

SESSION INFORMATION

Submission ID: 547540614
Submitted by: MITRE Corporation
Topic Category: Consumer and Patient Engagement
Sub-Topic: Remote Monitoring related to Devices and Functionality and Consumer Outreach & Education,
Format/Level: 60 Minute Lecture, Intermediate
Target Audiences: Physician, CMO, CMIO, Nurse, CNO, CNIO, Government or Public Policy Professional

Session Title: Lessons from an Empowered Patient and Their Caregiver

Brief Session Description:

When their child developed flu symptoms in 5th grade, her family had no idea that she would slowly lose the ability to read and attend school, and they were starting a ten-year journey back to full health. This patient-caregiver presentation shares the challenges encountered when managing complex chronic conditions, and the strategies and technologies they leveraged to become active partners with their providers and other professionals in managing their healthcare. This unique presentation offers both patient and caregiver insights into managing pediatric chronic conditions, tangible strategies and solutions used to support recovery, and the results of the patient empowerment research that was inspired by their experience. The patient-facing healthcare tools and strategies that resulted from this research will help other patients and their caregivers manage their chronic conditions and become active partners with their care teams.

Learning Objectives:

- Describe patient-facing tools and strategies that support bi-directional communication between patients, providers and other healthcare professionals, and discuss how these strategies result in improved health outcomes.
- Demonstrate tools and best practices for enabling patient self-management outside the clinical setting and discuss how to integrate the patient-generated data from these tools into the clinical setting.
- Show how real world experiences in engaging patients and their caregivers with their health and healthcare activities improves outcomes.
- Demonstrate application of IT best practices and methodologies to enable patients to optimize their daily activities.

CONTENT DETAILS

****Please describe the TOPIC/ISSUE that will be presented and how it was identified.**

Patient and caregiver engagement has become a central part of the healthcare system, but strategies to enable this type of engagement are often limited to the clinical setting. Healthcare and health IT have made significant progress in developing capabilities to support clinicians and tools to gather “passive” patient-generated health data between appointments. But there remains a gap in patient-facing capabilities to support patients and caregivers in their daily care between appointments and to enable patients to bring their voice into the clinical setting. Patients and caregivers are experts in living with medical conditions and research has shown that engaging patients to gather data such as observations of daily living between appointments provides meaningful information to both patients and clinicians, results in increased patient engagement, and improves clinical decisions. There is also emerging evidence that “...patients who are actively involved in their health and health care achieve better health outcomes, and have lower health costs, than those who aren’t.” This presentation is by a mother and daughter who successfully navigated a long-term health crisis, and experienced first-hand the value of patient engagement and participation as a care team member. They will share their experiences as a pediatric chronic patient and as a parent caregiver, and identify the key behaviors and strategies that enabled them to partner with their providers and successfully navigate the journey back to health. As a patient, Kate

will share why bi-directional communication with her providers, teachers and peers was so critical in her recovery. She will discuss techniques used to develop relationships with her providers in both emergency and routine situations, and the impact those relationships had on her level of care. Finally, she will discuss strategies and tools she used to self-manage her condition outside the clinical setting that abled her to separate from her disease and retain her own identify. As a caregiver/patient empowerment researcher, Kristina will share the methods used to gather a complete set of longitudinal data to tell her daughter's story that supported their providers in their diagnostic and treatment decisions. She will then describe the patient empowerment research their experience inspired and demonstrate how improved patient/family engagement, and effective application of technology enablers, can drive positive outcomes.

****Please describe the **APPROACH(ES)** used to address the topic/issue.**

This mother/daughter team will share firsthand experience in managing complex chronic conditions over a ten-year period. They will provide examples of navigating barriers and identifying solutions that enabled a successful recovery. The strategies shared for patient engagement focus on three areas: bi-directional communication, patient-provider relationships and self-management. The strategies for caregiver engagement include collecting and managing a full set of patient data (both patient-generated and clinical), leveraging data to assist in shared decision-making, and full partnership with their care team. This experience inspired a career change and a MITRE research project focused on empowering patients and providers to partner for best care. To identify how patients and caregivers can be engaged more effectively on a daily basis, the research team reviewed the activities common to chronic patients beyond the clinical setting. They developed process models capturing a patient's daily activities and interactions with their care team, and then developed a set of capabilities that can be leveraged by patients and caregivers on a daily basis to empower them to engage more effectively in their care. These capabilities included the development of a prototype application to demonstrate the ability to collect patient-generated data between appointments to support patients, caregivers and clinicians with awareness and decision-making. The team collaborated with Carnegie Mellon to conduct provider interviews to confirm the need for and clinical value of "active" patient-generated data gathered between appointments, and provided insights into visualization methods to ensure this data was easy to interpret. The team collaborated with the University of Virginia to conduct a clinical study to evaluate if patient-generated longitudinal symptom data could be reliably collected beyond the clinical setting. They identified how these capabilities can be integrated into existing care models to enhance patient engagements on a large scale. They met with federal partners, industry, not-for-profit organizations, and academic institutions to discuss the use and application of these types of capabilities and identified the barriers and challenges to making them available at a large scale. The presenters will share their experiences and the results of this research to empower providers, patients and caregivers to partner more effectively and improve health outcomes.

