Consumer Health Informatics

17.1.1 The Challenge of Improving Consumer Engagement
- Seminal work by sociologists and psychologists observed that consumers may become engaged because of an innate desire to be rewarded by participation or through external rewards.

17.1.2 The Challenge of Improving the Information Available to Consumers
- The advent of the Internet, **interactive television** and a host of widely available home technologies provide a rich source of tools to address this challenge.

17.2.3 Early Advances in Consumer-Consumer Communication
- Early electronic newsgroups, bulletin boards, and a **precursor to the World Wide Web** known as **Gopher** connected patients to information about various rare and chronic diseases
- At the same time, this increasing use of the Internet raised concerns about the quality of the material available to consumers. This concern, in turn, fueled an industry of groups consisting of content editors, clinicians, and technologists charged with creating legible and responsive consumer information that could be subscribed to on the Web, as well as others focused on rating the quality of this information. One notable group that promotes the deployment of useful online health information is the **Health on the Net Foundation (HON)**.

17.2.4 Early Advances in Consumer Decision-Facilitation
- A variety of approaches have been used to provide "just-in- time" information and decision assistance to consumers. As noted above, pamphlets and videos were created to explain treatment options and medical procedures to patients, as background for decision-making
- This was followed by an era of interactive video systems to help patients understand the risks and benefit of treatment options, but also to help define their values for possible future health outcomes. The prime examples of this type of system originated with the **Foundation for Informed Medical Decision Making.**

17.3.1 Consumer-Facing Software

The home and the community are fast becoming the most common sites where health care is provided.

With the ready availability of home computers and cellular phone platforms that support Web browsing and extensible software via "apps," there is a wealth of what is called "consumer-facing" software now available to consumers. These technologies can be categorized into four

modes in which consumers engage with health care through the use of technology. Table 17.1 summarizes these modes.

Table 17.1 Various modes of consumer engagement with health care technology

Mode of engagement	Definition	Examples
Communication	Support for patient-to-patient, computer-to-patient and patient-to-provider knowledge or information dissemination	Patient portals Patient-physician secure email Online support groups Social networking sites
Data storage	A patient-centered and managed repository for patient-entered data or "liquid" health-related information	Personal health records Data portals for devices, health systems and, pharmaceutical companies
Behavior management	Tools to support personal health goals, often by combining data storage, care protocols, information dissemination, and communication	Weight management tools Physical activity tools Medication reminder systems
Decision aids	Prepare people to participate in 'close call' decisions that involve weighing benefits, harms, and scientific uncertainty	Interactive tools for Breast Ca, Prostate Ca, Back Pain, End of Life, Heart Disease

17.3.2.1 Patient-Centered Communication

Patients frequently express frustration about the inability for electronic health records to support record-sharing. This frustration has led to recommendations by the Institute of Medicine (IOM) that recognize the central role of patients as a repository of their own medical information . culminating the explicit notion that quality health care should be "patient-centered" among other attributes.

Figure 17.3 depicts the information dimensions outlined in this work, which included a personal health dimension that emphasized data required for patients to communicate among or on behalf of their providers.
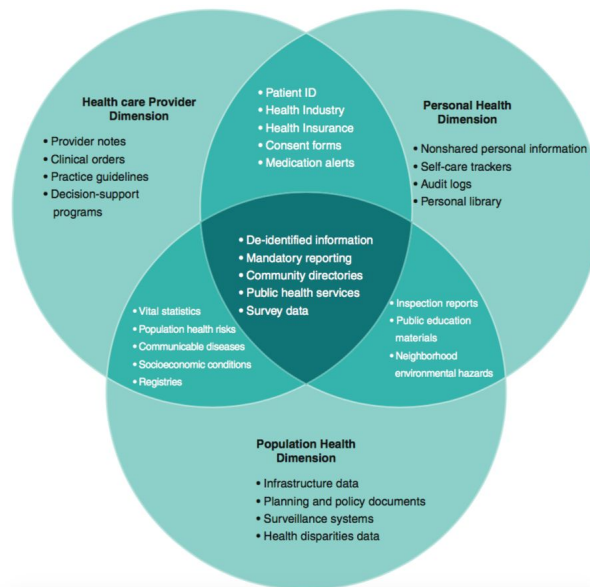
In addition to this lack of what has been termed "**data liquidity**" representing the ideal state of fast, free-flowing, and interoperable data - there are data important to health that may not be in

the typical electronic health record. For example, patient over-the- counter and data derived in physiologic monitoring.

