

The Promise of Information and Communication Technology

In Health Care:

Extracting Value from the Chaos

Burke W. Mamlin, MD

– and –

William M. Tierney, MD

Regenstrief Institute, Inc.

Indiana University School of Medicine

Indianapolis, Indiana

Corresponding author:

William M. Tierney, MD
President and CEO, Regenstrief Institute, Inc.
410 West Tenth Street, Suite HS2000
Indianapolis, IN 46202
Voice: (317) 274-9094
Fax: (317) 274-9303
E-mail: wtierney@regenstrief.org

- There was no grant support of this article.
- The authors have no relevant conflicts of interest.
- Short running title: The Promise of Health Information Technology
- Keywords (MeSH): Health information technologies, Electronic medical records, Telemedicine, Information management

Abstract

Health care is an information business with expanding use of information and communication technologies (ICTs). Current ICT tools are immature, but a brighter future looms in many areas. We examine six areas of ICT in health care: electronic health records (EHRs), health information exchange (HIE), patient portals, telemedicine, social media, and mobile devices and wearable sensors and monitors. In each of these areas, we examine the current status and future promise, highlighting how each might reach its promise.

Steps to better EHRs include a universal programming interface, universal patient identifiers, improved documentation, and improved data analysis. HIEs will require federal subsidies for sustainability and support from EHR vendors, targeting seamless sharing of EHR data. Patient portals must bring patients into the EHR with better design and training, greater provider engagement, and leveraging HIEs. Telemedicine needs sustainable payment models, clear rules of engagement, and quality measures and monitoring. Social media needs consensus on rules of engagement for providers, better data mining tools, and approaches to counter disinformation. Mobile and wearable devices will benefit from a universal programming interface, improved infrastructure, more rigorous research, and integration with EHRs and HIEs.

ICT tools are evolving quickly in health care and require a rational and well-funded national agenda for development, use, and assessment.

Introduction

Health care is mainly an information business. The quality, efficiency, and outcomes of care depend on effectively capturing and managing patient information. There is no health care without management, and there is no management without information. Currently, information management is done using information and communication technologies (ICTs) whose use is expanding dramatically in health care. More than three-quarters of U.S. hospitals and half of outpatient practices have installed electronic health records (EHRs).¹ Almost all practice venues have high-speed Internet connections and most clinicians use electronic media for professional and personal communications.^{2,3} Yet, chaos reigns:

- There are many different electronic health record systems serving U.S. health care and limited ability to share information between them. There is no secure access from one EHR to another, no national identifier for patients to allow linking of data, and few existing standards for formatting, summarizing, or displaying patient information.
- Mandates for billing, quality improvement, and other initiatives have expanded documentation requirements while funding constraints have reduced clinician time. As a result, clinicians use shortcuts (e.g. templates and copy-and-paste) that often increase the amount of information recorded but decrease its readability.
- The amount of available information is constantly increasing, but the tools to safely digest, summarize, and empower the provider are struggling to keep up.

Despite the chaos, a brighter future looms as ICT solutions are being applied to health care in new and exciting ways in many areas:

- Evolving EHRs

- Health information exchange
- Patient portals and personal health records
- Telemedicine
- Social media
- Mobile devices and wearable sensors and monitors
- Privacy and Security

In this article we consider each of these, looking at their current status, their promise for tomorrow, and how each might reach that promise. (See Table.)

Electronic Health Record Systems

Current status

EHR systems are longitudinal electronic records of patient health information. Nearly every physician in the U.S. has personal experience with one, since EHR use in the U.S. has expanded rapidly over the past decade under the Affordable Care and HITECH Acts.¹ Enacted in 2009, these acts direct the Department of Health and Human Services to spend \$25.9 billion to promote and expand the adoption of health information technology. While most providers are now using EHRs, the majority are unsatisfied or frustrated with the experience.⁴

Hospitals are using EHRs from a small number of large vendors, while outpatient practices have installed highly variable EHRs provided by a larger number of smaller vendors.¹ Each EHR has a unique user interface and its own approach for representing and storing clinical information. As a result, experience with one EHR rarely translates to another.

In addition, each EHR stands as a silo of information with little sharing of data between them. Standards to enhance data sharing are appearing, but information sharing between health systems, outpatient practices, and other clinical and paraclinical venues is still minimal.

The barriers to such data sharing are mainly logistical and organizational, not technical. U.S. Senator Lamar Alexander (R-Tenn.) recently asserted the “failed promise” of the nearly \$30 billion EHR program might stand in the way of the president’s precision medicine initiative until physicians are able to use systems that communicate with one another.⁵

Under the HITECH Act, EHRs must be certified to meet Meaningful Use Criteria, ensuring that EHR systems are capable of improving quality, reducing disparities, engaging patients, improving care coordination, and maintaining the privacy and security of patient health information. In recent years, meeting Meaningful Use Criteria has dominated vendor development, crowding out innovative responses to clinicians’ needs. As a result, EHRs have not yet realized the promises of early research in enhancing the quality, efficiency, safety, or outcomes of care. Currently, EHRs are serving health systems’ data management needs better than clinicians’ and patients’ needs. For example, documentation has become less focused on direct patient care as it is increasingly diluted to meet administrative and medicolegal needs.⁶ Along the way, the amount of documentation has increased, while the value of the documentation for clinical care has fallen.

