Consumers and Evaluation of Interactive Health Communication Applications

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Introduction

Interactive health communication (IHC) applications, through their information, emotional support, decision support and behavior change services, have the potential to dramatically improve the public's quality of life and reduce the total burden of illness and injury. Their emergence has been fueled by the growth and increasing sophistication of the Internet, which allows geographic barriers to fall and offers people an opportunity to learn from widely diverse resources. But their growth will be fertilized by the propensity for the health care system to push health care away from institutions, specialists, and even primary care providers. As patients are spending less time in the hospital and with their health care providers, they are being forced to assume more responsibility for their care, but often not provided resources to do it. Moreover, the increasing complexity of medicine, pressures for increased productivity, and growing recogni-

tion that there is more to dealing with illness than the standard medical model, is prompting providers to share responsibility with patients. There has been a separate but reinforcing trend toward patients and families wanting to participate in their own health care. The elderly, a growing percentage of the population, are becoming more assertive participants. Baby boomers, who have generally been more assertive, are moving into their late 40s and 50s, a time when chronic health conditions start to emerge and interactions with the medical system increase.[1] This assertiveness is generally good, if support is available to help patients be effectively assertive. IHC applications can help fill this growing need for individuals to understand and take greater control of their health and that of their families.

However, IHCs also pose a risk to consumers who cannot sort out inadequate and misleading applications from ones of high quality. The purpose of this article is to explore the potential risks and benefits of IHC applications to consumers, and discuss initiatives that may help consumers make more informed choices among IHC applications and make more-effective use of the applications they adopt. While the consumer is the ultimate beneficiary, the article is also intended for audiences who act as advocates for the consumer. For the consumer, this report addresses issues such as reasons why evaluation should be important to them, encourages development of an evaluation template customized for them in relevant language, and offers a list of consumer rights and responsibilities and how to exert them in this field. For those interested in consumer welfare, we identify opportunities in areas such as nutrition-labeling systems, research, Web-based surveys, consumer report services, and oversight through existing or new mechanisms.

The Need

Initially, the Web and other computer-based health support systems provided little more than electronic page flipping and ways to talk with other people. As the technology improves it becomes possible to use more

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sophisticated methods for learning, social support, decision support, behavior change, and, unfortunately, manipulation. Expert systems, video, and access to large databases are state of the art in stand-alone systems and becoming practical on Web-based systems accessible at home, at work, in clinics, and in public places such as libraries and/or kiosks. This extends opportunities for patients and families to become much more informed about their disease and potentially become a valuable partner in care.

At the same time, the amount of health information available from the Web and other electronic resources is vast. There are high-quality Web sites and stand-alone products developed by organizations and individuals committed to helping people in need. Other resources are factual but incomplete. They sometimes tell only one side of the story and are frequently out of date. Other IHCs are organized from a clinician's point of view, written in medical jargon, or assume the reader already knows a lot about a disease. In still other cases, the products are illogically structured or hard to use.

Most consumers will rapidly detect any of these weaknesses. However, an increasing number of products have more sophisticated deficiencies. These products can project a credibility that may not be deserved and may be potentially dangerous. They can be used as subtle ways to market products and services of dubious value with the reader being victimized by those with a financial interest in the information they provide. In fact, this biased or incomplete information may not appear to be marketing at all. Moreover, many products are based on untested algorithms, formulas, and premises. Even the personal stories placed on the Web can be misleading if they emphasize the rare health care disasters or miracle cures rather than give the reader a balanced presentation and discussion of average results necessary to place the personal stories in context.

It is important, therefore, to move away from a perspective that these systems can do no harm. Misinformation can lead patients with life-threatening conditions to lose trust in their provider, take actions that undermine the effectiveness of their treatment (e.g., by taking substances that interact in a negative way with prescribed medications), use their limited time with a provider unproductively in ways that ultimately increase costs of care, and even abandon a provider delivering high-quality care to pursue ineffective therapies. Vulnerable people may also be victimized by biased or incomplete information from those with a financial interest in the information they provide. As a result, they may take actions that may have a negative effect on their economic and social health. In a recent study, the Federal Trade Commission found more than 400 potentially false and deceptive claims on the Web; products and services were claiming to help cure, treat, or prevent AIDS, arthritis, cancer, diabetes, heart disease, and multiple sclerosis. J. Bernstein, Director of the

FTC's Bureau of Consumer Protection, said, "Hopeful and sometimes desperate consumers spend millions of dollars on unproved, deceptively marketed and often useless 'miracle cures' and the Internet should not become the newest medium for this age-old problem. In addition to wasting consumers' money, some products or treatment may even cause them serious harm or endanger their lives." For instance, Web sites that portray only disasters can cause unnecessary worry and lead consumers to take unwarranted actions.

