

SESSION INFORMATION

Submission ID#: 549711693

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

Audience Professional Roles: Physician, CMO, CMIO, Nurse, CNO, CNIO, Government or Public Policy Professional

Session Title: Democratizing Patient Data: A Story of Patient Empowerment

Submitted By: MITRE Corporation

Brief Description: The most critical member of the care team, the patient, is being left out. Their data are not captured in a way that can be leveraged at home by patients, or in the clinical setting by providers. There are few patient-facing tools designed to support their daily care at home, or capture how they are doing between appointments. 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. This unique presentation offers both patient and caregiver insights into managing pediatric chronic conditions, the value of patient-generated data, tangible strategies and solutions used to support recovery, and an update of the patient empowerment research that was inspired by their experience.

Learning Objectives:

- Discuss the barriers preventing clear communication from patients to providers, and describe patient-facing tools and strategies that support bi-directional communication.
- Show how the use of patient-generated health data can improve health outcomes, and discuss how this data can be integrated into the clinical setting.
- Demonstrate, with real-world experiences, how patient-facing tools can be leveraged to engage patients and their caregivers with their health, and empower patients to effectively manage their care outside the clinical setting.
- Explain why policies that incentivise the use of patient-generated data, and clinical studies that measure the benefit of this data, are necessary to the availability and use of patient-facing tools.

CONTENT DETAILS

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 active 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. 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 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. She will explain how capturing her own data and viewing along side her clinical data, enabled her to visualize her path to recovery. She will discuss strategies and tools she used to self-manage her condition outside the clinical setting. 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, 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 developed a set of capabilities to empower patients and caregivers on a daily basis. This 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 University to conduct provider interviews to confirm the clinical value of "active" patient-generated data gathered between appointments, and provided insights into visualization methods to ensure easy interpretation. The team collaborated with the University of Virginia to conduct a clinical study with Multiple Sclerosis patients to evaluate if patient-generated symptom data could be reliably collected beyond the clinical setting. The results of this study were published in the International Journal for Medical Informatics in April 2017, and will be shared as part of this presentation. 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. To address these barriers, this research team is now collaborating with the Billings Clinic in Montana to evaluate the impact of these capabilities on patient outcomes, clinical workflow and hospital costs. The presenters will share their experiences and the results of this research.

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, 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. From a legal standpoint, there are concerns about patient expectations for response to data provided between appointments. There are few clinical studies devoted to evaluating the impact of empowering patients which leaves a void in evidence, and hesitancy in adopting or integrating patient-facing tools into care models. 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. 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 that tracking longitudinal symptom severity data at home increases a patient's self-awareness of their disease state - 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 integration into electronic health systems, and gaps in current data standards In summary, this research demonstrates how patient-facing capabilities and the inclusion patient needs into healthcare strategies result in the expansion of patient engagement beyond the clinical setting and improved health 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 identify 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

If submitting for an Essential Conversation session, please list details on how you would facilitate this session with attendees. If not submitting for an Essential Conversation session, please continue.

SPEAKER DETAILS

Speaker Role: Primary Speaker

Name: Kristina D Sheridan, MS

Title/Org/City/State: Department Head/Researcher, MITRE Corporation, Mc Lean, VA

Worksite: Other

Time in Field: Greater than 15 years

Speaker at HIMSS17: Yes

If so, Venue: General Ed

Speaker at Past HIMSS Conferences: 3

Bio: Kristina Sheridan is an experienced long-term caregiver and patient advocate and has worked 25 years in systems engineering. She is the principal investigator for the MITRE research project, Empowering Patients and Providers to Partner for Best Care, researching how information technology solutions can empower patients to collect and track active patient-generated data, effectively manage their conditions between appointments and fully partner with their care teams. Ms. Sheridan combines her experience as a caregiver of chronic pediatric patients and a systems engineer to help the healthcare and health IT communities understand the complexities of managing chronic illness and to develop and provide tools that will ease the day-to-day burden of managing care. Ms. Sheridan advocates for the development of tools and processes that allow the patient's story and data to be captured and used to develop treatment plans that best meet the needs and goals of the patient. She is an experienced speaker and has advocated for solutions to empower patients and caregivers in over twenty-five national healthcare forums. Ms. Sheridan is the Department Head for the Enterprise Transition Planning and Execution department at MITRE and has been a trusted advisor to senior government officials at the U.S. Food and Drug Administration (FDA), the Centers for Medicare & Medicaid Services (CMS) and the Veterans Health Administration (VHA). She also spent 18 years working in the satellite industry and received her MS in Astronautics and Space Engineering from Cranfield University, UK.

Past Speaking Experience: Kristina Sheridan is an experience public speaker and has spoken as a caregiver and healthcare researcher in over twenty-five national conferences. Her most recent presentations include: 1. K.

