Chapter 7

Engineering information technology for actionable information and better health

Balancing social values through desired outcomes, complementary standards and decision-support

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The alternative route to transforming the system sets all of its sights on the destination. (Diamond, C., and Shirky, C. (2008). Health Information Technology: A Few Years of Magical Thinking? Health Affairs. 27(5), 383–390.)

Abstract: Information technology in health care (HIT) is getting a major boost in the United States through the passage of the American Recovery and Reinvestment Act (ARRA) of 2009. The portion of the Act that relates to health information technology (HITECH) seeks to achieve widespread implementation of electronic health records (EHRs) across the land and assure that these EHRs achieve sufficient levels of ‘meaningful use’ to improve care, reduce costs, and result in better outcomes. This chapter sets the stage for the other chapters that follow in this section. The chapter will review current thinking about how HIT will facilitate collection, dissemination, and evaluation of information throughout the system. Further, it will discuss the role and potential for HIT to support a learning organization [7,8]. Finally, it will outline the current widely identified barriers to progress, e.g., standards development, lack of interoperability and connectivity, and limited decision support that uses evidence-based guidelines created and maintained explicitly to be actionable through computer-based records and systems. Further, with the passage of HITECH, there is a continued attention given to privacy policy at the expense of access to person-specific health information for legitimate social purposes including research and community health. More will be said about this near the end of the chapter. Finally, the chapter will end with a discussion of the difference between information and communication and it will advocate for greater attention to the use of technology as a tool for improve communications and not simply storage and transmission of information.

1. Introduction

HIT has the capacity to capture, store, and retrieve information in a number of sites and formats virtually simultaneously. Amazingly, we are just now realizing that healthcare is essentially an information industry. Perhaps this is due to the role that research is now playing in adding more insight and new treatments and technology at an ever-increasing pace. It has been abundantly clear for some time that human memory is too limited for such a world and these limitations are increasingly apparent with the growth in relevant information [26]. Care of acceptable quality is dependent on information being available to clinicians, patients, and managers in a manner that is timely, valid, complete, accurate, and secure. In such instances, the information becomes a compelling communications tool to help change behavior that is stubbornly resistant.
HIT requires a great deal of infrastructure including robust terminology and classification that capture meaning accurately and moves it without loss of fidelity. While natural language processing has made real strides, there is still a tension between data recorded as a patient’s narrative and structured datasets for managing well-described clinical diseases. So, while progress has been made in promoting international adoption of standard terminology through the formation of the International Health Terminology Standards Development Organization (IHTSDO) and greater collaboration among ISO, CEN, HL7, IHTSDO, and CDISC, more remains to be done [3]. The organizations plus a few other terms and a brief description of each are included in Table 1. In general terms, this challenge is a renewed priority for the Office of the National Coordinator through the ARRA/HITECH legislation; time will tell how it is addressed by the committees on policy and standards constituted in early summer 2009 but the prospects are bright. The National Committee on Vital and Health Statistics remains interested and committed to this as well.

2. Standards

Progress has been made over the past five years in the area of HIT standards development, selection, and implementation. Among the items deserving mention are the HITSP implementation specification; structured product labels for approved drugs disseminated through DailyMed, linked to RxNorm and other knowledge sources, e.g., ClinicalTrials.gov; proactive expansion of LOINC to include genetic tests and newborn screening tests; a new version of the Surgeon General’s Family Health History tool, with SNOMED HL7 standards built in; the AHIC Working Group on Personal Health Care standards matrix (test LOINC) that detect conditions (SNOMED CT) for newborn screening; and, international standards published by ISO on the EHR and on privacy and security [12]. Finally, AMIA recently launched its Standard’s Standard, a quarterly newsletter summarizing current activities among the various global health standard setting groups [4].

The approach to the setting of HIT standards is at a historic flexion point from the past and we have to be alert to unintended consequences that may result. In the past, standards were developed through a bottom-up approach in which expert volunteers met on their own time and developed well-vetted standards prior to their adoption. There were downsides to this approach in that visions were limited to the focus of the group that led at times to too many standards. Also, this disaggregated approach slowed global harmonization. The emerging top-down approach means that actual standards will be set since approval and use by huge government agencies essentially creates a standard as the standard. There is greater potential for globalization as well as more stable funding for creation and maintenance and access to standards. Potential problems that may arise in this new structure may be that some needed standards will not be considered that would have gotten attention through expressions of concerned experts in the field, or some standards may move forward for the ‘wrong’ reasons, e.g., political pressure. It remains to be seen if there will be sufficient vetting of standards prior to adoption, or if other issues arise that are not discernable today. Idealism can gain the upper hand over pragmatism in either approach and must always remain a consideration.