Such risks are present in most media. Advertising for "Health Foods" and nutritional supplements sell billions of dollars of products without extensive evaluations. Health infomercials lead people to spend billions on fitness equipment and other health products that have little, if any, evaluation associated with them. Moreover, many health care services in the mainstream health care system have evolved without carefully developed and replicated clinical trials.

Still, there is a need to hold health information products to a high standard because of their increased potential for negative impact. Emerging research finds people assigning more credibility to computer-based information than television and other media,[2] because they can return time and again to a product that is becoming increasingly sophisticated at using expert systems, graphics and video, as well as tailoring messages to single consumers. In many other delivery systems (e.g., health professionals, health maintenance organizations, hospitals), the consumer is at least partially protected by certification, licensing, and credentialling systems. But there are no oversight mechanisms for IHC developers.

Risks to privacy and confidentiality are another reason for holding IHCs to a higher standard, particularly as technology becomes more proficient in securing and using information about users. A consumer may have no idea of what happens to information they enter into an IHC application—who uses it and how. The information may be sold, used to discriminate against them, or used to increase the power of a personalized marketing effort. The consumer may have no opportunity to "correct" this information. Issues such as HIV/AIDS and genetic screening illustrate how potentially damaging the lack of privacy might be to the user and his/her family.

A Consumer Focus to Evaluation

Consumers need to understand the risks associated with these products. They need a way of separating truth from fiction, anecdote from established fact. They need a way to judge the quality of the information and support provided as well as the privacy of the information they provide in return.

Unfortunately, evaluation of these products can be time-consuming and difficult. Many savvy evaluators shy

away from providing a single evaluation or ranking of health information resources because content changes so often (especially on the Web), because one cannot depend on "authorities" to keep up with or evaluate material, and because definitions of quality vary depending on the needs of the user. In fact, the difficulties make traditional methods of evaluation or certification of limited value. There are several approaches that can be taken to assist consumers. These might include external controls and policing, industry self-policing with verification, certification by some independent body, and consumer education.

Consumers (and evaluators) need to understand that good evaluations must consider more than just the quality or accuracy of the information. These products may make them feel anxious or overly confident, or may affect the trust they have in people important to them. What kind of emotional support does the product offer? Did it actually help them? Moreover, different consumers learn in different ways. Two products that have the identical information may have different effects on the same person. Consumers need to consider what style of learning works best for them in choosing IHC applications. In essence, consumers should develop their own evaluation framework, which teaches them not only what information to look for but also to consider how the IHC application made them feel and how it affected the confidence they have in their decisions.

When there is potential for harm, consumers need to be equipped to make informed choices among products. Evaluations need to be conducted and the consumer needs to be informed of, or at least have access to, the results. The greater the potential for harm the more extensive the evaluations should be.

Consumers need to understand and act on the potential risks as well as the potential rewards of health support technologies. To that end, carefully crafted examples and stories portraying both sides of an issue should be developed. Consumers need to know how valid the health information is. At the same time, they need to be realistic about what, if any, evaluation standards should be placed on developers and what evaluation expectations should be set for third parties such as consumer watchdog groups. It may not be reasonable (or even appropriate) to expect that a developer will conduct a randomized controlled trial of every product they develop. Some developers believe that evaluations are less likely to sell products than high-quality marketing. One of the goals of the Science Panel is to find ways to make it in the best interest of developers to secure high-quality evaluations of their products by promoting consumer demand for products of demonstrated quality.

Therefore, it is important that we not focus all our efforts on evaluations of products after they are developed. Resources must be put into preventing problems, making it easier for developers to create high-quality products in the first place. Quality background R&D could be promoted through public and philanthropic grant programs. For example, carefully constructed needs assessments,[3] conducted by an independent third party and made available at no cost to the developers, could raise the standard of quality without asking the developer to collect their own needs-assessment data. For instance, a research team could interview breast cancer patients and their families to better understand what it is like to have breast cancer. From these interviews a set of patient and family needs would emerge. Then a survey containing these needs could be distributed to many breast cancer patients and family members at varying times after diagnosis, asking them to rate each need in terms of importance and the degree to which the need has been satisfied.

