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PATIENT ENGAGEMENT

Bringing Patients into the Loop

Using Technology to Engage Patients and Improve Health Outcomes

By Catalina Danis, PhD; Sasha Ballen; Martha Jean (Marty) Minniti, RN, BS; Robert Farrell, MS, MPhil; Marion Ball, EdD, FAHEMA, FHIMSS, FCHIME, FAAN, FACMI, FMLA; Rosemary Kennedy, PhD, RN, MBA, FAAN; Thomas Blue, PhD; Scott Cashon; Allan, Crimm, M.D., FACP; Cara Dolan, BSN, RN, MA; Zuleika C. Font, M.D.; Diane Freed, MSN, RN; Ingrid Hilghman; Marjorie Miller, BS Ed.; Margaret Piscitelli, RN; Rachel Slutsky, BSN, RN-BC; Bency Thomas, BSN, RN, MA; and Sue Yeo, BSN, RN, MA

ABSTRACT

Leading healthcare experts in industry, government and academia argue that patient engagement is a critical component in the transformation of a system originally designed to treat acute health episodes into one that can effectively treat patients with long-term chronic diseases. However, meaningfully engaging patients in their own healthcare has often proven to be difficult. Our study investigates the use of technology to involve patients in monitoring their conditions between provider visits and to enable both clinicians and patients to utilize patient generated data to improve care and outcomes. We discuss the rationale for and present early observations from our ongoing study into the use of kiosk, mobile phone and web information technology by patients who have chronic diseases to engage with their primary care physician and healthcare team. In doing so, we address some of the obstacles to patient engagement identified by clinical and academic research studies over the past two decades. We argue that the use of well-designed, well-implemented health information technology can overcome many of the previously detected obstacles to engaging patients in their healthcare.

KEYWORDS

Patient engagement, chronic care management, IT/information technology, healthcare transformation, PCMH-level 3, health outcomes, medical adherence, individual differences

WIDESPREAD VARIATION in the quality of health-care in the United States, combined with a spend that is twice as much per capita as other Western countries while achieving worse health outcomes, cries out for significant changes.^{1,2} The need to measure performance, increase patient engagement, improve outcomes, and control costs is paramount. The Patient Protection and Affordable Care Act of 2010 includes several provisions targeting this initiative. One mandates the creation of a National Quality Strategy (NQS) to serve as a blueprint to improve the delivery of healthcare services, patient health outcomes, and population health. Released in March 2011 and updated yearly, the NQS identifies three overarching aims: better care, better health, and lower costs. It also spells out six priority areas for collective action to drive toward a high-value health system; these are health and well-being, prevention and treatment

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of leading causes of mortality, person- and family-centered care, patient safety, effective communication and care coordination, and affordable care.

The Federal Health Information Technology Strategic Plan contains a specific goal to better integrate individual and clinician communication through use of health information technology (HIT).² This objective is to empower individuals with health IT to improve health and reduce costs. The CMS Quality Strategy takes this goal one step further by recommending chronic disease management and care coordination as high priority areas for consumer engagement using health IT tools.³ These recommendations have created a national action plan that can be seen in programs such as *Aligning Forces for Quality*⁴ and the *Partnership for Patients* campaign to improve health in communities throughout the nation.⁵ The most recent report from the Agency for Healthcare Research and Quality indicates that there is a need for consumer engagement in quality measurement, realizing the importance of patient reported outcome data in quality reporting and improvement.⁶ Recommendations focus on targeting chronic disease management and tighter communication between providers and consumers using patient reported data in care delivery.

Seventy-five percent of all healthcare costs are related to chronic disease, which is prevalent in aging and in unfit populations. The traditional approach to healthcare in the United States (episodic rather than longitudinal), which derives from managing acute conditions, has not been effective at controlling costs or improving health as the population lives longer despite an increase in chronic disease.

Fortunately, there are many new approaches to improving healthcare delivery, including evidence-based medicine, care coordination and the patient-centered medical home (PCMH) model. Research shows that these strategies to improve outcomes and control costs are producing results, and a consensus has been building within the healthcare community that we must get patients involved to further improve outcomes. Dave deBronkart, a

well-known activist for healthcare transformation, has called the patient “the most underused resource in healthcare.”⁷ The justification is straightforward: Patient engagement – sometimes called patient activation or simply patient participation – has the promise of simultaneously lowering healthcare costs while improving health outcomes.

