

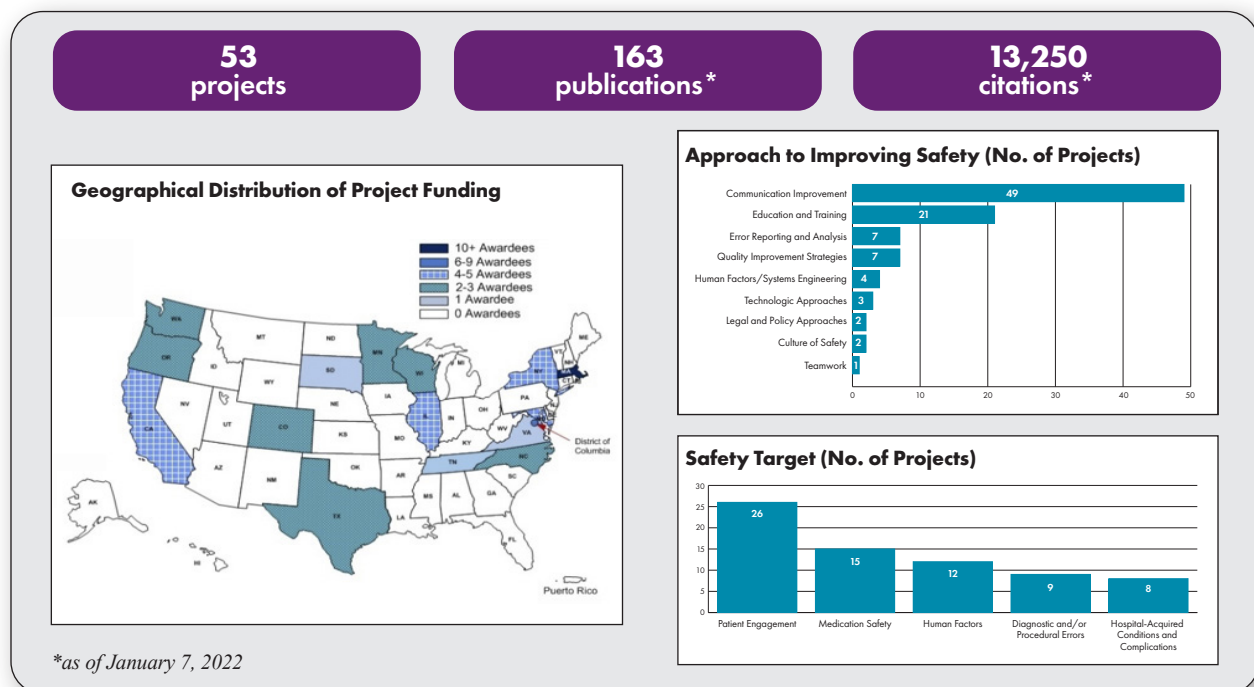
AHRQ-Funded Patient Safety Project Highlights

Improving Healthcare Safety by Engaging Patients and Families

Overview

Research has shown that involving patients, as well as their families and caregivers, in the planning, delivery, and evaluation of their healthcare can improve safety and quality. Since 2000, AHRQ has supported 53 patient safety projects related to increasing patient and family engagement. This publication summarizes AHRQ's investments in this promising pathway toward better care, including examples of project findings and products, collective outputs, and impacts of this work. Details about each AHRQ-supported project are available in the [Appendix](#).

Scope of AHRQ Investments



The largest number of projects was awarded to institutions based in Massachusetts (n=12), followed by Maryland and New York (n=5). These projects resulted in at least 163 publications, which have been cited over 13,250 times in other articles.

Twenty-nine (55%) of the projects were applicable to all AHRQ priority populations. Nearly 50 percent (n=26) of the projects aimed to improve patient and family engagement generally, while 15 (28%) had medication-related safety targets and 12 (23%) had human factor safety targets. Communication improvement was the general approach to improving patient safety in 92 percent (n=49) of the projects, followed by education and training in 40 percent (n=21) of the projects.



Examples of Project Findings

This collection of AHRQ-funded work includes projects that aim to create environments in which patients, families, and healthcare professionals work together to improve the quality and safety of care. Patient and family engagement efforts include involving patients and families in medical error reporting, using shared decision-making methods and resources, and training providers, as well as other activities designed to report and ultimately prevent medical errors and near-misses. These patient and family engagement research projects improved patient safety by generating new knowledge; developing, implementing, and evaluating tools, training modules, and other interventions; and disseminating research findings. Examples of these projects and summaries of their results are provided below and organized by research themes identified in this collection of work.

Increasing Patient and Family Reporting

To improve patient safety in hospital settings, AHRQ funded several projects focused on the role of patients and families in reporting and preventing medical errors and near-misses. For example:

- According to the researcher of an implementation study, a [Patient Advocacy Reporting System \(PARS\)](#) promoted professional self-governance, fostered a fair and just culture of patient safety, and reduced avoidable lawsuit risks by addressing “high-risk” physicians identified through analysis of unsolicited patient complaints.
- An AHRQ Patient Safety Learning Lab¹ (PSLL) developed a [MySafeCare application](#) with the goal of engaging patients, families, and professional care team members in the reliable identification, assessment, and reduction of patient safety threats in real time.
- A [program including the “We Want to Know” campaign](#) aimed to detect, address, and prevent patient-perceived breakdowns in care and encouraged patients and families to report their care experiences.
- One project demonstrated that [hospitalized patients can provide useful information about adverse events and quality of care](#) that is not captured through typical research methods (e.g., chart review) or administrative tools (e.g., hospital incident reports).

Improving Shared Decision Making

AHRQ funded projects exploring, developing, and implementing strategies to improve shared decision making (SDM) among patients and their healthcare providers. For example:

- One project interviewed emergency department (ED) providers and determined a [prioritized research agenda for the development and testing of ED SDM interventions](#) that considers what is most important to patients, caregivers, and clinicians.
- A contractor developed [two interactive educational modules—one for healthcare leaders and one for healthcare providers](#)—to make informed consent an informed choice in the hospital setting using a quality improvement approach.
- One project found that SDM has the potential to significantly reduce liabilities and hidden costs from informed consent deficiencies in surgical settings; it also disseminated an [SDM train-the-trainer toolkit](#) via [MedEdPORTAL®](#) that integrates practical solutions to implement SDM and lessons learned.
- Another project filled medical literature gaps regarding [how SDM relates to health disparities](#) by finding that service use related to social determinants of health is mediated by patients’ medical decision-making behaviors, including patient activation, depression, and health literacy.

¹PSLLs take a systems engineering approach that allows researchers and healthcare practitioners to evaluate clinical processes and enhance work and information flow to improve patient safety. AHRQ’s website has [more information on PSLLs](#).

Evidence-Based Training and Educational Resources for Healthcare Professionals

Several AHRQ-funded projects aimed to enhance the culture of patient and family engagement by helping institutions train and educate healthcare professionals. These resources include:

- A [Guide for Developing a Community-Based Patient Safety Advisory Council](#) composed of patients, practitioners, and professionals to drive changes in medication management through education, collaboration, and patient engagement.
- A [Toolkit to Engage High-Risk Patients in Safe Transitions Across Ambulatory Settings](#) that includes patient- and care partner-centered acute care discharge tools to help staff actively engage patients and their care partners to prepare for new appointments.
- A [Guide to Improving Patient Safety in Primary Care Settings by Engaging Patients and Families](#) for primary care practices and providers that includes four interventions and instructional materials for adoption and measurement of success.
- A [Guide to Patient and Family Engagement in Hospital Quality and Safety](#) that includes four strategies to help hospitals work as partners with patients and families to improve quality and safety.
- A [set of 233 quality improvement measures](#) designed to help healthcare organizations make it easier for patients with limited health literacy to navigate health systems and understand and use health information.

Impacts

AHRQ-funded patient and family engagement projects have aimed to equip healthcare organizations and institutions with the tools and knowledge needed to effectively incorporate patient and family engagement approaches into their cultures of safety. The 53 projects in this collection of work have achieved their aims with varied degrees of success but have collectively produced:

- A greater knowledge base (e.g., publications) about the role of patients in identifying potential errors and adverse events across various healthcare settings.
- Training tools, guides, and modules to help healthcare leaders and providers include patients and families in their medical decisions.
- User-friendly tools and resources to help patients and families better understand clinical risks, engage in provider decision making, and prevent and report diagnostic or medication-related errors.

In addition, the products and resources developed by this body of AHRQ-funded work have collectively helped to:

- Improve patient-provider communication (e.g., shared decision making, patient portals).
- Increase patient and family engagement in decision making (e.g., interactive educational modules, train-the-trainer toolkits).
- Improve health outcomes by increasing patient safety, self-efficacy, and adherence to care recommendations (e.g., digital medication managers, peer-led self-management programs).
- Reduce the rate of harms and errors within hospital settings (e.g., patient-focused recommendations).

