eHealth Literacy: Essential Skills for Navigating the Electronic Health Environment

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Institute of Medicine Roundtable on eHealth and Health Literacy
Outline

• The changing language of health & problem of literacy in an electronic environment
• eHealth literacy
• Measuring eHealth literacy
• Research and future considerations
Changing Health Landscape

- Generational shift from provider-centered care to consumer-centered care
  - Individuals are now expected to look after themselves as much as possible
- Information is the foundation of every health behavior change action
- The Internet provides more information than any tool ever to exist -- with no established guidelines on how to use it or how to produce content for it
Distance Health Support

- Over 80% of Internet users report seeking health information online; 86% of people with chronic conditions
  - Pew Internet & American Life Project, 2007
- Few check the sources of information thoroughly
- Widespread availability of health resources online; search engine is usually the start point
- Over half (58%) report that the information found on their search impacted health decisions
- 39% say the information changed the way they cope with a chronic condition or manage pain
  - Pew Internet & American Life Project, *Online Health Search 2006*
Sifting Through Frustration
Fundamental Challenge

• The Internet and networked tools for health represent a fundamentally new form of language requiring a new literacy form to fully engage with it.

Searching for Information on "the Common Cold"

A Case Study
Common Cold

What is a cold?

The cold is an illness caused by a virus. There are over 100 different cold viruses. Colds can occur any time of the year.

How is a cold spread?

A cold can be spread when someone who is sick coughs or sneezes tiny drops into the air or onto objects. People who breathe in or are in direct contact with these drops (example: by touching their nose or eyes with contaminated hands) can get the disease.

Signs and symptoms of a cold

The symptoms of a cold may include:

- runny nose
- sore throat
- watery eyes
- tiredness
- cough
- mild fever
- headache
## Is It a Cold or the Flu?

<table>
<thead>
<tr>
<th>Symptoms</th>
<th>Cold</th>
<th>Flu</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fever</td>
<td>Rare</td>
<td>Usual; high (100°F to 102°F; occasionally higher, especially in young children); lasts 3 to 4 days</td>
</tr>
<tr>
<td>Headache</td>
<td>Rare</td>
<td>Common</td>
</tr>
<tr>
<td>General Aches, Pains</td>
<td>Slight</td>
<td>Usual; often severe</td>
</tr>
<tr>
<td>Fatigue, Weakness</td>
<td>Sometimes</td>
<td>Usual; can last up to 2 to 3 weeks</td>
</tr>
<tr>
<td>Extreme Exhaustion</td>
<td>Never</td>
<td>Usual; at the beginning of the illness</td>
</tr>
<tr>
<td>Stuffy Nose</td>
<td>Common</td>
<td>Sometimes</td>
</tr>
<tr>
<td>Sneezing</td>
<td>Usual</td>
<td>Sometimes</td>
</tr>
<tr>
<td>Sore Throat</td>
<td>Common</td>
<td>Sometimes</td>
</tr>
<tr>
<td>Chest Discomfort, Cough</td>
<td>Mild to moderate; hacking cough</td>
<td>Common; can become severe</td>
</tr>
</tbody>
</table>

### Treatment

- **Cold**: Antihistamines, Decongestant, Nonsteroidal anti-inflammatory medicines
- **Flu**: Antiviral medicines—see your doctor

### Prevention

- **Cold**: Wash your hands often, Avoid close contact with anyone with a cold
- **Flu**: Annual vaccination; antiviral medicines—see your doctor

### Complications

- **Cold**: Sinus congestion, Middle ear infection, Asthma
- **Flu**: Bronchitis, pneumonia; can be life threatening

www.healthfinder.gov
Cold, common

Introduction

A cold is an infection that affects the upper respiratory tract - the nose, throat, sinuses (small spaces in the skull behind the eyes and nose), trachea (the main airway that runs to the lungs), larynx (voice box) and bronchial tubes (the airways in the lungs).

Colds are caused by viruses and can be spread in several ways. If you have a cold and you sneeze, cough or speak, tiny droplets of fluid containing the cold virus are launched into the air. If these are breathed in by someone else then they may become infected.

Colds can also spread through direct and indirect contact. If you have a cold and you touch your nose or eyes and then touch someone else, you may pass the virus on to them. Alternatively, if you touch an object such as a door handle or telephone, the virus may be transferred to the object. If someone touches the object a short time later and then touches their mouth, nose or eyes, they may become infected.

