

What is Consumer Health Informatics

It is a branch of health informatics that:

- Analyzes information needs of consumers. Look into the methods to implement these needs and make information and services available.
- Studies and implements methods of making health information and services accessible to consumers.
- Integrates consumer preferences into health care information systems. The most important thing to satisfy your clients (patient, consumer and public)
- CHI does a lot of things but these THREE are the main focus. All these things aim to enable your consumer to take the right decision by **informing and educating them.**
- 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 crossroad of several other disciplines, and areas such as nursing
 informatics, public health, very important. reaching, educating and engaging public is a part of CHI, health
 promotion, health education, library science (how we present, how we segment, how we make these info
 more available for consumers), and communication science.

Consumer Health Informatics

Subsidiary of health informatics which focuses on and addresses:

- Consumer or patient views (it's main focus is the patient, here most of the information services application should consider the patient as a **core**. In other speciality of health informatics, they also focus on the patient, but they also focus on the user)
- Patient-focused informatics
- Health literacy (this is important because in general, we want health awareness and informations about healthcare to be there, especially when we are talking about public health issues such as hygiene, DM)
- Consumer education
- Health information literacy
- Consumer-friendly language
- Personal health records, and internet-based strategies and resources
- Consumer empowerment (enabling & supporting the patient ability to take role of their health issue and to be part of it)
- Selfcare & self action (trying to support the concept of patient trying to take care of himself as much as they can, and be able to make decisions, or to be a part the decision making when the issue is about himself)

Consumer health informatics



Consumer health informatics as a subdiscipline is founded on the need for access.

• Integration of consumer health information and information technology in an environment of shared healthcare decision-making that supports effective self-health action. (remember the word environment, cause it is our goal here. We are dealing with consumer, so we want to create an environment that could help the patient, that could share the decision between healthcare professionals and the patient)

Who are the consumers?

- More broader than patient it may include the well, healthy and caregivers. Because consumers
 have more needs while patients they only need medical care. Also consumers could be your future
 'patient'
- It is a very diverse group, and includes patients, population and professionals.















