Remaining areas for HIT standards development, selection, and implementation are in at least six areas including decision support, personalized care, population health support, semantic interoperability (tying SNOMED CT to record structures), clinical knowledge models that reflect clinical best practices, and selection challenges (device terminology and identifiers). Further, additional standards used in care processes need national adoption. RxNorm identifiers should be available with the drug at the time of approval when the SPL is released. LOINC should be on all test kits and outputs from test devices should be labeled with LOINC.
Table 1
Some international health standards bodies and related terms

| **CDISC** | CDISC is a global, multidisciplinary, non-profit organization that has established open global standards to support the acquisition, exchange, submission/reporting and archive of medical research data. The CDISC standards are freely available via the CDISC website. |
| **CEN/TC 251** | CEN/TC 251’s domain is the application of information and communication technology in healthcare, social care and wellness. CEN/TC 251 is a regional (European) Standards Development Organisation (SDO) among international or domain specific SDOs and its focus is almost exclusively content technology and not communication technology. |
| **Daily Med** | DailyMed provides high quality information about marketed drugs. This information includes FDA approved labels (package inserts). |
| **HL7** | HL7 is an international community of healthcare subject matter experts and information scientists who work together to create accredited standards for the exchange, management and integration of electronic healthcare information. The HL7 community is organized in the form of a global organization (Health Level Seven, Inc.) and country-specific affiliate organizations. HL7 affiliate organizations exist in over 30 countries. HL7’s standards are accredited by the US ANSI organization and many HL7 standards have also been adopted as ISO standards. |
| **IHTSDO** | The International Health Terminology Standards Development Organisation (http://www.ihtsdo.org), a not-for-profit Danish association formed in 2007, purchased SNOMED CT (Systematized Nomenclature of Medicine – Clinical Terms) from the College of American Pathologists (CAP) in April 2007 and is now responsible for its ongoing maintenance, development, quality assurance, and distribution. The goal of the change in ownership was to promote international adoption and use of SNOMED CT. The IHTSDO recently announced that SNOMED CT licenses are now available free of charge in another 49 countries designated as low income economies by the World Bank. To oversimplify, SNOMED CT is ‘bottom up’ with its terminology while ICDL (International Classification of Diseases) is ‘top down’. |
| **ICD-10** | ICD-10 is the 10th edition of the International Classification of Diseases. ICD-10 was endorsed by the Forty-third World Health Assembly in May 1990 and came into use in WHO Member States as from 1994. The US Department of Health and Human Services is just now beginning a transition from ICD-9 to ICD-10. The ICD-10 code sets proposed rule would concurrently adopt the International Classification of Diseases, Tenth Revision, Clinical Modification (ICD-10-CM) for diagnosis coding, and the International Classification of Diseases, Tenth Revision, Procedure Coding System (ICD-10-PCS) for inpatient hospital procedure coding. The new codes would replace the International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) Volumes 1 and 2, and the International Classification of Diseases, Ninth Revision, Clinical Modification (CM) Volume 3 for diagnosis and procedure codes, respectively. |
| **ISO TC 215 on Health Informatics** | Technical Committee 215 of the International Standards Organization (ISO) on Health Informatics was formed in 1998. The parent ISO organization is non-governmental and based in Geneva. TC215 is structured into four core Working Groups: Data Structure (frameworks and models), Data Interchanges (harmonization and messaging), Semantic Content (terminology and knowledge), and Security (confidentiality, integrity, and availability). |
| **LOINC®** | LOINC® (Logical Observation Identifiers Names and Codes) is a coding system for laboratory and other clinical measures and documents used in electronic transactions between independent computer systems. LOINC is used worldwide by local hospitals and laboratories, public health departments, healthcare provider networks, electronic health information exchanges, software vendors, payers and managed care organizations. |
| **RxNorm** | RxNorm is a standardized nomenclature for clinical drugs and drug delivery devices produced by the National Library of Medicine (NLM). In RxNorm, the name of a clinical drug combines its ingredients, strengths, and/or form. |
| **SPL** | Structured Product Labels are Health Level-7 (HL7) version 3 Structured Product Labeling (SPL) standards for representing human readable label documents with computer-processable drug knowledge. SPL descriptions agree well with RxNorm. SPL can be used as the primary source of drug information for e-prescribing systems. |
| **UMLS** | According to the National Library of Medicine, the purpose of its Unified Medical Language System® (UMLS) is to facilitate the development of computer systems that behave as if they “understand” the meaning of the language of biomedicine and health. To that end, NLM produces and distributes the UMLS Knowledge Sources (databases) and associated software tools (programs) for use by system developers. See http://www.nlm.nih.gov/research/umls/about_umls.html. |
3. Workforce

