

# Hospitalized Patients' and Family Members' Preferences for Real-Time, Transparent Access to Their Hospital Records

Michael J. Waxman, MD, MPH; Kurt Lozier, MBA; Lana Vasiljevic, MS; Kira Novakofski, PhD; James Desemone, MD; John O'Kane, RRT-NPS, MBA; Elizabeth M. Dufort, MD; David Wood, MBA; Ashar Ata, MBBS, PhD; Louis Filhour, PhD, RN; and Richard J. Blinkhorn Jr, MD

**W**ith the goal of engaging patients and family members to more fully participate in their own healthcare and improve health-related behaviors, Meaningful Use regulations encourage enhanced communication with patients and family via health information technologies, such as patient portals.<sup>1</sup> Accordingly, outpatient-based patient portals have been shown to be effective in engaging patients through transparent access to medical records.<sup>2-8</sup>

Despite well-documented success in outpatient settings, few study findings show successful large-scale implementation of hospital-based patient portals.<sup>9-12</sup> Although the reasons for generalized low engagement by hospitalized patients and family members are not fully understood and may be multifactorial, some authors have suggested that hospital-based patient portals have not been created to optimize user functionality.<sup>13</sup> Gaps remain in knowledge regarding how to effectively engage patients and family members, the level of information that would improve patient satisfaction and outcomes, and specific health information technology platforms that are most effective in the hospital setting.

Our study aimed to better understand 1) patient satisfaction and perceived engagement with traditional hospital-based communications and 2) patient preferences for transparent data and health information technologies that would lead to improved patient satisfaction and enhanced engagement in the hospital setting.

## METHODS

We performed a mixed-methods study of hospitalized patients and their family members at a single large academic medical center with a daily census of approximately 640 inpatients. First, we conducted a qualitative analysis of 41 participant interviews to explore the range of ideas perceived by patients and family members. Second, we employed random sampling and surveyed 267 participants to quantify the proportion of hospitalized patients and family members who agreed with each of the major ideas developed during the qualitative analysis. All research

## ABSTRACT

**OBJECTIVES:** To better understand patient satisfaction and perceived engagement with traditional hospital-based communication and to elicit patient preferences for health information technologies that would lead to improved satisfaction and engagement.

**STUDY DESIGN:** We performed a mixed-methods study involving qualitative interviews followed by a survey of hospitalized patients and their family members at a single large academic medical center.

**METHODS:** We conducted semi-structured interviews with 41 patients and surveyed 267 patients or family members to elicit their perspectives on satisfaction with traditional hospital communication methods, information needed to more fully engage in the patients' medical care, and potential solutions for improved hospital-based communication.

**RESULTS:** Qualitative interviews revealed patients' and family members' dissatisfaction with current hospital-based communication methods. They would prefer more information, in more flexible forms, with real-time digital access and the ability to share within their social and healthcare networks. Quantitative results from the survey supported these premises, with at least the majority of the 267 patients surveyed agreeing across each survey question. Furthermore, participants identified a "communications point person" as the individual who organizes, understands, and communicates about the patient's care, who was often a family member not available at the bedside during daily rounds. Potential solutions included improved transparency about hospital processes, creating systems that allow patients and family to help coordinate and double-check their own health-related communications, and delivering hospital-based communications through digital media.

**CONCLUSIONS:** These study findings provide empiric evidence to hospital decision-makers regarding patient and family preferences for 21st-century hospital-based communication systems.

*Am J Manag Care.* 2018;24(1):e17-e23

## TAKEAWAY POINTS

- ▶ Patients and family members perceived mismatches between current hospital communications and their expectations.
- ▶ Hospitalized patients and family members wanted to be more engaged in the patients' healthcare and perceived that enhanced, transparent, and easy-to-access information would help them accomplish this goal.
- ▶ Hospital policy-makers should consider communication platforms that better meet the needs of patients and family members.

activities were approved by the Albany Medical College institutional review board.

### Qualitative Interviews

Our research team first performed qualitative interviews with a convenience sample of 41 hospitalized patients and their family members on the medical nursing units from November 2014 to February 2015. Participants were recruited until the study investigators, who met periodically during the data collection period, determined that saturation in the answers to the open-ended questions had been reached and no new concepts were discovered. The qualitative interviews were done using a semi-structured format, with responses recorded in real time. Individual concepts were categorized into discrete themes, and a qualitative analysis was performed. Three study investigators participated in coding of themes and subthemes, and a fourth investigator reviewed coded themes for inconsistencies (further detail of the qualitative analysis can be found in the [eAppendix](#) [available at [ajmc.com](#)]).

