



2019

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Recommended Citation

Sieck CJ, Huerta TR. Transformations in health information technology and the impact on patient experience. *Patient Experience Journal*. 2019; 6(2):5-8. doi: 10.35680/2372-0247.1391.

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Transformations in health information technology and the impact on patient experience

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Abstract

Changes in the way we collect and use health information, and the technology that enables these processes, have transformed the patient experience in health care. Compared to an earlier focus on using health information technology (HIT) for clinical purposes, patients are now also significant users of HIT, spurring the development of Patient-Facing Health Information Technology (PFHIT). These tools allow patients to use and interact with their health information and healthcare providers in new and transformative ways. We suggest that while these transformations have significant positive impacts, there are three important considerations which must be included as HIT continues to evolve: a focus on usability of HIT tools, providing appropriate training at all levels of use, and assessing individual patient's capacity to use such tools to alleviate disparities in use.

Keywords

Health information technology, patient experience

The relationship between information and technology in health care

Information has been a critical component of health care since the ancient Greeks methodically captured and organized patients' symptoms and experiences for the express purpose of improving care. However, our relationship with information has undergone a tremendous change as a result of technology that made collecting, storing, organizing and sharing that information easier, particularly with the introduction of Electronic Medical Records (EMRs). At the time, EMRs were used exclusively by clinicians to manage the significant volume of data that was coming to be generated in the provision of care. In the late 2000s digital connectivity, coupled with the prevalence of devices such as smartphones, created an opportunity for patients to engage their health care providers in fundamentally new ways. This perspective on patient empowerment caused a fundamental shift in the nature of Health Information Technology (HIT). While EMRs had been framed as a tool for clinicians, there was growing interest in involving patients in the use of technology as collaborative partners in their care and led to the rise of the Electronic Health Record (the EHR).

While the Electronic *Medical* Record focused on the patient's medical history in one clinical setting, the Electronic *Health* Record sought to provide a broader view of the patient's health which could be shared across settings. Policies such as the Health Information Technology for Economic and Clinical Health Act

(HITECH) and measures of Meaningful Use (MU) encouraged the adoption of EHRs and their associated attendant technologies, like patient portals^{1, 2}. Such tools enabled patients to see, and eventually interact, with their clinical record. MU policies fostered the rapid adoption of patient access to medical records and technology-mediated which transformed the health information technology landscape with a more patient-centered focus. As opposed to a focus on the role of the clinician in the care and management of disease, the patient has come to be recognized as central to the management of his/her own disease trajectory, supported by a personal (e.g., family and caregivers) and professional (i.e., healthcare) support system.

This intersection of information and technology in the realm of healthcare can be viewed within the Sociotechnical models of Health Information Technology³. In these types of models, *actors* utilize *technology* within a defined *structure* to accomplish a *task*. For example, in the early 2000's, when physicians were the primary users of health information technology, the Sociotechnical Model focused on the role of clinicians (actors) using technology (EHR) in the clinical encounter (structure) to assess a patient's health and provide treatment recommendations (task). The introduction of MU and accompanying efforts to provide patients with access to their health records added a new actor to the Sociotechnical Model. Patients and clinicians *both* became actors, technology included *provider-facing tools* such as EHRs as well as *patient-facing tools* such as patient portals, the structure in which each technology is used extended

beyond the clinic visit, and tasks could include *work done by providers and patients individually as well as collaboratively*. Adding patients as actors to the sociotechnical system spurred the *development of Patient-facing Health Information Technology (PFHIT)*, a class of tools used to facilitate communication, allowing patients to participate in their care and self-manage their health conditions to a greater extent than ever before⁴.

PFHIT as a force for transformational change

The outcome of the transition has been significant. For example, patient portals, have shown promise in facilitating self-management across a number of clinical conditions by allowing patients to input and track health information, facilitate communication, and delivering educational materials⁵⁻⁹. As a central hub of patient access and information, portals offer features that allow patients to engage wherever they are on the care continuum, improving patient-physician communication¹⁰⁻¹³, decreasing visit rates¹⁴, and increasing awareness of care and treatment adherence¹⁵.

The function of PFHIT is evolving as health services organization seek to provide technology to patients that both create both to their health data and use information that might be meaningful based on that data- *expanding the type and mechanisms of information included in a patient's health record*. The ability to integrate data collection in tools that we carry about in our day-to-day lives can transform how patients engage with their health. PFHIT is now a broad umbrella for technologies that link patient-reported data to clinical systems and empower patients to engage in their care through sharing, monitoring and reporting symptoms or activities, viewing their clinical data, and more recently, receiving care via telehealth. Patients can now transmit health information such as blood pressure readings, or conduct clinical visits remotely, potentially improving both access and engagement.

