

Project Title: **Detecting, Assessing, and Learning from Patient-Perceived Breakdowns in Care**

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## Structured Abstract

**Purpose:** To develop, implement, disseminate, and evaluate a program for detecting, addressing, and preventing patient-perceived breakdowns in care.

**Scope:** Providing patient-centered care requires that healthcare organizations and providers encourage patients to speak up about care breakdowns, respond to concerns in real time, and work to prevent recurrences.

**Methods:** We developed the We Want to Know (WWTK) program and implemented it in partnership with MedStar Health. The program included a campaign to encourage speaking up, multiple reporting options, and a WWTK specialist who facilitated responses. During the pilot, and continuing in one hospital, the specialist conducted “outreach interviews,” eliciting patients’ care experiences. Measures included number/types of events reported, responses to events, perceptions of the program, adoption, and reach.

**Results:** WWTK staff conducted outreach interviews with 5560 patients/family members. Of these, 1156 (21%) reported a care breakdown; 741 (64%) had associated harm. Relatively few patients initiated reporting. In the hospital with a dedicated WWTK specialist, 94 incoming reports were received; in the hospitals without a dedicated specialist, 23 reports were received. Patients’ responded positively to the WWTK program. Most clinicians and leaders supported encouraging patients to voice concerns, but implementation was inconsistent. Several hospitals adapted the program during adoption and implementation.

**Key Words:** patient experience; patient care; patient safety; patient engagement; hospitals; implementation

## **Purpose** (Objectives of Study)

There is growing recognition that patients and family members have unique and important information about care breakdowns, including information about adverse events and how they might be prevented. Our prior work suggested that as many as one in five patients with cancer believes that something has gone wrong in their care. Importantly, many are hesitant to speak up about their concerns.(1) There are a variety of reasons for this, including feeling poorly from their disease and its treatment or the belief that reporting would not lead to change. Most worrisome, however, is patient's fear that reporting their perceptions of care breakdowns might disrupt their relationship with their treatment team. As a result, many patients who believe something has gone wrong in their care "suffer in silence," impairing their experience of care and limiting the ability of providers and health plans to address the patient's concerns and to prevent similar breakdowns from recurring. (2-5)

Providing truly patient-centered care requires that healthcare organizations and providers create effective means to encourage patients to speak up when they perceive a breakdown in care, respond to these concerns in real time, and use patient reports to develop and implement plans for preventing similar breakdowns from occurring to other patients. These breakdowns are likely to be especially common when many providers are involved and sharing responsibility for different aspects of care, as is true for patients in medical/surgical units.

Building on our prior work, and in partnership with MedStar Health (MSH), a national leader in patient safety, we developed, implemented, disseminated, and evaluated a program for detecting, addressing, and preventing patient-perceived breakdowns in care, a program we call "We Want to Know." We sought to achieve the following specific aims:

- 1) To implement and evaluate the We Want to Know program in the adult medical/surgical units (MSU) of two MSH hospitals.

Implementation included a proactive, multimodal We Want to Know (WWTK) campaign encouraging patients to report if they perceive a breakdown in their care and a WWTK Navigator who coordinated real-time responses to breakdowns. We also sought to stimulate process improvement efforts to address significant events (i.e., events in which the patient experienced more than minor harm). Evaluation efforts included examination of program reach, adoption, and implementation through stakeholder interviews, audits, and analysis of patient reports of breakdowns (including number, harms, and actions toward resolution).

- 2) To disseminate and evaluate the We Want to Know program system-wide, across all units of all 10 MedStar hospitals.

The We Want to Know program was ultimately disseminated across all 10 MSH hospitals, incorporating enhancements based on lessons learned during Aim 1, and adaptations to take into account the specific culture, context and constraints at each hospital. Our evaluation included assessment of program reach, adoption, and implementation. We also sought to evaluate program effectiveness by examining the number and type of patient event reports. We also assessed maintenance, via assessing leadership's plans for continuing the program beyond the funding period.

Our goal was to demonstrate the value of actively encouraging patients to report if they perceive a breakdown in their care, to show that doing so enhances clinicians' and leaders' abilities to respond to and prevent care breakdowns and improve patient experiences.

## **Scope** (Background, Context, Settings, Participants, Incidence, Prevalence)

**Background.** A major emphasis in patient safety has been encouraging reporting of adverse events and errors by healthcare workers.(6) Such reporting allows healthcare systems to respond to a specific adverse event or error and to determine how the event occurred to prevent recurrences.(7) However, adverse event reporting systems continue to be underutilized, hampered largely by healthcare workers' fears about reporting. (8) In one recent survey of over 500,000 healthcare workers, 53% expressed concern that their mistakes would be held against them.(9) Such fear inhibits reporting and impairs efforts to improve patient safety.

This growing emphasis on adverse event reporting has occurred alongside an understanding that patients also have important insights about care breakdowns. As the ultimate recipient of healthcare, understanding the patient's perspective is critical to delivering healthcare that is truly patient centered. The patient's perspective is also important because patients know things about their healthcare that the care team does not. For example, Weissman and colleagues found that patients frequently knew of adverse events and errors in their care that were not detected by the institutional adverse event reporting systems or by chart review.(10) Increasing patient willingness to share these reports could markedly improve healthcare quality.

Yet, there is good reason to believe that many patients who experience adverse events and errors may hesitate to alert the healthcare institution or other entities to what went wrong, just as healthcare workers worry about reporting care breakdowns. In our prior study of nearly 500 patients with cancer, only 10% of those who thought something harmful and preventable had gone wrong in their care formally reported the event to their healthcare organization. (1) Evidence also suggests that other commonly used measures of patients' experiences of care, such as patient satisfaction surveys, are very insensitive to episodes of discrete care breakdowns. (11) Healthcare institutions and providers cannot remedy care breakdowns they did not know happened.

