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.”<sup>22</sup> Nearly half of all American adults have problems understanding and acting upon health information. Patients with low health literacy are less likely to adhere to treatment recommendations and have poorer health, higher rates of health care utilization, higher rates of mortality and lower use of screening and vaccination programs.<sup>23</sup> Patients need to be better informed and supported and have

more opportunities for participation to play an effective role in their care.<sup>24</sup> Little evidence suggests that educational materials on their own result in self-management and behavior change.<sup>25</sup> Coupling educational materials with professional advice and consultation has proven more impactful.<sup>26</sup> Hospitals and health systems should also involve target audiences in the design of health literacy materials and education.<sup>27</sup> Customizing health literacy and patient engagement strategies to specific populations can help reduce health care disparities. Below are some resources to help you assess and improve health literacy in your communities.

## HOW CAN THESE RESOURCES HELP YOU?

- » Understand how to provide useful information and services customized to your patient populations using [Health Literacy Resources and Recommendations](#) and [Health Literacy Studies: Strategies and Tools](#).

| RESOURCE TITLE  | ORGANIZATION                               | DESCRIPTION  |
|---|--|--|
| <b>Health Literacy Assessment Tools</b>                             | Agency for Healthcare Research and Quality | These tools can be used to assess health literacy in English and Spanish speakers.   |
| <b>Patient Education Materials Assessment Tool and User's Guide</b> | Agency for Healthcare Research and Quality | This tool helps to evaluate and compare the understandability and actionability of patient education materials.  |
| <b>Health Literacy Resources and Recommendations</b>                | Centers for Disease Control and Prevention | This website describes how to develop, evaluate and disseminate materials targeting a specific audience.   |
| <b>Health Literacy Studies: Strategies and Tools</b>                | Harvard School of Public Health            | This website provides assessments, guidelines and strategies to help translate health literacy research into practice.   |
| <b>10 Attributes of Health Literate Organizations</b>               | Institute of Medicine                      | This paper describes 10 attributes of health literate organizations, those that make it easier for people to navigate, understand and use health information and services.   |
| <b>Ask Me 3</b>   | National Patient Safety Foundation         | This patient education program is designed to improve communication between patients and health care providers; the website's free resources include a Words to Watch fact sheet, health literacy statistics and a report on health literacy policy implications.                              |
| <b>Visualizing Health</b>   | University of Michigan                     | This site contains 54 examples of tested visualizations, graphic displays of health information that were evaluated through research among the general public. These visualizations are distributed via a Creative Commons license, which allows anybody to adapt them for their own purposes. |

Source: HRET, 2015.

## HEALTH LITERACY: RESOURCES TO HELP PATIENTS COMMUNICATE WITH PROVIDERS AND MANAGE MEDICATIONS

Patients and families should feel comfortable communicating with their health care team. The traditional paternalistic relationship between patients and providers is a barrier to meaningful partnership and engagement.<sup>28</sup> Many patients want to learn more about their health as evidenced by the number of people looking for health information on the Internet. A 2012 national Pew Research Center survey found that 72 percent of adult internet users have searched online for information about a range of health issues, the most popular being specific diseases and treatments. According to the same survey, while clinicians are still the number one source of health information, adults supplement their advice with online information. Health care organizations have assembled checklists and sample questions for patients, but making this information readily available at the right time can pose a challenge; it is important to think about how these materials can be incorporated into existing workflows. Mobile applications and other electronic resources can help meet

this need. The Pew Research Center reported in 2013 that 91 percent of American adults own a mobile device. However, researchers caution that mobile health interventions require the same careful planning and testing with target audiences that behavior change campaigns and educational materials require.<sup>29</sup> Below are some resources that can be customized and used to educate and support patients and families.

### HOW CAN THESE RESOURCES HELP YOU?

- » Integrate [Doctella](#) checklists into the surgery preparation and recovery process.
- » Provide patient and families with resources such as [My Medicine List™](#) or [Patient Passport](#) to help manage medications and communicate with all of their providers.
- » Orient patients and families to mobile applications such as [Zibdy Health](#) and help them set medication reminders.
- » Direct patients to [Medline Plus](#) to find reliable online information about their disease or condition.
- » Provide patients with access to an online peer community and tracking tools through [PatientsLikeMe](#).

