

The Challenges of Internet-based Interactive Health Communication (IHC) Applications – A Discussion Based on American Experience¹

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Abstract

With the emergence of the Internet-based interactive health communication(IHC), people in the U.S. now can anonymously and electronically gain access to information, solicit physicians' suggestions, find emotional support, maintain health behavior, and make health-related decisions. However, the applications of IHC also raise concerns regarding the lack of accessibility, user-friendliness, readability, accuracy, credibility, and privacy. Based on these experiences, this paper suggests that information providers should make efforts to reduce information divide, create user-friendly Web sites, provide readable materials, supply accurate and credible content, and ensure health-related information seekers' privacy. On the other hand, health-related information seekers should know how to evaluate the IHC applications to choose those, which are most likely to be useful and beneficial to them. Only when health-related information providers provide a preferred future of Internet-based IHC and health-related information seekers know how to

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evaluate and to benefit from the applications of IHC, will IHC lead to desired health outcomes.

Keywords: Interactive health communication (IHC), Public access, User-friendliness, Technostress, Readability, Accuracy, Credibility, Privacy, Confidentiality

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Introduction

Some aspects of society in the U.S., including commerce, financial services, telecommunication, and delivery of news and information, have been dramatically changed by recent advances in information and communication technologies. Health communication is not excluded. Lately, health care and public health services are considerably affected by the practices of the Internet. People can acquire, use, exchange, disclose, and store health-related information via the Internet (Stephenson, 2002). FIND/SUP Inc. (1997) found that nearly half of US Internet users spent time looking for health-related information on the Internet in 1997; George Tech (1999) indicated that 82% of 3200 Internet users in its study had used the Internet to obtain health-related information; and Borzekowski & Rickert (2001) also mentioned that half of the sampled adolescents in their study had used the Internet to get health-related information. With the proliferation and use of the Internet, numerous commercial health-related Web sites and information seekers have emerged in recent years. Online health commerce is expected to reach \$10 billion by 2004, up from \$200 million in 1999 (Jupiter Communications press release, cited from Grimes et al, 2000).

Because people are increasingly turning to the Internet for health-related information, health improvement activities are taking advantage of the Internet that can target audiences, tailor messages, and engage people in active, ongoing exchanges about health. At the interface of this trend, the Internet has emerged to serve as a supplement to existing health care and public health services. As researchers (Robinson et al., 1998) put it, the Internet not only allows consumers to educate themselves on a variety of health-related topics from diseases to prescription drugs, but it also offers patients suggestions of questions that they can ask physicians, additional opinions and options regarding treatments, and links to online support groups or individuals.

New information technologies, such as the Internet, combining the attributes of both mass and interpersonal communication, are spurring the growth of technology-based health communication concepts, so researchers (e.g. Eng et al., 1999), interested in the health communication field, claimed that the “interactive health communication (IHC)” was emerging. They spent time on clarifying several issues raised in the field of IHC, providing an analysis of the major issues related to quality improvement and evaluation, and suggesting directions for future activities and policy in this area.

Recently many health communication campaigns in the U.S. began to integrate interactive Web sites into overall communication strategies and found that IHC generated far-reaching impact on health communication campaigns’ strategies (Buller et al., 2001; Finnegan et al, 2001; Preece & Ghazati, 2001). However, studies taking different perspectives also indicated some problems about online health-related information, such as the lack of accessibility (Eng et al., 1998), user-friendliness (Weli & Rosen, 1997), readability (Beresolin, 1999; Berland et al, 2001; D’Alessandro et al, 2001; Garber et al, 1999), accuracy (Berland et al, 2001), credibility (Notman et al, 2002), and privacy (Baur et al, 2001; Eng et al, 1998). Under such circumstances, people need to make efforts to clarify the weakness and strengths of IHC applications. In doing so, it will help them develop more effective health communication campaigns and lead to desired health outcomes in the near future.

By and large, new media that are commonly used in IHC applications include Web sites, online services, video conferencing, CD-ROM/DVD, video games, and other information storage formats. However, this paper cannot afford to discuss all of them, so it only focuses on Internet-based IHC. To begin, this paper presents the definition of IHC and applications of Internet-based IHC. Then, it also

touches on a few benefits and potential risks of Internet-based IHC. Finally, it discusses the challenges of internet-based IHC applications and how to achieve a preferred future for Internet-based IHC. Hopefully, people can understand more about Internet-based IHC and contribute some constructive suggestions to the field in the future.