Without question, there is also a need for a workforce that is more skilled with respect to the use of informatics [16]. This includes clinical informaticians, public health informaticians, translational bioinformaticians, and people employing informatics methods for research purposes, including construction of repositories of clinical and other databases, as well as data mining and data presentation. Whether these people will be ‘standard’ informaticians or some admixture of informatician/clinical epidemiologist is not clear yet to this writer. Among the needed sets of crucial skills are ‘people’ skills relating to implementing change in complex adaptive systems, how to be a successful ‘team worker’ who understands quality measurement and quality improvement, and how to develop systems and programs that put the patient into the center of communications as a critical member of the team. Today, too many people do not yet distinguish between an IT expert and an informatician. The differences are real, since informaticians deal specifically with both an in-depth knowledge of the topic area of focus, e.g., health sciences, as well as how human thinking and computer technology can best address specific challenges.

Beyond the workforce, there is a need for an underlying architecture that will manage information coming from three sets of communications and their related records. They include the patient record, e.g. the computer-based health record kept by clinics, hospitals, or other care facility or unit), personal health records, and public health/population records. Unless these three kinds of records are part of an integrated architecture that allows questions to be asked and solutions evaluated across all three perspectives, there will be serious limitations to the potential of such a system to evolve into a learning system for health and healthcare.

Ideally, there needs to be a set of clinicians, managers, and informaticians looking constantly at ways questions can be asked of the data in order to improve care quality, outcomes, and work processes from the perspectives of all key stakeholders. Also, there is a need for evaluation of the impact of changes in approaches to care and/or system management and having a data infrastructure that allows an array of queries. Dramatic improvements can only be expected from environments sharing these configurations. Such systems allow for ‘hypothesis testing’ prior to deciding to make a more formal study or implement an intervention, thereby saving a lot of time and resources.

4. Infrastructure

To assure a sufficiently robust infrastructure, or ‘infostructure’ as considered by the Canadian Infoway, since it will include both the technology and relevant health information, there needs to be an amalgam of computer-based standards and repositories plus organizational structures to assure appropriate change over time, as well as on-going system maintenance. Indeed, if one is to consider dimensions of ‘meaningful use’ as mandated in ARRA/HITECH from an informatics perspective, there is a hierarchy of functions from basic to more sophisticated in order to move toward creation of a ‘learning’ organization. While there is not yet a common agreement on the list of functionalities, one should continue to follow the ‘meaningful use’ discussions on the ONC website. Important elements and function include:

1. Data recording and results retrieval
2. The capability to move the data into a repository to track progress and outcomes
3. The creation of evidence-based workflow guidelines for decision-support
4. Implementation of workflows that assure high quality processes
5. Implementation of uniform care processes where applicable
6. Reviewing and sharing of results among key stakeholders
7. Evaluation of outcomes and further revision and/or improvement of processes
8. Engagement of patients through secure web-portals
9. Engagement of patients and/or populations (potential patients) who ‘didn’t show up’ but need care based upon an analysis of current utilization and ‘blind areas’ identified through Geo-mapping.

This final step is key to moving from a value-driven care system that focuses solely on individuals who manage to find care to a value-driven care system that is committed to the health of both individuals and populations, e.g., all those who would benefit greatly from care see Blue Ridge Group reports at http://whsc.emory.edu/blueridge/reports.cfm.

