



Consumer Health Informatics

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Learning Objectives

1. Definitions
2. Explain how current and emerging **technologies** have impacted and may continue to affect **consumer health informatics**
3. Describe the role of **genomics** in consumer health **informatics**
4. Describe the emergence of **personal health records** and their implications
5. Discuss how **consumerism** influences the ongoing development and use of **health information systems**

Health Communication

“The art and technique of informing, influencing, and motivating individual, institutional, and public audiences about important health issues.

The scope of health communication includes disease prevention, health promotion, health care policy, and the business of health care as well as enhancement of the quality of life and health of individuals within the community”

(Ratzan, 1994)

Interactive Health Communication

“The interaction of an individual with an electronic device or communication technology to access or transmit health information or to receive guidance on a health-related issue”

HHS (2000)

Consumer Informatics

Consumer Health Informatics

- Consumer informatics
 - Management of data and information
 - Supports consumers
 - Use of computers and computer technologies
- Consumer health informatics
 - Addresses the needs of the consumer

AHIMA (2012)

Interactive Health Communication

- e-Health?
- Technology
 - Internet?
 - Web services?
 - Wireless technology?

AHIMA (2012)

Interactive Health Communication

- Tools?
 - Online communities and support groups
 - Online health information
 - Online health self-management tool
 - Online communication with health care providers
 - Online access to personal health records

Impact on Consumer Health Informatics

- New roles and approaches to health management
 - Partnership:
 - Consumers and health care providers
- New expectations
 - Access to information when needed

(Gibbons et al., 2009)

How has the Internet
affected consumer health
informatics?

Impact of the Internet

- Increase in informed consumers
- Availability of online PHRs
- New forms of communication?
- Accessibility of health care products for purchasing

Impact of Emerging Technologies

- Convergence of **media** and emergence of the **Internet** results in a **networked communication** infrastructure
- **Facilitates access** to health information and health-related support services
- Expands the **communication choices** for health professionals, patients, and consumers

Social Media

- Social networks
- Blogs
- Forums
- Wikis
- Podcasts
- Crowdsourced medical treatment and diagnosis recommendations

Potential e-Health Value Propositions

- Stakeholder: Consumers (e.g., patients), **what else?**
- Benefits sought from consumer e-Health
 - Private, 24/7 **access** to resources
 - Expanded **choice** and autonomy
 - New forms of **social support**
 - Possibility of **better health**
 - More efficient **record management**
 - **Lower cost** health care services
 - Avoidance of **duplication** of services

Potential e-Health Value Propositions

- Stakeholder: Clinicians
- Benefits sought from consumer e-Health:
 - Greater **efficiency**
 - Better **communication**
 - More **adherent and satisfied patients**

Potential e-Health Value Propositions

- Stakeholder: Health care organizations
- Benefits sought from consumer e-Health
 - More **patient self-care** and health management
 - Lower administrative **costs**
 - Improved **quality** and patient outcomes

What challenges do these
technologies and media
present?

Challenges Presented

- Concerns with **privacy and security**
- Risk of **liability**
- Lack of **law or legislation** governing the boundaries
- Lack of **payment** for engagement
- Lack of frequent **data updates**
- **Resistance** by health care providers

Role of Genomics

- Supply a piece of the personal health record
 - Family history
 - A risk factor for many chronic diseases of public health significance

Describe the picture!

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Role of Genomics

- Personalized medicine?
- Genetic discrimination?

(Ades, 2009)

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Personal Health Record (PHR)

- Electronic record of health-related information on an individual
- Conforms to nationally recognized interoperability **standards**
- Drawn from **multiple sources**
- Managed, shared, and controlled **by the individual**

(NAHIT, 2008, p. 19)

What is the difference
between EHR & PHR?

Patient portal vs PHR

Contents of a PHR

- Personal **identification**
- Emergency **contact** information
- Physician, dentist, and specialists contact information
- Health **insurance** information
- Living wills, advance directives, or medical power of attorney

Contents of a PHR

- Organ donor authorization
- Significant **illnesses/surgical procedures** and associated dates
- Current **medications** and dosages
- **Immunizations** and their dates
- **Allergies/sensitivities** to drugs or materials
- Family history

Contents of a PHR

- Recent physical examination results
- Opinions of specialists
- Important test results
 - Eye
 - Dental
- Health related educational materials
- **Health information** imported from other systems, such as patient portals
 - Images
- Other health related information?

• (AHIMA, 2012, glossary P)

HL7? PHR System (PHR-S) Functional Model

- Three sections of functions for PHR-S
 - Personal health
 - Supportive
 - Information infrastructure

- Offers guidelines that facilitate HIE?
 - Among PHR systems
 - Between PHR and EHR systems

Role of PHRs

- Help consumers make **informed health care decisions**
- **Engage** consumers in their care
- Supply information to health care providers
- **Integrate the delivery of health care** and place the consumers at the **center of their care**

PHR Implications

- For consumers:
 - What to include?
 - What format?
 - Who has access?
 - What to share?
 - Where to store?

PHR Implications

- For health care providers:
 - Use in patient care
 - Confidence the information is reliable
 - Belongs to the patient
 - Accurate/complete/up-to-date
 - Impact on workflow
 - Integration without impeding workflow
 - Interoperable
 - Ability to share and exchange information

PHR Implications

- For sponsoring organizations:
 - Keeping the PHR private and secure
 - Controlled access
 - Reliability of the system housing the PHR
 - Available when needed
 - Ability to export as well as import information
 - Seamless integration
 - Standardized permissions and formats

What is Consumer
Health information?

Consumer health information

- “Information designed to help individuals understand their health and make health-related decisions for themselves and their families”

Health Consumerism

- Health consumerism
 - **Patient involvement** in their own health care decisions
 - Patient responsibility for making **smart health care decisions**, managing benefit spending, and maintaining their health
- Enabler of health care consumerism
 - Health information systems

Health Consumerism

“Once passive recipients of medical care, patients are increasingly regarded as **active ‘consumers’ (and potential critics)** with the **right to certain standards of service**, including the **right to full information**, to be treated with respect and to be actively involved in decision-making about treatment.”

(Mead and Bower, 2000)

Benefits of Consumerism

- Catalyst for patient-centric health information systems
- Push for the adoption of health information systems
- Health care providers' responses

Challenges of Consumerism

- Health information systems
 - Evaluation of technology needed and determining how to integrate
- Directly providing health information and/or serving as portals to other sites
 - Consumer literacy
 - Filtered based on need
 - Easy access
 - Trustworthy information
 - Engaging the consumer

Summary

- Definitions
- Impact of the **Internet** on consumer health informatics
- Effect of current and emerging **technologies** on consumer health informatics
- Role of **genomics** in consumer health informatics
- Challenges
- Role of PHRs
- PHR implications
- Impact of **health care consumerism**



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