



## Making Healthcare Safer IV

# Patient and Family Engagement

## *Rapid Response*



## Main Points

- Patient and family engagement as a patient safety practice (PSP) is an emerging area with few studies evaluating the effectiveness of such engagement in reducing patient harm.
- Two new applications of patient and family engagement to patient safety were identified in this review: patient and family engagement as a part of multicomponent interventions targeting patient falls, and patient and family engagement supported by patient portals and information tools targeting safety more broadly.
- For patient and family engagement within PSPs targeting patient falls, three distinct PSPs were evaluated: Fall Tailoring Interventions for Patient Safety program, Partnering with the Patient falls program, and a patient fall self-assessment tool. These interventions were evaluated in two prospective cohort studies and one pre-post study demonstrating reduction in falls.
- For patient and family engagement supported by technology and targeting safety more broadly, three distinct interventions were evaluated: a patient-centered discharge toolkit to identify and communicate issues with discharge information, a patient portal to identify and communicate safety issues, and an electronic patient safety dashboard. These interventions were evaluated in two cross-sectional studies and one pragmatic randomized controlled trial (RCT). The patient and family engagement PSP was associated with decreased hospital length of stay in two of these studies, decreased readmissions in two studies, and no difference in readmissions compared with usual care in one study.
- Studies reported that implementation of patient and family engagement PSPs was influenced by staff attitudes and availability, patients' perceptions and competing priorities, and organizational resources.
- Several toolkits are available to support implementation of patient and family engagement for fall reduction PSPs, while fewer resources are available to support implementation of information technology enabled patient and family engagement in patient safety.



**PATIENT  
SAFETY**



# 1. Background and Purpose

The Agency for Healthcare Research and Quality (AHRQ) Making Healthcare Safer (MHS) reports consolidate information for healthcare providers, health system administrators, researchers, and government agencies about practices that can improve patient safety across the healthcare system—from hospitals to primary care practices, long-term care facilities, and other healthcare settings. In spring 2023, AHRQ launched its fourth iteration of the MHS report (MHS IV).<sup>1</sup> Patient and family engagement was identified as high priority for inclusion in the MHS IV reports by a technical expert panel (TEP) that met in December 2022. The TEP included 15 experts in patient safety with representatives of governmental agencies, healthcare stakeholders, clinical specialists, experts in patient safety issues, and a patient/consumer perspective. See the MHS IV [Prioritization Report](#) for additional details.<sup>1</sup>

Patient centeredness is a core component of healthcare delivery and is necessary to ensure patients receive care aligned with their values and preferences. Patients and their families are the ones who directly experience safety events and are often most equipped to detect their occurrence, particularly when events are due to breakdowns in coordination of care across components of the health system.<sup>2-4</sup> Additionally, it is important to engage with patients and their families when safety events occur because safety events can undermine patients' trust in their healthcare providers, who are responsible for protecting patients from harm.<sup>5</sup> If healthcare providers are not forthright with information when safety events occur, patients may lose trust in the healthcare system and may become disengaged with their care.<sup>6,7</sup> Consequently, their perspective on and engagement with care delivery processes is critically important. By promoting active engagement of patient and family members with their care and authentic collaboration with healthcare professionals, unique patient and family perspectives can be incorporated into patient safety, ultimately reducing risks for adverse events. Numerous organizations have advocated for patient and family engagement to be a key strategy for reducing preventable patient harm.<sup>8-10</sup> The patient and family engagement topic was addressed in both MHS II and III. During the TEP prioritization process, 93 percent of the panel advised including this topic in the MHS IV review with no changes to the definition or scope.

## 1.1 Overview of the Patient Safety Practice

Patient and family engagement involves a broad spectrum of practices intended to promote partnerships between patients, their loved ones, and healthcare professionals. Prior literature discusses patient and family engagement as a philosophy that can be applied to many patient safety practices (PSPs), as a component of specific PSPs (e.g., inclusion of a mechanism for patients to report concerns in a rapid response system) or as a contextual moderator of the effectiveness of a PSP.<sup>11</sup> Furthermore, patient and family engagement involves active partnerships that should be differentiated from simply informing patients about aspects of their healthcare. Engagement consists of

empowering patients with skills and tools to work with their care team, partnering patients with their care team to impact care decisions, including about patient safety, and fully integrating patients and families as members of the care team.<sup>12</sup>

For this review, we define PSPs focused on patient and family engagement as any intervention specifically designed to promote engagement of patients and/or family members in reporting and/or reducing patient safety events and associated harms. This definition excludes interventions having the goal of solely informing patients and their families about their care or interventions lacking an intent to engage and partner with them. This rapid review differs from the rapid review, “Engaging Family Caregivers With Structured Communication for Safe Care Transitions.” That topic is specific to structured communication related to care transitions. Consequently, it can involve an intervention that only provides patients with information (unlike this rapid response, “Patient and Family Engagement,” which excluded information-only interventions). Secondly, it only addresses care-transition situations, whereas the scope of this rapid response included interventions within a single setting. Third, unlike this rapid response, “Engaging Family Caregivers With Structured Communication for Safe Care Transitions” can include interventions targeted at caregivers who are neither patients nor family members, whereas the rapid response only included those two groups of caregivers.

## **1.2 Purpose of the Rapid Response**

The overall purpose of this rapid response is to summarize the most relevant and recent literature on PSPs focused on patient and family engagement and ways these PSPs can be implemented. The response is organized around the following review questions:

### **1.3 Review Questions**

1. What is the frequency and severity of harms addressed by the patient and family engagement PSPs?
2. What measures or indicators have been used to examine the harms associated with the target of the patient and family engagement PSPs?
3. What patient and family engagement PSPs have been used to prevent, report, or mitigate harms to patients, and in what settings have they been used?
4. What is the rationale for the patient and family engagement PSPs that have been used to prevent, report or mitigate the harms
5. What studies have assessed the effectiveness and unintended effects of the patient and family engagement PSPs that have been used to prevent, report, or mitigate harms to patients and what new evidence has been published since the MHS III report of 2019?
6. What are common barriers and facilitators to implementing the patient and family engagement PSPs?
7. What resources (e.g., cost, staff, time) are required for implementation?
8. What toolkits are available to support implementation of the patient and family engagement PSPs?



## 2. Methods

We followed processes proposed by the Agency for Healthcare Research and Quality (AHRQ) Evidence-based Practice Center Program.<sup>13</sup> The rapid response is intended to present the end-user with an answer based on the best available evidence, but do not attempt to formally synthesize the evidence into conclusions. While the steps are similar to those of a typical systematic review, the methods are different (i.e., streamlined systematic review methods).<sup>14</sup>

For this rapid response, strategic adjustments were made to streamline traditional systematic review processes and deliver an evidence product in the allotted time. Adjustments included being as specific as possible about the questions, limiting the number of databases searched, modifying search strategies to focus on finding the most valuable studies (i.e., being flexible on sensitivity to increase the specificity of the search), and restricting the search to studies published recently (i.e., since 2019 when the search was performed for the MHS III report) in English and performed in the United States, and having each study assessed by a single reviewer. For this report, we used the artificial intelligence (AI) feature of DistillerSR (AI Classifier Manager) as a second reviewer at the title and abstract screening stage.

We answered Review Questions 1 and 2 by focusing on the harms and patient safety measures or indicators addressed in the studies identified for Review Question 5. For Review Question 2, we focused on identifying relevant measures included in the Centers for Medicare & Medicaid Services (CMS) patient safety measures, AHRQ's Patient Safety Indicators, or the National Committee for Quality Assurance patient-safety-related measures. For Review Question 3, we focused on interventions identified in Review Question 5 (i.e., those interventions with studies evaluating their effectiveness). We asked our content experts to answer Review Question 4 by citing selected references, including explanations of the rationale presented in the studies we found for Review Question 5. For Review Questions 6 and 7, we focused on the barriers, facilitators, and required resources reported in the studies identified in Review Question 5. For Review Question 8, we searched publicly available patient safety toolkits developed by AHRQ or other organizations that could help to support implementation of the PSPs, including AHRQ's Patient Safety Network (PSNet) (<https://psnet.ahrq.gov>) and AHRQ's listing of [patient-safety-related toolkits](#). We included any toolkits mentioned in the studies found for Review Question 5. We identified toolkits without assessing or endorsing them.

### 2.1 Eligibility Criteria for Studies of Effectiveness

We searched for original studies and systematic reviews on Review Question 5 according to the inclusion and exclusion criteria presented in Table 1.

**Table 1. Inclusion and exclusion criteria**

Study Parameter	Inclusion Criteria	Exclusion Criteria
Population	Adult and pediatric patients and their family members	Patient representatives or public representatives who are not patients or family members
Intervention	Any intervention intended primarily to focus on patient and/or family member engagement in reporting and/or reducing patient safety events and associated harms	Patient education interventions (e.g., interventions solely providing patients with information about their care or patient safety)
Comparator	Usual practice or other type of PSP	<ul style="list-style-type: none"> <li>No concurrent or historical comparison group</li> <li>No clear description of intervention</li> </ul>
Outcome	<p><b>Safety</b></p> <ul style="list-style-type: none"> <li>Adverse events and incidence of harm</li> </ul> <p><b>Quality of care measures</b></p> <p><b>Utilization of healthcare services</b> (focusing on the main utilization measure reported in the study)</p> <p><b>Implementation</b></p> <ul style="list-style-type: none"> <li>Barriers and facilitators</li> <li>Resources (cost, staff, time)</li> </ul>	<ul style="list-style-type: none"> <li>Measures of patient knowledge or engagement levels only</li> <li>No outcome of interest</li> </ul>
Timing	Original studies published since 2019, the year of the search done for the MHS III report on this topic	Published before 2019
Setting	Inpatient and outpatient care settings in the United States	Setting outside of the United States
Type of studies	<p>Systematic reviews (2019–2023)</p> <p>Original studies (2019–2023): Randomized controlled trials or observational studies with a comparison group, including pre-post studies</p>	Narrative reviews, scoping reviews, editorials, commentaries, and abstracts

MHS = Making Healthcare Safer; PSP = patient safety practices

## 2.2 Literature Searches for Studies of Effectiveness

We searched PubMed and the Cochrane Library for systematic reviews published from January 2019 through April 2023 that address the review questions. We also conducted searches of PubMed for original studies published from January 2019 through April 2023 (Appendix A).

## 2.3 Selection of Studies

We used the artificial intelligence (AI) feature of DistillerSR (AI Classifier Manager) as a semi-automated screening tool to conduct this review efficiently at the

title and abstract screening stage. The title and abstract of each citation were screened by a team member based on predefined eligibility criteria (Table 1), and then the AI Classifier Manager served as a second reviewer of each citation. The full text of each potentially eligible article was reviewed by a single team member to confirm eligibility and prepare a summary of the study, including author, year, study design, number of study participants, and main findings relevant to each of the review questions. A second team member checked a 10 percent sample of the full-text reviews to verify that important studies were not excluded.

## 2.4 Risk of Bias (Quality) Assessment

For studies that addressed Review Question 5 about the effectiveness of PSPs, we used the Cochrane Collaboration's tool for assessing the risk of bias of RCTs or the ROBINS-I tool for assessing the Risk Of Bias In Non-randomized Studies – of Interventions.<sup>15,16</sup>

For RCTs, we used the items in the Cochrane Collaboration's tool that cover the domains of selection bias, performance bias, detection bias, attrition bias, reporting bias, and other bias.<sup>15</sup> For nonrandomized studies, we used specific items in the ROBINS-I tool that assess bias due to confounding, bias in selection of participants into the study, bias in classification of interventions, bias due to deviations from intended interventions, bias due to missing data, bias in measurement of outcomes, and bias in selection of the reported results.<sup>16</sup> The risk of bias assessments focused on the main outcome of interest in each study.

For a recent eligible systematic review, the primary reviewer used the criteria developed by the United States Preventive Services Task Force Methods Workgroup for assessing the quality of systematic reviews.<sup>17</sup>

- **Good** – Recent relevant review with comprehensive sources and search strategies; explicit and relevant selection criteria; standard appraisal of included studies; and valid conclusions.
- **Fair** – Recent relevant review that is not clearly biased but lacks comprehensive sources and search strategies.
- **Poor** – Outdated, irrelevant, or biased review without systematic search for studies, explicit selection criteria, or standard appraisal of studies.

