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Personalized Health Care and Health Information Technology Policy: An Exploratory Analysis

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Abstract

Personalized healthcare (PHC) is envisioned to enhance clinical practice decision-making using new genome-driven knowledge that tailors diagnosis, treatment, and prevention to the individual patient. In 2012, we conducted a focused environmental scan and informal interviews with fifteen experts to anticipate how PHC might impact health Information Technology (IT) policy in the United States. Findings indicated that PHC has a variable impact on current clinical practice, creates complex questions for providers, patients, and policymakers, and will require a robust health IT infrastructure with advanced data architecture, clinical decision support, provider workflow tools, and re-use of clinical data for research. A number of health IT challenge areas were identified, along with five policy areas including: interoperable clinical decision support, standards for patient values and preferences, patient engagement, data transparency, and robust privacy and security.

Keywords:

Translational Bioinformatics; Informatics, Clinical; Decision Support Systems, Clinical; Electronic Health Records; Personalized Medicine; Decision-Making, Shared; Patient Engagement.

Introduction

Expanded use of genomic and molecular data to better target healthcare delivery in the United States has been accelerated by the falling cost of whole genome sequencing, the proliferation of molecular marker research, improved methods for analyzing large datasets, and a maturing electronic health record (EHR) infrastructure. Personalized health care (PHC), anticipated to improve healthcare quality, lower cost, and enhance the patient experience, is heavily reliant on health Information Technology (IT) for point-of-care decision-making, capturing and aggregating data, and bringing new scientific knowledge into patient care decisions. Understanding the interaction between health IT policy and PHC advances is important given PHCs dependence on a robust health IT infrastructure.

Methods

An exploratory qualitative analysis using a focused environmental scan and informal discussions with experts was conducted over three months (July to September 2012). The focused review of current literature included industry white papers and Web media (e.g., blogs, discussion groups, websites) identified in the 2008 U.S. publication of the Priorities for Personalized Medicine report to the President's Council of Advisors on Science and Technology (PCAST) report [1], by expert participants, and by internet searches using the search terms "personalized medicine", "personalized health care", and "precision medicine". The informal discussions by telephone with 15 experts from a variety of domains included clinicians, geneticists, oncologists, health informatics researchers, patient advocates, EHR vendors, and health system leaders (see Table 1). The Personalized Medicine Coalition (www.personalizedmedicinecoalition.org) and contacts known to the research team to be actively engaged in PHC research or policy were used to identify contacts. The list of experts was finalized in consultation with the funder. Semi-structured discussions explored the definition of PHC, key issues relating to health IT, and stakeholder views on possible approaches to resolving them, using an interview guide. Themes were identified and refined based on meeting notes and the environmental scan in an iterative manner by the coauthors.

Results

Definition and Scope of PHC

The PCAST report created broad exposure for the term personalized medicine, described as "the tailoring of medical treatment to the specific characteristics of each patient… [fostering] the ability to classify individuals into subpopulations that are uniquely or disproportionately susceptible to a particular disease or responsive to a specific treatment" [1]. The anticipated value of this approach was to concentrate preventive or therapeutic interventions on those who would benefit, sparing expense and side-effects for those who would not. While the principle of adjusting treatment to specific patient characteristics dates back centuries [2], recent advances in genomics and molecular biology are revealing new, genome-related molecular markers for the presence of disease, susceptibility to disease, and differential response to treatment" [1]. The Center for Personalized Health Care (CPHC) at the Ohio State University (cphc.osu.edu) extends the concept to incorporate knowledge of the patient's environment, health-related behaviors, culture and values. CPHC describes personalized health care as "predictive, preventive, personalized and participatory" [3]. Another term, "precision medicine", has been proposed to describe greater specificity in identifying meaningful patient subgroups [3-5]. In this project we adopted the CPHC notion of PHC for purposes of discussion and analysis.

Current Impact of PHC on Clinical Practice

Practitioner familiarity with PHC concepts was reported to be highest for oncologists and geneticists, and more variable among others depending on the frequency of use of molecular markers in each clinical area. For example, in breast cancer, treatment response to Herceptin for HER2-positive tumors and elevated risk associated with positive BRCA1 and BRCA2 markers are well known [6], whereas nine other gene variants associated with breast cancer risk found in several commercially available tests are less clinically used, and less useful because they have low penetrance – they usually do not pro-

duce clinical abnormalities even though they are sometimes associated with abnormalities. Many newly publicized and promising findings, such as the use of molecular markers to predict stroke, are still being validated and have yet to be used routinely [7].

Many providers have gaps in knowledge about molecular marker testing options, the clinical significance of the results, the process for interpretation, and the incorporation of newly emerging scientific knowledge. Even knowledgeable clinical experts complain of cognitive overload as the number of relevant molecular markers for a condition rises into the teens, twenties, fifties, or higher. Further complicating matters, similar genetic lab tests from different lab facilities may not be consistently reported [6], and lab reports frequently provide narrative test interpretations poorly suited for automated processing in decision support systems.