Active outreach by healthcare organizations to patients regarding their care experiences is required to overcome patients' reluctance to share negative care experiences.(4) Yet, simply reaching out to patients to solicit their feedback about care, as many organizations currently do with post-hospitalization outreach phone calls, only overcomes a small part of the problem. For those patients who worry that raising concerns about their care could have adverse consequences for their treatment going forward, much more active trust building will be required. These patients not only will need to be persuaded that the healthcare institution genuinely wants to hear about their care experiences, both positive and negative, but also will need to be confident that sharing concerns about care will not have negative repercussions. Vulnerable patients, including those who are sicker patients, less educated, or unemployed, may be even less likely to speak up. (2, 3, 12)

A system of active outreach to patients to solicit their concerns about care, endorsed by a supportive healthcare system, could have multiple advantages. Some patients may be mistaken and believe an adverse event happened when in fact that was not the case. Communicating directly with such patients allows the healthcare system to hear the patient concerns and to correct their mistaken impression. Other patients, however, may accurately perceive care breakdowns, including adverse events. Hearing about these breakdowns directly from patients allows the healthcare system to respond and correct what went wrong for that individual patient in real time. Active, intensive, and multimodal outreach, endorsed by clinicians and leadership, is needed to persuade patients that sharing their concerns about care breakdowns is safe. Also needed are means of providing a real-time response to the affected patient and system-level processes to

analyze patients' reports and to develop plans to prevent recurrences. This demonstration project sought to develop, implement, and evaluate the We Want to Know program to achieve these goals.

### Context, Setting, Participants

**Overview.** The study was conducted at MedStar Health (MSH), a large regional healthcare system in the mid-Atlantic region of the United States. The MSH system is composed of 10 hospitals that provide care to an ethnically and socioeconomically diverse patient population. The program was initially piloted at two of the MSH hospitals. The results of the pilot and input from organizational stakeholders led to a decision to develop and implement two somewhat different models of this program, which we describe in detail in subsequent sections. The first model, which we refer to as WWTK-intensive, included active, in-person outreach to patients (as well as a campaign and multiple modes for patient-initiated reporting); was very resource intensive; and was implemented at a single hospital (one of the two hospitals that were included in the pilot). The second approach, which also included a patient-facing campaign, multiple modes for patient-initiated reporting, was implemented at the remaining nine hospitals. Because implementation of the program raised questions about how to encourage patients to speak up and how to respond if they do, we also conducted an online survey of a nationally representative sample of over 1000 adults to systematically evaluate the impact of different ways of inquiring about breakdowns in care. Details and results of this effort are reported in a separate section near the end of this report.

**Table 1. Characteristics of Participating Hospitals**

Hospital	Total # Discharges Annually	Primary Payer		Payer		Race					Ethnicity	
		Medicare	Medicaid	Medicare	Medicaid	White	African American	Asian	American Indian	Pacific Islander	Spanish/Hispanic	Non-Spanish/Hispanic
Georgetown University Hospital	16,751	37.71%	25.62%	38.42%	28.63%	45.57%	37.47%	2.72%	0.26%	0.07%	5.92%	86.38%
Union Memorial Hospital	11,010	57.86%	31.85%	58.96%	37.30%	46.00%	51.44%	0.32%	0.10%	0.01%	0.64%	98.25%
Washington Hospital Center \$	36,744	42.09%	43.33%	42.49%	50.40%	18.76%	67.53%	0.92%	0.15%	0.01%	7.15%	80.67%
National Rehabilitation Network	2173	48.60%	21.17%	50.76%	30.14%	19.88%	63.05%	0.41%	0.09%	0.05%	3.68%	77.50%
Montgomery Medical Center	7773	52.31%	25.91%	53.38%	28.87%	61.83%	22.63%	4.75%	0.58%	0.06%	7.23%	87.64%
Southern Maryland Hospital	11,776	43.14%	38.11%	43.78%	43.61%	20.43%	75.07%	0.77%	0.18%	0.06%	3.38%	95.03%
Harbor Hospital	8543	34.94%	51.05%	35.42%	55.34%	60.99%	32.80%	0.64%	0.18%	0.05%	6.92%	85.24%
Good Samaritan Hospital	9376	63.23%	32.69%	64.03%	40.07%	33.40%	63.47%	0.32%	0.09%	0.02%	0.47%	97.80%
Franklin Sq. Medical Center \$ #	23,949	43.14%	38.57%	43.73%	42.03%	70.81%	21.61%	1.22%	0.30%	0.03%	1.73%	84.82%
St. Mary's Hospital	8649	40.48%	31.85%	41.01%	36.10%	76.12%	19.24%	1.29%	0.09%	0.01%	1.62%	97.51%

Table Note: \$ Hospital participated in the pilot phase; # Hospital participated in the WWTK-intensive program

**Methods** (Study Design, Data Sources/Collection, Interventions, Measures, Limitations)

**Study Design.** This demonstration project proceeded in phases. We began by piloting the WWTK program at two hospitals (Aim 1). Based on what we learned during piloting, we went on to implement two alternative versions of the program: WWTK-Intensive, in which a WWTK specialist conducted outreach interviews with patients, asking about their care experiences and specifically eliciting information on breakdowns in care. WWTK-Intensive was implemented at one hospital. The second version, WWTK-Core, did not include 1:1 outreach interviews. Details of WWTK-Core are provided below. Evaluation activities were guided by the RE-AIM framework and included both qualitative and quantitative approaches. These are also detailed below.

**Interventions.** The components of the WWTK program (i.e., the intervention) are summarized in Table 2. As this table shows, the WWTK specialist conducted active outreach during the pilot phase and as part of the WWTK-Intensive program. The WWTK specialist did not conduct active outreach at the hospitals participating in the WWTK-Core program; instead, frontline clinicians were expected to encourage patients to speak up about breakdowns. An example of WWTK campaign materials is included on the final page of this report.