The recent enthusiasm surrounding the use of the term patient engagement⁸ requires a precise definition of the term. While the provider diagnoses, treats, and educates, ultimately the patient must execute the plan. Ideally, this initiates a feedback loop wherein the provider and patient communicate to understand if the plan is working, then adjust and execute again. Activated, engaged patients are well prepared to provide regular information to their healthcare team, so they may adjust the plan according to the unique needs of a given patient. Furthermore, through self-monitoring, engaged patients may be able to identify symptoms for early intervention.

Health policy and legislation have embraced patient engagement as essential to meet cost, quality and safety goals, yet actually achieving high levels of patient engagement is complex and difficult. We have called the research we describe in this article – which investigates the role of information technology in supporting patients’ engagement with their healthcare – *The Engagement in Practice* study, precisely to point out that delivering on what many experts in the health industry believe is the promise of patient engagement will be as difficult as it is worthwhile. Simply providing a personal health record (PHR) or a similar tool^{9,10} has not been shown to improve patient engagement. Care managers, social workers and concierge-style medicine are all effective, but costly and non-scalable. In order to realize the benefits of patient engagement, the payment model, physician training and ambulatory care environments must be adjusted to incorporate the patient as a first-class member of the care team with the proper tools to participate. We believe patient-facing technology will play a fundamental role in making good on the promised ben-

efits of patient engagement and improved care management

PATIENT PROVIDED DATA: NECESSARY, EFFECTIVE & POSSIBLE

A large body of academic and clinical research, largely produced over the past two decades, indicates that patient involvement in personal disease management is a key ingredient in achieving positive health outcomes.¹¹⁻¹⁴ A major motivation for past inquiries into the potential role of patients in their disease management came from alarming statistics regarding increases in the prevalence of chronic diseases. According to a recent World Health Organization report¹⁵ the prevalence of chronic disease has risen steadily around the world since the 1990s. Almost one in two adults in the United States had at least one chronic disease in 2005¹⁶ and this increases to four out of five for adults over the age of 50¹⁷ The reported rates are expected to rise due to increases in related disease-specific underlying conditions, like obesity (for diabetes and heart disease), as well as from more sensitive detection methods.¹⁸

The overall trend toward chronicity of disease has illuminated issues with a health delivery model that evolved to treat acute health episodes. Increasingly, focus has shifted from “fixing” a problem to “managing” a problem. Among other impacts, this paradigm shift has disturbed the established roles and responsibilities of healthcare providers and their patients.¹⁹ One important aspect of this shift is vividly captured in the words of Robert Johnstone, from the International Alliance of Patients’ Organization, who said “doctors should get down from their pedestals, but patients must get up from their knees.”²⁰ He elaborates that it is not about *wresting control* but about the need for patients to play a synergistic role with health providers that will enable them to “... lead more proactive fulfilling lives.”²¹ A major part of the role of the patient is in the area of lifestyle choice and compliance with medical advice. Daily lifestyle choices and medication adherence are under the exclusive control of the patients, who ultimately must be accountable for their healthcare. Additionally, interactive feedback between

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provider and patient plays a critical role in improving the overall quality of care provided by improving the level of understanding and establishing a relationship between the two parties.²¹

As research has established, the synergistic role of patients in managing chronic conditions includes becoming knowledgeable about their disease(s), learning problem-solving skills so they can adapt to their changing condition, developing improved confidence in their personal self-efficacy and maintaining motivations for increasing involvement in health management. Managing chronic conditions, in addition to taking prescribed medication, often requires long-term lifestyle changes such as stopping smoking and adopting a healthier diet and a regular exercise regimen. All these factors, which require commitment and perseverance, positively impact health outcomes.¹¹⁻¹⁴ Recent analyses indicate that in chronic care, factors under patient control play as important a role in influencing outcomes as direct medical treatment. Thus, it is increasingly accepted that: “People with chronic conditions are their own principal caregivers, and health professionals – both in primary care and specialty care – should be consultants supporting them in this role.”²² However, enabling patients to play this important role requires that they receive high quality and timely guidance and support from their healthcare team—guidance that is only available if there is effective communication among the parties.

Elucidation of the necessary types of patient support comes from “face-to-face” clinical intervention studies that established the feasibility of shifting from a “traditional model” in which “the professionals are the experts and the patients are passive” to a model of “shared expertise with active patients.”²³ Examples of successful programs include the Diabetes Prevention Program (DPP) at George Washington University and the Randomized Controlled Trial of Nonpharmacologic Interventions in the Elderly (TONE study).²⁴ However, these interventions typically require considerable involvement from trained medical personnel in the role of health coaches, take as much as 18 months to show results,

and ultimately reach only small numbers of patients because of limited resources. Given resource constraints that make increased healthcare provider involvement unsustainable^{25,26} there is interest in developing more scalable approaches which tax neither the patient nor the providers.