Routine collection and use of family history (FHx), while a longstanding practice described as a "well-proven, personalized genomic tool that… can serve as the cornerstone for individualized disease prevention"[8], has major limitations even with the use of EHRs [9] due to clinician time constraints, inadequate training in taking a FHx, insufficient FHx detail, lack of FHx updates, patient unawareness of their FHX details, or limited knowledge on how to act on a positive FHx [10]. Ongoing technology strategies to improve family history data quality, including efforts to promote interoperability and define a minimum core data set [11], tools to promote self-entry of family history [12], and standards work including the international Family History Information Standardization Organization (http://FHISO.org), are steps in the right direction but have limited impact without other changes in strategy.

Shared Decision-Making (SDM), a systematic approach to engage patients in understanding decision options, exploring preferences and values along with best evidence, and selecting an option after considering risks and benefits in a personal context, was developed initially to help support conversations between a provider and patient in life-threatening conditions. SDM has been extended for use in general practice and is ideally suited for preference sensitive care—situations where evidence supports more than one approach, treatment/testing options involve significant trade-offs, and decisions should be responsive to personal values, preferences, and life circumstances [13]. SDM requires time and skills to employ effectively, and is identified as a critical component of patient empowerment and patient-centered care [14] with high relevance to PHC decisions that fit the description of preference sensitive care.

Though advances in molecular medicine are driving dramatic changes in the amount and pace of discovery for gene-related information, they are only part of the picture. PHC decisions draw just as strongly on non-molecular data including phenotypic information (how illness presents itself), patient values and preferences, family history, prior responses to treatment, level of patient activation [8,9], levels of health literacy [15], and the personal context of an individual's decision-making—factors that may collectively have a greater impact on decision-making than molecular markers.

Anticipated Impact of PHC on Health IT

Advancing the impact of PHC on clinical practice will require patient and scientific data to be obtained, analyzed, communicated, documented, monitored, and used to tailor medical decisions to the specific needs of each patient. Core components of the EHR will require adaptation to realize this vision.

Electronic Data Storage, Access, and Accuracy

Large patient clinical datasets such as gene sequencing and proteomic data, and diverse data sources with varying data types used to support decision making are likely to be distributed among multiple source systems, creating technical, operational, and policy challenges compared to accessibility through a single system. If clinical decisions and the data supporting them must be documented in the patient record, a robust mechanism for storing copies of external data or pointers to the source information are needed. The anticipated drop in the cost of full genome sequencing, along with an increase in the number of significant biomarkers, patient self-monitoring, and growing environmental data will lead to much greater amounts of patient data than are currently available.

Beyond the challenge of accessing and aggregating data for real-time or near-time use, the ability for the EHR and other health IT to process machine understandable data will continue to be a bottleneck unless narrative reports, nuanced interpretations of lab results, and discrete testing results are stored or processable as structured data rather than as free text.

Accuracy is also a challenge. Multiple studies show that some portion of a patient's EHR data is routinely missing, outdated, mis-entered, poorly converted, or unavailable (due to system downtime, for example) [16], suggesting that the precision of Clinical Decision Support (CDS) recommendations should be adjusted to reflect data quality, assuming it can be monitored and reported. Prompts for clinician-users to enter missing data or confirm data accuracy are likely to be time consuming and difficult to scale.

With increased patient connectivity and engagement, patient-entered data and review for data accuracy is becoming much more feasible. In early pilots, patients can update pre-appointment medication, allergy, diabetes self-management, health maintenance and family history information [17-21] using secure web portals. The routine use of both paper-based and electronic data review tools in office waiting rooms is becoming more common [22]. Patient updates or correction requests typically require provider review and/or approval, requiring policy and/or process changes as the EHR data visible to patients through Web portals and data extracts such as Blue Button [23] increases.

Robust Clinical Decision Support (CDS)

Current CDS challenges, such as having accurate, updated, and machine understandable patient data, decision rules, and in-stream triggers will be intensified as busy clinicians access knowledge resources, educational material for themselves, and patient educational materials. Monitoring for alert fatigue and allowing tailoring of CDS rules for local patient panels will help to ensure usefulness and usability, as well as system maintenance requirements. Quickening the pace of standards adoption for CDS content (e.g., rules, educational materials) among different EHR products without stifling innovation is critically important since locally developing, updating, and/or managing CDS content could require more resources than many organizations have available.