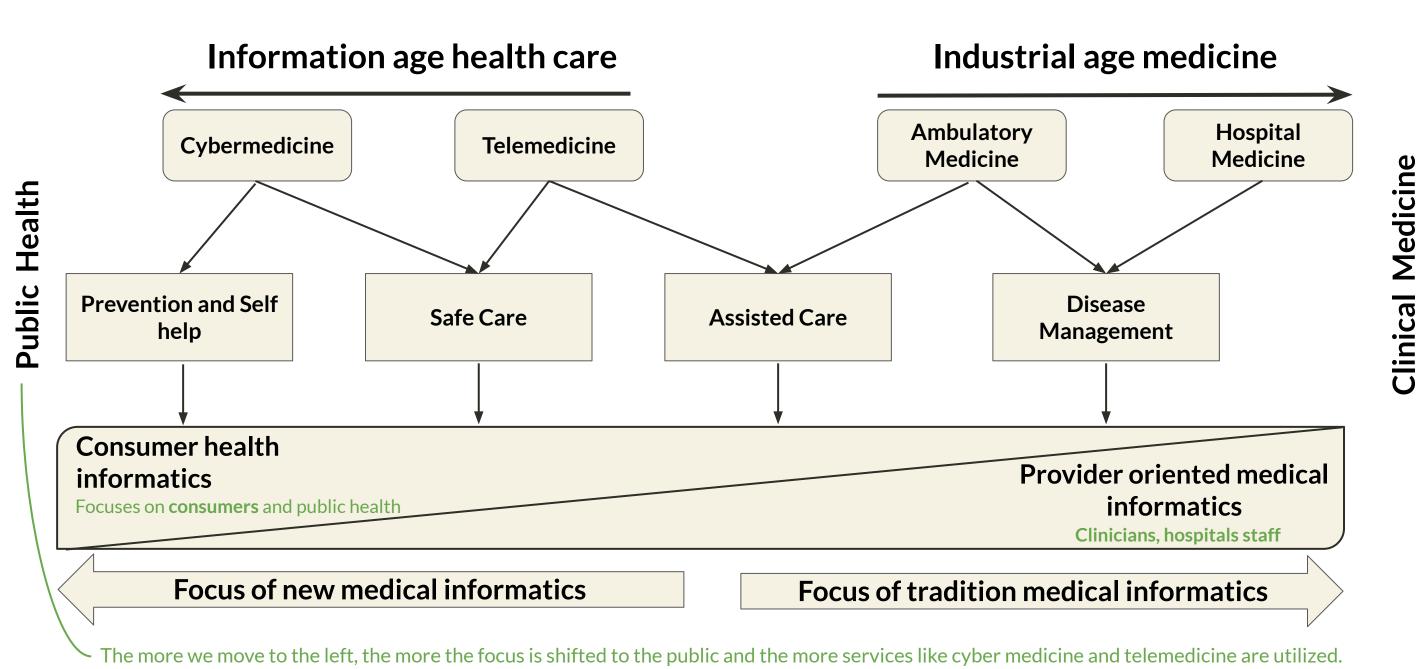








What is Consumer Health Informatics



The focus of healthcare consumer health informatics is shifting from health professionals to be consumer centered.

Empowering Consumers

"Empowerment" Is granting of power to a dependent, group or enhancing an individual ability for self determination. We're trying to make this dependent group independent. It is a holistic approach.

- "A social (have friendly environment) (Don't forget the word) process of recognizing, promoting and enhancing people's abilities to meet their own needs, to solve their own problems, and mobilize the necessary resources (could be information or e-services) in order to feel in control of their lives" (Gibson, 1991)
- Consumers health informatics applications support the empowered consumers concept (a power balance in the patient-health professional relationship) by e.g.
 - Providing informing (for consumer especially) about health concerns. Education. Awareness of symptoms, diseases and the actions needed to be taken in certain situations.
 - Assisting in finding others with similar concerns. (for example: cancer patient, if we make a community for them, they will learn from each other and they will support each other)
 - Assisting in navigating the healthcare system and services. Teaching patients the skills they need and teach them how to search and obtain information.
 - Access to clinical records and personal care management tools. We want patients to be able to request services, retrieve and view their records through patients portals

History of Consumer Health Informatics (CHI)

- Consumer movement of 1970s.
 - **Increased demand for information.** Consumer, public, and healthcare professionals
 - Greater participation in "medical" decision making.
- Prominence of "self-help" phenomenon of 1980s. Because hospitalization is not the answer
 - Huge increase in health information for lay audience.
- wide spread use of the internet.
 - Increased dramatically throughout 1990s

















































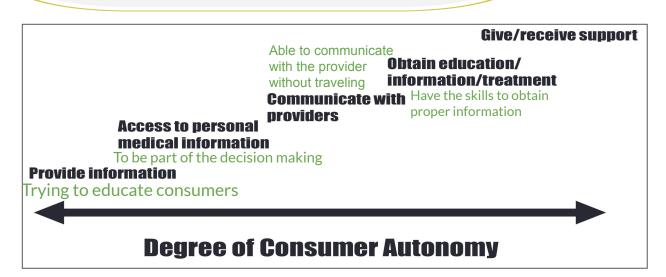




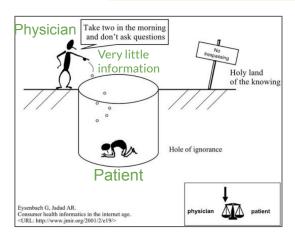


What is consumer health informatics

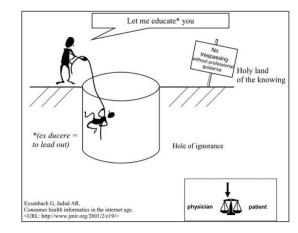
CHI Continuum



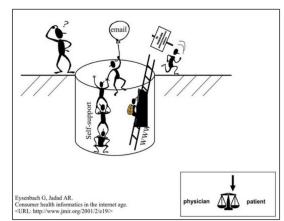
Degree of Consumer Autonomy



In 1960s and below, the relationship was bad that there was not any balance. No education for the consumer.