**Table 2. WWTK Program Description**

<b>Program Component and Description</b>
<b>Program Awareness</b> Patient-focused campaign materials intended to encourage patients and family members to speak up about perceived breakdowns in care. Clinicians and staff asked to reinforce the WWTK message during patient rooming and rounding. Campaign materials included videos, pocket cards, posters, tent cards, and note pads.
<b>Active Outreach to patients</b> <i>Via WWTK Specialist.</i> The WWTK specialist reaches out to patients to explicit ask about breakdowns in care. During the pilot, outreach is done via phone post discharge and in person via conducting active outreach to patients. Pilot findings led us to focus on in-person outreach only. The WWTK specialist conducted outreach during the pilot phase at two hospitals and throughout the project for the one hospital that implemented the WWTK intensive program. <i>Via Frontline Clinicians.</i> Frontline clinicians were expected to encourage patients to speak up about breakdowns for the nine WWTK-Core hospitals (and ultimately in the WWTK-Core hospital also).
<b>Patient-Initiated Reporting Systems.</b> A dedicated WWTK telephone hotline (monitored), email address, and website at which patients and family members could report events
<b>Response and Resolution.</b> Protocols for event review and coordination with both local hospital and health system’s response and resolution teams (e.g., unit leaders, hospital leaders, risk management, system patient safety and quality) to respond to the reported concern. Protocols for patient and family follow-up, resolution, and service recovery.
<b>Tracking and Learning.</b> Systems for event tracking and protocols to facilitate local and system learning. During the pilot and WWTK-Intensive, the WWTK specialist emailed hospital leaders providing brief narrative text of outreach results. For the WWTK-Intensive approach, research staff provided hospital leadership detailed quantitative reports summarizing interview findings for the month and the quarter.

**Implementation of the WWTK-Intensive Program.** The decision to continue implement active outreach at one hospital (referred to from this point forward as the WWTK-Intensive program) grew out of the pilot effort. The investigators and hospital leaders valued the data collected during the outreach interviews conducted by the WWTK Specialist; therefore, the decision was made to expand the WWTK-Intensive program at one hospital. The WWTK Specialist began to conduct outreach interviews on all units (with the exception of the labor and delivery and behavioral health units), and generated narrative summaries of results in real time for unit and hospital leadership. The specialist worked directly with unit and hospital leadership to respond to

breakdowns in real time. She also entered her interview data into the study database; the research team created monthly and quarterly summary reports, which were sent to hospital leaders. Campaign materials were present in the hospital, including small posters in patient rooms. The WWTK Specialist (or other members of the MSH research team) also monitored and responded to patient-initiated reports, engaging others as needed.

**Implementation of the WWTK-Core Program** was facilitated by integrating the program into the Interdisciplinary Model of Care (IMOC), a system-wide initiative supported by the highest levels of system-level leaders, which was planned for implementation during the same time period that we sought to implement WWTK. Because IMOC had been developed, endorsed, and prioritized for dissemination by MedStar leaders, it provided an ideal means of delivering the WWTK training and program. Although we did not originally envision partnership with and integration into IMOC as our dissemination strategy, it became clear over the course of the project that, to be successful, we needed such a partnership.

Hospital-level adaptation of the WWTK-Core program occurred as the program was disseminated and adopted by each hospital. Leaders from each of the MedStar hospitals met with the MedStar health site PI (Kelly Smith) and/or her team members to plan the how the WWTK program would be implemented at their site. Adaptations occurred in the following areas: 1) selection of campaign materials and in some case modification of the wording; 2) tailoring of processes for delivering the materials to patients (e.g., whether the materials are included with the admissions packet or placed in the room by environmental services as the room is prepared); 3) identification of the hospital-level contact people for the WWTK specialist to contact if and when patients report concerns via the WWTK website; and 4) determination of the contact information to be included on the WWTK materials. Some hospitals elected to adapt the WWTK materials to provide hospital-specific telephone numbers rather than the system-wide WWTK telephone number.

**Data Sources/Collection.** Data sources are summarized in Table 3, and described in detail below.

**Table 3. Data Sources**

	Pilot at two hospitals	Single hospital implementation of WWTK-Intensive	System-wide implementation of WWTK-Core
<b>Data Source: WWTK Specialist outreach to patients</b>			
Number of patients asked about their care by the WWTK specialist	X	X	
Number (%) of patients reporting a breakdown in care (when asked)	X	X	
Types of breakdowns reported	X	X	
Harm(s) associated with breakdowns	X	X	
Actions taken toward addressing/resolving breakdown		X	
<b>Data Source: Patient- or family member-initiated reports of breakdowns</b>			
Number of patients (or family members) initiating a report about a breakdown in care	X	X	X
Types of breakdowns reported	X	X	X
Harm(s) associated with breakdowns	X	x	X
<b>Data Source: HCAHPS Surveys</b>			
HCAHPS – hospital-level ratings on standard items	X	X	X
HCAHPS – individual- and hospital-level ratings on comfort speaking up		X	X
<b>Data Source: In-hospital observations (Audits)</b>			
Number of audits conducted		X	X
Number (%) of audits where campaign materials present in public area or unit		X	X
Number (%) of audits where campaign materials present in patient rooms or admissions packets		X	X
Number (%) of patients asked who indicate awareness of the WWTK program		X	X

**Patient Reports of Breakdowns and Harms.** For all outreach interviews (e.g., during the pilot phase and during the WWTK-Intensive implementation), we collected data on patients' reports of breakdowns and associated harms as reported to the WWTK Specialist as she conducted outreach interviews. Breakdowns and harms were categorized using the Patient Experience Coding Tool (PECT). The PECT was developed by the investigators to categorize the variety of events that patients are likely to report as problematic. Initially based on Dr. Mazor's and Dr. Gallagher's prior experiences, the PECT was refined over the course of the study and was used to categorize all patient-reported breakdowns. Informed by input from hospital leadership and investigators' review and analysis of the data, we also collected systematic information on the steps the WWTK specialist took in response to patients' reports. We also collected data on patient-initiated reports (e.g., reports that patients or family members initiated using the website, email, or telephone). This information was collected throughout the pilot, during the WWTK-Intensive implementation, and for patient-initiated reports that came into the centralized WWTK-reporting systems for the WWTK-Core implementation. (Some hospitals chose to use local reporting, rather than the centralized WWTK system; data on incoming reports at those hospitals were not available to the research team.)

