KnowMe –Creating A Personal Electronic Health Record

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Abstract. KnowMe is a patient created personal story of key life events and other information, both medical and non-medical, that enables clinicians to understand what matters to the patient, not just what is the matter with them. By shifting the Electronic Health Record (EHR) focus to knowing when a patient is at their best, what is important to them, his/her personal health goals and care preferences, clinicians and patients can collaboratively work together to create a treatment plan that aligns resources tailored to the their needs and changes the patient experience for the better – to change the conversation between patients and clinicians.
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Introduction

Personalization is at the forefront of modern day life and most importantly in health care. While many personalized medicine efforts focus on what is in a person's DNA, the KnowMe project focuses on what is in a person's heart and mind that a lab test cannot uncover.

In order for clinicians to better care for patients, they should know what matters *to* the patient, not just what is the matter *with* the patient. The health care team must also be able to see what is important to the patient and what his/her goals for health are. What was the person like at their best, before they became a patient? Clinicians must be able to see the patient's health care team as he/she defines it. That team may be a spouse and children for one person and a neighbor or friend from church for another. People are unique and the information their clinician sees should be too. That's why Cerner and Island Health are creating "KnowMe."

KnowMe brings together common demographics (address, next of kin, etc.) in a more patient-centered way to tell a person's story. It also allows for patient entered data so the patient's voice is part of that story. Finally, KnowMe allows clinicians to enter both clinical and non-clinical data to document and help fellow clinicians understand a patient better. *"Patients are the ultimate stakeholders. They have the most at stake, and can contribute real value in new ways."* [1] Dave deBronkart

1. Problem Statement

The problem this project aims to solve begins with the story of one of Island Health's patients. Mrs. G. was a healthy and active woman in her community, on Vancouver Island. She fell and broke her wrist. What followed was a tragic series of events where

Mrs. G. was transitioned from place to place and her health slowly declined until she was confined to a wheel chair in a residential care facility, where she ultimately passed away. In reviewing the case, it was determined that each caregiver along the way generally provided good care. However, the system itself created an environment where transitions, discontinuous planning, and a lack of understanding of Mrs. G. as a person (her status, her history, and her recent abilities) resulted in this rapid decline.

With the permission of Mrs. G's daughter, Island Health documented her story in detail. The most tragic part of Mrs. G.'s story was that it is happening to other elderly people under the care of the Health Authority. From the patient perspective, clinicians often only see their patients as a diagnosis rather than focusing on the daily living impact and side effects of their conditions. This in turn requires a patient to be their own advocate, providing the same personal information or story to every clinician in their circle of care. Without the ability to contribute to or view what is being documented, a patient or their loved ones are without the tools to even provide that information. Subsequently, clinicians do not have a picture of a patient at their best, as they often only interact with a patient as they are triaged through care. Reactive care, managing current symptoms, prevents or provides an obstacle to the creation of a treatment plan to return a patient to the ideal state for him/her.

Telling Mrs. G.'s story helps to deepen the understanding of caregivers and underlines the importance of improving the care cycle to ensure the holistic view of a patient as a person is not lost in the system. Through documenting the story, her daughter described a better future state where if caregivers really knew what her mother was like, at her best, they might have been able to set higher goals and different plans to return her to that state of health.

Other Examples?

2. Investigation and Methodology

In the case of KnowMe, there are several end user groups. Of course, clinicians are expected to benefit from a deeper understanding of a patient's story but the patients themselves will be 'end users' because KnowMe will give the ability to contribute to a patient's story, in his/her own words, through the use of a patient portal or some other means.

KnowMe observational research involved extensive interviewing of clinicians, physicians, and patients. Patients were determined to be the primary focus of end-user interviews and came first. Island Health has an established Patient Voices Network, where citizens can volunteer to participate in Island Health projects or committees. Patients were invited to participate based upon their interests and the amount of time they wanted to commit. Fifteen patient advisors accepted an invitation to participate and were interviewed. They represented a broad cross-section of demographic groups and experiences. These 15 individuals had 350 health care experiences over the preceding 12 months, across five different communities on Vancouver Island. The patient interviews provided a rich background on how the EHR might support a better experience.