The good news is that many patients appear to be willing to take on the demands of the expanded patient role required under new healthcare models. According to one recent assessment of chronic care in the United States,²² patients would like to be more involved in their own care, including having opportunities for communicating needs to their providers, gaining an understanding of the preferred course of treatment for their conditions and its impact on their health, and having access to methods they can use at home to evaluate whether they are on or off target. This is an encouraging finding, as these factors correlate not only with improved health outcomes but also with patient satisfaction.²² The latter is important because it creates a sort of “virtuous cycle” in which satisfied patients continue to interact and collaborate with their health providers.²²

While increased patient engagement has many benefits, subsequent research has uncovered some limitations to this generally positive outlook.^{27,28} Patient realities, including having multiple co-morbidities, cognitive capacity problems and mood disorders²⁷ make taking on the role of a partner to one’s health providers a complex one. For example, there is evidence that in cases of multiple co-morbidities, limitations to the patients’ involvement derive from both the cumulative burdens of caring for multiple chronic conditions and the debility that often exists in such cases. Additionally, limitations in knowledge, either because of the inherent lack of agreement that may exist among medical professionals for complex diseases or because of a patient’s lack of medical literacy,²⁸ point to the need for multi-faceted patient support that extends through time in order to realize the potential value of patient engagement. We discuss how technology support to patients may help them circumvent some of the obstacles to successful engagement.

CAN TECHNOLOGY-BASED SUPPORT HELP REALIZE THE PROMISE OF PATIENT ENGAGEMENT?

The increased penetration of computers, mobile phones, tablets, and personal medical-sensing devices across all age groups raises the possibility that it might be possible to implement the necessary support indicated by successful face-to-face intervention programs across large populations at relatively low cost. Discretionary uses of technology for health related goals is gaining popularity. For example, the Quantified Self movement, described as “a collaboration of users and tool makers who share an interest in self-knowledge through self-tracking,” as well as food and exercise tracking sites such as LoseIt™ and SparkPeople™ provide evidence that many people are willing to use technology over extended periods of time to manage their health-related needs. In the medical context, an example of widespread use is the Blue Button program, developed under the Meaningful Use Initiative²⁹ with which over nine million veterans access their medical records electronically.³⁰

Despite this growing acceptance of technology-mediated access to healthcare information, medical practices often report poor uptake of their web portals providing access to online medical records,³¹ and there have been some notable failures to attract patients to online medical record systems. Nonetheless, the need for the quality of care afforded by better self-care and recognition of the convenience of integrated personal health records³² is unabated. Many have therefore turned to explore a broader suite of IT-based functionality to help patients overcome some of the limitations previously noted.

FURTHERING PATIENT ENGAGEMENT THROUGH TECHNOLOGY

In this section, we describe how the literature reviewed earlier informed the design and implementation of our study of the use of technology for enabling patient engagement and provide some examples of participants’ initial experiences in the study. We organize our presentation around a set of four design goals that we believe

A LARGE BODY OF ACADEMIC and clinical research, largely produced over the past two decades, indicates that patient involvement in personal disease management is important for achieving a high quality of care.

the technology has to meet to successfully support patient engagement. The issues identified in the previous section can be thought of as *obstacles* to enabling widespread patient engagement. Our study design, in combination with the functionality available through the suite of patient engagement tools we used, represents our attempt to overcome or minimize the various obstacles to bring about patient engagement on a broad scale in an ambulatory practice setting.

We selected the Wellby™ platform from Care Partners Plus³³ to support patient engagement for its completeness and for its extensibility potential. Its point-of-care kiosk, patient mobile support and web portal access for patients provide the broad, multifactor access required to support patients in an ambulatory setting. It also provides significant functionality for providers through extensive report capability and rule-based integration with a practice's standards of care thereby increasing the probability of a practice being able to consume the newly available patient-generated data. The components that comprise the engagement support tools address a wide spectrum of patient and provider needs. Though not utilized in this study, the platform provides in-patient engagement support. The point-of-care (PoC) kiosk assesses gaps in care immediately following a visit, before a patient leaves the provider office, and allows the patient to document shared goals agreed to during the visit. The mobile experience can be customized to the specific requirements of particular diseases

(e.g., incorporating a symptom checklist for congestive heart failure or one for diabetes). The patient portal available over the web provides full patient health record functions, general support for health-related education and support for management of chronic conditions through goal setting and tracking, and for coordinating patient support from family and friends. Importantly, the software company's principal product designer and its chief technologist are both members of this research team, so we are able to make extensions and modifications to the suite of products to meet our technology support needs.

