Lost in Translation: 
Consumer Health Information in an “Interoperable” World

Introduction
In the continuing conversation about how to fix health care, information technology is seen as a silver bullet solution that can simultaneously reduce costs, improve quality, and increase efficiency. This discussion of the potential benefits of unified electronic health records and other such applications is taking place at the same time that consumers are being asked to shoulder more of the burden of health care spending through increased deductibles, tiered benefits, and other cost-sharing arrangements. In addition, the proliferation of Internet health care resources and a rising distrust of health care institutions are driving consumers to search online for disease-specific information or data on quality of hospitals or providers.

While momentum is building among health care professionals, payers, and the government for the creation of a National Health Information Network (NHIN), it remains unclear what role patients will play in the interconnected world of providers. Traditionally, consumers have received their clinical information through conversations or letters received from their provider. In an interoperable world of Regional Health Information Organizations (RHIOs), however, that same clinical information becomes more directly available to the consumer — through the Internet or through other electronic communications from the provider.

But a mechanism for meaningful translation to engage consumers is lagging. For example, a diabetic patient accessing his personal health record could determine that his or her hemoglobin A1c test is 10 percent, but what does the patient do with that information? Are there ways for the patient to understand the data without having to schedule a visit with a provider? Are there ways of ensuring that an Internet search could supply the patient with meaningful information?

This report takes a first look at consumer-based information and what could be done to better integrate consumer health information standards into the NHIN framework.

Background
As consumer-centered care gains momentum, serious hurdles loom in the absence of national standards for the development of health information and delivery systems targeted specifically to lay people. Such standards would not only foster efficient translation of medical terms for the average consumer, but also offer access to consistent content stored in a variety of locations. In this scenario, individuals could readily link to, view, assimilate, and cross-reference health information that addresses their special needs at any point during their care.

The Current State of Consumer-Focused Electronic Health Information
Consumers who go online to choose or manage their own care often encounter clinical information and technical jargon that they are
unable to decipher because it is presented in a format that reflects the provider’s point of view (diagnosis, treatment, outcome). While much information exists to explain a disease or describe a possible treatment option, most of the information doesn’t allow an individual to inject his or her own demographic and medical characteristics into the mix, much less important psychosocial factors regarding his or her self-care, comfort with risks associated with treatment, and other preferences and limitations (doctors, hospitals, health plan, insurance type, etc.). As such, the information may not be personally relevant and no bridge exists to integrate these disparate concerns into a consumer-centered resource (Figure 1).

In the private sector, changes in consumer and purchaser expectations are fueling demand for health information that lay people can easily understand. Consumers want to know about their care options and the quality of providers and health plans available to them. Indeed, each day more people seek information online than see a physician on an inpatient or outpatient basis, according to the Pew Internet Project.

At the same time, employers face severe financial pressure to shift a bigger share of health care costs and decision making to employees. New models of care delivery, including consumer-directed health plans (CDHPs) and chronic disease management, encourage patients to inform themselves before choosing among options. And with the growth of personal health records, more patients have more access to data about their care.

Government action also is placing greater responsibility on consumers. The federal Medicare Modernization Act of 2003, for example, promotes CDHPs. In nine states, chronic care improvement programs provide self-care guidance and support to chronically ill Medicare beneficiaries.

Meanwhile, the storage and exchange of electronic health information is becoming widespread. With the rise of electronic medical records, e-prescribing, computerized physician order entry systems, and other mechanisms, there is broad support in the health care community for technical interoperability standards. Such standards address the need for different types of computer systems to share quantitative, discreet data — ICD-9 codes, for example, diagnosis codes used primarily for claims and other administrative purposes—in ways that don’t jeopardize security or confidentiality.

Technology standards involve a far-reaching web of health care interests that range from hospitals, health plans, and traditional insurers to physicians and pharmacists. Although the efforts of technology-minded organizations and professionals have been essential in building an infrastructure that makes information exchange possible, much of the raw data they generate are of limited value to average consumers, for whom qualitative, descriptive, easily distilled content is more meaningful and useful.