| RESOURCE TITLE  | ORGANIZATION  | DESCRIPTION   |
|---|---|---|
| <a href="#">Questions are the Answer</a>              | Agency for Healthcare Research and Quality  | This question builder helps patients formulate questions for their different appointment types.   |
| <a href="#">Employee Health Communication Toolkit</a> | American Institutes for Research, Robert Wood Johnson Foundation and the California Healthcare Foundation | This toolkit is designed to help employers communicate with their employees or members about getting good quality health care, making good health care decisions and engaging with providers. |

| RESOURCE TITLE  | ORGANIZATION   | DESCRIPTION  |
|---|--|--|
| <b>My Medicine List™ in English and Spanish</b>   | American Society of Health System Pharmacists Foundation | This tool can help patients keep track of the medications they are taking, including the medication’s name and dose; providers can customize this tool with their hospital’s logo. |
| <b>Safe and Sound: How to Prevent Medication Mishaps</b>  | Caregiver Action Network                                 | This short guide provides recommendations to caregivers on medication management.  |
| <b>Aftershock</b>   | Center for Advancing Health                              | This mobile application offers a roadmap for patients facing a serious diagnosis.  |
| <b>Be a Prepared Patient</b>  | Center for Advancing Health                              | This website provides a collection of resources, tips and patient stories.   |
| <b>Taking Charge of your Healthcare Toolkit: Your Path to Being an Empowered Patient</b>  | Consumers Advancing Patient Safety                       | This patient toolkit includes tips for talking to clinicians, posters and brochures.   |
| <b>Engaged Patients Campaign checklists related to:</b> <ul style="list-style-type: none"> <li>» <a href="#">Choosing an Advocate and Preparing Documents</a></li> <li>» <a href="#">Dealing with Hospital Bills</a></li> <li>» <a href="#">Decision Support Guide</a></li> <li>» <a href="#">Important Documents and Forms</a></li> <li>» <a href="#">Important Questions for Your Hospital Care Team</a></li> <li>» <a href="#">Informed Consent</a></li> <li>» <a href="#">Inpatient Daily Progress Sheet</a></li> <li>» <a href="#">Inpatient SBAR Communication Guide</a></li> <li>» <a href="#">Keep Your Hospital Room Safe and Clean</a></li> <li>» <a href="#">Questions to Ask a Surgeon After a Procedure</a></li> </ul> | Empowered Patient Coalition                              | The guides and checklists are designed to support patients and families as they navigate the health care system and help them effectively communicate with providers.              |

| <b>RESOURCE TITLE</b>   | <b>ORGANIZATION</b>                      | <b>DESCRIPTION</b>  |
|---|--|---|
| <b>Patient Journal App</b>  | Josie King Foundation                    | The app opens a list of prompts for information that should be tracked during a hospital stay and the notes can be shared via email.  |
| <b>Medline Plus in English and Spanish</b>  | National Institutes of Health            | MedlinePlus is the National Institutes of Health's website for patients and their families. It provides information about diseases, conditions and wellness issues in plain language.   |
| <b>Patient Passport</b>   | National Quality Forum                   | This tool is designed to help patients have a conversation with health professionals and communicate their most important needs. Conversely, the passport helps health professionals see the patient as a human being and collect accurate, real-time information.  |
| <b>Taking Care of My Health and My Medicine List in English, Spanish and French</b> | National Transitions of Care Coalition   | These resources were developed as a guide and tool for patients and their caregivers to use, so they can be better prepared when they see a health care professional.   |
| <b>Doctella</b>   | Patient Doctor Technologies, Inc.        | This free website and mobile application developed by physicians at Johns Hopkins Medical Center returns a series of patient questions based upon the person's diagnosis or procedure for a particular point in care (e.g., before surgery, day of surgery) and includes the NQF patient passport.  |
| <b>PatientsLikeMe</b>   | PatientsLikeMe                           | This website allows patients to input data on their conditions, treatment history, side effects, hospitalizations, symptoms, disease-specific functional scores, weight, mood, quality of life and more on an ongoing basis. This data becomes a detailed longitudinal record that allows patients to gain insight and identify patterns. |
| <b>Patient's Toolkit for Diagnosis</b>  | Society to Improve Diagnosis in Medicine | The toolkit is a form that patients can complete to partner with their medical care team; it includes sections on appointment preparation, pain symptoms, medications and follow-up.  |

| RESOURCE TITLE | ORGANIZATION | DESCRIPTION   |
|----------------|--------------|---|
| Zibdy Health   | Zibdy Inc.   | This mobile application can help patients manage their medications, calling attention to any contraindications and setting reminders. |

Source: HRET, 2015.