FOUR DESIGN GOALS IN THE ENGAGEMENT IN PRACTICE STUDY

The four goals that drove the design of our study are: 1) motivate patients to reliably report data for the duration of the study 2) educate patients to produce valid and relevant data, 3) determine if there are diverse subgroups of patients within our sample that require specialized techniques for successful engagement and 4) develop techniques to enable providers to consume the new data without undue burden.

First Design Goal. The first design goal of this study is to enhance patients' understanding of the importance of their role in chronic disease management. Patients must be willing to provide input regarding their health and treatment. Two important parts to this first goal are: addressing patients' potential reticence to contribute and motivating patients to continue to provide input over the long-term. Patients need to feel

comfortable including their voice in the healthcare conversation. This is a change to the status quo and can be challenging for as the patient's voice becomes louder, physicians and other health providers must be comfortable receiving feedback, being challenged and including the patient voice in an ongoing conversation.

The healthcare setting is critical in creating an environment in which patient input is encouraged and incorporated into the process. We were helped greatly towards this goal by having as our clinical partners the [9th Street Internal Medicine](#) (NSIM) practice, a medical practice in Philadelphia, in the United States with 30,000 annual patient visits. NSIM was among the first ten practices in the U.S. to be recognized as a level 3 PCMH by the National Committee for Quality Assurance (NCQA). The PCMH model stresses care coordination, communication, and patient engagement. As a NCQA PCMH level 3 recognized health provider since 2008, our clinical partner has a history of embracing a healthcare delivery model based on patient inclusion in the care team. Their commitment was immediately visible when we broached the possibility of doing the study and continued unabated when it became clear that the study would have to be run as a purely volunteer effort. Most PCMH practices struggle to engage patients according to the PCMH framework, as resources are always in tight supply. This practice is no different, so the opportunity to gain access to patient engagement tools was in alignment with the larger practice goals. Prac-

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tice management provided leadership in recognizing the important role the team of physicians and other care providers would need to play in encouraging their patients to use the engagement tools. To be effective, this philosophy must be renewed in practice daily.

At the clinic, the care team provided the framing for patients to understand the importance of structured feedback (as gathered by the point-of-care kiosk) toward improving the practice. In this way, the conversation shifted from evaluating the individual provider to evaluating the system of delivering healthcare. This is critical in that it helps give patients permission to give honest feedback, and by increasing the patient voice, will lead to more direct evaluation of the entire healthcare team.

An incident early in the study concerning patient perception of over-the-counter (OTC) medications highlighted the potential role of the study in improving the efficacy of the practice. Medication reconciliation is a key part of any ambulatory care visit, and the practice has long-established procedures in place to facilitate this effort. The process includes a printed copy of the medication list from the EHR for the patient to review in the waiting room, initial reconciliation by the clinical assistant and then a final reconciliation by the provider. All of these conversations should include OTC medications, and the practice assumed that the patient consistently provides this information. However, results from the kiosk over a 30-day period indicated that only 75.9 percent of patients reported reviewing OTCs in their appointment. By comparison, 94.8 percent of the patients in the same period reported reviewing their prescription medications. The practice chose to view this identified gap as an opportunity to provide additional training to the clinical staff about how to discuss medication lists with patients.

Another challenge to realizing patient participation stems from pragmatic issues – patients are busy dealing with their health conditions, among other demands of daily living, and they need as easy as possible a way to engage in their care management. A mobile application was used to

TABLE 1: Design Goals of Practice Study

Study Goals
1. Motivate patients to reliably report data
2. Educate patients to produce valid and relevant data
3. Determine if there are diverse subgroups that require specialized techniques for successful engagement
4. Develop techniques to enable providers to easily consume the new data

collect brief, daily, targeted feedback from patients about their condition. The application was designed to keep patients focused on the importance of their role as partner to their healthcare provider. As is the case with the PoC surveys, the daily electronic dialogs with each participant were personalized according to their primary medical condition. Two weeks after the on-boarding process was completed, participants began to receive a series of three questions each day. The first question asked them to make an overall assessment of how they feel, the second asked if they took all prescribed medications and the third asked them to report the values for the primary health indicator relevant to their condition (i.e. blood pressure for hypertensive patients and blood glucose level for diabetic and pre-diabetic patients). These daily probes arrived on the mobile phone to maximize ease of access and required minimal time and effort to satisfy. Capability for the patient to view a history of their reported values on these questions through the personal health record (PHR) on the web interface provides additional direct value to the patients that reinforces their daily reporting.

