7- Consumer Health Informatics (CHI)

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- **References:** 436 Doctor's Slides and notes , E.H. Shortliffe and Marsden , 435 teamwork

Editing File

Objectives

Not found ☹

Color index

- ■ Doctor's notes
- ■ Extra information and further explanation
- ■ Important
- ■ Main titles
- ■ Subtitles

This slide from doctor's slides   This slide from the book

Introduction

- Health informatics has 2 main subspecialties:

  1. Clinical informatics: it supports clinical practice e.g. electronic medical record, COPE, CDSS, PACS (Picture Archiving and Communication System), radiology informatics

  2. Public health informatics: it focuses more on population, disease, causes, management and manipulation of data and information and knowledge. E.g. bioinformatics (management and manipulation of data and information and knowledge on molecular level to understand the pathophysiology of the disease and the response on the medication)

- Consumer health informatics (which is sub field under medical informatics area) intersects with other specialties like, public health medical education, communication science

- نركز على ال consumer information needs Focuses on 2 main things:

1. what are the information needed for the consumer (patient)? Why? So the patient can understand → they become more compliant → we have better management

2. Accessibility for the patient (the patient can access her/his file and have full knowledge about the condition and can be part of the management)

3. Designing and developing methods for the best way to communicate with the consumer. E.g. patient engagement, ,we have to engage patient with us How we can educate them? How we can engage them? Make them part of the clinical process

4. Integrate consumer preferences and values evidence based medicine: latest or best research, patient value, clinical expertise

5. The third point is patient value

- Consumer health information resource and medline are NOT an example of patient-specific application in biomedical information

- Both consumer health informatics & telehealth are ways to bridge the distance between patient and necessary health resources

Consumer Health Informatics

- **What is Consumer Health Informatics?** **A branch of health informatics** (social informatics) **that:**
    1. Analyzes information needs of consumers. (information of your concern as well, the clinically important information not any information)
    2. Studies and implements methods of making health information and services accessible to consumers. (Why make it accessible? Because I need to make the patient close, engaged)
    3. Integrates consumer preferences into health care information systems.

- In this view, consumer health informatics analyzes consumers' needs for information; studies and implements methods for making information and services accessible to consumers; and models and integrates consumers' preferences into health information systems.

- Consumer informatics stands at the crossroads of other disciplines, such as nursing informatics, public health[1], health promotion, health education, library science, and communication science.

- **Consumer Health Informatics** (to create environment الهدف This environment has 2 main characteristics):

- Integration of consumer health information and information technology[2] in an environment that has 2 characters:
    1. shared healthcare decision-making
    2. Supports effective self-health action.المريض أو الكونسيومر عند القدرة على الإعتماد على نفسه

- **Consumers**

- Broader than "patient " it may include the well, healthy and caregivers.

- It is a very diverse group. (Consumers include patient and healthier)

- ❖ If the patient has no knowledge about a specific topic then he cannot participate in decision, so we have to educate the patient If the patient don't have the ability to self-depend (impairment, don't know how to), they must depend on others, as long as I give the patient skills, knowledge and accessibility he will be engaged in decision and management وهذا يدعم المجتمع Consumer health informaticsوهذا الهدف الساسي من ال

