

Update: Patient Engagement in Safety

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<https://psnet.ahrq.gov/perspective/update-patient-engagement-safety>

Annual Perspective 2018

Background

Patient engagement has become a cornerstone of patient safety. A [Patient Safety Primer](#) and [2017 Annual Perspective](#) describe the evolution of the field. Decades ago, patients and [high-profile national organizations](#) alike [called for engagement](#). However, a number of skeptics questioned whether patients actually wanted to be engaged in protecting their own safety and, if so, whether such engagement would be productive. Since then, studies have established that [patients wish to be engaged](#) and that their voices [make care safer](#). Contemporary literature now focuses on refining how to engage patients sustainably, reliably, and in ways concordant with their diverse needs and preferences.

The 2018 literature on patient engagement in safety reflects the consensus regarding the value of patient engagement and then builds on it in four key ways. First, new studies sought patient perspectives on safety in inpatient and outpatient settings. Second, the concept of psychological harm as a safety event rose in prominence. Third, as real-world patient engagement efforts become more common, many studies revealed practical lessons for scientists and health care systems wishing to engage patients. Finally, the 2018 literature provides insight into the next iteration of patient engagement research, particularly how health information technology (IT) can reach its full potential as a patient engagement tool.

Patients as Reporters of Unique Safety Events

Studies published this year corroborate earlier work demonstrating that patient and family reporting brings to light concerns that are often not identified by other detection methods. A [representative sample](#) of outpatients in the United Kingdom found that 8% reported an adverse event, many of which occurred in nonprimary care settings like dental offices, and very few of which were captured through traditional incident reporting. In a population-based study in Iowa, 20% of participants shared that they or someone close to them had experienced a [medical error](#) in some kind of health care setting. Two studies of [patient complaints](#) reveal that a significant proportion of complaints represent true safety concerns, although complaints encompass problems extending [beyond safety](#). An additional study found that patients

preferred a novel health IT platform for soliciting patient complaints rather than traditional means for identifying problems.

Of the studies above, two highlighted that [diagnostic errors](#) and delays are both [common](#) and [emotionally damaging](#) to patients. Nevertheless, patients and families continue to voice their reluctance to directly question clinical staff's decisions and assessments in the moment. While patients are skilled at detecting diagnostic errors and identifying health care system blind spots, this reluctance means that methods other than requesting patients to [speak up](#) are likely needed to address and prevent those errors.

Emerging Emphasis on Psychological Harm

In studies of patient-reported safety issues, patients have emphasized the [psychological and emotional repercussions](#) of safety hazards. Although this concept took time to gain traction, it has now percolated into the practice of patient safety with two high-profile examples. (i) The World Health Organization revised its [international classification](#) of safety incidents in primary care to incorporate psychological harm. The definition of each level of harm from near miss to severe now includes a psychological component. (ii) A conference grant supported by the Agency for Healthcare Research and Quality (AHRQ) convened a [diverse group of stakeholders](#) this year to develop a research agenda for understanding and combatting emotional harm.

The acceptance of the concept and consequences of psychological harm is an example of how the patient voice has permeated the safety world. Scientists are now delineating the impact of psychological harm in diverse settings, including in recent studies looking at [critical care](#) and [maternity care](#). Both studies emphasized the critical role of communication in influencing the extent of psychological harm.

Interventions to Engage Patients

Multiple recent studies showcase how to effectively encourage patients to engage in safety. A [cluster-randomized controlled trial](#) in the United Kingdom (the PRASE study) elicited safety events from patients using a short survey. Out of nearly 1200 patient reports, one-third constituted safety incidents. While this intervention did not reduce safety incidents like [pressure ulcers or falls](#), it did identify unique and actionable safety concerns. A children's health care system [shared its strategies](#) for reducing safety events through pediatric patient and family engagement. They used brochures, posters, and video to encourage engagement using best principles of health communication, including developing literacy-friendly materials in English and Spanish. Patient input was incorporated into process and system redesign. In addition to these research interventions, AHRQ released a [patient and family engagement guide in primary care settings](#). This pragmatic collection of materials and tools is intended to foster a partnership between care teams, patients, and families that promotes meaningful engagement.

Although it is important to promote engagement for its own sake, few studies to date have directly addressed what aspects of patient engagement durably improve care. An exception comes from the quality improvement literature—a robust meta-analysis examined which patient engagement interventions increase [clinician adherence to guidelines](#). Both educating patients directly about guideline-recommended practices and tools like those used in the PRASE study to enhance information elicited from patients improved clinician performance. Patient decision aids, by contrast, did not impact clinician behavior.

Health Information Technology and the Next Iteration of Patient Engagement Science

Health IT tools illustrate both the promise and the limitations of present patient engagement efforts. Electronic health records (EHRs) have offered patients unprecedented access to their health information, including the ability to review test results and, in some [cases](#), their clinician's notes. However, information availability does not automatically translate into meaningful engagement. In a 2018 study, most patients who [viewed their online test results](#) did not receive explanations of what those results meant. Similarly, access to clinician documentation ([OpenNotes](#)) was found to be judged positively by patients and families, but a significant proportion of patients do not access their own documentation despite its availability.

The next frontier in patient engagement science is likely to be to fully incorporate the patient voice into health care systems that were not designed with patients at the center. For example, a health IT patient engagement intervention used tablet computers to show patients potentially harmful [medication discrepancies](#), but lack of integration with the EHR made the discrepancies difficult to correct. This example speaks to larger [interoperability shortcomings](#) that plague EHRs. Beyond health IT, a survey of [hospital incident managers](#) found that, although they valued the patient perspective, they struggled to find a role for patients and families in incident investigations beyond confirming details of the incident. Tools like AHRQ's [primary care patient and family engagement guide](#) offers vital methods to more holistically include patients and families as partners and will be most effective when combined with implementation science that assesses how to best use those tools. This will allow engaged patients to help health care systems identify safety hazards, regain trust after safety hazards occur, and codesign solutions sustainably and as part of their day-to-day work.