The promise

Best practices and standards for user interaction will evolve, improving provider experience with EHRs. As the more popular systems are widely adopted and the number of competing systems decline, there will also be reduced variability between systems, especially on core EHR features. Assuming the trend toward app stores and sharable programming platforms continues, the number of EHR features that can be adopted across EHRs will increase, further improving the experience for providers as they can use their favorite apps between vendors.^{7,8}

Widely accepted, adopted, and implemented standards will facilitate the ability of applications to use data and share data between systems. Imagine health care providers pulling up a patient's EHR and seeing not only their hospitals' data, but also all data from any other hospital systems, doctors, or clinics their patients have visited (anywhere in the U.S.) seamlessly presented as a single, comprehensive patient chart.

Documentation could be simple, easy, and accurate, allowing providers to spend more time focusing on clinical care. The need to document administrative and medicolegal tasks will disappear as these are automatically captured. For example, a physician will no longer need to document examining a patient's shoulder or completing a review of systems, because these data will already be recorded during the physician's interaction with the patient. The technology to do this exists today; it's just not being used by current EHRs.

Eventually, the traditional EHR will disappear. Instead of being an electronic version of the paper patient record, the EHR will become an active participant in care. Rather than distracting the doctor from the patient, an interactive and anticipatory EHR system will join the conversation, facilitating and enhancing the doctor and patient interaction. The EHR will understand what the provider is doing during a patient visit and anticipate what information will be needed, organizing and presenting it in an easily consumable format (e.g., summarizing past history or predicting patient risk). The same EHR will help manage practices and health systems (e.g., identifying quality gaps), enhance public health (e.g., surveillance and identifying unmet needs), and understand patient and population health and health care needs (e.g., filling knowledge gaps, better understanding benefits and harms).

Getting there

We need to create a universal application programming interface (API) defining how EHRs and apps communicate, building EHR and app libraries for this API in all common

programming languages so every certified EHR and app can support the API without requiring developers to consume hundreds of pages of complicated specifications. HL7's Fast Healthcare Interoperability Resources (FHIR) standard is a promising start.⁹

We need to demand and commit to creating and using a universal patient identifier. Sharing data between health care providers requires an easy and accurate way to identify individual patients via a national health care identifier or an agreed-upon minimum set of unique identifying data.

Each health care providers must document their unique observations, interpretations, decisions, and plans to populate the record of each clinical encounter rather than expecting physicians to do it all. To accomplish this efficiently, we need to develop innovative solutions to automate recording of metadata, i.e. a set of data that describes and stores information about other data. For example, automated analysis of audio or video recordings of the encounter could serve as a record of tasks performed and instructions given; vital signs could be captured directly into the patients chart using low-energy and low-cost identification and tracking technologies such as radio frequency identifiers (RFID) to ensure data collected by devices are automatically attributed to the correct patient record.

Physicians are increasingly being asked to record information for practice management and billing. These tasks detract from providing care and should be handled by less expensive dedicated specialists.

The field of clinical database epidemiology needs to grow and evolve. We should agree on a common analytic data model (such as OMOP's common data model) into which data from any EHR can be translated.¹⁰ We must agree on definitions of conditions and outcomes, cognizant of messy EHR data and balancing sensitivity and specificity. For example, there are multiple different published definitions of "diabetes" that variably use recorded diagnoses, test

results, and pharmacy data that, when applied to a single EHR, produce different sets of patients.¹¹ Robust methods for minimizing and managing bias and confounders must be developed.¹² Because clinicians must be allowed to record whatever they want to document their clinical encounters, there will always be erroneous or inconsistent data in EHRs. Methods to accommodate bad and inconsistent data and to sequester data later found to be wrong are needed to provide better separation of signal from noise. We also need to establish accepted, efficient, inexpensive methods to reliably de-identify patient data for analysis.

Health Information Exchange

Current status

Health Information Exchange (HIE) is the process of exchanging healthcare information across or between health care organizations. Most HIEs exist as state or regional hubs connecting data across ambulatory clinics and hospital systems. Dozens of HIEs exist within the United States; however, few are financially stable, solvent, and sustainable and there is as yet no long-term commitment or support from the federal government, although the National Coordinator for Health Information Technology has recently strongly committed to broad interoperability.^{13,14}

There is no standard content or data model for storing, sharing, or managing clinical content across HIEs, although standards development efforts are finally making demonstrable progress after decades of stagnation.¹⁵ Competition between health care providers remains a barrier to sharing data. On the other hand, alternative models to fee-for-service, such as Accountable Care Organizations, are increasing in number and size and provide strong incentives for cooperation and data sharing.¹⁶

Even when data are shared, the HIE is typically treated as a separate health record independent from the patient's EHR at any given hospital or clinic. Because of this separation, most providers with access to HIEs are forced to look in two places for patient health information (their own local EHR or paper chart and the HIE). If a provider must take this extra step to view HIE data, HIE goes underused and has little chance to benefit care.¹⁷