> When you are communicating with the consumer (patient) you have to know what is the best and effective way of communication with your patient
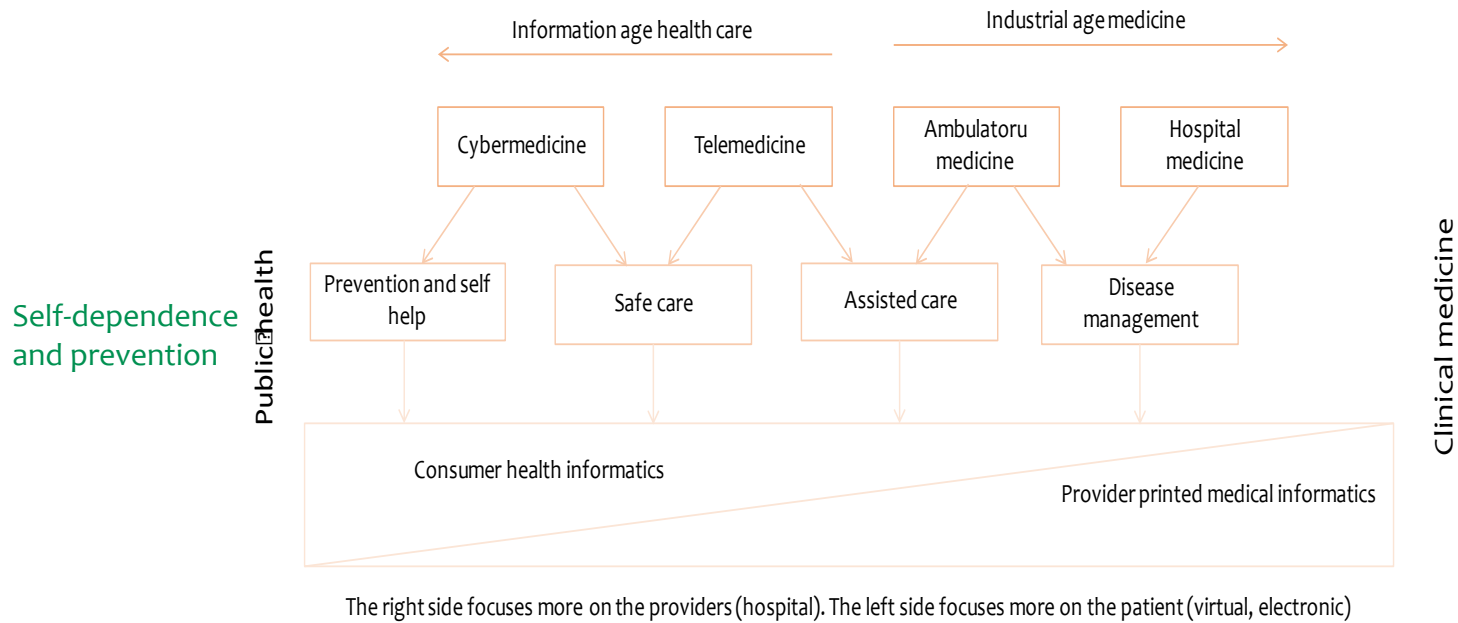
[1] CHI may overlap with public health
[2] the information is medical and clinical information and the way to deliver this information is by technology

Consumer Health Informatics

- **The focus of traditional health care and medical informatics is shifting from health professionals to consumers**

The right side focuses more on the providers (hospital). The left side focuses more on the patient (virtual, electronic)

The more we go to the left side, the more we go to consumer health informatics (we make the consumer part of the decision) but if we go to the right then it is more provider printed (the decision is mainly based on the provider not the patient)

Empowered Consumers

- **Empowerment:** Granting (giving) of power to a dependent group المجموعات الاعتمادية or enhancing an individual's **ability** for <u>self</u> determination (عارف وعنده وعي عن حالته وعنده القدرة إنه يسوي اللي تبيه)

- "a **social** process of recognizing, promoting and enhancing people' abilities to meet their own **needs,** to **solve** their own problems, and **mobilize** (give patient access) the necessary resources in order to feel in control of their lives" (Gibson, 1991) مثال عليها التطبيقات الجديدة اللي طلعتها وزارة الصحة مثل استشارة، شاركنا وتطبيقات التطعيمات، فيعني يصير المريض يقدر يحصل على خدمات طبية بدون حتى ما يضطر إنه يترك بيته

- Patient empowering: Assisting people in finding others with similar concerns to share experiences regarding health

- ❖ **Consumers Health Informatics applications support the empowered consumers concept (a power balance in the patient-health professional relationship) by e.g. :**

- Providing Informing about health concerns. (educate consumers smartly in particular to what is their needs, so they can be part of the decision).

- Assisting in finding others with similar concerns. emotionally support patients and their families (usually virtual "cyber" communities). Support group, share experiences, peer education

المشكلة لما احد يستخدم مضاد حيوي ويبغى الكل يستخدمه

That's why it has to be done under moderator وسيط to make sure that discussion is positive.

- Assisting in navigating the health care system and services. How to search info and how to use electronic health care services.

- Access to clinical records and personal care management tools. Peers education. E.g. the patient will be able to know the lab results, يعني بدل ما يصير يأخذها نسخة ورقية ممكن تضيع، أو الدكتور ينسى يطبعها له والمريض يحتاج الورقة عشان موعده الجاي، هنا خلاص يقدر يدخل على ملفه ويعرف كل النتائج المتعلقة فيه

# Consumer Health Informatics (CHI) مب مهم

❖ History of CHI

- Consumer movement of 1970s.

