

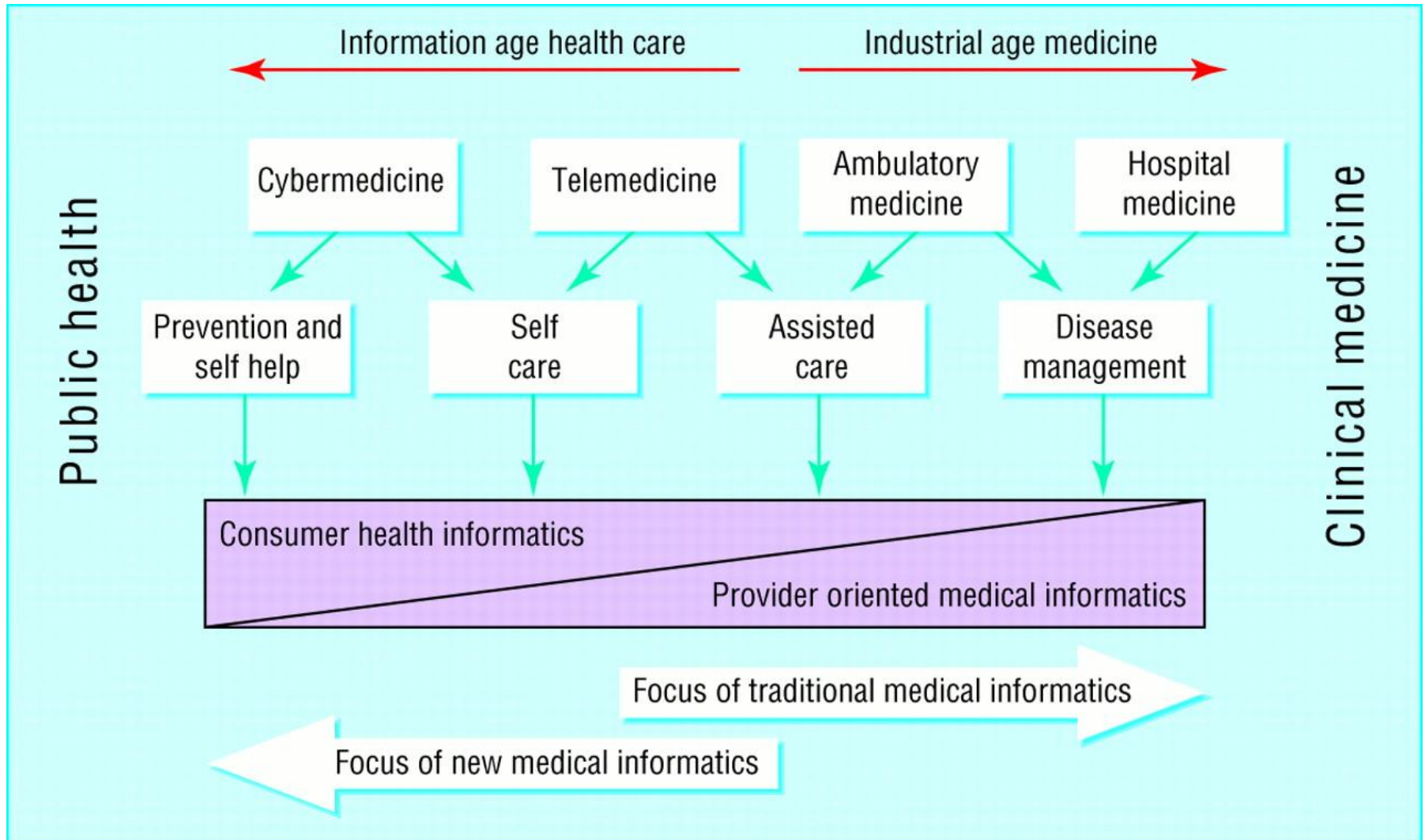
CONSUMER HEALTH INFORMATICS (CHI)

Ranyah Aldekhyyel
301 Medical Informatics
College of Medicine
King Saud University

Outline

- Definition and Scope of CHI
- Demand and supply of HI
- How Credible is HI on the Web?
- How can Consumers Assess Health Information?
- Patient accessible health records, PHR
- Different CHI tools and applications
- Web 2.0

The focus of traditional medical informatics is shifting from health professionals to consumers



Consumer Health Informatics

- Branch of health informatics that:
 - Analyzes information needs of consumers
 - Studies and implements methods of making health information accessible to consumers
 - Integrates consumer preferences into health care information systems

Other definitions of CHI

- Use of information technology to support the health and communication needs of patients and lay persons

Brennan PF. (1999). Health informatics and community health: support for patients as collaborators in care. *Methods of Information in Medicine*. 38, 274-8,

Other definitions of CHI

- Integration of consumer health information and information technology in an environment of shared healthcare decision-making that supports effective self-health action.

Lewis, D. & Friedman, C. (2002). Consumer health informatics. In M.J. Ball, K.J. Hannah, S.K. Newbold, & J.V.Douglas (Eds.). *Nursing informatics: Where caring and technology meet (3rd ed.)*. New York; Springer-Verlag.

A distinct subfield of medical informatics?

- Because of its frequent patient centered approach CHI may have a stronger overlap with public health
- The design of CHI applications require more frequent input from patient and consumer

“Consumers”

- All persons, sick or well, who seek information and take action in accord with personal preferences, life situations and individual health goals.
- Broader than “patient “ – includes the well and caregivers
- Very diverse group

Empowered Consumers

- Empowerment: Granting of power to a dependent group or enhancing an individual's ability for self determination
- “a social process of recognizing, promoting and enhancing people’ 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” (Gibson, 1991)

Brennan&Safran.Chapter 2 Empowered consumers.
In: Lewis, Eysenbach, Kukafka, Stavri, Jimison. Consumer Health Informatics
Springer, 2005

Empowered Consumers

- CHI applications support the ideology of empowered consumers (a power balance in the patient-health professional relationship) by: e.g
 - ✓ Informing about health concerns
 - ✓ Assisting in finding others with similar concerns
 - ✓ Assisting in navigating the health care system
 - ✓ Access to clinical records and personal care management tools.

