



Quality of health information on the internet – 10 years on

2007 Workshop Report

Quality of health information on the internet – 10 years on

This report is a compilation of views expressed during the 2007 workshop by participants. These views do not necessarily reflect the official views of Health Improvement Institute, workshop sponsors, participants' organizations, or any other organization associated with the workshop.

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For additional information about the 2007 workshop, visit www.hii.org.



Executive Summary

On November 12, 2007, Health Improvement Institute (“Institute”) held a one-day, interactive workshop to follow on the Institute’s groundbreaking 1997 workshop regarding the quality of health information on the internet. Representatives from 40 organizations participated in the 2007 workshop. Participants discussed the changes that had taken place in the past 10 years and explored current trends in consumers’ use of online health information.

The workshop agenda consisted of three components: expert presentations, workgroup discussions, and plenary presentations of workgroup results and discussion of next steps. Discussion workgroup topics included:

- What consumers want & will use
- Trustmarks, ratings, & consumer feedback
- Information for the consumers to make healthcare decisions
- Gathering evidence & improving research.

Workshop participants concluded that:

- The increasing number of internet users who search for health information online means substandard information may affect more people and cause greater damage
- Consumers are increasingly turning to social networking, search engines, and community sites for health information
- As consumer demographics become more complex, there is a need to adjust the presentation of information to cater to growing diversity
- Trustmarks aren’t necessarily trustworthy.

Participants’ recommendations include:

- Personalize online health information to cater to consumers’ specific needs
- Integrate the use of online health information with the provision of health care
- Present information in ways that appeal to consumers of different cultures, health literacy levels, ages, and socio-economic statuses
- Encourage health websites to identify themselves with company information and to make efforts to protect consumer privacy in order to create trust
- Increase the transparency of the processes by which the quality of information is rated, a trustmark is granted, and/or evidence is gathered
- Educate consumers to continue seeking information from trusted sources.

With an increasing number of consumers going online to search for health information, it is now more important than ever to ensure that information on the internet is of excellent quality. The 2007 workshop provided an opportunity for representatives from various sectors of the health/care industry, government, and consumers to evaluate efforts made in the last decade toward this goal and to develop new ideas to realize the promise of online health information, and to avoid its pitfalls by protecting consumers from fraudulent and sub-quality information. Workshop results are expected to generate further discussions, plans to improve the quality of health information on the internet, and evaluations of the effectiveness of these efforts.



Quality of Health Information on the Internet – 10 Years On

Introduction

In 1997, Health Improvement Institute (“Institute”) held a groundbreaking workshop to address concerns regarding the quality of health information on the internet. ^[1] Its main goal was to provide a forum to allow representatives of diverse organizations to formulate requirements for systems to allow consumers to evaluate the quality of health information on the internet. As a result of the workshop, the Institute developed a pilot program to rate the raters. The Institute developed criteria to assess websites that published ratings of health websites, recruited volunteer panels of assessors to apply them to websites, and published the resultant ratings on its website. In 2003, the Institute entered into an ongoing partnership with Consumer Reports WebWatch to provide consumers with independent ratings of health websites and to publish these ratings on www.healthrating.org.

In the 10 years since the first workshop, the number of internet users has soared from less than 100 million to more than 1.2 billion. ^[2] In 1997, the percentage of the population that went online was estimated to be 30%; ^[3] in 2007, 79%. ^[4] The percentage of online users seeking health information had increased from 50% ^[5] to 80% ^[6]. In the same 10 year period, the size of the health sector of the US economy grew from 3.6% of gross domestic product to 16.2%. In 2007, health care expenditures amounted to about \$7,400 per person, an 80% increase from 1997. ^[7,8] Increasingly, policy decision-makers see the informed consumer as a force to contain ever-rising health care expenditures.

In 2007, approximately 113-160 million people searched for health information on the internet. Consumers are increasingly turning to the internet for health information, even though such information is often incomplete or inaccurate. In 1997, the number of health websites was estimated to be about 10,000. ^[9] By 2002, that number had swelled to more than 100,000 ^[10] – a tenfold increase in 5 years – and by 2007, to as many as perhaps one million health websites. Concerns about the quality of health information on the internet are affecting more consumers than ever. The challenges they face today in assessing the quality of online health information are more or less the same as they were 10 years ago. Additionally, the proliferation of such online offerings as blogs, videos, social networking, and message boards is raising new issues for consumers.