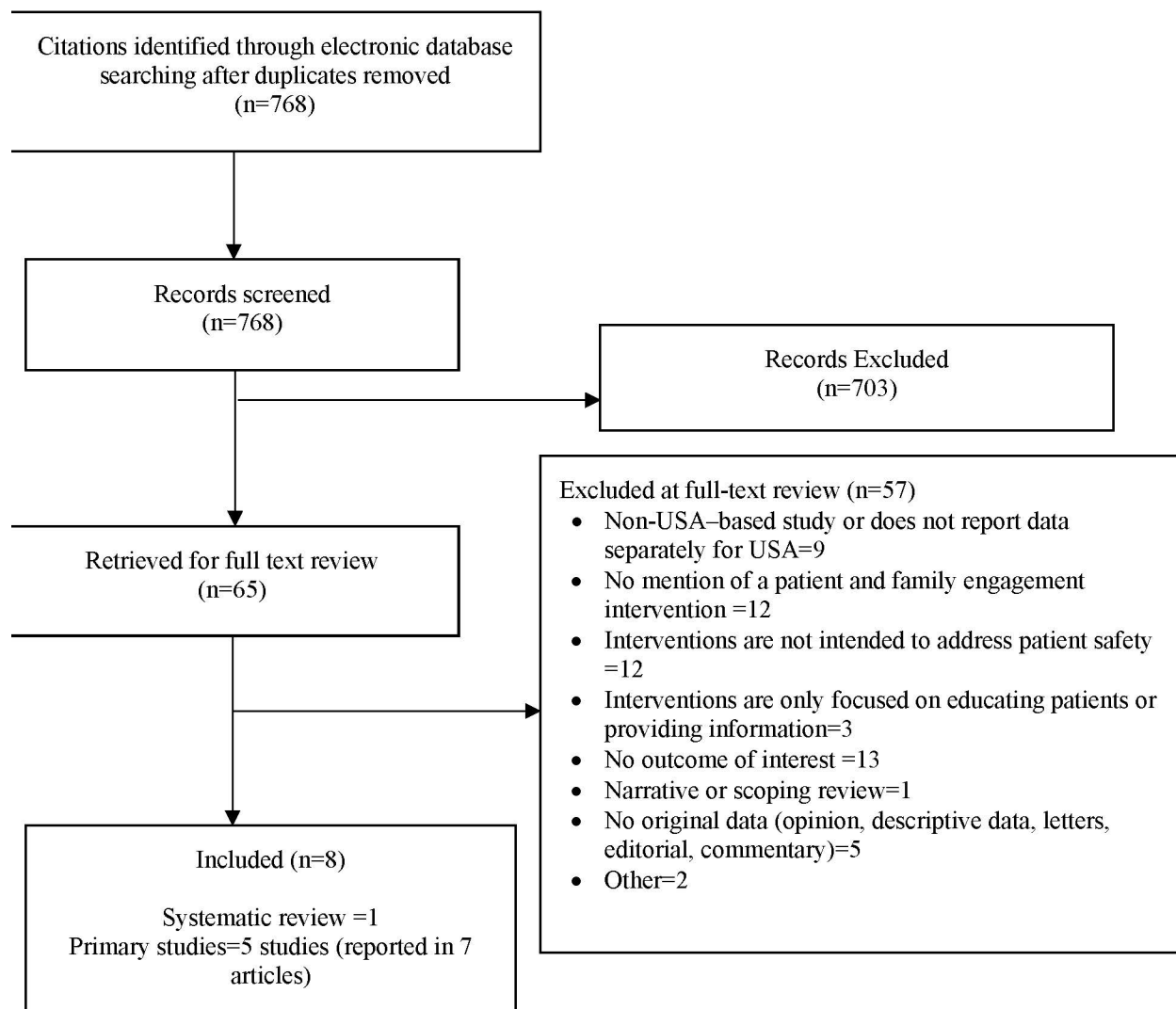


## 3. Evidence Base

### 3.1 Number of Studies

Our search retrieved 768 unique titles and abstracts from which we reviewed 65 full-text articles for eligibility. We found one systematic review and five studies (reported in 7 articles) that met the inclusion criteria (Figure 1). Appendix B lists the 57 studies excluded at full-text review.

**Figure 1. Results of the search and screening**



## 3.2 Findings for Review Questions

An overview of the relevant systematic review and original studies is presented in Tables 2a and 2b. The systematic review summarized 26 articles, 6 of which were published since 2019. Those articles included two U.S.-based studies that were reported in three articles. In our own search for original studies, we found 5 U.S.-based studies that were reported in 7 articles, including one study covered in the systematic review. This resulted in a total of 6 U.S.-based original studies since 2019.

**Table 2a. Overview of the included systematic review**

Author, Year	Objective	Number of Articles Included	Number of Articles Published in 2019 and Later	Quality Assessment*
Newman, 2021 <sup>18</sup>	This review identifies the strategies used to engage patients in safety during direct care, explores who is engaged, and determines the mechanisms that impact effectiveness.	26	US: 3 articles (reporting on 2 studies) UK: 1 Canada: 1 Vietnam: 1	Fair

UK = United Kingdom; US = United States

\*We used the criteria developed by the U.S. Preventive Services Task Force Methods Workgroup for assessing the quality of systematic review

**Table 2b. Overview of the included original studies**

Intervention	Author, Year Study Design	Setting	Number of Participants	PSP	Risk of Bias*
Patient and family engagement multi-component interventions targeting patient falls	Dykes, 2020 <sup>19</sup> Christiansen, 2020 <sup>20†</sup> Pre-post	14 adult medical units in 3 academic medical centers, hospitalized patients	Pre-intervention: 17,948 Post-intervention: 19,283	The fall prevention program Fall Tailoring Interventions for Patient Safety	Moderate
	Radecki, 2020 <sup>21</sup> Prospective cohort	A large, urban, academic, level 1, trauma center, hospitalized patients	Total: 203 103 at baseline 100 during the intervention	Patient fall self-assessment tool	Serious
	Rochon, 2019 <sup>22‡</sup> Prospective cohort	A US federal hospital, medical-surgical units, hospitalized patients	Not reported	Implementation of the Partnering with the Patient falls program	Serious
Patient and family engagement in patient portals and information tools targeting	Fuller, 2020 <sup>23</sup> Cross-sectional	An academic medical hospital, general medicine units, hospitalized patients	Total: 752 Submitted checklist: 510 Did not submit checklist: 242	Patient-centered discharge toolkit to identify and communicate issues with discharge information	Serious

Intervention	Author, Year  Study Design	Setting	Number of Participants	PSP	Risk of Bias*
safety more broadly	Grossman, 2019 <sup>24</sup> Masterson Creber, 2019 <sup>25</sup>  Pragmatic randomized controlled trial	An urban academic medical center, medical and surgical cardiac units, hospitalized patients	Usual care: 148  Intervention (Tablet-only): 132  Intervention (Portal): 146	Access to patient portal to identify and communicate issues, including medical errors	Unclear
	Schnock, 2022 <sup>26</sup>  Cross-sectional	An academic medical center, oncology and neurology units, hospitalized patients	Low portal usage: 69  Moderate portal usage: 92  High portal usage: 27	Electronic patient safety dashboard	Serious

PSP=Patient Safety Practice; US=United States; SR=systematic review

\* We used the Cochrane Risk of Bias Tool for assessing the risk of bias of randomized controlled trial. For non-randomized studies, we used Randomized Studies of Interventions (ROBINS-I tool).

† Captured in our search and included in the SR as well

‡ Included in the SR only

### 3.2.1 Review Question 1. What Are the Frequency and Severity of Harms Addressed by the Patient and Family Engagement PSPs?

The first category of patient and family engagement PSPs included in this review focused on preventable harms associated with patient falls.<sup>19, 21,22</sup> Estimates by AHRQ indicate that between 700,000 and 1 million hospitalized patients experience a fall event each year, with approximately 250,000 of those events resulting in injury and 11,000 in deaths.<sup>27</sup> Falls are the most common adverse event in hospital settings<sup>28, 29</sup>

The second category of patient and family engagement PSPs included in this review seeks to address a broader range of patient safety concerns labelled “medical error” or mistakes comprising medication errors, diagnostic errors, lack of followup, communication errors, and a range of other patient-reported safety concerns.<sup>23-25</sup> As such, it is more challenging to quantify frequency and severity of such a broad range of safety events, and population estimates vary widely. A recent large scale chart review study showed preventable adverse events occurring in 6.8 percent of all admissions and events with serious or higher levels of severity occurring in one percent of admissions<sup>30</sup> A meta-analysis of 70 studies indicated that approximately 1 in 20 hospitalized patients experience preventable harm with 12 percent of those harms being categorized as serious.<sup>31</sup> The Office of Inspector General for the U.S. Department of Health and Human Services estimated that 25 percent of hospitalized Medicare patients experienced patient harm during a hospitalization.<sup>32</sup> This higher estimate from the Office of Inspector General study is due, at least in part, to the study’s population of older patients who are more likely to experience adverse events.

Manual review of clinical documentation is the primary method used in studies generating these estimates of harm. The studies included in this review use patient reports or ratings of medical error, and little is known about how these measures align with traditional methods of identifying adverse events. The early existing literature indicates patients identify safety issues missed by current reporting systems<sup>33</sup>

Studies from both categories of patient and family engagement PSPs included hospital length of stay as an outcome of interest.<sup>22,23</sup> Patient and family engagement PSPs targeting medical error more broadly also included readmissions as indicators of the safety of care.<sup>23-25</sup> Hospital length of stay and readmission rates are not direct measures of safety or patient harm<sup>34,35</sup> but both are influenced by the safety and quality of care patients receive.<sup>36-40</sup> The frequency and severity of harms reported in each included study are summarized in Appendix C.

### **3.2.2 Review Question 2. What Measures or Indicators Have Been Used To Examine the Harms Associated With the Target of the Patient and Family Engagement PSPs?**

Question 2 focuses on the availability of standard measures for the harms targeted by patient and family engagement PSPs included in this review. Patient falls have mature measurement and reporting systems in place, as do the indirect measures of safety and quality of care: hospital length of stay and readmission rates. The National Database of Nursing Quality Indicators (NDNQI) includes patient fall measures. AHRQ provides further guidance on how patient fall measurement systems aligned with NDNQI measures in its Preventing Falls in Hospitals Toolkit.<sup>41</sup> Readmission rates and hospital length of stay are both commonly available measures from administrative data, and, through its Hospital Readmissions Reduction Program, CMS offers excess readmission rates for several conditions and procedures.<sup>42</sup>

In contrast to the well-developed and widely implemented measurement systems for falls, hospital length of stay and readmissions are not standard measures for the broad “medical error” category of patient-reported safety events. Additionally, like healthcare worker safety reporting systems, patient-reported safety events are non-rate-based measures for which a denominator (i.e., representing a standard for risk of exposure to harm) does not exist. This limits the ability to develop standard measures and active surveillance systems. For example, safety concerns communicated by patients in Fuller<sup>23</sup> included uncertainty about the care plan, medication changes, self-care and plan for followup; Masterson Creber and Grossman surveyed patients on medical errors or inaccuracies in information they noticed during their hospital stay.<sup>24,25</sup>

### **3.2.3 Review Question 3. What Patient and Family Engagement PSPs Have Been Used To Prevent, Report, or Mitigate Harms to Patients, and in What Settings Have They Been Used?**

The MHS III report in 2020<sup>43</sup> identified one additional systematic review and only one additional study since MHS II was published in 2013.<sup>44</sup> The systematic review found three studies of patient and family engagement in hand hygiene, and one study on patient and family engagement in other hospital-acquired infection reduction work.

The 2021 systematic review included in our analysis summarizes 27 patient engagement strategies in safety activities during direct care, the mode of these engagements, and extent of engagement.<sup>18</sup> These strategies were reported in 26 papers (13 in the United States) published between January 2010 and December 2020 in English.<sup>18</sup> Seventeen of the 26 studies were focused on inpatient safety, 3 on safety in specific clinics or treatments, and 6 on treatment between face-to-face visits.<sup>18</sup> Four studies included in this systematic review<sup>18</sup> were also captured in the reviews included in the MHS III report. The studies were conducted in a range of clinical areas including inpatient adult general medical services, inpatient surgical departments, adult oncology, outpatient radiology clinics, adult intensive care, residential aged care facility, and inpatient pediatric services, with 2 studies spanning hospital, homecare, appointments, discharge and community pharmacy.<sup>18</sup> The 9 engagement strategies were classified as consultations with a low level of engagement (including 2 original studies included in this review),<sup>19,22</sup> 7 as interventions with a moderate level of involvement (i.e., more than just information provision, but not full collaborative partnerships with patients), and 12 as partnerships with a high level of engagement.

The original studies targeting patient falls developed and evaluated their own PSPs: The fall prevention program Fall Tailoring Interventions for Patient Safety;<sup>19,20</sup> patient fall self-assessment tool;<sup>21</sup> and Partnering With the Patient falls program.<sup>22</sup> These programs were implemented among hospitalized patients, either in adult medical units of academic medical centers,<sup>19,20</sup> a trauma center,<sup>21</sup> or medical surgical units of a U.S. Federal hospital.<sup>22</sup>

Fall Tailoring Interventions for Patient Safety is the multimodality nurse-led three-step fall prevention process that supports patient and family knowledge of their personalized fall risk factors and developing and following through on a personalized fall prevention plan.<sup>19,20</sup> The patient fall self-assessment tool is self-administered by patients and engages patients to coproduce the fall prevention plan.<sup>21</sup> The Partnering With the Patient falls program involves patients as active participants, employs education materials, and rewards patients for not falling throughout their hospital stay.<sup>22</sup>

Three studies that used patient portals and information tools targeting safety more broadly were conducted engaging patients who were hospitalized, either on general medicine units of an academic medical hospital,<sup>23</sup> medical and surgical cardiac units of

an urban academic medical center,<sup>24,25</sup> or oncology and neurology units of an academic medical center.<sup>26</sup>

One study developed and used an inpatient portal, and patients in one intervention group were offered iPads to use the portal's real-time access to their clinical data, sourced directly from the electronic health record (EHR), including to assess patient-identified medical errors.<sup>24,25</sup> Features of this portal included: names, photos, and roles of care team members; medications; allergies; diagnostic laboratory test orders and results; current diet; vital signs; glucose levels; weights; patient-reported pain levels; patient-generated messages to the portal team and hospital staff; written and video educational materials on medications and tests; portal navigation tutorials; and Spanish translation.