Brennan&Safran.Chapter 2 Empowered consumers.
In: Lewis, Eysenbach, Kukafka, Stavri, Jimison. Consumer Health Informatics
Springer, 2005

Empowerment (political science view)

- Key dimensions (Melville, 1997):
 - **Information** (health concerns)
 - **Access** (resources)
 - **Choice** (resources)
 - **Representation** (decisions about structure and deployment of resources)
 - **Redress of grievances** (mechanisms to address concerns of how resources are used)
- The use of Internet is one facilitator for empowerment. (CHI)

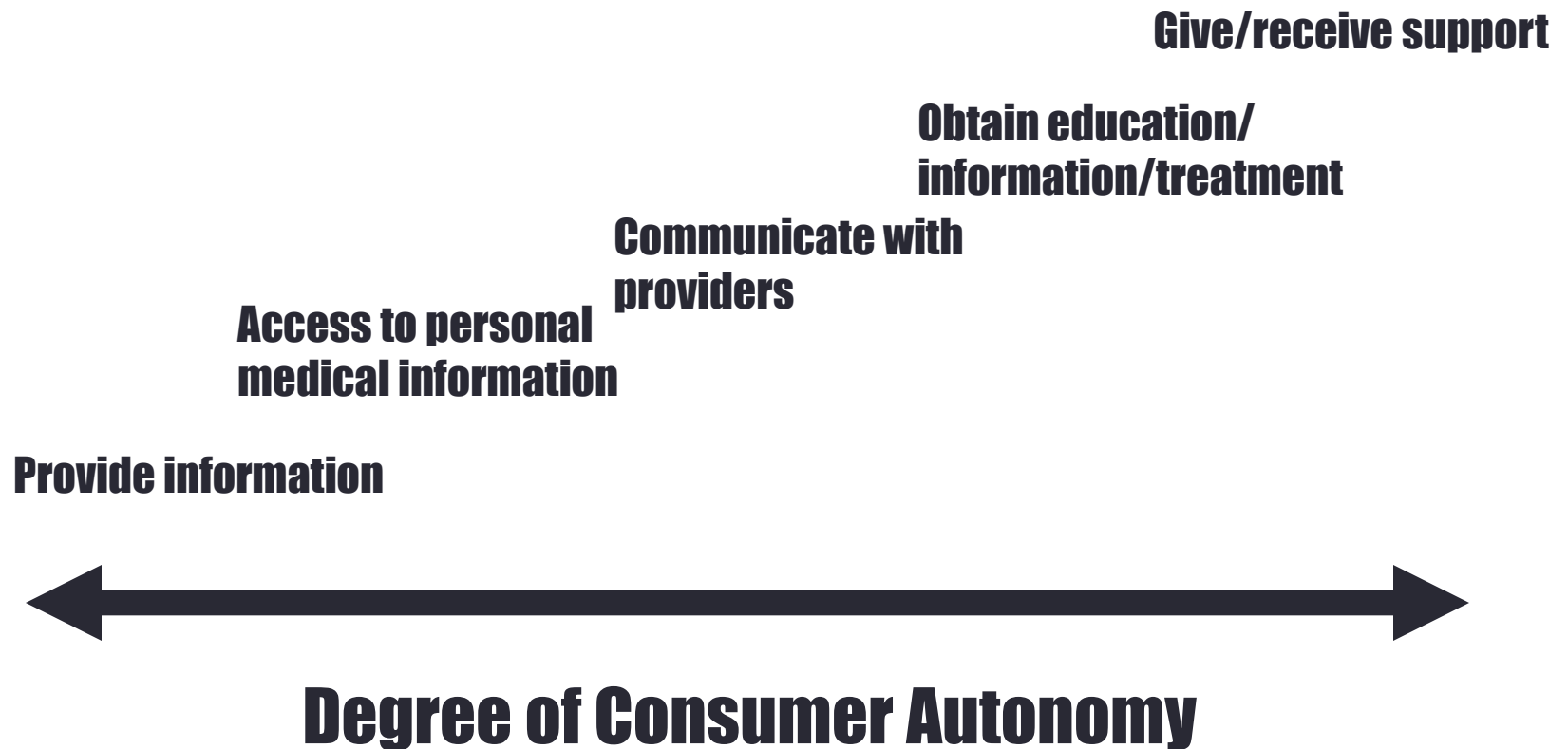
Consumer Health Informatics

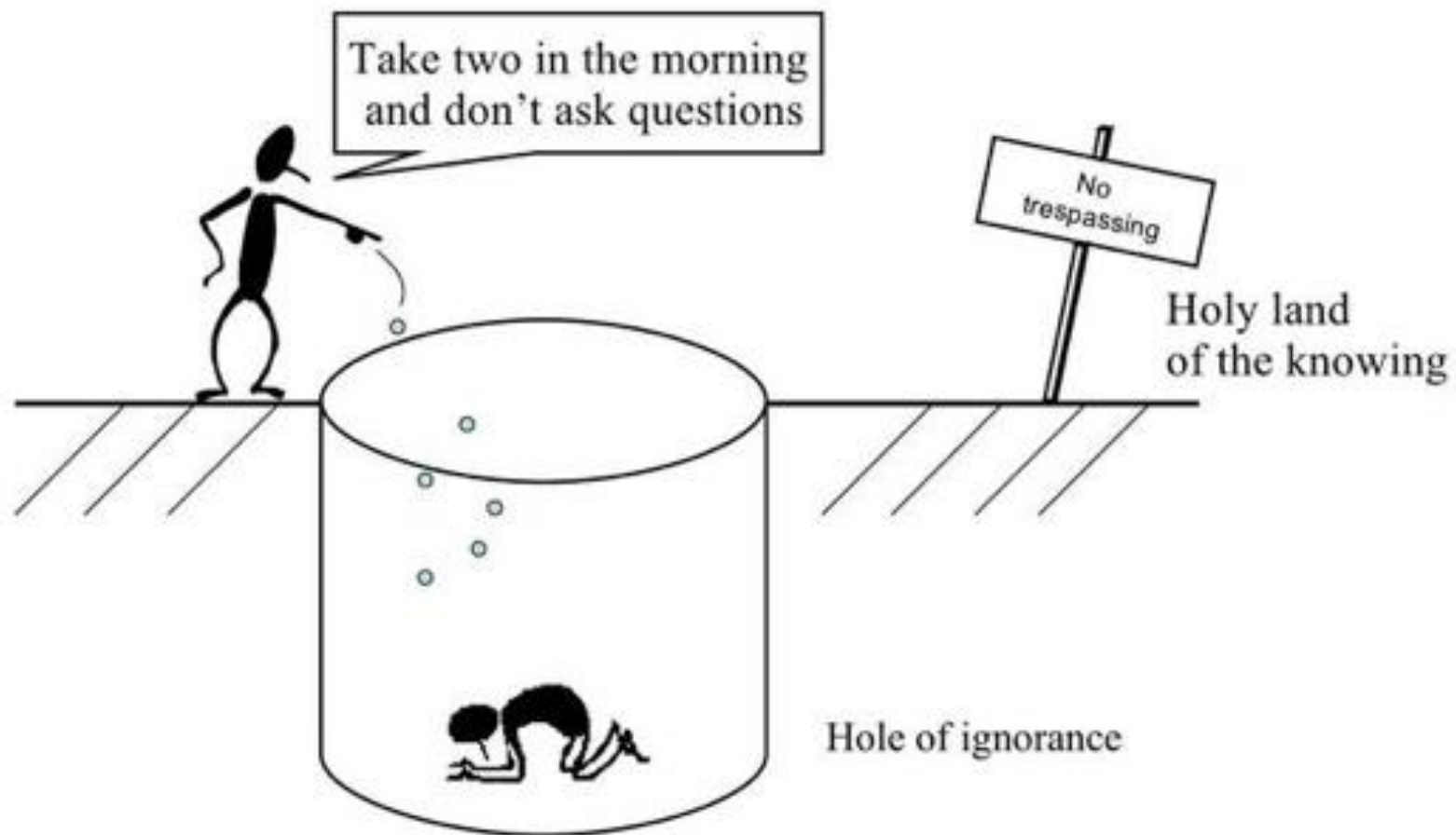
- the most challenging and rapidly expanding field in medical informatics; it is paving the way for health care in the information age.