Equally important is the need for electronic records (including relevant decision support) that looks at the care needs as a continuum as emphasized by Naylor of the University of Pennsylvania [20–22]. Stakeholders need relevant information but what they really need is information arrayed so that caregivers and care systems can integrate care across important dimensions. Decision support should not simply inform but be presented in ways that facilitate appropriate action by clinicians, patients, and managers.

For example, Naylor conceives of a care continuum for the elderly that tracks people across four life stages including healthy, acutely ill, living with chronic illness/disability, and frail/coping with illness at the end of life. Each stage has its information needs and the information needs to be transmitted in actionable language and content. At the healthy level, EHRs need data acquisition and decision support for tracking people at a population level and helping them assure a health environment, “healthy home”. For those who have been acutely ill, EHRs having the same kind of actionable advice is needed to assure transitional support to avoid readmissions and avoidable setbacks. For those with chronic illness/disability, help is needed for chronic care management that is keyed to local resources and environments. And, finally, at the end of life, EHRs are needed that comprise a program for all-inclusive care of the elderly (PACE) as well as hospice care. Today, we know that billions of care dollars are spent in what prove to be the last few months of life. Further, we know that the entire domain relating to advance directives for end-of-life care are poorly managed. Finally, we know from places like the Gunderson Lutheran Hospital in La Crosse, Wisconsin that programs can and do work and achieve both better human outcomes for those involved as well as resulting in much less costly care [15]. Complimentary sets of standards are needed relating to functional aspects of care itself, and then communications among critical parties to assure that details are attended to properly.

5. Information and communication

I propose that one set of content could be seen as primarily being relevant information such as facts and treatment guidelines while the other set relates to the support of critical communications needed to meet these practice standards. Most computer-based EHRs are more information-based than communication-based in this context, even those that seek as a routine to remind a clinician to order a preventive test. In contradistinction, one might consider an e-mail or text message to be first a communication that then morphs into information stored in the record, even though information itself is passed along. Most doctors when seeing a patient are primarily interested in communicating with the patient, that is, working together to find words and concepts (the relevant information) that may convey a shared clear meaning between them.

The EHR ends up containing a distillate of such communications as well as related relevant information. However, simply exchanging information does not assure that the information was accurately
communicated. This is most evident when language and cultural barriers intervene. Could explicitly developed communications technologies better align information technology with such communication technology? What one wishes to convey is meaning, caring and conviction in terms that engage the patient as a unique person can focus upon. To achieve greater effectiveness in care and enhance learning as a system objective, we need to focus both on information itself as well as how it is communicated for the information to become alive for the patients and clinicians so that they can and will internalize it and pursue relevant actions. An example follows.

First, we need end-of-life standards that are Health Information Technology templates to accurately express information on the personal choices of patients in a clearly understandable fashion for clinicians to use. We know that such choices can shift when one moves from a state of full health to critical illness. Thus, we need Health Communication Technology templates to support clinicians and patients working together to assess options over time and what is then involved for each of them to do justice to their decisions. For example, there could be periodic reminders scheduled for both clinicians through their EHRs and for patients (via their integrated PHR) urging them to review and refine prior wishes if shifts in health status occur that might have long-term implications for survival or major quality of life considerations. At the time of hospitalization, an alert could go to both the clinician and patient or a designated family member (depending on the level of illness) that shows the current directives so the HIT information becomes communicated among those involved. Finally, alerts to the relevant clinical teams engaged in the direct care of the patient would be communicated when the patient’s clinical status either approached or crossed the decision thresholds.

While simply knowing that a directive exists (as information) may be useful but what is essential is help all along the way so that the critical information is timely and actionable and is communicated appropriately. Standards in this sense are explicit representations that reflect our view of the world, and hence, what we choose to recognize and value. Short of having such standards, we risk what Rene Dubos has noted, “That which is measured drives out that which is important.” Today, our approach to clinical decision support and related directives are undervaluing our humanity and our moral attitudes and habits. HICT may be used to make us more fully human in our care. It is not clear that we should maintain the distinction between HIT and HCT for the communications. However, clinicians focused on traditional HIT are at risk of disproportionately focusing on the information rather than the communications. A patient values the personal connection that comes through clear, direct communications with their care-giver [18]. This makes the information come alive.