The second study in this category engaged hospitalized patients, caregivers, and their care team in preparing for discharge and checking their knowledge and understanding about a patient-centered discharge toolkit. The toolkit was a suite of EHR-integrated digital health tools that enabled patients to self-assess and communicate discharge preparedness to their care team and request secure text messaging with a hospital physician after discharge.<sup>23</sup> That suite included an expected discharge date display, discharge video, discharge checklist, clinician dashboard discharge column, process for checklist submission and review, and secure messaging post discharge.<sup>23</sup>

The third study in this category used an electronic patient safety dashboard (Safety Advisor) web application, which provides real-time information about patient safety risks in addition to tailored educational content to promote patient engagement in self-care.<sup>26</sup>

### **3.2.4 Review Question 4. What Is the Rationale for the Patient and Family Engagement PSPs That Have Been Used To Prevent, Report, or Mitigate the Harms Associated With the Target of the PSPs?**

The included studies cited varying theoretical groundwork, evidence of benefits, and practical resources when providing the rationale for their patient and family engagement PSPs. For instance, the implementation of patient fall self-assessment tool was guided by the Conceptual Model of Healthcare Service Coproduction framework that considers that healthcare services, including patient safety, are the result of co-production between healthcare providers and patients at the micro-system level.<sup>21,45</sup> The Fall Tailoring Interventions for Patient Safety program was guided by their earlier evidence that when patient engagement was integrated in their process and tool development, the study team saw a decrease in falls with injury. The implementation of Partnering with the Patient falls program was guided by the theory of patient inclusion.<sup>22</sup> Specifically, they cited the 2015 National Patient Safety Foundation report "Free from Harm: Accelerating Patient Safety Improvement 15 Years After To Err Is Human" and referred to how partnering with patients and families for safe care was

one of the report's eight recommendations.<sup>22,46</sup> This group also noted that the curriculum from AHRQ's Team Strategies & Tools to Enhance Performance & Patient Safety (TeamSTEPPS 2.0) also promotes partnering with the patient to improve safety.<sup>22,47</sup>

A study that used an inpatient portal to assess patient-identified medical errors reasoned that portals empower patients to report safety concerns, facilitate patient recognition of errors, and improve patients' perceptions of safety and their trust.<sup>24,25</sup> A study that used a patient-centered discharge toolkit cited AHRQ's "IDEAL Discharge Planning" and the Centers for Medicare and Medicaid Services' "Your Discharge Planning Checklist" as its groundwork sources. The sources promote engagement of patients and caregivers by offering access to discharge preparation materials that include checklists for patients.<sup>23,48,49</sup> Finally, one study that used an electronic patient safety dashboard web application reasoned that improving patient-physician relationships requires both encouraging patients to ask more questions about their care and educating patients on their care and which questions are right to ask. They further cited AHRQ's application that allows patients to compile appropriate questions to ask their healthcare provider before their visit.<sup>26,50</sup>

Other studies did not provide a specific rationale for the patient and family engagement PSPs. Since the studies that did provide a rationale varied so much, it was not possible to identify a common theoretical rationale for all the patient and family engagement PSPs we reviewed.

### **3.2.5 Review Question 5. What Studies Have Assessed the Effectiveness and Unintended Effects of Patient and Family Engagement PSPs That Have Been Used To Prevent, Report, or Mitigate Harms to Patients and What New Evidence Has Been Published Since the MHS III Report of 2019?**

The included systematic review did not include a formal assessment of effectiveness of interventions as one of its review questions.<sup>18</sup> However, it presented the main findings of each of the included articles. This review included three articles with two studies conducted in the United States and published since 2019. Both studies are included in this review and described below (see Table C-1).<sup>19,22</sup> The systematic review was assessed as having fair quality.

For patient and family engagement PSPs targeting patient falls, two of the studies<sup>21,22</sup> used a prospective cohort design, implementing their intervention at a single healthcare institution, while the remaining study<sup>19,20</sup> conducted a pre-post assessment of a large-scale program implemented at 3 medical centers with over 35,000 patients involved. Three studies targeting patient falls demonstrated evidence of reduction in falls following the implementation of their patient and family engagement PSPs (see Table C-2).<sup>19-22</sup> These findings are consistent with the studies summarized by reviews included in the MHS III report of 2019.<sup>11,43,51</sup>

In the studies that engaged patients in patient portals and information tools targeting safety more broadly, two studies employed a cross-sectional design<sup>23,26</sup> and one was a pragmatic RCT.<sup>24,25</sup> Indicators of the effectiveness were patient-reported concerns<sup>23</sup> and potential medical errors.<sup>24,25</sup> These studies also reported decreased hospital length of stay.<sup>23,26</sup> Additionally, decreased length of stay was reported in one falls prevention study.<sup>22</sup> The PSP was associated with no difference in readmissions within 30 days in one study<sup>23</sup> and lower rates of readmission within 30 days in two studies (see Table C-3).<sup>24-26</sup> These data on patient-reported concerns and potential errors and on length of stay and readmission measures of effectiveness represent new evidence since the MHS III report of 2020.<sup>43</sup> Most of the new original studies had serious or unclear risk of bias.

### **3.2.6 Review Question 6. What Are Common Barriers and Facilitators to Implementing the Patient and Family Engagement PSPs?**

The included systematic review listed enablers and barriers for each included study. The review also synthesized the mechanisms that influence the effectiveness of consumer engagement approaches in enhancing safe care and treatment as one of its research questions.<sup>18</sup> The review identified four common sets of factors influencing the success of strategies: the value of patient–professional collaboration; the requirement for strategies to be pragmatic and user-friendly; the benefit of promoting confidence and safety proactively; and the need for organizational sponsorship and culture.

One study that reported on the patient fall self-assessment tool noted that adoption and fall safety plan completion rates varied widely. They noted that implementation was impeded by patients perceiving their fall risks as low and was facilitated by multiple modes of communication to support intervention adoption as well as by higher percentages of experienced nurses involved in implementation.<sup>21</sup> The Fall Tailoring Interventions for Patient Safety program study team similarly noted the belief by younger and independent at home patients that they were at low risk for falls in the hospital as a barrier, and the inclusion of multiple modalities and languages that patients and families could understand was a facilitator.<sup>19,20</sup> One study on Partnering with the Patient falls program reported on concerns throughout the project regarding the amount of nurse and healthcare staff involvement due to competing priorities.<sup>22</sup>

The study encouraging patients to use a portal to identify medical errors indicated that resources provided by the study, including iPads, training, and assistance with technology facilitated implementation.<sup>24</sup> Among noted potential barriers were illness severity, stress due to hospitalization, concerns about privacy, and patient–provider relationship factors, such as a lack of communication and trust.<sup>24</sup>

One study that implemented an electronic patient safety dashboard noted as a barrier that some participants expressed the desire for more information regarding their health, beyond patient safety information. This was noted as especially evident for the

less sick patients who did not have as many safety risks.<sup>26</sup> Other barriers included patients being too ill, or simply forgetting about the study due to a demanding inpatient stay.<sup>26</sup>

One study that implemented a patient-centered discharge toolkit noted a series of barriers on the provider side.<sup>23</sup> For instance, clinicians did not view the patient-reported concerns in the digital system very frequently, mostly due to workflow challenges. While a large percentage of patients requested post discharge messaging, very few clinicians opted in.<sup>23</sup> At the same time, this study identified additional workflow integration, optimization, facilitation by research assistants, and leadership as facilitators to promote a more robust adoption of these tools.<sup>23</sup>

Importantly, four of the six included original studies identified barriers related to their use of health information technology to engage patients.<sup>19,20,23,24,26</sup> The associated challenges were related to health and digital literacy, the digital health divide, and other disparities in technology use in underrepresented groups.

### **3.2.7 Review Question 7. What Resources (e.g., Cost, Staff, Time) are Required for Implementation of Patient and Family Engagement PSPs?**

The included systematic review did not include information on resources used for implementation of patient engagement strategies.<sup>18</sup> The patient fall self-assessment tool involved clinical nurse champions, education for the nursing staff, and ongoing reminders and encouragement on the process.<sup>21</sup> The patient fall self-assessment tool also used laminated boards to record the coproduced decisions and display the fall prevention plan, updating it as needed.<sup>21</sup> Similarly, the Fall Tailoring Interventions for Patient Safety program relied on support from hospital leadership and unit champions, a peer-champion model of nursing staff for education and training; study staff provided training during the go-live week.<sup>19,20</sup> Nurses used posters and dry-erase markers at admission and during each shift to go over the plan with the patient and family.<sup>19,20</sup> The Partnering with the Patient falls program used two rounds of education and required the coordinator to assist with the program, enlisting staff to assist with rounding. The program also provided certificates to patients.<sup>22</sup>

The study encouraging patients to use a portal to identify medical errors provided free access to hospital-provided iPads and the Internet, assistance in establishing their portal account, basic training on how to use the portal, and regular troubleshooting.<sup>24</sup> The participants of the study that implemented the electronic patient safety dashboard were given the choice to use either study tablet computers or their own devices.<sup>26</sup> The operation of the electronic patient safety dashboard to provide safety-related information in real-time and educational content required ongoing integration with an EHR system to calculate patient safety scores and create tailored content.<sup>26</sup> The study on a discharge patient-centered discharge toolkit used research assistants to coach patients in submitting the checklist, indicating a lack of dedicated discharge advocate personnel.<sup>23</sup> Each of the study units was codirected by a physician and nurse pair and

staffed by its own group of nurses.<sup>23</sup> The study integrated a bedside display, a patient portal, and a safety dashboard into their EHR environment.<sup>23</sup> Patient or caregiver participants were offered access to the patient portal on either personal devices or study-issued mobile devices with options to complete and submit the checklist (including by study staff, on their behalf) via the patient portal or a web-based survey that was analyzed by the research team.<sup>23</sup>

### **3.2.8 Review Question 8. What Toolkits Are Available To Support Implementation of the Patient and Family Engagement PSPs?**

Several toolkits are available to help implement patient and family engagement PSPs focused on patient falls. The Fall Tailoring Interventions for Patient Safety program<sup>19,20</sup> has a supporting toolkit detailed in published articles,<sup>52,53</sup> on the AHRQ website,<sup>54</sup> and available in full on the Fall Tailoring Interventions for Patient Safety website.<sup>55</sup> In practice, Fall Tailoring Interventions for Patient Safety is used in more than 100 hospitals and continues to spread.<sup>56</sup> Interested hospitals have free access to the Fall Tailoring Interventions for Patient Safety Fall Prevention Toolkit and training materials through the Fall Tailoring Interventions for Patient Safety Collaborative.<sup>56</sup> While no toolkits are available for the patient fall self-assessment tool,<sup>21</sup> AHRQ's Preventing Falls in Hospitals includes information on fall risk assessments.<sup>57</sup> Similarly, a toolkit does not exist for the intervention evaluated in Rochon et al., 2019,<sup>22</sup> however, the authors indicate that portions of the TeamSTEPPS<sup>®</sup> 2.0 curriculum informed their approach to including patients as members of the care team.<sup>58</sup>

Fewer toolkits and resources are available for patient and family engagement PSPs employing information technology to target broader patient-reported safety concerns. The Patient-Centered Discharge Toolkit evaluated in Fuller et al., 2020 does have a toolkit available online,<sup>23,59</sup> and integrated existing discharge planning tools from CMS and AHRQ in an interactive digital format.<sup>48,49</sup> Although this toolkit does not support implementation of the interactive digital tools central to the intervention, it does provide detailed description of what was done.

In addition to these toolkits for PSPs included in this review, several general resources for engaging patients in safety exist, some of which target patient engagement in specific areas.

- AHRQ's Toolkit for Engaging Patients to Improve Diagnostic Safety, which includes interventions for patients (e.g., "Be the expert on you") and providers (e.g., "60 seconds to improve diagnostic safety") as well as implementation resources.<sup>60</sup>
- AHRQ's Guide to Improving Patient Safety in Primary Care Settings by Engaging Patients and Families, which includes strategies for collaboratively creating a safe medication list, teachbacks, and warm handoffs.<sup>61</sup>

- AHRQ’s Guide to Patient and Family Engagement in Hospital Quality and Safety, which includes strategies for Patient and Family Advisory Councils, improved communication, nurse bedside shift reports, and discharge planning.<sup>8</sup>
- AHRQ’s Toolkit to Engage High-Risk Patients In Safe Transitions Across Ambulatory Settings, which includes checklists for preparing patients for new appointments, appointment aides, and a robust set of implementation tools.<sup>62</sup>
- CMS’s Person and Family Engagement Toolkit, which focuses on engagement within a measure development process but contains many resources broadly applicable and relevant for patient and family engagement in quality and safety improvement work within healthcare organizations.<sup>63</sup>
- The World Health Organization (WHO) Patient Engagement for Safer Primary Care, guidance that discusses strategies for educating patients and healthcare providers, obtaining feedback, and engaging in improvement efforts.<sup>64</sup>
- National Partnership for Women and Families’ Patient & Family Engagement Toolkit, which compiles a list of many relevant tools and resources from professional societies and other organizations with an emphasis on equity.<sup>65</sup>



## 4. Discussion

### 4.1 Interpretation of Findings

The findings of the rapid response indicate that patient and family engagement as a PSP remains an emerging area with few rigorous studies evaluating the effectiveness for reducing patient harm. However, there are a modest number of new studies, and in new areas. In MHS II, three original studies were included which focused on medication management and hand washing. MHS III identified one additional systematic review since MHS II and one original study focusing on a patient- and family-initiated rapid response system. The six original studies and one systematic review included in this rapid response represent a modest increase in the availability of research on patient and family engagement as a PSP since prior reports. However, no additional studies were found on the specific PSPs identified in previous MHS reports, except that patient fall prevention was mentioned but not highlighted in MHS III, indicating a shift in the focus of patient and family engagement in patient safety.

