


# The benefits and opportunities: Engaging patients in identifying and reporting patient safety incidents

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## Abstract

There is growing recognition that patients can and should be engaged in the identification of patient safety incidents arising during their experiences across health systems. In this article, we describe the benefits that can be harnessed from engaging patients in reporting patient safety incidents; identify opportunities to support patient engagement in reporting and learning from patient safety incidents; and describe the potential role of health leaders in connecting patient experience and patient safety using patient-reported patient safety incident data.

## Introduction

A comprehensive understanding of healthcare safety can be accomplished by engaging patients in identifying and reporting patient safety incidents arising during patient experiences across the healthcare system. Historically, the patient safety paradigm did not fully embrace patient experience. There is growing recognition that patients' experiences and understanding of safety can and should inform patient safety improvement efforts.<sup>1–3</sup> The World Health Organization (WHO) published the *2021–2030 Global Safety Action Plan: Towards Eliminating Avoidable Harm in Health Care* outlining seven guiding principles to reduce avoidable patient harm.<sup>1</sup> The authors explicitly called for involving patients and families across the healthcare system. Strategy 4.2 specifically aligns with this call: “learn from the experiences of [patients] exposed to unsafe care to improve understanding of the nature of harm and foster the development... of solutions.” Further, the authors identified governments and healthcare organizations need to act by creating opportunities for patients to share experiences with the goal of understanding the reality of care delivery.

Health leaders across the system are well positioned to connect patient experience and patient safety. Leaders play a role in fostering a culture supportive of identifying and learning from past patient safety incidents. Further, they have a role in responding to and reviewing safety concerns raised by team members and patients; supporting the implementation of interventions to improve safety; as well as measuring and monitoring the safety of care delivery within the teams they lead (e.g. monitoring key performance indicators).<sup>4</sup>

By capturing the patient perspective on patient safety incidents across the healthcare system, our understanding of past harm can be expanded. One way to capture this perspective is to capitalize on the benefits gained through Incident Reporting and Learning Systems (IRLSs). These systems have been a key improvement tool in the patient safety movement. Although they have limitations—such as reporting bias, poor data quality, and underreporting—they can record a sample of patient safety incidents and be the initial step

in learning from reported past harm.<sup>5</sup> In most IRLSs, clinicians are encouraged to voluntarily report incidents in an e-form or on paper, with few organizations providing patients with reporting opportunities.<sup>6–8</sup> There is an opportunity for health leaders to build robust IRLSs to capture not only clinician-reported patient safety incidents, but also patient-reported incidents. Vincent et al. indicated multiple measures are required to gain deep insight into the safety of a system.<sup>9</sup> By combining the data on patient-reported patient safety incidents with those predominantly reported by clinicians, leaders can uncover a deeper understanding on the impact and causes of poor quality and safety outcomes, as well as develop strategies to target the issues identified by both patients and clinicians.<sup>10</sup>

In this article, we describe relevant studies supporting the argument that benefits and opportunities exist with incorporating the patient voice in incident reporting; identify opportunities to support patient engagement in reporting and learning from patient safety incidents; and describe the potential role of health leaders in connecting patient experience and patient safety. We primarily focus on patient-reported incidents across the healthcare system (e.g. acute care, long-term care, and community care), rather than family, caregiver, and substitute decision maker reporting in one particular care area.

## The benefits

### *Broadening the understanding of harm*

Healthcare systems commonly monitor and measure system safety by tracking and analyzing past patient harm (e.g. adverse

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drug events and falls).<sup>9</sup> Patients and clinicians are both well positioned to detect and report patient safety incidents; however, they can both provide different perspectives on past harm.<sup>7,10</sup> Consider a patient who experiences a preventable fall while admitted in hospital that does not result in injury. A clinician may not report this as a patient safety incident if no identifiable physical harm was detected. However, a patient may identify harms such as, a lack of trust with the healthcare system or a fear of ambulation post-fall limiting their physical activity.