Definition of IHC

What is IHC? As defined by the Science Panel on Interactive Communication and Health, IHC is the interaction of an individual (e.g., consumer, patient, caregiver, or professor) with an electronic device or communication technology to access or transmit health information or to receive guidance on a health-related issue (Robinson et al, 1998). Interactivity is the dimension of communication and information technology with the greatest implications for health promotion, related both to interacting with a system or data and to interacting with other people (Brenan & Fink, 1997; Rimal & Flora, 1997). Thus, the Internet-based IHC can be a way to allow health-related information seekers to relay information, enable informed decision-making, maintain healthy behaviors, promote peer information exchange and emotional support, help self-care, and manage demand for health service via the Intranet, health Web sites, online chat room, listserves and newsgroups, and stand-alone kiosks (Linda et al, 1999; Stephenson, 2002).

Benefits and Potential Disadvantages of Internet-based IHC Applications.

In the U.S., there are a variety of health-related Web sites designed for different purposes. For example, the Rapid Early Action for Coronary Treatment (REACT) Web site is designed for reducing delay in responding to heart attacks (Finnegan et al, 2001). People can access useful background information about heart attacks, the problem of patient

delay, and REACT study itself. They can link to other resources related to heart attacks and emergency medicine, but also community-based approaches to public health interventions. Another Internet-based program titled “*Consider This*” is a Web-based smoking cessation and prevention program for children ages 12 to 15. A variety of software applications for multi-media programming, graphics, audio and video editing, and digital compression are used to produce this program. Content, activities, and graphics of this program are tailored to address certain needs of various populations of children within the targeted age ranges. Adolescents at different sites can interact and share ideas with each other from within the Web site and contribute to a larger community of their peers. Most importantly, the “*Consider This*” Web gives adolescents online, anonymous opportunities to discuss smoking prevention and cessation with others (Buller et al., 2001). As to the Bob’s ACL bulletin board, it is one kind of online community. Starting in the mid-1990s by a skier Bob who suffered from a complete anterior cruxiate ligament (ACL) tear in both knees at the end of a day skiing, now the bulletin board is embedded within a Web site that provided other information. Bob regularly comments on particular messages, provides advice, and watches the flow of message. There are around 30 messages per day. Most people post on their own behalf, but there are also a few parents and spouses posting (Preece, 1998). Preece & Ghazati (2001) used content analysis to classify the overall content and intention of the messages posted and found that 44.8% of the responses were empathic, 17.4% contained predominantly factual information, 32% were personal stories about how their accident occurred and neither solicited nor offered empathy, and there were no hostile response.

In addition to these illustrated examples, recently research finding in the U.S. also demonstrated that Web-based information has the potentials to improve health and leads to efficient use of health services. Brennan et al. (2001) examined an Internet-based information and support service

“HeartCare” finding that IHC (1) provides information and support, tailored to patients’ individual and changes recovery needs during coronary artery bypass graft (CABG) recovery, (2) makes recovery information more accessible for timely use by patients, and (3) extends the scope of nursing services to CABG patients from hospital through home. Steinter et al. (2002) also found that through the Care~Web [C] , caregivers of persons with stroke are able to ask questions of a nurse specialist and rehabilitation team, discuss issues with other caregivers and the nurse by e-mail, and obtain educational information stroke. Similarly, Borzekowski & Rickert (2001) reported that the Internet, for adolescents, is a valued information source on a wide range of sensitive health issues, such as sexually transmitted diseases, diet, fitness and exercise, and sexual behaviors. Gustafson et al. (1999) demonstrated in a randomized trial with HIV patients that the Comprehensive Health Enhance Support System (CHESS), with treatment components including online support groups, interactions with health experts, and access to decision-making aids, increased social support, physical activity, and participation in health care.