While PSPs targeting patient falls are not new and were covered in two reviews included in the MHS III report, the increased emphasis on patient and family engagement in fall prevention is important. A recent meta-analysis of patient fall prevention interventions in hospital settings found the strongest evidence for effectiveness of staff and patient education interventions.<sup>66</sup> The patient and family engagement PSPs focused on patient falls covered in this review included more than just education (i.e., one-way flow of information to patients and family members) and supported some form of partnerships where patients coproduce or copersonalize their fall prevention plans or are rewarded for not falling throughout their hospital stay. However, in these studies, and more broadly in patient and family engagement research and practice, the line between passive education and more active engagement is not always clear.

Patient and family engagement in safety event reporting using patient-reported measures is an emerging area with promise for improving patient safety.<sup>67-71</sup> None of the included studies that use patient reporting<sup>23-25</sup> linked their interventions to reduction in patient harm, but this has been a challenge for staff safety event reporting systems as well.<sup>72</sup> The identification of safety events through a reporting system is an important first step in a learning process, but reporting is often disconnected from analysis, improvement and evaluation activities.<sup>73,74</sup> However, patient and family members consistently identify safety events missed by other forms of safety reporting and surveillance, which highlights the critical role they could play in safety and quality improvement.<sup>75</sup>

Another distinct aspect of this area is that patient and family engagement often relies on patient-reported outcomes rather than traditional measures of harm. While in Grossman and colleagues<sup>24,25</sup> patients reported the broad category of potential medical errors, other recent studies of patient-reported experiences and/or outcomes used qualitative analyses to characterize those as diagnostic safety opportunities<sup>67</sup>, blind

spots,<sup>68</sup> patient-reported diagnostic process-related breakdowns,<sup>69</sup> patient and family experiences and safety concerns related to ambulatory visit notes,<sup>71</sup> or patient-reported diagnostic errors.<sup>70</sup> The Safer Dx Patient Instrument helps patients identify concerns related to several dimensions of the diagnostic process based on note review and recall of recent "at-risk" visits.<sup>76</sup> Patients and families identify breakdowns in communications to them and between institutions and settings that have not been measured before and do not have existing measures. Similarly, patients and caregivers are important sources of safety information to improve systems of medication safety that may not be recorded by other surveillance methods.<sup>75</sup>

Consistent with information reported in the studies included in this review, a systematic review of barriers and facilitators of patient and family engagement in patient safety concluded that both staff and patient unwillingness as well as inadequate infrastructure (i.e., organizational issues, communication failures, or lack of a patient-centered approach) were primary barriers.<sup>77</sup> Encouraging patients, sharing information, building trusting relationships, establishing patient-centered care, and improving organizational resources were primary facilitators.<sup>77</sup> The increased emphasis on technology as a means to support patient and family engagement identified in this review may introduce new implementation dynamics. Technology could support more consistent patient and family engagement activities, but general technical challenges with integrated health technology solutions and cost may inhibit spread of these interventions. In an implementation science evaluation of different modalities of engagement in the Fall Tailoring Interventions for Patient Safety program, no differences were found between more traditional "paper" falls risk communication devices and more interactive digital ones in terms of adherence to fall prevention protocols.<sup>56</sup> Future work should carefully consider the costs and benefits of technology enabled patient and family engagement compared to more traditional modalities.

Almost all included studies used the research team's capacity to implement the intervention. This raises concern about the feasibility and sustainability of relying on new health information technology that increases strain on resources required from healthcare institutions to implement patient and family engagement PSPs. For patient and family engagement PSPs to be scalable and adaptable throughout the healthcare delivery, PSPs must be sustained without extra capacities brought by research infrastructure.

## 4.2 Limitations

This rapid response has five limitations. First, rapid responses use streamlined processes to complete the effort in a narrow timeline. In this review, we limited the studies to published works since 2019, performed within the clinical practices and health care systems of the US. Second, the search allowed for inclusion of studies conducted during the Coronavirus disease 19 (COVID-19) pandemic. Many patient care practices were affected by the COVID-19 pandemic and may impact any studies conducted during this timeframe. Third, the definition and reporting of patient and family engagement activities in included studies is variable. A recent systematic

review (excluded from this rapid response because identified studies that report on effectiveness are either non-U.S.-based or published prior to 2019) characterized patient and family engagement PSPs according to their level of patient engagement: information (i.e., patients are passive recipients), involvement (i.e., patients participate more actively, but healthcare workers maintain most of the power), and true partnership or shared leadership.<sup>78</sup> They found studies of interventions at only the first two of these levels, with information interventions being effective at improving perceptions of safety, and involvement interventions having more inconsistent findings across diverse outcomes. This finding highlights the importance of the conceptual distinction between education and engagement. In practice, interventions may blend these approaches and their description in articles can leave uncertainty about the degree to which education and engagement were employed. Fourth, study outcomes for patient and family engagement PSPs include patient-reported outcomes or events. This is reasonable given the goal is to engage patients in safety, but interpreting these measures as effective in reducing patient harm is challenging with no current benchmarks or comparisons. Fifth, we did not conduct a comprehensive search for measures of patient and family engagement because of the narrow scope of this rapid response report. A separate review would be needed to identify the full range of measures used in the growing field of patient and family engagement.

### **4.3 Implications and Conclusions**

Patient and family engagement as a PSP remains an emerging field. The research is progressing and demonstrates promising results of including patient and family engagement as a component of interventions targeting specific preventable harms and engaging patients in safety more broadly. Consistent with previous MHS reviews of this topic, we find an insufficient evidence base to guide broad implementation of patient and family engagement as a PSP.

Since prior reviews, two new applications of patient and family engagement to patient safety were identified: patient and family engagement as a part of multicomponent interventions targeting patient falls, and patient and family engagement supported by patient portals and information tools targeting safety more broadly. Patient and family engagement PSPs targeting patient falls demonstrated evidence of reduction in falls. Technology enabled patient and family engagement PSPs targeting safety more broadly demonstrated decreased hospital length of stay and mixed findings on readmissions. Both staff and patient attitudes as well as organizational resources were identified as barriers or facilitators for implementation of patient and family engagement PSPs. Several toolkits are available to support implementation of patient and family engagement for fall reduction PSPs, while fewer resources are available to support implementation of information technology enabled patient and family engagement in patient safety.



## 5. References

1. Rosen M, Dy SM, Stewart CM, et al. Final Report on Prioritization of Patient Safety Practices for a New Rapid Review or Rapid Response. Making Healthcare Safer IV. (Prepared by the Johns Hopkins, ECRI, and Southern California Evidence-based Practice Centers under Contract No. 75Q80120D00003). AHRQ Publication No. 23-EHC019-1 Agency for Healthcare Research and Quality. Rockville, MD: 2023.  
[https://effectivehealthcare.ahrq.gov/sites/default/files/related\\_files/prioritization-report.pdf](https://effectivehealthcare.ahrq.gov/sites/default/files/related_files/prioritization-report.pdf)
2. Harrison R, Walton M, Manias E, et al. The missing evidence: a systematic review of patients' experiences of adverse events in health care. *Int J Qual Health Care*. 2015 Dec;27(6):424-42. doi: 10.1093/intqhc/mzv075. PMID: 26424702.
3. Giardina TD, Haskell H, Menon S, et al. Learning From Patients' Experiences Related To Diagnostic Errors Is Essential For Progress In Patient Safety. *Health Aff (Millwood)*. 2018 Nov;37(11):1821-7. doi: 10.1377/hlthaff.2018.0698. PMID: 30395513.
4. Ozavci G, Bucknall T, Woodward-Kron R, et al. A systematic review of older patients' experiences and perceptions of communication about managing medication across transitions of care. *Res Social Adm Pharm*. 2021 Feb;17(2):273-91. doi: 10.1016/j.sapharm.2020.03.023. PMID: 32299684.
5. Burrows Walters C, Duthie EA. Patients' Perspectives of Engagement as a Safety Strategy. *Oncol Nurs Forum*. 2017 Nov 1;44(6):712-8. doi: 10.1188/17.onf.712-718. PMID: 29052666.
6. Khullar D. Building Trust in Health Care- Why, Where, and How. *Jama*. 2019 Aug 13;322(6):507-9. doi: 10.1001/jama.2019.4892. PMID: 31305868.
7. Rhodes P, Campbell S, Sanders C. Trust, temporality and systems: how do patients understand patient safety in primary care? A qualitative study. *Health Expect*. 2016 Apr;19(2):253-63. doi: 10.1111/hex.12342. PMID: 25644998.
8. Guide to Patient and Family Engagement in Hospital Quality and Safety. Rockville, MD Agency for Healthcare Research and Quality; 2023.  
<https://www.ahrq.gov/patient-safety/patients-families/engagingfamilies/index.html>. Accessed on June 28, 2023.
9. Enhance patient and family engagement for the provision of safer health care: the expert consultation meeting report. World Health Organization; 2020.  
<https://www.who.int/publications/m/item/enhance-patient-and-family-engagement-for-the-provision-of-safer-health-care-the-expert-consultation-meeting-report>. Accessed on June 28, 2023.
10. Person and Family Engagement. Baltimore, MD: Centers for Medicare & Medicaid Services; 2021.  
<https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/QualityInitiativesGenInfo/Person-and-Family-Engagement>. Accessed on June 28, 2023.
11. Berger Z, Flickinger TE, Pfoh E, et al. Promoting engagement by patients and families to reduce adverse events in acute care settings: a systematic review. *BMJ Qual Saf*. 2014 Jul;23(7):548-55. doi: 10.1136/bmjqs-2012-001769. PMID: 24336575.

12. Kim JM, Suarez-Cuervo C, Berger Z, et al. Evaluation of Patient and Family Engagement Strategies to Improve Medication Safety. *Patient*. 2018 Apr;11(2):193-206. doi: 10.1007/s40271-017-0270-8. PMID: 28795338.
13. Evidence-based Practice Centers. Rockville, MD: Agency for Healthcare Research and Quality; 2023. <https://effectivehealthcare.ahrq.gov/about/epc>. Accessed on June 28, 2023.
14. EPC Program Procedures Guide. Rockville, MD: Agency for Healthcare Research and Quality; 2021.
15. Higgins JP, Altman DG, Gøtzsche PC, et al. The Cochrane Collaboration's tool for assessing risk of bias in randomised trials. *Bmj*. 2011 Oct 18;343:d5928. doi: 10.1136/bmj.d5928. PMID: 22008217.
16. ROBINS-I tool. The Cochrane Collaboration; 2022. <https://methods.cochrane.org/methods-cochrane/robins-i-tool>. Accessed on September 9, 2022.
17. Procedure Manual Appendix VI. Criteria for Assessing Internal Validity of Individual Studies. Rockville, MD: U.S. Preventive Services Task Force; 2017. <https://www.uspreventiveservicestaskforce.org/uspstf/about-uspstf/methods-and-processes/procedure-manual/procedure-manual-appendix-vi-criteria-assessing-internal-validity-individual-studies>. Accessed on June 29, 2023.
18. Newman B, Joseph K, Chauhan A, et al. Do patient engagement interventions work for all patients? A systematic review and realist synthesis of interventions to enhance patient safety. *Health Expect*. 2021 Dec;24(6):1905-23. doi: 10.1111/hex.13343. PMID: 34432339.
19. Dykes PC, Burns Z, Adelman J, et al. Evaluation of a Patient-Centered Fall-Prevention Tool Kit to Reduce Falls and Injuries: A Nonrandomized Controlled Trial. *JAMA Netw Open*. 2020 Nov 2;3(11):e2025889. doi: 10.1001/jamanetworkopen.2020.25889. PMID: 33201236.
20. Christiansen TL, Lipsitz S, Scanlan M, et al. Patient Activation Related to Fall Prevention: A Multisite Study. *Jt Comm J Qual Patient Saf*. 2020 Mar;46(3):129-35. doi: 10.1016/j.jcjq.2019.11.010. PMID: 31948814.
21. Radecki B, Keen A, Miller J, et al. Innovating Fall Safety: Engaging Patients as Experts. *J Nurs Care Qual*. 2020 Jul/Sep;35(3):220-6. doi: 10.1097/ncq.0000000000000447. PMID: 32433144.
22. Rochon R, Salazar L. PARTNERING WITH THE PATIENT TO REDUCE FALLS IN A MEDICAL-SURGICAL UNIT. *International Journal of Safe Patient Handling & Mobility (SPHM)*. 2019;9(4):135-42. PMID: 141485524.
23. Fuller TE, Pong DD, Piniella N, et al. Interactive Digital Health Tools to Engage Patients and Caregivers in Discharge Preparation: Implementation Study. *J Med Internet Res*. 2020 Apr 28;22(4):e15573. doi: 10.2196/15573. PMID: 32343248.
24. Grossman LV, Masterson Creber RM, Ancker JS, et al. Technology Access, Technical Assistance, and Disparities in Inpatient Portal Use. *Appl Clin Inform*. 2019 Jan;10(1):40-50. doi: 10.1055/s-0038-1676971. PMID: 30650448.
25. Masterson Creber RM, Grossman LV, Ryan B, et al. Engaging hospitalized patients with personalized health information: a randomized trial of an inpatient portal. *J Am Med Inform Assoc*. 2019 Feb 1;26(2):115-23. doi: 10.1093/jamia/ocy146. PMID: 30534990.