Challenges
A consumer-oriented approach to health information sharing poses many challenges. Patients who undergo medical tests, for example, need information organized around three moments in care: decision support (“Should I take the tests? What are the pros and cons of each one?”); test preparation (“What happens during these tests? How can I prepare so the results will be accurate?”); and interpretation of results (“What do they mean? What, if anything, should I do differently now?”). Often missing from these moments are standardized language and processes that facilitate, rather than hinder, consumers’ decision making.

To be relevant and useful, the information patients retrieve must take into account their demographics
Figure 1. Translating Clinical Data to Engage Consumers

**Issues with Lab Report**
- All data derived from clinical and administrative databases.
- Test names not in plain language.
- Reference ranges may not be given for defining “normal”; even if they are added, without context for the individual person, they may not be meaningful.
- Explanations needed for what the implications of the test are—for example, what does “abnormal” mean?
- Content needed that explains what the test is for and why it’s important.
- Details needed regarding next steps, such as what might cause an error (e.g., eating too close to a test) or when to get re-tested.
- Guidance needed regarding what to do with the information, such as what to ask your doctor about the results.

**Personal Health Record (PHR)** accessible through secure portal.
Consists of:
- MD Directory
- Medications Taken
- Lab Results

**Confused Consumer** searches Internet for clarification.
(such as age and gender), health risks, and other medical conditions. Ideally, three men—a healthy 50-year-old, a healthy 90-year-old, and a 55-year-old with lung cancer—could tap information tailored in a way that would help each one decide if screening for prostate cancer is appropriate. A patient at greater risk for heart disease whose cholesterol test result is “LDL=130 mg/dL” would quickly discover that LDL means “low-density lipoprotein, or ‘bad cholesterol,’” and that “130 milligrams per deciliter” is a moderately high level in his or her case (Figure 2). Simple language and context add tremendous value to this kind of information.

Consumers also need to know how a decision at any one moment of care, such as choosing a treatment, might affect other aspects of care, such as paying for it. Currently, individuals trying to gauge the financial impact of various health care options cannot automatically link to benefit information to find out which therapies are covered or what the out-of-pocket expense will be.

Similarly, the LDL lab value they see on screen is not linked to an encyclopedia that explains what low-density lipoprotein means relative to a given patient’s risk factors, nor is it linked to other sources of information about drugs for high cholesterol, the cost of these medications, and formularies. And as consumers switch from one provider or insurer to another, they can’t access their full medical history to compare old test results with new results—a chief advantage of personal health records.

However, even personal health records only go so far. Without standards for translating raw health data into simple terms and integrating the data with other essential information and infrastructure tools, individuals who manage their own health records may still feel overwhelmed or lost.

As yet, there isn’t a standard “plug and play” interface between the electronic medical records maintained by providers and the electronic health resources targeted to consumers—content, risk assessment software, and the like. Vendors supply some of these resources in a

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**Figure 2. Making Online Lab Reports Useful for Patients**

**Online Lab Report**

<table>
<thead>
<tr>
<th><strong>Definition</strong></th>
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<tbody>
<tr>
<td>LDL (&quot;low-density lipoprotein&quot;) is often described as &quot;bad cholesterol.&quot; It can lead to heart problems that some doctors call “plumbing problems” by clogging the pipes (arteries) that bring blood to your heart. An LDL of 130 is a little high, but the risk it poses in the long term depends a great deal on your own risk factors.</td>
</tr>
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<table>
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<tr>
<th><strong>Impact on You</strong></th>
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<tbody>
<tr>
<td>Given your family history of heart disease, your age, and your history of diabetes, you have a significant long-term risk of heart problems. Here are some resources to help you think about what steps you can take to prevent serious problems:</td>
</tr>
</tbody>
</table>

**Questions to Ask Your Doctor**
- Decision Aid: Should I take a statin (LDL-lowering drug)?
- Action Tool: What else can I do to prevent heart problems on my own?
- Exercise Plan
- Diet Plan

Note: Impact data comes from electronic medical record, health risk assessment, claims forms, etc.
variety of formats. Health organizations that are implementing electronic records typically don’t have the time and money to develop interfaces themselves and aren’t likely to do so anytime soon. Even if they did, the lack of standards would make their individual efforts somewhat redundant.