## HEALTH LITERACY: RESOURCES TO HELP PATIENTS PREVENT ADVERSE EVENTS IN THE HOSPITAL

Patients agree that they can help prevent adverse events and that hospitals should educate them about error prevention.<sup>30</sup> However, a 2006 study found that patients felt more comfortable asking questions about their health and medications and less comfortable asking about hand-washing and helping to mark their surgical site. Patients and families should be educated about what they can do to prevent adverse events

in the hospital and encouraged to actively participate in their care. Patients with greater participation are more likely to report high quality care and less likely to experience adverse events.<sup>31</sup> Below are some resources to help you activate patients and their families as members of the health care team.

### HOW CAN THESE RESOURCES HELP YOU?

- » Be open with patients and families about the types of adverse events that could occur in the hospital during their stay and provide them with [Safety Checklists](#) and/or [Patient Education FAQ Guides](#).



| RESOURCE TITLE  | ORGANIZATION   | DESCRIPTION  |
|---|--|--|
| <p><b>Patient education FAQ Guides on:</b></p> <ul style="list-style-type: none"> <li>» <a href="#">Catheter-Associated Urinary Tract Infection (CAUTI) in English and Spanish</a></li> <li>» <a href="#">Central Line-Associated Bloodstream Infection (CLABSI) in English and Spanish</a></li> <li>» <a href="#">Clostridium difficile in English and Spanish</a></li> <li>» <a href="#">Methicillin-resistant Staphylococcus aureus (MRSA) in English and Spanish</a></li> <li>» <a href="#">Surgical Site Infection (SSI) in English and Spanish</a></li> <li>» <a href="#">Ventilator-Associated Pneumonia (VAP) in English and Spanish</a></li> <li>» <a href="#">Vancomycin-Resistant Enterococcus (VRE) in English</a></li> </ul> | <p>American Hospital Association , Association for Professionals in Infection Control and Epidemiology, Centers for Disease Control and Prevention, Infectious Diseases Society of America, The Joint Commission, The Society for Healthcare Epidemiology of America</p> | <p>These patient education guides are intended to be FAQ documents for the following infections: CAUTI, CLABSI, C. diff, MRSA, SSI, VAP and VRE.</p> |
| <p><b>Fall Prevention Tips for Hospital Patients and Families</b></p>   | <p>American Hospital Association/ Health Research &amp; Educational Trust, Institute for Patient- and Family-Centered Care</p>   | <p>These tips are provided to help patients and families prevent falls while in the hospital.</p>  |
| <p><b>Top Ten Safety Tips for Hospital Patients and Families</b></p>  | <p>American Hospital Association/ Health Research &amp; Educational Trust, Institute for Patient- and Family-Centered Care</p>   | <p>These tips are designed to help patients and families take an active role in care during a hospital stay.</p>                                     |



| RESOURCE TITLE   | ORGANIZATION  | DESCRIPTION   |
|--|---|---|
| <b>20 Tips to Help Prevent Medical Errors</b>  | Agency for Healthcare Research and Quality                          | These tips explain how patients can be involved in their care and stay safe in the hospital.  |
| <b>Infection Prevention and You</b>  | Association for Professionals in Infection Control and Epidemiology | This website provides materials for both patients and providers on infection prevention, including infographics, videos and eCards. |
| <b>Safety checklists for patients and families:</b> <ul style="list-style-type: none"> <li>» <a href="#">Prevent Blood Clots</a></li> <li>» <a href="#">Prevent C. diff Infection</a></li> <li>» <a href="#">Prevent Falls and Fractures</a></li> <li>» <a href="#">Prevent Medication Mix-Ups</a></li> <li>» <a href="#">Prevent Painful Bed Sores</a></li> <li>» <a href="#">Prevent Pneumonia from a Ventilator</a></li> <li>» <a href="#">Prevent Staph Infections</a></li> <li>» <a href="#">Prevent Surgery Errors &amp; Complications</a></li> <li>» <a href="#">Prevent Urinary Tract Infections</a></li> <li>» <a href="#">Tips for Supporting Your Loved One's Care in the Hospital</a></li> </ul> | Campaign Zero   | These checklists are designed to help patients and families prevent adverse events during a hospital stay.                          |

| RESOURCE TITLE   | ORGANIZATION                       | DESCRIPTION  |
|--|------------------------------------|--|
| <p><b>Engaged Patients Campaign checklists related to:</b></p> <ul style="list-style-type: none"> <li>» <a href="#">Who Do You Call? Getting Help in a Hospital</a></li> <li>» <a href="#">Warning Signs of a Rapidly Declining Patient</a></li> <li>» <a href="#">Hospital Guide for Patients and Families</a></li> <li>» <a href="#">Drugs Associated with Severe Adverse Events</a></li> <li>» <a href="#">Prevent CAUTI</a></li> <li>» <a href="#">Prevent Pressure Ulcers (Bed Sores)</a></li> <li>» <a href="#">Recognize and Prevent Surgical Site Infections</a></li> <li>» <a href="#">Ventilator-Associated Pneumonia</a></li> </ul> | <p>Empowered Patient Coalition</p> | <p>The guides and checklists are designed to support patients and families and help avoid adverse events during a hospital stay. The campaign's resources are available through a free membership.</p> |

Source: HRET, 2015.