On November 12, 2007, Health Improvement Institute convened another one-day, interactive workshop, in Bethesda, Maryland, to follow up on its successful 1997 workshop. The 2007 workshop provided an opportunity for healthcare professionals and consumers to discuss the changes that had taken place in the past 10 years and to explore current trends in consumers’ use of online health information. This report summarizes workshop results toward improving the quality of health information on the internet. Workshop discussions were far-reaching; participants explored many topics pertaining to the workshop’s purpose. Necessarily, this report can capture only highlights of results and the essence of participants’ recommendations.



Workshop objectives

The objectives of the 2007 workshop were to:

- Analyze changes and issues regarding web-based health information and services
- Share the methods organizations used to publish and evaluate health information on the internet
- Discuss how to improve the quality and utility of health information on the internet.

Workshop methods

Health Improvement Institute developed the 2007 workshop over a one-year period, beginning in the fall of 2006. In April 2007, the Institute convened a Workshop Planning Group (WPG) to assist the Institute in determining the workshop agenda and format, and in nominating and identifying moderators and expert resources for workgroups. Registration for the workshop began in September 2007; it took place on November 12, 2007. A total of 51 people from 40 organizations participated in the workshop. They represented the following types of organizations:

- Academia
- Award/rating organizations
- Consulting companies/think tanks
- Consumer organizations
- Federal and local government agencies
- Health care providers
- Health information technology and software organizations
- Health professional and trade associations
- International organizations
- Law firms
- Media companies, including, health website publishers
- Voluntary health organizations and associations.

At the workshop, participants received a workbook that contained the following materials:

- Workshop information – agenda, workshop objectives and description, and evaluation form
- Participants information – list of participants and their biographical sketches
- Presentation materials – abstracts, slides, and handouts
- Workgroup information – workgroup assignment, description, and list of discussion points
- Reference materials – Information about Health Improvement Institute, workshop sponsors, and workshop planning group members.

Workshop agenda

The 2007 workshop agenda consisted of the following three components:

- Expert presentations
- Discussion workgroups
- Plenary presentation of workgroup results and discussion of next steps.



The workshop began with five expert presentations. They provided a context for the four discussion workgroups that followed. These presentations addressed, from various perspectives, current issues and challenges regarding the quality of online health information and its assessment. Considered broadly, they evaluated the changes that have occurred since the Institute's 1997 workshop and proposed solutions to ensure the quality of online health information in the future.

Following the expert presentations, workshop participants assembled in their assigned discussion workgroup. The purpose of these workgroups was to give participants the opportunity to express their concerns and to contribute their expertise to a conversation regarding the workgroup topic. For each workgroup, the Institute selected one participant to serve as the facilitator and another to serve as an expert resource. The four discussion workgroups were:

- Workgroup 1: What consumers want & will use
- Workgroup 2: Trustmarks, ratings, & consumer feedback
- Workgroup 3: Information for the consumers to make healthcare decisions
- Workgroup 4: Gathering evidence & improving research.

Following the discussion workgroups, participants gathered again in plenary session to share and to discuss workgroup findings. Each workgroup selected one of its members to present discussion results and to answer questions or field them to other workgroup members. A general discussion followed workgroup presentations; it focused on future undertakings to improve the quality of health information on the internet. The workshop rapporteur summarized the views and opinions expressed during workshop presentations and plenary session discussions. In closing the workshop, its organizer emphasized next steps and echoed participants' suggestion for another follow on workshop in 2017.

Workshop results

What consumers want & will use

Participants in this workgroup discussed the kinds of information consumers want and will use. They determined that the following factors influence consumers' decisions to use online health information:

- Consumers' need for information
- How information is presented on the website
- Level of consumers' trust in information and its provider.

Workgroup participants reasoned that consumers' need for information:

- Depends on stage of illness, emotions, life, circumstances, etc
- Builds as illness progresses
- Depends on consumers' culture and social economic status.