****Please describe the **CHALLENGES/BARRIERS** faced.**

There are several barriers to enabling patient engagement beyond the clinical setting and full patient-provider partnership. At the patient and caregiver level, there is the difficulty of managing a chronic illness on a daily basis. Patients must mitigate the impact of their symptoms, take medications at appropriate times and in the appropriate manner, employ medical devices designed for medical professionals, endure hospitalizations for tests and surgeries, arrange appointments, manage insurance claims and billing, and research their conditions to understand their diagnoses and treatment options. Patient-facing IT capabilities must be designed in a way that does not add burden to an already over-burdened population. Patient-generated health data is still in its infancy with regard to integration and interoperability. The policies and standards required to enable providers to visualize this data alongside clinical data need to be defined and implemented to enable full sharing of information. At the clinical and infrastructure level (1,2) there is a lack of standards for patient-generated health data, such as data

definitions, communication protocols, and data analytics. There are issues of authentication for both the sender and the receiver, privacy and security concerns, and a lack of data sets for patient-generated health data. There are processing concerns such as the context around when and why the data was collected, processes for receiving, processing and responding to data, and methods for avoiding information overload. From a legal standpoint, there are concerns about patient expectations for response to data provided between appointments. At the community level, a patient's level of health, language and technical literacy, and access to services and technology vary considerably. There is a risk of increased disparities when patient engagement capabilities are not deployed in multiple modes to maximize access to them. Healthcare clinics often focus primarily on direct health issues rather than working with the social determinants of health required to support community functions such as access to employment, education, nutrition, research, and health. 1. Robert Wood Johnson Foundation. "Project HealthDesign: Rethinking the Power and Potential of Personal Health Records," April 20, 2015 2. ONC Commissioned White Paper, RTI International, April 2012: Patient-Generated Health Data White Paper [PDF - 993 KB

****Please describe the CONCLUSION/OUTCOMES ACHIEVED.**

On a personal level, this presentation describes how one family successfully navigated the journey of complex chronic conditions back to a state of health. The research this experience inspired resulted in a prototype that demonstrates how patient-facing health IT capabilities can be developed to empower patients and caregivers to partner with their providers, and expand their engagement beyond the clinical setting. This expansion of individual patient and caregiver engagement improves patient-provider communication and partnership, enables the collection and use of patient-generated health data to support clinical decision making, and increases patient awareness. These capabilities and methods demonstrate how patients can be empowered to manage their day-to-day care effectively, increase treatment plan adherence, and engage as a partner with their providers. Finally, this research provides specific examples where strategies, policies and standards can be adapted to proactively drive the expansion of patient engagement beyond the clinical setting. Examples of specific outcomes achieved by this work include: - Creation of a vision for patient engagement beyond the clinical setting that includes patients engaging daily in their care and partnering with the providers - Evidence that "active" patient-generated health data can be reliably collected outside the clinical setting and adds value to patients and providers - Demonstration of how patient-facing capabilities can be applied, and best practices for deploying these capabilities - Capture of patient daily workflow processes that identify touch points where patient-facing capabilities support care management for patients and caregivers - Identification of data sets needed to support patient engagement and enable patients to understand their health status, track their progress, and identify and communicate concerns - Identification of patient-generated health data standards needed to support compatibility with other systems, and gaps in current data standards In summary, this research demonstrates how patient-facing capabilities and the inclusion of community and patient needs into healthcare strategies result in the expansion of patient engagement beyond the clinical setting and improved health and community outcomes.