"The more information I'm able to provide about "who" I am and what I hope for in terms of health results, the easier it is for ALL medical professionals to be on the same page, whether I've seen them before or not. I think this will also help them see me more as a "person" and not just another "patient". Pamela, Patient Advisor

The team then proceeded to interview physicians and the interdisciplinary care team to observe their current workflow and coordination of care. In all, 55 clinicians were interviewed and/or observed, across 25 different specialties in 7 communities across Vancouver Island. The goal was to understand what information or details they felt were missing from what they currently know about a given patient. If patients were able to better 'tell their story,' how might the plan or treatment change? The innovation team discovered that there were many gaps in the story that were supplemented through a series of notes and whiteboards and that the multi-disciplinary care team had been cobbling together their patients' stories. Care personnel involved in the interview process were excited about the prospect of the EHR facilitating better communication.

"Getting back to the basics of meeting together, as a team to go over relevant information pertaining to our patients, assigning jobs, and daily follow-ups is an efficient way to maintain and maximize team based care. We are living our values of being better together." Dr. Sam Williams, Chief of Staff- West Coast General Hospital

Overall, the investigation process highlighted the patient's desire for clinicians to see them as a person and not just another patient. Patients want clinicians to know about their family, values, daily living, fears, triggers, and hobbies. In turn, clinicians want to really understand their patients so they can provide better care.

4. Case Study: Patient Advisor

Mrs. E is a patient advisor that has shared her story and provided feedback on KnowMe. This is her story, in her own words:

My name is Mrs. E. I live in Victoria, and I'm a retired teacher and school administrator (I've been retired for four years). I live with my husband, Chris, and I have two children, Scott and Amber who are in their twenties, and live in Vancouver. My mother, Barb, is 89 and living in Ottawa. We all consult and support one another about anything healthcare related.

My health started to decline about 8 years ago, mainly due to bi-lateral hip replacement and chronic Urinary Tract Infections. I am in constant pain and it is affecting all parts of my live. I used to love yoga and hiking, and I just can't do those things anymore.

I have had frequent referrals and frequent medical appointments due to my conditions, and I am often asked to "start from scratch" with each new doctor. I know that files are sent electronically from doctor to doctor, so why should I start from scratch? I think it would be helpful for both patient and health care provider to have a short summary of key points for easy reference prior to the beginning of the appointment.

My Bio as I want it stated to my health care team in the EHR:
Health and wellness are very important to me. I like to be physically active, vital person who wants to do everything she can from a self-management perspective to enhance health in her life. I prefer to manage the use of medications, knowing they are necessary treatments for some of my illnesses and conditions. Mrs. E

6. Methodology

Cerner employs a User Centered Design and Agile methodology to develop software. These methodologies value individuals, interactions, and their goals over processes and tools. Working software demonstrated early and often is more important than comprehensive documentation. Responding to change is valued over following a plan that doesn't deliver value each release. And, most importantly for this project, end user collaboration is at the centre of all the work. Agile methodology calls for iterative design and development with end users (in this case, both patients and clinicians) involved throughout the process. This project works to ensure that the design will evolve and change based upon use in real time and in different venues of care. Initial design and discovery was fueled by a series of interviews with care providers and patients across the island and plans include further opportunities for demonstration and feedback from both.

Development is focused on robust, efficient and current design and testing guidelines. Service-level and UI automated testing with continuous integration are being utilized. Work is divided into phases and then larger releases. Milestone releases validate the packaging process, functionality, and install/build documentation. The first release of KnowMe is scheduled for June, 2015.