History of CHI

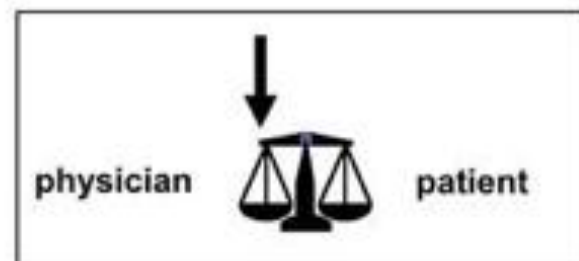
- Consumer movement of 1970s
 - Increased demand for information
 - Greater participation in “medical” decision making
- Prominence of “self-help” phenomenon of 1980s
 - Huge increase in health information for lay audience
- Widespread use of the Internet
 - Increased dramatically throughout 1990s

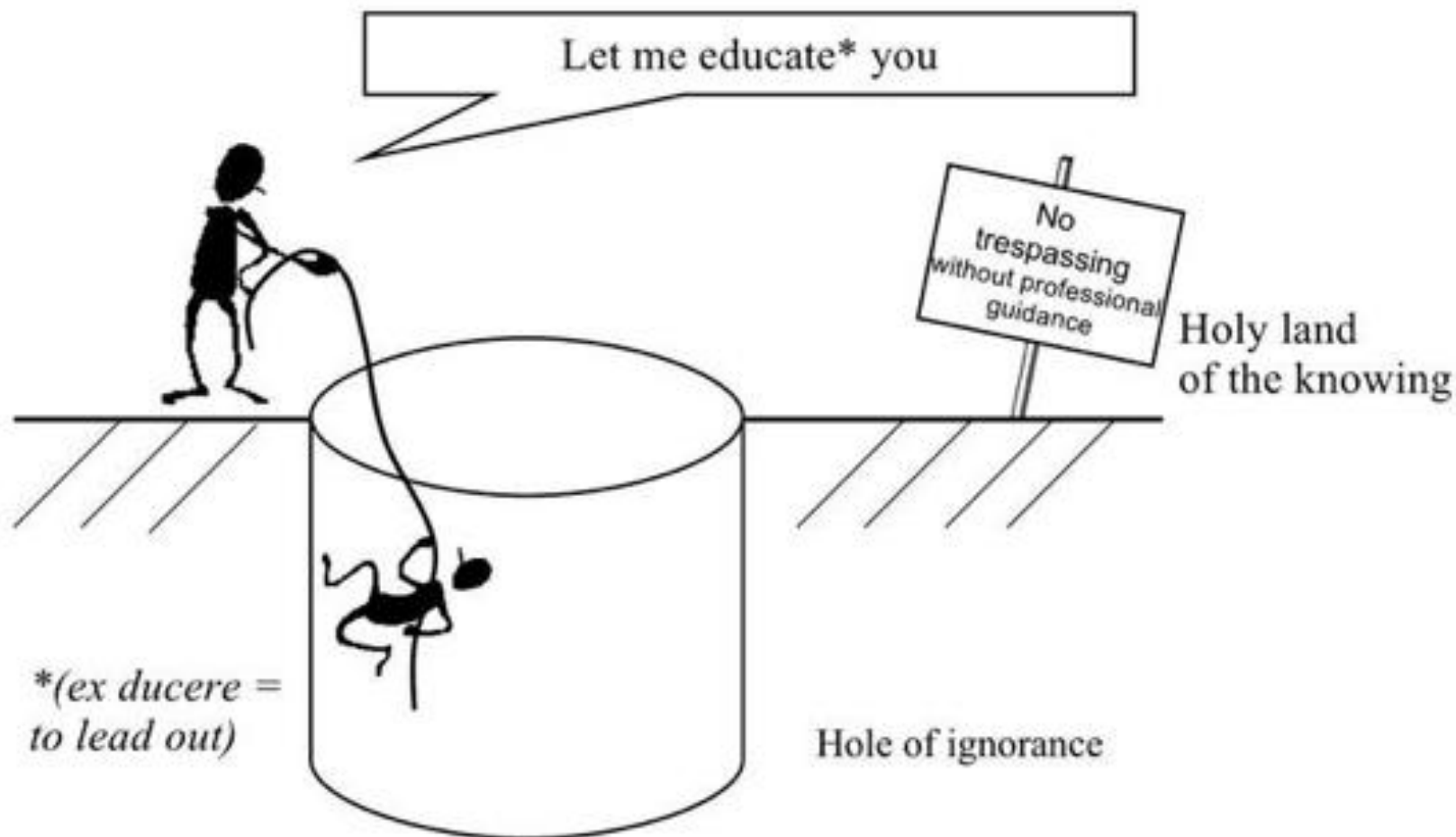
CHI Continuum



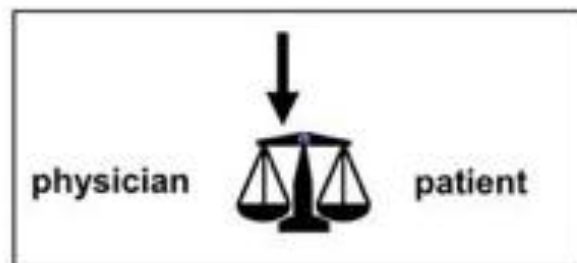


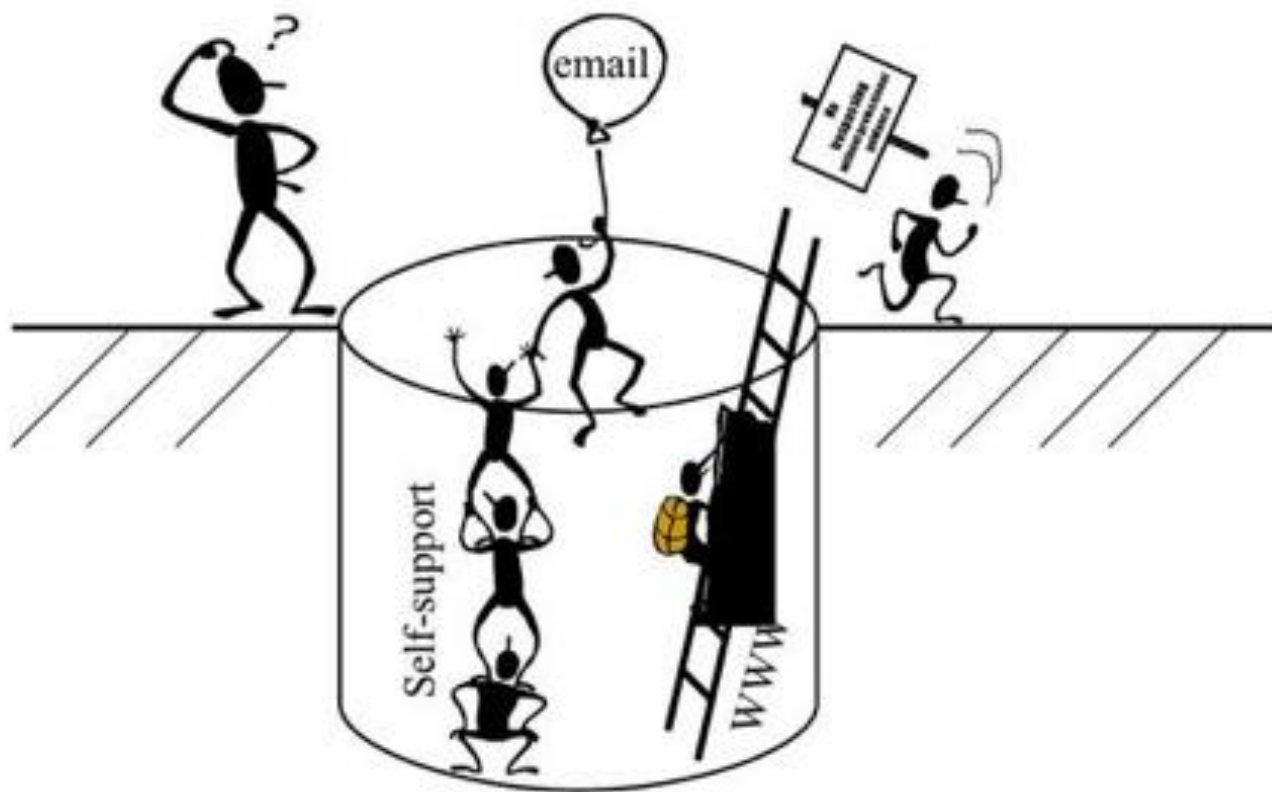
Eysenbach G, Jadad AR.
Consumer health informatics in the internet age.
<URL: <http://www.jmir.org/2001/2/e19/>>