Part of the STEEEP ("Safe, Timely, Effective, Efficient, Equitable, Patient-Centered") care framework by the IOM.

Patient-centeredness implies that liquidity is facilitated by patients being able to access and direct other's access to their information according to clearer laws and protocols that provide consistency and transparency.

17.3.2.2 Electronic Support Groups

One of the earliest electronic support groups was developed by Johnson and Ravert, who recognized the ease with which adolescents adopted technology. Hopkins Teen Central was an internet support group developed initially using a device known as WebTVTM, which provided Internet access via phone lines and household televisions. This project proved extremely successful. It demonstrated, for example, the power of patient-to- patient email, as well as the role of moderated health discussions in answering questions common to patients with a shared medical need. Electronic support groups, also known as Internet Support Groups (ISGs), have since become an almost ubiquitous way for patients comfortable with the Internet to communicate with each other. ISGs use four modes of communication alone or in combination: e-mail lists, instant messaging, bulletin boards, and chat rooms. Chat room use appeared to be associated with lower levels of depression. Patients with breast cancer appeared to get the most value from ISGs.

17.3.2.3 Social Networks

The for-profit online health-related social networking community Patients Like Me has demonstrated that individuals with a severe chronic disease amyotrophic lateral sclerosis are highly willing, even without compensation, to contribute data and observations to a patient community to accelerate learning about their disease.

17.3.3 Patient Access to Health Information

Szolovits' **Guardian Angel Proposal** represents **one of the first**, if not the first, example of recognizing the role of the patient as a curator of his or her lifetime of health data. The Guardian Angel "Manifesto" was posted when the Web was only 2 years old at the then readily available 2-letter domain name www.ga.org.

17.3.3.1 Portals

Many of these portals also include functions besides viewing EHR information, such as secure physician-patient messaging, appointment scheduling, and viewing and managing medical bills. Users of the Group Health Cooperative patient portal most frequently viewed test results, requested medication refills, participated in secure messaging with their provider(s), and viewed after-visit summaries. Many of these portals also provide secure messaging systems, allowing patients to communicate concerns about their clinical record to their health care providers.

17.3.3.2 Personal Health Records

PHR is An electronic application through which individuals can access, manage and share their health information, and that of others for whom they are authorized, in a private, secure, and confidential environment.

The immunization blue book is a quintessential, efficient system with portable information that supports entry by multiple providers and storage by the patient.

Data from two competing health care networks may reside in the same PHR without cumbersome agreements between those two networks. The patient asserts her claim to the data for each network independently. This consumer-driven model of data aggregation may promote data liquidity far more than competing approaches, such as health information exchanges which require centralized management of data sharing agreements between networks and institutions.

17.3.3.3 Personally-Controlled Health Records

Closely replicating the patient-centered functionality and convenience of the immunization blue book is the personally controlled health record (PCHR), a special instance of personal health records.

The first instance, called the **Personal Internetworked Notary and Guardian or PING.**
PING was later renamed to **Indivo**. Indivo became the reference model for subsequent PCHRs, including:

- Microsoft's HealthVault
- GoogleHealth (now defunct)
- Dossia consortium of large employers

Barriers of PCHR:

- EHR vendors have been slow to allow data liquidity. Important data may reside in unstructured clinical notes, text blobs, or even scanned images, or data may be structured but may not be sufficiently demarcated to separate the entry into usable pieces.
- Data within an EHR may not conform to published standards for interoperability. For example, although the system may share laboratory data, it may not code the data in a standard such as LOINC .