While regional and statewide HIEs are being formed, we are not yet leveraging them to support data analysis for care management, public health, or research generating new knowledge. Ironically, those who stand to benefit the most from effective interoperability – i.e., patients – often have little interaction with the HIE. In most cases, patients have little control or knowledge of when or how their data are being shared in either EHRs or HIEs.¹⁸

The promise

Unless or until there is a universal API that allows all providers' EHRs to securely and rapidly share data in the cloud, HIE will be needed and the number of successful HIEs will grow as they find models for sustainability. Health systems and providers must see value in cooperating on patient safety and health care quality while competing on service.¹⁹ This will come primarily through federal and local initiatives designed to require, promote, and reward seamless sharing of data across systems. As a result, patients' health-related data will be available whenever and wherever they seek care. A standardized representation of clinical data will allow EHRs to incorporate HIE data seamlessly into the patient's local EHR, so providers will not have to manage multiple EHRs and platforms and connections to benefit from HIE.

Sustainable HIEs will no longer be seen as connecting data amongst EHRs; rather, they will be the "central nervous system" for health data providing a seamless shared health record across all EHRs and health-related apps. While distributing patient data to where it is needed to support quality care, HIEs will be leveraged to support data analyses for patient care, public

health, and research. Providers and patients will be able not only monitor use of their data across institutions, but also control access through a portal or using an app on their phone.

Getting there

We should establish federal subsidies for HIEs to help them become sustainable. Federal mandates for interoperability must come with federal support for HIEs conditioned on adhering to accepted standards for data coding and interoperability, reliable and universal patient identification, and rules of governance, access, and use of data.²⁰

EHR vendors should have capabilities to routinely send data generated within their health system to other health systems' EHRs and receive data from external health systems and incorporate them into the patient's local EHR. The same level of data exchange must be required for the growing number of health-related mobile apps. Providers and patients should be demanding not only that HIE data be integrated into their EHRs and apps, but also data generated locally is contributed back to the HIE, so comprehensive clinical information is available wherever it may be needed.

Rather than creating yet another EHR and source of data for patients and providers to check, HIEs need to focus on delivering data to existing EHRs and apps. They also need to work closely with EHRs and patients to allow patients to monitor, control access to, and even contribute to their HIE data through their preferred portal.

Patient Portals and Personal Health Records

Current status

Patient portals and personal health records (PHRs) are required for health systems to meet current Meaningful Use Criteria. As a result, the number of PHRs is increasing rapidly, yet

the majority of patients are not actively using them.²¹ Use appears to be lowest among minorities and patient with few medical problems.²² PHRs can be standalone, tethered to an EHR, or integrated into the EHR.²³ In nearly all cases, PHRs are siloed within a single health system, so patients end up with a separate PHR account for each health care system they encounter. Efforts like the Blue Button initiative have helped simplify the process for patients to download records from various EHRs.²⁴

Many PHRs fail to follow best practices in their user interfaces.²⁵ Despite this variability, existing patient portals do share many common features such as providing access to progress notes, educational materials, medication renewal, appointment requests, patient input of content, and patient reminders.²²

Large national PHRs such as Google Health or Microsoft's HealthVault, have been discontinued or have not caught on: they are little used by health care providers, and many patients are concerned and suspicious about secondary data uses.²⁶⁻²⁸ Finally, while there is some evidence of PHRs improving the management of chronic diseases, the effect of patient portals on health outcomes remains largely unknown.²²

The promise

Patients will have open, user-friendly access to their data across health systems and health apps. Through their interaction with their portal, patients will better understand their health risks and will have effective tools for lowering their risks, managing their medical conditions, and helping them adhere to treatments, ultimately leading to better health outcomes. Patient portals will be integrated into EHRs, rather than standalone or tethered systems, bringing patients into the EHR as a member of the care team, and will take advantage of HIE to provide patients with a seamless view of their health data regardless of source. Over time, as systems evolve to better support both providers and patients in patient-centered care, the

distinction between a PHRs and EHRs will blur as patients become active members of their health care teams.

Getting there

We need to design better patient portals and PHR platforms. Usability studies can help identify practices and approaches that work best for patients. These findings should be shared and incorporated by all PHR vendors and should include enhancements that target minorities and patients with low literacy and communication disabilities.

Patient portals as standalone applications or separate applications tethered to the EHR are short-term solutions. EHR vendors need to begin incorporating patients as a member of the health care team – i.e., another (very important) user of the EHR. Providers have historically been reticent to share records with patients; however, there is growing evidence that sharing the record, including clinical notes, with patients has more benefits than risks.^{24,29}

Creating decent patient portals is not enough. We need programs to educate consumers on how to understand and interact with their electronic medical records. Consumers need to be educated on how to leverage their EHR to improve their health and then do so.

In order for PHRs to coordinate and improve the interaction between providers and patients, we must develop payment models that incentivize patients and providers to interact using PHRs. Integrating PHRs within the EHR will help make these interactions more intuitive and should improve workflow.