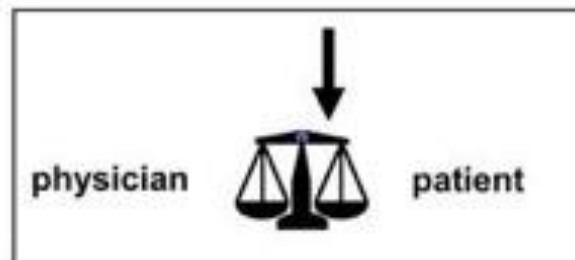


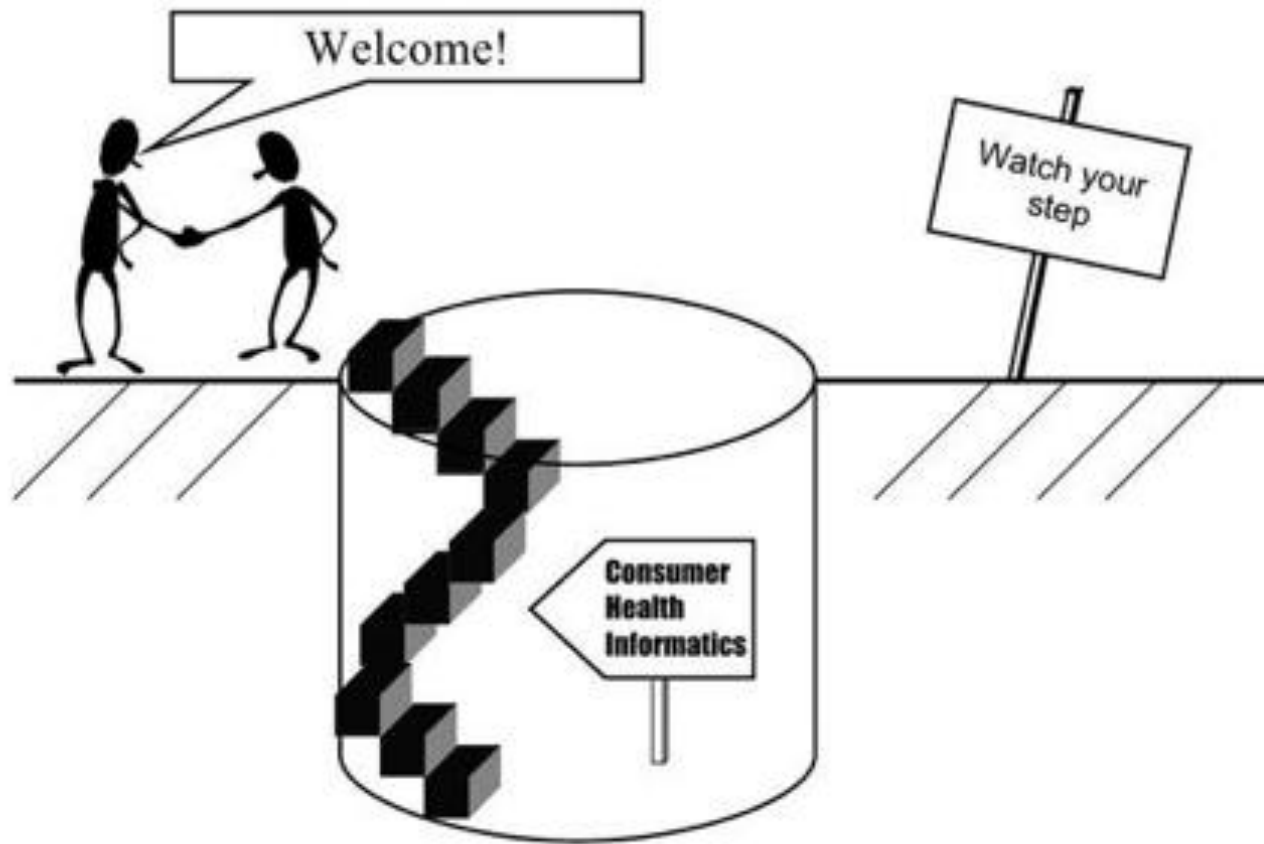
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Consumer health informatics in the internet age.
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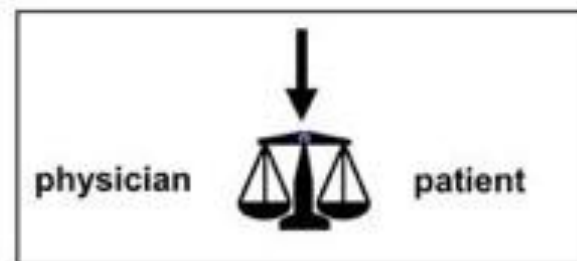


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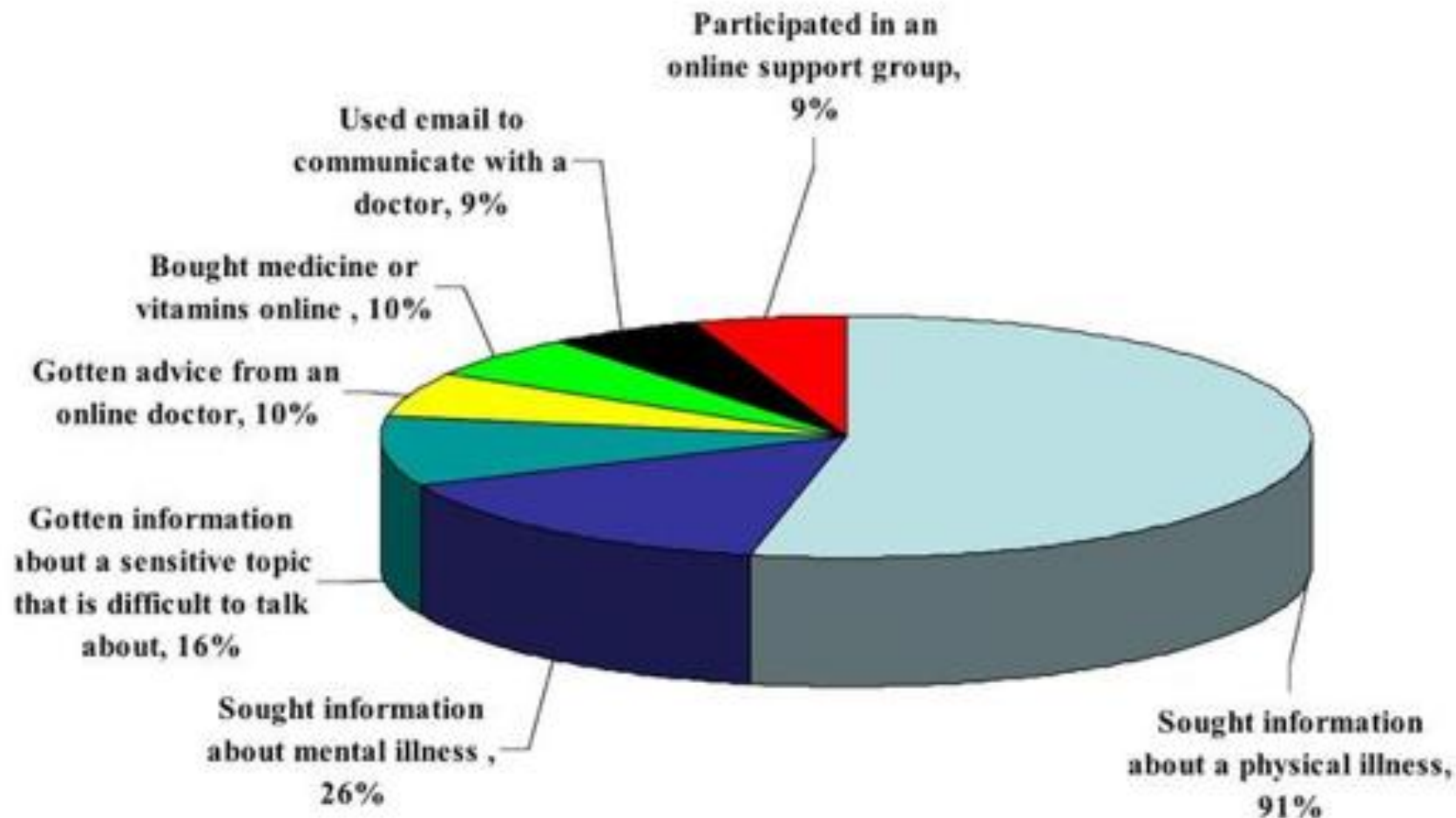


What is Consumer Health Informatics?