### SHARED DECISION MAKING

While in some situations a patient's course of treatment is clear, in many others the clinical decision requires the careful consideration of potential benefits and risks and should take into account the patient's goals, preferences and circumstances. Shared decision making is necessary in many situations, and clinicians **can facilitate** the process by asking patients questions about what they care about and providing decision aids that effectively communicate treatment options and possible outcomes.<sup>32</sup> These decision aids can be provided as an electronic or paper document or via video. Health information technology can allow providers to prescribe decision aids to patients through the electronic health record. HIT can also aid in collecting patient information on knowledge gaps related to their condition and treatment options.

Patients differ from one another and their physicians; they may select care options that lack evidence or increase the cost of health care.<sup>33</sup> Former CMS Administrator, Dr. Donald Berwick, contends that evidence-based medicine must at times take a back seat to providing true patient-centered care.<sup>34</sup> While shared decision making could theoretically increase costs, current evidence related to surgery decisions suggests the opposite is true. A program that would encourage shared decision making was authorized under the Affordable Care Act, but funding was not appropriated, despite the evidence that effective physician-patient communication does have a positive impact on health outcomes and cost efficiency.<sup>35,36</sup> Below are resources to facilitate the practice of shared decision-making in your organization.

## HOW CAN THESE RESOURCES HELP YOU?

- » Integrate [Advanced Care Planning Decisions](#) videos and [Option Grids](#) into the shared decision-making process in your organization.
- » Start by asking one clinician to test a shared decision-making model using [Shared Decision Making: A Model for Clinical Practice](#).

| RESOURCE TITLE  | ORGANIZATION                                   | DESCRIPTION  |
|---|--|--|
| <a href="#">Advanced Care Planning Decisions</a>  | ACP Decisions                                  | The website and mobile application provides videos as decision support tools and includes the evidence of their impact; it also features patient checklists and provider resources.  |
| <a href="#">Effective Healthcare Options</a>  | Agency for Healthcare Research and Quality     | This website is designed to help patients communicate with health care providers; it hosts patient stories and a tool to help identify priorities. Another section of this website provides decision aids.   |
| <a href="#">Treatment Options in English and Spanish</a>  | Agency for Healthcare Research and Quality     | This website provides clear, unbiased treatment options for patients and their families.   |
| <a href="#">Choosing Wisely Lists</a>   | American Board of Internal Medicine Foundation | This catalog features more than 100 patient and provider education resources developed by professional societies. These resources are intended to facilitate wise decisions about the most appropriate care based on a patient's individual situation; the patient resources are provided in both English and Spanish. |
| <a href="#">Getting Tools Used: Lessons for Health Care from Consumer Decision Aids</a>             | Center for Advancing Health                    | This research identifies the key elements of success from consumer decision aids and describes the implications of these findings for health care decision aids.   |
| <a href="#">Decision aids to help people who are facing health treatment or screening decisions</a> | Cochrane Review                                | This article discusses the results of a study conducted to assess the impact of decision aids.   |
| <a href="#">Shared Decision Making: A Model for Clinical Practice</a>                               | Journal of General Internal Medicine           | This article translates conceptual descriptions of shared decision making into a three-step practice model.  |

| <b>RESOURCE TITLE</b>   | <b>ORGANIZATION</b>                                   | <b>DESCRIPTION</b>  |
|---|---|---|
| <b>Shared Decision Making Center</b>  | Mayo Clinic   | This website provides decision aids, the literature supporting them and resources to support their effective use by clinicians.   |
| <b>Shared Decision Making: Advancing Patient-Centered Care Through State and Federal Implementation</b> | National Academy for State Health Policy              | This report outlines the approaches that states have pursued to implement shared decision-making.   |
| <b>OpenNotes Toolkit</b>  | OpenNotes   | OpenNotes is a national initiative working to give patients access to the visit notes written by their doctors, nurses or other clinicians. This toolkit provides communication and policy suggestions, a sample FAQ and a PowerPoint to help clinicians make the case for OpenNotes in their organization. |
| <b>Ottawa Personal Decision Guides</b>  | Ottawa Hospital Research Institute                    | These guides can help patients identify their decision making needs, plan next steps and share their views about the decision. The guides are available in English, French, Spanish, Japanese, Swedish and Dutch.   |
| <b>Option Grid</b>  | The Dartmouth Center for Health Care Delivery Science | These short decision aids are designed to help patients and health care professionals compare and discuss treatment options for specific diagnoses.   |
| <b>Person-centered care: from ideas to action</b>   | The Health Foundation                                 | This report is a review of the evidence for shared decision-making and self-management support.   |

Source: HRET, 2015.