26. Schnock K, Roulier S, Butler J, et al. Engaging Patients in the Use of Real-Time Electronic Clinical Data to Improve the Safety and Reliability of Their Own Care. *J Patient Saf.* 2022 Mar 1;18(2):e407-e13. doi: 10.1097/pts.0000000000000831. PMID: 33797462.
27. Currie L. Fall and Injury Prevention. In: Hughes RG, ed *Patient Safety and Quality: An Evidence-Based Handbook for Nurses.* Rockville (MD): Agency for Healthcare Research and Quality (US); 2008.
28. Miake-Lye IM, Hempel S, Ganz DA, et al. Inpatient fall prevention programs as a patient safety strategy: a systematic review. *Ann Intern Med.* 2013 Mar 5;158(5 Pt 2):390-6. doi: 10.7326/0003-4819-158-5-201303051-00005. PMID: 23460095.
29. LeLaurin JH, Shorr RI. Preventing Falls in Hospitalized Patients: State of the Science. *Clin Geriatr Med.* 2019 May;35(2):273-83. doi: 10.1016/j.cger.2019.01.007. PMID: 30929888.
30. Bates DW, Levine DM, Salmasian H, et al. The Safety of Inpatient Health Care. *N Engl J Med.* 2023 Jan 12;388(2):142-53. doi: 10.1056/NEJMs2206117. PMID: 36630622.
31. Panagioti M, Khan K, Keers RN, et al. Prevalence, severity, and nature of preventable patient harm across medical care settings: systematic review and meta-analysis. *Bmj.* 2019 Jul 17;366:l4185. doi: 10.1136/bmj.l4185. PMID: 31315828.
32. Adverse Events in Hospitals: A Quarter of Medicare Patients Experienced Harm in October 2018 HHS Office of Inspector General. Washington, DC: 2022. <https://oig.hhs.gov/oei/reports/OEI-06-18-00400.asp>
33. Gillespie A, Reader TW. Patient-Centered Insights: Using Health Care Complaints to Reveal Hot Spots and Blind Spots in Quality and Safety. *Milbank Q.* 2018 Sep;96(3):530-67. doi: 10.1111/1468-0009.12338. PMID: 30203606.
34. Brasel KJ, Lim HJ, Nirula R, et al. Length of stay: an appropriate quality measure? *Arch Surg.* 2007 May;142(5):461-5; discussion 5-6. doi: 10.1001/archsurg.142.5.461. PMID: 17515488.
35. Chin DL, Bang H, Manickam RN, et al. Rethinking Thirty-Day Hospital Readmissions: Shorter Intervals Might Be Better Indicators Of Quality Of Care. *Health Aff (Millwood).* 2016 Oct 1;35(10):1867-75. doi: 10.1377/hlthaff.2016.0205. PMID: 27702961.
36. Wang Y, Eldridge N, Metersky ML, et al. Analysis of Hospital-Level Readmission Rates and Variation in Adverse Events Among Patients With Pneumonia in the United States. *JAMA Netw Open.* 2022 May 2;5(5):e2214586. doi: 10.1001/jamanetworkopen.2022.14586. PMID: 35639379.
37. Friedman B, Encinosa W, Jiang HJ, et al. Do patient safety events increase readmissions? *Med Care.* 2009 May;47(5):583-90. doi: 10.1097/MLR.0b013e31819434da. PMID: 19318996.
38. Bath J, Dombrovskiy VY, Vogel TR. Impact of Patient Safety Indicators on readmission after abdominal aortic surgery. *J Vasc Nurs.* 2018 Dec;36(4):189-95. doi: 10.1016/j.jvn.2018.08.002. PMID: 30458941.
39. Ahmed AH, Thongprayoon C, Schenck LA, et al. Adverse in-hospital events are associated with increased in-hospital mortality and length of stay in patients with or at risk of acute respiratory distress syndrome. *Mayo Clin Proc.* 2015 Mar;90(3):321-8. doi: 10.1016/j.mayocp.2014.12.015. PMID: 25638301.
40. Zhan C, Miller MR. Excess length of stay, charges, and mortality attributable to medical injuries during hospitalization. *Jama.* 2003 Oct 8;290(14):1868-74. doi: 10.1001/jama.290.14.1868. PMID: 14532315.

41. Preventing Falls in Hospitals. Rockville, MD: Agency for Healthcare Research and Quality; 2013.  
<https://www.ahrq.gov/patient-safety/settings/hospital/fall-prevention/toolkit/measure-fall-rates.html>. Accessed on June 28, 2023.
42. Hospital Readmissions Reduction Program (HRRP). Baltimore, MD: Centers for Medicare & Medicaid Services; 2022.  
<https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Value-Based-Programs/HRRP/Hospital-Readmission-Reduction-Program>. Accessed on June 28, 2023.
43. Hall KK, Shoemaker-Hunt S, Hoffman L, et al. Making Healthcare Safer III: A Critical Analysis of Existing and Emerging Patient Safety Practices. Rockville (MD): Agency for Healthcare Research and Quality (US); 2020.
44. Shekelle PG, Wachter RM, Pronovost PJ, et al. Making health care safer II: an updated critical analysis of the evidence for patient safety practices. *Evid Rep Technol Assess (Full Rep)*. 2013 Mar(211):1-945. PMID: 24423049.
45. Batalden M, Batalden P, Margolis P, et al. Coproduction of healthcare service. *BMJ Qual Saf*. 2016 Jul;25(7):509-17. doi: 10.1136/bmjqs-2015-004315. PMID: 26376674.
46. Berwick DM, Shojania KG, Atchinson BK. Free from Harm: Accelerating Patient Safety Improvement 15 Years After To Err Is Human National Patient Safety Foundation. Boston, MA: 2015.
47. TeamSTEPPS®. Rockville, MD: Agency for Healthcare Research and Quality.  
<https://www.ahrq.gov/teamstepps/index.html>. Accessed on June 28, 2023.
48. Strategy 4: Care Transitions From Hospital to Home: IDEAL Discharge Planning. Rockville, MD: Agency for Healthcare Research and Quality; 2017.  
<https://www.ahrq.gov/patient-safety/patients-families/engagingfamilies/strategy4/index.html>. Accessed on June 28, 2023.
49. Your Discharge Planning Checklist: For patients and their caregivers preparing to leave a hospital, nursing home, or other care setting. Centers for Medicare & Medicaid Services; 2019.  
<https://www.medicare.gov/Pubs/pdf/11376-discharge-planning-checklist.pdf>. Accessed on June 28, 2023.
50. The 10 Questions You Should Know. Rockville, MD: Agency for Healthcare Research and Quality; 2020.  
<https://www.ahrq.gov/questions/10questions.html>. Accessed on June 28, 2023.
51. Park M, Giap TT. Patient and family engagement as a potential approach for improving patient safety: A systematic review. *J Adv Nurs*. 2020 Jan;76(1):62-80. doi: 10.1111/jan.14227. PMID: 31588602.
52. Dykes PC, Adelman JS, Alfieri L, et al. The Fall TIPS (Tailoring Interventions for Patient Safety) Program: <em>A Collaboration to End the Persistent Problem of Patient Falls</em>. *Nurse Leader*. 2019;17(4):365-70. doi: 10.1016/j.mnl.2018.11.006.
53. Dykes PC, Carroll DL, Hurley A, et al. Fall prevention in acute care hospitals: a randomized trial. *Jama*. 2010 Nov 3;304(17):1912-8. doi: 10.1001/jama.2010.1567. PMID: 21045097.
54. Fall TIPS: A Patient-Centered Fall Prevention Toolkit. Rockville, MD: Agency for Healthcare Research and Quality; 2021.  
<https://www.ahrq.gov/patient-safety/settings/hospital/fall-tips/index.html>. Accessed on June 28, 2023.
55. Fall T.I.P.S. <https://www.falltips.org/>. Accessed on June 28, 2023.

56. Duckworth M, Adelman J, Belategui K, et al. Assessing the Effectiveness of Engaging Patients and Their Families in the Three-Step Fall Prevention Process Across Modalities of an Evidence-Based Fall Prevention Toolkit: An Implementation Science Study. *J Med Internet Res*. 2019 Jan 21;21(1):e10008. doi: 10.2196/10008. PMID: 30664454.
57. 3.3. What is a standardized assessment of risk factors for falls, and how should this assessment be conducted? Rockville, MD: Agency for Healthcare Research and Quality. <https://www.ahrq.gov/patient-safety/settings/hospital/fall-prevention/toolkit/practices.html#3-3>. Accessed on June 28, 2023.
58. TeamSTEPPS 2.0. Rockville, MD: Agency for Healthcare Research and Quality; 2022. <https://www.ahrq.gov/teamstepps/instructor/index.html>. Accessed on June 28, 2023.
59. Patient Safety Learning Lab. Boston MA: Patient Safety Learning Laboratory 2019. <https://psll.bwh.harvard.edu/patient-centered-discharge-toolkit-pdtk/>. Accessed on June 28, 2023.
60. Toolkit for Engaging Patients To Improve Diagnostic Safety. Rockville, MD: Agency for Healthcare Research and Quality; 2022. <https://www.ahrq.gov/patient-safety/settings/ambulatory/tools/diagnostic-safety/toolkit.html>. Accessed on June 29, 2023.
61. Guide to Improving Patient Safety in Primary Care Settings by Engaging Patients and Families. Rockville, MD: Agency for Healthcare Research and Quality; 2018. <https://www.ahrq.gov/patient-safety/reports/engage/strategies.html>. Accessed on June 28, 2023.
62. Toolkit to Engage High-Risk Patients In Safe Transitions Across Ambulatory Settings. Rockville, MD: Agency for Healthcare Research and Quality; 2017. <https://www.ahrq.gov/hai/tools/ambulatory-care/safe-transitions.html>. Accessed on June 28, 2023.
63. Person and Family Engagement TOOLKIT: A Guide for Measure Developers. Baltimore, MD: Centers for Medicare & Medicaid Services; 2023. <https://mmshub.cms.gov/sites/default/files/Guide-PFE-Toolkit.pdf>. Accessed on June 28, 2023.
64. Patient Engagement. World Health Organization; 2016. <https://apps.who.int/iris/bitstream/handle/10665/252269/9789241511629-eng.pdf>. Accessed on June 28, 2023.
65. Patient & Family Engagement: Improving Health and Advancing Equity. National Partnership for Women and Families; 2021. <https://nationalpartnership.org/wp-content/uploads/2023/02/patient-family-engagement-toolkit.pdf>. Accessed on June 28, 2023.
66. Morris ME, Webster K, Jones C, et al. Interventions to reduce falls in hospitals: a systematic review and meta-analysis. *Age Ageing*. 2022 May 1;51(5)doi: 10.1093/ageing/afac077. PMID: 35524748.
67. Bell SK, Dong ZJ, Desroches CM, et al. Partnering with patients and families living with chronic conditions to coproduce diagnostic safety through OurDX: a previsit online engagement tool. *J Am Med Inform Assoc*. 2023 Mar 16;30(4):692-702. doi: 10.1093/jamia/ocad003. PMID: 36692204.
68. Bell SK, Bourgeois F, Dong J, et al. Patient Identification of Diagnostic Safety Blindspots and Participation in "Good Catches" Through Shared Visit Notes. *Milbank Q*. 2022 Dec;100(4):1121-65. doi: 10.1111/1468-0009.12593. PMID: 36539389.
69. Bell SK, Bourgeois F, DesRoches CM, et al. Filling a gap in safety metrics: development of a patient-centred framework to identify and categorise patient-reported breakdowns related to the diagnostic process in ambulatory care. *BMJ Qual Saf*. 2022 Jul;31(7):526-40. doi: 10.1136/bmjqs-2021-013672. PMID: 34656982.

70. Gleason KT, Peterson S, Dennison Himmelfarb CR, et al. Feasibility of patient-reported diagnostic errors following emergency department discharge: a pilot study. *Diagnosis (Berl)*. 2021 May 26;8(2):187-92. doi: 10.1515/dx-2020-0014. PMID: 33006949.
71. Bourgeois FC, Fossa A, Gerard M, et al. A patient and family reporting system for perceived ambulatory note mistakes: experience at 3 U.S. healthcare centers. *J Am Med Inform Assoc*. 2019 Dec 1;26(12):1566-73. doi: 10.1093/jamia/ocz142. PMID: 31504576.
72. Stavropoulou C, Doherty C, Tosey P. How Effective Are Incident-Reporting Systems for Improving Patient Safety? A Systematic Literature Review. *Milbank Q*. 2015 Dec;93(4):826-66. doi: 10.1111/1468-0009.12166. PMID: 26626987.
73. Macrae C. The problem with incident reporting. *BMJ Qual Saf*. 2016 Feb;25(2):71-5. doi: 10.1136/bmjqs-2015-004732. PMID: 26347519.
74. Imogen M, Anne S, Katherine S, et al. Patient safety incident reporting: a qualitative study of thoughts and perceptions of experts 15 years after 'To Err is Human'. *BMJ Quality & Safety*. 2016;25(2):92. doi: 10.1136/bmjqs-2015-004405.
75. Prakasam D, Wong AL, Smithburger PL, et al. Benefits of Patient/Caregiver Engagement in Adverse Drug Reaction Reporting Compared With Other Sources of Reporting in the Inpatient Setting: A Systematic Review. *J Patient Saf*. 2021 Dec 1;17(8):e765-e72. doi: 10.1097/pts.0000000000000734. PMID: 32555051.
76. Giardina TD, Shahid U, Mushtaq U, et al. Creating a Learning Health System for Improving Diagnostic Safety: Pragmatic Insights from US Health Care Organizations. *J Gen Intern Med*. 2022 Nov;37(15):3965-72. doi: 10.1007/s11606-022-07554-w. PMID: 35650467.
77. Chegini Z, Arab-Zozani M, Shariful Islam SM, et al. Barriers and facilitators to patient engagement in patient safety from patients and healthcare professionals' perspectives: A systematic review and meta-synthesis. *Nurs Forum*. 2021 Oct;56(4):938-49. doi: 10.1111/nuf.12635. PMID: 34339525.
78. Lee M, Lee NJ, Seo HJ, et al. Interventions to Engage Patients and Families in Patient Safety: A Systematic Review. *West J Nurs Res*. 2021 Oct;43(10):972-83. doi: 10.1177/0193945920980770. PMID: 33353509.