- Increased demand for information.

- Greater participation in "medical" decision making.

- Prominence of "self-help" phenomenon of 1980s .

- Huge increase in health information for lay audience.

- Widespread use of the Internet.

- Increased dramatically throughout 1990s.

Consumer Health Informatics: Past, Present, and Future of a Rapidly Evolving Domain G Demiris - IMIA Yearbook, 2016

Degree of consumer autonomy:

1. Provider information
2. Access to personal medical information
3. Communicate with providers
4. Obtain education / information / treatment
5. Give / receive support
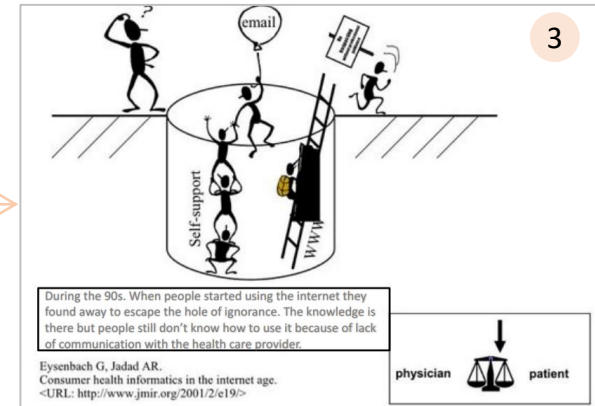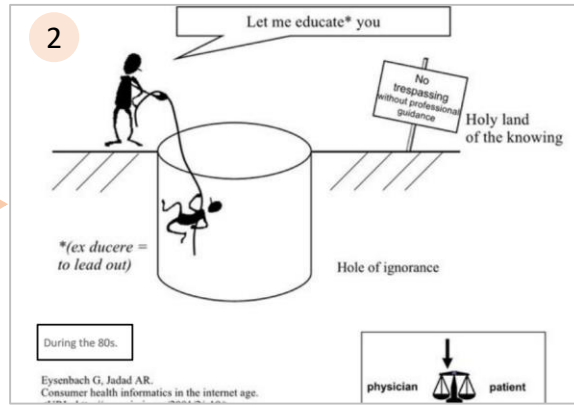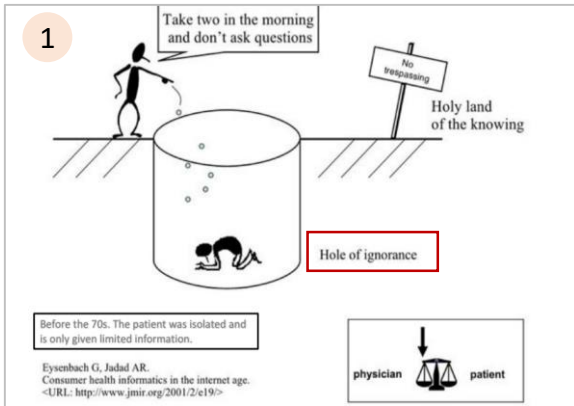
1. Right after world war 1, there was missing communication between the consumer and provider + there wasn't any awareness regarding the consumer (disaster mood) the communication between the physician and the patient is not fair (they don't educate the patient they just give direct instruction)
2. They start to make some small programs for prevention and education but it was very slow and basic
3. 1990 CHI dramatically increased After the internet, they found that communication has improved the healthcare (by e-mail and websites 'www'). The problem that they have the information but don't know how to use it, e.g. they know the drug but don't know how to use it أي مثلًا كانوا لمن يجيهم التهاب يروحون عند الطبيب يقوله اصرف لي مضاد وهم مب عارفين إن مب كل الالتهابات تحتاج مضاد
4. The hole of ignorance wasn't a concern anymore after building the bridge of communication and accessibility of the consumers. This happened by consumer health informatics
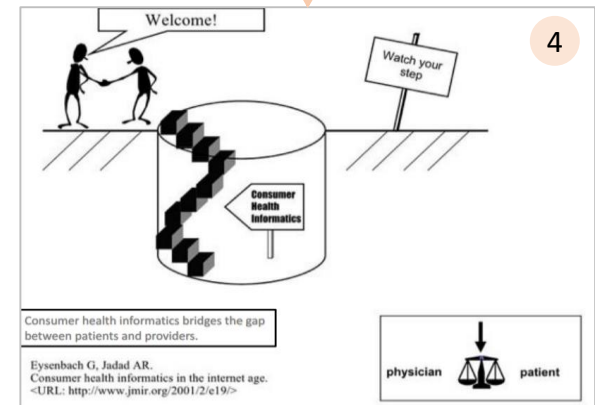
Mobile health (M-Health)