### Quantitative Survey Development

Based on the results of this qualitative analysis, we developed a quantitative survey for patients (or their family members) that consisted of questions related to 3 distinct overarching themes identified in the initial qualitative interviews: 1) satisfaction with traditional hospital communication methods, 2) perspectives on information needed to more fully engage in their medical care, and 3) potential solutions for improved hospital-based communication.

The quantitative survey instrument was refined in an iterative fashion using the input of an additional 93 patients and family members. This included cognitively testing the survey questions on sequential potential participants until the research team was confident that there was appropriate content, comprehension, and quality (61 participants)<sup>14</sup> and pilot-testing the entire survey to ensure clarity and prevent survey fatigue (32 participants).

### Patient Selection for Quantitative Survey

Patients were randomly selected (using a random number generator) daily from the medical nursing units between 9 AM and 5 PM from January 2016 to May 2016. Patients were included if they were 18 years or older, admitted more than 48 hours prior to

the time of screening, and English-speaking. Only 1 study participant (either the patient or a family member) was allowed per hospitalized patient. Patients who were deemed to not have capacity to answer questions (based on nursing assessment) and who did not have a family member at the bedside were excluded. When a family member was available, patients were given the option to complete the survey themselves or to have a family member complete it. Verbal consent was obtained by a trained research assistant.

### Data Collection and Analysis of Quantitative Survey

The survey was administered on an iPad, with the research assistant available to assist as needed. Age was sorted, in part, by generational labeling: under 27 years (Millennial), 28 to 51 years (Generation X), 52 to 70 years (Baby Boomer), 71 to 88 years, and over 88 years.

Three survey questions had answers of "Yes," "No," or "This does not concern me." Twenty-three survey questions had standardized "Agree" answers on a 4-point Likert scale, with the additional option of "This does not concern me." Through the cognitive testing of the survey questions mentioned above, we developed the option of "This does not concern me" for situations in which either the participant did not have an opinion or the question raised a scenario that was not applicable to their medical care. When appropriate, to dichotomize results, "Strongly agree" and "Agree" were grouped together to indicate the response as "Agree." We analyzed survey responses by respondent characteristics using a  $\chi^2$  analysis. Data analysis was performed using Stata version 14.0 (StataCorp LLC; College Station, Texas).

## RESULTS

### Participant Characteristics and Patient Demographics

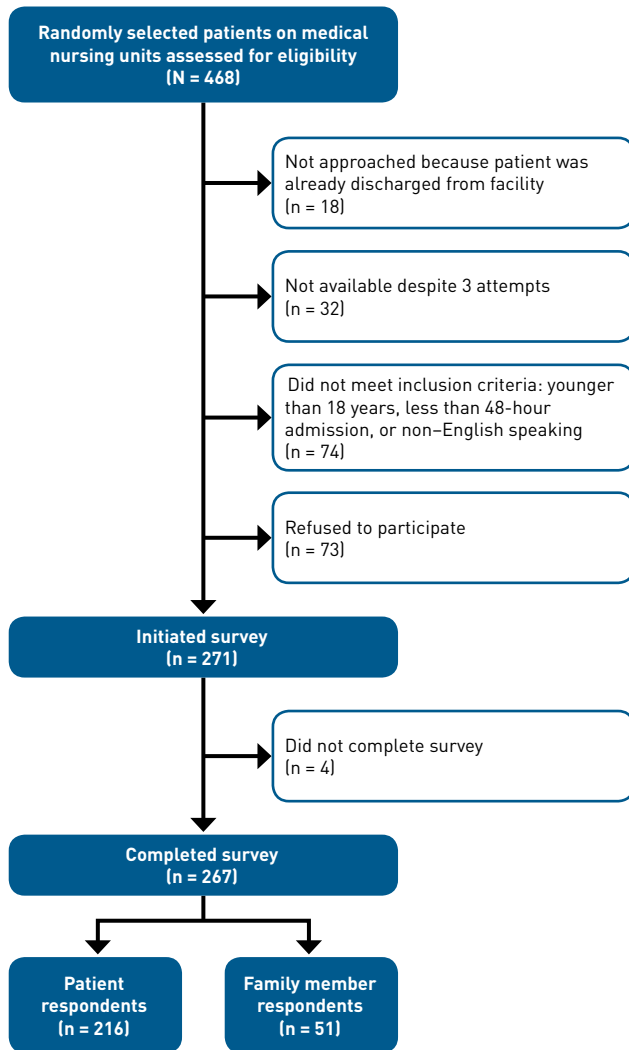
For the qualitative interviews, there were 4 patients aged 18 or 19 years, 5 patients aged 20 to 39 years, 10 patients aged 40 to 59 years, 15 patients aged 60 to 79 years, and 6 patients 80 years or older (categorical age was missing for 1 patient). Forty-five percent of the patients were female (gender status was missing for 1 patient).