6. Broader perspective

The proper role of and the potential for IT and information systems is to take personal, patient, and population records, and personal health records and integrate them in such a way that a learning organization is created and supported. This means more than simply having patient or clinician alerts for such items as drug-drug interactions. Ultimately, it means that clinicians and patients collaborate in the evaluation of care guidelines to determine circumstances in which a given care protocol is adopted by all providers as the standard for that environment. Obviously, there is a great deal of science and evaluation that must stand behind such an approach and continued tracking of outcomes is needed to assure that the protocol is as rigorous as possible and also is fully compatible with appropriate actions in care environments.

It is for this reason that the American Medical Informatics Association is most enamored with personal health records that are structured within the EHR system via secure web portals that allow patients
and clinicians to communicate directly with one another while viewing the same clinical data [13]. ‘Integrated’ personal records of this type stay up to date and are complete and audited by both patients and clinicians. At the minimum, they should include access to appointments, the problem list, medications, allergies and/or reactions, a subset of test results, demographic and insurance information, and educational materials. In addition, some actionable functions are essential including requests for appointments, medication delivery through the mails, secure messaging among those involved, and family members should be able to have access to view data with permission and within some constraints.

In sum, it is not sufficient to have simply the right information for decision-making purposes, it is also essential that the key stakeholders know how best to accomplish better care outcomes through the use of such information. Thomas Jefferson made this distinction years ago when he envisioned the University of Virginia to be a site and source for ‘useful’ knowledge. Getting the knowledge applied is central to achieving care outcomes. It is relevant that medical specialties are moving from their traditional structure of continuing education that consisted of attending lectures, etc. to a new target of actual professional performance improvement. It remains a challenge to refocus quality improvement initiatives away from measuring performance to improving actual performance. This movement within medicine toward performance improvement also takes the focus solely off the individual provider and moves the focus to achievement of clinical objectives and performance of a clinical team or unit responsible for care that works within a complex adaptive system. This shift of focus will have implications on how EHRs will be structured to report performance as well as how clinical guidelines are developed and used by teams. Further, the shift to performance improvement within the group responsible for the total care of the patient is certain to stimulate clinical decision support activities and in new directions.

7. Clinical decision support

According to the Clinical Decision Support (CDS) Roadmap report done for the Office of the National Coordinator, CDS is “providing clinicians, patients, or individuals with knowledge and person-specific or population information, intelligently filtered or present at appropriate times, to foster better health processes, better individual patient care, and better population health” [24]. According to this report, “the challenge is to create a national coordinated action to ensure that usable and effective clinical decision support is widely used by providers and patients to improve healthcare.” Today, there are multiple aspects in which we underachieve including lack of interoperability, guidelines lacking the capability to be put into computer-usable language or precluding implementation into EHRs, wheel-reinvention, a slow path from new knowledge to widely usable knowledge and limited adoption for financial or legal reasons. To enhance health and healthcare through CDS will require activity in three domains and integration of work across them. The domains include having the best knowledge available when it is needed, high adoption and effective use, and continuous improvement of CDS methods and knowledge. To achieve these goals will require practical, standard formats for knowledge representation and interventions, standard approaches for collecting, organizing, and distributing CDS, addressing a variety of policy, financial, and legal barriers and creating additional support and enablers, compiling and disseminating best practices for usability and implementation, developing methods to collect, learn from, and share experience with CDS, and using EHR data systematically to advance knowledge. Work is progressing on many of these dimensions [25]. Certainly, the HITECH legislation will move this along as well.

Translational Bioinformatics: From Organs And Systems To Molecular medicine The transition from clinical care based upon clinical phenotype (largely organs and systems) to molecular medicine
based upon one’s unique biology will come slowly but it has already begun. The reports from use of the HANES database in this country and the Wellcome Trust Case Control Consortium in the UK have shown that the era of genome-wide scans is here [10,29].

Two public policy challenges that are emerging already as a result of this emerging discipline are how best to manage the implications of these developments in a consumer-driven commercial environment. The first relates to personal privacy and the second relates to getting a sound interpretation of what the data reveal about one’s health and future prospects. Recent research has made it clear that it is very difficult to camouflage one’s personal identify if one’s genomic information is available and it is likely to be equally difficult to find a cost-effective source for data interpretation of what a genetic analysis may actually mean for one’s life. The innovations are certain to generate greater public discussion in the near future as the costs continue to drop. Having said this, we are in early days since ultimately, there will be some clinical implications from structural genomics but also more from functional genomics, proteomics and other effector molecules.