To learn more about each project included in the synthesis, refer to the [Appendix](#) that follows.

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Appendix

Patient and Family Engagement Grant and Contract Summary

This appendix briefly describes AHRQ-funded projects related to patient and family engagement. Projects are organized chronologically by state. If applicable, the number of products (e.g., guides, modules, toolkits) each project developed is indicated in parentheses within the right-most column, after the number of publications. The grants listed below are linked to the [NIH RePORTER](#), an electronic tool that allows users to search a repository of federally funded research projects and access publications resulting from such funding.

Principal Investigator Organization City, State	Project Number [Type] Title	Project Period	Total Research Investment	Purpose and Key Findings/Impact	Number of Publications (Products)
California					
Michael Seid Children's Hospital Research Center San Diego, California	R03 HS11751 [Grant] Managing the Health Needs of Vulnerable Children	2001- 2003	\$96,251	<p>Purpose: To gain insight into the experiences of vulnerable children's families: how they define their children's health needs, decisions regarding where and when to seek care, and their experiences with care received.</p> <p>Key Findings/Impact: Parents defined a healthy child as active, happy, and energetic, with a good appetite. They emphasized good nutrition, exercise, and culturally mediated practice such as regulating heat and cold as ways to prevent illness. Parents tended to seek medical care as a last resort after trying to treat symptoms themselves. They received much of their information from family and friends and used complementary or alternative medicine and home remedies fairly frequently. There was much frustration with wait times and access. Parents want doctors to explain clearly, be thorough, listen, and be a partner. Several parents shared stories of doctors who went above and beyond in their duties.</p>	0
Michael Seid Children's Hospital Research Center San Diego, California	R03 HS13058 [Grant] Barriers to Care for Chronically Ill Vulnerable Children	2002- 2004	\$99,250	<p>Purpose: To develop and test a questionnaire in both English and Spanish that identifies and measures modifiable barriers to care that affect the link between vulnerability factors and healthcare structures, processes, and outcomes for children with special healthcare needs (CSHCN).</p> <p>Key Findings/Impact: A final report was unavailable; however, this grant resulted in a 39-item Barriers to Care Questionnaire (BCQ). Barriers to care are conceptualized as a multidimensional construct consisting of pragmatics, health knowledge and beliefs, expectations about care, skills, and marginalization. It was found that the BCQ total scale and subscales correlated in the expected direction with validated measures of primary care characteristics and health-related quality of life. BCQ scores were higher (fewer barriers) for children with a primary care physician and for those who reported no problems getting care or who had forgone care. The BCQ is a feasible, reliable, and valid instrument for measuring barriers to care for CSHCN. Its use may inform efforts to support patient choice, enhance provider accountability, and spur quality improvement.</p>	2

Principal Investigator Organization City, State	Project Number [Type] Title	Project Period	Total Research Investment	Purpose and Key Findings/Impact	Number of Publications (Products)
John Heritage University of California, Los Angeles Los Angeles, California	RO1 HS13343 [Grant] Addressing Patients' Multiple Concerns in Primary Care	2002-2005	\$303,627	<p>Purpose: To investigate the extent of patients' unarticulated complaints and physicians' management of multiple complaints in the acute primary care context.</p> <p>Key Findings/Impact: Researchers sought to determine whether a simple communication intervention (asking patients about additional concerns in one of two ways: "Is there ANY/SOMETHing else you want to address in the visit today?") helped patients articulate multiple complaints and allowed them to be addressed more fully and effectively. Findings showed that, relative to controls, the SOME condition nearly halved the odds of unmet concerns (OR=0.57, p=.036). The ANY condition had no impact on unmet concerns relative to controls. Neither arm of the intervention influenced visit length. Although the SOME condition generated many additional concerns, it was not associated with the expression of concerns not listed in previsit surveys. Neither arm of the intervention influenced visit length or patient satisfaction. Although the SOME condition generated many additional concerns, it was not associated with the expression of concerns not listed in the previsit survey.</p>	3
Anthony Jerant University of California, Berkeley, Berkeley, California	RO1 HS13603 [Grant] A Randomized Trial of Home Self-Efficacy Enhancement	2003-2008	\$2,270,621	<p>Purpose: To determine whether Homing in on Health (HIOH), a variant of the peer-led Chronic Disease Self-Management Program (CDSMP), improves patient outcomes at 1 year.</p> <p>Key Findings/Impact: In-home (but not telephone) HIOH led to significantly higher self-efficacy at 6 weeks (effect size = 0.27, 95% CI = 0.10, 0.43), an effect attenuating by 1 year. Of other 1-year outcomes, only EuroQol Visual Analog Scale (EQ VAS) scores were significantly improved (effect size = 0.40, 95% CI = 0.14, 0.66). HIOH enhanced self-efficacy primarily in participants with: (1) more depressive symptoms; (2) lower perceived control; and (3) higher levels of neuroticism or lower levels of conscientiousness, agreeableness, and extraversion. Additional studies are required to explore long-term effects of the CDSMP.</p>	8

Principal Investigator Organization City, State	Project Number [Type] Title	Project Period	Total Research Investment	Purpose and Key Findings/Impact	Number of Publications (Products)
Colorado					
Joann Congdon University of Colorado, Denver Denver, Colorado	R18 HS10926 [Grant] Quality Factors in Nursing Home Choices	2000- 2004	\$732,477	<p>Purpose: To develop and evaluate information strategies to assist patient use of quality factors in making nursing home (NH) choices.</p> <p>Key Findings/Impact: A three-part Nursing Home Choice Tool was developed: (1) First Steps in Choosing a NH, (2) NH Quality Report Card, and (3) NH Tour Guide. Seven quality domains identified in qualitative interviews were incorporated: environment, food and dining, staff-resident-family relationships, quality care, safety, family involvement, and administrative issues. The instrument was evaluated for content and format by 9 focus groups with 50 patients and healthcare providers. Parts I and III were rated positively but Part II (report card) needs refinement. Patients valued quality of life factors in NHs; these findings were incongruent with the science-based quality indicators in the public domain.</p>	1(1)
Angela Brega University of Colorado, Denver Denver, Colorado	HHSP233201500025 I-HHSP23337002T [Contract] Making Patient Navigation and Understanding Easier: Developing Quality Improvement Measures	2015- 2017	\$297,123	<p>Purpose: To identify and establish face validity of a set of meaningful quality improvement measures of organizational practices that make it easier for people to navigate health systems and to understand and use health information.</p> <p>Key Findings/Impact: This project resulted in the identification and preliminary evaluation of 233 unique quality improvement measures designed to help healthcare organizations assess health literacy-related features of their environments and monitor the impact of quality improvement efforts aimed at increasing support for patients with limited health literacy. A Delphi Panel reviewed 70 of the measures, 34 of which were perceived to have strong usefulness and face validity. These measures, which make up the Recommended Organizational Health Literacy Measurement Set (ROHL-MS), address all domains of OHL. A large percentage (38%) addresses organizational performance related to communication, with 26% focusing on organizational structure, policy, and leadership. A smaller percentage of measures addresses the remaining two OHL domains (Ease of Navigation and Patient Engagement & Self-Management Support [12% each]). An additional 12% of measures included in the ROHL-MS addresses more than one OHL domain.</p>	2

Principal Investigator Organization City, State	Project Number [Type] Title	Project Period	Total Research Investment	Purpose and Key Findings/Impact	Number of Publications (Products)
District of Columbia					
Naj Wikoff Society for the Arts in Healthcare Washington, DC	R13 HS10953 [Grant] Diabetes and the Arts and Humanities: Planning Conference	2001- 2002	\$49,900	<p>Purpose: To support a planning conference at the Veterans Affairs Education Center in Durham, North Carolina, to develop model strategies and protocols for using and determining effectiveness of arts and humanities activities in conjunction with the diagnosis and treatment of people living with type 2, adult-onset diabetes.</p> <p>Key Findings/Impact: No final report or publications are available, but according to an AHRQ research announcement, this grant provided support for a January 2002 conference to identify ways to use arts and humanities activities in the education and treatment of patients at high risk for developing or living with type 2 diabetes. Attendees included professionals in education and treatment of diabetes, cultural competency, the arts, arts programs in healthcare settings, research and evaluation techniques, hospital planning, government, foundations, and corporate entities, as well as patients and caregivers of people living with diabetes. Participants identified questions, arts projects, protocols, and evaluation procedures that could be of value in the education and treatment of patients with or at risk for type 2 diabetes.</p>	0
Lauren Leroy Grantmakers in Health Washington, DC	R13 HS13672 [Grant] Making Quality Health Care Decisions	2004- 2005	\$34,500	<p>Purpose: To bring together representatives from foundations, government, research, and advocacy to share experiences, expertise, and perspectives while learning about specific strategies to inform patients about healthcare quality.</p> <p>Key Findings/Impact: During the issue dialogue, health grant makers and experts from the field participated in an open exchange of ideas and perspectives on how quality is assessed and how the resulting information is disseminated to the public, as well as how patients use information in the decision-making process. The meeting also explored strategies for funders to effectively support patients and shared lessons from foundation-supported activities already underway.</p> <p>The resulting Issue Brief focused on how patients can use information on healthcare quality in making important decisions. The brief noted that patient information about healthcare must be available, understandable, and relevant. It discussed a variety of mechanisms for providing information to patients, including the use of report cards, decision support tools such as decision aids, and online resources. Meeting participants also considered the role of private funders in developing and disseminating decision-making tools; ways to translate technical data into understandable, useful formats; and strategies for working with the public sector.</p>	0 (2)