**HCAHPS.** The MSH system implements the HCAHPS survey for all 10 hospitals. The study team developed a new item to be administered in the context of the ongoing HCAHPS survey at MSH hospitals. The question read, "How often did you feel comfortable speaking up if you had any problems in your care?" Response options included *no problems* during hospitalization, *always* felt comfortable speaking up, *usually* felt comfortable speaking up, *sometimes* felt comfortable speaking up, and *never* felt comfortable speaking up. This item is now included on HCAHPS surveys administered for all 10 MSH hospitals, and results are reported to hospital leaders.

**In-Hospital Observations (Audits).** In order to examine program implementation fidelity and adoption, members of the research team conducted routine audits and in-hospital observations at all 10 hospitals. The observers checked whether WWTK campaign materials were present in public areas of the hospitals (e.g., screens in the lobby), on units (e.g., at nurses' stations), and in patient rooms. Auditors also assessed whether patients were aware of these materials by asking patients.

**Evaluation Interviews.** Interviews were conducted at all participating hospitals both during the pilot phase and during implementation of WWTK-Intensive and WWTK-Core. Interviewees represented hospital leadership (e.g., Chief Medical Officer, Medical Director, Chief Nursing Officer, Director of Nursing, Director of Patient Care Services), Allied Health Services (e.g., Clinical Supervisor Occupational Therapy), marketing and communications leaders, patient experience leaders (e.g., Patient Advocacy, Patient Care Manager), unit leadership (e.g., nurse manager, charge nurse), and frontline clinicians (e.g., physician, nurse).

Interview questions focused on 1) views on the WWTK program, including the WWTK message and specific program components; 2) experiences with the program, particularly in relation to learning of and responding to patient reported breakdowns; 3) barriers and challenges in adopting or implementing the program; and 4) recommendations for improvements. Interviews were conducted by three investigators experienced in conducting semi-structured interviews; most were conducted in person, but telephone interviews were conducted in instances where scheduling precluded in-person participation. Both group and individual interviews were conducted, depending on setting, scheduling, and roles. Detailed notes were compiled and summarized after the interviews. The evaluation interviews yielded qualitative data, which we reviewed to identify predominant themes.



**Results (Principal Findings and Outcomes)**

Because of the differences in implementation of the program during the different phases of the program, we report the results for each phase separately (i.e., Pilot study, WWTK-Intensive, and WWTK-Core).

**RESULTS: PILOT STUDY**

The pilot implementation of WWTK was conducted in two hospitals between June 2014 and February 2015. Three medical-surgical units (MSUs) at each hospital participated.

**Outreach Interviews.** During this time, a WWTK specialist interviewed a total of 1145 patients or family members. Overall, 440 of 1145 interviewees (38.4%) believed that they had experienced at least one breakdown in care. The ten most frequently reported types of breakdowns are listed in Table 4.

**Table 4. Ten Most Frequently Reported Breakdowns in Care (Pilot Phase)**

Type of Breakdown	Percentage of Interviewees reporting (N=1145)
Insufficient or inaccurate information; information not given at the time it was needed/wanted	10.0%
Delay/long wait on admission	8.7%
One or more people rude, cold, or uncaring; dismissive of patient’s concerns; patient preferences ignored/discounted; one or more providers seemed not to know (or ignore) patient	6.5%
Providers appeared not to be communicating with each other/not know what each were other doing/had done; different/conflicting opinions; kept changing things; not on the same page	6.0%
Problems with what medications were prescribed; available	5.3%
Untreated/inadequately treated pain	5.2%
No/suboptimal access to provider(s); insufficient time with provider(s)	4.4%
Nurses and/or staff unresponsive to calls, alarms, immediate patient needs	4.1%
Problems with nursing care (IVs, dressings, toileting, feeding)	3.9%
Difficulty getting questions answered; or request for information ignored; family members phone calls not returned or not returned in a timely manner	3.1%

Of the 440 interviewees who perceived a breakdown in care, 173 (39%) perceived harm associated with the event. The most common harms were physical (e.g., pain; n =77; 17.5%) and emotional (e.g., distress, worry; n=89; 20.2%). In addition, patients reported damage to relationships with providers (n=31; 7.1%) resulting in a loss of trust, with participants citing breakdowns as a reason for not seeking care at a particular hospital or from a particular provider in the future. In other cases, patients believed that breakdowns in care resulted in the need for additional care or a prolonged hospital stay (n=17; 3.9%), disrupted their life (n=16; 3.6%), or resulted in additional costs (n=6; 1.4%).

**Patient-initiated Reports.** Overall, three patient-initiated reports of breakdowns were received during the pilot phase.

**Evaluation Interviews.** During the pilot phase, 14 interviews involving 25 interviewees were conducted at the two pilot hospitals; major themes identified during interviews are summarized in Table 5.

**Table 5. Themes from Evaluation Interviews During WWTK (Pilot Phase)**

Helpful aspects of WWTK program
<ul style="list-style-type: none"> <li>• Timeliness of information</li> <li>• Potential for real-time response and resolution</li> <li>• Description of associated patient harms (not currently available)</li> <li>• Specialist is neutral entity not part of care team; reduces patient reluctance to report concerns)</li> </ul>
Concerns about WWTK program
<ul style="list-style-type: none"> <li>• Overlap with existing efforts</li> <li>• Concern about patients suffering call/rounding fatigue</li> <li>• Resource intensive</li> <li>• Ensuring adequacy of response</li> </ul>