The final sample of 267 survey participants included 216 (81%) patients and 51 (19%) family members. [Figure 1](#) depicts the flow of participant eligibility assessment, recruitment, enrollment, and survey participation. [Table 1](#) lists participant characteristics and patient demographics.

### Satisfaction With Traditional Hospital Communication Methods

The initial qualitative analysis revealed that patients and family members were dissatisfied with current hospital communication

**FIGURE 1.** Participant Eligibility Assessment, Recruitment, Enrollment, and Quantitative Survey Participation



methods. In particular, respondents felt that important information about their healthcare was not being communicated to them and expressed frustration with face-to-face interactions as the sole mode of communication. Participants felt this process lacked effectiveness both in understanding the complexity of their medical care and in relaying important health information to family members and the patient's health support network.

Additional quantitative analysis supported these findings. Although the majority of patients agreed that they knew why they were taking each medication in the hospital and why each test was being done, 63% felt that there was more information available than was being communicated by their care team, and 71% reported that they sometimes forgot information the doctor

**TABLE 1.** Participant Characteristics and Patient Demographics

Patient Characteristic	n (%)
Patient categorical age, years (n = 267)	
≤27 (Millennial)	21 (7.9)
28-51 (Generation X)	87 (32.6)
52-70 (Baby Boomer)	98 (36.7)
71-88	54 (20.2)
>88	7 (2.6)
Patient gender (n = 267)	
Male	128 (47.9)
Female	139 (52.1)
Frequency of hospitalization in prior 3 years (n = 265)	
1	63 (23.8)
2	44 (16.6)
3-5	83 (31.3)
>5	75 (28.3)
Respondent: patient vs nonpatient/family member (n = 267)	
Patient	216 (80.9)
Nonpatient/family member respondent	51 (19.1)
Nonpatient/family member respondent: relationship to patient (n = 51)	
Patient's daughter	20 (39.2)
Patient's partner	19 (37.2)
Patient's son	6 (11.8)
Patient's parent	3 (5.9)
Other: patient's niece, friend, granddaughter	3 (5.9)

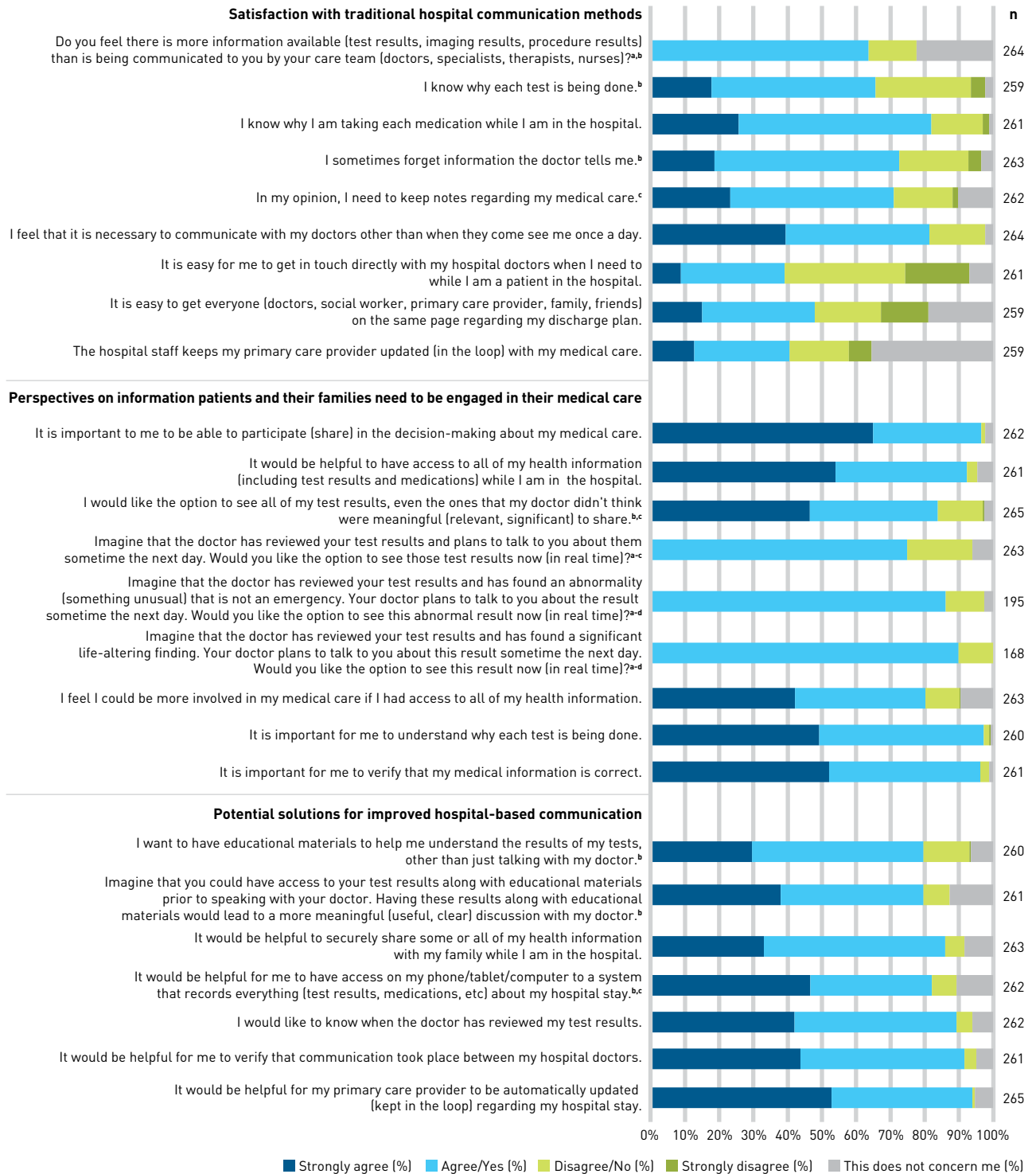
told them. Furthermore, only 38% of participants perceived that it was easy to contact their doctor outside of their daily interactions and less than half (46%) that it was easy to coordinate with their entire healthcare team and health support network regarding their discharge planning (Figure 2).