- Branch of health informatics that:
 - Analyzes information **needs** of consumers
 - Studies and implements methods of making health information accessible to consumers
 - Integrates consumer preferences into health care information systems

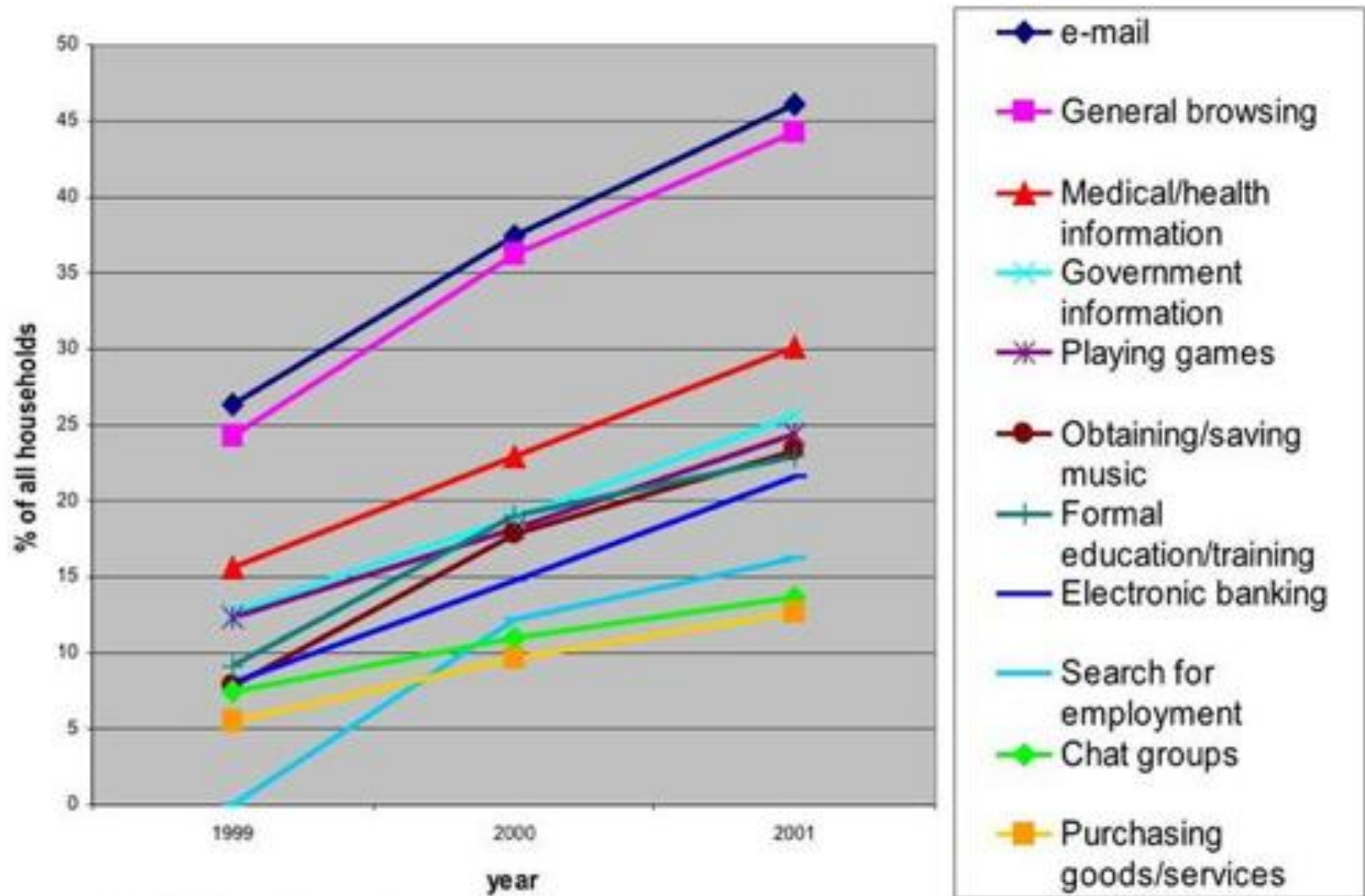
The demand side: Health Seekers on the net

In the US, (52 million) of those with internet access have used the web to get health or medical information



Source: Pew Internet & American Life Project health seekers survey, August, 2000

Canada



Source: Statistics Canada

Saudi Arabia: Internet Growth and Population Statistics

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 %	ITU
2010	9,800,000	25,731,776	38.1 %	ITU

<http://www.internetworldstats.com/me/sa.htm>

Demand: Online Health Information

- In 2010, it was estimated that:
- **Google:** 34,000 searches per second (2 million per minute; 121 million per hour; 3 billion per day; 88 billion per month, figures rounded)
- **Yahoo:** 3,200 searches per second (194,000 per minute; 12 million per hour; 280 million per day; 8.4 billion per month, figures rounded)
- **Bing:** 927 searches per second (56,000 per minute; 3 million per hour; 80 million per day; 2.4 billion per month, figures rounded)
 - <http://searchengineland.com/by-the-numbers-twitter-vs-facebook-vs-google-buzz-36709>
- Manual Analysis of 3.000 search engine queries show that 4.5% of all queries are health related

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Is cyber medicine killing you?

So viel Information war nie

Es ist die Zeit der Informationsflut, die die meisten vermöglichen Patienten. Auch die Betroffenen sollten beachten, dass diese Medien ungenügend.

Wie eine Meta-Analyse der letzten Jahre (Literatur) zeigt, ist der Informationsfluss nicht unbedingt der wissenschaftlichen Fakten. Das ist...

Sjúka bíla sjúkara nær de hárstar kunsköpur på netið

Íslendingar eru óvæðir þessu við afhæðinguna sína og hafa verið óvæðir á netinu. Þetta er ekki gott, því netið er ekki sjúkara náð og hafa verið óvæðir á netinu. Þetta er ekki gott, því netið er ekki sjúkara náð og hafa verið óvæðir á netinu.

Failure Of Internet Health Advice Questioned

A University College London study suggests that many people with chronic disease would not rely on the internet for health advice.



Fears over health 'cures' on the web

Warning on internet health advice

People with chronic disease should think twice before relying on the internet for health advice, research suggests. A University College London study found many would be in a better condition if they had simply listened to their doctor's advice.



Logging on can make you sicker

Patient, don't try to heal thyself

Internet-based health information may be hazardous: study

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Click To Get Sick?

People who get health advice from the Internet may get sicker, a study shows.

People who get health advice from the Internet may get sicker, a study shows.