Space limits what can be described here but the field of ‘translational bioinformatics’ is expanding rapidly through greater developments of informatics methods of data mining as well as availability of phenotypic data sets for comparison with genomic data as referenced above. Patient populations clustered for their Coumadin sensitivity based up the trial-and-error method used by clinicians to regulate Coumadin sensitivity were analyzed against their structural data. Use of this approach suggests that it is likely that only two only clinically significant single-nucleotide polymorphs (SNPs) are disease-related genes [11]. Strictly using evolving data-mining approaches are also yielding both stronger methods and interesting findings. A mix of diseases and conditions are implicated, including insights that relate to complex behaviors. For those outside this field, yet interested in keeping up with these developments, the annual year-in-review given by Russ Altman at the AMIA Translational Bioinformatics Summit held each March is strongly advised [1,2]. For insights into progress in not only translational bioinformatics but informatics in general, the annual year-in-review by Daniel Masys given at the AMIA Annual Symposium each November is equally valuable. Kindly, each puts their presentations on the web [1,2,17].

Since most conditions are multi-factorial and include a mix of biology, environment, access to care and its quality, the manner in which this powerful rising new science will evolve and integrate into clinical and public health practice will be intrinsically complex yet powerful. Robust computer-based health records must be the norm in care settings, in the home, and in public health environments in order to carry out such work. Data interpretation will require an ongoing structured ‘assessment of the knowledge base’ with a combination of ‘carbon- and silicon-based’ intelligence akin to the comparative effectiveness studies mandated in the ARRA legislation. Among the dimensions that will be impacted by these developments include prediction of disease, more commonly susceptibility and risk for developing disease, prevention, screening, early diagnosis, and therapeutic interventions. Translational bioinformatics is transforming rapidly from a field focused on methods to a discipline that generates scientific discovery in their own right through the use of high end computing. The outcome of this work will seep into all of the domains listed above in both subtle and dramatic ways.

8. Towards success

Today, there are many barriers to achieving the right mixture of human and HIT capabilities to assure a value-driven care system that focuses on individuals and populations. Among the barriers to achieving more rapid progress through organizational adoption are dysfunctional attitudes and habits, costs, privacy
policy and related issues, lack of standard definitions, lack of interconnectivity/interoperability standards, and lack of a well developed program and approach to actionable decision support equally cued to key stakeholders, including patient, clinicians, and managers. That is, some of the challenges relate to policies and procedures, others to organizational structures, rewards and incentives for key players including some that are monetary. Before speaking to issues at the institutional level, a few words are appropriately focused at federal and state policy with respect to privacy and access to person-specific health information and unique personal identifiers.

With the passage of ARRA/HITECH, privacy policy continues to crowd out efforts to meet other legitimate social goods. Policy makers who are disproportionately concerned about privacy enact more and more regulation limiting timely access to person-specific health information for totally legitimate social purposes including safety, legitimate biomedical and health services research, freedom, and personal autonomy. Policy supporting altruistic behavior is displaced by this excessive focus on privacy. And, misplaced privacy fears even result in added risks to patient safety. For example, unique health identifiers help assure that an individual patient’s data is authenticated properly so that one patient does not receive data relating to another patient with the same name and/or similar demographic data.

Today, citizens are not even allowed the option of having a personal health identifier if they wish to have one. Rather, they are faced with the higher risk of receiving another person’s health information into their own EHRs, or having their information not be sent to them but to someone else’s record, thereby invading yet another person’s privacy. Similarly, citizens supportive of legitimate biomedical research are not allowed as a matter of national government policy, to opt to agree to have their EHR data made available to the research community. There should be a national clearinghouse that allows citizens to agree to offer access to their personal health data for legitimate biomedical and public health research.

A number of studies now confirm that legitimate biomedical and health research is being harmed in this country as a result of national privacy policy [19,28]. This includes research sponsored by the National Institutes of Health and other publically funded research. Public policy must develop and implement ways to allow individuals to offer an informed blanket approval for their data to be accessed for legitimate biomedical and health research, e.g., IRB approved research protocols. Further, citizens should be given a simple way to offer access to their own DNA data for research uses if they so desire.