Sheridan, K. Sheridan, "Lessons from an Empowered Patient and a Caregiver", HIMSS17 Education Session 2. K. Sheridan, K. McKenna, "State of Patient Engagement: Advocacy, Empowerment and Policy", Decision Health Care Coordination Summit, Baltimore, May 2016 3. K. Sheridan, "Empowering Patients and Providers to Partner for Best Care", HIMSS Nor Cal Chapter, Patient Engagement Summit, Stanford University, CA April 9016 4. K. Sheridan, "How Patient Engagement Supports PCMH Standards and Principles", HIMSS Nor Cal Webinar for State of CA, Feb 2016 5. K. Sheridan, "Expanding Patient Engagement Strategies Beyond The Clinical Setting", HIMSS 16 Fed Health Pavilion 6. K. Sheridan, K. McKenna, "Policy: The Missing Piece of Patient Engagement", Federal Health Architecture Deep Dive Learning Series, Feb 2016 7. K. Sheridan, "Extending Patient Engagement Beyond the Clinical Setting", HIMSS Patient Engagement Summit, San Diego, Oct 2015 8. K. Sheridan, K. McKenna Diamond, "State of Patient Engagement and A Way Forward", Workgroup for Electronic Interoperability, Reston, VA, Oct 2015 9. K. Sheridan, K. McKenna Diamond: "Policy: The Missing Piece of Patient Engagement", Workshop on Health IT and Economics Conference, Washington DC, Oct 2015. 10. K. Sheridan, "Patient Toolkit: Enabling Patient and Caregiver Engagement", The Open Group Partners Pavilion, Washington D.C., July 2015 11. K. Sheridan, "The Integration of Patient-Generated Health Data (PGHD)", Workgroup for Electronic Data Interchange (WEDI) 24th Annual National Conference Patient Engagement Symposium, Phoenix, AZ, May 2015 12. K. Sheridan, K. Farrar, "Patient / Consumer Engagement - Key to Successful Population Health Management", Healthcare Information and Management Systems Society (HIMSS) Clinical and Business Intelligence Symposium, Chicago, April 2015 13. K. Sheridan, "Journey Toward Integrated Health Communities: PCMH and Medical Health Homes", Office of National Coordinator (ONC) Annual Meeting, Washington DC, February 2015 14. K. Sheridan, "Enabling Patient and Caregiver Engagement", Federal Health Architecture Deep Dive Learning Series, March 2015

Speaker Introduction: Kristina Sheridan is an experienced long-term caregiver and patient advocate and has worked for 25 years in systems engineering. Her experience as a long term caregiver for pediatric chronic patients inspired her to change careers from launching satellites to researching ways to empower patients and caregivers. Ms. Sheridan advocates for the design and development of patient-facing health IT to support patient self-management at home, and to facilitate an authentic patient-provider partnership within the clinical setting. She has been a trusted advisor to senior government officials at the U.S. Food and Drug Administration, the Centers for Medicare & Medicaid Services, and the Veterans Health Administration.

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 your session to a broader audience: Yes

Will comply with the HIMSS18 deadline dates to be published upon acceptance: Yes

Speaker Role: Co-Speaker 1

Name: Kate R. Sheridan

Title/Org/City/State: Student, George Mason University, Vienna, VA

Worksite: Academic Education Institution

Time in Field: 6 - 10 years

Speaker at HIMSS17: Yes

If so, Venue: General Ed

Speaker at Past HIMSS Conferences: 1

Bio: Kate Sheridan is a patient empowerment advocate and speaker studying Health Administration and Policy at George Mason University. Ms. Sheridan is also a chronic patient who survived a challenging journey through middle and high school battling a combination of complex chronic conditions. After losing the ability to read or play sports, Ms. Sheridan learned multiple coping skills to manage her symptoms, communicate effectively with her providers and to self-manage her medical conditions. She created an art portfolio telling the story of her recovery. Her experience as a pediatric chronic patient inspired Kate to become certified as an Emergency Medical Technician and then to pursue a degree in health administration with a long term goal to increase patient empowerment and improve patient outcomes.

Past Speaking Experience: Kate Sheridan shares her story as a chronic patient in public forums, and the skills and lesson learned that enabled her recovery. By sharing her story she hopes to help other patients, caregivers and providers communicate, self-manage and partner more effectively. Most recently, Ms. Sheridan shared her story as a chronic patient at a HIMSS17 Education Session titled "Lessons from an Empowered Patient and a Caregiver". In addition, she presented at the Nor Cal HIMSS Patient Engagement Summit held at Stamford University School of Medicine in April 2016. In October 2014 Ms. Sheridan shared her story at the National Capital Lyme Disease Association's Lyme Disease Awareness Forum held to educate teachers about the impact of Lyme disease.

Speaker Introduction: Kate Sheridan is a patient empowerment advocate and speaker studying Health Administration and Policy at George Mason University. Ms. Sheridan is also a chronic patient who survived a challenging journey through middle and high school battling a combination of complex chronic conditions. After losing the ability to read or play sports, Ms. Sheridan learned multiple coping skills to manage her symptoms,

communicate effectively with her providers and to self-manage her medical conditions. Her experience as a pediatric chronic patient inspired Kate to become certified as an Emergency Medical Technician and then to pursue a degree in health administration with a long term goal to increase patient empowerment and improve patient outcomes.

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