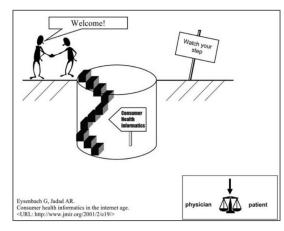


There is basic education; not well established. 1980recognize need for educating. We started to acknowledge that we should educate patients.



1990; explosion of access methods to knowledge; people have knowledge but not able to understand and put it into context.

Sometimes it's correct info but sometime it's misleading. The patient here is trying to get out the hole.



CHI development to bridge the gap between clinician and patients. We offer guidance & support.

Consumer Health Informatics

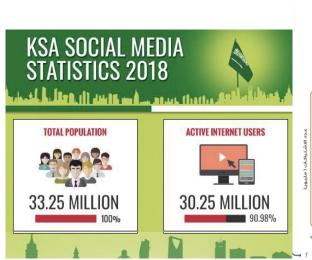
- Diverse and at a crossroad of several specialities; including:
 - Mobile health (mHealth) almost 100% have access to mHealth.
 - Telehealth monitoring patient at home by monitoring their vitals.
 - Patient education through mHealth, telemedicine and video conferencing.
 - o Patient health record.
 - Patient portal.
 - Health literacy, health promotions and games for health.
 - o Internet-based strategies and resources.

Saudi Arabia: Internet Growth

Now our population/consumer has access to internet, so we can reach them easily. And this is very supporting fact that we should utilize & capitalize to reach our patients/consumers

- More people use that internet that's why we should utilize it
- 2011= 12.5 million
- 2014= 16.5 million
- 2015= 21.5 million

YEAR	Users	Population	% Pop.	Usage Source
2000	200,000	21,624,422	0.9 %	ITU
2003	1,500,000	21,771,609	6.9 %	ITU
2005	2,540,000	23,595,634	10.8 %	C+I+A
2007	4,700,000	24,069,943	19.5 %	ITU
2009	7,761,800	28,686,633	27.1 %	<u>ITU</u>
2010	9,800,000	25,731,776	38.1 %	<u>ITU</u>











1

7

7

Mobile health

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



Mobile is the most Pervasive technology ever invented

As you can see, mobile has deeper penetration than electricity and safe drinking water.

All the evidence and statistics are suggesting that patients (consumers) have smartphones and have access to information on the internet and on social media, so we should utilize these service to support patients health and well-being.

Consumer health informatics

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

	Definition	Examples
one-way communication	provide health information to the user	CD-ROC, online health articles. For example an article on how to change your diet.
customized communication	Tailor specific information to the user's unique situation	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.
two-way communication	allow the user to communicate and interact with healthcare providers or other users	electronic mail, electronic bulletin boards, online discussion groups

Roles of Health Professionals in CHI. Professionals include physicians, technicians, nurses, pharmacist, dietitians, etc.

- Professionals serve as sources of content. Many researches shows that patients consider healthcare professionals as their main source of content.
 - Professionals provide important guidance in moderating public electronic discussion groups and responding to patients' electronic messages
- Clinicians become information **brokers** and interpreters for patients. Advising the patient for what informations are valid/outdated or which informations applies for them and which doesn't.















































Now patients can easily communicate with physicians. The good thing in this situation is that the patient trust the physicians, because he or she knows who the physician is, and they know where he works. Also from the other side the physician knows who the patient is, he has her /his file number and on top of that he has access to patient information, so he is not giving a floating decision, he is giving the info based on the message he received from the patient and the previous info that he can get from the patient file. And the communication is not necessarily an emergency, it may be a consultation



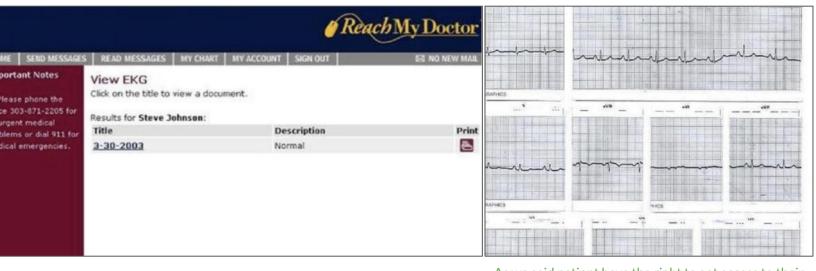
The other thing is Requesting appointment. For example: diabetic patients should not come all the way from their homes to the hospital just to take an appointment to see a nephrologist or a dietitian.