- M-health or Mobile health is a term used for the practice of medicine and public health, supported by mobile devices. The term is mainly used in reference to using mobile communication devices, such as mobile phones, tablets and PDAs, for health services and information. The mobile Health is a sub-segment of eHealth.

- Mobile is the most Pervasive technology ever invented. Every mobile now has health application e.g. diabetic applications.

- The M-Health market earned revenues of $230 million in 2010 and is estimated to reach $392 million in 2015 in USA, according to a new report from research firm Frost & Sullivan.

- The main reason for influencing a person to use smartphones rather than feature phones is the availability of application
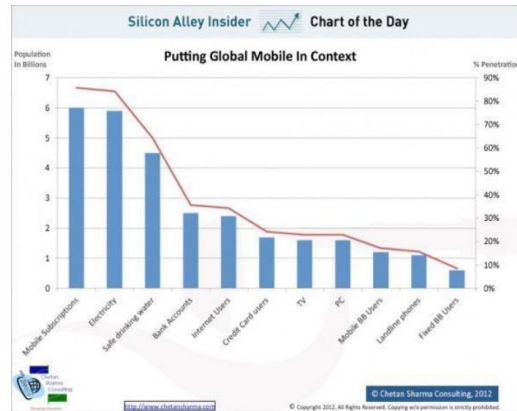
In 2014, mobile services became the most used intervention in history, even more than electricity, TV and other services. This means there is a huge increase in internet usage even in communication, so in healthcare should get advantage of this.

- Consumer health informatics should be based on:
  1. The theory and methodology (Empowered Consumers, communicate with the consumer)
  2. The fact that almost everybody has an access to internet and has mobile, so we can improve the health services by using mobile application and internet

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Consumer Health Informatics

❖ **Types of Consumer Health Informatics**

1. Consumer or patient views.
2. Patient-focused informatics.
3. Health literacy and consumer education. تعليم وتثقيف المرضى فيما يخص حالتهم الصحية
4. Health information literacy.
5. Consumer-friendly language.
6. Personal health records, and internet-based strategies and resources and give access[3]

❖ **Benefits of consumer health informatics:**

1. Trust and confidence: patient know who is he contacting
2. Physician is confident enough to answer his patient
3. Physician has access to patient information, so the answer will be a tailored answer not general
4. If simple can give diagnosis and medication
5. ممكن توفر حضور البيشنت للعيادة

❖ **Where clinical IS and Consumer health informatics meet**

▪ **Patient Portals:** Patient interface to clinical information systems.

▪ **Personal Health Record:** Internet based- set of tools that allows people to access and coordinate their life-long health information and make appropriate parts of it available to those who need it. (web based system that enables patients to gather, access for healthcare delivery)

❖ **Consumer Health Informatics Systems**

▪ **Consumer health informatics can be organized into three general systems that:**

1. provide health information to the user (one-way communication) e.g. literature paper, static website, BMJ best practice articles

2. tailor specific information to the user's unique situation (customized communication) for specific disease, e.g. preventive healthcare program for cardiovascular

3. allow the user to communicate and interact with health care providers or other users (two-way communication) I can response and communicate (e.g. online discussion group, by email, social media)

[3] the patient can request appointment, refill of their medications, they even can get the medication by Saudi Post, they even can request referral (nutrition, ophthalmologist, nephrologist. They can view their own EKG so they can get another opinion, they can view their medication

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Consumer Health Informatics

- **One-way communication:** CD-ROMs, online health articles

- **Tailor:** automated systems that obtain information from the consumer about his or her general health or other health-related factors (such as family disease histories and smoking habits) and, on the basis of this information, suggest a need for preventive health procedures (such as mammograms), or identify actions to curb high-risk behaviors. Focus group, or both one way and two ways

- **Two-way communication:** electronic mail, electronic bulletin boards, on-line discussion groups.