Fitting CDS into the appropriate PHC workflow when making a diagnosis, selecting a treatment, ordering a medication, or determining prognosis or future risk requires not only careful technical system design, but process design as well. Advanced CDS is also emerging, in which more complex pre-processing of patient contextual data is used to adjust the core CDS algorithms based on an individual's molecular and non-molecular profile, allowing CDS rules to execute more precisely for that individual. The data and system infrastructure needed to sustain advanced CDS will be substantial.

Panel-wide analysis, such as query tools identifying all patients with elevated risk for diabetes based on a newly identified gene pattern, will have a larger role in supplementing point-of-care CDS. And while CDS precision may increase, the number of inconsistent and irrelevant alerts and reminders from CDS may also be amplified with growth in PHC. Improvement of decision models informed by feedback from a broad user community such as the eMERGE network (http://emerge.mc.vanderbilt.edu/) could more rapidly improve CDS ordering, diagnosing, treating, and risk prediction.

Attentional Capacity and Cognitive Load

Clinician time is overburdened in many areas such as prevention activities, care coordination, and participatory decision-making [24-27]. PHC activities requiring additional time will pose a significant challenge. In the past, time spent accessing patient clinical data and scientific information created a significant bottleneck. In the future, voluminous patient data and abundant "rules" for making decisions will limit the amount of data providers can review to inform decisions [28]. EHR design and workflow tailoring will need to streamline physician work activities and reduce cognitive load by facilitating many different kinds of clinical decisions.

The net impact of PHC on clinician time is difficult to predict. Decisions that are complex or require deliberation with the patient may take more time, whereas others may be faster due to helpful automation, such as picking an alternative medication suggested by a CDS rule.

Patient attentional capacity may also be saturated as self-management, research activity, and patient engagement activities are complemented and supplemented by online communities that alert patients to new diagnostic approaches, treatment options, risk factors, and biomarker interpretations, supplementing what's been discussed with a provider.

Health IT Policy

As EHR capabilities advance and a federated systems architecture [29] is used in support of PHC, a number of policies should be addressed, including:

- Policies for use of remote data and application services in conjunction with an EHR's local data and services, known as a federated approach;
- Policies governing liability resulting from problems with remote or local data or software;
- Policies supporting transparency of CDS recommendations, including their sensitivity to changes in data;
- Standardized ways to store and present CDS content, represent patient data, locate and retrieve patient data, and curate scientific knowledge;
- Alerting requirements to keep providers and patients informed of new knowledge that brings fresh and perhaps critical insight to genetic and other tests conducted months or years earlier.

Interface of Clinical Care with Research

Clinical care workflows and research will intersect more frequently as patients and clinicians seek early information about emerging diagnostic tests, medication tailoring, and other prognostic indicators. Patients seeking clinical trials and researchers seeking participants will use online communities and anonymous registries to recruit one another. Alerting of anonymized research participants about potentially important research findings using consumer/patient-facing technologies may become feasible, allowing researchers making new discoveries to broadcast their findings widely—to no patient or individual in particular—and inform those having an active interest in that knowledge [30].

Patient Engagement

PHC is likely to help patients become more aware of the health decisions they face, the information they can provide, the need to understand health concepts, and resources that can help them. In addition to viewing and providing clinical data, patients will increasingly supply and have access to important non-clinical data such as communication and decision-making preferences, online social supports, and consents or authorizations for certain uses of their data.

Greater awareness of PHC opportunities and Internet tools will enable more patients to participate in online communities, obtain online information and support, activate PHC notifications, seek research opportunities, and receive or provide coaching services to others. Patients may use an online health profile to identify resources of interest such as relevant clinical trials, top-tier specialists for their medical problems, or selected individuals who share common health concerns.

Current patient engagement challenges may intensify for patients wanting to benefit fully from PHC. Privacy and security concerns will be important for patients who want alerts when new significant interpretations of their findings are available [31], especially if information learned about one family member impacts others in unexpected ways. Health literacy challenges, already a handicap for many patients [32], could intensify as patients work to understand gene-based risks, diagnostic test, and treatments.

Consents are likely to become more challenging in the context of PHC, since testing for a specific purpose (e.g., a genetic risk) may be accompanied by broad genome-wide testing with a less clear focus. Coaching to assist consumers in learning about resources, preparing for face-to-face visits, exploring their preferences, and practicing patient engagement behaviors [33] provides value according to the expert interviews and the published literature. Support tools to assist health consumers while they are well or after they've started treatment will be essential, such as the Alzheimer's Association Web site (http://www.alz.org/) with risk factor and other resources.

The participatory role of the patient is prominent in PHC—any decision about diagnosis, treatment, or prevention should reflect patients' values and preferences, and should begin with the patient as a critical and valued member of the care team. For patients already engaged, this approach is welcome. For the large group of patients not yet actively engaged in their health, it is important to determine how to reliably and effectively change their behavior and attitudes [34] to fully leverage PHC.

Discussion

Health IT operational and policy challenges were identified through the environmental scan and expert discussions, with recommendations for policymakers formulated below.