Now patients can ask for refill, or renewal of medication, the patient can get to the portal and order them by himself, and the doctor can see the order and give permission and even deliver it to patients. So no need for patient to go forward and backward just to get his prescriptions and medications.



Patients can also ask for referral. Mabey a patient want to see another doctor in other speciality just by requesting a referral in the portal.



As we said patient have the right to get access to their images, scans, etc. We even can say that they own those data and information in most of the cases.

In addition, patient can go on to their records so they can look into their patient record and see for example their lap results, and if they did any analysis whether it is positive/ negative, or what was the blood glucose level. Even they can look at their imaging, for example X-ray, and get a second opinion elsewhere. And there is no harm in that.





























































Consumer health informatics

The quality of health information on the internet rests on <u>four pillars</u>:

- **Educating** the consumer to identify and find good quality information.
- Health information providers encourage self-regulation and self-labeling. 2.
- 3. Having independent and external third parties to evaluate the information.
- enforcement legislation, in the case of fraudulent or harmful information and in cases of dissemination of 4. fraudulent or harmful information. To protect privacy and security

Challenges & Barriers

- **Privacy**; Security concerns especially in PHR where patients are uploading and accessing information. Such data and information are vulnerable to <u>cyber</u> risks and hacking. e.g. identity theft.
- Usability and User-friendly users reported PHR as too complicated while clinicians have concerns about over-simplified view presented to the uses of in these systems. A collection of mobile and online health applications are complicated than they should be.
- Access to computer and internet: Digital divide where different population segments having different access to internet. not all have access, and not all have same quality of access. Having access is an assumption but not a fact
- Patients comes from different regions and the internet connection and quality of the connection differ in each region.
- Physical disability; Elderly users may not be able to access PHR, internet and mobile apps without assistance. Making it simple and support disability
- Access to PHR systems; as benefits and business case for the adoption of PHR are limited and technology which support the evolution of PHR is still progressing. So Acceptance and use of PHR in large scale will not happen until tangible values to users and associated costs are justified.
- Cognitive disabilities functions and low literacy in computer or computer literacy and anxiety is a concern among consumers, mainly for many consumers especially elderly people.
- Low health literacy consumers with low health literacy may not be able to access and identify the improvements without education. They may be able to maintain some of their health records and services independently after having a proper training, they might not understand the readings and the interpretations
- **Terminology**; specific terms or "medical jargon" used in a PHR or health application could be too complex and confusing for users without medical training."
- **Familiarity**; consumers are most likely to use applications if they are comfortable with an interface or know intuitively how it works based on their familiarity with other systems.
- **Ensuring data accuracy**; consumers are naturally concerned with accuracy, meaning both complete and without error
- Legal Barrier; prevent doctors from practicing telehealth in different countries. Two main reported obstacles facing telehealth: legislative, to remove trade barriers and technical, to improve data security.
- **Speed and connectivity**; the system will run on different levels of connectivity; network quality and interruption especially for "life-
- sized" or high-definition video conferencing used for consultation and diagnosis
- Cost; costs of implementation and running and maintaining the system. It is important to provide solution tailored to budget, and work with low speed internet.
- **Resistant to change:** Patient acceptance of mobile and telehealth is also a challenge, also there could be resistance from the other side of support; for training and maintenance
- Lack of physician support.
- Lack of patient motivation.
- Lack of existing technology was cited as the biggest barrier. Especially when talking about primary care centers.
- **Lack of support.** Having the technology without proper technical support is an obstacle.
- Reliability of the technology;most of the elderly people are not able to trust and adapt to these technologies. you will quickly lose trust.
- Low availability; may not be available in the specific criteria or may not be customized to our needs.
- Lack of search precision; i.e. an elderly heart patient might read and follow advice only appropriate for younger patients, and a patient reading a warning about a medication on a discussion board might stop using it.
- Language centered on the western society English is the universal language, but there's a huge number of consumers that don't understand English.
- **Extensive health information** require high level of reading ability and literacy.
- Fast developing field, new systems. and adaptability, unwillingness to change to use new applications among skilled professionals and patients is one of the barriers which make them unable to leverage these technologies.