## **HEALTH INFORMATION TECHNOLOGY**

The quality of health care in the U.S. varies widely between different states and hospitals.<sup>37</sup> The Health Information Technology for Economic and Clinical Health (HITECH) act was enacted to accelerate the adoption of electronic health records as a means to drive improvement in quality of care and to effectively engage patients. While the adjustment has been painful and rife with unintended consequences, HIT will likely

improve efficiencies and play a critical role in helping patients to become more informed and involved in their own care.<sup>38</sup> A literature review found that 92 percent of 154 recent articles on HIT reached positive overall conclusions.<sup>39</sup>

In a Kaiser Permanente study of 35,423 people with diabetes and/or hypertension, the use of secure patient-physician e-mail within a two-month period was associated with a statistically significant improvement

in the effectiveness of care.<sup>40</sup> While the study has limitations, it provides some insight into the potential benefits of HIT, which organizations are just beginning to realize. The health care industry should continue to share information on organizational HIT challenges and effective strategies to address them. Below are resources to help hospitals and health systems achieve meaningful use and take advantage of HIT benefits.

Stage 2 and ultimately Stage 3 criteria.

- » Understand how organizations have implemented patient-reported measurement systems and how the system has improved care by reviewing [Using Patient-Reported Information to Improve Health Outcomes and Health Care Value: Case Studies from Dartmouth, Karolinska and Group Health](#).

## HOW CAN THESE RESOURCES HELP YOU?

- » Use [How to Implement EHRs: Achieve Meaningful Use Stage 2](#) to support your organization’s efforts to achieve

| RESOURCE TITLE   | ORGANIZATION  | DESCRIPTION   |
|--|---|---|
| <b>Enabling Patient-Centered Care Through Health Information Technology</b>  | Agency for Healthcare Research and Quality            | This report reviews the evidence on HIT applications related to patient-centered care, identifying barriers and opportunities.                                  |
| <b>Patient Engagement Framework</b>  | Healthcare Information and Management Systems Society | This model guides health care organizations in developing and strengthening their patient engagement strategies through the use of eHealth tools and resources. |
| <b>Personal Health Information Technology – Paradigm for Providers and Patients to Transform Healthcare through Patient Engagement</b> | Healthcare Information and Management Systems Society | This white paper identifies trends in personal health information technology and describes how patient engagement connects to the HITECH Act.                   |
| <b>Health IT and Patient Safety: Building Safer Systems for Better Care</b>  | Institute of Medicine                                 | This report evaluates health IT safety concerns and recommends ways to make patient care safer using health IT.   |
| <b>Building a Strategy to Leverage Health Information Technology to Support Patient Engagement</b>                                     | National Committee for Quality Assurance              | This report includes recommendations for advancing opportunities to use health IT to support patient engagement and progress toward the Triple Aim.             |

|  |  |  |
|--|--|--|
| <b>Blue Button® Connector</b>  | Office of the National Coordinator for Health Information Technology | The Blue Button Connector takes patients and caregivers to the doorstep of hospitals, labs, pharmacies and/or health information exchanges that have health information online, so patients and caregivers can log-in and receive their electronic health information.   |
| <b>How to Implement EHRs: Achieve Meaningful Use Stage 2</b>   | Office of the National Coordinator for Health Information Technology | This website details how providers can meet the Stage 2 Meaningful Use requirements, increasing the sophistication, functionality and interoperability of electronic health records. Stage 2 increases health information exchange between providers and promote patient engagement by giving patients secure online access to their health information. |
| <b>Family Caregivers are Wired for Health</b>  | Pew Research Center  | This report discusses the results of a nationwide survey of more than 3,000 adults exploring the relationship between patients, caregivers and HIT.  |
| <b>A Vision for Using Digital Health Technologies to Empower Consumers and Transform the U.S. Health Care System</b>                                 | The Commonwealth Fund  | This report describes early efforts to use digital technologies to redesign care models around the common needs of discrete patient populations. The approaches described focus on the needs of patients with complex and costly health conditions.  |
| <b>Using Patient-Reported Information to Improve Health Outcomes and Health Care Value: Case Studies from Dartmouth, Karolinska and Group Health</b> | The Dartmouth Institute for Health Policy and Clinical Practice      | This peer- reviewed technical report discusses the value of patient-reported outcome data and describes how measurement systems can be implemented; the report features three case studies.  |

Source: HRET, 2015.