Principal Investigator Organization City, State	Project Number [Type] Title	Project Period	Total Research Investment	Purpose and Key Findings/Impact	Number of Publications (Products)
Pam Dardess American Institutes for Research Washington, DC	290-06-00019-7 [Contract] Guide to Patient and Family Engagement in Health Care Quality and Safety in the Hospital Setting: Development, Implementation, and Evaluation	2009- 2012	\$1,900,000	<p>Purpose: To develop a guide that helps patients, families, and health professionals work together as partners to promote quality and safety improvements in care and promote stronger engagement.</p> <p>Key Findings/Impact: The contractor conducted an environmental scan to assess the current literature, tools, and resources available to engage patients and families in their care in the hospital setting. This scan was the foundation for the Guide to Patient and Family Engagement in Hospital Quality and Safety, a tested, evidence-based resource that:</p> <ul style="list-style-type: none"> • Consists of four specific strategies that represent critical opportunities for hospitals to improve patient and family engagement: <ul style="list-style-type: none"> ○ Strategy 1: Working With Patient and Families as Advisors ○ Strategy 2: Communicating To Improve Quality ○ Strategy 3: Nurse Bedside Shift Report ○ Strategy 4: IDEAL Discharge Planning • Contains tools, materials, and training for each of the four strategies for use by patients, families, hospital clinicians and staff, hospital leaders, and those who will support the involvement of patients and family members in the safety and quality of the patient’s care during the hospital stay. • Includes information to help hospitals support implementation of the specific strategies through broader organizational changes. • Describes critical opportunities for hospitals to engage patients and families and to create partnerships between patients, families, and hospitals around the same goals. • Addresses real-world challenges; the Guide was developed, implemented, and evaluated with the input of patients, family members, clinicians, hospital staff, and hospital leaders. • Helps hospitals engage patients and families, which in turn can help improve quality and safety, respond to healthcare reform and accreditation standards, improve CAHPS® Hospital Survey scores, improve financial performance, and enhance market share and competitiveness. • Facilitates implementation and evaluation of each strategy with detailed guidance and customizable tools. 	0 (1)

Principal Investigator Organization City, State	Project Number [Type] Title	Project Period	Total Research Investment	Purpose and Key Findings/Impact	Number of Publications (Products)
Pam Dardess American Institutes for Research Washington, DC	290-10-00018I-1 [Contract] Guide to Patient and Family Engagement in Health Care Quality and Safety in the Hospital Setting: Development, Implementation, and Evaluation	2012- 2013	\$1,900,000	Purpose: To develop a guide that helps patients, families, and health professionals work together as partners to promote quality and safety improvements in care and promote stronger engagement. Key Findings/Impact: Refer to Contract 290-06-00019-7 in this table for the details about the guide.	0 (1)
Illinois					
Martin Hatlie Consumers Advancing Patient Safety Chicago, Illinois	R13 HS17605 [Grant] Workshop on Consumer Engagement in Selected Patient Safety Topics	2008	\$46,000	Purpose: To inform six topics that depend on consumer engagement to be optimally successful: <ol style="list-style-type: none"> 1. Patient reporting of medical errors and near misses; 2. Patient and family engagement in healthcare organization policymaking and operation via participation in safety, quality, or policymaking activities at the organizational level; 3. Active patient and family engagement in ensuring the safety of their own care or that of their loved ones; 4. Effective response to error and engaging patients in organizational learning from such events; 5. Prioritizing of error prevention initiatives in Chicago; and 6. Improvement of communication between patients and clinicians. Key Findings/Impact: Across the six topics, two recurring platforms for change emerged. First, healthcare organizations in Chicago “open the doors” and integrate consumers into their existing safety and quality committees, processes, and other infrastructure. Second, healthcare organizations in Chicago engage in collaborative projects to implement change initiatives and measure progress. A notable contribution made by workshop participants of African ancestry was their raising the theme of racial discrimination in healthcare and its impact on the safety of minority patients. Products included six topical action plans; a Challenge to Chicago; scholarly articles, public communications; and videotaped interviews.	0 (1)

Principal Investigator Organization City, State	Project Number [Type] Title	Project Period	Total Research Investment	Purpose and Key Findings/Impact	Number of Publications (Products)
Barbara Edson Health Research and Educational Trust (HRET) Chicago, Illinois	HHSP233201500 0161 [Contract] Toolkit To Engage High-Risk Patients in Safe Transitions Across Ambulatory Settings	2016- 2021	\$670,484	<p>Purpose: To adapt select evidence-based patient and care partner-centered acute care discharge tools and create a toolkit to help staff actively engage patients and their care partners to prepare for new appointments.</p> <p>Key Findings/Impact: Few staff used the support materials in the original pilot-tested toolkit. They noted the need for the toolkit but found it long and hard to implement due to necessary staffing and time. They were more likely to implement the toolkit if it fit into the current workflow. Many suggested integrating it with after-visit summaries to reduce burden, streamline workflow, and decrease redundancy. In interviews, staff noted the importance of teamwork, communication, and mutual support. Staff encouraged other facilities to adapt the toolkit to fit their needs.</p> <p>The contractor revised the tools accordingly. They made key changes to facilitate adaptation and use in existing or new ambulatory care workflows. These findings frame the opportunities and challenges in engaging patients and their care partners as active participants in preventing harm during transitions of care. Further study is needed to evaluate the impact of the tools and resources on quality and patient safety outcomes and patient and clinician experiences.</p>	0
Kevin O'Leary Northwestern University at Chicago Chicago, Illinois	R18 HS25649 [Grant] Redesigning Systems To Improve Quality for Hospitalized Patients	2017- 2022	\$1,974,465	<p>Purpose: To implement a set of evidence-based complementary interventions across a range of clinical microsystems, identify factors and strategies associated with successful implementation, and evaluate the impact on quality.</p> <p>Key Findings/Impact: To date, the grant has produced the REdesigning SystEms to Improve Teamwork and Quality for Hospitalized Patients: RESET Project Implementation Guide. This guide helps hospital staff redesign their systems to optimize care for hospitalized patients. The project's first publication reported findings from a multisite, cross-sectional study of interprofessional teamwork and collaboration on general medical services. The teamwork climate among nurses, nurse assistants, and physicians working on general medical services in four midsize hospitals was assessed using the Safety Attitudes Questionnaire. The study found significant differences in teamwork climate perceptions across sites and in collaboration across professional categories. The investigator concluded that leaders should consider assessing teamwork and collaboration among general medical services staff within their own hospitals.</p>	1 (1)

Principal Investigator Organization City, State	Project Number [Type] Title	Project Period	Total Research Investment	Purpose and Key Findings/Impact	Number of Publications (Products)
Jonah Stulberg Northwestern University Evanston, Illinois	R18 HS027331 [Grant] Preventing Opioid Misuse Through Safe Opioid Use Agreements Between Patients and Surgical Providers (PROMISE ME)	2020- 2023	\$448,522	Purpose: To test the use of 23 contractual agreements to improve safe opioid use and prevent misuse and opioid-related harm. Key Findings/Impact: This grant is ongoing, and no final report or publications are available yet.	0
Maryland					
Hanan J. Aboumatar Johns Hopkins University Baltimore, Maryland	R13 HS21921 [Grant] Identification and Dissemination of Best Practices for Patient-Centered Care	2012- 2013	\$49,728	Purpose: To identify and disseminate healthcare innovations and promising practices for making hospital care patient centered. Key Findings/Impact: Survey responses from 138 informants and 57 conference presentations revealed that high-performing hospitals use multiple concurrent strategies and similar interventions to achieve improvement. Conference attendees, who provided highly positive ratings for the conference, stated the conference helped inspire them and offered practical ideas they intended to apply at their own organizations. It also helped to surface and disseminate evidence-based practices to improve the patients' experiences of care within the hospital and introduced a new approach to learning about successful improvement strategies in this area. This approach centers on use of objective criteria for best practice identification and disseminating those via peer learning methods. Learning from this conference was also widely shared with a broad national and international audience through the widespread circulation of electronic conference proceedings, conference presentations, and peer-reviewed publications.	2