Second Design Goal. The second design goal in our study was to shape quality responses from participants. Once participation is engendered, the next goal is to help patients provide valuable and valid data to enable the care team make more informed decisions about continued care. This includes educating patients about their condition and, more subtly, training them to become observant about factors that affect their condition. In this study we do not provide explicit training

and education about the patient's disease as has been a centerpiece of studies like DPP¹⁷ and TONE.²⁶ Instead we integrated teaching opportunities into the context of the interactions with the suite of tools we have made available. For example, education functions are provided through the disease-specific dialogs presented through the mobile application, as when an out-of-range value on a health indicator reported by the patient leads to a follow-up question regarding the circumstances surrounding the event. One of the potentially important attributes of these dialogs is that they contextualize standard disease facts within the patient's experience and hence may enable the patient to transform the data into knowledge through reflection. It is hoped that once patients are able to integrate their personal data into their experience, they will be more effective in problem solving and taking action. For example, various forms of instruction may teach patients that morning blood glucose level of 300 mg/mL is too high and to be avoided. However, contextualizing the reported level over time and the corresponding judgment of how they feel may help them reason about what they might have done the night before that produced such a high level and how to avoid it in the future. In other words, once patients are able to see that every day their blood sugar is not well controlled corresponds to a "feeling poorly" day, the need, and perhaps the motivation to modify behavior is clearer.

The surveys on the PoC kiosk serve to reinforce practice goals; an example is the diabetic foot exam query. Reporting whether a physician examined a patient's feet not only ascertains whether the phy-

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sician followed care guidelines, but also serves to educate patients about the most critical aspects of caring for their condition. A simple monofilament foot exam will indicate neuropathy and ultimately help avoid an amputation. The practice has trained clinical assistants to educate patients on the importance of the foot exam and reinforcement by the kiosk further informs patients of the importance of this test. Better-informed patients will be more likely to report relevant experiences and ask relevant questions during subsequent physician appointments, and they are likely better able to engage in successful problem solving when needed. In addition, repeating the same questions on the kiosk on each office visit serves to reinforce important points about the condition to the patient, a technique that is believed to lead to improved learning.

Third Design Goal. The third design goal of the study is to identify the most effective techniques for patient engagement across different sub-groups of patients. This was recognized by the early education attempts delivered as part of studies such as the DPP and TONE included extended instructional components that were individualized through discussion and the use of one-on-one coaching. Most likely, the educational interventions through patient engagement platforms will have to be extended to take into account lessons from early face-to-face studies that point to the importance of the patient's starting healthcare literacy level. And, as noted earlier, we have followed this guidance by tailoring our dialogues to the individual patient's medical disease progression.

In this study we are additionally exploring the impact of individual psychosocial functioning on the degree to which the patient is able to engage in their healthcare management. We assess participants on six behavioral measures to explore whether the resulting picture of patient characteristics can be used to predict levels of adherence behavior and to aid in targeting software-based supportive techniques. One important behavioral measure is Patient Activation Measure (PAM)³⁴, a validated scale that measures patients'

self-assessment of their knowledge, skill and confidence in health management. We also use the Ten-Item Personality Inventory (TIPI)³⁵, a quick assessment of factors that comprise the dominant model of personality, and a depression self-assessment with the Patient Health Questionnaire-9 (PHQ-9).³⁶ Factors assessed through these scales have been found to impact patients' ability to participate in care self-management and on care utilization. We measure patients on these scales at the start of the study and then repeat the assessment twice over the course of the six-month study to determine if there are changes that may be associated with use of the patient engagement technology. In addition, the study team identified key clinical and social data in NSIM's Electronic Health Record (EHR) to enable a comparison with a control group of patients at the practice. The study team will incorporate and analyze the patient/practice interactions as they are captured in the EHR, the clinical data in the EHR and the patient-reported data from the study tools.

Our study only begins to scratch the surface of the complex topic of the effects of individual differences on degree and success of patient engagement. We would expect the effects of individual patient differences to affect how and what people learn but to also to impact willingness and ability to take a role in managing their care. Previous research has noted the limitations that result when patients are burdened with multiple chronic conditions and psychological and cognitive impairments. At the end of our study, we expect to be able to speak to the impact such factors have had on health indicators over a six-month period.