How information is presented on a website is important in capturing consumers' interest and assisting comprehension. In order to facilitate readability and usability, workgroup participants urged creators of websites to:



- Present information at a depth appropriate to consumers' health literacy level
- Incorporate the use of pictographs
- Present information in multiple languages
- Demonstrate cultural sensitivity.

Further, participants determined that consumers will use information if they trust the website and its content. They concluded that consumers trust:

- Websites that contain links to evidence-based data or abstracts of scientific articles
- Individual experiences of consumers with similar conditions
- Information provided by "consumer experts."

Additional recommendations from this workgroup included:

- Present information in layers so that consumers can search to the depth they need, and would not be overwhelmed by the complexity or volume of the information
- Avoid lowering quality standards of information when lowering health literacy level of content
- Develop information in a foreign language in that language – and not translate from English – as cultural nuances can be lost in translation
- Create mechanisms to assess (and regulations to assure) the quality of information
- Educate consumers on how to search for information.

Trustmarks, ratings, & consumer feedback

Participants in this workgroup evaluated consumers' attitudes toward trustmarks and ratings. They concluded that while trustmarks do not necessarily create trust, they do remove distrust.

Workgroup participants determined that to earn a trustmark, health websites must be judged on the following criteria:

- Usability
- Accuracy
- Comprehensiveness
- Appropriateness of volume of information
- Transparency
- Objectivity – provision of unbiased information.

This workgroup suggested that responsible entities:

- Set standards for trustmarks – "trustmark for trustmarks"
- Incorporate consumers' input when setting standards for trustmarks
- Make trustmarks dynamic to reflect constantly changing contents and conditions
- Create page-specific trustmarks, rather than website-wide trustmarks.

Information for consumers to make healthcare decisions

Participants in this workgroup decided to rephrase the main discussion topic as follows: What kind of information is effective or helpful to consumers in making health/care



decisions? They found that consumers often encounter, and have to choose among, different types of health information on the internet, including:

- Interactive information – dialogues (e.g. emails, chats), rather than static information on websites
- Evidence-based data – information that is supported by scientific research
- Consumer-generated information – provided, in blogs, message boards, readers' reviews, etc, by other consumers who have similar conditions.

Many consumers prefer consumer-generated information – which can be inaccurate – because they can relate to the provider of information; patients feel less isolated when they receive information from fellow patients. Consumer-generated information is also easier to understand than scientific data. And, consumers judge the quality of the information based on the provider's personal profile.

What is effective or helpful information for consumers? Workgroup participants discussed strategies to present information so that consumers can easily understand and absorb it. They concluded that information should be:

- Contextualized – providing guidelines for how and when to use information and taking into account consumers' stage of illness as well as their emotions
- Personalized – regarding consumer's health literacy level, language fluency, culture, etc
- Customized – tailoring information to assist consumers to accomplish their primary health goal
- Comprehensive – providing medical or clinical, as well as care, information
- Accessible – using text and graphics to convey information effectively
- Trusted – originating from a trusted source, such as a medical doctor.

Participants proposed various methods to convey information to consumers, including:

- Use new media, such as cell phones and wikis, to present information or to draw consumers to existing information on the internet
- Increase accessibility by:
 - Presenting information in multiple languages
 - Making it easier for people with physical disabilities (e.g., diminished hearing or sight) to retrieve information.

This workgroup's recommendations included:

- Integrate evidence-based data and consumer-generated anecdotal information (e.g., embed links that lead to scientific data in message boards or blogs)
- Present evidence-based data in a compelling way to attract consumers
- Improve the quality of consumer-generated information (e.g., moderated message boards and wikis, which are constantly revised by users, etc)
- Educate consumers to search for credible information or websites.

Gathering evidence & improving research



Participants in this workgroup discussed the impact that today's increasingly diverse consumers have on research. Consumers of online health information now include people of:

- Different cultural backgrounds
- Different levels of health literacy
- Different age groups
- Different socio-economic statuses.

The workgroup concluded that because of this diversity, trust has become decentralized and consumers now have different perceptions of what they consider to be "evidence." Thus, trusted sources of information include:

- Government websites
- Anecdotes on blogs
- Peer networks.