## ENGAGING TO REDUCE DISPARITIES

The 2014 National Healthcare Quality and Disparities Report found that large economic, racial and ethnic disparities in health care quality and outcomes were not substantially improving.<sup>41</sup> These disparities stand to impact a larger portion of the population as U.S. demographics shift. By 2060, the U.S. will no longer have a majority racial and ethnic group, and the elderly population will more than double in size.<sup>42</sup> Health care organizations cannot meet the needs of increasingly diverse and older communities with a one-size-fits-all approach. To fully understand disparities that may exist, hospitals and health systems need to collect and analyze demographic data on the populations they serve. In a recent study of over 79,000 patients with acute cardiovascular disease, pneumonia and major surgery, Asian and Hispanic patients had significantly higher rates of hospital-acquired infections than white non-Hispanic patients.<sup>43</sup> The nature of these findings suggest that language barriers may play an important role in health care disparities. When organizations understand the variations in quality of care that different patient populations experience, they can develop culturally and linguistically appropriate services and targeted

interventions to address disparities. Below are resources to help hospitals and health systems provide more patient-centered care to the populations they serve.

### HOW CAN THESE RESOURCES HELP YOU?

- » Develop a reliable system for collecting and analyzing race, ethnicity and language data using [Equity of Care: A Toolkit for Eliminating Health Care Disparities](#).
- » Conduct an organizational assessment, review case studies and develop a plan to address health care disparities in your organization using the resources available through [National Center for Cultural Competence](#).
- » Review the [National Standards for Culturally and Linguistically Appropriate Services \(CLAS\) in Health Care and The Blueprint](#) and ensure the patient and family advisors council and the leadership board reflect the level of diversity found in the community.
- » Develop a workforce training program consisting of orientation materials, brown bag lunches and in-services on ways to meet the unique needs of diverse populations and integrate the [HealthReach](#) resources.

| RESOURCE TITLE  | ORGANIZATION            | DESCRIPTION   |
|---|-------------------------|---|
| <a href="#">A Toolkit for Serving Diverse Communities</a> | Administration on Aging | This toolkit serves as a resource for aging agencies and their partners to provide services for diverse communities. It outlines a four-step process consisting of 1) assessments, 2) identifying community resources, 3) designing services and 4) program evaluation. |



| <b>RESOURCE TITLE</b>  | <b>ORGANIZATION</b>   | <b>DESCRIPTION</b>   |
|--|---|--|
| <b>Equity of Care: A Toolkit for Eliminating Health Care Disparities</b>                 | American Hospital Association/<br>Health Research & Educational Trust | This compendium of resources is designed to aid in accelerating the elimination of health care disparities. It includes “Improving Health Equity through Data Collection and Use” and “A Framework for Stratifying Race, Ethnicity and Language Data,” among other guides.                             |
| <b>2014 National Healthcare Quality and Disparities Report</b>                           | Agency for Healthcare Research and Quality                            | This report integrates health care quality and health care disparities findings into a single document that provides a comprehensive overview of the health care received by the general U.S. population and the disparities in care experienced by different racial, ethnic and socioeconomic groups. |
| <b>Culturally Effective Care Toolkit</b>   | American Academy of Pediatrics  | This toolkit helps practicing pediatricians provide culturally effective care to their patients and families.  |
| <b>Health Information Translations</b>   | Central Ohio Hospital Council   | This website provides health education resources in multiple languages for health care professionals and others to use in their communities.   |
| <b>Patient-Centered Care for Underserved Populations: Definitions and Best Practices</b> | Economic and Social Research Institute/Kellogg Foundation             | Developed from a literature review and case study analysis, this research report delineates the core concepts of patient-centered care for vulnerable populations and outlines best practices, critical support structures and processes.  |
| <b>National Center for Cultural Competence</b>   | Georgetown University   | This comprehensive website provides assessments, guides, checklists and patient stories to increase the capacity of health care and mental health care programs to design, implement and evaluate culturally and linguistically competent service delivery systems.                                    |