HIEs should be utilized to support patient portals and help patients navigate between health care systems without becoming yet another PHR. HIEs need to support patient-contributed data, data from patients' apps including wearable activity sensors and other technology, and patient-driven additions and corrections to their health record.

Rather than becoming a patient portal themselves, HIEs should be the unifying construct providing the services and linkages necessary for patients to access and control their complete online record, including monitoring and controlling access across and between health systems, whether using their doctor's portal or an app on their phone.

Telemedicine

Current status

Telemedicine is the use of information technology to deliver health care services at a distance. It is already in wide use. Hundreds of millions of virtual visits are taking place annually and nearly half of employers plan to offer telemedicine consultations to their workers.³⁰ Historically, telemedicine has been mostly used in narrow content areas, such as teleradiology, monitoring critical care patients, reading retinal photographs, managing type-I diabetes, emergency rooms, and home health care.^{31,32} Broadband connectivity exists for most U.S. health care venues and their patients' homes, making telemedicine far more feasible than it was a decade ago.² Billing for telemedicine is in evolution. While cost benefits of specific uses have been demonstrated, the effectiveness and cost-effectiveness of telemedicine compared to face-to-face medicine is unknown.³¹

Telemedicine impacts the provider-patient relationship, both positively and negatively.³³ While telemedicine can be much more convenient for patients and allow a provider to reach many more patients, the interaction is not always as robust as a face-to-face interaction.³⁴

The use of teleconsultation (video advice and, sometimes, care from a previously unknown provider) is expanding rapidly, though state-focused licensing of providers limits the geographic spread of telemedicine programs.³⁰ Their primary focus is on urgent primary care (general medicine, dermatology, and behavioral health). There are concerns that

teleconsultation may be used in addition to, rather than replacing, standard care and thus result in higher healthcare costs, more communication errors, and safety issues.³⁰ The lower barrier to the use of teleconsultation may also increase the consumption and costs of health care if people use the system who otherwise might have limited access to providers. Virtual visits may also result in more prescriptions than face-to-face visits and may reduce care coordination.³⁰

Telemedicine vendors are experimenting with subscription vs. pay per use models. Some are targeting employers and insurers, while others are selling directly to consumers. Reimbursement for telemedicine service is a work in progress.³⁵

The promise

Telemedicine will change the practice of medicine, allowing for disconnected care, where patients typically don't have to physically visit providers, reserving both the time and expense of face-to-face care for when it's truly needed. In fact, telemedicine will become the *de facto* standard expected by patients for routine care. While telemedicine will deliver care over wide geographic areas where resources are scarce or travel is difficult, it will also allow for more convenient, asynchronous care for non-urgent issues such as blood pressure checks and follow-up of milder acute events.

Teleconsultation will be provided in a safe and secure manner, improving patient outcomes and contributing to the patient's medical record.

Recent and ongoing advances in virtual reality will make telemedicine cheaper and simplify access for developers and usher in a new wave of exciting telemedicine opportunities.³⁶

Getting there

We need to establish realistic and sustainable payment models for telemedicine. Ongoing experimentation with payment models should be accompanied with rigorous research to identify the most efficient, effective, and cost-effective payment models in each context. Ultimately, we need to understand which approaches in which context are cost-effective and lead to improved outcomes.

Techniques and best practices for engaging and informing users should be shared and widely adopted. Usability research focusing not only on user experience, but also on cost and outcomes should drive system design. Capabilities for measuring vital signs and point-of-care tests should be incorporated into increasingly sophisticated telemedicine applications. To facilitate communication and coordination of care between providers, information generated via telemedicine should be seamlessly incorporated into patients EMRs and local HIEs.

In April 2014, the Federation of State Medical Boards released a model for the appropriate use of telemedicine, addressing licensing, physician-patient relationships, consent, evaluation and treatment, continuity, referral to emergency services, medical records, privacy, and disclosures.³⁷ We should agree on such a model and then strive to educate providers engaging in telemedicine. The federal government should facilitate simplifying and aligning these rules across states to reach consensus, reduce confusion, and minimize errors especially among patients receiving care across borders.

With the explosion of mobile devices and health-related solutions, there is no doubt that the use of telemedicine will grow over time. To ensure we are improving care and not simply increasing the use of health care services without improving outcomes, we must invest in meaningful evaluations of the technology and the care it supports.

Social Media

Current status

People are already using Facebook, Twitter, reddit, YouTube, and other social media sites to document and discuss their health and health care issues as well as seek health care information.³⁸ Health care specific social media sites are emerging for the general public (e.g., PatientsLikeMe) and by advocacy groups for patients with specific conditions (both common and rare conditions). The literature has many examples of how social media might be used to disseminate health information and improve care.³⁹ Most prior studies focused on implementation or observation, while rigorous evaluations are lacking.³⁹ Mining Facebook, Twitter posts, and Google searches for disease surveillance, e.g. influenza is increasing, yet social media content remains a mostly untapped resource.⁴⁰

Providers are using social media to advance their craft, and social media is demonstrating the ability to affect changes in health care at unprecedented scale.⁴¹ For example, Dr. Aaron Carroll hosts a YouTube channel called *Healthcare Triage* that has over 130,000 subscribers and nearly 7 million views. Dr. Joel Topf (@kidney_boy) has nearly 5000 followers on Twitter and hosts a twitter-based nephrology journal club twice a month called #NephJC. When Johns Hopkins turned to Facebook to solicit organ donations, they boosted organ donation registrations 21-fold in a single day.⁴²

Yet there are concerns about privacy and security of patient information. For example, in 2012 the Federation of State Medical Boards issued a policy on the appropriate use of social media in medical practice, discouraging interaction between providers and patients on personal social networking platforms.⁴³

The promise

The medical establishment will find effective ways to not only disseminate health information through social media but also engage with consumers through social media. Social media will help bring health care providers and consumers closer together.