5. Phases of Development

As of January, 2015 KnowMe is in its early design and development iterations. The first phase of the project leverages data that already exist in the EHR. Through the normal registration, scheduling, and assessment processes at Island Health, information is captured that can start to tell someone's story. Today the data is collated in a clinical manner, but this project challenges the status quo to aggregate the data from the patient's perspective. This creates a medium in which the person can tell their story and provide what is important for a clinician to know, a paradigm shift.

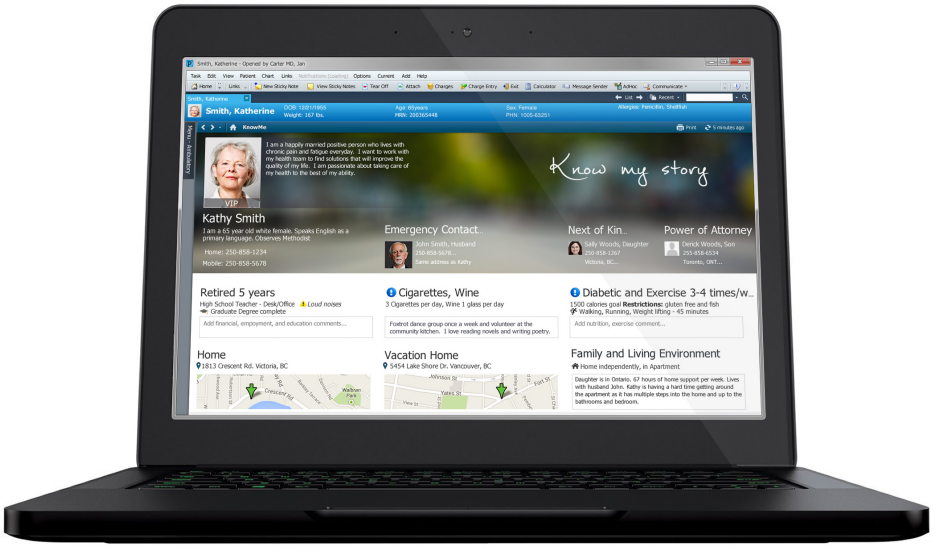

Figure 2. Release 1 KnowMe

Privacy and security are important considerations in the KnowMe project. EHR's have robust controls over which clinicians have access to different types of information. The literature to date does not fully address the blend of clinician and patient inputs and access by patients to edit their own record. A grant has been awarded to fund the organization of a research study to create a new access control model that will sufficiently deal with this dramatically different approach to a patient and their personal care team's involvement in their care.

The overall objective of the research project is to research the Circle of Care-based access control system for KnowMe. According to Price, the Circle of Care (CoC) is *a system that is centered on a patient and contains the providers, information and activities related to that patient's care* [2]. Relationships between patients and actors in their individual and evolving "*circles of care*" (CoC) are ephemeral and depend on changing conditions and healthcare contexts. Moreover, Price points out that providers in the CoC include not only physicians, nurses, other formal providers, but also informal providers (lay people providing care, such as family members or friends).

7. The Future of KnowMe

Ms. G and Mrs. E's stories are just two of thousands, which is why Cerner and Island Health are working together to create a "KnowMe" view of the patient. The view will allow patients to update his/her information and provide clinicians and health coaches a mechanism to access the information and update the view. Island Health will be deploying a patient portal to further facilitate the KnowMe approach. Through the patient portal, patients and/or their personal care team will be able to document and edit their goals, their living situation, and their care team, as they perceive it, as their story unfolds.

Figure 1. Early stage vision for KnowMe design

Island Health continues to evolve to a model of integrated primary and community care and new roles are emerging that will enhance the KnowMe process and will benefit from its potential. Health coaches will proactively work with patients to document their goals and track progress in real time. KnowMe will become a regular part of how patients actively engage in their care throughout their journey of health, as well as through episodic moments of care.

> *"My doctor is a diabetes expert, but I am the leading expert in my diabetes. My opinion and preferences are just as important as those of my health care team, and working together with my doctor to create a personalized approach in managing my Type 1 diabetes has earned me the best health outcomes."* [3] *Kerri Sparling*

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