Through published work on patient-reported incidents, researchers demonstrated patients can detect and report harm and safety concerns occurring during their healthcare trajectory that may go otherwise unnoticed by clinicians.<sup>7,8,11</sup> Clinicians have been criticized for having a narrow view of past harm focused on physical outcomes.<sup>12</sup> It is becoming increasingly recognized that harm can also be non-physical (psychological and financial).<sup>3,13</sup> Sokol-Hessner et al. described emotional harm as a loss of dignity from inadequate respect. Although clinicians may recognize emotional harm from patient safety incidents, this type of harm is likely underreported in IRLSs by clinicians due to a lack of knowledge/expectation to report emotional harm.<sup>13</sup> Focusing on physical harm resulting from patients' safety incidents does not account for holistic patients experiences, ultimately limiting the healthcare system in developing a comprehensive understanding of avoidable patient harm.<sup>3</sup>

Researchers demonstrated patients have a broader understanding of harm.<sup>7,11,13</sup> Hernan et al. characterized the nature and type of patient-reported incidents in primary care. In this study, the most common incident type reported by patients was "administration" (e.g. accessing care services). Further, a common patient-reported outcome was psychological and emotional distress, rather than solely physical harm. With a recognition that non-physical harm is underrepresented in patient safety incident reports by clinicians, capturing patient-reported incidents may provide an opportunity to understand the nature of non-physical harm events, and the potential link between non-physical and physical harm.<sup>13</sup>

Further, Armitage et al. compared patient-reported patient safety concern data to data collected in three existing information systems detecting patient safety incidents in the inpatient ward setting: patient case notes, staff incident reports, and patient complaint reports.<sup>7</sup> The authors found patients detected incidents not captured in the existing data sources. The safety concerns raised by patients were mostly related to observations of the care team and clinician interactions with other patients. Further, 68 of the 155 (55%) patient-reported safety concerns were agreed to be incidents by clinicians. Additionally, Weisman and colleagues compared hospital adverse events detected in the medical record to those identified by patients during post-discharge interviews. The authors found the review of medical records identified approximately 25% of the adverse events identified by patients.<sup>14</sup> By comparing the patient-reported concerns with data captured in existing systems, researchers demonstrated patients' ability to detect incidents which

may not be identified by clinicians or through the existing information systems, which leaders often rely on to capture patient safety metric data.<sup>2,3,9,14</sup>

### *Support a view of safety across the patient journey*

Patients are the only care team member present at every interaction across their care journey.<sup>10</sup> For example, consider the medication process (procuring, prescribing, dispensing, administering, or monitoring medications).<sup>15</sup> This process can cross multiple care environments in a care journey, such as a patient can have a medication prescribed in an emergency department, dispensed in a community pharmacy, self-administered at home, and monitored within a family health team. This example describes how multiple care environments are connected in the delivery of care. A narrow view of past harm or limiting reporting of harm to a certain care setting may prevent leaders from uncovering contributory factors impacting care safety across the patient journey. As patients' healthcare interactions are not limited to one encounter, they can describe interactions crossing boundaries of the healthcare system. Some researchers have called for a comprehensive understanding of safety across the care journey as each interaction in the healthcare system is connected and influences outcomes.<sup>16</sup> Identifying and analyzing patient-reported patient safety incidents occurring across stages within the care journey can deepen insight on harmful patient experiences.

### *Identify contributing factors to harm*

One of the key aspects of an IRLS is to generate knowledge from reported patient safety incidents.<sup>6</sup> Researchers analyzed reported patient safety incidents to identify common themes and monitor contributing factor trends identified in IRLS reports.<sup>17,18</sup> The contributing factors can inform recommendations to improve safety.<sup>18</sup> In addition to being able to recognize past harm, patients also identify patient safety incident contributing factors.<sup>7,18,19</sup> For example, in the study by Armitage et al., patients reported safety concerns not only resulting in harm but also concerns with potential to cause harm.<sup>7</sup> These latent conditions are unlikely documented in-patient case notes and in clinician incident reports. Further, patients are observing actions in healthcare environments relevant to safe care delivery (e.g. infection control methods).<sup>2</sup> Barrow et al. identified that patient observations of patient safety-related activities could contribute to measuring and monitoring safe care.<sup>2</sup> Overall, patient-reported safety incidents could potentially help healthcare leaders identify, address, and monitor latent and active system conditions with potential to result in patient harm.<sup>12,20</sup>

## **The opportunities**

### *Patient informed definition of patient safety incident*

The term "patient safety incident" is not well-known outside of healthcare.<sup>20</sup> When collecting information from patients on patient safety incidents, researchers used general terms, such as "safety concern" and "safety experience."<sup>7,20</sup> These terms do

not have standardized definitions making it challenging to compare results. Additionally, because of poor awareness and understanding of the term “patient safety incident” by patients, some do not trust patients to identify/report patient safety incidents.<sup>21</sup> In order to capture patient-reported patient safety incidents, researchers will need to co-develop a definition of “patient safety incident” reflecting the patient perspective.<sup>22</sup> However, researchers will be challenged with co-designing an expansive definition reflective of patient voices.<sup>2</sup> Barrow et al. conceptualized “patient safety” from the perspective of in-patients and identified future work will need to engage with ethnic minority groups to iterate their conceptual framework of patient safety.<sup>2</sup> The same will be true for the conceptualization of a definition for “patient safety incident” that is expanded to include the patient perspective.