Health IT Challenges

- Systems require updates and users require training as long as health IT systems remain in use. As software, dictionary, interface, and database updates are performed, system and user testing will be essential to ensure that systems remain reliable and keep pace with provider workflows and patient activities.
- A system monitoring "dashboard" for key health IT components and interfaces, such as record locator services, data aggregators, and the CDS knowledgebase

will be important for monitoring overall system reliability, though data and systems in a federated architecture could be challenging to monitor. The source of each data element should be visible, and systems should also be able to confirm the presence or absence of a requested data item in a source system.

- Configurable and coordinated systems are essential in the context of PHC so that CDS adapts to changes in data and workflow. For example, if a molecular marker predicts increased risk of developing a disease and a drug-drug interaction, two rules should be coordinated in the CDS system—one for prevention planning and the other for e-prescribing.
- Use of data standards that promote the capture and reuse of patient clinical data, values and preferences, and environmental data will require professional and stakeholder agreement and discipline even in emerging areas such as gene-based test results, in which standards are not yet mature.
- Data quality, capture, and accuracy will continue to be a challenge given the breadth of data types and sources relevant to PHC, the different modalities employed for capturing and recording data, the limited time providers spend with each patient capturing and discussing clinical data, and the anticipated explosion in data volume as PHC advances.
- PHC will require basic and advanced CDS that uses environmental and contextual data to calculate intermediate probabilities used to tailor patient assessment.
- A knowledge management lifecycle is essential for CDS rules to avoid orphaned content and to support an orderly change process as scientific knowledge advances in PHC. For example, ruleset curation and change management procedures will help to ensure that decision support for a single patient visiting several different doctors over a short time period would trigger consistent rules at each visit.
- CDS rule transparency for patients, providers, and interested stakeholders is critically important since CDS often involves human judgment in the face of uncertainty. Transparency allows the strengths, weaknesses, and logic behind CDS rules to be examined and challenged where necessary.
- Usability of health IT, increasingly identified as critical to successful use by providers and patients, is important for patient safety and reliable system performance, and is a critical area in the context of PHC.

Policy Considerations

Five policy areas that will help to advance PHC are: 1) an interoperable framework for CDS across different EHRs, patient data sources, and users; 2) standardized recording of patient values and preferences based on professional and stakeholder agreements; 3) work to promote patient access to health information and participation in clinical decisions; 4) consistent data access and data transparency rules for providers and patients across health systems; and 5) consistent, clear privacy and consent policies to promote patient and stakeholder trust in systems that handle sensitive health data and support safe handling of patient data used for PHC decisions.

Conclusion

The promise of PHC—enabling providers and patients to enjoy greater tailoring of diagnostic, treatment, and prognostic decisions—requires a health IT infrastructure that enables advanced clinical decision support, shared decision-making, ongoing research, and the human workflow challenges of processing multiple complex decisions in limited available time to be addressed for non-molecular as well as molecular data.

From this environmental scan and discussions with experts, health IT policy to advance PHC should address a number of policy areas including: interoperable clinical decision support, standards for patient values and preferences, patient engagement, data transparency, and robust privacy and security.

Table 1 – Experts contacted about Personalized Health Care

Name	Affiliation
Sandy Aronson, ALM, MA	Partners HealthCare, Center for Personalized Genetic Medicine
Elly Cohen, PhD	University of California San Francisco, Program Director, BreastCancerTrials.org
Sarah Corley, MD, FACP	Chief Medical Officer, NextGen Healthcare Information Systems
Gregory Downing, DO, PhD	U.S. Department of Health & Human Services
Leslie Kelly Hall	Senior VP, Policy, Healthwise
Tonya Hongsermeier, MD, MBA	Principal Informatician, Partners HealthCare
Kevin S. Hughes, M.D., FACS	Surgical Director, Breast Screening, Co-Director, Avon Comprehensive Breast Evaluation Center, Massachusetts General Hospital
Gil Kuperman, MD, PhD	Director of Interoperability Informatics, NewYork- Presbyterian Hospital
Clay Marsh, MD	Executive Director, Center for Personalized Health Care (CPHC), The Ohio State University
Lawrence N. Shulman, MD, FACP	Chief of Staff and Senior VP for Medical Affairs Dana-Farber Cancer Institute
Nancy Smider	Epic Systems Corporation
Blackford Middleton, MD, MPH, MSc	Corporate Director of Clinical Informatics Research & Development, Partners HealthCare
Michael Murray, MD	Clinical Chief, Genetics Division, Brigham & Women's Hospital
Charlene Underwood, MBA, FHIMSS	Senior Director, Government and Industry Affairs Siemens Healthcare
James M. Walker, MD, FACP	Chief Health Information Officer, Geisinger Health System

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