



Empowering Patients in their Own Healthcare

A Conversation with Kristina Sheridan

March 2018 – MITRE's Kristina Sheridan discusses how her research identifies and evaluates methods to empower patients with chronic illnesses to better manage their care and to fully engage with providers to improve their health outcomes.

Q: Why have you been focusing your research on empowering patients?

Sheridan: I'm a mom to four kids, two of whom have been battling chronic conditions for many years. The experience of being their caregiver inspired me to get involved in research for empowering patients. So, for the last seven years I've been leading the research at MITRE around empowering patients to partner with their providers for best care. There's a lot of evidence that shows that patient engagement is very important and that it makes a big difference to health outcomes. But there's very little research that shows how to empower those patients to engage in a beneficial way. We've been focusing upon determining what tools patients need to empower them to engage, and how to integrate their information through the healthcare system.

Q: What challenges are we trying to address with your research to help patients and their providers?

Sheridan: The problem is that right now we don't view patients or their caregivers as experts in the healthcare industry. Patients have important information that only they can provide. Often, it's referred to as the "patient voice." Right now, the problem is they cannot easily capture that information in a way that they can leverage to make better decisions, or in a way that their providers can look at and use to make better decisions on the clinical side. We must recognize that patients are the only ones who can really explain what's happening to them, accurately, and how their illness is impacting them daily.

Q: Why are chronic health problems particularly challenging?

Sheridan: Managing chronic conditions is difficult. Patients have little time in the day to organize everything that is happening to them. Without tools to help them, it is not reasonable to expect patients to collect information, and share it in a way that's usable. We want to determine the type of tools that will support patients in the management of their care and in the collection and sharing of the information.



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Q: What are the barriers to patient empowerment within a clinical setting?

Sheridan: The overarching challenge is integrating patient data through the clinical setting in such a way that it doesn't add burden to the doctors, but allows them to use it to make improved decisions. There are three key barriers that keep this from happening. The first is that patients don't have tools to help them to collect this information in a way that they and providers can leverage. The second is that the provider electronic health record systems aren't designed to integrate this specific type of patient-generated data so that the providers can use it effectively. And the third is that measures and policies don't specifically address how we can leverage this data to evaluate the quality of care that's being provided.

Q: What is MITRE doing to address these barriers?

Sheridan: We're looking at three areas within patient engagement. The first is determining what tools patients need to capture patient-generated data that is useful to them and their providers. We've developed the Patient Toolkit that will support patients in gathering this data. The second is we're executing clinical studies to look at how specifically these tools and this data would integrate through the clinical workflow. For instance, when does the provider look at the information? How does it need to be integrated into their electronic health record systems? And third, MITRE's looking at the clinical quality measures and the types of incentives that are available to providers to encourage them to use this type of data within the clinical setting. That way, we can identify the gaps and what must be put in place to incentivize the use of patient-generated data.

Q: You mention tools—haven't patient information tools of different kinds existed for some time?

Sheridan: Yes, but most existing patient tools are designed around one disease state. We created the Patient Toolkit to allow patients to capture their existing state of health. For example, within the tool, we have a symptom picker that allows the patient to identify a full set of symptoms across all their disease states, and track those symptoms that are specific to them. And to fully empower patients, we not only have to develop a tool, but must understand and demonstrate how that tool fits end-to-end into the healthcare ecosystem.

Q: What partners are you working with?

Sheridan: We're working with the Billings Clinic in Montana to pioneer research in how tools like the Patient Toolkit can be integrated not only at home, but all the way through the hospital setting. And we partnered with the University of Virginia to prove that collecting patient-generated data at home, rather than in the clinic, was as reliable as if they were sitting right in front of their provider. That study also proved that as patients track their symptom data at home, that they gain an increased understanding of their health situation. The information from that study informed the



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development and design of the Patient Toolkit, because patients also gave us feedback in terms of how they wanted to capture that information. We also partnered with Carnegie Mellon on a national provider survey that showed us that providers wanted longitudinal symptom severity data and medication compliance data to help inform their clinical decisions.

Q: Who will find the Patient Toolkit useful?

Sheridan: The toolkit is particularly beneficial for patients who have multiple chronic conditions. For example, for veterans seeing multiple providers both inside and outside the VA for multiple conditions, the toolkit allows them to capture all their information across all their illnesses and ensures that each provider has the same set of information. It also helps the patients capture that information remotely. If they have a long way to travel, patients need an accurate understanding of what's happening to them before they pick up the phone and call their providers.

Q: How do you measure success in patient empowerment?

Sheridan: Patients leave the hospital today with a piece of paper. When we truly empower patients, they'll leave with tools that will help them manage at home, capture information that they can share with their doctors, and partner for better health outcomes. We're executing a clinical study that looks at the barriers that patients face in leveraging these tools, and the impact the tools and this data have on the clinicians' workflow to ensure it doesn't add burden. And we're looking at the health outcomes of the patients when this patient data is integrated in and leveraged by the providers. We're also looking at the cost implications to the hospital. Are there incentives available to support the use of this data and these tools, and does the use of these tools reduce the costly part of hospital care? For example, do patients have a reduced number of ER visits and readmissions—and increased numbers of standard visits? We also need to evaluate if this patient data can be used to measure the quality of care to patients and potentially increase the level of incentives hospitals receive.



Kristina Sheridan

Principal Investigator

Patient Empowerment

Kristina Sheridan, M.S., is an expert in patient empowerment. A published author and seasoned presenter, Ms. Sheridan works with patients and providers to partner for the best care possible. As a principal investigator for MITRE, she identifies and evaluates methods to empower patients with chronic illnesses to better manage their care and to fully engage with providers to improve their health outcomes.