Principal Investigator Organization City, State	Project Number [Type] Title	Project Period	Total Research Investment	Purpose and Key Findings/Impact	Number of Publications (Products)
Kelly Smith Medstar Health Research Institute Hyattsville, Maryland	HHSP2332015000 221/ HHSP23337002T [Contract] Guide to Improving Safety in Primary Care Settings by Engaging Patients and Families	2015- 2018	\$1,964,408	<p>Purpose: To develop a guide for primary care practices to use to engage patients and families in their care to improve patient safety.</p> <p>Key Findings/Impact: This contract generated a guide to help primary care practices, primary care providers, and patients increase patient and family engagement (PFE) in care. This project created many resources, including:</p> <ul style="list-style-type: none"> • An environmental scan report describing approaches to engage patients and families in primary care settings. • Case studies on exemplar practices that have increased PFE in primary care and affected patient safety. • Four interventions and accompanying instructional materials for primary care practices to adopt aimed at engaging patients and families to improve patient safety. • A comprehensive guide of interventions, instructional materials, and guidance for adoption and measurement of success. <p>The final interventions were "Be Prepared To Be Engaged," "Create a Safe Medicine List Together," "Teach-Back," and "Warm Handoff Plus." The guide dissemination efforts reached more than 18,000 people and resulted in more than 60,000 page views or downloads during the study.</p>	0 (2)
Alicia Arbaje Johns Hopkins University Baltimore, Maryland	ROI HS26599 [Grant] Making Health Care Safer for Older Adults Receiving Skilled Home Health Care Services After Hospital Discharge	2019- 2022	\$1,499,781	<p>Purpose: To develop tools to allow skilled home healthcare agencies to identify and act on threats to older adults' safety in real time to prevent readmissions.</p> <p>Key Findings/Impact: This grant is ongoing, and no final report or publications are available yet.</p>	0
Chris Goeschel Medstar Research Institute Hyattsville, Maryland	HHSP233201 5000221/75P 00119F37006 [Contract] P26: Capacity Building Related to Diagnostic Safety	2019- 2022	\$3,729,010	<p>Purpose: To support the recommendation of "Providing dedicated funding for research on the diagnostic process and diagnostic errors."</p> <p>Key Findings/Impact: This ongoing contract produced a resource to engage patients and families in the diagnostic process. The Toolkit for Engaging Patients To Improve Diagnostic Safety contains two strategies: Be the Expert on You and 60 Seconds To Improve Diagnostic Safety. When paired together, these strategies enhance communication and information sharing within the patient-provider encounter to improve diagnostic safety. Each strategy contains practical materials to support adoption of the strategy within office-based practices.</p>	1

Principal Investigator Organization City, State	Project Number [Type] Title	Project Period	Total Research Investment	Purpose and Key Findings/Impact	Number of Publications (Products)
Brandwyn Lau Johns Hopkins University Baltimore, Maryland	R18 HS27415 [Grant] Disseminating a Patient- Centered Venous Thromboembolism Prevention Bundle	2020- 2025	\$400,000	Purpose: To scale a venous thromboembolism (VTE) intervention that empowers patients to make informed decisions about their VTE preventive care and improve adherence to VTE prophylaxis medication regimens in hospitalized patients in heterogeneous environments. Key Findings/Impact: This grant is ongoing, and no final report or publications are available yet.	0
Massachusetts					
Jay Callahan National Patient Safety Foundation (NPSF) Boston, Massachusetts	R13 HS10955 [Grant] Conference on Communication and Patient Safety	2001	\$49,250	Purpose: To convene the third national “Annenberg Conference on Patient Safety,” which focused on the role of research in communication for the purpose of reducing medical error and improving patient safety. Key Findings/Impact: According to a brief report published in <i>Journal for Healthcare Quality</i> , more than 600 healthcare professionals attended the conference, which took place May 16-18, 2001, in St. Paul, Minnesota. “Let’s Talk Communicating Risk and Safety in Health Care” explored ways improved communication skills can reduce healthcare errors, enhance patient safety, and provide a more effective infrastructure for interactions among healthcare providers and patients.	1
William Hendee National Patient Safety Foundation (NPSF) Boston, Massachusetts	U18 HS12043 [Grant] Improved Patient Safety Through Web-Based Education	2001- 2004	\$782,588	Purpose: To develop, evaluate, and disseminate web-based, population-specific education modules on patient safety under the direction of the NPSF. Key Findings/Impact: Healthcare professionals developed education modules on patient safety to inform physicians, nurses, patients, and families about specific ways to make healthcare safer for patients in all healthcare settings and in the home. Specifically, the modules were developed for the following audiences: physicians (12 units); nurses (13 units); patients and families (8 units); and patients and families anticipating anesthesia (7 units); and the information center (4 units).	3

Principal Investigator Organization City, State	Project Number [Type] Title	Project Period	Total Research Investment	Purpose and Key Findings/Impact	Number of Publications (Products)
Saul Weingart Dana-Farber Cancer Institute Boston, Massachusetts	K08 HS11644 [Grant] Partnering With Patients To Find Adverse Events	2001- 2007	\$588,214	<p>Purpose: To understand the role of patients in identifying adverse events (both inpatient and ambulatory settings).</p> <p>Key Findings/Impact: This grant consisted of two projects focused on patient reporting of adverse events. The first documented the capacity of hospitalized patients to identify adverse events affecting their care and characterize these events. Inpatients reported adverse events at a rate of 8.7 percent and near-miss errors at a rate of 5.7 percent. Thirty-nine percent of patients reported service quality incidents, but none were reported in the hospital incident reporting system.</p> <p>The second project was a pilot study of adult patients enrolled in MedCheck, a patient portal used to solicit feedback from patients after receiving a new prescription, at three primary care practices affiliated with a teaching hospital. It demonstrated that patients opened 79 percent of MedCheck messages and responded to 12 percent; 77 percent responded within 1 day. Patients often identified problems filling their prescriptions (48%), problems with drug effectiveness (12%), and medication symptoms (10%). Clinicians responded to 68 percent of patients' messages; 93 percent answered within 1 week.</p> <p>These studies helped show that hospitalized patients can provide information about adverse events and quality of care that is not captured through usual research methods (such as chart review) or administrative tools (such as hospital incident reports). In addition, in another controlled study, the investigators showed that internet portals can enhance patient-physician communication and patient-reported adverse events.</p>	14

Principal Investigator Organization City, State	Project Number [Type] Title	Project Period	Total Research Investment	Purpose and Key Findings/Impact	Number of Publications (Products)
Blackford Middleton Brigham and Women's Hospital Boston, Massachusetts	R01 HS13326 [Grant] Shared Online Health Records for Patient Safety and Care	2002-2007	\$1,675,279	<p>Purpose: To assess the impact on patient care and safety of tools for electronic patient-provider communication and shared online health records.</p> <p>Key Findings/Impact: This grant resulted in at least eight publications, five of which determined that:</p> <ul style="list-style-type: none"> • Creating shared information resources to support a collaborative care model required analysis of the business, architectural, and workflow requirements of the patient-controlled clinical portal and the physician-controlled electronic medical record (EMR) system. • Concordance between documented and patient-reported medication regimens and reduction in potentially harmful medication discrepancies can be improved with a medication review tool in the personal health record (PHR) linked to the provider's medical record. • EMRs and EMR-connected patient portals offer patient-provider collaboration tools for visit-based care. • Patients receiving reminders through an electronic PHR were significantly more likely to receive mammograms (48.6% vs. 29.5%, $p=0.006$) and influenza vaccinations (22.0% vs. 14.0%, $p=0.018$), but no significant improvements were observed for other screening types. <p>More patients with access to a diabetes mellitus (DM)-specific PHR had their DM treatment regimens adjusted (53% vs. 15%; $p < 0.001$) compared with active controls. However, there were no significant differences in risk factor control between study arms after 1 year ($p = 0.53$).</p>	8
Melanie Wasserman Abt Associates Cambridge, Massachusetts	290-06-00011-9 [Contract] Improving Patient Safety System Implementation for Limited English Proficiency (LEP) Patients - Patient Safety B1 FY '09	2009-2012	\$499,978	<p>Purpose: To develop tools for healthcare professionals to address language barriers that must be overcome to engage patients with limited English proficiency.</p> <p>Key Findings/Impact: A final report was not available, but the project team used a comprehensive mixed-methods research approach to develop content and test the new limited English proficiency (LEP) tools. Both tools developed for this contract were field tested. The guide for hospitals was field tested in interviews with nine hospital quality and safety leaders. The TeamSTEPPS LEP module was tested in three hospitals that varied in size, geographic location, mission, and level of TeamSTEPPS experience. The project team completed a cross-case report to distill lessons learned across all three sites, which informed revisions to the module.</p>	1 (2)