Compared to “old” media including radio, television, and printed text or pictures, IHC applications in the U.S. demonstrated that now the Internet-based health communication is changing the nature of health communication and exerting widespread effectiveness. Obviously, IHC applications have potential advantages for health communication efforts including: (1) improving opportunity to find information tailored to meet specific needs of individuals or groups; (2) improving capabilities of various media to combine with text, audio, and visuals and of matching specific media to the particular purposes of the intervention or the learning style; (3) increasing possibility for users to remain anonymous by providing access to sensitive information that people may be uncomfortable acquiring in a public forum or during a face-to-face discussion; (4) increasing access to information and support on demand;

and (5) increasing opportunity for users to interact with health professionals or to find support from others. (Robinson et al., 1998; Stephenson, 2002).

While responses by some studies revealed considerable interest and enthusiasm regarding the perceived benefits of using Internet-based IHC applications for information seeking and networking tools, some also indicated a variety of problems the applications of IHC exerted. Studies found that health-related information seekers were concerned about the accuracy (Berland et al, 2001), credibility (Notman et al, 2002), and privacy (Baur et al, 2001; Eng et al, 1998) of online health-related information. Worst of all, there were still certain populations having difficulty in accessing online health-related resources because most Internet-based IHC applications were designed primarily for educated, literate, and non-disabled audience. Studies also reported that many people without adequate skills in science, technology, or reading literacy could not understand or use health-related information on the Internet (Impicciatore et al., 1997; Keoun, 1996; Saksena S. & Nickelson, D. E., 1995; Stephenson, 2002; Yom, 1996).

Towards Preferred Effectiveness of Internet-based IHC

Obviously, widespread availability and use of health-related information lead to some challenges to IHC applications. These challenges are related to health-related information seekers' access to the Internet, user-friendliness of Web design, and readability, accuracy, credibility, and privacy of online health-related information. Health-related information providers need to work on these issues if they look forward to achieving preferred effectiveness of Internet-based IHC.

Public Access to the Internet

Will everyone benefit from the increased availability of online health resources or do people head toward a society of information “haves” and “have-nots”? According to U.S. Department of Commerce (DOC) (2000), 51% of all U.S. homes had a computer, and 41.5% of all U.S. homes had Internet access. In other words, more than half of all U.S. homes still could not access to the Internet. Barriers to access the Internet may be caused by socio-economic status (SES), education (Jimison et al., 1999; Patrick et al., 1999), age, gender (Aspden et al., 2001; Grimes et al., 2000), race (Aspden et al., 2001; Grimes et al., 2000; Novak & Hoffamn, 1998), geographic location, disability (Eng et al., 1998; Patrick, 1999), etc. DOC (2000) concluded that lower-SES people, rural households, African-American, and Hispanic persons in the U.S. are less likely to own a computer or have Internet access than others. Therefore, health-related information providers should take accessibility into account, because those who were most likely to have health problems and lack health insurance coverage were least likely to have access to the Internet or have the skills to use it (Eng et al., 1998). As Stephenson (2002) said, if medical information on the Internet was accessible, people could quickly and easily access this information from home, work, or even the public library.

Providing universal access requires a collaborative effort among a wide range of stakeholders on all levels. In 1997, approximately 60% of public library systems in the US offered some forms of public access to the Internet. Providing access through libraries is a good model. By the same token, there is little reason why other public facilities cannot support public access terminals. Health communication providers may necessitate a combination of private (e.g., home) and public (e. g., schools, libraries, public buildings, post offices, shopping malls, community centers, health care facilities, places of worship) points to help people access online health-related information (Eng et al, 1998).

In addition, much of the infrastructure to deliver interactive media to the home may already exist. Advances in communication technology promise high-speed Internet access through various channels, such as existing telephone lines, coaxial cable, and wireless transmission. The costs of computers and communication services are rapidly declining and the promise of converging information appliances may make home access more affordable (Eng et al., 1998).

The notion of universal access to health information and support should be integrated into international, national, state, and local health planning processes to improve access to both services and health information and support. By reducing the information divide, the next century may bring us closer to health equality.

User-friendliness of Web Design

Even with access to information and service, disparities may still exist because some people who lack computer literacy may suffer from “TechnoStress”, a modern disease of adaptation caused by an inability to cope with a new technology (Weli, Rosen, 1997), and do not know how to master computers well. People who are technology-savvy may embrace computers enthusiastically, whereas people who are afraid of adopting new technologies may feel lost, inept, frustrated, scared, intimidated and unhappy. As many as 85% of people in America have at least some level of discomfort around technology (Weil & Rosen, 1997). A 1995 Associated Press poll also found that almost 50% of the over 1,000 American adults felt that the advance of technology was leaving them behind (Clark & Pope, 1995). Since computers are the tools used to convey health-related information, health-related information providers should create user-friendly Web sites in order to help people suffering from computerphobia adapt themselves to every demand of using computers and the Internet.