| RESOURCE TITLE   | ORGANIZATION                   | DESCRIPTION  |
|--|--------------------------------|--|
| <b>Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care</b>                                       | Institute of Medicine          | Released in 2002, this report found that a large body of research demonstrates significant variation in the rates of medical procedures by race, even when insurance status, income, age and severity of conditions are comparable. The report recommends cross-cultural curricula and continuing education for providers, health literacy programs and the collection, reporting and monitoring of patient care data, among other strategies. |
| <b>The Disparities Solutions Center</b>  | Massachusetts General Hospital | The Disparities Solutions Center website hosts several publications that highlight practical solutions to identify and address disparities within hospitals and other health care organizations.   |
| <b>HealthReach</b>   | National Institutes of Health  | This resource library houses health education materials in various languages and formats as well as provider tools. Tools include best practices, cultural information and guidance on the effective use of interpreters.  |
| <b>National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health Care and The Blueprint</b> | Office of Minority Health      | The National CLAS Standards provide a framework for culturally and linguistically appropriate services; the accompanying Blueprint describes implementation strategies for each standard.  |
| <b>Speaking Together Toolkit</b>   | Robert Wood Johnson Foundation | This toolkit provides advice to hospitals on improving quality and accessibility of language services.   |
| <b>Promising Practices for Patient-Centered Communication with Vulnerable Populations: Examples from Eight Hospitals</b> | The Commonwealth Fund          | Through site visits and focus group discussions, this report elucidates “promising practices” from hospital efforts to lower language barriers and ensure safe and effective interactions. Leaders can use these practices as starting points to encourage patient-centered communication in their own organizations.  |

| RESOURCE TITLE   | ORGANIZATION             | DESCRIPTION  |
|--|--------------------------|--|
| <b>Advancing Effective Communication, Cultural Competence, and Patient-and Family-Centered Care: A Roadmap for Hospitals</b> | The Joint Commission     | The Roadmap provides recommendations to help hospitals address unique patient needs, meet the patient-centered communication standards and comply with related Joint Commission requirements. Example practices, information on laws and regulations, links to supplemental information, model policies and educational tools are also included. |
| <b>EthnoMed</b>  | University of Washington | EthnoMed contains information about cultural beliefs, medical issues and related topics pertinent to the health care of immigrants and refugee groups in Seattle.  |

Source: HRET, 2015.

## VIDEOS

Videos are great tools that can be used to initiate deeper discussions about patient-centered care in your organization. They are another way to provide education to patients and families. In 2013, the Pew Research Center reported that 78 percent of online adults watch or download videos, and 50 percent of online adults say they watch educational videos. Using mobile technology, videos are now easily created and uploaded to video sharing sites such as YouTube and Vimeo. Videos are also enduring material, so they can be used as shared decision-making tools and health literacy resources to support non-English speaking patient populations.<sup>44</sup> Below are some of the PFE videos available to inform, educate and stimulate discussion in hospitals and health care systems.

## HOW CAN THESE RESOURCES HELP YOU?

- » Foster strategic discussions about quality and PFE at the board level using the [Eliminating Harm, Improving Patient Care: Trustee Guide](#).
- » Play [I have been a patient since I was born: Institute for Healthcare Improvement Faculty and Patient/Family Advisor, Tiffany Christensen](#) and [My Prepared Patient Story: Jessie Gruman](#) at a front-line staff meeting and discuss the difference between patient priorities and non-compliance.
- » Learn how organizations have instituted shared decision-making through the [Shared Decision-Making Videos](#).

| VIDEO TITLE   | ORGANIZATION                  | DESCRIPTION   |
|---|-------------------------------|---|
| <b>Patient- and Family-Centered Care: Partnerships for Quality and Safety</b> | American Hospital Association | This video defines patient- and family-centered care and outlines its core concepts; it can be downloaded from the American Hospital Association website. |

| VIDEO TITLE  | ORGANIZATION   | DESCRIPTION  |
|--|--|--|
| <b>Eliminating Harm, Improving Patient Care: Trustee Guide</b>   | American Hospital Association/ Health Research & Educational Trust | This video series and accompanying workbook strive to enhance the board’s ability to connect their work in the boardroom to quality in their organization and the patient experience.  |
| <b>Waiting Room</b>  | Agency for Healthcare Research and Quality                         | This video features patients and clinicians discussing the importance of asking questions at medical visits.   |
| <b>Frontline Innovators: Patient- and Family-Centered Care</b>   | Agency for Healthcare Research and Quality                         | This video series describes the diagnoses and unique circumstances of specific patients and details how clinicians customized their care.  |
| <b>My Prepared Patient Story: Jessie Gruman</b>  | Center for Advancing Health  | In this video, Jessie Gruman describes her experience as a cancer patient and the trade-offs she made at times with her treatment.   |
| <b>Cleveland Clinic YouTube Channel</b><br><br>» <a href="#">Cleveland Clinic’s Empathy Series Continues -- Patients: Afraid and Vulnerable</a><br>» <a href="#">Empathy: The Human Connection to Patient Care</a> | Cleveland Clinic   | These videos serve as a reminder of the emotions patients dealing with a serious condition may experience and the importance of empathy.   |
| <b>How Effective Healthcare Communication Contributes to Health Equity</b>   | Health Resources and Services Administration                       | This video defines health disparities and explains how three patient factors (i.e., health literacy, linguistic competency and cultural competency) are interdependent; it also encourages providers to take HRSA’s health literacy training course. |