**HCAHPS.** Time series analyses detected no impact of the WWTK program on HCAHPS scores, as shown in Table 6 below.

**Table 6. Parameter Estimates of Interrupted Time Series Analysis for HCACPS Surveys – Franklin Square Phase 1 Units**

HCACPS Variable	Background Trend		Score shift since intervention		Trend Change After intervention	
	Parameter	p-value	Parameter	p-value	Parameter	p-value
Did everything to help your pain	0.13	0.848	-3.85	0.476	-0.24	0.737
Drs explained things understandably	0.20	0.744	-4.80	0.312	-0.22	0.722
Drs listened carefully to you	0.67	0.217	-7.97	0.067	-0.67	0.227
Got help as soon as wanted	-0.15	0.824	-3.62	0.495	0.05	0.937
Help going to bathroom as soon as wanted	1.04	0.212	-6.11	0.355	-1.27	0.141
Nurses explained things understandably	1.07	0.049	-12.94	0.004	-0.98	0.079
Nurses listened carefully to you	0.72	0.186	-6.45	0.137	-0.84	0.137
Pain well controlled during stay	0.40	0.638	-3.15	0.640	-0.47	0.595
Rate hospital	0.21	0.757	-2.68	0.610	-0.34	0.616
Treated w/courtesy/respect by Drs	0.28	0.559	-3.26	0.396	-0.33	0.507
Treated w/courtesy/respect by Nurses	0.27	0.546	-0.71	0.843	-0.42	0.368
Would recommend hospital to family	0.68	0.319	-9.63	0.078	-0.72	0.306
Drs composite score	0.38	0.393	-5.34	0.135	-0.41	0.376
Nurses composite score	0.69	0.100	-6.70	0.046	-0.75	0.084

## RESULTS: WWTK-INTENSIVE PROGRAM

**Outreach Interviews.** From March 2015 through June 2018, a WWTK Specialist conducted outreach interviews with 4415 patients or family members. Of these, 716 (16%) believed they had experienced at least one breakdown in care. The types of breakdowns reported were consistent with those reported in during the pilot phase. The most prevalent breakdown was delay or other problems during admissions (N=179) followed by problems with communication (e.g., patient given insufficient or inaccurate information, info not given when needed/wanted) (N=155) and nurses/techs unresponsive to calls, alarms, immediate patient needs (N=137). Of the 716 interviewees who perceived a breakdown in care, 568 (79%) perceived harm associated with the event. The most common harms were emotional (e.g., distress, worry; N=524) and physical (e.g., pain; N=204). In addition, patients reported instances of damage to relationships with providers (N=76). In other cases, patients believed that breakdowns in care resulted in the need for additional care or a prolonged hospital stay (N=40), life disruption (N=80), or additional costs to the patient (N=7).

Table 7 lists illustrative breakdowns and typical approaches the WWTK specialist used to achieve resolution.

**Table 7. Approaches to Resolution**

Type of breakdown	Resolution approach/outcome
Delay on admission, no other problems	Problem is in past at time of identification, specialist apologizes to patient and reports problem to hospital leadership, no other action or resolution performed
Providers or staff noted to be unresponsive to patient's needs or to have disrespectful bedside manner	We Want to Know specialist alerts charge nurse to problem, individual staff/provider is educated and re-assigned, specialist reports problem to hospital leadership
Patient reports problem with getting information, such as difficulty getting questions answered	We Want to Know specialist alerts charge nurse and facilitates provision of requested information by nurses and/or physicians
No breakdown identified	Patient indicates appreciation of the program, keeps We Want to Know materials with contact information for future reference

**Patient-Initiated Reports for the WWTK-Intensive Program.** All channels for patient-initiated reporting were also active at this hospital during this time (dedicated telephone line, website and email). Overall, 94 patient or family-initiated reports of breakdowns were received from May 2015 through May 2018. These were received via telephone (N= 89), email (N = 2), and the online reporting form (N= 3). Forty-seven were initiated by patients; 45, by family members; and two, by an “other” person. Of the 94 reports of breakdowns, 90 (95.7%) indicated that harm had occurred. Of the 84 cases for which data were available on whether the patient or family member had previously spoken to someone at the hospital about the breakdown, 50 (59.5%) indicated that they had done so.

**In-hospital Observations and Audits.** Audits of the WWTK-Intensive program were conducted from October 2015 through May 2018. During this time, 28 audits were conducted. WTTK campaign materials were observed in public areas (e.g., on plasma screens in the lobby) during 96% of hospital audits. Staff observed 294 patient rooms and interviewed patients in those rooms about awareness of the program. WWTK campaign materials (e.g., posters) were present in 76% of patient rooms audited, and 5% of patients indicated that they had heard of the WWTK program prior to the audit.

**Evaluation Interviews.** WWTK investigators conducted a total of 10 evaluation interviews involving 13 unit and hospital leaders about the WWTK-Intensive program. Leaders noted the value of the detailed reports from the WWTK specialist and the timely provision of information that enabled real-time responding. Once the specialist was active on unit, leaders were no longer concerned about patients potentially suffering from rounding fatigue or identifying insignificant or un-addressable concerns. Interviewees also noted that the data provided by the WWTK Specialist were not redundant; they were not getting this data from other sources. Interviewees noted the value of the daily feedback reports. They also noted that the WWTK specialist’s ability to connect with patients was a plus and that her knowledge of the system and growing ability to problem solve was valuable. Some interviewees also noted the value of having someone who is not on the care team inquire about care, as patients would be more willing to speak up. The primary continuing concern was the resource-intensive nature of the program (i.e., the cost of the WWTK Specialist salary) in the context of tight budget constraints.

**HCAHPS Results.** We conducted a second interrupted time series (ITS) analysis to examine the effectiveness of the WWTK-Intensive program at the one hospital. The ITS did not detect any positive impact of the program.

## RESULTS: SYSTEM-WIDE IMPLEMENTATION OF THE WWTK-CORE PROGRAM

**Patient-Initiated Reports for the WWTK-Core Hospitals.** Nine hospitals participated in the WWTK-Core implementation. These hospitals began implementation at different times, and offered different approaches to collecting patient initiated reports (additional details follow below in Figure 1). All channels for patient-initiated reporting were available to all hospitals (dedicated telephone line, website, and email), but some hospitals chose to use their own internal/local telephone line and/or email. Reports entered through a local hospital resource were not captured in the research database. In total, 23 reports of breakdowns were received. Of these, 11 (47.8%) were initiated by patients; 11 (47.8%), by family members; and one (4.3%), by an “other” person. These were received via telephone (N=18), email (N=4), and the online reporting form (N=1).