### ***Robust analysis frameworks***

Robust methods to analyze and trend patient identified contributing factors are needed to understand patients’ conceptualization of patient safety incident contributing factors, and methods to drive improvements with patient-reported incident data.<sup>11,23</sup> Great effort has been made in developing and applying frameworks to structure data collection and/or analysis of reported patient safety incidents and contributing factors.<sup>17,24,25</sup> Specifically, the authors of the “PISA” framework developed four classes using the WHO International Classification for Patient Safety conceptual framework which does not incorporate non-physical harm.<sup>17,26</sup> Additionally, when Hernan et al. applied the “PISA” framework to code patient-reported incidents, the contributory factor coding framework did not consistently align with patient-identified contributing factors. As a result, Hernan et al. called an expansion of the “PISA” framework which would incorporate a broader perspective of patient safety incidents to generate learning from the patient-reported incidents.<sup>11</sup> Further, within healthcare organizations, leaders can incorporate patient safety incident analysis frameworks (e.g. root cause analysis and fishbone diagrams) that encompass a broader understanding of avoidable patient harm into their existing processes.

### ***Methods for engaging patients in reporting patient safety incidents***

Patient-reported patient safety incidents are influenced by how parties are engaged. Researchers identified patient engagement in patient safety as a key challenge.<sup>22,27</sup> For example, patients have varying perceptions on their role in patient safety engagement—some patients viewed themselves as being more responsible for patient safety than others.<sup>2,22,27</sup> With this understanding, leaders cannot assume all patients are interested in being engaged in patient safety incident reporting or view themselves as responsible for reporting. Researchers also identified patients may require special considerations when engaging in reporting.<sup>8,27</sup> Vulnerable patients (e.g. very ill patients)—who may be at higher risk

for incidents—are underrepresented in some studies analyzing patient-reported incidents.<sup>7,8,28,29</sup> However, being vulnerable may limit patient engagement. With poor engagement strategies for vulnerable populations, the conceptualization of patient-reported incidents captured to date in the literature may not be generalizable. Additionally, researchers identified patient safety disparities exist related to race and ethnicity.<sup>30</sup> Thus, methods to address inequities in reporting are likely also required. Further, there may be other barriers preventing patients from raising patient safety incidents. Bell et al. investigated factors influencing intensive care patients and families in raising concerns at the bedside and found this population can be reluctant for many reasons, such as: perceive clinicians as too busy to address their concern, fear being labelled a difficult patient, fear a clinician will get in trouble or their professional relationship with a clinician will be damaged. Future researchers will need to develop strategies to capture the patient perspective so IRLS can reach their full potential, which must also include methods to engage vulnerable groups and address barriers to speaking-up through reporting.<sup>22,27</sup> The methods developed need to balance the need to capture comprehensive and high-quality data from patients, with the feasibility of collecting this data across the healthcare journey.<sup>8</sup>

As previously described, patient safety incident reporting by patients has primarily been captured through research rather than routine operations in healthcare organizations.<sup>7,8</sup> Interviewing in research studies resulted in richer data on patient safety incidents from patients.<sup>20</sup> However, offering interviews for all interested patients is likely not feasible outside of research and could be costly for an organization.<sup>14</sup> A method to capture high-quality data at the right place and time of the patient journey is required.<sup>7</sup> Weissman and colleagues suggested healthcare organizations could incorporate questions to identify adverse events in existing post-discharge patient experience surveys which can then lead to targeted reviews of the care to identify opportunity for improvement. This would require collaboration between the leaders of patient safety and patient experience within a healthcare organization—if they are not within the same department. In Canada, the Institute for Safe Medication Practice Canada captures medication error and adverse drug reaction reports from consumers (e.g. patients and caregivers) at any point in their care journey (e.g. post-discharge from hospital or community pharmacy) anonymously through an e-form on mederror.ca.<sup>31</sup> In addition to post-discharge patient experience surveys, anonymous e-forms may be a method to capture patient-reported incidents.