Roles of Health Professionals in CHI

- Professionals serve as sources of content مصدر المعلومة الأوثق بالنسبة للمرضى هو الطبيب لذلك المفترض نحرص احنا كأطباء نزيد نزيد التواصل مع medical team is the source of content to also المرضى ونشرح لهم ونوضح لهم كل شيء عن مرضهم حتى يزيد الالتزام بالخطة العلاجية عند المرضى patient support group

- Professionals provide important guidance in moderating public electronic discussion groups and responding to patients' electronic messages إذا يبغى معلومات زيادة عن مرضه أعطيه موقع معين يساعده أو منشور

- Clinicians become information brokers and interpreters for patients. يصحح المعلومات اللي يجيبها له المريض من مصادر غير موثوقة

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Quality control of health information on the internet

❖ **The quality control of health information on the internet rests on four pillars:**

1. Educating the consumer. موقع ليس تجاري

2. Encouraging the self regulation of providers of health information.

3. Having third parties evaluate the information. وجود طرف ثالث لتحكيم محتوى الموقع

4. Enforcing consents in cases of dissemination of fraudulent or harmful information. خصوصية المرضى

Credibility Criteria
مو مطلوبة

❖ **The FA4CT Algorithm (A New Model and Tool for Consumers to) :**

1. **F**ilter and **A**ssess Health Information on the Internet

2. **C**redible Criterion

3. **C**urrent and frequently updated.

4. **R**eference cited.

5. **E**xplicit purpose.

6. **D**isclosure of sponsors.

7. **I**nterest disclosed and no conflicts found (e.g. financial).

8. **B**alanced.

9. **L**evel of Evidence.

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❖ **Patient Centric Healthcare**

▪ "care that is respectful of, and responsive to, individual patient preferences, needs, and values" and that ensures "that patient values guide all clinical decisions."

▪ This definition highlights the importance of clinicians and patients working together to produce the best outcomes possible.

▪ You move the services and information to the patient rather than moving the patient to hospital مثل أبشر تبع وزارة الداخلية
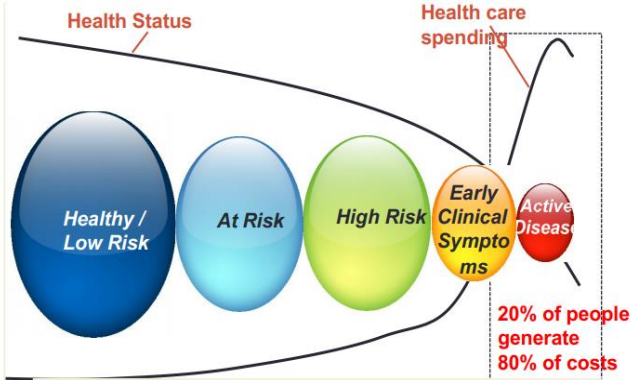
❖ **Patient / People Engagement** or People Centered Care

▪ **WHO defines People Centered Care as:** "Care that is focused & organized around the health needs & expectations of people & communities rather than on disease"

❖ **Characteristics of Patient Centered Care** (all supported by CHI)

▪ Respect for patients values, preferences & needs.

▪ Coordinated and integrated care.

▪ Information, Communication & Education.

▪ Physical Comfort. Because you don't have to go or travel always, you can get all you need at home

▪ Emotional Support cyber communities.

▪ Involvement of family & friends.

▪ Continuity of care. Emailing, ask for refill, second consultation

▪ Access to care.

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It's a Different Ballgame	Is "At the Point of Care" Too Late?	Actions
• In an eHealth environment, Information Moves rather than the Physician or the Patient eHealth ePhysician – eConsumer	• Early detection of at-risk patients. • Provide personalized evidence to enable pro-active decisions. 	1. Technology victories and chronic disease. 2. e-Health takes a prominent role in the management of healthcare 3. To aggregate rather than segregate healthcare system 4. Consumer health education and empowerment 5. Preventive medicine takes precedence over treating the sick 6. Focus on vulnerable members of society

Health Status
Health care spending
Healthy / Low Risk
At Risk
High Risk
Early Clinical Symptoms
Active Disease
20% of people generate 80% of costs

The Challenge of Improving Consumer Engagement

- Seminal (productive/ important) work by sociologists and psychologists observed that consumers may become engaged to be rewarded by participation or through external rewards.