An equally important question we will be able to address is the role patients might be interested in playing and how that role may be tailored to take advantage of specific patient strengths or compensate for patient deficiencies (e.g., taking action in changing their behavior vs. sharing in the decision making with the provider vs. simply reporting data). It is likely that individual differences, as measured by the battery of assessments of patient characteristics,

including readiness to take action, personality characteristics and health status, will make some more likely to play more active roles than others.

Fourth Design Goal. The fourth design goal of the study is enabling providers to respond to the newly available patient data in a realistic and effective manner. A national shortage of primary care physicians, payment reform that lags behind the cost of maintaining a PCMH-style practice and a fractured and complex healthcare environment all combine to squeeze the ambulatory care physician working to provide patient-centered care. While the NSIM physicians were intellectually excited to improve patient engagement, the reality of their working environment limits the amount of time they can devote to additional initiatives. We aimed to provide realistic tools to enable the care team to utilize the new data, without creating excess work or an unrealistic expectation of physician involvement.

Defining and implementing appropriate risk alerts based on kiosk responses or mobile data is perhaps the most important way that the study endeavored to meet this goal. The practice is committed to reducing unnecessary hospitalizations and Emergency Department (ED) visits, and managing diabetic and hypertensive patients is an effective way to further this goal. The clinical team at the practice defined what they believed to be effective criteria for real time alerts based on out-of-range blood pressures and blood sugars. The providers were interested in finding a balance where a clinical disaster could be averted, but they would not be so inundated by data that they would be unable to keep up. This balance ended up being consecutive days of out-of-range values, extremely out of range values for one day or consecutive days of missed data entry.

Another element of managing this new information stream was taking advantage of the entire care team. The practice worked with the study team to define the roles of different members of the practice team. For example, clinical risk alerts are directed to the triage phone staff who are already trained to triage and direct clinical informa-

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tion to the appropriate member of the care team. However, professionalism risk alerts are directed to the practice administrator, as she is the most well-equipped to manage the situation when patients are dissatisfied by the service they have received. Another example of diversified roles is the study and kiosk promotion. The provider and their clinical assistants are key in promoting the kiosk quality check as part of the visit to patients, but in the end, the checkout staff proved instrumental in actually encouraging the patients to step up to the kiosk and take the survey.

In addition, survey questions on the kiosk are carefully crafted to address issues that are of importance to the practice from the standpoint of quality of care targets. Where possible, questions were related to concrete events relevant to the delivery of care for various types of patients, not about opinions of the quality of care. For example, diabetic patients were asked if their physician did a foot exam during the just-concluded appointment. By keeping the reference grounded in facts, the feedback that is collected can be related to specific events in the delivery of care. While the PoC kiosk has a large number of reports that summarize the collected data and which are accessible through a provider dashboard, the research team has had to devise highly condensed reports to provide the physicians with the most important results of the study. While we are still iterating on exactly what information should be contained in these reports and in what form, we have found that these play a role in motivating the providers to continue encouraging their patients to participate in the study. Seeing results has proven to be reinforcing for them to make the extra effort motivate their patients to provide data.

The role of the non-clinical practice staff in encouraging study participation has also become clear over the first month of the study. We have therefore been devising an approach to also provide them with some study feedback that illustrates the value of the data collection and thus will reinforce their efforts in encouraging patients to participate in the study.

CONCLUSION

The unsustainable growth in healthcare costs in the United States has necessitated new approaches to healthcare delivery. High-quality healthcare outcomes depend on more than good medical advice; patient engagement is critical. While previous studies have established the importance of involving patients in the healthcare process, we investigated the role of technology in supporting patients to make changes. We recognize the difficulty surrounding the fundamental transformation of the role of the patient – they must shift from passive participant to a technology-enabled active partner. Providing technology to help patients uncover gaps in care, identify barriers to their adherence to doctor's orders, identify gaps in their understanding, monitor their medical condition and alert medical providers to critical problems could boost adherence, reduce cost of care, provide more accurate data, and ultimately improve the quality of care while also controlling costs. **JHIM**

Marion J. Ball EdD, FAHEMA, FHIMSS, FCHIME, FAAN, FACMI, FMLA, is Senior Advisor Healthcare Informatics IBM Research, Professor Emerita, Johns Hopkins University, and a member of the Institute of Medicine.

Sasha Ballen is a Senior Consultant at HealthPower Associates, Inc. focusing on data analytics for quality improvement programs that support population management.