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Health Do Not Want Foundation

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Warning over bad health advice online

People who use their computers to find health information often wind up in worse condition than if they had listened to their doctor

CBC Health & Science News

Internet-based health information may be hazardous: study

Too much information bad for your health, study shows

Internet-based health information may be hazardous: study

BMJ 1997;314:1875 (28 June)

Information in practice

Reliability of health information for the public on the world wide web: systematic survey of advice on managing fever in children at home

Piero Impicciatore, *research fellow*,^a Chiara Pandolfini, *research fellow*,^a Nicola Casella, *research fellow*,^a Maurizio Bonati, *head*^a

^aLaboratory for Mother and Child Health Istituto di Ricerche Farmacologiche "Mario Negri", Via Eritrea 62, 20157 Milan, Italy

Correspondence to: Dr Bonati Mother_Child@ufma.mnegr.it

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Empirical Studies Assessing the Quality of Health Information for Consumers on the World Wide Web

A Systematic Review

Main issues with CHI

- Quality of web based information
- Credibility

Quality control of health information on the internet

- The quality control 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 applied by consumers

- Authority of source
- Layout and appearance
- Advertising
- Readability
- Outbound links
- Picture of the site owner
- Email
- Credentials and Qualifications
- Updated of content
- Quality seal and third party endorsements
-

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
- Explicit purpose
- Disclosure of sponsors
- Interest disclosed and no conflicts found (e.g financial)
- Balanced
- Level of Evidence
 - Eysenbach G, Thomson M. The FA4CT Algorithm: A New Model and Tool for Consumers to Assess and Filter Health Information on the Internet. In: Kuhn K (ed.) Medinfo 2007 Proceedings (in press)

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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

Impact on Patient-Provider Relationship

- Patient role is evolving
- Informed patients more satisfied and better able to cope with illness
- Shared vs informed decision making
- “Different (not always better) relationships”
- Physician adoption of e-communication low

Decision aids to support consumers' choices

- **Computer based applications** are being developed:
- To help clinicians integrate a patient's preferences (values) with scientific evidence, the patient's history, and local constraints.
- To help patients make choices for treatment or screening on the basis of their preferences for different outcomes.

Decision aids to support consumers' choices

- Differ from information aids mainly in that they contain explicit components to help users clarify their values: the patient's personal values and the utility or importance of the risks and benefits of each alternative are elicited.

Important Notes

Please phone the office at 360-675-2286 for urgent medical problems or dial 911 for medical emergencies.

Your physician will respond to your message Monday through Friday during office hours. If you do not receive a timely response, please phone the office. During evenings and weekends, please

Contact My Doctor/Provider

Please complete the following information:

To: ▼

Subject: ▼

Message:

Dr Jones, the sample medication you gave me at my last visit does not seem to be working. Should I continue to use this or should we change to something else?

Thanks,

Steve

Important Notes

Please phone the office at (800) 475-1000 for urgent medical problems or dial 911 for medical emergencies.

Request an Appointment

Our appointment scheduling staff will handle your request, and will reply with date and time options for you to confirm.

Please complete the following information:

Type of Appointment

Complete Physical Exam



Reason for Appointment
(Optional)

I need my yearly physical exam

Special Requests, Comments, etc.

Calendar

Date Requested:

Time

☒ Morning ☐ Afternoon ☐ No Preference

Send Appointment Request

Important Notes

Please report any medication side effects or allergies.

All patients must be seen at regular intervals to evaluate your medical problems and medications.

Some insurance plans will only permit enough medication for one month at a time.

We will forward your

Refill/Renew My Medications

Please complete the following information regarding your medication refills.

(Check only those medications you need refilled or renewed at this time. You must select at least one checkbox. If you do not see your medication listed below, please [Click here](#) to update your medication list. Once you have updated your medication list, you can return to this page and request a refill.)

[Add/Edit Meds](#)

Check to Refill	Medication Name	Dosage (mg, ml)	Dosage Frequency	Quantity
<input type="checkbox"/>	Lantus	14 units	Once Daily	1 ▾ Days ▾
<input type="checkbox"/>	Regular insulin	as needed	Three Times	1 ▾ Days ▾
<input checked="" type="checkbox"/>	Lasix	20 mg	Once Daily	1 ▾ Days ▾
<input type="checkbox"/>	Lovastatin	20 mg	Once Daily	1 ▾ Days ▾
<input type="checkbox"/>	Lisinopril	10 mg	Once Daily	1 ▾ Days ▾

Important Notes

This form will be reviewed by your doctor for approval. You will be notified about approval, the need to visit your primary care doctor, etc.

Request a Referral

To receive a referral to a specialist, please complete the following:

Specialist Type	Allergist
Specific Doctor	Dr Green
Medical or Surgical Problem (Describe)	Allergies
Have you seen this specialist before?	<input checked="" type="radio"/> Yes <input type="radio"/> No
Have you consulted your primary care physician for this problem?	<input checked="" type="radio"/> Yes <input type="radio"/> No
Comments	


Important Notes

Please phone the
office 303-871-2205 for
urgent medical
problems or dial 911 for
medical emergencies.

View EKG

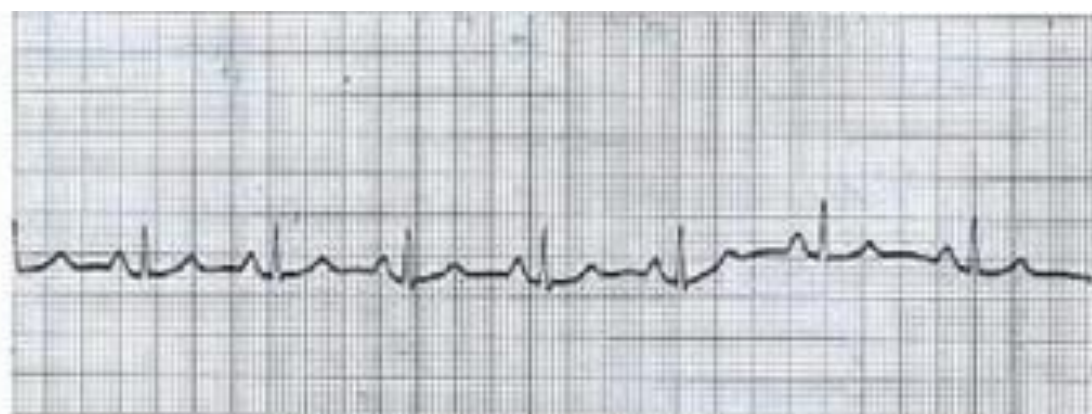
Click on the title to view a document.