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# Disclaimers

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## Afterword

Recognized for excellence in conducting comprehensive systematic reviews, the Agency for Healthcare Research and Quality (AHRQ) Evidence-based Practice Center (EPC) Program is developing a range of rapid evidence products to assist end-users in making specific decisions in a limited timeframe. AHRQ recognizes that people are struggling with urgent questions on how to make healthcare safer. AHRQ is using this rapid format for the fourth edition of its Making Healthcare Safer series of reports, produced by the EPC Program and the General Patient Safety Program. To shorten timelines, reviewers make strategic choices about which processes to abridge. However, the adaptations made for expediency may limit the certainty and generalizability of the findings from the review, particularly in areas with a large literature base. Transparent reporting of the methods used and the resulting limitations of the evidence synthesis are extremely important.

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# Appendixes

## Appendix A. Methods

### Search Strategies for Published Literature

Table A-1. PubMed search strategy

#	Concept	Search Terms
1	Patient and Family Engagement	Patient Participation[Mesh] OR "patient participation"[tiab] OR "patient engagement" [tiab] OR "patient involvement" [tiab] OR "patient empowerment" [tiab] OR "patient partnership" [tiab] OR "patient activation" [tiab] OR "patient-activated" [tiab] OR "family participation"[tiab] OR "family engagement" [tiab] OR "family involvement" [tiab] OR "family empowerment" [tiab] OR "family partnership" [tiab] OR "family activation" [tiab] OR "consumer participation"[tiab] OR "consumer engagement" [tiab] OR "consumer involvement" [tiab] OR "consumer empowerment" [tiab] OR "consumer partnership" [tiab] OR "consumer activation" [tiab] OR "caregiver participation"[tiab] OR "caregiver engagement" [tiab] OR "caregiver involvement" [tiab] OR "caregiver empowerment" [tiab] OR "caregiver activation" [tiab] OR "patient context" [tiab] OR "patient capacity" [tiab] OR "patients capacity" [tiab] OR "Physician-Patient Relations"[Mesh] OR "Professional-Patient Relations"[Mesh] OR "Professional-Family Relations"[Mesh]
2	Patient safety/harm	"patient safety"[mh] OR "patient safety" [tiab] OR "Patient Harm"[mh] OR "Patient Harm*" [tiab] OR "patient risk*" [tiab] OR "quality care" [tiab] OR "adverse event*" [tiab] OR "undesired event*" [tiab] OR "medical errors"[mh] OR "medical error*" [tiab] OR "Diagnostic Errors" [mh] OR "diagnostic error*" [tiab] OR "diagnostic mistake*" [tiab] OR "health care error*" [tiab] OR "healthcare error*" [tiab] OR "medical fault*" [tiab] OR "medical mistake*" [tiab] OR "erroneous diagnos*" [tiab] OR "failure to diagnose" [tiab] OR "false diagnos*" [tiab] OR "faulty diagnos*" [tiab] OR misdiagnos* [tiab] OR "mistaken diagnos*" [tiab] OR "wrong diagnos*" [tiab] OR "safety management" [tiab] OR "safety management" [mh]

#	Concept	Search Terms
3	#1 AND #2	("patient participation"[MeSH Terms] OR "patient participation"[Title/Abstract] OR "patient engagement"[Title/Abstract] OR "patient involvement"[Title/Abstract] OR "patient empowerment"[Title/Abstract] OR "patient partnership"[Title/Abstract] OR "patient activation"[Title/Abstract] OR "patient-activated"[Title/Abstract] OR "family participation"[Title/Abstract] OR "family engagement"[Title/Abstract] OR "family involvement"[Title/Abstract] OR "family empowerment"[Title/Abstract] OR "family partnership"[Title/Abstract] OR "family activation"[Title/Abstract] OR "consumer participation"[Title/Abstract] OR "consumer engagement"[Title/Abstract] OR "consumer involvement"[Title/Abstract] OR "consumer empowerment"[Title/Abstract] OR "consumer partnership"[Title/Abstract] OR "consumer activation"[Title/Abstract] OR "caregiver participation"[Title/Abstract] OR "caregiver engagement"[Title/Abstract] OR "caregiver involvement"[Title/Abstract] OR "caregiver empowerment"[Title/Abstract] OR "caregiver activation"[Title/Abstract] OR "patient context"[Title/Abstract] OR "patient capacity"[Title/Abstract] OR "patients capacity"[Title/Abstract] OR "Physician-Patient Relations"[MeSH Major Topic] OR "Professional-Patient Relations"[MeSH Major Topic] OR "Professional-Family Relations"[MeSH Major Topic]) AND ("patient safety"[MeSH Terms] OR "patient safety"[Title/Abstract] OR "Patient Harm"[MeSH Terms] OR "patient harm"[Title/Abstract] OR "patient risk"[Title/Abstract] OR "quality care"[Title/Abstract] OR "adverse event"[Title/Abstract] OR "undesired event"[Title/Abstract] OR "medical errors"[MeSH Terms] OR "medical error"[Title/Abstract] OR "Diagnostic Errors"[MeSH Terms] OR "diagnostic error"[Title/Abstract] OR "diagnostic mistake"[Title/Abstract] OR "health care error"[Title/Abstract] OR "healthcare error"[Title/Abstract] OR "medical fault"[Title/Abstract] OR "medical mistake"[Title/Abstract] OR "erroneous diagnos*[Title/Abstract] OR "failure to diagnose"[Title/Abstract] OR "false diagnos*[Title/Abstract] OR "faulty diagnos*[Title/Abstract] OR "misdiagnos*[Title/Abstract] OR "mistaken diagnos*[Title/Abstract] OR "wrong diagnos*[Title/Abstract] OR "safety management"[Title/Abstract] OR "safety management"[MeSH Terms])
4	#3 AND 2019-April 14,2023	
5	PubMed Filters: English	AND ((english[Filter]))
6	No protocols or case reports	NOT ("study protocol"[Title] OR "trial protocol"[Title] OR "review protocol"[Title] OR "editorial"[Publication Type] OR "letter"[Publication Type] OR "case reports"[Publication Type])

**Table A-2. Cochrane search strategy**

#	Concept	Search Terms
1	Patient and Family Engagement	("patient participation" OR "patient engagement" OR "patient involvement" OR "patient empowerment" OR "patient partnership" OR "patient activation" OR "patient-activated" OR "family participation" OR "family engagement" OR "family involvement" OR "family empowerment" OR "family partnership" OR "family activation" OR "consumer participation" OR "consumer engagement" OR "consumer involvement" OR "consumer empowerment" OR "consumer partnership" OR "consumer activation" OR "caregiver participation" OR "caregiver engagement" OR "caregiver involvement" OR "caregiver empowerment" OR "caregiver activation" OR "patient context" OR "patient capacity" OR "patients capacity"):ti OR ("patient participation" OR "patient engagement" OR "patient involvement" OR "patient empowerment" OR "patient partnership" OR "patient activation" OR "patient-activated" OR "family participation" OR "family engagement" OR "family involvement" OR "family empowerment" OR "family partnership" OR "family activation" OR "consumer participation" OR "consumer engagement" OR "consumer involvement" OR "consumer empowerment" OR "consumer partnership" OR "consumer activation" OR "caregiver participation" OR "caregiver engagement" OR "caregiver involvement" OR "caregiver empowerment" OR "caregiver activation" OR "patient context" OR "patient capacity" OR "patients capacity"):ab OR Patient Participation[Mesh] OR "Physician-Patient Relations"[Mesh] OR "Professional-Patient Relations"[Mesh] OR "Professional-Family Relations"[Mesh]

#	Concept	Search Terms
2	Patient safety/harm	("patient safety" OR "Patient Harm*" OR "patient risk*" OR "quality care" OR "adverse event*" OR "undesired event*" OR "medical error*" OR "diagnostic error*" OR "diagnostic mistake*" OR "health care error*" OR "healthcare error*" OR "medical fault*" OR "medical mistake*" OR "erroneous diagnos*" OR "failure to diagnose" OR "false diagnos*" OR "faulty diagnos*" OR misdiagnos* OR "mistaken diagnos*" OR "wrong diagnos*" OR "safety management"):ti OR ("patient safety" OR "Patient Harm*" OR "patient risk*" OR "quality care" OR "adverse event*" OR "undesired event*" OR "medical error*" OR "diagnostic error*" OR "diagnostic mistake*" OR "health care error*" OR "healthcare error*" OR "medical fault*" OR "medical mistake*" OR "erroneous diagnos*" OR "failure to diagnose" OR "false diagnos*" OR "faulty diagnos*" OR misdiagnos* OR "mistaken diagnos*" OR "wrong diagnos*" OR "safety management"):ab OR "patient safety"[Mesh] OR "Patient Harm"[Mesh] OR "medical errors"[Mesh] OR "Diagnostic Errors" [Mesh]
3	#1 AND #2	((("patient participation" OR "patient engagement" OR "patient involvement" OR "patient empowerment" OR "patient partnership" OR "patient activation" OR "patient-activated" OR "family participation" OR "family engagement" OR "family involvement" OR "family empowerment" OR "family partnership" OR "family activation" OR "consumer participation" OR "consumer engagement" OR "consumer involvement" OR "consumer empowerment" OR "consumer partnership" OR "consumer activation" OR "caregiver participation" OR "caregiver engagement" OR "caregiver involvement" OR "caregiver empowerment" OR "caregiver activation" OR "patient context" OR "patient capacity" OR "patients capacity"):ti OR ("patient participation" OR "patient engagement" OR "patient involvement" OR "patient empowerment" OR "patient partnership" OR "patient activation" OR "patient-activated" OR "family participation" OR "family engagement" OR "family involvement" OR "family empowerment" OR "family partnership" OR "family activation" OR "consumer participation" OR "consumer engagement" OR "consumer involvement" OR "consumer empowerment" OR "consumer partnership" OR "consumer activation" OR "caregiver participation" OR "caregiver engagement" OR "caregiver involvement" OR "caregiver empowerment" OR "caregiver activation" OR "patient context" OR "patient capacity" OR "patients capacity"):ab OR Patient Participation[Mesh] OR "Physician-Patient Relations"[Mesh] OR "Professional-Patient Relations"[Mesh] OR "Professional-Family Relations"[Mesh]) AND ((("patient safety" OR "Patient Harm*" OR "patient risk*" OR "quality care" OR "adverse event*" OR "undesired event*" OR "medical error*" OR "diagnostic error*" OR "diagnostic mistake*" OR "health care error*" OR "healthcare error*" OR "medical fault*" OR "medical mistake*" OR "erroneous diagnos*" OR "failure to diagnose" OR "false diagnos*" OR "faulty diagnos*" OR misdiagnos* OR "mistaken diagnos*" OR "wrong diagnos*" OR "safety management"):ti OR ("patient safety" OR "Patient Harm*" OR "patient risk*" OR "quality care" OR "adverse event*" OR "undesired event*" OR "medical error*" OR "diagnostic error*" OR "diagnostic mistake*" OR "health care error*" OR "healthcare error*" OR "medical fault*" OR "medical mistake*" OR "erroneous diagnos*" OR "failure to diagnose" OR "false diagnos*" OR "faulty diagnos*" OR misdiagnos* OR "mistaken diagnos*" OR "wrong diagnos*" OR "safety management"):ab OR "patient safety"[Mesh] OR "Patient Harm"[Mesh] OR "medical errors"[Mesh] OR "Diagnostic Errors" [Mesh])
4.	No protocols or case reports	NOT (("study protocol" OR "trial protocol" OR "review protocol"):ti OR ("editorial" OR "letter" OR "case reports"):pt)
5	#3 AND #4	
6	2019-April 14, 2023 and English only filter	