Where clinical health and hospital IS and Consumer health informatics meet?

- **Patient Portals:** Patient interface to clinical information systems. In other words, it is interface between the patient from one side to the health system from the other side. Portal is a set of different applications.
- **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.



























































CHI

Credibility Criteria

- The FA4CT Algorithm: A New Model and Tool for Consumers to Assess and Filter Health Information on the Internet
- **CREDIBLE** Criterion
 - Current and frequently updated
 - Reference cited 0
 - **E**xplicit purpose 0
 - Disclosure of sponsors they have to reveal any sponsorships to consumers. 0
 - Interest disclosed and no conflicts found (e.g financial) 0
 - **B**alanced 0
 - Level of Evidence 0

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." So they are trying to say that we should keep the patient as the focal, not the disease or the profession.
- This definition highlights the importance of clinicians and patients working together to produce the best outcomes possible.

Crossing the Quality Chasm, IOM

Patient/People Engagement

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

- **Respect** for patients values, preferences & needs
- **Coordinated** and integrated care
- Information, Communication & Education
- **Physical Comfort.** No traveling
- **Emotional Support**
- **Involvement** of family & friends social support
- **Continuity** of care. Key element, using Telehealth, patient portal and PHR Are examples
- Access to care

Is 3At the Point of Care Too Late?

- Early detection of at-risk patients. Chances of being treated is less in the early clinical symptoms phase
- Provide personalized evidence to enable pro-active decision

It's a Different Ball game

In an eHealth environment, Information Moves rather than the Physician or the Patient eHealth ePhysician - eConsumer

Health Status spending Healthy / At Risk High Risk Sympto Low Risk 20% of people generate 80% of costs

Actions

- Consumer Health Informatics and technology victories for healthcare and chronic diseases in particular.
- E-health should take a prominent role in the delivery and management of healthcare.
- To work on barriers and challenges
- To aggregate rather than segregate healthcare system
- Consumer health education and empowerment
- Preventive medicine takes precedence over treating the sick
- Focus on vulnerable members of society





















































Reference Summary

- CHI current technologies are personal health records, patient portals, personal health apps and social networking.
- The distributed managed care model states that consumers must serve as their own case managers. This will improve the patient outcome. Although patient portals can somewhat serve the purpose it is not that enough. Reward system can encourage the patients to engage in this model
- CHI goal is to make the patients the real decision maker of their health care
- Consumer facing softwares are becoming important, they are either directed towards communication, data storage, behaviour management or decision aids.
- Data liquidity refers to the ideal state of fast and free flowing data important to healthcare
- STEEEP framework (safety, timely, effective, efficient, equitable, patient centered) requires data liquidity.
- Electronic support groups (groups containing patients having the same disease) are important for consumers. It can help to disseminate knowledge faster. However, the quality is not that good
- CHI resources originate from two major perspectives; professional and self help. To make these information resources reliable, they must be **credentialed**.
- Privacy and security are major concerns for CHIs
- Guardian angle proposal: The patient must be the one responsible for his data safety.
- The phenomenon of **social networking** has grown rapidly and is a new form of patient-patient communication.

The for-profit online health- related social networking community PatientsLikeMe 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

Important

MCQs:

1- Which of the following is a free educational source for patients knowledge in CHI?

A- Kaiser permanente health facts

B- Mayo health

C-A+B

2- Which of the following is a commercially available educational source for patients knowledge in CHI?

A- Kaiser permanente health facts

B-C+D

C-Health Wise

D- Health Desk

3- Which of the following is a web based educational source for patients knowledge which combines both professional and self help?