Software templates (e.g., for tracking patient behavior or for making decisions) could be developed and made available to developers so they would not have to develop their own. Databases of frequently asked questions (and high-quality answers) as well as high-quality published articles could be made available in the public domain for all developers to use. In this way, we can raise the minimum standard of information that could be easily provided by any product.

Goals

This article addresses opportunities for action that are intended to achieve the following goals:

1. Increase the recognition of the potential and the risks of these systems. Unless the consumer sees the risks of buying or using these products and has the skills to discriminate, they are unlikely to search for or demand high-quality products. Moreover, health-care providers will continue to treat these products as only marketing devices unless they have more evidence that these systems can improve costs of care and quality of life. Finally, unless the risks as well as benefits to the consumer can be clearly demonstrated, policy-makers are unlikely to seriously examine ways to influence access to and quality of these systems.
2. Offer a vision of what a high-quality consumer health support system can be. Consumers don't know what to expect when shopping (over the Internet or in stores) for a consumer health support system.

- What can such systems reasonably be expected to accomplish? For instance a program that offers only information and not social support may be less likely to promote behavior change or enhance coping with a disease.[4]
- What variations in consumer types should lead to what differences in products and services?

- What specific measures of performance exist and how should they be used?
- What does a good evaluation process look like?
- What type of expertise should be involved in product development and evaluation?
- What environmental factors are likely to affect the quality of these products and their evaluations?
- What information (e.g., about consumer needs) should reasonably be expected to form the basis of products and evaluations?
- What technology features could be part of a product and which of those features should be a part of a system that will meet their needs.

3. Provide <u>support</u> and encouragement for them to carefully select and appropriately use IHC applications. Even if the consumer knows that there are variations in quality and dangers involved in not choosing the right application, they need to be encouraged to make informed choices. It will be difficult, even under the best of circumstances, for them to find the products that would help them and the information they need about the products. When they get frustrated and discouraged, there needs to be help to keep their expectations high. At the time they are considering the application, consumers should have access to the results of formal evaluations of the product that are free from conflict of interest.

4. Provide them with the <u>skills and resources</u> they need to select high-quality IHC applications. In many cases, there will not be evaluations of specific products. The consumer will need to become his/her own judge of the quality of these products. Because these are new kinds of applications, few consumers will have the skills needed. In some cases these skills need to be acquired under circumstances of high-stress. How are we going to create these skills with just-in-time training? Moreover, if consumers are expected to assume some responsibility for evaluating applications, then the tools and presentation of information available to them should take into account the diversity of potential users (e.g., educational/computer skills level, disabilities such as vision-impaired).

5. Give them a <u>strategy</u> they can use to find and select these systems. Once they have the motivation to carefully select an application, a vision of what a good service can be, and the skills to select it, many will still need a step-by-step process for doing so. A carefully developed (and very easy to learn and implement) process is going to be essential.

6. Allow them to provide <u>feedback</u> that others can use when they seek similar systems. As consumers learn about applications and realize their strengths and weaknesses, we need to build a way for that information to be shared with other consumers. But the information also needs to inform developers, providers, and regulators. A process needs to be put in place that makes it easy for users to provide that feedback and for other people to access it.

Opportunities for Action

At present, the digital media may be too fluid for rigid regulation. As an alternative, if enough people are concerned about finding good information, their demand will drive someone—nonprofit or commercial—to offer such evaluations. The government can foster, standardize, and promote the development and dissemination of these evaluations.

There are no studies of what consumers need in the way of information from evaluations of computer-based health support systems. However, there have been studies of what consumers would need from evaluations of health plans as they choose among competing alternatives. The findings of one study[5] offer some insight into how to construct evaluations of IHC applications.