The most common types of breakdowns reported were problems with manner (N=10; one or more persons rude, uncaring, dismissive, patient treated like a number); discharge (N=9; delayed/too soon; problems with discharge arrangements); problems with tests/procedures/treatments (N=8; too aggressive/not aggressive enough, delayed, inappropriate, poorly performed); access (N=7; nurses/techs unresponsive to calls, alarms, immediate patient needs); listening (N=7; patient not listened to); and information flow (N=6; patient given insufficient or inaccurate information, information not given when needed). Of the 23 reports, 22 (95.7%) indicated that harm had occurred. Of the 18 cases for which data were available on whether the patient or family member had previously spoken to someone at the hospital about the breakdown, 11 (61.1%) indicated that they had done so.

**In-Hospital Observations and Audits.** Members of the research team visited all nine hospitals participating in the WWTK-Core program to assess whether WWTK program materials were in place and to assess patient awareness. From September 2016 through June 2018, 115 hospital audits were conducted at the nine WWTK-Core hospitals. During audits, research staff checked for the presence of materials in public places and approached a small number of patients (typically five patients) to determine whether they were familiar with the WWTK program as well as whether the materials were present in their room. Overall, WWTK materials were found in public areas during 19% of the audits; WWTK materials were found in admissions packets in 36% of the audits. WWTK research staff observed 548 patient rooms. WWTK campaign materials (e.g., pocket cards) were present in 66 patient rooms (12% of rooms audited). A total of 48 patients (9%) indicated that they had heard about the program prior to the audit. Audits were to be conducted monthly but were not scheduled to begin until hospital leadership reported active implementation of at least some components of WWTK. Planned audits were sometimes canceled due to hospital request (e.g., The Joint Commission visit) or research staff unavailability.

Figure 1 provides a graphical overview of the audit schedule and results over the initial 18-month period. In this figure, each row represents one hospital (e.g., H1 is hospital 1), and each column represents a month (e.g., M1 is month 1). Shading in a cell indicates that an audit took place that month for that hospital; absence of shading indicates that no audit occurred. The H icon indicates that at least some WWTK materials were present in a public area (e.g., virtual posters were displayed on a plasma screen in the lobby); the bed icon indicates that WWTK materials were observed in at least one patient room, and the person icon indicates that at least one of the patients approached reported some awareness of the WWTK program. For most hospitals, there was a lag between the anticipated start date of the WWTK program (defined as when 80% of staff and clinicians had been trained according to the IMOC team and indicated in the figure by a thick vertical line) and the first appearance of materials on the unit audits.

**Figure 1. We Want to Know-Core Audit Overview**

Hospital	Month																	
	M1	M2	M3	M4	M5	M6	M7	M8	M9	M10	M11	M12	M13	M14	M15	M16	M17	M18
H1	Person							Person		Scale				Person		Person		Person
H2		Scale	Scale			Scale					Scale							
H3																		
H4					Person				Scale							Person	Person	
H5													Person	Person	Person	Person		Person
H6										Person						Scale	Scale	Scale
H7										Person			Person		Scale	Scale	Scale	Scale
H8										Scale				Person		Scale		Person
H9														Person	Person	Person	Person	Person

**Evaluation Interviews.** In total, 52 evaluation interviews involving 90 interviewees were conducted at the nine hospitals implementing WWTK-Core between October 2016 and May 2018. Key themes identified during these interviews are summarized in Table 7.

**Table 7. WWTK Evaluation Interviews – Key Themes**

<b>Positive Aspects of the Program</b>
Valuable/desirable to learn about patient concerns; importance of learning of these early; support for transparency
WWTK tools (e.g., WWTK notepads) simple to use; not labor intensive
WWTK approach uncovers new concerns that are often fixable
Patients like the program; like the focus on learning about and solving problems; variety of reporting modalities
<b>Implementation Challenges</b>
Patient awareness is low – need to have providers deliver and reinforce campaign message to patients
Nurse, physician awareness of program is low/mixed
Campaign materials distribution is inconsistent
Need for continued attention to determine who should be delivering the message and when
Confusion about what WWTK is; staff focus largely on materials; encouraging patients to “write down your questions for the doctor”), <i>not</i> on WWTK message
WWTK roll-out in conjunction with other initiative (interdisciplinary models of care); WWTK may be overlooked
Some problems difficult to resolve; not doing so is worse than not knowing; need assurance that administration is going to address concerns that are brought up
Desire for different verbiage to make language less “negative” – concern patients may see this as an ask to complain
Concern that WWTK is “another thing to do”, “another thing to document” – not enough time, not clear value to providers
<b>Areas Where Mixed Reactions Were Noted</b>
Value to having an “external” person as the contact for WWTK telephone, website versus “external” number introduces middleman, additional, unnecessary complexity
WWTK redundant with existing processes versus belief WWTK elicits information not captured elsewhere; redundant communication is good; belief that staff has provided WWTK message to patients all along, WWTK just gives it a name
Perception that patients are comfortable speaking up via existing channels (most common view) versus belief that explicit outreach is necessary, desirable, as patient feel vulnerable, do not speak up (less common view)
Frontline staff feels more WWTK training needed versus leadership feels 1-2 presentation slides is adequate

**HCAHPS Data.** Table 8 (below) summarizes patient responses to the newly created item, “How often did you feel comfortable speaking up if you had any problems in your care?” that was included on the HCAHPS survey at all MSH hospitals.

**Table 8. Patient-Reported Comfort Speaking Up by Hospital by Month**

Hospital	Month												
	M1	M2	M3	M4	M5	M6	M7	M8	M9	M10	M11	M12	M13
H1							80	76	88	74	67	100	
H2	72	60	61	72	71	61	70	70	69	70	68	66	75
H3	81	57	68	77	79	78	70	63	79	90	88	60	67
H4												68	80
H5	61	63	69	61	88	80	71	72	67	90	71	70	76
H6	81	72	71	80	83	69	77	86	78	71	76	79	74
H7	63	62	56	62	71	69	76	84	65	57	71	65	57
H8	67	90	81	74	70	56	94	60	84	64	82	60	80
H9	68	67	62	77	75	70	77	72	77	70	52	56	53

Numbers in cells reflect the percentage of respondents indicating they “Always” felt comfortable speaking up.

We also conducted additional interrupted time series analyses, focusing particularly on two hospitals with the most consistent implementation based on audits and interviews. We examined both the general positive item (i.e., intent to recommend) and the newly created item on comfort speaking up. Again, we were unable to detect improvement post implementation.