## Appendix B. List of Excluded Studies Upon Full-Text Review

1. Ammenwerth E, Neyer S, Hörbst A, et al. Adult patient access to electronic health records. *Cochrane Database Syst Rev*. 2021 Feb 26;2(2):Cd012707. doi: 10.1002/14651858.CD012707.pub2. PMID: 33634854. - **Interventions are only focused on educating patients or providing information**
2. Asan O, Choudhury A, Somai MM, et al. Augmenting patient safety through participation by design - An assessment of dual monitors for patients in the outpatient clinic. *Int J Med Inform*. 2021 Feb;146:104345. doi: 10.1016/j.ijmedinf.2020.104345. PMID: 33260089. - **No outcomes of interest**
3. Bell SK, Bourgeois F, DesRoches CM, et al. Filling a gap in safety metrics: development of a patient-centred framework to identify and categorise patient-reported breakdowns related to the diagnostic process in ambulatory care. *BMJ Qual Saf*. 2022 Jul;31(7):526-40. doi: 10.1136/bmjqs-2021-013672. PMID: 34656982. - **No mention of a patient and family engagement intervention**
4. Bell SK, Bourgeois F, Dong J, et al. Patient Identification of Diagnostic Safety Blindspots and Participation in "Good Catches" Through Shared Visit Notes. *Milbank Q*. 2022 Dec;100(4):1121-65. doi: 10.1111/1468-0009.12593. PMID: 36539389. - **No mention of a patient and family engagement intervention**
5. Bell SK, Dong ZJ, Desroches CM, et al. Partnering with patients and families living with chronic conditions to coproduce diagnostic safety through OurDX: a previsit online engagement tool. *J Am Med Inform Assoc*. 2023 Mar 16;30(4):692-702. doi: 10.1093/jamia/ocad003. PMID: 36692204. - **No mention of a patient and family engagement intervention**
6. Bourgeois FC, Fossa A, Gerard M, et al. A patient and family reporting system for perceived ambulatory note mistakes: experience at 3 U.S. healthcare centers. *J Am Med Inform Assoc*. 2019 Dec 1;26(12):1566-73. doi: 10.1093/jamia/ocz142. PMID: 31504576. - **No outcome of interest**
7. Brierley-Jones L, Ramsey L, Canvin K, et al. To what extent are patients involved in researching safety in acute mental healthcare? *Res Involv Engagem*. 2022 Feb 28;8(1):8. doi: 10.1186/s40900-022-00337-x. PMID: 35227330. - **Interventions are only focused on educating patients or providing information**
8. Burns KK, Davis D, Popescu I, et al. Patient Engagement in a Large-Scale Change Initiative: "As Safe as Possible, as Soon as Possible". *Healthc Q*. 2020 Feb;22(Sp):27-39. doi: 10.12927/hcq.2020.26049. PMID: 32049613. - **No original data (opinion, descriptive data, letters, editorial, commentary)**
9. Busch IM, Saxena A, Wu AW. Putting the Patient in Patient Safety Investigations: Barriers and Strategies for Involvement. *J Patient Saf*. 2021 Aug 1;17(5):358-62. doi: 10.1097/pts.0000000000000699. PMID: 32195779. - **No mention of a patient and family engagement intervention**

10. Butterworth JE, Hays R, McDonagh ST, et al. Interventions for involving older patients with multi-morbidity in decision-making during primary care consultations. *Cochrane Database Syst Rev*. 2019 Oct 28;2019(10)doi: 10.1002/14651858.CD013124.pub2. PMID: 31684697. - **No outcomes of interest**
11. Carvalho PR, Ferraz ESD, Teixeira CC, et al. Patient participation in care safety: Primary Health Care professionals' perception. *Rev Bras Enferm*. 2021;74(2):e20200773. doi: 10.1590/0034-7167-2020-0773. PMID: 34161542. - **No outcomes of interest**
12. Chegini Z, Arab-Zozani M, Shariful Islam SM, et al. Barriers and facilitators to patient engagement in patient safety from patients and healthcare professionals' perspectives: A systematic review and meta-synthesis. *Nurs Forum*. 2021 Oct;56(4):938-49. doi: 10.1111/nuf.12635. PMID: 34339525. - **No outcomes of interest**
13. Chien LJ, Slade D, Dahm MR, et al. Improving patient-centred care through a tailored intervention addressing nursing clinical handover communication in its organizational and cultural context. *J Adv Nurs*. 2022 May;78(5):1413-30. doi: 10.1111/jan.15110. PMID: 35038346. - **Non-USA based study or does not report data separately for USA**
14. Cresham Fox S, Taylor N, Marufu TC, et al. Paediatric family activated rapid response interventions; qualitative systematic review. *Intensive Crit Care Nurs*. 2023 Apr;75:103363. doi: 10.1016/j.iccn.2022.103363. PMID: 36473743. - **Narrative or scoping review**
15. Dijkstra BM, Felten-Barentsz KM, van der Valk MJM, et al. Family participation in essential care activities: Needs, perceptions, preferences, and capacities of intensive care unit patients, relatives, and healthcare providers-An integrative review. *Aust Crit Care*. 2022 Mar 31doi: 10.1016/j.aucc.2022.02.003. PMID: 35370060. - **Interventions are only focused on educating patients or providing information**
16. Duckworth M, Adelman J, Belategui K, et al. Assessing the Effectiveness of Engaging Patients and Their Families in the Three-Step Fall Prevention Process Across Modalities of an Evidence-Based Fall Prevention Toolkit: An Implementation Science Study. *J Med Internet Res*. 2019 Jan 21;21(1):e10008. doi: 10.2196/10008. PMID: 30664454. - **No outcome of interest**
17. Elger BM, Esparaz JR, Nierstedt RT, et al. Engaging the patient and family in the surgical safety process utilizing. *J Pediatr Surg*. 2020 Apr;55(4):597-601. doi: 10.1016/j.jpedsurg.2019.06.012. PMID: 31262502. - **No outcomes of interest**
18. ElKefi S, Asan O. How technology impacts communication between cancer patients and their health care providers: A systematic literature review. *Int J Med Inform*. 2021 May;149:104430. doi: 10.1016/j.ijmedinf.2021.104430. PMID: 33684711. - **Interventions are only focused on educating patients or providing information**
19. Giap TT, Park M. Implementing Patient and Family Involvement Interventions for Promoting Patient Safety: A Systematic Review and Meta-Analysis. *J Patient Saf*. 2021

- Mar 1;17(2):131-40. doi: 10.1097/pts.0000000000000714. PMID: 33208637. - **Non-USA based study or does not report data separately for USA**
20. Gibson B, Butler J, Schnock K, et al. Design of a safety dashboard for patients. *Patient Educ Couns*. 2020 Apr;103(4):741-7. doi: 10.1016/j.pec.2019.10.021. PMID: 31767242. - **No original data (opinion, descriptive data, letters, editorial, commentary)**
  21. Gleason KT, Peterson S, Dennison Himmelfarb CR, et al. Feasibility of patient-reported diagnostic errors following emergency department discharge: a pilot study. *Diagnosis (Berl)*. 2021 May 26;8(2):187-92. doi: 10.1515/dx-2020-0014. PMID: 33006949. - **Interventions are only focused on educating patients or providing information**
  22. Gonçalves-Bradley DC, Lannin NA, Clemson L, et al. Discharge planning from hospital. *Cochrane Database of Systematic Reviews*. 2022(2)doi: 10.1002/14651858.CD000313.pub6. PMID: 35199849. - **No mention of a patient and family engagement intervention**
  23. Groves PS, Bunch JL, Cannava KE, et al. Nurse Sensemaking for Responding to Patient and Family Safety Concerns. *Nurs Res*. 2021 Mar-Apr 01;70(2):106-13. doi: 10.1097/nnr.0000000000000487. PMID: 33630533. - **No mention of a patient and family engagement intervention**
  24. Hall KK, Shoemaker-Hunt S, Hoffman L, et al. Making Healthcare Safer III: A Critical Analysis of Existing and Emerging Patient Safety Practices. Rockville (MD): Agency for Healthcare Research and Quality (US); 2020. -**Other: MHS III report**
  25. Harrington A, Darke H, Ennis G, et al. Evaluation of an alternative model for the management of clinical risk in an adult acute psychiatric inpatient unit. *Int J Ment Health Nurs*. 2019 Oct;28(5):1099-109. doi: 10.1111/inm.12621. PMID: 31206989. - **Non-USA based study or does not report data separately for USA**
  26. Harris K, Russ S. Patient-completed safety checklists as an empowerment tool for patient involvement in patient safety: concepts, considerations and recommendations. *Future Healthc J*. 2021 Nov;8(3):e567-e73. doi: 10.7861/fhj.2021-0122. PMID: 34888443. - **No original data (opinion, descriptive data, letters, editorial, commentary)**
  27. Harris K, Søfteland E, Moi AL, et al. Patients' and healthcare workers' recommendations for a surgical patient safety checklist - a qualitative study. *BMC Health Serv Res*. 2020 Jan 16;20(1):43. doi: 10.1186/s12913-020-4888-1. PMID: 31948462. - **Non-USA based study or does not report data separately for USA**
  28. Jull J, Köpke S, Smith M, et al. Decision coaching for people making healthcare decisions. *Cochrane Database of Systematic Reviews*. 2021(11)doi: 10.1002/14651858.CD013385.pub2. PMID: 34749427. - **Interventions are only focused on educating patients or providing information**
  29. Kerr AM, Harrington NG, Scott AM. Communication and the Appraisal of Uncertainty: Exploring Parents' Communication with Credible Authorities in the Context of Chronic Childhood Illness. *Health Commun*. 2019 Feb;34(2):201-11. doi:

- 10.1080/10410236.2017.1399508. PMID: 29120241. - **No mention of a patient and family engagement intervention**
30. Klein LW, Anderson HV, Cigarroa J. Shared Decision-Making in Cardiovascular Practice. *Cardiol Rev.* 2023 Jan-Feb 01;31(1):52-6. doi: 10.1097/crd.0000000000000434. PMID: 35349540. - **Interventions are only focused on educating patients or providing information**
  31. Laukka E, Huhtakangas M, Heponiemi T, et al. Health Care Professionals' Experiences of Patient-Professional Communication Over Patient Portals: Systematic Review of Qualitative Studies. *J Med Internet Res.* 2020 Dec 8;22(12):e21623. doi: 10.2196/21623. PMID: 33289674. - **No outcomes of interest**
  32. Lear R, Freise L, Kybert M, et al. Patients' Willingness and Ability to Identify and Respond to Errors in Their Personal Health Records: Mixed Methods Analysis of Cross-sectional Survey Data. *J Med Internet Res.* 2022 Jul 8;24(7):e37226. doi: 10.2196/37226. PMID: 35802397. - **No outcomes of interest**
  33. Lee M, Lee NJ, Seo HJ, et al. Interventions to Engage Patients and Families in Patient Safety: A Systematic Review. *West J Nurs Res.* 2021 Oct;43(10):972-83. doi: 10.1177/0193945920980770. PMID: 33353509. - **Interventions are only focused on educating patients or providing information**
  34. Lee NJ, Ahn S, Lee M. Requirement Analysis for Developing a Patient Participation Program in Patient Safety. *Stud Health Technol Inform.* 2019 Aug 21;264:1849-50. doi: 10.3233/shti190679. PMID: 31438374. - **Non-USA based study or does not report data separately for USA**
  35. Li C, Xu X, He L, et al. Questionnaires measuring patient participation in patient safety- A systematic review. *J Nurs Manag.* 2022 Oct;30(7):3481-95. doi: 10.1111/jonm.13690. PMID: 35593487. - **No outcomes of interest**
  36. Louch G, Reynolds C, Moore S, et al. Validation of revised patient measures of safety: PMOS-30 and PMOS-10. *BMJ Open.* 2019 Nov 28;9(11):e031355. doi: 10.1136/bmjopen-2019-031355. PMID: 31784438. - **No outcomes of interest**
  37. Lu Y, Elwyn G, Moulton BW, et al. Shared Decision-making in the U.S.: Evidence exists, but implementation science must now inform policy for real change to occur. *Z Evid Fortbild Qual Gesundhwes.* 2022 Jun;171:144-9. doi: 10.1016/j.zefq.2022.04.031. PMID: 35599230. - **No original data (opinion, descriptive data, letters, editorial, commentary)**
  38. Mackintosh NJ, Davis RE, Easter A, et al. Interventions to increase patient and family involvement in escalation of care for acute life-threatening illness in community health and hospital settings. *Cochrane Database Syst Rev.* 2020 Dec 8;12(12):Cd012829. doi: 10.1002/14651858.CD012829.pub2. PMID: 33285618. - **Interventions are only focused on educating patients or providing information**
  39. Martinez W, Browning D, Varrin P, et al. Increasing Patient-Clinician Concordance About Medical Error Disclosure Through the Patient TIPS Model. *J Patient Saf.* 2019

Dec;15(4):305-7. doi: 10.1097/pts.0000000000000284. PMID: 28492422. -

**Interventions are only focused on educating patients or providing information**

40. Neves AL, Smalley KR, Freise L, et al. Determinants of Use of the Care Information Exchange Portal: Cross-sectional Study. J Med Internet Res. 2021 Nov 11;23(11):e23481. doi: 10.2196/23481. PMID: 34762063. - **Non-USA based study or does not report data separately for USA**
41. New L, Goodridge D, Kappel J, et al. "I just have to take it" - patient safety in acute care: perspectives and experiences of patients with chronic kidney disease. BMC Health Serv Res. 2019 Mar 28;19(1):199. doi: 10.1186/s12913-019-4014-4. PMID: 30922299. - **No outcomes of interest**
42. Nijhuis FAP, Esselink R, de Bie RMA, et al. Translating Evidence to Advanced Parkinson's Disease Patients: A Systematic Review and Meta-Analysis. Mov Disord. 2021 Jun;36(6):1293-307. doi: 10.1002/mds.28599. PMID: 33797786. - **Interventions are only focused on educating patients or providing information**
43. Nissling L, Fahlke C, Lilja JL, et al. Primary Care Peer-Supported Internet-Mediated Psychological Treatment for Adults With Anxiety Disorders: Mixed Methods Study. JMIR Form Res. 2020 Aug 20;4(8):e19226. doi: 10.2196/19226. PMID: 32815819. - **Interventions are only focused on educating patients or providing information**
44. Otsuka S, Smith JN, Pontiggia L, et al. Impact of an interprofessional transition of care service on 30-day hospital reutilizations. J Interprof Care. 2019 Jan-Feb;33(1):32-7. doi: 10.1080/13561820.2018.1513466. PMID: 30156942. - **No mention of a patient and family engagement intervention**
45. Park M, Giap TT. Patient and family engagement as a potential approach for improving patient safety: A systematic review. J Adv Nurs. 2020 Jan;76(1):62-80. doi: 10.1111/jan.14227. PMID: 31588602. - **Other: Already included in MHS III**
46. Prakasam D, Wong AL, Smithburger PL, et al. Benefits of Patient/Caregiver Engagement in Adverse Drug Reaction Reporting Compared With Other Sources of Reporting in the Inpatient Setting: A Systematic Review. J Patient Saf. 2021 Dec 1;17(8):e765-e72. doi: 10.1097/pts.0000000000000734. PMID: 32555051. - **No mention of a patient and family engagement intervention**
47. Quigley PA, Votruba L, Kaminski J. Outcomes of Patient-Engaged Video Surveillance on Falls and Other Adverse Events. Clin Geriatr Med. 2019 May;35(2):253-63. doi: 10.1016/j.cger.2019.01.005. PMID: 30929886. - **No mention of a patient and family engagement intervention**
48. Schenk EC, Bryant RA, Van Son CR, et al. Developing an Intervention to Reduce Harm in Hospitalized Patients: Patients and Families in Research. J Nurs Care Qual. 2019 Jul/Sep;34(3):273-8. doi: 10.1097/ncq.0000000000000354. PMID: 30198945. - **No original data (opinion, descriptive data, letters, editorial, commentary)**
49. Scott J, Heavey E, Waring J, et al. Implementing a survey for patients to provide safety experience feedback following a care transition: a feasibility study. BMC Health Serv