- Evaluation data need to be easily accessible to consumers;
- Evaluations should include examples of high- as well as low-quality applications;
- Explanations of findings should be written in lay terms with easy-to-understand graphics;
- Qualitative experiences and stories are needed as side bars to highlight evaluation results;
- Evaluation information should first be presented in summary form and then in more detail as desired;
- Access to people who have used the program and can comment on its quality should be available;
- Consumers should have access to complaints filed and actions taken against developers;
- Evaluations should be conducted by independent unbiased evaluators;
- Evaluators should use a consistent set of criteria for judging different applications;
- A worksheet should be constructed to help consumers decide what kind of program they need; and
- Evaluations should describe populations, sample size, recency of data, and number of observations.

A multifaceted approach can help raise consumer awareness of the risks and potential benefits of using IHC applications and to equip consumers to be discerning in their selection and use of such systems. Key possibilities include:

1. <u>A statement of protections and responsibilities</u> that are appropriate to the emerging IHC field should be adopted and promoted.[6] This is important not only for the consumer but for developers and providers of these applications and services because it establishes a baseline of trust while at the same time

asserting the responsibilities of the consumer. This list could cover:

- *Choice:* awareness of and selection among a variety of IHC applications.
- *Evaluation:* detailed and timely information to assess the quality of a product consumers are considering. At minimum, this would include information on: sponsor/creator institution, intended objectives, what topics are and are not covered by the product, what topics are science-based and which are opinions, as well as developer credentials. In addition, there should be information and skills training on how consumers can conduct their own evaluation of these applications.
- *Education:* to interpret and critically assess health information.
- *Appeals and grievances:* external remedies if the product is misleading or deceptive and advocacy for consumer protection.
- *Confidentiality and privacy:* confidentiality of personal information, including the right to say who may access the information, to be consulted prior to release of the information for any use, to know what kind of security provisions are included in the program, to know what privacy risks use of the application creates for the user, and to know how the information in the application will be used to influence their thinking and behavior.
- *Buyer beware:* consumers need to recognize the risks of using these applications and services, acquire and use evaluation skills, and use the applications and services with a clear understanding of their limitations.

2. A <u>consumer-oriented evaluation and certification entity to evaluate IHC applications</u> could promote standards, conduct evaluations of health information, certify high-quality applications, point consumers to other evaluations of IHC applications, and help them recognize the quality of and effectively use evaluations. This entity could raise consumer awareness of issues (such as privacy) and conduct and publish (through print and electronic venues) evaluations of new Web-based as well as stand-alone programs. The service could be designed to support not only consumers but others concerned about their welfare. The service could examine the needs assessment on which a program is based, the intended uses of the program, and the quality and bias of content. It might evaluate usability, system security, user acceptance, and use, as well as the impact of the system. The evaluation process and results could be presented in easy-to-understand formats and be widely disseminated. If evaluations have already been completed, the service might comment on the quality of those evaluations.

- The certification process could take several forms ranging from a free-standing body modeled after National Committee for Quality Assurance (NCQA) to one run by an interest group such as a medical society. It should be independent from developers or their advocates. The certification body could develop and widely publicize its standards. Certification would be voluntary and time-limited and this entity should have resources to monitor compliance with this time limitation. Any developer could apply for certification from this body. Benefits of certification might include the right to advertise the certification. However, consumers would have the right to access the full results of the evaluation, which would be published on the Web site. The certification service could initially concentrate on larger applications focusing on topics where there is the greatest potential to do harm. As it grew in resources and stature, the service might expand its evaluation efforts to include less-risky applications. In any case it should be an entity without vested interest in an IHC application.
- The financial base could follow an existing model. Consumers who are shopping for health information and willing to pay for evaluations might help finance it (the Consumer Reports model). It could also be financed by the industry (the Underwriters Laboratories model). A developer might pay a fee to have its product evaluated and select among levels of evaluation ranging from a randomized controlled trial to a lab-based assessment. The results of the evaluation would be made available to the public, regardless of outcome. Readers would be told the strengths and weaknesses of the evaluation as well as the outcome. If the product were good enough it could receive certification. A start-up grant might be provided to initiate this service.

This service could encourage consumers to seek evaluation information about these applications and provide them with tools for interpreting evaluation results and for conducting their own evaluations.

The service could work with advocacy groups to search out, identify, and have competitions for the best software in a particular area. The service and the advocacy groups could publicize the results to their.