- ❖ **The Challenge of Improving the Information Available to Consumers**

- The advent of the Internet, **interactive television** and available home technologies provide a rich source of tools to address this challenge.

Early Advances in Consumer-Consumer Communication

- a precursor to the World Wide Web known as **Gopher (protocol)** connected patients to information about various rare and chronic diseases

- increased use of the Internet raised concerns about the quality of the material available to consumers. This concern, in turn, fueled an industry of groups charged to create a legible and responsive consumer information, as well as other groups who focused on rating the quality of this information

- Example of a group that promotes the deployment of useful online health information **is the Health on the Net Foundation (HON)**

- to provide "just-in- time" information and decision assistance to consumers, videos were created to explain treatment options and medical procedures to patients 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**

Consumer Decision-Making

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

- **Decision tools:**

1. Helping parents know when to take their child to the doctor or start treatment at home

2. Deciding screening test

3. Deciding between surgery or drug therapy.

4. Simpler decision aids are offered in paper form, take the form of decision trees, where answers to questions lead patients   to a recommendation.

5. Dynamic assistance for health behavior change interventions through mobile devices.

6. Web complex decision models that support tailored risk information and utility assessment tools

7. Weight Watchers Online 5 represent more reference based decision aids

8. Vandemheen's decision aid to help patients with cystic fibrosis consider lung transplantation as an option, use more sophisticated approaches

Consumer-Facing Software

- most common sites where health care is provided are home, community and web browsing by computer and phone.

The Challenge of Improving the Information Available to Consumers

- The advent of the Internet, **interactive television** and available home technologies provide a rich source of tools to address this challenge.

- technologies can be categorized into four modes in which consumers engage with health care through the use of technology (this table summarize the 4 categories)

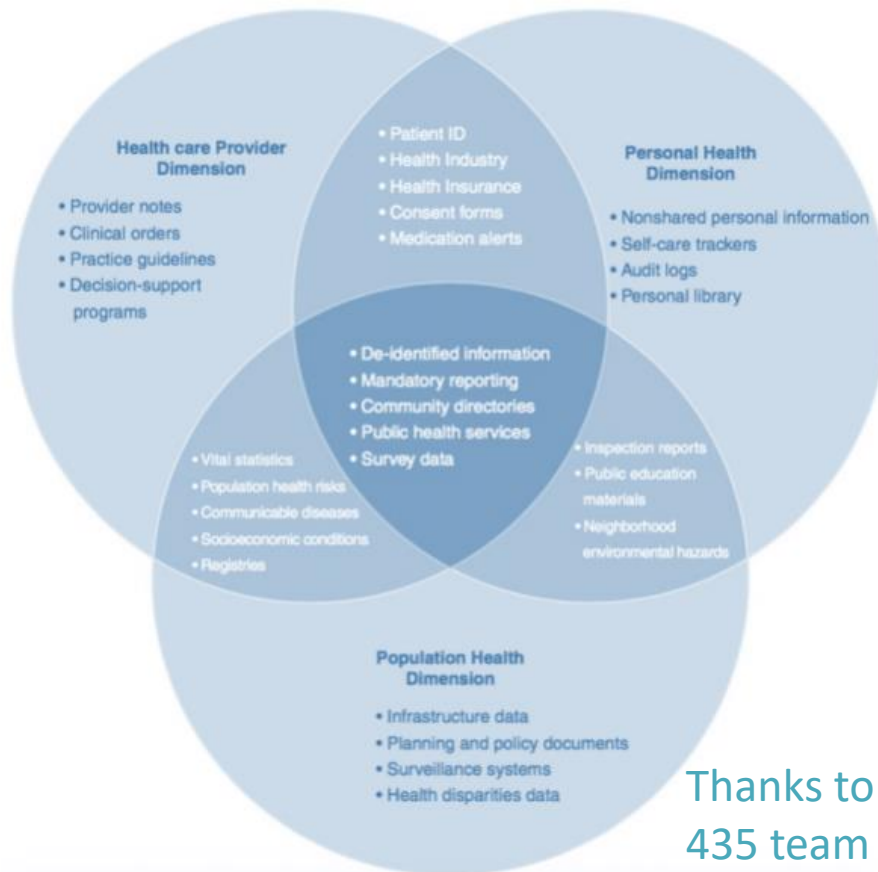## Various modes of consumer engagement with health care technology