There will be more peer-to-peer social support for patients, especially those with rare conditions. Patient engagement in research will increase, especially among those with rare conditions.

Information from social media will supplement traditional public health surveillance activities. We will be better at monitoring and detecting health trends through social media.

Getting there

We need to expand our understanding of social media. Consumers are not only using Facebook and Twitter to discover and discuss health related issues, but also YouTube, reddit, Instagram, LinkedIn, Pinterest, and others. This landscape is likely to continue to grow over time, and each platform presents unique opportunities for enhancing patient care and health.

We need to reach consensus on rules of engagement and methods for assuring privacy and confidentiality of social media. We need to expand our understanding of the ethical and privacy aspects of using social media in health care.⁴⁴ Part of this includes evolving and adapting our understanding how physicians can appropriately engage patients through social media.^{41,43} We need to provide patients with a range of options that enhance their personal comfort in the security and usability of their information in social media.

Researchers and care providers must gain a deeper understanding of the data being placed in social media. We need to learn what types of questions we can ask and develop

guidelines and tools for reliably finding the answers. To assure sustainability, patients, providers, and social media companies must engage in a dialogue on the appropriate secondary uses of health information placed in social media.

Consumers have embraced social media. A small number of providers have found ways to engage other providers and patients through social media. We need to learn from these pioneers and find ways to replicate their success to enhance public health communication, engaging county, state, and federal public health agencies where appropriate. We need to learn how to effectively leverage not only to disseminate appropriate health information, but also to counter existing disinformation.

Mobile Devices and Wearable Sensors and Monitors

Current status

Mobile health and wearable sensors are fastest moving areas in informatics. We are currently in a mobile health revolution: mobile devices (smartphones, tablets, GPS devices) have been adopted globally and are increasingly being applied to health care.^{45,46} We already have evidence that mobile devices can improve health care. For example, mobile phone programs can enhance medication adherence.^{47,48} Myriads of health-related apps (e.g. fitness programs using cellular positioning programs, activity logs, etc.) are available, and their adoption and use are rapidly increasing. Mobile devices are rapidly replacing desktop and laptop computers as portals for health care providers to record and view patient data.⁴⁹

As the use of mobile devices and apps continues to expand, we are in the early stages of the use of wearable sensors and monitors (e.g. Fitbit®, Jawbone®, etc.). This has resulted in a myriad of data, but relatively little useful information so far. What information is being generated is generally not provided to or used by health systems and providers. But it could be: activity

monitors could identify elderly patients who have fallen, incapacitated, or non-mobile for whatever reason. Exercise prescriptions for diabetics could be followed. Sleep patterns and arrhythmias could be monitored. The possibilities are huge.

Mobile technologies have the potential to reshape the practice of medicine in the coming decades. To put things in perspective, a recent report from Telcare found over half of diabetic millennials would trust a mobile health app over a health professional for advice.⁵⁰

The promise

The number of apps and devices for sensing and monitoring generic measures (e.g. steps walked, calories burned) and condition-specific measures (mobility among elders, blood sugar in diabetics, vital signs among heart failure patients, etc.) will continue to grow exponentially. Data from mobile devices, sensing devices, and other apps will be linked to patients' EHRs and HIEs and become the most common means by which patients engage and inform the health care system. Prescriptions for health care activities, and their documentation, will be incorporated into everyday health care plans.

Wearable sensors and monitors will continue to grow in capabilities as they shrink in size, eventually finding their way into our very clothing.⁵¹ The ubiquity of the "internet of things" will present endless opportunities for innovation and intervention as the amount of data relevant to health care explodes.

Getting there

We need to develop a universal platform/API to encourage rapid development of apps for capturing data into mobile devices. APIs like Apple Health Kit and Google Fit, middleware services like Validic that connect to dozens of different wearable sensors and present their data in a uniform format for developers, and standards like Observational Medical Outcomes

Partnership's common data model and FHIR are moving us the right direction by encouraging adoption of normalized models and web services. Supporting efforts that drive us toward a convergent model and API will simplify the job for developers.

We need to enhance our communication infrastructure to allow widely available, fast connectivity. Telecommunication networks are improving each year, but reliable, affordable, broadband connectivity remains elusive for many poor and rural communities.⁵²

Despite the explosion of health-related mobile apps, the majority of research has been focused on implementation and observations. We need more rigorous evaluations describing the effects, outcomes, costs, and generalizability of mobile health solutions.