Models of health behavior change:

1. **Self-efficacy:** An individual's impression of one's own knowledge and skill to perform any task.
2. **Social cognitive theory:** Behavior change is determined by personal, environmental and behavioral elements, which are interdependent.
3. **Theory of planned behavior:** A link between attitudes and behavior. It asserts that behaviors viewed positively and supported by others (subjective norm) are more likely to have higher levels of motivation and more likely to be performed.
4. **Transtheoretical/ stages of change model**

17.3.5 Consumer Decision-Making

These applications of medical informatics technologies focus on the **patient as the primary user**.

Decision tools:

- Helping parents know when to take their child to the doctor or start treatment at home,
- Deciding screening test,
- Deciding between surgery or drug therapy.
- Simpler decision aids are offered in paper form, take the form of decision trees, where answers to questions lead patients to a recommendation.
- Dynamic assistance for health behavior change interventions through mobile devices.
- Web complex decision models that support tailored risk information and utility assessment tools
- Weight Watchers Online 5 represent more reference based decision aids
- Vandemheen's decision aid to help patients with cystic fibrosis consider lung transplantation as an option, use more sophisticated approaches

17.3.6.1 Passive Information Access	17.3.6.2 Active Information Access
provide patients with condition-specific information about the problems they face <u>when they search for it.</u> The presentation of CHI is heavily influenced by the **perspective of the system developer:** 1. **Professional-developed consumer resources:** developed by health care clinicians and their organizations 2. **self-help perspective (more inclusive):** The information may address daily living concerns and lifestyle issues along with, or in place of, content deemed credible by established medical authorities. 3. **Combination:** provide pointers/access to other Web sites that represent professional or self-help perspectives. Examples: ○ The Fred Hutchinson Cancer Research Center. ○ HealthGate Data Corporation.	<u>Actively</u> provide information based on specific patient needs (does not require searching). The Project HealthDesign teams developed many demonstrations of active access. For example, ● **"Conversational assistant":** provide patients with a daily checkup and information to mitigate exacerbations of their heart disease. ● Allow older adults to manage complex medication regimens at home. ● Use of monitoring data from sensors in the home to produce automated feedback and intelligent alerts for coaching interventions. E.g. motion sensors, pressure mats, contact switches, wireless medication dispensers, etc. ● MyMediHealth project provide medication reminders to patients in real time using text messaging to their phones. When a dose is missed, MyMediHealth is able to escalate its medication reminder to a parent or other adult

17.4.1 Health Information Technology for Economic and Clinical Health Act of 2009

The **HITECH** Act provides that, for covered **entities using or maintaining an EHR**, "the individual shall have a right to obtain from such covered entity a copy of such information in an electronic format."

Early stage efforts have arisen to promote data liquidity through the very **well-marketed Blue Button** initiative from the Department Veterans Affairs, and the Direct Project, a federally initiated, health specific implementation of the **SMTP protocol** to enable **point to point communication** of health information in a secure, standards-based.

17.4.2 Information Credentialing

key issue in CHI lies in determining the <u>quality and relevance of health information</u> found on Web sites **credentialing** or **certification** by recognized bodies, such as respected health care providers or clinical professional associations, represents one approach to ensuring the quality of health information available to consumers.

It has the advantage of: delivering an imprimatur to a Website, which informs the user that the information presented meets a standard of quality.

Information presented by alternative therapies and other non-clinical groups is no less susceptible to bias than is information presented by professional sources.

Inherent in the credentialing approach are **three disadvantages**.

1. The challenge to ensure that every information element every link in a decision program or pathway in a Web site is tested exceeds the resources available to do so. In many cases, the credentialing approach rests on certification of the group or individuals providing the information rather than approval of the content itself.
2. The credentialing approach leaves control of the authority for health care information in the hands of traditional care providers, reflecting both the expertise and the biases of established medical source.
3. Credentialing alone is inherently contradictory to healthcare consumerism, which empowers the consumer to make choices consistent with her own worldview.

A **source's credential** is just an additional piece of information that may be considered in making **personal health decisions.**

informatics team:

Deema Alfaris
Lina Alshehri
Luluh Alzeghayer
Munira Alhussaini
Moneerah Alomari
Nora Alkhayal
Renad Alqahtani
Rifan Hashim
Samar Alotabi
Sara Alqahtani
Sara Alkhalifah