This state of affairs has implications for scientific research because diversity of culture gives rise to:

- Different contexts in which science happens
- Different understandings of science and health information
- Different usages of scientific findings
- Different ways of communicating science.

Given these realities, participants suggested that responsible entities use the internet:

- To increase participation in research; diversity of participants can lead to more generalizable, applicable results
- To engage and inform consumers at all levels of the research process.

Workshop conclusions

Workshop participants – drawn from 40 organizations – agreed that:

- The increasing number of internet users who search for health information online means that substandard information may affect more people and cause greater damage. Thus, there is a need to provide consumers with reliable, accurate information in ways that consumers can understand and use
- Consumers are increasingly turning to social networking, search engines, and community sites for health information
- As consumer demographics become more complex, there is a need to adjust the presentation of information to cater to growing diversity
- Consumers need to know where the best sources are for definitive information; where they are not bombarded by industry propaganda masquerading as "patient education"
- Trustmarks aren't necessarily trustworthy. Consumers should be able to click on a trustmark symbol and be taken to a page that lists the requirements for earning that certification. But sometimes, the links are dead, the ratings are outdated, or the information is not helpful



- Consumers should be able to evaluate the quality of health information on the internet – we need to teach people what to ask for and what to look for.

Workshop recommendations

Workshop participants suggested the following actions:

- Personalize online health information to cater to consumers' specific needs
- Integrate the use of health information on the internet with the provision of health care:
 - Integrate consumer-generated information with evidence-based data
 - Use infomediaries, where applicable, to interpret information for consumers – people want to talk to someone
- Present information in ways that appeal to consumers of different cultures, health literacy levels, ages, and socio-economic statuses
- Encourage health websites to identify themselves with company information and to make efforts to protect consumer privacy in order to create trust
- Increase the transparency of the processes by which the quality of information is rated, a trustmark is granted, and/or evidence is gathered so that consumers are aware of the criteria and methods that experts use to judge the quality of health websites
- Educate consumers to continue seeking information from trusted sources.

Next steps

With an increasing number of consumers going online to search for health information, it is now more important than ever to ensure that information on the internet is of excellent quality. The 2007 workshop provided an opportunity for representatives from various sectors of the health/care industry, government, and consumers to evaluate efforts made in the last decade toward this goal and to develop new ideas to realize the promise of online health information, and to avoid its pitfalls by protecting consumers from fraudulent and sub-quality information. Workshop results are expected to generate further discussions, plans to improve the quality of health information on the internet, and evaluations of the effectiveness of these efforts. Health Improvement Institute plans to use workshop results to guide the development of its programs, including its health website ratings project – www.healthratings.org – which it has conducted since 2003 in collaboration with Consumer Reports WebWatch.

References

1. Goldschmidt, PG, Liao, J. Quality of health information on the Internet – telling fact from fraud. Bethesda, MD: Health Improvement Institute, 1998.
2. Worldwide internet users top 1.2 billions in 2006. USA tops 210M internet users [press release]. Arlington Heights: Computer Industry Almanac, Inc, Feb. 12, 2007.
3. Taylor, H. Those with internet access to continue to grow but at a slower rate. The Harris Poll. 2003; #8.
4. Four in five of all US adults – an estimated 178 million – go online. Harris Interactive. November 12, 2007.



5. Eng, TR, Maxfield A, Patrick, K, Deering, MJ, Ratzan, SC, & Gustafson, DH. Access to health information and support: a public highway or a private road? *Journal of the American Medical Association*. 1998; 280:1371-1375.
6. Number of "Cyberchondriacs" – Adults who have ever gone online for health information – increases to an estimated 136 million nationwide. The Harris Poll. 2006; #59.
7. Catlin A. et al. National health spending in 2006: a year of change for prescription drugs. *Health Affairs*. 2008; 27:14-29.
8. Keehan, S. et al. Health spending projections through 2017: the baby boom generation is coming to Medicare. *Health Affairs*. 2008; 27:w145-w155.
9. Virtual doc. *US News and World Report*. 1997; July: 14:62.
10. Facts of life: Issue briefing for health reporters. Center for the Advancement of Health. 2002; Vol 7, #6.

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