We need to continually improve human-computer interfaces and interactions for consumer-facing solutions. Health care apps should be adhering to the well-documented style guides developed by companies leading in the mobile space (Apple and Google). Human-computer interface researchers should be expanding on existing best practices in the mobile space to describe and demonstrate health care specific interactions and workflows relevant to mobile devices.

Except for apps built specifically to integrate with EHRs, most mobile apps are creating new silos of data. We need to treat mobile apps that collect personal, medically relevant data as extensions of the medical record. Just like the EHR, mobile apps should be interacting with the HIE. Mobile apps should be able to both extract data from EHRs/HIEs (e.g. an app for improving diabetes management should have access to treatments and test results) and contribute any new data to the patient's record so it can be made seamlessly available within other systems used in the patient's care.

Medical education has not kept up with the revolution in information technology inside and outside of the health sector. As the number of sensors and monitors increases, so will the amount and variety of data. In order to make the most of these data, we will need innovative ways to presents these data to providers and providers must be both literate in the technologies and understand how to employ them and their data in everyday patient care. Mobile app data displays in the form of graphs, summary reports, aggregate statistics, trends, etc. should be a uniform weapon in every clinician's armamentarium.

Privacy and Security

Current status

Security breaches have become all too commonplace and health information is being increasingly targeted.{Liu, 2015}{Cascardo, 2014} Since 2009, over 1100 breaches of health data have exposed data of more than 120 million people.{Peterson, 2015} Most recently, highly sensitive data for over 21 million people were stolen from the Office of Personnel Management.{NYTimes, 2015}

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) and its subsequent amendments provided vague statistical thresholds for de-identification, a “safe harbor” provision of removing 18 data elements, and a “limited data set” for specific uses.{McGraw, 2013} Additional guidance in 2012 provided some clarification, but still left too much to subjectivity and was still based on the outdated law.{OCR, 2012}{Blumenthal, 2015}. Most laws and regulations do not cover de-identified data.{McGraw, 2013}

The amount of health information is rapidly growing in detail and diversity and is increasingly collected outside of the traditional medical record within mobile devices, personal sensors, and home networks. Mobile health apps covered by patchwork of policies.{Yang,

2014}{Cortez, 2014} Beyond basic security infrastructure that is ubiquitous such as transport layer security (TLS), each health care organization faces their own siloed efforts to secure data.

While healthcare organizations are beginning to shift from a reactive to a more holistic approach toward security, there are still many challenges and many organizations still consider security to be a technical issue independent of providing care.{Kwon, 2013} There is a struggle between security and usability.{Cresswell, 2014} Security measures that can decrease the threat of hackers, such as multi-factor authentication (MFA), are not commonly used.{HITC, 2015} The atmosphere is one of fear of litigation and penalties with little reward for getting security right.

Use of the cloud is increasing, where data may be beyond control or oversight and even in different countries.{Malin, 2013} Similarly, there is limited oversight of telehealth applications.{Hall, 2014} Meanwhile, patients want more control than they usually have.{Caine, 2015}{Kim, 2015}

Promise

Standardized approach and tools for security will ensure data are safe, access is secured, and breaches are rare. There will be an objective process for vetting security and standards for statistical de-identification. Health care organizations will be learning from each other's security failures and celebrating successes as they address both technical and non-technical aspects of security.

The increasing amount of health data in the cloud and used for telehealth will be better protected by standards for security that adapt to changing privacy expectations over time. Advances in secure infrastructure across domains will also benefit the healthcare domain, making it easier to secure health information while providing patients with granular control over privacy.

Getting there

We need to update laws to match current methods for recording and transmitting data. As we do, we need to re-align security priorities with patient priorities and establish a process to regularly update policies to adjust to changing privacy expectations.

Although media attention and bad press will continue to be a deterrent, we can no longer afford to vilify victims of breaches. Instead, we need to standardize and share best practices, make security practices more transparent, insist on learning from our failures, and find better ways to incentivize best practices.

We need to increase public awareness and transparency of use of de-identified data. {McGraw, 2013} Companies should be able to get certified in providing de-identification as a service.

Health care organizations should avail themselves of existing advances in security – e.g., implement MFA – and routinely budget for security enhancements so new advancements can be adopted more quickly.

Policy Implications and Conclusions

All of the six types of health information technology discussed above are still in early stages of development and use in health care. Now is the time for a rational and well-funded national agenda for ICT development in health care. The National Coordinator for Health Information Technology is in a position to lead this effort. Funding for research and development should come from both federal sources (for general infrastructure such as enhanced wireless communications, the universal platform/API, and objective research showing what works and what benefits can be expected) and the private sector for EHRs, HIEs, and other large-scale software systems along with apps. Only then can health care, and information business,

maximize the benefits realizable by leveraging existing and rapidly developing information and communication technology. Only then can we extract value from the chaos.