**Implications**

The potential consequences of not bringing more uniformity to this realm are real. Consumer-centered health care offers opportunities to empower patients with knowledge, improve overall health, deliver services more efficiently, and save money. But these opportunities could be lost if consumer health information and tools become a roadblock instead of a bridge.

First, scattershot and arcane information is a drain on human resources if patients need help finding and interpreting it. Second, if resources that enable informed choices are beyond the average person’s reach, consumer decision making and health care delivery suffer. Predominant economic theory holds that a free market can’t function efficiently if those who need services have less information than those who provide the services. Third, the hurdles could prove so daunting and frustrating for some people that they may simply abandon the consumer-focused model of care.

Timing is also an issue. Comprehensive standards must be in place as soon as possible so that organizations that are implementing electronic medical records can take advantage of them.

**Solutions**

Developing these standards will require that an array of health care experts work together, including: standard-setting bodies working on health-care-related data transfer issues; computer technology specialists; clinicians, given their central role in health care; library science professionals, who know how to find, retrieve, store, categorize, and organize information; and researchers in health services and communications, whose focus is meeting the information needs of consumers in ways that maximize the likelihood of high-quality care.

Among key issues needing study are:

- The critical elements that would enable a robust interaction of electronic content, tools, and infrastructure.
- Mechanisms for translating clinical terminology into lay terminology.
- Common protocols for transmitting consumer content.
- A common vocabulary that accommodates all moments of care.
- The types and range of tools necessary to achieve a smooth flow of consumer-friendly information.
- Ways to evaluate the quality of consumer health information — its credibility, accuracy, and comprehensiveness.

Another important issue is how consumer health information standards and tools would dovetail with existing laws — such as the Health Insurance Portability and Accountability Act, or HIPAA, and the Medicare Modernization Act — and with proposed legislation regarding health information technology, patient safety, and chronic disease management.

The health industry already has made great strides on the technology front, providing an infrastructure platform for future progress and precluding the need to “reinvent the wheel.” The HL7 Clinical Context Object Workgroup, the National Center for Vital and Health Statistics, the National Health Information Infrastructure, and various regional health information networks all have made noteworthy advances. Models
for a consumer-oriented vocabulary might be the Systematized Nomenclature of Medicine (SNOMED), and the National Library of Medicine’s Unified Medical Language System (UMLS) and Medical Subject Headings (MeSH).

Numerous federal agencies have set their sights on a national health information infrastructure. Among them are the office of the National Health Information Technology Coordinator, National Committee on Vital and Health Statistics, Centers for Medicare & Medicaid Services, Veterans Health Administration, Department of Defense, Centers for Disease Control and Prevention, Agency for Healthcare Research and Quality, and units within the Department of Health and Human Services.

These agencies, public-private partnerships, and independent oversight organizations, such as the National Quality Forum, the National Committee for Quality Assurance, and the Joint Commission on Accreditation of Healthcare Organizations, have invested enormous resources and intellectual capital in studying the infrastructure issue. Their accomplishments offer a foundation for future efforts to make comprehensive, consumer-oriented standards a reality.

**Conclusion**

Consumers are increasingly responsible for directing their own health care, yet the electronic information and tools they need for this purpose aren’t keeping pace.

Much of the information is arcane, scattered, inaccessible, or unusable, partly because it doesn’t address the unique circumstances of each patient at any moment of care. Tools to retrieve and manage the information—if they even exist—often are designed for medical and technical professionals rather than lay people. Nor do the tools provide a consistent way for consumers to link to information across the continuum of care from any delivery point.

National standards would provide common ground for further advances in consumer-centered health care. Without standards in this model of care, the efficiency of services, patient empowerment, cost savings, and better consumer health it promises could be seriously compromised in the years ahead.

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