Principal Investigator Organization City, State	Project Number [Type] Title	Project Period	Total Research Investment	Purpose and Key Findings/Impact	Number of Publications (Products)
Suzanne Mitchell Boston Medical Center Boston, Massachusetts	K08 HS19771 [Grant] Shared Decision Making in Diverse, Disadvantaged Populations; Addressing Health Disparities	2010- 2015	\$728,795	Purpose: To develop expertise as an independent investigator in shared decision making (SDM) and healthcare disparities affecting vulnerable populations. Key Findings/Impact: This series of research studies and professional development activities resulted in contributions to the medical literature that fills some of the gaps in understanding how shared decision making relates to health disparities. These projects examined how communities viewed medical decision making and experienced chronic disease self-management (e.g., diabetes self-management education among women, advance care planning among individuals living with serious physical disabilities). It was found that service use, such as cardiac catheterization and hospital readmissions, are mediated by patients' medical decision-making behaviors, including patient activation, depression, and health literacy.	6
Sarah Shoemaker Abt Associates Cambridge, Massachusetts	HSA2902010000 311, TO #3 [Contract] Improving Informed Consent in Hospitals	2013- 2018	\$550,000	Purpose: To develop interactive educational modules to train healthcare leaders and professionals to make informed consent an informed choice. Key Findings/Impact: This contract resulted in the development of two 1.5-hour training modules and a companion guide. AHRQ's Making Informed Consent an Informed Choice: Training for Health Care Leaders addressed improvements that can be made on the hospital level, and its Making Informed Consent an Informed Choice: Training for Health Care Professionals teaches 10 strategies for communicating clearly, presenting choices, and helping individual patients make an informed choice. The contractor created an implementation guide as a companion to the two modules, providing guidance for implementing the training modules with a quality improvement approach. The guide is based on the implementation experiences of four hospitals that participated in a pilot test of the training modules, as well as the experiences of other hospitals implementing quality improvements.	1 (3)

Principal Investigator Organization City, State	Project Number [Type] Title	Project Period	Total Research Investment	Purpose and Key Findings/Impact	Number of Publications (Products)
Kathleen Michele Mazor Meyers Primary Care Institute Worcester, Massachusetts	R18 HS2275Z [Grant] Detecting, Addressing, and Learning From Patient-Perceived Breakdowns in Care	2013- 2018	\$2,481,312	Purpose: To develop, implement, disseminate, and evaluate a program with a campaign titled “We Want to Know” [WWTK] that builds trust and encourages patients and family members to report on their care experiences, to detect, address, and prevent patient-perceived breakdowns in care. Key Findings/Impact: WWTK staff conducted outreach interviews with 5,560 patients and family members. Of these, 1,156 (21%) reported a care breakdown; 741 (64%) had associated harm. Relatively few patients initiated reporting. In the hospital with a dedicated WWTK specialist, 94 incoming reports were received; in the hospitals without a dedicated specialist, 23 reports were received. Patients responded positively to the WWTK program. Most clinicians and leaders supported encouraging patients to voice concerns, but implementation was inconsistent. Several hospitals adapted the program during adoption and implementation.	6
David Bates Brigham and Women’s Hospital Boston, Massachusetts	P30 HS23535 [Grant] Making Acute Care More Patient Centered	2014- 2018	\$3,967,318	Purpose: To develop tools to engage patients, families, and professional care team members in reliable identification, assessment, and reduction of patient safety threats in real time using health information technology before they manifest in actual harm. Key Findings/Impact: This Patient Safety Learning Lab intervention included three projects that were implemented on 12 inpatient units during the 18-month study period, potentially affecting 12,628 patient admissions. The first project developed the Fall TIPS tool , which decreased fall rates to 3.22/1,000 patient days during the pilot testing period. Patient feedback showed that patients were more likely to believe they needed a fall prevention plan and then follow that plan if they knew their risks of harm from falling, so the investigators integrated the ABCs of harm into both the electronic and paper Fall TIPS toolkit. The second project piloted implementation of a patient safety rounding checklist/clinician dashboard on medical ICUs and medicine, neurology, and oncology units. The tools were refined based on user feedback, to include additional safety icons, graphs for laboratory test results, and hospital resources. The third project pilot tested the MySafeCare dashboard to assess participant engagement, increase awareness and use of the reporting dashboard, and assess willingness to engage with the reporting dashboard. User interviews informed modifications to the MySafeCare application.	15

Principal Investigator Organization City, State	Project Number [Type] Title	Project Period	Total Research Investment	Purpose and Key Findings/Impact	Number of Publications (Products)
Elizabeth Schoenfeld BayState Medical Center Springfield, Massachusetts	R03 HS24311 [Grant] Physician Perspectives Regarding the Use of Shared Decision Making in the Emergency Department	2015- 2017	\$91,364	<p>Purpose: To better understand physician-identified barriers to and facilitators of shared decision making (SDM) in the emergency department.</p> <p>Key Findings/Impact: Fifteen practicing emergency physicians were interviewed regarding their SDM motivations, perceptions, barriers, and facilitators. They described the following barriers that often deterred them from using SDM: time constraints, clinical uncertainty, fear of a bad outcome, certain patient characteristics, lack of followup, and other emotional and logistical stressors. They noted that risk stratification methods, the perception that SDM decreased liability, and their own improving clinical skills facilitated their use of SDM. They also noted that institutional culture could play a role in discouraging or promoting SDM and that patients could encourage SDM by asking about alternatives. The grantee drew the following conclusions:</p> <ol style="list-style-type: none"> 1. Many barriers to using SDM are logistical issues (e.g., time constraints and lack of followup). 2. Physicians are motivated to use SDM to engage patients and decrease their use of resources or deviate from standard practice when in the best interest of the patient. 3. Physicians are split as to whether they believe their use of SDM makes them more or less likely to be sued. 4. Physicians used SDM less when supervising residents for many reasons (residents have fewer opportunities to practice SDM). 5. Many physicians believe SDM is not possible or beneficial for a subset of patients who are perceived to either not want SDM or not be capable of understanding SDM. 6. The culture of medicine is changing to be more supportive of patient involvement in decision making. <p>This grant produced one research agenda, three oral presentations at academic conferences, at least seven peer-reviewed publications, and one survey for follow-on research.</p>	7

Principal Investigator Organization City, State	Project Number [Type] Title	Project Period	Total Research Investment	Purpose and Key Findings/Impact	Number of Publications (Products)
Yuri Quintana (formerly Charles Safran) Beth Israel Deaconess Medical Center Boston, Massachusetts	R18 HS24869 [Grant] Leveraging a Social Network of Elders and Families To Improve Medication Safety at Transitions of Care	2016-2020	\$1,498,719	<p>Purpose: To expand the functionality of the InfoSAGE platform to include a mobile-first/point-of-care medication manager to help elderly people and their families keep an accurate medication list, coordinate the list with prescribing clinicians, track the impact of medications on symptoms, view medication precautions and drug-drug interactions, and become more engaged as partners in their care.</p> <p>Key Findings/Impact: The grantee identified facilitators and barriers to the use of a shared online medication list and assessed the usability and e-health literacy needs for platform adoption and usage. The grant showed that it is possible to recruit elders over 75 and their families to use online and mobile technologies for information sharing and care coordination.</p>	6
Sigall Bell Beth Israel Deaconess Medical Center Boston, Massachusetts	R01 HS27367 [Grant] Answering the Call To Engage Patients and Families in the Diagnostic Process: A New Patient-Centered Approach Using Health Information Transparency To Identify Diagnostic Breakdowns in Ambulatory Care	2019-2022	\$993,312	<p>Purpose: To develop a new patient-centered framework (PCF) codesigned with patients and families to identify, describe, and analyze patient-reported diagnostic breakdowns (PRDBs); develop and implement a new portal-based tool (OurDX) to engage patients and families in diagnosis based on the PCF using transparent electronic health information; and evaluate OurDX outcomes in three domains (i.e., safety, implementation, and stakeholder experience).</p> <p>Key Findings/Impact: This grant is ongoing, but two manuscripts have been submitted and a third is in progress. Work from this grant was presented to the Washington Patient Safety Coalition in June 2021 and the Washington State Hospital Association in July 2021. A scientific abstract was submitted to the annual Society to Improve Diagnosis in Medicine meeting describing the diagnostic error experiences of patients and families with limited English-language health literacy and a disadvantaged socioeconomic position. At the meeting in October 2021, the grantee's staff planned to present a workshop with patients and families on development of OurDx and its application to Spanish-preferring patients.</p> <p>In addition, the OurDx project is posted on an OpenNotes website, which raises awareness about the potential for open notes to improve patient engagement in diagnosis. The site will rapidly share tools and educational materials stemming from the grant with a broad readership across the United States (and enhanced further by the CURES Act) when grant materials are finalized.</p>	0