In order to more fully understand responses to the newly created item, “*How often did you feel comfortable speaking up if you had any problems with your care?*” (Never, Sometimes, Usually, Always, Did not have any problems), we analyzed responses of 8399 patients. Of these, 51% indicated *no problems*; 34% *always* felt comfortable speaking up; and 16% *usually/sometimes/never* felt comfortable speaking up. Younger patients and those in better health were more likely to *always* speak up. Patients who *always* felt comfortable speaking up (versus those who did not), reported better nurse communication (80.2 vs 47.9, respectively,  $p<0.001$ ) and physician communication (81.8 vs 55.7 respectively,  $p<0.001$ ), provided higher hospital ratings (8.7 vs 7.2,  $p<0.001$ ), were more likely to always get help after pressing the call button (86.8% vs 65.7%;  $p<0.001$ ), and were more likely to definitely recommend the hospital (72.1% vs 39.2%;  $p<0.001$ ).

### **Results** (Discussion, Conclusions, Significance, Implications)

Efforts to detect and respond to breakdowns in care among hospitalized patients can yield important information about consequential events and lead to opportunities to respond in real-time to individual patients. This demonstration project, and our results with respect to the WWTK pilot and WWTK-Intensive programs in particular, provide evidence that hospitalized patients and their family members have important insights into care breakdowns. Although it is difficult to estimate the true percentage of patients who believe that they have experienced a breakdown in their care, our results suggest that this percentage is at least 20% and possibly higher, depending on how patients are queried. In addition, the majority of patients who experience a breakdown experience associated harms, including distress, loss of trust, and physical harm.

By implementing two approaches to encouraging patients to speak up about breakdowns in their care, we were able to compare the relative effectiveness of actively querying patients about care versus a campaign that encouraged patients to initiate reporting if a breakdown occurred. The number of breakdowns reported when the WWTK specialist queried using active outreach (during the pilot and WWTK-Intensive) exceeded by an order of magnitude the number of reports initiated by patients in the WWTK-Core program. This was true despite dissemination of the WWTK message through a multimodal, patient-facing campaign in both programs and efforts to encourage frontline providers to reinforce the WWTK message at the bedside. However, the major (and obvious) downside to WWTK-Intensive program is the cost of the dedicated WWTK Specialist. By the end of the demonstration project, hospital leaders at the WWTK-Intensive hospital expressed only enthusiastic positive feedback for the WWTK Specialist and her work, but they did not choose to continue to fund her to conduct active outreach after the close of the grant.

We faced several challenges in implementing the WWTK program. Some challenges were practical, such as how to manage getting campaign materials disseminated so that patients and family members would notice the materials, attend to the message, and ultimately take action if they experienced a breakdown in their care. Other challenges in implementation were related to the actual content of the message and call to action. Providers and leaders expressed a variety of concerns about the WWTK program prior to and during adoption and early implementation. One of the most common concerns was that, by explicitly focusing the messaging on problems, patients would focus on the negative only and thus would have more negative views about their care overall. Related to this, some worried that the program would open a “Pandora’s Box” and that asking

about concerns would result in a deluge of complaints that could not be addressed. Others worried that, if asked about problems, patients would focus on trivial issues that would distract staff without truly improving care. In fact, patients' responses to the program and messaging were overwhelmingly positive, and no negative effects of the program on patient perceptions of care were detected.

This demonstration project also provided evidence of how challenging it is to get patients and family members to speak up when they experience a breakdown in care. Though a substantial percentage of patients identified a breakdown in care when queried by the WWTK Specialist, many patients did not immediately bring up their concern but instead mentioned it after additional questioning (e.g., "Did anything go wrong related to any treatments or medications you had?"). We also found that breakdowns were more likely to be identified if a family member or friend was present when the WWTK Specialist asked. Patients' responses to the item we created on comfort speaking up provided more evidence that many patients are not comfortable speaking up, as did the results of our national survey (reported below).

Uncovering breakdowns in care in real time not only provides opportunities for remediation for individual patients but also provides a foundation for system learning. Though we were able to identify and describe multiple instances of the former, we were not able to gather systematic data on the latter and so do not have insight into whether or how the program contributed to system-level learning. Many leaders referred to the value of learning of patient-perceived breakdowns in care in a timely fashion and the value of detailed feedback, but evidence of the impact of this information at a system level was not available.

In conclusion, hospitals that effectively encourage patients and their family members to speak up about perceived breakdowns will identify many opportunities to address patient concerns, potentially leading to improved patient safety and experience. Based on our experience implementing the WWTK-Intensive program at a large hospital over several years, we recommend the following elements as fundamental to such efforts: 1) inclusion of systematic, active outreach with targeted probing to engage patients and their family members in identifying breakdowns, 2) staff dedicated to facilitating responses to patients who identify a breakdown, and 3) a structured reporting process to provide timely and detailed information about breakdowns and resolution efforts to appropriate hospital staff and leaders. Campaign materials to increase patient awareness and channels for patients to initiate reports are of lower impact but may still be of value.

### **Special Section: A supplemental national survey to gather evidence of how to elicit and respond to patient concerns.**

As noted above, over the course of implementing the WWTK program, the research team identified questions about the outreach process that were difficult to answer in the context of "live" implementation. For that reason, we undertook a supplemental national survey, which we describe in this section.

**Background.** The development and implementation of this program uncovered a need for a stronger evidence base on the most effective strategies for eliciting patient concerns. This experience also suggested that providers and organizations may be reluctant to inquire about patients' concerns due to uncertainty about how to respond effectively if a patient does identify a breakdown in care. We therefore undertook a national survey using a randomized experiment to examine the impact of three variables on intent to speak up about three common breakdowns in care. We examined the impact of two potentially modifiable factors (the role of the person inquiring about the patient's experience and the wording of the inquiry) on intent to speak up about three common breakdowns in care and on intent to recommend the hospital. We also examined the extent to



which participants would be upset about each breakdown and whether feeling upset was related to intent to speak up. Finally, we investigated the influence of apology on intent to recommend the hospital.