Mode of engagement	Definition	Examples
Communication	Support for patient-to-patient and patient-to-provider knowledge or information dissemination (e.g. of patient-patient interaction is social support group for diabetes on Facebook)	- Patient portal - Patient-physician secure email - Online support group (system under CHI) - Social networking sits
Data storage	A patient-centered and managed repository for patient-entered data or 'liquid' health-related information	- Personal health record - Data portal for devices, health system 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 system
Decision aids	Prepare people to participate in 'close call' decisions that involve weighing benefits, harms, and scientific uncertainty	Interactive tools for breast cancer, prostate cancer, back pain, End of Life, Heart disease

Patient-Centered Communication

- frustration about the inability for electronic health records to support record-sharing 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 .

- Making a clear concept on how the quality of health care should be "patient-centered" among other attributes

- Figure below describe the information dimensions outlined in this work.

Health care Provider Dimension
- Provider notes
- Clinical orders
- Practice guidelines
- Decision-support programs

- Patient ID
- Health Industry
- Health Insurance
- Consent forms
- Medication alerts

Personal Health Dimension
- Nonshared personal information
- Self-care trackers
- Audit logs
- Personal library

- De-identified information
- Mandatory reporting
- Community directories
- Public health services
- Survey data

- Vital statistics
- Population health risks
- Communicable diseases
- Socioeconomic conditions
- Registries

- Inspection reports
- Public education materials
- Neighborhood environmental hazards

Population Health Dimension
- Infrastructure data
- Planning and policy documents
- Surveillance systems
- Health disparities data

Thanks to 435 team

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❖ Electronic Support Groups

- Electronic support groups, also known as Internet Support Groups (ISGs), have become an almost ubiquitous way for patients 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.**

❖ Social Networks

- The for-profit of online health-related social networking community help in contributing data and observations to a patient community to accelerate learning about their disease.

❖ 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.

❖ Portals

- Many of these portals also include functions besides viewing EHR information, such as secure physician-patient messaging that allow patients to communicate concerns about their clinical record to their health care providers. Also, appointment scheduling, and viewing and managing medical bills

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.

❖ 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:

- **1- Microsoft's** HealthVault   **2- Google Health** (now defunct)   **3- 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 <u>own knowledge and skill</u> 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 <u>supported by others (subjective norm)</u> are more likely to have higher levels of motivation and more likely to be performed.

4. **Trans theoretical/ stages of change model**

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.

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Information Credentialing

- key issue in CHI lies in determining the **quality and relevance of health information** 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.

Advantages	Disadvantages
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.	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

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

Format Access

Active
Actively provide information based on specific patient needs (does not require searching).
- The Project Health Design 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

Passive:
provide patients with condition-specific information about the problems they face **when they search for it**. The presentation of CHI is heavily influenced by the **perspective of the system developer:**

Professional-developed consumer resources: developed by health care clinicians and their organizations

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.

Combination: provide pointers/access to other Web sites that represent professional or self-help perspectives. Examples:
- The Fred Hutchinson Cancer Research Center.
- Health Gate Data Corporation.

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Questions

1. **Insures that the patient has access to information resources necessary to participant fully in the health care process:**

A. Telemedicine   B. health informatics   C. consumer health informatics   D. bioinformatics

2. **What is the main reason influencing physician to use smart phones rather than feature phones:**

A. Available application   B. Battery life   C. Internet and email access   D. Multimedia capability

3. **Patient interface to clinical information systems:**

A. Personal health record   B. Electronic Medical Record   C. patient portal   D. Telemedicine

4. **project provide medication reminders to patients in real time using text messaging to their phones:**

A. E-Sehi   B. MyMediHealth   C. HL7   D. Absher

5. **electronic records that are owned, maintained and updated by an individual is known as which of the following:**

A. Patient Health Education Record   B. Personal Health Record   C. Electronic health record

D. Electronic Medical Record

6. **A special instance of personal health records that replicates the patient-centered functionality:**

A. Patient portal   B. consumer health informatics   C. Empowered Consumers   D. personally controlled health record

1. C
2. A
3. C
4. B
5. B
6. D

FEEDBACK