The strategies for correcting these imbalances vary widely but there is little structure today to support necessary reforms. For example, the recently enacted American Recovery and Reinvestment Act of 2009 with its support for a national health information infrastructure and support for comparative effectiveness research offers a window of opportunity. Clearly, there will need to be access to data for quality control and research if we are to make progress in the area of comparative effectiveness. At the same time, within the same law, increasing privacy constraints to the “liquidity” of health information were enhanced [5]. The Booz Allen Hamilton report favors giving citizens the right to choose a unique health identifier for caregivers and researchers to use for better authentication as well as making an ‘altruistic’ choice that might help others while not necessarily helping themselves.

Ideally, it should be an option for those who elect to participate, to be contacted if they would meet the human subject criteria for a particular research project so they might participate or decline to do so. What this would require is both standards for dealing with the information itself in a structured manner, e.g., templates using information technology plus standards for contacting them with relevant information if they sought to participate, e.g., communications technology.

The value of supportive societal policies for connecting citizens and researchers is becoming ever more important as we approach the area of molecular medicine. In short, public policy should support
an infrastructure to foster value-driven health care for a healthy society that is also altruistic in its public policies, including support of education and research. Only policy and standards relating to health IT and health CT to support actions that are more adaptive for continued improvement, greater sustainability and better outcomes would accomplish this end. Policy needs to orchestrate harmony and balance across the knowledge, care and payment domains. So, a greater dialogue is needed if we are to develop policy supportive of health within the broader society as well as within the healthcare delivery system and the standards to make them operational. Standards, in the sense used for electronic health records and record systems, should be benchmarked against desired outcomes and processes. Such standards would then be reformulated over time to better achieve desired social ends. Government must learn to tolerate the ongoing creative tension across policy efforts that relate to system management, care standards and related education and research.

According to the Blue Ridge Academic Health Group [6], “a value-driven health system would utilize performance-based incentives and balanced competition between the care and payment domains in achieving national health goals. It would develop incentives to improve the health outcomes of both individuals and populations, while achieving the highest possible value for the dollars invested and spent. A national health information infrastructure would allow secure communications of relevant data for diagnosis, treatment and outcomes tracking by those with a right and need to know.”

As progress continues through discoveries utilizing computational biology and translational bioinformatics, we will continue to see a shift from the traditional focus on organs and organ systems to cells and molecules as the basis of human therapeutics. We will need information and communications standards that speak to these discoveries within our EHRs and the ongoing clinical and health services research agenda. Communications standards will increasingly gravitate to mobile communications technology when favored by the patient or the clinician, including wireless monitoring, etc. The focus should be on the involved patient and clinician and in some cases the community as we can derive evidence on community health from pooled clinical and other public health databases while still tending to legitimate data security needs.

Since the Institute of Medicine published the Computer-based Patient Record in 1991, the focus of nearly all of the energy and investment within the healthcare industry has been on information technology [14]. The focus and the resultant standards that have evolved to support EHRs and EHR systems have related heavily to documentation, e.g., preserving meaning and context while moving from paper-based to computer-based records. Certainly, functionality with respect to decision support has focused heavily on professional clinicians with little focus on supporting health related decision making of either patients or improved decision relating to the general health of citizens. Unfortunately, the acronym HITECH focuses on the technology rather than the more relevant challenge of integrating human dimensions of work processes and change with computer/communications technology. Connectivity, decision support and data mining are at least as important as automation as pointed out by the NRC [27].

9. Conclusions

Essential to making progress is having an enterprise-wide sense of mission and commitment that allows for systems to try new approaches, evaluate them and then move the best ideas into uniform practice. What this entails is ongoing education and research and an environment that is flexible and capable of change. Typically, the least of one’s problems are the HIT system(s) themselves; the work comes when the interface between people and the systems is engaged. Today’s systems are far from perfect and an attitude of openness and willingness to help improve the system is crucial. With a commitment to
ongoing education and research, we can improve quality, safety, cost-efficiency, effectiveness, equity, patient-centered and timely care. At the same time, we must assure that public policy and environmental factors are in alignment to be supportive.

References


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