

---

# Sharing Health Information in the Care of Diabetes

**Aisling Ann O’Kane**

UCL Interaction Centre  
University College London  
London, UK, WC1E 6BT  
a.okane@cs.ucl.ac.uk

**Helena M. Mentis**

Socio-Digital Systems  
Microsoft Research  
Cambridge, UK, CB3 0FB  
hementis@microsoft.com

**Abstract**

Chronic illnesses are becoming more prevalent worldwide breeding an interest in supporting patients’ care through electronic health information exchange. Through a study of diabetes patients and the specialists in their care network, the challenges involved in sharing health information from the two perspectives become apparent. There are opportunities in the design of electronic medical information exchange to support the patients’ need for knowledge and the specialists’ need for data while facilitating an appropriate level of sharing to bridge the gap which leads to tensions and inefficiencies in the management of illness trajectories.

**Introduction**

Chronic illnesses affect approximately half of all American and British adults – 133 million Americans and 17.5 million Britons [1,4] – and these numbers are expected to significantly rise over the next ten years. Chronic illness is one that can be controlled but not cured and thus requires a lifetime of ongoing care and communication between the patient and their healthcare providers.

This particular group of healthcare concerns has been a driving force behind many initiatives with Electronic Medical Records (EMR) in order to maintain and chart a patient’s medical data over a lifetime. More recently,

there has been a rise in Personal Health Records (PHR) systems, where patients collect and document their self-care activities and data from their healthcare providers.

With the new GE-Microsoft joint venture aimed at global healthcare system transformation, system developers are now turning their attention to bridging the gap between patient and practitioner records recording and management [3]. For instance, one of the first initiatives of the new company is "To help patients and their physicians work together more efficiently to manage chronic conditions". To do this, their intention is to "support the sharing of data from at-home medical devices (such as blood pressure cuffs, scales and glucometers) with caregivers to facilitate better tracking of chronic conditions, coordination of treatment schedules, management of medication regimens and timely interventions".

It is safe to assume that, in the management of long-term health, there needs to be a symbiosis between the activities taken by the health practitioners and those taken by the patient in order to maintain a positive illness trajectory. However, an illness trajectory is more than simply the data and information associated with the patient's illness. Rather, it is also a process that is embedded in a social framework that effects and mitigates how that data is gathered, used, understood, and acted upon.

An understanding of how both patients and their network of healthcare providers regard the information they generate and share and how that plays a part in the illness trajectory is necessary to provide a

perspective on how to design for a continuum of care in a socially situated manner.

### **Ongoing Work**

For the work we are currently engaged in, we have run a study of information sharing behavior between diabetes patients and diabetes health specialists in the UK.

Diabetes is a chronic illness that grows more prevalent every year, with estimates by the World Diabetes Association that 1 in 10 will have the condition by 2030 worldwide [2]. It effects the production of insulin, which is needed to process digested sugars. This health condition needs to be cared for with a range of treatments including diet, exercise, and medication, all of which need to be balanced by the patient to self-control their levels of ingested glucose. Low glucose levels can lead to ill health effects immediately, but long-term excess levels of sugar can lead to serious complications including eye, foot, kidney and heart disease. As this is the case, diabetic patients tend to have a wide range of medical practitioners in their care network, including, their family doctors, diabetes specialist nurses, diabetes specialist dieticians, diabetes specialist doctors, ophthalmologists, podiatrists, and midwives. It also requires a level of engagement from the patient for his or her own self-care. The factors around this condition present an interesting case study for how a patient's medical information is used and shared over time and what this means not only for the design of shared electronic medical records, but also for the shift towards more patient centric care plans.

To date, we have interviewed 12 diabetes patients, attended three and held one group interview with four

diabetes support groups predominantly in eastern England, and interviewed six England-based diabetes health specialists: two senior diabetes consultants, a diabetes midwife, a diabetes nurse, a diabetes podiatrist, and a diabetes dietician.

We have also had the opportunity to interview three medical record systems developers. Two from a US-based enterprise solutions company for large medical record systems, and a designer/developer who was involved with the UK's public healthcare initiative to move all health records online and in healthcare informatics policy decision making.

