

Provided to: *Office of the National Coordinator for Health IT in preparation for***Panel 1: Meaningful Use of HIT in the Real Lives of Patients & Families****By: IDEO LLC****The context - from our perspective as designers of new experiences**

The considerable investment in health information technology (HIT) by government and industry presents us with a tremendous opportunity for improved health, but also with great potential for error, huge waste of resources, and maybe even harm. Solutions and approaches that are implemented during this period of rapid change will have long-term consequences for the quality of healthcare in the USA.

Information technologies have changed all of our lives in the past 50 years, but they have had a very minimal impact on most areas of health, wellness and health care. This is especially apparent if one compares the applications and services that have been driven by the medical industry in comparison to those emerging from the consumer electronics, apparel and publishing industries. Most HIT solutions fall far short of the usability and user experience standards of mainstream business successes such as Facebook, the iPhone, and iTunes. Despite their less serious focus, these IT solutions are important examples. The global appeal and swift adoption of these designs, by broad sections of the public and by both amateur and professional developer communities, should serve as a beacon for what should be possible in HIT.

Some health IT systems in use today are helpful in improving health outcomes, some are simply disliked by users, but more concerningly, others have been shown to create medical errors, reduce productivity or lower the standard of care in more subtle ways. Though IDEO is perhaps biased by our historical methods, we honestly believe that incorporating human centered design in the process of specifying, developing, testing and implementing future health information technologies will help to ensure they have a positive impact for all stakeholders.

General design principles for development of Meaningful HIT

- "Meaningful" is in the eyes of the beholder- to be considered meaningful it must be relevant, useful and engaging for the intended stakeholders: users, caregivers, health professionals of all types, insurance companies, the government and other relevant parties
- Design of HIT systems should start and end with the needs of the user, not with the technology and what it might be capable of doing
- Every system should be tested prior to certification from a usability perspective - this perspective will necessarily vary based on the target uses and users, but the approach must be rigorously applied
- Testing should be done on target users and other stakeholders, not by expert testing firms
- Government and industry should create a joint institute to advance the state of the art and standards of usability with the goal of enabling innovation, not locking in a standard or proprietary interface or use model

Answers to HIT Policy Committee questions*a. What are consumers' health information needs in the context of their real lives?*

From the perspective of the patient (though it can be reframed through the eyes of a caregiver) people need health information that enables them to:

- Understand their own health, and any medical intervention or interaction, to a sufficient extent that they can make informed choices – e.g. patients should be provided information that helps them easily understand the benefits, risks and day-to-day correct application of any therapy.
- Take appropriate action in the face of their unique cognitive, physical, emotional or financial constraints and burdens – e.g. patients should be supported in navigating the healthcare and healthcare insurance system to help optimize their own care.
- Believe in their ability to succeed in managing their health, and to grow that belief based on appropriate feedback – e.g. patients should be presented with data about their progress managing a health issue in an engaging and understandable way.

All of these goals must be achieved ethically, preserving the ultimate safety, privacy, dignity and independence of the individual to the extent they desire.

b. How do results of ethnographic studies of individuals with chronic health conditions inform our understanding of how HIT can improve their use of health information and connectivity with their providers to improve their health?

Ethnographic studies can provide better insight into the real-world hurdles that people face in managing a chronic condition, relative to traditional survey methods. Ethnographic studies can expose underreported and unnoticed problems and inspire the iterative design of improved solutions. Opportunities for greater positive impact from HIT solutions are numerous, varied and dependent upon the unique chronic condition and HIT system, but findings from such studies have included:

- Previously undetected incorrect use, interpretation and resultant actions by patients (often despite claimed understanding of a new health information service) due to poor interface design or inadequate training.
- The desire for layered and easily navigable information which provides critical or actionable guidance up-front to all patients, while allowing the concerned or curious user to dive deeper in search of reason and reassurance.
- The excellent potential for HIT to assist people's efforts to integrate multiple health-related activities such as health state, therapies, diet and exercise.
- The alarming potential for HIT to negatively impact relations between healthcare providers and patients by becoming an inappropriate mediator for in-person interactions.

c. What is the evidence base for patient benefit from their direct use of PHRs and other HIT that interacts with EHRs?

IDEO has not yet had an opportunity to investigate the use of Personal Health Records in sufficient depth that our experience could be regarded as “evidence”. Making inferences from related work we suspect that PHR’s could be a useful tool for consumers, but that they will be impactful only if they (and the solutions that they are part of) can successfully engage people in better managing their health through a PHR.

d. What is the role of mobile applications in improving health of individuals? Is there a specific role for underserved populations?

Mobile interactions offer many benefits beyond applications intended for static / desktop interfaces. In particular they represent an opportunity for health information and prompts to be provided at the point of action or decision e.g. “Shall I eat this item in front of me right now or is it a bad decision for my health?”

Obviously but significantly, mobile applications increase accessibility to health information by allowing people to employ a whole new class of IT hardware, most notably mobile phones. Given the cellular network connectivity that is inherent in most mobile devices these applications certainly have excellent potential to help underserved populations gain better access to health information and services.

e. How can we use HIT to make information and knowledge actionable for patients?

HIT can be employed to help process health “data” into health “meaning” that the layperson can understand and respond to appropriately. HIT can simply process and more recognizably present data (e.g. graphing), or can integrate available codified knowledge to partially interpret data, thereby assisting a healthcare professional or patient in deciding on a particular course of action.

It is important to remember that there limits to this role due to:

- The importance of incorporating the tacit knowledge and experience, and intuitive in-person diagnostic appraisal, which healthcare professionals can offer.
- The need for face-to-face personal communications between healthcare professionals and patients to, for example, ensure understanding, provide emotional support and address unexpected issues.
- Liability risks for any HIT provider who offers data interpretation that could be construed as the provision of medical advice.

f. How does HIT enhance collaboration between patients and their providers and change how the patient’s health is managed?

HIT helps empower patients to play a more substantial role in collaborative decision-making with their healthcare provider by better informing the patient of their health condition and the possible actions that can be taken to attempt to improve it. While some healthcare professionals are unsettled by this shift in power and there is real potential for patients to misuse health information, overall we believe that greater engagement and more considered input from patients regarding their healthcare is a positive societal change to pursue using HIT.