### Defining the Communications Point Person

A second overarching theme identified in the qualitative analysis was the importance of an individual who served as the communications hub to relay the patient's health information to family, the patient's healthcare providers, and others within the patient's health support network. Patients and family identified circumstances in which a family member was not necessarily the medical decision-maker for the patient, but was responsible for coordinating among all involved parties. We have termed this the communications point person (CPP), defined as the person who organizes, understands, and communicates about the patient's care.

In support of this concept, the quantitative survey found that 182 (68%) participants identified someone other than the patient

**FIGURE 2.** Hospitalized Patient and Family Member Survey Questions and Responses



<sup>a</sup>Question responses were presented as "Yes," "No," or "This does not concern me."

<sup>b</sup>Family respondents were statistically significantly ( $P < .05$ ) more likely to agree compared with patient respondents.

<sup>c</sup>Millennial and Generation X respondents were statistically significantly ( $P < .05$ ) more likely to agree compared with respondents who were Baby Boomers and older.

<sup>d</sup>Participants were only shown this question if they answered "Yes" to the previous question (directly above it).

(family member, friend, or other) as the CPP, whereas 85 (32%) identified the patient as the CPP (Table 2). Of those who identified someone other than the patient, respondents identified the CPP as a spouse (38%), daughter (32%), son (14%), parent (11%), sister (8%), partner (6%), brother (2%), or another person (defined as friend, cousin, nephew, niece, or grandparent) (15%). (Participants were able to identify more than 1 CPP, producing a total greater than 100%.)

Of the 182 participants for whom the CPP was someone other than the patient, information was elicited on CPP availability for face-to-face in-hospital communication. Responses indicated CPP availability during the morning (39%), afternoon (45%), evening (41%), or night (6%). (Participants were able to identify more than 1 time of day, for a total greater than 100%.) Additionally, 30% of respondents reported that the CPP's availability varied by day and 7% of respondents reported that their CPP was unable to be at the hospital at all.

**Information Required by Patients/Family Members to Be Engaged in Their Medical Care**

During our qualitative interviews, we found that patients and family members wanted to be more engaged in their healthcare. They relayed that they did not have access to all of the information they needed (eg, test results, hospital medications, etc) and that they wanted more specific and transparent information in real time in the hospital setting. The quantitative survey results supported these findings. Ninety percent of participants agreed that it would be helpful to have access to all of their health information (including test results and medications) while they were in the hospital, and 79% felt they could be more involved in their medical care if they had access to all of their health information.