### ***Patient-reported incidents driving improvement***

Although patients can describe patient safety incident contributing factors, researchers suggested clinicians and leaders may need to improve how they apply/respond to the broad information captured from the patient perspective on incidents to drive improvement.<sup>18,23</sup> This was seen in the first randomized

control trial conducted by Lawton et al. on the effectiveness of patient feedback on hospital ward safety. The intervention was named *Patient Reporting and Action for a Safe Environment (PRASE)* and consisted of supplying wards with patient feedback captured through the *Patient Measures of Safety (PMOS)* survey and the *Patient Incident Reporting Tool*. The ward staff were then asked to address feedback through action planning. However, there was insufficient evidence to suggest PRASE improved the wards' safety. The research team identified it was challenging to engage ward staff in action planning. They also suggested ward staff require additional support in incorporating broad patient feedback into action plans. Improvers and researchers within healthcare organizations will have to learn how to incorporate the patient perspective on patient safety into their improvement strategies and monitor the impact of including this perspective.<sup>23</sup> Future researchers can identify what skills and knowledge healthcare leaders require to utilize data captured in patient-reported patient safety incidents. Researchers in Finland analyzed patient-reported incidents identifying suggestions for improvement. They also analyzed the changes these reports prompted within healthcare organizations.<sup>32</sup> The authors found the patient suggestions were usually discussed at the local level, but not commonly used to inform corrective actions at a system level. The authors identified this may be due to a lack of dedicated time and resources to analyze/review patient reports, or organizations' inability to absorb and process this knowledge. Further, patient-identified incidents may not be taken as serious or simply viewed as a complaint.<sup>32</sup> Health leaders must learn how to maximize the utility of all data within the healthcare system that has potential to provide insight into patient safety, which may require dedicating resources and time to patient-reported incidents. The WHO also called for creating a comprehensive understanding of patient safety by combining data sources capturing risk information. Specifically, the authors indicated healthcare organizations should identify all avoidable harm data sources (e.g. patient-reported incidents and patient-reported experiences) within systems, and track this data to make improvements.<sup>1</sup> Future research could examine if incorporating patient-reported incident data improves organizational outcomes and understanding of organizational safety.

### Implications for health leaders

Although there are associated weaknesses and challenges with engaging patients in incident reporting, improving patient engagement can expand the understanding of safety and inform the identification of strategies to target safety issues identified by patients during their experience of accessing healthcare services across systems (acute care, rehabilitation facilitates, long-term care, and community care). Engaging patients in reporting is also a way for leaders to "engage others" to make "system transformation" in alignment with

the LEADS framework.<sup>33</sup> In order to do so, health leaders must be committed to broadening their own perspectives of what constitutes harm and create opportunities for others to incorporate the patient view of harm into practice. Specifically, clinicians need to be supported in understanding the need to report harms beyond physical outcomes which may require education. Further, health leaders can respond to the WHO's call to create a comprehensive understanding of patient safety by collaborating across the organization to identify existing data sources within their system that can provide insight into patients' experiences of avoidable harm, or develop strategies (e.g. post-discharge surveys) to capture this patient perspective.<sup>1</sup> Further, clinicians and leaders will need to be coached on using patient-reported incident data to inform and monitor improvement efforts.<sup>23</sup> Leaders can also build partnerships with researchers to develop methods to engage patients in reporting incidents occurring during the patient journey across the continuum of care, as well as methods to combine this data with the clinician perspective in order to glean insight into patient safety.<sup>1,8,27</sup> Specifically, an expanded definition of "patient safety incident" that is co-developed with patients and improved analysis methods (contributory factor frameworks inclusive of patient-reported factors) are required.<sup>11</sup> Further, leaders can advance the patient safety domain by incorporating patient-reported measures of safety. Patient experience and safety are connected, especially from the patient perspective.<sup>2</sup> For example, this may be achieved by incorporating patient-reported incident measures on corporate scorecards monitoring quality/safety indicators or incorporating patient experience in organizational quality and safety improvement/strategic plans. The leaders on boards of high-quality hospitals are focused on clinical quality metrics.<sup>34</sup> Incorporating patient-reported safety metrics may support improved care delivery in alignment with patient desires. In future work, leaders may describe the experience of changing IRLSs to capture patient-reported incidents, the use of patient-reported incident data to drive change and the methods to engage patients in reporting through routine healthcare system operations.

### Conclusion

It is time to consistently capture, aggregate, and analyze both the patient and clinician experience of patient safety incidents to drive improvement efforts. In this article, we provide a summary of the benefits and opportunities with integrating the patient voice into IRLSs. Leaders have the potential to push healthcare organizations in a direction that acknowledges the interconnectedness of patient safety and patient experience and maximizes the potential insights on safety that can be gained with patients.

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