The REACT project is a good example. The REACT Web team

spent a lot of time surfing other Web sites, especially those concerned with Web design. With lower-tech end users in mind, the team opted for a general page design that would be readable on small as well as large computer monitors. The team avoided complex, heavily layered page designs that often took longer to download. Finally, in the next year (2000-2001), the National Heart Attack Alert Program (NHAAP) incorporated the REACT Web site as part of its education program in providing communities with continuing assistance in reducing patient delay in seeking care for heart attack symptoms (Finnegan et al, 2001). The success of the REACT Web team demonstrates that user-friendliness is another remarkable factor that health-related information providers cannot overlook if they use Web sites as tools for disseminating health-related information.

Readability of Materials on the Internet

Health-related information may be organized from a clinician's point of view, written in medical jargons, or assumed that the users have already known a lot about a disease (Brooks, 2001). As a result, most health Web sites are primarily text-based and are designed for educated, literate, and non-disabled audiences (Eng et al., 1998). Many people who are illiterate, especially old and sick patients, cannot read and understand basic health-related information (Bresolin, 1999). Studies found that the reading level of health-related information on the Internet was higher than the median grade reading level of the U.S. population (Berland et al, 2001; D'Alessandro et al., 2001; Garber et al, 1999). Not surprisingly, the gap between the readability of health-related materials and seekers' reading comprehension may eliminate health care quality and lead to poor health outcomes (French & Larrabee, 1999). Therefore, health-related information providers had better measure seekers' reading level (Eysenbach & Jadad, 2001), evaluate readability of medical materials (Brooks, 2001; Doak et al., 1998) and improve seekers' health literacy

(Brooks, 2001; Davis et al., 2002) periodically to reach better health communication effects (Brooks, 2001).

Health-related information providers can measure the reading level of their desired audience via instruments, such as Ohio Literacy Test (MacDiarmid et al., 1998), PIAT-R (Davis et al., 1993), Stanford Diagnostic Reading Test (Williams et al., 1996), WRAT-R2 (Estey et al., 1991), Reading Assessment of Adult Literacy in Health (REALM) (Davis et al., 1991), and Test of Functional Health Literacy in Adults (TOFHLA) (Parker et al., 1995) in order to tailor information to fit the level of literacy of their target individuals. On the other hand, health-related information providers should evaluate the complexity of words and sentences, sentence length, and diversity of words to make information readable before they impart any health-related message to their target audience (Brooks, 2001).

Doak et al. (1996) suggested that medical materials should be aimed at eight-grade level or below, because the average reading level in the U.S. is eight to ninth grade. Especially, they indicated that materials targeted for low-level readers should change difficult words into common words, explain the meaning of academic terms, and use large fonts and layouts which substantial amounts of white or blank space to make the text look easy to read. If appropriate materials exist, then measurable improvements in health literacy for the least literate can occur.

Accuracy and Credibility of Content

The growth and increasing sophistication of the Internet makes geographic barriers disappear and offers people opportunities to learn health-related information from various resources at different places (e.g., home, work places, libraries and kiosks) (Gustafson et al., 1999). People are turning to the Internet for answers to their health questions and in some cases are relying on the Internet solely for advice. Under such circumstances, it is critical that the information available be of the highest

quality.

With the advent of the Internet, diagnosis and cures will be dispensed interactively and electronically. Unfortunately, there is little doubt that the power of interactive applications can also be harmed by inaccurate, misleading, fraudulent, and dangerous information (Henderson et al., 1999). The quality of online health-related information needs to improve in the U.S. (Eysenbach et al., 2002). Impicciatore et al. (1997) indicated that few pages related to health information retrieved online provided complete and accurate information; In a March/April 1999 online survey, 69% of respondents agreed that the quality of health sites needed to improve, up from 53% in the preceding year. Health-related information seekers with more experience (more than 3 years on the Internet) were more concerned about the low quality of health-related information than new seekers (less than 6 months on the Internet) – 74% vs. 60%, respectively (HON, 1999); Biermann et al. (1999) searched for web sites concerning a specific form of cancer finding that only half actually contained information on this topic and only 60% had peer-reviewed information. They noted that in addition to the time-consuming and cumbersome search process, health-related information seekers may end up with incorrect and harmful information.