Furthermore, most participants (83%) wanted unfettered real-time access to their medical records. This was true even when we challenged participants to imagine scenarios in which their doctor had not yet had a chance to review the test results (74% of the original survey cohort still wanted access to their medical records) and when the test results revealed a life-altering finding (57% of the original cohort still wanted access).

**Potential Solutions for Improved Hospital-Based Communications**

We identified possible hospital-based communications solutions during qualitative interviews. Patients and family wanted 1) to be more prepared for their discussions with their healthcare providers; 2) transparency about in-hospital processes, including communications among hospital providers and status updates on the care plan; 3) a solution that assists in coordination of care among healthcare providers, family members, and others in their health support network; and 4) consumer-friendly digital access to their hospital information (eg, access to an easy-to-use phone,

**TABLE 2.** Identity of Communications Point Person and Time at Hospital<sup>a</sup>

Identity of Patient's CPP (other than self)	% of Participants <sup>b</sup> (n = 267)
Parent	11.0%
Spouse	38.0%
Partner	6.0%
Brother	1.7%
Sister	7.7%
Son	13.7%
Daughter	31.6%
Other: friend, cousin, nephew, niece, grandparent	14.5%
Time Family Member CPP Can Be at Hospital	% of Participants <sup>c</sup> (n = 181)
Morning, approximately 6 AM – 11 AM	39.0%
Afternoon, approximately 12 PM – 3 PM	44.7%
Evening, approximately 4 PM – 8 PM	40.9%
Night, approximately 9 PM – 5 AM	5.5%
It depends on the day	30.4%
Unable to be at the hospital	7.0%

CPP indicates communications point person.  
<sup>a</sup>Patients were asked, "Who is the communications point person for your care... The person who organizes, understands, and communicates your care?"  
<sup>b</sup>Participants were able to identify more than 1 CPP; therefore, the total is not equal to 100%.  
<sup>c</sup>Only participants who answered that they had a nonself CPP were directed to this question. Participants were able to identify more than 1 time of day; therefore, the total is not equal to 100%.

tablet, or computer system that enables them to interact with their medical records and hospital providers).

Further quantitative analyses revealed that 78% of participants agreed that face-to-face interactions would be more meaningful if they had access to their test results, along with educational materials, prior to speaking to the doctor; 90% of participants wanted to verify that communication took place among their hospital providers; and 87% wanted to know when the doctor reviewed their test results. Moreover, 80% of participants thought it would be helpful to have access to a digital system that records activities and results during their hospitalization, and 85% of participants thought it would be helpful to securely share some or all of their health information while in the hospital.

**Comparison of Survey Results by Participant Characteristics and Patient Demographics**

For 11 of the 25 questions, family member respondents were statistically significantly ( $P < .05$ ) more likely than patient respondents to choose answers that agreed with more transparent, user-friendly communications that would produce more patient and family engagement (Figure 2). Despite this, family members were

statistically significantly ( $P < .05$ ) more likely to report that they knew why each test was being done.

Patient respondents younger than 52 years were statistically significantly ( $P < .05$ ) more likely than those 52 years or older to agree that they wanted the option to see all of their test results, wanted to see their health information in real time, and believed it would be helpful to have transparent access on their phone, tablet, or computer to “everything” regarding their medical care. There were no statistically significant differences (all  $P > .05$ ) in answers given by frequently hospitalized patients, defined as patients with 3 or more admissions over the past 3 years, versus other hospitalized patients.

## DISCUSSION

Although communication systems in the outpatient setting are adapting to newer technologies, hospitals have been slow to complement traditional face-to-face interactions with updated communication modalities. Our study found that hospitalized patients and their family members perceived themselves to be disempowered, as they remained dissatisfied with the extent of information provided, frequency of communication, level of access to data, and current communication modalities. We used the term communications mismatches to define and label the disparities between traditional in-hospital communications and the expectations that patients and families have regarding today’s social structures and the digital network environment.

As an example, when interviewing patients and family, we discovered that in many circumstances, there was 1 family member who took on the role of organizing, understanding, and communicating about the patient’s care, who we defined as the CPP. Whereas the patient’s healthcare proxy (proxy medical decision-maker) and surrogates/care partners (individuals allowed access to the patient’s medical records and communication with healthcare providers) are technically or legally defined terms,<sup>15,16</sup> the CPP is a patient-derived concept of the key communications leader in each patient’s health support network.

Not surprisingly, our quantitative survey revealed a communications mismatch between the CPP’s availability and typical bedside rounds, as most CPPs were not available during the morning, which is when physicians typically perform face-to-face rounds. These empiric findings quantify, and emphasize, the need to identify the CPP for each patient and create more flexible communications systems to empower CPPs in their role within each patient’s social network. Although the concept of identifying and digitally connecting with care partners has been explored in the outpatient setting,<sup>17</sup> there is limited discussion in the medical literature on this topic in the hospital setting.