Principal Investigator Organization City, State	Project Number [Type] Title	Project Period	Total Research Investment	Purpose and Key Findings/Impact	Number of Publications (Products)
Minnesota					
Patrick O'Connor HealthPartners Research Foundation Bloomington, Minnesota	U18 HS11919 [Grant] Patient-Based Strategy To Reduce Errors in Diabetes Care	2001- 2005	\$1,203,753	<p>Purpose: To assess whether providing medical error information to patients and physicians reduces diabetes medical errors.</p> <p>Key Findings/Impact: Among patients with errors at baseline, 59.3 percent of errors were resolved by the end of the study followup period, but study interventions had a negative effect on A1c testing within 6 months of intervention ($p = 0.01$) that resolved by 12 months ($p = 0.35$). When baseline A1c ≥ 7 percent, interventions had no effect on A1c values ($p = 0.10$), but when baseline A1c ≥ 8 percent, interventions unfavorably affected A1c values ($p < 0.01$). Interventions negatively affected LDL test ordering ($p < 0.001$) but had no effect on LDL values ($p = 0.64$), which improved overall. Interventions failed to reduce errors of commission (inappropriate use of medications) ($p > 0.05$) or errors of omission (failure to intensify therapy when indicated) ($p > 0.05$).</p> <p>Numerous interaction effects were observed. Economic evaluation identified some effect of error status on subsequent healthcare utilization. Some conclusions were that customized feedback interventions to patients and physicians failed to reduce errors of omission or commission related to diabetes care. Future researchers should consider providing point-of-care decision support with redesign of office systems and incentives to increase appropriate actions in response to decision support information.</p>	6
New York					
Jennifer Carroll University of Rochester Rochester, New York	R03 HS14105 [Grant] Cultural Competency and Maternal Health in African Women	2003- 2005	\$99,998	<p>Purpose: To identify specific cultural competency techniques that improve the quality of maternal healthcare and birth outcomes through the analysis of the relative contribution of patient, clinician, and institutional-related factors to health disparities in African (specifically Somali) women.</p> <p>Key Findings/Impact: While all women were familiar with basic health promotion practices, immunizations, and routine medical examinations, few understood cancer prevention services. Three (9%) women recognized that the purpose of Pap tests was to screen for cervical cancer. Six (18%) women had heard of mammography. Themes indicated the importance of maintaining good hygiene (70%), having an adequate source of safe food and water (59%), having access to a regular source of healthcare (74%), and being able to function well at home (65%). Other themes were that health maintenance for acute survival took precedence over long-term prevention of disease and use of both U.S.-based and traditional techniques to prevent illness.</p>	1

Principal Investigator Organization City, State	Project Number [Type] Title	Project Period	Total Research Investment	Purpose and Key Findings/Impact	Number of Publications (Products)
PI Unknown The Advertising Council New York, New York	290-05-0019 [Contract] Public Service Advertising Campaign	2005- 2011	\$7,607,228	<p>Purpose: To develop and sustain a new series of public service ads that encourage patients to be more involved in their healthcare and empowered to make shared decisions about their treatment with their clinicians based on the best evidence available.</p> <p>Key Findings/Impact: A final report was unavailable, but the contract resulted in the development and deployment of four campaigns:</p> <ul style="list-style-type: none"> • Patient Involvement – Consumer & Clinician Campaign • Men’s Preventive Health Campaign • Hispanic Health Campaign • Treatment Options Awareness Campaign <p>The ads encouraged patients to visit the AHRQ website or call the AHRQ Publications Clearinghouse.</p>	0
Rita Kukafka Columbia University, School of Health Sciences New York, New York	R03 HS16333 [Grant] Communicating Probabilities Through Interactive Computer Graphics	2006- 2009	\$100,000	<p>Purpose: To develop novel interactive computer graphics to communicate risks and assess their impact on decision making and risk perception.</p> <p>Key Findings/Impact: Understanding quantitative information about probabilities is critical for health literacy, but many people cannot understand or manipulate probabilities when they are presented as numbers. In addition, people with poor numeracy have difficulty drawing emotional conclusions about quantitative risk information. A quantitative questionnaire study showed that participants who used the interactive graphic to learn about the risk were more willing to take protective action against the risk than participants who viewed noninteractive graphics illustrating the risk. The interactive graphics were rated as very helpful in understanding the risk, especially by participants who performed poorly on a numeracy scale. Interactive graphics may represent a novel way of exploiting computer gaming techniques to explain quantitative risks in health contexts.</p> <p>It is possible and potentially beneficial to tailor graphics for people with different levels of expertise or skills, and designing graphics to support specific goals (i.e., information, education, persuasion, or decision making) is important. Key findings relevant to future design work pertained to emotional impact, stick figures, and interaction.</p>	5

Principal Investigator Organization City, State	Project Number [Type] Title	Project Period	Total Research Investment	Purpose and Key Findings/Impact	Number of Publications (Products)
Steven Barnett University of Rochester Rochester, New York	K08 HS15700 [Grant] Deaf People and Healthcare	2006- 2012	\$634,959	<p>Purpose: To assess the healthcare access and quality of deaf people who primarily communicate with American Sign Language (ASL).</p> <p>Key Findings/Impact: This grant successfully adapted the Consumer Assessment of Healthcare Providers and Systems (CAHPS®) for use in ASL and piloted that instrument with 99 deaf adult ASL users. The research identified important domains not measured by the source English survey and found a high prevalence of emergency department use reported by participants. Findings from the survey adaptation process and pilot administration of CAHPS-ASL informed future research and healthcare with deaf ASL users and identified potential changes to the source English survey and surveys with other language minority populations.</p>	7
Tina Nabatchi Syracuse University Syracuse, New York	R21 HS23562 [Grant] Using Public Deliberation To Define Patient Roles in Reducing Diagnostic Error	2014- 2016	\$385,581	<p>Purpose: To deliberately engage healthcare patients in developing informed, practical, patient-focused recommendations for preventing, identifying, and reporting diagnostic error.</p> <p>Key Findings/Impact: A patient deliberation group developed 16 Patient-Centered Recommendations for Reducing Diagnostic Error and Improving Diagnostic Quality in five overarching categories, which were well received by other healthcare patients and professionals. In addition to the recommendations, the participants identified several obstacles that could reduce the effectiveness of the recommendations, as well as solutions that may mitigate the negative impact of the obstacles. For the recommendations, obstacles, and solutions, see Patient Recommendations To Improve Diagnostic Quality.</p> <p>Results of this work have been published in a report by the Society to Improve Diagnostic Medicine titled Clearing the Error: Using Public Deliberation To Define Patient Roles as Partners in the Diagnostic Process. Strategic Report. In addition, the results from this grant not only show the efficacy of deliberation as a tool that can successfully engage patients and the public on complex healthcare issues, but also suggest that deliberation is more meaningful than traditional methods of participation such as education.</p>	3 (3)

Principal Investigator Organization City, State	Project Number [Type] Title	Project Period	Total Research Investment	Purpose and Key Findings/Impact	Number of Publications (Products)
North Carolina					
Jennifer Uhrig Research Triangle Institute Research Triangle Park, North Carolina	R18 HS11008 [Grant] Helping Elders Include Quality in Health Plan Choice	2000- 2004	\$1,090,711	<p>Purpose: To develop and evaluate Choose With Care—a decision support tool for employers to use to educate and counsel people approaching age 65 about their Medicare health plan options and how to incorporate quality information into their health plan choices.</p> <p>Key Findings/Impact: Two products—the first of their kind to integrate information on cost, benefits, and quality for employer-based retiree health plans and Medicare Advantage (MA) plans—were developed and tested in a randomized controlled trial (RCT). The results of the RCT (3 arms, 152 subjects) indicated that older patients who received the intervention materials found the materials easier to use, gained greater knowledge about Medicare from them, were more likely to value comparative quality information, were more likely to select higher quality plans, and were more likely to choose a plan that reflected the dimensions they found most important compared with older patients receiving the control materials. This study builds on past work by incorporating concepts from the patient information processing model, findings from decision-making research, lessons learned from prior research, and results from cognitive and usability testing into the materials development process.</p>	1