Similarly, Notman et al. (2002), conducting an exploratory study to examine the effectiveness of interactive health communications technology as a resource for disseminating useful prevention, treatment, and health education information to school-aged children and their family, indicated that nearly 60% of respondents rated the Internet as the most useful IHC application, but only 20% considered the health-related information they found online to be “very reliable.” Respondents were concerned that they could only fully reap the benefits of IHC technologies if they were directed toward reliable and organized sources of health information; McClung et al. (1998) studied 60 articles from the first 300

hits on a search for information about children diarrhea and also found that 80% had inaccurate or out-of-date information; Berland et al. (2001) found that people relying on the Internet to make treatment decisions might have a difficult time finding complete and accurate information on a health problem.

Quackery and misinformation on the Internet may become a matter of life and death. The challenge in offering high-quality information is clear. To provide high-quality information, health-related information providers should first identify the authors of Web site content, list the original sources and references of materials completely, disclose the ownership of web sites. Most importantly, health-related information providers should indicate the date on which all materials are posted or updated to ensure credibility of online health information (Silberg et al., 1997), because a number of Web sites are initially developed and implemented without regard to maintenance and rapidly become outdated and useless (Finnegan et al., 2001).

In addition, medical information online was frequently dispensed by participants without formal medical training (Culver et al., 1997). Health-related information providers should have physicians help them scrutinize the content on the Web sites to guarantee accuracy of information. If health professionals can play as “Internet filters” in helping health-related information providers assess and assure the quality of online information periodically, health-related information providers will avoid offering incorrect information to their target audience (Deye et al., 1997; Robinson et al., 1998).

Privacy and Confidentiality on the Internet

Personal identifiable health information is now more available through the Internet, providing benefits such as greater patient autonomy (Carlton et al., 2000) improved treatment (Guendelman et al., 2002), broader dissemination of medical research and practice (Rodrigues, 2000;

Taylor, 1994), and faster diagnoses (Rodrigues, 2000). However, such systems also motivate a debate about individuals' privacy rights, including the right to be anonymous on the Internet and the right to control individual's personal information (Baur et al., 2001; Eng et al., 1998). In fact, visitors to health Web sites are often not anonymous and sites are collecting their personal information without their consent (Goldman, Hudson & Smith, 2000). Information collected by Web sites may be sold, used to discriminate against or embarrass users (Hodge, Gostin & Jacobson, 1999), or used to increase the power of a personalized marketing effort (Gustafson et al., 1999). Therefore, a survey of Internet users found that 66% of online health-related information seekers are concerned or very concerned about their personal privacy (California Health Care Foundation & Internet Healthcare Coalition, 2000).

In the U.S., there are only federal and state laws providing selective privacy protection. For example, the Privacy Act of 1974 "covers health information held by federal agencies but only in the same way it protects all other personal information, without reference to the special character of health information " (Baur et al, 2001, p. 370). To enact comprehensive and national legislations to provide fundamental privacy rights for online health-related information seekers still fails to progress. Worst of all, the Congress has missed the August 1999 deadline it set for itself to pass health privacy legislation under the Administrative Simplification Provisions of the Health Insurance Portability and Accountability Act (HIPAA) (Baur et al, 2001). Fortunately, groups in the U.S. have already proposed many ethic codes and legislative frameworks, such as "Best Principles for Health Privacy" (Health Privacy Group, 1999), "Health Internet Ethics: Ethics Principles for Offering Internet Health Services to Consumers" (Hi Ethics, 2000), and legislative frameworks (Hodge et al, 1999), to fill the gap in existing privacy laws and regulations before their government takes any action to enact

nation-wide privacy regulations related to online health-related information.