Active engagement of patients and family to participate in the maintenance of their own health has gained importance on the national healthcare agenda.<sup>18-21</sup> Available research in the outpatient

setting suggests that patient portals empower patients to participate in their own care<sup>3,9</sup> and shared decision making has become an important feature of high-quality patient care.<sup>22,23</sup> At least 1 prior study has broached this topic in the hospital setting and found that patients wanted more access and detail in their medical records, although these findings came mostly from qualitative interviews.<sup>11</sup> Our study also found that the majority of hospitalized patients and family wanted to be more engaged in their hospital care. Patients and family members believed that more transparent and user-friendly access to their medical records would empower them to track their medical progress, better understand and plan for the discharge process, and identify errors in their medical records. Moreover, most participants believed that reviewing their results before their provider interactions would ultimately prepare them for and augment these important discussions and that access to their medical records would enable them to serve as their own quality-assurance and patient-safety advocate. Furthermore, we found that most participants wanted to see their test results in real time, even when their providers had not yet viewed the test results or in situations that involved life-changing news.

Finally, we explored patient- and family-driven solutions to meet communication needs and wants in the hospital setting. Patients and family members wanted hospitals to 1) enhance the amount, level, and timing of information and access to medical data via consumer-friendly digital platforms; 2) actively identify the CPP for each patient and ensure communication with the CPP through appropriate timing and modalities; 3) allow the opportunity for medical information to be easily and securely shared with family, healthcare providers, and others in the health support network; and 4) provide a forum for verification and updated status on steps and processes that are part of the hospital healthcare plan. These strategies may be particularly important for younger patients and family, as Millennial and Generation X respondents wanted more information and more real-time access on digital platforms compared with participants classified as Baby Boomer generation and older.

### Limitations

This study was performed at only 1 hospital center on medical nursing units. It is possible that results may be different within broader settings, in other hospital systems with different communication modalities, or in other hospital settings. Also, inherent selection biases exist with survey studies. Our overall response rate was 57% of patients approached. Nevertheless, we followed a rigorous recruitment strategy, and we believe that this represents a high rate of participation given the study setting. Finally, although our findings revealed patient and family members’ perspectives, this cross-sectional survey cannot comment on whether having more transparent electronic health records would actually improve patient perception of service, engage patients and family members in shared decision making, or achieve better outcomes.

## CONCLUSIONS

Our study results suggest that patients and family want 21st-century methods to bridge current communication mismatches, improve their knowledge of and engagement in their care, enhance coordination within their healthcare team, and involve their CPP and health support network. Hospital leaders should consider platforms that better meet the communications needs of patients and family members. Further study is needed in the implementation of specific digital communication platforms and evaluation of whether they improve information sharing, communication, satisfaction, patient engagement, and health outcomes. ■

**Author Affiliations:** Department of Emergency Medicine (MJW, AA), and Department of Medicine (JD, RJB), Albany Medical College (LV, KN, EMD), Albany, NY; Somml Health, Inc (KL, JO, DW), Albany, NY; Albany Medical Center Hospital (LF), Albany, NY.

**Source of Funding:** Albany Medical Center, the authors' host institution, provided support for this project.

**Author Disclosures:** Dr Waxman is employed by Albany Medical College, which has an interest share in Somml Health, Inc. Mr Lozier is a co-founder, board member, and majority stakeholder of Somml Health, Inc. Dr Novakofski and Mr O'Kane are minority shareholders in Somml Health, Inc. Dr Dufort is adjunct faculty and married to an employed faculty member at Albany Medical Center and College, which has a financial interest in the product being developed to address this issue. Mr Wood is a board member and shareholder of Somml Health, Inc; the initial research for this paper was completed as customer discovery for Somml Health, Inc. Dr Filhour is employed by Albany Medical Center. Dr Blinkhorn is employed by Albany Medical College. The remaining authors report no relationship or financial interest with any entity that would pose a conflict of interest with the subject matter of this article.

**Authorship Information:** Concept and design (MJW, KL, KN, LV, JD, JO, DW, LF, RJB); acquisition of data (MJW, LV, JO, DW); analysis and interpretation of data (MJW, KN, LV, JD, EMD, DW, AA, RB); drafting of the manuscript (MJW, KL, KN, LV, JD, JO, EMD, RJB); critical revision of the manuscript for important intellectual content (MJW, KL, KN, LV, JD, JO, EMD, LF, RJB); statistical analysis (MJW, EMD, AA); provision of patients or study materials (MJW); obtaining funding (MJW); administrative, technical, or logistic support (MJW, KL, KN, JO, LF, RJB); and supervision (MJW, KL, JO, RJB).