Thomas R. Blue, PhD, is Research Lead for CarePartners Plus where he studies factors affecting Total Quality Management, particularly the impact of engagement on operating cycles.

Scott Cashon is Vice-President for Health Information Technology for CarePartners Plus and leads development of the Wellby platform.

Allan Crimm, M.D., FACP, is a board certified internist, and the Managing Partner of Ninth Street Internal Medicine Associates, an 11-provider private practice in Philadelphia, PA that was one of the first practices in the country to achieve NCQA Level 3 certification as a Patient-Centered Medical Home.

Catalina Danis, PhD, is a Research Staff Member at IBM TJ Watson Research Center in Yorktown Heights, NY where she studies human computer interaction, most recently in the healthcare domain.

Cara Dolan, BSN, RN, MA, in Nursing Informatics.

Robert G. Farrell MS, MPhil, is a Research Staff Member at IBM TJ Watson Research Center in Yorktown Heights, NY where he works on social computing and patient engagement.

Zuleika C. Font, M.D., is a board certified in Internal Medicine and Geriatrics who has practiced in Philadelphia at Ninth Street Internal Medicine, a Level 3 recognized Patient Centered Medical Home, for the past 10 years.

Diane Freed, MSN, RN, is Vice-President for Product Management for CarePartners Plus and leads development of system content.

Ingrid Hilghman is an adjunct professor at Thomas Jefferson University, School of Nursing and an instructor for the Prenatal Parent Education program at Thomas Jefferson University Hospital.

Rosemary Kennedy, PhD, RN, MBA, FAAN, is Associate Professor, Associate Dean of Strategic Initiatives, and Director of Nursing Informatics at the Jefferson School of Nursing.

Marjorie Miller, BS Ed., is President of HealthPower Associates, a practice management consulting firm, and has interests in strategic planning and developing new models of care.

Martha Jean (Marty) Minniti, RN, BS, is an entrepreneur, author, and presenter on contemporary health issues and a co-founder of CarePartners Plus, a company specializing in patient engagement technology.

Margaret Piscitelli, RN, is currently working on her Master's Degree in Nursing Informatics.

Rachel Slutsky, BSN, RN-BC, is a charge nurse and chairperson of the Pain Resource Group at Thomas Jefferson University Hospital. She is currently working on her Master's Degree in Nursing Informatics.

Bency Thomas, BSN, RN, MA, in Nursing Informatics.

Sue Yeo, BSN, RN, MA, in Nursing Informatics.