Finally, this change created *two new classes of tasks – patient work and collaborative work*. As patients became partners in their care, they have grown in their use of tools to self-manage and report these findings back to their clinicians. Tools like insulin pumps are now Bluetooth enabled and continuous glucose monitoring has become mainstream¹⁶. Patient-facing tools have opened new frontiers in self-management and have empowered patients to have greater agency, increase trust in their physicians, and ask more informed questions in clinic visit and redefined the care process as one composed of *collaborative work which introduced a new element into the patient-physician relationship*.

Future Challenges

These role expansions require care and consideration that scholars have noted must guide future HIT design and

implementation efforts: implementing user-centered design principles to address usability issues; providing appropriate levels of training; and addressing the persistent disparities in access and use.

Addressing usability issues

Physician complaints about the challenges that EHRs have introduced into care are well documented. However, patients are far more likely to suffer from choices that made by technology designers which limit their usability in the real world. Lack of usability can undermine the effectiveness and subvert the value of PFHIT and as technology becomes focused on the patient, issues of usability and more recently, the user experience, have become growing concerns. For example, while clinicians spend a significant part of their training learning the language of medicine, all too often, technology fails to express that clinical information using patient-centered approaches.

A focus on user-centered design (UCD) is critical to providing tools that can be readily adopted by patients and providers. UCD is an approach to creating products that solicits and incorporates end-user feedback throughout the design process, typically in an iterative process to develop “products that are intuitive, intelligible and not cumbersome”¹⁷. Patients are increasingly included as end-users in UCD processes for the development of patient decision aids, health behavior change interventions, and self-management programs¹⁷⁻²⁰. HIT tools designed using this approach may be easier for patients to use and thus that patients may be more likely to use them. In addition, when particular attention in recruiting end-users is given to including under-represented members of the population or those who typically face challenges using existing tools, these products can help to address disparities in use.

The role of training in successful technology use

As HIT has become more integrated into the ecosystem of health care, there is a significant need for training which reaches beyond the “how” of accomplishing a task and incorporates the “why” of the task, and more recently, training in how providers and patients can use HIT collaboratively. When users do not fully understand why a technology can improve their lives, they implement workarounds, which might alleviate challenges they encounter, but might simultaneously circumvent gains. Training needs may change as users gain experience with these tools²¹. Patients need individualized and, as a result, varying levels of training in the use of HIT as well. Those with difficulty reading or limited computer skills might need to acquire basic literacy, health literacy and e-health literacy skills. Others might be familiar with technology, such as using a tablet or accessing the internet, and will need only instruction in the use specific to the tool. The availability of training that can address all levels of end

users' needs is critical to fully realizing the potential of HIT.

Beyond training in the individual work of HIT, providers and patients need training in how to collaborative use. For example, in the clinic visit, EHRs allow providers share their screen to show patients lab and test results or verify the accuracy of information, yet such use is rarely included in EHR training. Between visits, secure messaging through patient portals, which allows asynchronous asking of questions or provision of updates, can facilitate conjunctive work. Studies show that both patients and providers value this convenience, but both suggest that additional training in how and when to communicate, beyond which buttons to click on the screen, would improve its use^{22, 23}.

Asking patient about their access and use

While UCD and appropriate training are important considerations in design of HIT, both assume a given patient has access to the tools designed. Many PFHIT tools require a device such as a computer or smartphone with which to use the tool, and access to the Internet. The most recent US Census data shows that 13% of Americans lack a computer in their home and 21% lack an Internet subscription and may therefore lack access to HIT tools²⁴. Even if a patient has a device and Internet access, they need sufficient levels of e-health literacy by the patient to be able to understand and use the tool, and a healthcare provider who offers such tools.

Physicians may understand the impact of issues such as access and capabilities, but they currently lack a means to systematically assess them for an individual patient and to easily incorporate that assessment into the EHR. Thus, such questions are not routinely asked in a clinic visit, and patients may therefore receive a recommendation for a tool they cannot use or may not be offered the tool because of assumptions about their access, willingness or ability to use it. Because disparities in access and use of HIT mirror, and can often exacerbate, disparities in health outcomes, those who may benefit the most from improvements in access and engagement are less likely to actually be able to use HIT. The development and systematic use of measures to assess a patient on these levels informs not only the individual patient-provider interaction but the UCD approach to design and identification of training needs described above.

HIT has evolved and broadened its scope of application significantly in the last four decades and shows no signs of slowing its continued evolution. Development of tools used by providers, patients and both collaboratively have changed how patients experience healthcare in significant ways. Continued attention to the impact on healthcare disparities, tools designed with the end-user in mind, and an understanding of the levels of training required for

effective and efficient use will shape the development of HIT in ways that can most improve the patient experience.

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