A- Fred Hutcinson

B- HealthGate

C-A+B

4- Which of the following is the difference between PCHR and PHR?

A- In PCHR is more controlled by the patient

B- PCHR can be given attributes based on the semantics

C-A+B

Mode of engagement	Definition	Examples
Communication	Support for patient-to-patient, computer-to-	Patient portals
	patient and patient-to-provider knowledge or information dissemination	Patient-physician secure email
		Online support groups
		Social networking sites
Data storage	A patient-centered and managed repository for	Personal health records
	patient-entered data or "liquid" health-related information	Data portals for devices, health systems and, pharmaceutical companies
Behavior management	Tools to support personal health goals, often by	Weight management tools
	combining data storage, care protocols,	Physical activity tools
	information dissemination, and communication	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

Passive information access (Require patients to search)	Active information access			
 CHI resources originate from two major perspectives: professional and self-help. Professional-developed resources are developed by health care clinicians and organizations such as HMOs, and they complement the services offered by professionals. CHI resources developed from a self help perspective complement and augment those provided by the formal health care delivery system & is more inclusive than a professional perspective. 	In addition to the passive models there is an addition increasing number of personal health applications that actively provide information based on specific patient needs.			
Examples: Professional developed: -Kaiser Permanente Health FactsMayo Health Advisor. Combination of self-help & professional -Fred Hutchinson Cancer Research CenterHealthGate Data.	Examples -"conversational assistant" provides patients with a daily checkup and information to mitigate exacarbtions of heart diseases -MyMediHealth: provides medication reminders			

71 6



reminders.

Summary

200

23

Consumer Health Informatics (CHI)	 It's the integration of consumer health information and information technology in an environment of shared healthcare decision-making that supports effective self-health action. Who are the consumers? They more broader than patient, and may include the well and caregivers 		
CHI Specialities	 Mobile health (mHealth) Telehealth Patient education Patient health record Patient portal Health literacy, health promotions and games for health Internet-based strategies and resources 		
Empowering Consumers	 A social process of recognizing, promoting and enhancing people's' abilities to meet their own needs, to solve their own problems, and mobilize the necessary resources in order to feel in control of their lives. Examples of empowering consumers: Providing information about health concerns Assisting in finding others with similar concerns Assisting in navigating the healthcare system and services Access to clinical records and personal care management tools 		
CHI systems	 provide health information to the user (one-way communication) Tailor specific information to the user's unique situation (customized communication) allow the user to communicate and interact with healthcare providers or other users (two-wa communication) 		
Quality of HI	 The quality of health information on the internet rests on four pillars: Educating the consumer Encouraging the self regulation of providers of health information Having third parties evaluate the information Enforcing consents in cases of dissemination of fraudulent or harmful information. 		
Credibility Criteria	 CREDIBLE Criterion Current and frequently updated Reference cited Explicit purpose Disclosure of sponsors Interest disclosed and no conflicts found (e.g financial) Balanced Level of Evidence 		
Characteristics of Patient Centered Care	 Respect for patients values, preferences & needs Coordinated and integrated care Information, Communication & Education Physical Comfort Emotional Support Involvement of family & friends social support Continuity of care 		

Access to care

MCQs

1- Insures that the patient has access to information resources necessary to participate fully in the health care process:

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

5-Which of the following is NOT a speciality of consumer health informatics?

A. Telemedicine

B. health informatics

C. consumer health informatics

D. bioinformatics

A. Patient Health Education Record

B. Personal Health Record

C. Electronic health record

D. Electronic Medical Record

A- Patient portal

B-Telehealth

C- Mobile health

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

4- Patient and public health information technology in an environment of shared healthcare decision-making that supports self-health action, this best describes?

A- Empowering consumer

B-Public health

C-Consumer health informatics

D- E-health

6- The process of recognizing, promoting and enhancing people's abilities to meet their own needs and solve their own problems is the definition of which of the following?

A-health informatics

B-Empowering consumers

C-Telemedicine

D- Consumer health informatics

Answers key

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

