Interviews were conducted in a semi-structured format with interview questions probing people's experiences with the current medical information exchange network along with their personal preferences. Questions were asked regarding ability to use, share, and access health information.

### **Preliminary Findings**

#### *Specialists want Data, Patients want Knowledge*

Although currently in the UK patients have the legal right to see their medical information, this is often not seen in the specialist-patient exchange. There are patients, particularly older Type 2 patients, which do not feel like they can request documents or information beyond what the specialists share with them verbally. In addition, it seems to be common practice for specialists not to share anything unless specifically requested for it.

The specialist-patient exchanges that do occur are oftentimes not what the receiver needs or wants. For instance, information that the specialist provides the

patient is not an exchange of knowledge, but rather an exchange of information or data without context. Many times the patient receives the same letter that goes back to their General Practitioner with medical terms and numbers that do not aid the patient in understanding for the purpose of their own self-care.

In contrast, the information that the patients bring to the specialists at appointments is often knowledge or information rather than data, which is not helpful for the specialists. For instance, news articles are brought to consultants and resulting discussions take up what the consultants think is precious time better used towards discussing more relevant data.

As diabetes requires patient engagement in order to accurately control blood sugars, patients are actively turning to friends, family, support groups, online sources, and anything available to them to understand the condition and treatment options. Although patients that are more comfortable with technology are already going online for information, many are gaining information from sources that are not the most accurate or efficient, such as word of mouth or sensationalist newspaper articles.

#### *Specialists and Patients Want to Share...Sometimes*

Patients' attempts to develop their own self-care methods such as counting calories as well as carbohydrates, or by using an equation to figure out their insulin doses rather than the accepted practice of rounding their doses are not encouraged by the specialists, with patients sometimes hiding these practices when asked about them.

Most patients recognize that the nature of diabetes requires specialists to have a holistic view of their illness trajectories and would be in favor of granting all specialists full access to their medical information. Some have had privacy breaches in the past, though, and are not comfortable with specialists receiving information that they do not believe is relevant to their treatment, such as pregnancy records that are accessible to their optometrists. Most patients would like to have some say in what is available for their specialists to access, and perhaps what should be withheld from easy access. Specialists believe they should have full access to all medical histories and believe that their ability to access childhood records or psychiatric records that may not be directly related to their expertise allows them to better triage and treat the patient through a deeper understanding of the situation.

Likewise, most specialists have some reservations about giving full access to the patients. Their communications between professionals and their personal notes are currently very carefully crafted and secured for legal reasons, but they would also worry about the effects on the patients. A podiatrist would like to be able to record that a patient will probably require amputation without having to translate this into softer language for a patient's eyes.

### **Opportunities and Challenges**

Our perspectives on the opportunities and challenges for bridging the two settings are based on the disconnect between information needs and wants between the patients and the specialists. The patients want to give the specialists information that is important to themselves and specialists want to do the

same when sharing with patients, causing tensions and inefficiencies in the shared responsibility of a patient's illness trajectory.

There is a clear interest in sharing information between both groups of stakeholders. They want to bridge this gap and view electronic records as the means to do that. Health specialists want their patients to record more data and share that with them, and patients want to be able to see and monitor the data the health practitioners collect. But there is a large gray area where both patients and practitioners feel some information is not suitable to be shared 'with the other'.

In addition, the level of engagement with one's health and the information associated with it varies greatly, along with the abilities of the patients to effectively use and understand this information for their own self-care. The act of deciphering the reams of data available can be overwhelming for patients, which is apparent in their need to search for other sources to 'understand' their condition. Thus, it is more than simply sharing the information, but wrapping it up into knowledge that is the hefty challenge to overcome.

### **References**

- [1] [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_4075213.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4075213.pdf)
- [2] <http://www.idf.org/media-events/press-releases/2011/diabetes-atlas-5th-edition>
- [3] <http://www.microsoft.com/Presspass/press/2011/d/ec11/12-07MSGHealthcarePR.msp>
- [4] Wu, S.Y. and Green, A. Projection of Chronic Illness Prevalence and Cost Inflation. RAND Health, Santa Monica, CA, USA, 2000.