The symptoms of a cold usually begin 2-3 days after you become

www.nhsdirect.nhs.uk
eHealth Literacy

• “the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem.”
eHealth Literacy: Components

- **Traditional Literacy**: Reading & Writing, Numeracy
- **Computer Literacy**: IT skills
- **Media Literacy**: Media analysis skills
- **Health Literacy**: Health knowledge comprehension
- **Information Literacy**: Info seeking & understanding
- **Science Literacy**: Science process & outcomes
Lily Model

- Traditional Literacy
- Information Literacy
- Media Literacy
- Science Literacy
- Computer Literacy
- Health Literacy

Norman & Skinner (2006a). JMIIR, 8 (2) e9
General Skills

- Traditional Literacy
- Computer Literacy
- Media Literacy
- Information Literacy
- eHealth Literacy

✓ Traditional (Basic) Literacy & Numeracy
✓ Media Literacy
✓ Information Literacy
4 out 10 Americans and Canadians struggle with low literacy

- Little change from 1994 – 2003
  - Statistics Canada (2007) International Adult Literacy Survey

One quarter of U.S. 15–year olds scored at or below the lowest proficiency level in mathematics (numeracy)

Identifying Problems

- Inability to read simple text
- Difficulty understanding printed materials
- Inability to perform basic mathematical calculations such as addition or subtraction
- Considerable difficulty reading maps or understanding simple charts
Media Literacy

- Refers to the skills necessary to critically think and act based on media-based messages
- Places information in a social and political context
- Considers issues such as the marketplace, audience relations, and the role of the medium in the message
Identifying Problems

• Lack of awareness of bias or perspective taking in media -- both in terms of what *is* and *is not* presented

• Inability to discern both explicit and implicit meaning from media messages

• Difficulty deriving meaning from media messages
Information Literacy

• An information literate person knows “how knowledge is organized, how to find information, and to use information in a way that others can learn from them”
  ♦ American Library Association Presidential Committee on Information Literacy (1989)
Identifying Problems

- Inability to see connections between information from multiple sources such as books, pamphlets and websites
- Unfamiliar with local libraries and other information repositories
- Inability to frame search questions in a manner that produces desired results
Specific Skills

- Computer Literacy
- Science Literacy
- Health Literacy

- Traditional Literacy
- Computer Literacy
- Media Literacy
- Information Literacy
- eHealth Literacy

✓ Computer Literacy
✓ Science Literacy
✓ Health Literacy
Computer Literacy

- General awareness and skill in using computer-based technology to solve problems
- Relates directly to both **absolute** access to information technologies, but also **relative** or **quality** of access
  - See Skinner et al. (2003a,b), *Journal of Medical Internet Research, Social Science & Medicine*
Identifying Problems

- Unfamiliarity with basic computer terms such as *email, keyboard* etc.
- Inability to use simple input devices properly (e.g., mouse)
- Lack of exposure to information technology in everyday life
Science Literacy

- An understanding of the nature, aims, methods, application, limitations and politics of creating knowledge in a systematic manner
- 17% of Americans are considered scientifically literate
- 87% of online users (128M adults) use the Internet as a research tool
- 70% have used the Internet to look up a scientific term
  - Pew Internet & American Life Project (2007)
Identifying Problems

• Lack of understanding about the cumulative, dynamic nature of scientific knowledge
• No awareness that science can be understood and used by non-scientists
• Unfamiliarity with simple science terminology, the process of discovery, or science translation into practice
Health Literacy

- 64% of Americans have searched online for health information (80% of Internet users overall)
- conditions were more likely to report that the results of an online search influenced their health and care behavior related to their condition
Identifying Problems

- Difficulty following simple self-care directions or prescription instructions
- Fear of taking medications without assistance
- Unfamiliarity or lack of understanding of basic health care terms
eHEALS: eHealth Literacy Scale

- **Purpose:** To provide a brief measure of patient’s self-perceived skill and comfort in using information technology for health
- **10-item instrument, 5-point Likert scale questions**
- **Measures:**
  - Knowledge of existing eHealth resources
  - How to find resources
  - How to evaluate
  - How to use resources
  - How to apply eHealth resources to health problems
Results: eHEALS

- Tested in both intervention trials and population health surveys in multicultural samples (ages 12 to 91 years)
- Excellent internal consistency reliability
  - Scale alpha = .89 – .97
- Single dimension measuring eHealth literacy
- Good test–retest reliability
- Currently in use in 10 countries worldwide

WebMD Meets Facebook (and Wikipedia): A Medical Revolution or a Nightmare?

By STEPHEN J. DUBNER

A new healthcare Web site called iMedix has just been launched, and it could revolutionize the way people take care of themselves. Or it might gum up the works further; at this point, it’s hard to tell.

But you have to applaud the effort. A privately funded startup launched by Amir Leitersdorf and Iris Amirav, it allows users to search for relevant medical information, share that information with others, form online communities, and rank the helpfulness of the information they find. Think WebMD + Facebook + Wikipedia.

Concluding Remarks

- eHealth literacy is as much about a *process* of learning than an outcome – one’s literacy levels are always in flux
- How the literacy skills are expressed and their demands are related to the medium in which they are applied: the *medium really is the message*
- These skills are teachable, but they require constant remediation and updating