****Please describe the RECOMMENDATION(S) you would offer.**

Recommendations from the patient perspective: • Provide tools and processes to empower patients to recognize and communicate the appropriate information to their providers, teachers and peers • Develop a relationship with patients beyond their diagnosis to ensure there is a complete understanding of how their health conditions, and factors outside of their health, are impacting them on a daily basis. • Educate and provide tools to support patients in the daily self-management of their conditions and provide resources to enable them to maintain their identity beyond their medical condition. • Include patients in the design of health IT systems. Recommendations from the caregiver perspective: • Consider the caregiver and the patient as a valuable contributor to their care, both between and during appointments.

- Design provider IT systems to include outreach to patients beyond the clinical setting, and to integrate patient-generated health data.
- Provide technology solutions designed from the patient and caregiver perspective to be in the hands of patients.
- Include caregivers in the design of health IT systems.

Recommendations of best practices for developing patient-facing IT tools:

- Optimize data collection schedules as activity occurs by designing applications to integrate with the patient's ongoing daily activities
- Apply appropriate data standards to patient-generated health data to enable full exchange and integration of data
- Leverage checklists to help patients identify a full set of information to share
- Visualize the data to ensure patient, caregivers and providers can extract value (e.g. enable cause-and-effect analysis through use of graphical interface and layered data (symptoms, treatment compliance, medication changes, etc.))
- Design technology solutions from the patient perspective and actively engage patients in the design, development and testing of these capabilities

****The HIMSS IT Value Suite** is a robust library of value-focused, evidence based examples of value using the HIMSS IT Value STEPS that benefits patients, healthcare providers and communities. Describe how your topic demonstrates the various stages of STEPS (where applicable) and include metrics to support the value your organization received:

S=Satisfaction, T=Treatment/Clinical, E=Electronic Information/Data, P=Patient Engagement/Population Management

S=Savings

STEP 1: Patient Engagement/Population Management

STEP 2: Satisfaction

STEP 3: Treatment/Clinical

STEP 4: Electronic Information/Data

STEP 5: Savings

STEPS Description: This topic demonstrates value in all five HIMSS Health IT Value Steps: First, increased patient-provider engagement increases Satisfaction by improving two-way communication between patients and providers. Second, empowering patients with capabilities that allow them to gather data between appointments and clearly communicate that data to their care team can provide Treatment and Clinical value by improving the use of clinical alerts based on patient-generated health data. Third, increased availability of patient-generated data that can be integrated into the clinical setting increases the ability to provide evidence-based medicine, and increases data sharing and reporting, which supports Electronic Information/Data. Fourth, bridging the Patient-Provider divide improves both Prevention and Patient Education by: - providing longitudinal patient-generated data for analysis - improving patient engagement - improving patient compliance - increasing patient awareness of disease. Finally, increased patient engagement has been demonstrated to reduce costs, supporting Savings.

****If submitting for an Essential Conversation session, please list details on how you plan on facilitating this session. (Note: this is not a panel session or a lecture session). If not submitting for an Essential Conversation session, please continue to next question.**

N/A

****If submitting for a roundtable discussion session, please list details on how you would facilitate a group discussion with approximately 200 attendees. (Note: this is not a panel session or a lecture session). If not submitting for a roundtable session, please continue to next question.**

N/A

SPEAKER DETAILS

****Primary Speaker Role:** Primary Speaker

****Speaker Information:**

Kristina D Sheridan, M.S.

****Speaker Worksite:** Federal, State or Local Government

****Speaker Bio:**

****Speaker at HIMSS16:** Yes

****If so, in what venue:** Exhibition Floor Sessions

****Speaker at past HIMSS conferences:** 3

****Speaking Experience:**

****Time in field:** Greater than 15 years

****Speaker will provide up to two pieces of content (i.e., a blog post, pod cast, twitter chat, or other type of content) leading up to conference that will promote the session to a broader audience:** Yes

****Speaker will comply with deadlines:** Yes

****Co-Speaker Role:** Co-Speaker 1

****Speaker Information:**

Kate R. Sheridan

****Speaker Worksite:** Academic Education Institution

****Speaker Bio:**

****Speaker at HIMSS16:** No

****If so, in what venue:**

****Speaker at past HIMSS conferences:** 0

****Speaking Experience:**

****Time in field:** 6 - 10 years

****Speaker will provide up to two pieces of content (i.e., a blog post, pod cast, twitter chat, or other type of content) leading up to conference that will promote the session to a broader audience:** Yes

****Speaker will comply with deadlines:** Yes