Res. 2019 Aug 30;19(1):613. doi: 10.1186/s12913-019-4447-9. PMID: 31470853. - **Non-USA based study or does not report data separately for USA**

50. Subbe CP, Tomos H, Jones GM, et al. Express check-in: developing a personal health record for patients admitted to hospital with medical emergencies: a mixed-method feasibility study. *Int J Qual Health Care*. 2021 Sep 12;33(3)doi: 10.1093/intqhc/mzab121. PMID: 34410422. - **No outcomes of interest**
51. Suclupe S, Efrain Pantoja Bustillos P, Bracchiglione J, et al. Effectiveness of nonpharmacological interventions to prevent adverse events in the intensive care unit: A review of systematic reviews. *Aust Crit Care*. 2022 Dec 24doi: 10.1016/j.aucc.2022.11.003. PMID: 36572576. - **No mention of a patient and family engagement intervention**
52. Tyler N, Giles S, Daker-White G, et al. A patient and public involvement workshop using visual art and priority setting to provide patients with a voice to describe quality and safety concerns: Vitamin B12 deficiency and pernicious anaemia. *Health Expect*. 2021 Feb;24(1):87-94. doi: 10.1111/hex.13152. PMID: 33180344. - **Non-USA based study or does not report data separately for USA**
53. Vitger T, Korsbek L, Austin SF, et al. Digital Shared Decision-Making Interventions in Mental Healthcare: A Systematic Review and Meta-Analysis. *Front Psychiatry*. 2021;12:691251. doi: 10.3389/fpsyt.2021.691251. PMID: 34552514. - **Interventions are only focused on educating patients or providing information**
54. Welch ML, Hodgson JL, Didericksen KW, et al. Family-Centered Primary Care for Older Adults with Cognitive Impairment. *Contemp Fam Ther*. 2022;44(1):67-87. doi: 10.1007/s10591-021-09617-2. PMID: 34803217. - **Interventions are only focused on educating patients or providing information**
55. Willis MA, Hein LB, Hu Z, et al. Feeling better on hemodialysis: user-centered design requirements for promoting patient involvement in the prevention of treatment complications. *J Am Med Inform Assoc*. 2021 Jul 30;28(8):1612-31. doi: 10.1093/jamia/ocab033. PMID: 34117493. - **Interventions are only focused on educating patients or providing information**
56. Yu C, Choi D, Bruno BA, et al. Impact of MyDiabetesPlan, a Web-Based Patient Decision Aid on Decisional Conflict, Diabetes Distress, Quality of Life, and Chronic Illness Care in Patients With Diabetes: Cluster Randomized Controlled Trial. *J Med Internet Res*. 2020 Sep 30;22(9):e16984. doi: 10.2196/16984. PMID: 32996893. - **Non-USA based study or does not report data separately for USA**
57. Zavalkoff S, Mazaniello-Chezol M, O'Donnell S, et al. Improving transparent team communication with the 'Glass Door' decal communication tool: a mixed methods analysis of family and staff perspectives. *BMJ Open Qual*. 2021 Sep;10(3)doi: 10.1136/bmjoq-2021-001507. PMID: 34593521. - **No mention of a patient and family engagement intervention**

## Appendix C. Data Tables

**Table C-1. Overview of the systematic review of studies of patient safety practices focused on patient and family engagement**

Author, Year	Number of Papers Included, n	Number of Papers Published pre-2019, n	Number of Papers Published in 2019 and Later, n	List of papers Published in the United States in 2019 and Later*
Newman, 2021 <sup>18</sup>	26	20	U.S. studies: 3  U.K.: 1  Canada: 1  Vietnam: 1	<ul style="list-style-type: none"> <li>• Duckworth M, Adelman J, Belategui K, et al. Assessing the effectiveness of engaging patients and their families in the three-step fall prevention process across modalities of an evidence-based fall prevention toolkit: an implementation science study. J Med Internet Res. 2019;21(1):2.</li> <li>• Dykes PC, Burns Z, Adelman J, et al. Evaluation of a patient centered fall-prevention tool kit to reduce falls and injuries: a nonrandomized controlled trial. JAMA Netw Open. 2020;3(11): e2025889.</li> <li>• Rochon R, Salazar L. Partnering with the patient to reduce falls in a medical-surgical unit. Int J Safe Pat Handl Mob. 2019;9(4):135-142.</li> </ul>

UK = United Kingdom

\*Dykes et al., 2020 and Duckworth et al., 2019 are papers on the same study

**Table C-2. Overview of the studies of patient safety practices focused on patient and family engagement in multicomponent interventions targeting patient falls**

Author, Year	Study Design	Objectives	Study Years	Setting	Number of Participants, n	Funding	PSP	Main Findings
Dykes, 2020 <sup>19</sup> Christiansen, 2020 <sup>20</sup>	Pre-post	Assess whether a fall-prevention tool kit that engages patients and families in the fall prevention process throughout hospitalization is associated with reduced falls and injurious falls.	2015-2018	14 Adult medical units in 3 academic medical centers, hospitalized patients	Pre-intervention: 17,948  Post-intervention: 19,283	Agency for Healthcare Research and Quality	The fall prevention program Fall TIPS (Tailoring Interventions for Patient Safety)	<ul style="list-style-type: none"> <li>• Overall adjusted 15% reduction in falls after implementation of the fall-prevention tool kit (rate ratio 0.85; 95% CI 0.75-0.96; p=.01)</li> <li>• Adjusted 34% reduction in injurious falls (rate ratio, 0.66; 95% CI 0.53-0.88; p=.003)</li> </ul>

Author, Year	Study Design	Objectives	Study Years	Setting	Number of Participants, n	Funding	PSP	Main Findings
Radecki, 2020 <sup>21</sup>	Prospective cohort	To evaluate the impact of the patient fall self-assessment tool on patient knowledge in action, its usability as rated by nurses, and incidence of falls.	2018	A large, urban, academic, level 1, trauma center, hospitalized patients	Total: 203  103 at baseline  100 during the intervention	No external funding reported	Patient fall self-assessment tool	<ul style="list-style-type: none"> <li>• A statistically significant improvement (p=0.0007) in the patient's participation in the development of the safety plan</li> <li>• A 25% reduction in total falls</li> <li>• A 67% reduction in injury falls</li> </ul>
Rochon, 2019 <sup>22</sup>	Prospective cohort	Evaluating falls prevention program aimed at decreasing falls and improving patient safety by including patients in their care.	2018	A US federal hospital, medical-surgical units, hospitalized patients	Not reported	No external funding reported	Implementation of the Partnering with the Patient falls program	<ul style="list-style-type: none"> <li>• Falls rate decreased 71% from 8.06 to 3.18</li> <li>• Average number of falls decreased from 4 to 1.7</li> <li>• Average length of stay decreased 17% from 2.84 to 2.39</li> </ul>

CI = confidence interval; n = sample size; PSP = patient safety practice

**Table C-3. Overview of the studies of patient safety practices focused on patient and family engagement in patient portals and information tools targeting broader safety**

Author, Year	Study Design	Objectives	Study Years	Setting	Number of Participants, n	Funding	PSP	Main Findings
Fuller, 2020 <sup>23</sup>	Cross-sectional	To evaluate the implementation of a suite of digital health tools integrated with the EHR to engage hospitalized patients, caregivers, and their care team in preparing for discharge.	2017-2018	An academic medical hospital, general medicine units, hospitalized patients	Total: 752  Submitted checklist: 510  Did not submit checklist: 242	Agency for Healthcare Research and Quality	Digital health tools integrated with the EHR	<ul style="list-style-type: none"> <li>• 4.24 concerns were reported per each of the 510 checklist submissions, most commonly on medications (30.7%) and followup (30.3%)</li> <li>• Mean length of stay, among those who submitted checklist was 8.78 and among those who did not submit checklist 11.5 (p=0.02)</li> <li>• Readmissions within 30 days, among those who submitted checklist was 88 (17.3%) and among those who did not submit checklist 39 (16.1%) (p=0.18)</li> </ul>

Author, Year	Study Design	Objectives	Study Years	Setting	Number of Participants, n	Funding	PSP	Main Findings
Grossman, 2019 <sup>24</sup> Masterson Creber, 2019 <sup>25</sup>	Pragmatic randomized controlled trial	To examine predictors of frequent versus infrequent portal use among hospitalized patients who received free access to an iPad, the Internet, and technical assistance.	2014-2017	An urban academic medical center, medical and surgical cardiac units, hospitalized patients	Usual care: 148  Intervention (Tablet-only): 132  Intervention (Portal): 146	Agency for Healthcare Research and Quality; National Library of Medicine; National Institute of Nursing Research	Inpatient portal	<ul style="list-style-type: none"> <li>• Patients in inpatient portal group had lower 30-day hospital readmissions (5.5% vs. 12.9% tablet-only and 13.5% usual care; p=0.044)</li> <li>• A greater percentage of frequent users noticed potential medical errors during their hospital stay (22 vs. 4%; p=0.010).</li> <li>• About half (51%) of potential medical errors related to medication dosage or administration.</li> <li>• A greater percentage of frequent users noticed inaccurate information in their medical record (20 vs. 9%, p=0.133), although that difference lacked statistical significance.</li> </ul>

Author, Year	Study Design	Objectives	Study Years	Setting	Number of Participants, n	Funding	PSP	Main Findings
Schnock, 2022 <sup>26</sup>	Cross-sectional	To evaluate the association between use of an electronic patient safety dashboard (Safety Advisor) and health outcomes.	2018	An academic medical center, oncology and neurology units, hospitalized patients	Low portal usage: 69  Moderate portal usage: 92  High portal usage: 27	Robert Wood Johnson Foundation; The Ullem Foundation.	Electronic patient safety dashboard	<ul style="list-style-type: none"> <li>• Patients who used the application more had lower 30-day readmission rates (<math>p=0.01</math>) compared with the lower-usage group.</li> <li>• Shorter hospital stays were correlated with higher application usage (high-usage group 8.3 days in average, moderate-usage group 6.8 days in average, and low-usage group 7.1 days in average)</li> <li>• Although the mortality rate was too small for P value calculation, a decrease was still observed in the high-portal-usage group (high-usage group [<math>n=27</math>; 0.5%], moderate-usage group [<math>n=92</math>; 2.1%], and low-usage group [<math>n=69</math>; 1.1%])</li> </ul>

EHR = electronic health record; n = sample size; PSP = patient safety practice

**Table C-4. Cochrane risk of bias assessment for randomized controlled trials**

<b>Author, Year</b>	<b>Selection Bias: Random Sequence Generation</b>	<b>Selection Bias: Allocation Concealment</b>	<b>Performance Bias</b>	<b>Detection Bias</b>	<b>Attrition Bias</b>	<b>Reporting Bias</b>	<b>Other Bias</b>	<b>Final</b>
Grossman, 2019 <sup>24</sup> Masterson Creber, 2019 <sup>25</sup>	Low	Unclear	High	High	Unclear	Low	Low	Unclear

**Table C-5. Cochrane risk of bias assessment for nonrandomized studies**

<b>Author, Year</b>	<b>Confounding</b>	<b>Patient Selection</b>	<b>Classifying Interventions</b>	<b>Deviations From Intended Interventions</b>	<b>Missing Data</b>	<b>Measurement Outcomes</b>	<b>Selection of Reported Results</b>	<b>Overall Assessment</b>
Radecki, 2020 <sup>21</sup>	Serious	Low	Low	Low	Low	Serious	Low	Serious
Fuller, 2020 <sup>23</sup>	Serious	Low	Low	Low	Low	Serious	Low	Serious
Schnock, 2022 <sup>26</sup>	Serious	Low	Low	Low	Low	Serious	Low	Serious
Rochon, 2019 <sup>22</sup>	Serious	Low	Low	Low	Low	Serious	Low	Serious
Dykes, 2020 <sup>19</sup> Christiansen, 2020 <sup>20</sup>	Moderate	Low	Low	Moderate	Low	Serious	Low	Moderate