**Address Correspondence to:** Michael J. Waxman, MD, MPH, Albany Medical College, 47 New Scotland Ave, Albany, NY 12203. Email: waxmanm@mail.amc.edu.

## REFERENCES

1. Meaningful use definition & objectives. HealthIT.gov website. healthit.gov/providers-professionals/meaningful-use-definition-objectives. Updated February 6, 2015. Accessed October 13, 2016.
2. Wald JS, Burk K, Gardner K, et al. Sharing electronic laboratory results in a patient portal--a feasibility pilot. *Stud Health Technol Inform.* 2007;129(pt 1):18-22.
3. Delbanco T, Walker J, Bell SK, et al. Inviting patients to read their doctors' notes: a quasi-experimental study and a look ahead [erratum in *Ann Intern Med.* 2015;162(7):532. doi: 10.7326/L15-5077]. *Ann Intern Med.* 2012;157(7):461-470. doi: 10.7326/0003-4819-157-7-201210020-00002.
4. Wright E, Darer J, Tang X, et al. Sharing physician notes through an electronic portal is associated with improved medication adherence: quasi-experimental study. *J Med Internet Res.* 2015;17(10):e226. doi: 10.2196/jmir.4872.
5. Esch T, Mejilla R, Anselmo M, Podtschaske B, Delbanco T, Walker J. Engaging patients through open notes: an evaluation using mixed methods. *BMJ Open.* 2016;6(1):e010034. doi: 10.1136/bmjopen-2015-010034.
6. Woods SS, Schwartz E, Tuepker A, et al. Patient experiences with full electronic access to health records and clinical notes through the MyHealthVet Personal Health Record Pilot: qualitative study. *J Med Internet Res.* 2013;15(3):e65. doi: 10.2196/jmir.2356.
7. Goldzweig CL, Orshansky G, Paige NM, et al. Electronic patient portals: evidence on health outcomes, satisfaction, efficiency, and attitudes: a systematic review. *Ann Intern Med.* 2013;159(10):677-687. doi: 10.7326/0003-4819-159-10-201311190-00006.
8. Alpert JM, Krist AH, Aycock RA, Kreps GL. Applying multiple methods to comprehensively evaluate a patient portal's effectiveness to convey information to patients. *J Med Internet Res.* 2016;18(5):e112. doi: 10.2196/jmir.5451.
9. Irizarry T, DeVito Dabbs A, Curran CR. Patient portals and patient engagement: a state of the science review. *J Med Internet Res.* 2015;17(6):e148. doi: 10.2196/jmir.4255.
10. King G, Maxwell J, Karmali A, et al. Connecting families to their health record and care team: the use, utility, and impact of a client/family health portal at a children's rehabilitation hospital. *J Med Internet Res.* 2017;19(4):e97. doi: 10.2196/jmir.6811.
11. O'Leary KJ, Sharma RK, Killarney A, et al. Patients' and healthcare providers' perceptions of a mobile portal application for hospitalized patients. *BMC Med Inform Decis Mak.* 2016;16(1):123. doi: 10.1186/s12911-016-0363-7.
12. Curtis JR, Treece PD, Nielsen EL, et al. Randomized trial of communication facilitators to reduce family distress and intensity of end-of-life care. *Am J Respir Crit Care Med.* 2016;193(2):154-162. doi: 10.1164/rccm.201505-0900OC.
13. Feldman HJ, Walker J, Li J, Delbanco T. OpenNotes: hospitalists' challenge and opportunity. *J Hosp Med.* 2013;8(7):414-417. doi: 10.1002/jhm.2052.
14. Mello MJ, Merchant RC, Clark MA. Surveying emergency medicine. *Acad Emerg Med.* 2013;20(4):409-412. doi: 10.1111/acem.12103.
15. Who will speak for you? New York State Department of Health website. health.ny.gov/professionals/patients/health\_care\_proxy/. Updated April 2016. Accessed November 13, 2017.
16. Mishuris RG, Stewart M, Fix GM, et al. Barriers to patient portal access among veterans receiving home-based primary care: a qualitative study. *Health Expect.* 2015;18(6):2296-2305. doi: 10.1111/hex.12199.
17. Sarkar U, Bates DW. Care partners and online patient portals. *JAMA.* 2014;311(4):357-358. doi: 10.1001/jama.2013.285825.
18. O'Connor AM, Wennberg JE, Legare F, et al. Toward the 'tipping point': decision aids and informed patient choice. *Health Aff (Millwood).* 2007;26(3):716-725. doi: 10.1377/hlthaff.26.3.716.
19. Stiggebout AM, Van der Weijden T, De Wit MP, et al. Shared decision making: really putting patients at the centre of healthcare. *BMJ.* 2012;344:e256. doi: 10.1136/bmj.e256.
20. Gruman J, Rovner MH, French ME, et al. From patient education to patient engagement: implications for the field of patient education. *Patient Educ Couns.* 2010;78(3):350-356. doi: 10.1016/j.pec.2010.02.002.
21. Mosen DM, Schmittlidel J, Hibbard J, Sobel D, Remmers C, Bellows J. Is patient activation associated with outcomes of care for adults with chronic conditions? *J Ambul Care Manage.* 2007;30(1):21-29.
22. Etwyn G, Frosch D, Thomson R, et al. Shared decision making: a model for clinical practice. *J Gen Intern Med.* 2012;27(10):1361-1367. doi: 10.1007/s11606-012-2077-6.
23. Barry MJ, Edman-Levitan S. Shared decision making--pinnacle of patient-centered care. *N Engl J Med.* 2012;366(9):780-781. doi: 10.1056/NEJMp1109283.