| VIDEO TITLE   | ORGANIZATION                                 | DESCRIPTION   |
|---|--|---|
| <p><b>Institute for Healthcare Improvement YouTube Channel</b></p> <ul style="list-style-type: none"> <li>» <a href="#">Effective Patient Engagement</a></li> <li>» <a href="#">Engaging Patients to Improve Pain Management</a></li> <li>» <a href="#">How Do You Partner with Patients to Improve Health Care?</a></li> <li>» <a href="#">How to Make Care More Person- and Family-Centered</a></li> <li>» <a href="#">I Have Been a Patient Since I Was Born</a></li> <li>» <a href="#">One Little Pebble: Tiffany Christensen on the Power of Storytelling</a></li> <li>» <a href="#">How to Partner with Patients to Improve Health Care</a></li> <li>» <a href="#">A Patient and Family Advisor’s Advice on Engaging Patients as Partners</a></li> <li>» <a href="#">A Patient and Family Advisor on How to Make Care More Person- and Family-Centered</a></li> <li>» <a href="#">Asaf Bitton, MD, MPH, on Engaging Patients as Partners in Care</a></li> </ul> | <p>Institute for Healthcare Improvement</p>  | <p>Patient and family advisors and faculty at the Institute for Healthcare Improvement describe how and why health care organizations should effectively engage patients and families. Speakers include Libby Hoy, Tiffany Christensen, Frank Frederico and Asaf Bitton</p> |
| <p><b>Shared Decision-Making Playlists</b></p>  | <p>Informed Medical Decisions Foundation</p> | <p>This YouTube channel has playlists for both patients and providers on shared decision-making; the site hosts 12 videos for patients, 14 videos for providers and 4 videos that delve into specific shared decision-making scenarios.</p>                                 |

| <b>VIDEO TITLE</b>   | <b>ORGANIZATION</b>                              | <b>DESCRIPTION</b>   |
|--|--|--|
| <b>Better Together Contra Costa Medical Center</b>                   | Institute for Patient- and Family-Centered Care  | These three videos outline the process that Contra Costa Regional Medical Center underwent as it transitioned from a “visitation” policy to a welcoming policy.  |
| <b>Hospital Videos</b>   | Institute for Patient- and Family-Centered Care  | This website links to a number of videos from hospitals nationwide; these videos cover discharge planning, bedside rounding, cultural competency, health IT, PFACs and patient safety, among other topics.   |
| <b>MedStar Health: Quality and Safety Playlist</b>                   | MedStar Health                                   | MedStar’s quality and safety playlist is home to over 80 videos; many explain how to apply high reliability principles and organizational approaches to PFE. They also include “60 seconds for safety” videos on hospital-acquired infections and patient stories. |
| <b>Patient and Family Engagement Video Series</b>                    | National Institute for Children’s Health Quality | This website hosts three videos, two of which are family stories. The third video emphasizes the value of including parent partners in quality improvement work.   |
| <b>Pioneer Toolkit Involving CNAs in Care Planning</b>               | Pioneer Network                                  | This video describes the benefits of involving CNAs in care planning in a long-term care facility.   |
| <b>Solutions: Stopping the Revolving Door of Readmissions</b>        | Robert Wood Johnson Foundation                   | This video provides case studies of the readmissions reduction efforts at University of Utah Health Care, Cullman Regional Medical Center and Northern Piedmont Community Care.  |
| <b>Quality &amp; Patient Safety Roadmap 2014 – Storyboard Videos</b> | Symposium for Leaders in Healthcare Quality      | In these videos, hospital and state hospital association quality leaders share their strategies to engage patients and families in eliminating harm.   |
| <b>Worlds Apart: A Series on Cross-Cultural Health Care</b>          | The Commonwealth Fund                            | This series calls attention to the experiences of minority Americans and patients from other countries in the U.S. health care system.   |

Source: HRET, 2015.

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