References

1. The ONC Health IT Dashboard. 2015. <http://dashboard.healthit.gov/index.php>. Accessed June 20, 2015.
2. *Health Care Broadband in America*. 2010. <http://download.broadband.gov/plan/fcc-omnibus-broadband-initiative-%28obi%29-working-reports-series-technical-paper-health-care-broadband-in-america.pdf>.
3. Physician Adoption and Predictions of Mobile in 2015. *wwwmeddatagroupcom*. 2015. <http://www.meddatagroup.com/wp-content/uploads/Physician-use-of-mobile-2015-2.pdf>. Accessed June 26, 2015.
4. What Doctors Really Want -- and Aren't Getting -- From EHRs. 2015. <http://www.medscape.com/viewarticle/845690>.
5. Alexander: Failing Electronic Health Records Program May Stand in Way of Precision Medicine. *helpsenategov*. 2015. <http://www.help.senate.gov/chair/newsroom/press/alexander-failing-electronic-health-records-program-may-stand-in-way-of-precision-medicine>. Accessed May 5, 2015.
6. **Payne TH, Corley S, Cullen TA, et al.** Report of the AMIA EHR 2020 Task Force on the Status and Future Direction of EHRs. *Journal of the American Medical Informatics Association*. 2015.
7. **Newman J.** Epic Systems to open its own app exchange. *Wisconsin State Journal*. February 18, 2015.
8. A Robust Health Data Infrastructure. *healthitgov*. 2014. http://healthit.gov/sites/default/files/ptp13-700hhs_white.pdf. Accessed June 25, 2015.
9. HL7 FHIR®. *hl7org*. 2015. <http://www.hl7.org/fhir/>. Accessed June 25, 2015.
10. **Overhage JM, Ryan PB, Reich CG, et al.** Validation of a common data model for active safety surveillance research. *Journal of the American Medical Informatics Association*. 2012;19(1):54-60.
11. **Richesson RL, Rusincovitch SA, Wixted D, et al.** A comparison of phenotype definitions for diabetes mellitus. *Journal of the American Medical Informatics Association*. 2013;20(e2):e319-e326.
12. **Bosco JLF, Silliman RA, Thwin SS, et al.** A most stubborn bias: no adjustment method fully resolves confounding by indication in observational studies. *J Clin Epidemiol*. 2010;63(1):64-74.
13. **Vest JR, Champion TR, Kaushal R, HITEC Investigators.** Challenges, alternatives, and paths to sustainability for health information exchange efforts. *J Med Syst*. 2013;37(6):9987-9988.
14. **DeSalvo KB.** Health Information Technology: Where We Need To Go. 2015. <http://www.healthit.gov/buzz-blog/from-the-onc-desk/incentivizing-interoperability->

- standards-data-security-privacy/. Accessed June 25, 2015.
15. **Richesson RL, Chute CG.** Health information technology data standards get down to business: maturation within domains and the emergence of interoperability. *Journal of the American Medical Informatics Association.* 2015;22(3):492-494.
 16. **Tu T, David I, Lawrence I, Ross I.** Origins and Future of Accountable Care Organizations. 2015.
 17. **Rahurkar S, Vest JR, Menachemi N.** Despite the spread of health information exchange, there is little evidence of its impact on cost, use, and quality of care. *Health Aff (Millwood).* 2015;34(3):477-483.
 18. **Meslin EM, Alpert SA, Carroll AE, et al.** Giving patients granular control of personal health information: Using an ethics “Points to Consider” to inform informatics system designers. *International Journal of Medical Informatics.* 2013;82(12):1136-1143.
 19. **McDonald CJ, Overhage JM, Barnes M, et al.** The Indiana network for patient care: a working local health information infrastructure. An example of a working infrastructure collaboration that links data from five health systems and hundreds of millions of entries. *Health Aff (Millwood).* 2005;24(5):1214-1220.
 20. Connecting Health and Care for the Nation. *healthitgov.* 2015. <http://www.healthit.gov/sites/default/files/nationwide-interoperability-roadmap-draft-version-1.0.pdf>. Accessed May 28, 2015.
 21. **Patel V, Barker W, Siminerio E.** Individuals' Access and Use of their Online Medical Record Nationwide. *healthitgov.* 2014. http://www.healthit.gov/sites/default/files/consumeraccessdatabrief_9_10_14.pdf. Accessed June 21, 2015.
 22. **Goldzweig CL, Orshansky G, Paige NM, et al.** Electronic patient portals: evidence on health outcomes, satisfaction, efficiency, and attitudes: a systematic review. *Ann Intern Med.* 2013;159(10):677-687.
 23. **Studeny J, Coustasse A.** Personal health records: is rapid adoption hindering interoperability? *Perspect Health Inf Manag.* 2014;11(Summer):1e.
 24. Blue Button. 2015. <http://en.wikipedia.org/wiki/Blue%20Button>. Accessed June 21, 2015.
 25. **Cruz Zapata B, Hernández Niñirola A, Idri A, Fernández-Alemán JL, Toval A.** Mobile PHRs compliance with Android and iOS usability guidelines. *J Med Syst.* 2014;38(8):81–16.
 26. Google Health. 2012. <http://en.wikipedia.org/wiki/Google%20Health>. Accessed June 26, 2015.
 27. Microsoft HealthVault. 2012. <http://en.wikipedia.org/wiki/Microsoft%20HealthVault>. Accessed June 26, 2015.
 28. **Angst W.** Privacy safeguards in PHR adoption. *Health Manag Technol.* 2008;29(4):40–