Results for **Steve Johnson**:

Title	Description	Print
<u>3-30-2003</u>	Normal	



GRAPHICS



GRAPHICS



GRAPHICS



Consumer Health Informatics

- Is not restricted to the use of computers and telecommunications but also includes:
 - The delivery of information to patients through other media: the theoretical framework of consumer informatics, for example the analysis of their information needs, is independent of the media through which the information is presented.

Consumer Health Informatics Tools

- CHI use tools such as telecommunications and electronic systems as a means to optimize the retrieval, storage and recording of health information.
- It uses standard medical terminologies in nursing and medical care in its communication system.
- It utilizes other mediums for storing and sharing medical information to patients like video and audio tapes, computer discs, brochures and computer-generated fact sheets to involve patients in their treatments and screenings.

Consumer Health Informatics Tools

- These tools provide Information about the risks and benefits of making alternative choices
- Example- the choice between "watchful waiting" and surgery as responses to low back pain or for benign prostatic hyperplasia

Consumer Health Informatics Systems

- Consumer health informatics can be organized into three general systems that:
 - *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 health care providers or other users (two-way communication)

One-way communication

- CD-ROMs containing health encyclopedias
- on-line health articles
- bulletin boards
- telephone systems automatically connected to databases that provide consumers with appointment reminders.

Tailor: customized communication

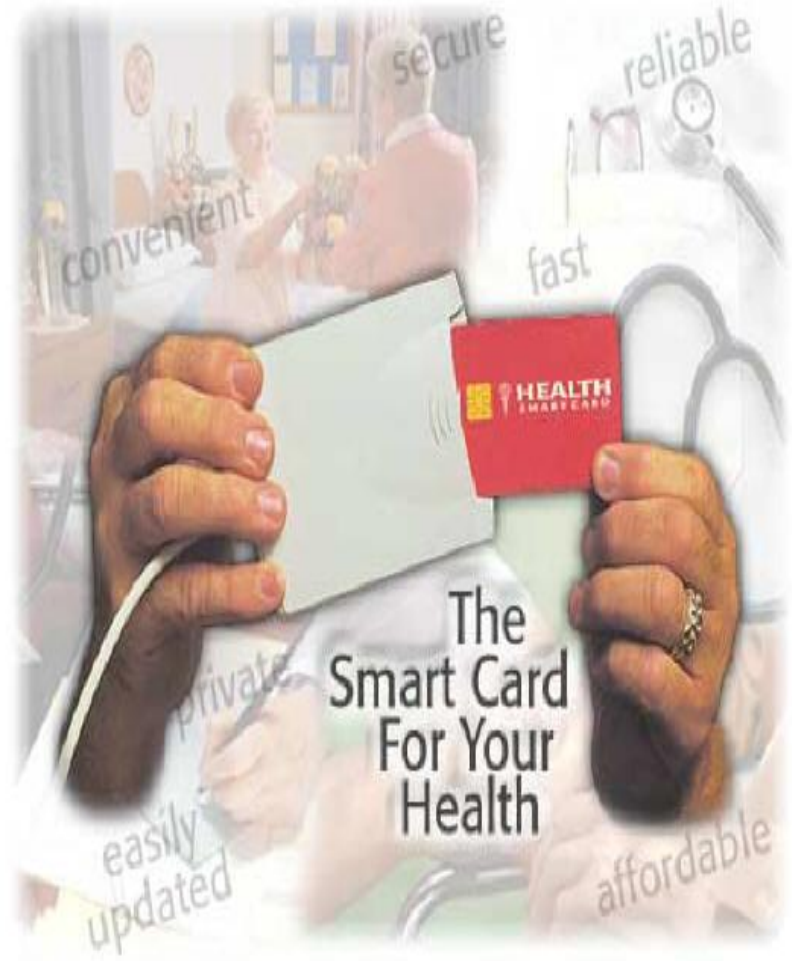
automated systems that obtain information from the consumer about his or her general health or other health-related factors (such as family disease histories and smoking habits) and, on the basis of this information, suggest a need for preventive health procedures (such as mammograms), or identify actions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

Interactive: two way communication

- electronic mail
- electronic bulletin boards
- on-line discussion groups.
- Consumers not only obtain professional advice, but also receive support from others who may be experiencing similar health problems.

The Future: Trends

- Universally, present computing
- Powerful handheld devices
- Applications with consumer awareness





Portable Patient Health Record **PR-ICE™**

Writing in the July 28, 2005 edition of the New England Journal of Medicine, John Halamka, M.D., chief information officer at BIDMC and Harvard Medical School and an emergency room physician, says the chip implanted in his arm would allow anyone with a handheld reader to scan his arm and obtain his 16-digit medical identifier. Any authorized health care worker can visit a secure Web site hosted by the chip manufacturer and retrieve information about his identity and that of his primary care physician, who could provide medical history details.

Implantable Chips



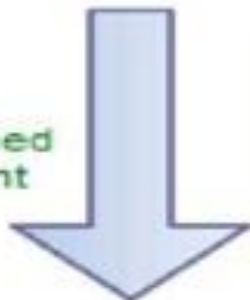
Web 1.0

"the mostly read-only Web"

250,000 sites



published
content



*user
generated
content*



45 million global users

1996

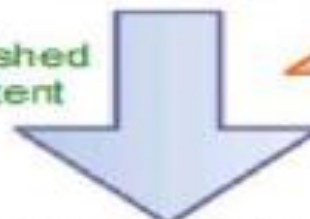
Web 2.0

"the wildly read-write Web"

80,000,000 sites



published
content



*user
generated
content*



1 billion+ global users

2006

Source: <http://web2.wsj2.com/>

eHealth Care 2.0



- Online Support Groups
- Discussion Forums
- Social Networks



- Web Search
- Provider Selection based on eRatings and preferences



- Secure Email teleadvice
- Triage
- VideoConference



- Email follow-ups
- Mobile Health reminders
- Online Rx refills

Health Care Providers (Networked)

Distributed, interoperable EHR



- Access to own EHR/PHR
- Annotate entries
- Symptom Diaries



- Tailored Patient Education
- Online Health Risk Assessments



- Online Scheduling for Office Visits
- Waiting list management



Quality ratings

Further Reading