Full text and PDF at [www.ajmc.com](http://www.ajmc.com)

## **eAppendix: Detailed Methodology for Qualitative Analysis**

### **Study inception and design**

The inception of this qualitative study came from a quality initiative (originally stemming from our institutions stage two *meaningful use* attestation related to patients accessing their medical record information after an inpatient stay via a patient portal) to improve the communication between hospital providers and patients and family. This quality initiative included a Lean customer value discovery process designed to surface the breadth of information that patients and family members desired in the hospital setting. (Blanks S. *The Four Steps to the Epiphany: Successful Strategies for Products that Win*. 5, illustrated ed: K & S Ranch 2013) During this process, semi-structured interviews were conducted on 41 hospitalized patients and/or their family members. The project was approved by the authors' institutional review board.

### **Selection of participants**

Participants were selected from a convenience sample of patients on the medical nursing units from November 2014 to February 2015. Patients who were too ill participate and did not have a family member present and/or did not speak English were not interviewed. Because this study was intended to gain the perspectives of all of the individuals who might access a patient's medical records – including a patient's caregiver and/or family member – both patients and family members were invited to participate in the interview and included in the data analysis. Participants were recruited until the study investigators, who met periodically during the data collection period, determined that there was saturation in the answers to the open ended questions and there were no new concepts discovered.

### **Interview structure and data collection**

Because the project's goal was to determine how patients and family could be better engaged in accessing information using a patient portal during a hospital admission, patients and family were inherently viewed as consumers of health care and hospital communications. Therefore, the interview structure and design was based in the Lean customer discovery process, which typically views the participant as a consumer, and identifies the breadth of commonalities



of what participants want in a particular product. The interviews were semi-structured, beginning with an open-ended question, “What do you want to know while you are here in the hospital?” The interviewers listened to the participants’ responses and then asked probing questions to give the participants a full chance to discuss any thoughts/concepts that they might be able to contribute. If there was a concept that was not well-understood or fully fleshed out, the interviewer would give the participant additional opportunities to fully convey their thoughts. While it may not have been possible to avoid interviewer bias all-together, the interviewers paid particular attention to listen to the participants responses and not interject any of their own opinions into the discussion.

The interviewers (KL, KN, and DW) approached patients in the patients’ room on the medical ward and gained permission to talk to either the patient or the family member in the patient room. The interviewers took notes during the interviews, making sure to capture all pertinent concepts and perspectives. The notes were then transcribed into discrete concepts by one of the investigators (KN) and were available and referenced during the coding.

## **Analysis**

A qualitative analysis was performed on the de-identified discrete concepts. Three of the study investigators (KL, KN, and MW) participated in the coding. The discrete concepts were coded into themes and sub-themes by 2 of the coders. If there was agreement, then the concept was coded as such. Discrepancies were discussed, with the potential of the third coder as a tie-breaker. The original notes were available for reference, when needed. The investigators noticed data saturation after approximately two-thirds of the concepts were coded. However, the remainder of the concepts were coded to ensure thoroughness. A fourth investigator (DW) reviewed the data for any gross inconsistencies and to ensure that notes did not include any concepts that were inappropriately coded.