- 39.
29. **Walker J, Meltsner M, Delbanco T.** US experience with doctors and patients sharing clinical notes. *BMJ*. 2015;350(feb10 14):g7785-g7785.
 30. **Tahir D.** Telehealth services surging despite questions about value. *Mod Healthc*. 2015;45(8):18-20.
 31. **Ward MM, Jaana M, Natafji N.** Systematic review of telemedicine applications in emergency rooms. *International Journal of Medical Informatics*. 2015.
 32. **Ekeland AG, Bowes A, Flottorp S.** Effectiveness of telemedicine: a systematic review of reviews. *International Journal of Medical Informatics*. 2010;79(11):736-771.
 33. **Blake JH, Schwemmer MK, Sade RM.** The patient-surgeon relationship in the cyber era: communication and information. *Thorac Surg Clin*. 2012;22(4):531-538.
 34. **Sabesan S, Allen D, Caldwell P, et al.** Practical aspects of telehealth: doctor-patient relationship and communication. *Intern Med J*. 2014;44(1):101-103.
 35. **Weinstein RS, Lopez AM, Joseph BA, et al.** Telemedicine, Telehealth, and Mobile Health Applications That Work: Opportunities and Barriers. *The American Journal of Medicine*. 2014;127(3):183-187.
 36. Beyond games, Oculus virtual reality headset finds medical uses. 2015. reuters.com/article/2015/06/11/us-oculus-medicine-idUSKBN0OR02620150611. Accessed June 10, 2015.
 37. Model Policy for the Appropriate Use of Telemedicine Technologies in the Practice of Medicine. *fsmb.org*. 2014. http://www.fsmb.org/Media/Default/PDF/FSMB/Advocacy/FSMB_Telemedicine_Policy.pdf. Accessed June 20, 2015.
 38. **Burke-Garcia A, Scally G.** Trending now: future directions in digital media for the public health sector. *J Public Health (Oxf)*. 2014;36(4):527-534.
 39. **Capurro D, Cole K, Echavarría MI, Joe J, Neogi T, Turner AM.** The use of social networking sites for public health practice and research: a systematic review. *J Med Internet Res*. 2014;16(3):e79.
 40. **Schmidt CW.** Trending now: using social media to predict and track disease outbreaks. *Environmental health perspectives*. January 2012:A30-A33.
 41. **Perna G.** Trend: social media. The surface is being scratched. Providers are using social media to engage patients, collaborate with each other. *Healthc Inform*. 2014;31(2):24-25.
 42. The Facebook Effect: Social Media Dramatically Boosts Organ Donor Registration. *hopkinsmedicine.org*. 2013. http://www.hopkinsmedicine.org/news/media/releases/the_facebook_effect_social_media_dramatically_boosts_organ_donor_registration. Accessed June 21, 2015.

43. Model Policy Guidelines for the Appropriate Use of Social Networking in Medical Practice. *libraryfsm.org*. 2012. <http://library.fsm.org/pdf/pub-social-media-guidelines.pdf>. Accessed June 21, 2015.
44. **Denecke K**. Ethical aspects of using medical social media in healthcare applications. *Studies in health technology and informatics*. 2014;198:55-62.
45. **Ainsworth B, Cahalin L, Buman M, Ross R**. The current state of physical activity assessment tools. *Prog Cardiovasc Dis*. 2015;57(4):387-395.
46. **Wools-Kaloustian KK, Sidle JE, Selke HM, et al**. A model for extending antiretroviral care beyond the rural health centre. *J Int AIDS Soc*. 2009;12(1):22.
47. **Dayer L, Heldenbrand S, Anderson P, Gubbins PO, Martin BC**. Smartphone medication adherence apps: potential benefits to patients and providers. *J Am Pharm Assoc (2003)*. 2013;53(2):172-181.
48. **Pop-Eleches C, Thirumurthy H, Habyarimana JP, et al**. Mobile phone technologies improve adherence to antiretroviral treatment in a resource-limited setting: a randomized controlled trial of text message reminders. *AIDS*. 2011;25(6):825-834.
49. **Sclafani J, Tirrell TF, Franko OI**. Mobile tablet use among academic physicians and trainees. *J Med Syst*. 2013;37(1):9903-9906.
50. Telcare Diabetes Awareness Index Reveals National Knowledge Gap for the Common and Deadly Disease. 2015. <http://www.marketwired.com/press-release/telcare-diabetes-awareness-index-reveals-national-knowledge-gap-common-deadly-2028304.htm>. Accessed June 20, 2015.
51. **Zeng W, Shu L, Li Q, et al**. Fiber-Based Wearable Electronics: A Review of Materials, Fabrication, Devices, and Applications. *Advanced Materials*. 2014;26(31):5310-5336.
52. Bureau UC. Nearly 8 in 10 Americans Have Access to High-Speed Internet. 2014. <http://www.census.gov/newsroom/press-releases/2014/cb14-202.html>. Accessed June 1, 2015.