Before comprehensive and national legislations are passed in the U.S., self-regulation of health-related information providers will be the first step to ensure online health-related information seekers' privacy (Eysenbach, 2000). Federal Trade Commission (2000) suggested that self-regulation of health-related information providers includes four elements: notice, consent, access and correction, and security. It means that individuals can control, create, collate, annotate, modify and access their own information while protecting their privacy (Mandl et al., 2001). On the other hand, the government in the U.S. should propose privacy laws to assure privacy of online health-related information in the near future. As Hodge et al. (1999) said, the government should (1) recognize identifiable health information as sensitive, (2) provide privacy safeguards based on fair information practices, (3) notice the use of any individual's personal information and give his/her consent to its use, (4) incorporate security protections, (5) establish a nation-wide data protection authority, and (6) provide a national minimal level of privacy protections.

Discussion and Conclusion

Internet technology is evolving by leaps and bounds. Undoubtedly, this technology will continue to impact the delivery of health care services and certain issues will continue to dominate the health care arena. As Liberman (2001) put it, many new questions about human-computer interaction and mediated interpersonal communication should be investigated.

Technology, if used appropriately, will help increase people's knowledge of health, enhance their ability to negotiate the health care

system, understand and modify their health risk behaviors, and acquire coping skills and social support (Eng et al., 1998). On the flip side, it may also raise serious concern regarding the accuracy, quality, design, and health impact of health information and programs. Under such circumstances, health-related information providers have to ask themselves some questions over and over again when they use the Internet as a channel to convey health-related information. Questions should include “Is the source credible?” “Is the content of web site suitable and accurate?” “Is the information relevant to users?” “Can the target audience access them?” “Is the resource timely?” “Is there clear and adequate disclosure?” “Are there clear caution statements?” “Is the Web site user-friendly?” and “Does the Web site care about the privacy of personal health information?”

By the same token, health-related information consumers need to adopt a tool to evaluate the applications of interactive health communication, making sure which applications are most likely to be of benefit (Shepperd et al., 1999). Robinson et al. (1998) proposed an Evaluating Reporting Template for Internet-based IHC based on the rationale that all applications should undergo some level of evaluation and that the nature and results of such evaluations should be available to potential users and purchasers of the application. By and large, the template is divided into four sections. The first section focuses on identification of the developers, the sources of funding for the application, the purpose of the application, its target audience, technical requirements, and issues of confidentiality; the second section focuses on the result of formative and process evaluations, as contributors to application design and development; the third section concentrates on the results of any outcome evaluations performed; and the final section focus on information about evaluators and funding to disclose potential biases or conflicts of interest relevant to the evaluation.

The template is designed to assist health professionals, consumers, and purchasers in judging the appropriateness of a given Internet-based IHC application for their needs and compare one application with another. It also prevents the development of flawed applications and wasted resources, help health-related information seekers determine which applications are most likely to be beneficial, and assist them to understand health issues and make informed choices (Robinson et al., 1998).

Only when health-related information providers ensure to achieve a preferred effectiveness of IHC and health-related information consumers know how to evaluate the applications of IHC, will IHC foster more responsive communication networks, heighten users' health knowledge, strengthen treatment decisions, and thereby improve health outcomes.

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從美國經驗談網路互動式健康傳播實際運用時所面臨的挑戰

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摘要

網路互動式健康傳播概念問世並實際運用後，美國人民當下得以不受時間限制，在網路上以匿名及互動方式接近及使用健康訊息、徵詢醫師的建議、尋求情感的支持、維持健康行為及下與健康有關的決定。然而，互動式健康傳播在美國實際運用後也產生頗受注意的問題，如網路接近使用；網站設計對使用者的適用性；健康訊息的可讀性、正確性、可信度及個人隱私等問題。透過對美國經驗探討，本文章建議，選擇以網路作為通道來傳遞健康訊息的訊息提供者，未來應致力於消弭資訊落差；設計使用者適用性強的網站；並提供具可讀性、正確性、可信度的健康訊息；及確保網路健康訊息尋求者的個人隱私。一旦健康訊息提供者開創一個可欲的網路互動式健康傳播新未來，健康資訊尋求者也懂得評估對是否有益的互動式健康傳播相關運用，互動式健康傳播將能為眾人的健康許一個美好未來。

關鍵詞：互動式健康傳播；公眾的接近使用；使用者適用性；科技壓力；可讀性；正確性；可信度；隱匿性。