Principal Investigator Organization City, State	Project Number [Type] Title	Project Period	Total Research Investment	Purpose and Key Findings/Impact	Number of Publications (Products)
Jo Anne Earp University of North Carolina, Chapel Hill Chapel Hill, North Carolina	R13 HS15635 [Grant] Patient Advocacy Summit: Patients at the Center of Care	2004- 2006	\$25,500	<p>Purpose: To provide participants with high-quality, up-to-date, research-based information about patient advocacy from a public health perspective and to allow individuals from a broad range of personal and professional backgrounds who share a commitment to patient advocacy to interact with each other, share ideas and information, and begin to develop partnerships.</p> <p>Key Findings/Impact: The conference included 75 attendees and 36 presenters specializing in six different topic areas who presented their work via a professional paper and seminar session. Of the 17 manuscripts submitted for the conference, 13 became chapters in a 600-page patient advocacy textbook with 48 authors. The textbook chapters are organized according to five overarching strategies of the social ecological framework:</p> <ol style="list-style-type: none"> 1. Individual Level: Understanding What Patients Are Doing Now, and What Providers Can Do To Support Them 2. Interpersonal Level: Improving Providers' Ability To Communicate and Create Relationships 3. Organizational Level: Transforming Hospital and Medical School Culture To Support Patient- and Family-Centered Care 4. Institutional Level: Making Consumers' Voices Heard in Policy and Law 5. Advancing Education and Professional Roles in Advocacy <p>Final products included a patient advocacy conference, a textbook, a national survey, and a graduate-level, distance-learning course offered through the School of Public Health at the University of North Carolina at Chapel Hill.</p>	1
Anna Beeber University of North Carolina Chapel Hill, North Carolina	R01 HS26473 [Grant] A Safer Assisted Living: Creating a Toolkit for Person and Family Engagement	2019- 2022	\$1,491,806	<p>Purpose: To explore how to translate and adapt existing patient and family engagement (PFE) work to the assisted living (AL) setting and develop a comprehensive toolkit to increase PFE in AL safety.</p> <p>Key Findings/Impact: This grant is ongoing, and no final report or publications are available yet.</p>	0

Principal Investigator Organization City, State	Project Number [Type] Title	Project Period	Total Research Investment	Purpose and Key Findings/Impact	Number of Publications (Products)
Oregon					
Ellen Peters Decision Research Eugene, Oregon	R03 HS11500 [Grant] How Do Consumers View the Risks of Medical Errors?	2001- 2003	\$100,000	<p>Purpose: To explore consumer risk perceptions and anticipate their responses to medical-error reporting as it unfolds in communities.</p> <p>Key Findings/Impact: Patients perceived medical-error risks based on dreadedness and preventability, and a model was built of the antecedents and consequences of worry about medical errors. Worry about medical errors was a better predictor of behavioral intentions than were estimated fatalities and rated likelihood of medical errors. Most recommended actions for preventing medical errors were viewed as effective. However, respondents indicated they were unlikely to engage in many of the recommended actions. Having a greater sense of self-efficacy in being able to prevent medical errors and worrying more about medical errors both were linked with a greater likelihood of engaging in preventive action. An understanding of how self-efficacy and worry influence preventive efforts will help in building strategies for communicating with the public.</p>	2
Ravi Singh Foundation for Accountability Portland, Oregon	R13 HS10975 [Grant] Consumer Activation: Research in Practice	2002- 2003	\$48,930	<p>Purpose: To support a conference that summarized and communicated research findings to organizations and individuals that can then improve the outcomes and quality of healthcare services.</p> <p>Key Findings/Impact: No final report or publications are available, but according to an AHRQ Research Activities brief published in November 2003, this grant provided support for a national 1-day conference held in Washington, DC, in 2002. Participants included representatives of patient advocacy and consumer organizations. The topic was methods to translate research findings into practice and engage consumers more effectively in their own healthcare. After the conference, the Foundation for Accountability planned to feature online dialogues with the speakers as well as discussion groups for sharing information and experiences and ongoing dissemination of research findings to this important link to the healthcare consumer.</p>	0

Principal Investigator Organization City, State	Project Number [Type] Title	Project Period	Total Research Investment	Purpose and Key Findings/Impact	Number of Publications (Products)
Mary Minniti Sacred Heart Medical Center Eugene, Oregon	P20 HS17143 [Grant] Medication Management at Home: Patient-Identified Processes and Risk Assessment	2007- 2009	\$199,977	<p>Purpose: To assess the risks associated with ambulatory care medication management from the patient perspective.</p> <p>Key Findings/Impact: Four high-level medication management processes were common among participants, providing a framework for discussion between patients and healthcare providers. They related to medication storage, container usage, use of routine and memory triggers, and usage methods. Investigators found that medication management methods used by patients are diverse and very individual. More than 300 risks were identified either by patients or the clinical team reviewing the transcripts. The potential risks identified are from the patients' perspective and have highlighted some possible areas where interventions might improve medication management safety. A vital few represent areas for further study and exploration with patients and their healthcare team.</p>	0
South Dakota					
Wendell Hoffman Sanford Health Sioux Falls, South Dakota	R21 HS19571 [Grant] A Plan To Use Sanford Health Patient Complaints To Promote Safety/ Reduce Claims	2010- 2011	\$299,995	<p>Purpose: To establish and assess a patient complaint reporting system on reducing harm and improving care and patient safety culture, to ultimately improve capture of patient and family complaints, enhance service recovery, and identify physicians at highest risk for unsafe practices and unnecessary lawsuits.</p> <p>Key Findings/Impact: A final report was unavailable, but a summary of the project findings can be found on the AHRQ website. Before implementing the Patient Advocacy Reporting System (PARS) throughout Sanford Health System (SHS), Vanderbilt's Center for Patient and Professional Advocacy staff assessed its readiness via the presence of 10 elements (e.g., leadership commitment, resources) deemed critical for success. The grant showed how in 1 year, a large multistate healthcare system became prepared to implement an intervention process that promotes professional self-governance, fosters a fair and just culture of safety and kindness, and reduces avoidable lawsuit risk. Use of this system has continued beyond the grant funding and results of the effort have been published.</p> <p>After successfully implementing PARS, SHS trained peer physicians to serve as "messengers" to share local and national PARS data comparisons with physicians whose risk scores exceeded intervention thresholds. As of 2016, six rounds of annual interventions had been completed. The peer physician messengers delivered PARS data with high fidelity to intervention elements for 6 years to 124 high-risk physicians; 60 percent improved, 7 percent departed, and 33 percent were unimproved. Overall, risk scores declined 24 percent ($p < 0.001$), and SHS's return on investment in PARS exceeded \$4 for every \$1 spent.</p>	0 (1)

Principal Investigator Organization City, State	Project Number [Type] Title	Project Period	Total Research Investment	Purpose and Key Findings/Impact	Number of Publications (Products)
Tennessee					
Alan Storrow Vanderbilt University Nashville, Tennessee	R18 HS25931- OIA1 [Grant] Safely Improving Emergency Diagnostic Testing Through Clinical Safe Harbors	2019- 2024	\$1,749,990	Purpose: To establish and define a predetermined standard of care (a “safe harbor”) for a selected number of clinical conditions within the specialty of emergency medicine (EM) to reduce healthcare resource utilization within EM. Key Findings/Impact: This grant is ongoing, and no final report is available yet, but the first publication to result from this grant is a JAMA Health Forum insights article focused on medical liability constraints through malpractice safe harbors.	1

Principal Investigator Organization City, State	Project Number [Type] Title	Project Period	Total Research Investment	Purpose and Key Findings/Impact	Number of Publications (Products)
Texas					
Carol Ashton Baylor College of Medicine Houston, Texas	P01 HS10876 [Grant] Racial and Ethnic Variation in Medical Interactions	2000- 2006	\$9,207,042	<p>Purpose: To assess the extent to which remediable problems in doctor-patient communication result in racial and ethnic variations in the use of medical services and in health outcomes.</p> <p>Key Findings/Impact: A final report was not available for this grant, but it resulted in a broad portfolio of research on racial and ethnic variation in medical interactions. Variations in healthcare intervention preferences stem from differences in perceived benefit, knowledge of risk factors, physician-patient relationships, medical system access, and treatment beliefs. In addition, most active participation behaviors were patient initiated (84%), and more active patients received more facilitative communication from physicians, were more educated, and were more likely to be White than of another race. Women more willingly expressed negative feelings and concerns. Patient participation in medical encounters therefore depends on a complex interplay of personal, physician, and contextual factors.</p> <p>Physicians could more effectively facilitate patient involvement by using partnership-building and supportive communication more often. The physician-patient relationship is also strengthened when patients see themselves as similar to their physicians in personal beliefs, values, and communication. Perceived personal similarity is associated with higher ratings of trust, satisfaction, and intention to adhere. Race concordance is the primary predictor of perceived ethnic similarity, but several factors affect perceived personal similarity, including physicians' use of patient-centered communication.</p> <p>This grant produced multiple interventions and products, including:</p> <ul style="list-style-type: none"> • The CONNECT instrument, a tool that enables researchers to measure important aspects of patients' and physicians' views on the patient's illness. It showed that physicians were not good judges of patients' health beliefs. Strategies recommended for increasing physicians' awareness of patients' health beliefs included preconsultation assessment of patients' beliefs, implementation of culturally appropriate patient activation programs, and greater use of partnership building to encourage active patient participation. • "How To Talk to Your Doctor" community education forums and seminars showed improvement in patient-doctor communication across diverse cultural settings, with individuals stating they were more confident about speaking with their doctor and asking clarifying questions. 	29