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REFERENCES

1. McKinsey Center for U.S. Health System Reform. Accounting for the cost of U.S. Healthcare. <http://healthcarereform.mckinsey.com>. Published Dec, 2011. Accessed November 6, 2013.
2. The Office of the National Coordination for Health Information Technology, 2013 Strategic Plan Progress Report. Available <http://www.healthit.gov/policy-researchers-implementers/strategic-plan-progress-report/clinical-quality-improvement>. Accessed 3 February 2014.
3. <http://partnershipforpatients.cms.gov/about-the-partnership/patient-and-family-engagement/the-patient-and-family-engagement.html>. Accessed February 5, 2014.
4. Agency for Healthcare Research and Quality (AHRQ), Health IT Enabled Quality Measurement, Perspectives, Pathways and Practical Guidance. September, 2013.
5. <http://partnershipforpatients.cms.gov/about-the-partnership/patient-and-family-engagement/the-patient-and-family-engagement.html>. Accessed February 5, 2014
6. Agency for Healthcare Research and Quality (AHRQ), Health IT Enabled Quality Measurement, Perspectives, Pathways and Practical Guidance. September, 2013.
7. deBronkart D. Why is the patient the most under-used resource in healthcare? http://www.ted.com/conversations/4547/why_is_the_patient_the_most_u.html Published Jul 27, 2011. Accessed November 6, 2013.
8. Munro D. Patient engagement: Blockbuster drug or snake oil? <http://www.forbes.com/sites/danmunro/2013/08/17/patient-engagement-blockbuster-drug-or-snake-oil/> Accessed November 6, 2013.
9. Ball MJ, Smith C, Bakalar R. Personal health records: Empowering consumers. *Journal of Healthcare Information Management*. 2007;21:1.
10. Ball MJ, Gold J. Banking on health: Personal records and information exchange. *Journal of Healthcare Information Management*. 2006;20:2.
11. The Diabetes Prevention Program Research Group (Biostatistics Center, George Washington University). Description of lifestyle intervention. *Diabetes Care*. 2002;25,12: 2165-2171.
12. Isetts BJ, Schondelmeyer SW, Atrz MB, et al. Clinical and Economic Outcomes of Medication Therapy Management Services: The Minnesota Experience. *J Am Pharm Assoc*. 2008;48,2:203-214.
13. Skinner C, Korbin S, Campbell M, et al. New technologies and their influence on existing interventions. In *Patient Treatment Adherence: Concepts, Interventions and Measurement*. HB Bosworth, EZ Oddone, M Weinberger (Eds.), Lawrence Erlbaum Associates, Inc., New York, 2006: 491-518.
14. Coulter A. Patient engagement-what works? *J Ambul Care Manage*. 2012;35(2):80-9.
15. World Health Organization. Global Status Report on Non-communicable Diseases. http://www.who.int/chp/ncd_global_status_report/en/index.html Published April 2011. Accessed November 1, 2013.
16. Centers for Disease Control and Prevention. Chronic Disease Prevention and Promotion. <http://www.cdc.gov/chronicdisease/overview/index.htm>. Accessed November 1, 2013.
17. American Association of Retired Persons (AARP). Chronic Care: A Call to Action for Health Reform. http://www.assets.aarp.org/rgcenter/health/beyond_50_hcr.pdf. Accessed November 1, 2013.
18. Howard DH, Thorpe KE, Busch SH. 2010. Understanding recent increases in chronic disease treatment rates: More disease or more detection? *Health Econ Policy Law*. 2010;5(4):411-35.
19. Anderson RM, Funnell M. *Patient Educ and Couns*. 2005;57:153-157.
20. The Lancet. 2012;379(9827):1677. doi:10.1016/S0140-6736(12)60699-0.
21. Harris Interactive & GlaxoSmithKline, 2003. Chronic Care in America: Improving the Patient-Physician Interaction. <http://www.policyarchive.org/handle/10207/95528> Accessed November 1, 2013.
22. Holman H, Lorig K. Patients as partners in managing chronic disease: Partnership is a prerequisite for effective and efficient health care. *BMJ*. 2000;320(7234):526-7.
23. Bodenheimer T, Lorig K, Holman H, et al. Patient self-management of chronic disease in primary care. *JAMA*. 2002;288,19:2469-2475.
24. Whelton PK, Appel LJ, Espeland MA, et al. Sodium reduction and weight loss in the treatment of hypertension in older persons: a randomized controlled trial of nonpharmacologic interventions in the elderly (TONE). *JAMA*. 1998; 18;279(11):839-46. Erratum in: *JAMA*. 1998;24;279(24):1954.
25. CapGemini Consulting, 2011. Patient Adherence: The Next Frontier in Patient Care. <http://www.capgemini.com/consulting>. Accessed June 19, 2012.
26. European Commission, 2012. Eurobarometer Qualitative Study on Patient Involvement. http://ec.europa.eu/public_opinion/archives/quali/ql_5937_patient_en.pdf Accessed October 23, 2012.
27. May C, Montori VM, Mair FS. We need minimally disruptive medicine. *BMJ*. 2009;11;339:b2803. doi: 10.1136/bmj.b2803.
28. Schulz PJ, Nakamoto K. (2011, March). "Bad" literacy, the Internet, and the limits of patient empowerment. In *AAAI Spring Symposium: AI and Health Communication*.
29. Healthit.gov. Achieve Meaningful Use. http://www.healthit.gov/providers-professionals/ehr-implementation-steps/step-5-achieve-meaningfuluse?utm_source=google&utm_medium=cpc&utm_campaign=implementing_ehrs. Accessed November 1, 2013.
30. Button.org. 2012. *What is BlueButton?* <http://bluebuttondata.org/about.php>. Accessed November 6, 2012.
31. Chillmark Research. 2013. Much Ado About Patient Portals. <http://www.chillmarkresearch.com/2011/03/18/much-ado-about-patient-portals/>. Accessed November 1, 2013.
32. Ball MJ, Gold J. Banking on health: Personal records and information exchange. *Journal of Healthcare Information Management*. 2006;20:2.
33. CarePartners Plus. <https://www.carepartnersplus.com/>.
34. Patient Activation Measure (PAM). <http://www.insigniahealth.com/ha/measure.html>. Accessed February 6, 2014.
35. Ten-Item Personality Inventory (TIPI). <http://homepage.psy.utexas.edu/HomePage/Faculty/Gosling/tipi%20site/tipi.htm>. Accessed February 6, 2014.
36. Patient Health Questionnaire (PHQ9). <http://www.phqscreeners.com/>. Accessed February 6, 2014.