**Context and Participants.** We partnered with Gfk (formerly, KnowledgeNetworks), an international survey research organization. Participants were sampled from the KnowledgePanel®, an online panel representative of the entire US population. After preliminary testing and piloting, Gfk administered the online survey to a nationally representative sample of noninstitutionalized US adults aged 35 and older between 6/28/2017 and 7/11/2017. A total of 1188 adults aged 35 years or older participated; the response rate was 65.5%.

**Design.** The survey was administered using an experimental design. The vignette-based questionnaire asked the respondent to imagine being in the hospital and experienced three care breakdowns that we had found to be common based on the results of the active outreach interviews. The breakdowns were slow response to call bell, rude aide, unanswered questions. Three factors were randomly varied: the role of the person inquiring about concerns (physician, nurse, or patient care specialist), extent of the inquiry (extended, intermediate, or routine), and level of apology after the breakdown had been mentioned (full, limited, or none). We assessed participants affective responses to the care breakdowns (i.e., feeling of upset), intent to report, and willingness to recommend the hospital.

**Results.** Twice as many participants receiving the extended inquiry about care would (probably/definitely) recommend the hospital compared with those receiving no inquiry (18.4% vs 8.8%, respectively [ $p = 0.0067$ ]). Almost three times as many participants receiving a full apology would (probably/definitely) recommend the hospital compared with those receiving no apology (34.1% vs 13.6%, respectively [ $p < 0.0001$ ]). Feeling upset was a strong determinant of intent to speak up, but a substantial number of upset participants would not necessarily speak up. A more extensive inquiry did not result in greater likelihood of speaking up. The inquirer's role influenced speaking up for two of the three breakdowns (rudeness and slow response).

**Conclusion.** Patients and family members have unique insights into care but are often reluctant to speak up, resulting in missed opportunities for learning and improvement. In this study, we found that common care breakdowns can be upsetting to patients and that the extent to which patients feel upset strongly influences whether they will speak up. This implies that patients who *do* speak up are likely to be quite upset even if, from the provider's perspective, what has occurred is not cause for significant distress. This also suggests that providers who recognize the negative emotions that underpin and stimulate some patients to speak up about breakdowns in care will be better positioned to respond fully and effectively to patient concerns.

Our efforts to identify specific strategies that hospitals might use to more effectively encourage patients to speak up yielded mixed results; the role of the person asking mattered in two of the three situations we described. It is not surprising that relatively few patients would report rudeness or a slow response to a call bell to a physician, as most patients would not see these as the physician's responsibility. However, physicians should be aware that their patients may have experienced these types of problems and be upset as a result, but still not tell the physician. The fact that, in some instances, patients are most likely to speak up to the patient specialist suggests that hospitals should consider having someone who is not part of the care team inquire about care, but our finding that patients would be more likely to recommend the hospital if a nurse or physician inquired about care argues that a nurse or physician should inquire. The best answer may be to have multiple people inquire about care to both learn about breakdowns that patients may be reluctant to report to the care team and convey that frontline providers care about the patient experience.

### **List of Publications and Products (Bibliography of Published Works and Electronic Resources)**

- Mazor KM, Smith KM, Fisher KA, et al. Speak up! Addressing the paradox plaguing patient-centered care. *Annals of Intern Medicine*. 2016 May;164(9):618-9. PMID: 26857030.
- Fisher KA, Smith KM, Gallagher TH, et al. We want to know: eliciting hospitalized patients' perspectives on breakdowns in care. *J Hosp Med*. 2017 Aug;12(8):603-609. PMID: 28786425.
- Fisher, KA, Smith KM, Gallagher TH, et al. We want to know: patient comfort speaking up about breakdowns in care and patient experience. *BMJ Qual & Saf*. 2018. PMID: 30269059.

### **Manuscripts in Submission**

- Fisher KA, Gallagher TH, Smith KM, et al. Communicating with patients about breakdowns in care: empirical evidence of how to elicit and respond to patient concerns based on a population survey. Submitted to: *Annals of Internal Medicine*.
- Fisher KA, Smith KM, Gallagher TH, et al. We want to know: implementation and findings of a facilitated program designed to detect and address patient-reported breakdowns in care. Submitted to: *British Medical Journal – Quality and Safety*.

### **List of Presentations at National and International Meetings**

- Mazor KM, Smith KM, Morales CL, et al. Partnering with patients to identify and address breakdowns [poster presentation]. HMORN Annual Meeting; 2015 March; Long Beach, CA.
- Smith KM, Mazor KM, Morales CL, et al. Detecting, addressing, and responding to patient perceived breakdowns in care: the we want to know campaign [poster presentation]. International Forum on Quality and Safety in Healthcare; 2015 April; London, United Kingdom.
- Smith KM, Gallagher T, Fisher K, et al. Partnering with Patients to Identify and Address Breakdowns in Care [oral presentation]. International Conference on Communicating Medical Error; 2015 June; Montecatini Terme, Italy.
- Fisher KA, Smith KM, Sandford L, et al. How would patients improve hospitals? A content analysis of comments provided on the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) [poster presentation]. AcademyHealth Annual Research Meeting (ARM). 2016 June; Boston, MA.
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- Fisher KA, Smith KM, Gallagher T, et al. We want to know: patient comfort speaking up about breakdowns in care and patient experience [oral presentation]. International Conference on Communication in Healthcare (ICCH) & Health Literacy Annual Research Conference (HARC). 2017 October; Baltimore, MD.
- Fisher KA, Smith KM, Gallagher TH, et al. We want to know: patient comfort speaking up about breakdowns in care and patient experience [oral presentation]. Health Care Systems Research Network (HCSRN); 2018 April; Minneapolis, MN.
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Example of Campaign Materials: We Want to Know Pocket Card



**We Want to Know.**  
Have you experienced a problem  
in your care?  
**We Want to Know** if you have  
questions or concerns, so we can  
work to make it better for you.  
Contact us today:  
844-990-WWTK (9985) **PHONE**  
WeWantToKnow@medstar.net **EMAIL**  
**WeWant2Know.org**



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