Principal Investigator Organization City, State	Project Number [Type] Title	Project Period	Total Research Investment	Purpose and Key Findings/Impact	Number of Publications (Products)
Jason Etchegaray Rand Corporation Houston, Texas	R03 HS022944 [Grant] Parent Perceptions of NICU Safety Culture: Parent- Centered Safety Culture Tool	2014- 2017	\$99,958	<p>Purpose: To conduct a two-phase study to learn how parents of infants in the neonatal intensive care unit (NICU) can provide insight about patient safety issues in the NICU environment, specifically focused on safety culture.</p> <p>Key Findings/Impact: It was determined through interviews that NICU parents viewed infant safety based on security of the NICU environment, clinician-parent communication, infection control, and provider interactions with infants. NICU parents also adopt a variety of roles in the NICU: caregiver, advocate, decision maker, guardian, and learner.</p> <p>Parent perceptions of staff competency to provide safe care are not solely based on skills and expertise, but rather on staff behaviors that support a partnership with parents. When present, these staff behaviors are key facilitators in building this partnership but when absent can be significant barriers in the relationship and how parents engage in their parental roles. Maintaining an ongoing assessment of parent perceptions of care and training nurses in the behaviors that affect the parent-clinician partnership can facilitate the roles of parents in the NICU.</p> <p>Several presentations on this project were transformed into manuscripts.</p>	1 (1)
Yan Xiao University of Texas, Arlington Arlington, Texas	R18 HS27277 [Grant] PROMIS Learning Lab: Partnership in Resilience for Medication Safety	2019- 2023	\$2,493,137	<p>Purpose: To redesign primary care work systems to address multiple types of medication-related harms among older adults by collaborating with clinics and patients, including those with low socioeconomic status.</p> <p>Key Findings/Impact: This grant is ongoing, and no final report is available yet. However, the first publication to result from this grant presents the significant difficulties and obstacles faced by older adults during the COVID-19 pandemic. It also provides guidance to healthcare professionals in geriatrics, a framework for clinical evaluation and screening related to five domains of healthy aging, and additional strategies to enhance healthy aging in the era of COVID-19.</p>	1

Principal Investigator Organization City, State	Project Number [Type] Title	Project Period	Total Research Investment	Purpose and Key Findings/Impact	Number of Publications (Products)
Virginia					
Jonathan Peck Institute for Alternative Futures Alexandria, Virginia	R13 HS13927 [Grant] Consumer-Led Conference To Advance Patient Safety	2003- 2004	\$50,000	<p>Purpose: To invite consumers into the lead role in advancing patient safety and create a partnership between consumers and other stakeholders in improving healthcare.</p> <p>Key Findings/Impact: The Consumer-Led Workshop To Advance Patient Safety was organized to unfold in two distinct phases over 3 days. On the first day, consumers gathered and, through a facilitated sharing of experiences and stories, envisioned a safe, patient-centered healthcare system of the future and then articulated a mission for achieving it. On days 2 and 3, consumer participants were joined by nonconsumer stakeholders for continued work in refining vision and mission, development of goals and actions, and discussion of recommendations and next steps.</p> <p>Consumers Advancing Patient Safety (CAPS), a nonprofit organization was developed because of this conference to serve as a platform for consumers to be heard on issues related to healthcare safety and a patient-centered resource for reform initiatives. CAPS also aimed to further disseminate the output of the workshop on a continuing basis and realize the national goals articulated through its processes. A number of recommendations to AHRQ came out of the meeting and were documented in a report to AHRQ.</p>	0 (1)
Washington					
Lynne Robins University of Washington Seattle, Washington	R01 HS13172 [Grant] Effects of Establishing Focus in the Medical Interview	2002- 2006	\$1,436,169	<p>Purpose: To implement and comprehensively evaluate the effects of a piloted intervention to improve physicians' communication skills (Establishing Focus – EF) on the behaviors and attitudes of community practice physicians and the health outcomes, functional status, and attitudes of patients.</p> <p>Key Findings/Impact: Intervention group physicians used significantly more additional elicitations and requests for problem lists than controls. However, orientation, prioritization, and negotiation, which are core to EF and facilitate collaborative agenda setting, patient autonomy, and informed decision making, were negligible in the sample. The intervention changed physician behavior but in ways that were unanticipated and had no effect on physician or patient satisfaction or patient health outcomes and trust.</p>	4

Principal Investigator Organization City, State	Project Number [Type] Title	Project Period	Total Research Investment	Purpose and Key Findings/Impact	Number of Publications (Products)
Karen Domino University of Washington Seattle, Washington	R21 HS19532 [Grant] Shared Decision Making (SDM) in Surgery To Improve Patient Safety	2010- 2012	\$295,387	<p>Purpose: To develop and implement user-friendly SDM tools and processes for patients undergoing elective orthopedic surgery in the University of Washington Health Care System.</p> <p>Key Findings/Impact: After receiving broad stakeholder feedback, the grantee revised anesthesia decision aids. In addition, the grantee implemented a patient activation pamphlet and developed an SDM training toolkit. The most challenging elements of SDM were establishing the patient role, encouraging patients to seek input, eliciting patient preferences, and assessing patient understanding. Implementation of SDM into clinical practice is challenging but can significantly reduce liability and previously unappreciated hidden costs associated with deficiencies in informed consent. The grant was successful in describing institutional barriers and providing practical solutions to inform ongoing implementation of SDM within the hospital system.</p> <p>An SDM "Train-the-Trainer" Toolkit was developed to overcome training barriers and disseminate the methodology. Trainer observation and surgeon self-assessments of clinical encounters suggested that the SDM elements most overlooked were a patient seeking input from trusted others (65%), establishing a patient's role in DM (53%), using teach-back (42%), eliciting patient preference (24%), and communicating uncertainty (24%). Pre- and posttraining audiotaping of clinical DM showed surgeons made minimal improvement in the element establishing the patient role in DM. The grant culminated in an SDM train-the-trainer toolkit that integrates the processes developed and lessons learned.</p>	1

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Wisconsin					
Kathryn Leonhardt Aurora Health Care Milwaukee, Wisconsin	U18 HS15915 [Grant] Patient Partnerships To Improve Safety in the Clinic Settings	2005- 2007	\$567,073	<p>Purpose: To implement a patient partnership model as an intervention to improve safety in the outpatient setting and to develop strategies and tools that can be used to engage patients and providers in medication management in clinic and community settings.</p> <p>Key Findings/Impact: The Walworth County Patient Safety Council, a community-based advisory council composed of 11 patients and 12 provider representatives, established a demonstration project that significantly improved medication safety for local seniors. The project team disseminated more than 16,600 medication lists and 7,800 medication bags at more than 80 educational programs. The rate of accurate medication lists significantly increased from 55 percent to 72 percent ($p < 0.001$). This increase was significantly better than changes seen in the comparison group ($p < 0.001$). This grant culminated in the development of a toolkit, Guide for Developing a Community-Based Patient Safety Advisory Council, and produced two publications. The grant also received national recognition in 2007 by the Institute for Safe Medication Practices.</p>	2 (1)

Principal Investigator Organization City, State	Project Number [Type] Title	Project Period	Total Research Investment	Purpose and Key Findings/Impact	Number of Publications (Products)
Elizabeth Cox University of Wisconsin, Madison Madison, Wisconsin	R18 HS18680 [Grant] Engaging Families in Bedside Rounds To Promote Pediatric Patient Safety	2010- 2016	\$2,395,515	<p>Purpose: To leverage family engagement in bedside rounds to improve the safety of care provided to hospitalized children.</p> <p>Key Findings/Impact: This grant applied a participatory ergonomics (PE) approach to redesign the family-centered rounds process to improve family engagement and used systems engineering methods to develop and implement the Family-Centered Rounds (FCR) Checklist. Eighty-three (55%) of the 150 families participating in the study raised 318 medication topics during 347 FCRs. The most common medication topics raised by families were scheduling (24%) and adverse drug reactions (11%). Although most healthcare team responses were provision of information (74%), appropriate changes to the child's medications occurred in response to 8 percent of family-initiated dialogue, with most changes preventing or addressing adverse drug reactions or scheduling issues.</p> <p>The intervention significantly increased the number of checklist elements performed ($\beta = 1.2, p < 0.001$). Intervention rounds were significantly more likely to include asking the family (OR = 2.43, $p = 0.05$) or healthcare team (OR = 4.28, $p = 0.002$) for questions and reading back orders (OR = 12.43, $p < 0.001$). Compared with usual care, intervention families did not engage more or report better safety climate. Performance of specific checklist elements was significantly associated with changes in family engagement and improved perceptions of safety. For example, reading back orders was associated with greater family engagement in decision making. Asking the family for questions was associated with more positive views of the safety of handoffs and transitions. Most families initiated dialogue regarding medications during FCRs, including both inpatient and home medications. They raised topics that altered treatment and were important for medication safety, adherence, and satisfaction. Study findings suggest specific medication topics that healthcare teams can anticipate addressing during FCR.</p>	10