3. An <u>evaluation template</u>[7] could be developed to help consumers conduct their own evaluation of IHC applications. One format could be a Web-based interactive program including:

- An assessment to help them understand their own needs as they search for an IHC application (because no application is going to meet the needs of every person),
- Questions to ask about an IHC application and what

good and bad answers would be within the context of their own needs,

- A worksheet to document their findings about programs,
- A database of evaluations conducted by the consumer report service,
- A search engine to help them identify other applications that might meet their needs, and
- A database of legal actions taken against developers (including results) as well as information on how to take legal action of their own.

4. A <u>Web-based source of product evaluation data</u> could collect and disseminate additional data about applications. Advocates could use it to address privacy and confidentiality issues. Developers could use this site to complete a survey providing uniform information to consumers about applications and their evaluations. Consumers could get explanations of what the questions mean and how to interpret the answers. To use this database, the developer might certify the accuracy and currency of their information. This site could also act as a forum where some of the best IHC Web sites and stand-alone applications (without implied endorsement for the future) could help pinpoint some of the questionable practices and strategies already prevalent on the Net.

5. A <u>research agenda</u> supported by government, foundation, and industry could include:

- *Critical elements:* Research to identify the aspects of IHC technologies that make a difference to consumer use, acceptance, and benefit. This is a developing field where we need to know much more about how health messages, in this medium, affect people. Such evaluation research will help consumers by helping developers create the best possible applications.
- *Prototype evaluations* of systems within selected topic areas (e.g., topics where there is the potential for systems doing harm). These prototypes would demonstrate the value of such evaluations and serve as a template for future evaluations in similar areas. A single topic area (e.g., asthma, breast cancer) could be selected where several applications might exist and a comparative evaluation conducted of several available applications. The variation in available applications could be documented, along with an assessment of the impact these systems had on people that use them. Both dangers and positive aspects need to be clearly defined. Wide dissemination would be crucial.
- *Measures.* Valid, reliable, and sensitive measures of system effectiveness as well as guidelines on how to carry out these evaluations need to be developed. Some existing measures of effectiveness may not be specific enough to detect program effects. There are many outcome measures with proven reliability and validity (e.g., the SF-36 or the FACT cancer quality-of-life scale). But none may be appropriate for evaluating a particular IHC application. These measures must capture, but not go beyond, the consumer needs addressed by an application. Outcome measurement scales often combine several statistically related but conceptually different elements, and a system's impact on one element may be diluted by its lack of effect on another element. For instance, a scale from an instrument of proven validity and reliability examines physician-patient relationship by using two questions: one addressing confidence in the physician and the other addressing availability of the physician. An IHC application intended to improve confidence but not physician availability may show no effect because of dilution occurring with the use of this scale. Program developers must define precisely what effects their systems are designed to achieve before selecting an existing outcome measure. And measures must be developed to measure only those effects.

6. <u>Vision.</u> A panel of expert developers, providers, change theorists, and influential consumers might be convened to create a vision of a high-quality consumer health support. Principles that might be an important part of such a vision were developed by the Vision Roundtable.[8] This vision could be crisp, realistic, and easily understandable, and endorsed by leaders from the consumer and provider sectors. A respected opinion leader could act as spokesperson for the activity. The vision could be widely shared by advocacy groups, government, and providers. Like the needs assessment results, this vision needs to be disseminated through several venues, not the least of which would be the Internet.

7. <u>Public domain raw materials for developers.</u> Public domain raw materials and tools could be created that would make it easier for developers to produce high-quality IHC applications. In this way, we might be able to raise the minimum standard of information that could be provided easily by any new product. These resources could include:

- *Documentation of consumer needs.* Research on dissemination of innovations consistently demonstrates that understanding customer needs is the single most important predictor of new product success. Needs assessments should be constructed around principles of market research that allow one to distinguish between what customers want and what needs they have.[9] These needs assessment studies could provide databases containing needs prioritized by importance but also classified by demographics that will allow analysis of the data in ways that will tailor results to the specific clientele being served by the new

product. These data could provide developers with high-quality information about consumer needs (not wants)[10] that they might not have the resources to gather themselves.

- *Software templates* (e.g., programs for tracking patient behavior or for helping consumers make decisions) could also be developed and made available to developers so they would not have to develop their own.
- *Databases of frequently asked questions* (and high-quality answers) as well as high-quality articles could be maintained in the public domain for all developers to use.
- *Databases of high-quality literature for a given subject* (such as Medline) could be made available at little or no cost for any software product to use.

8. <u>Health literacy</u> programs designed to help consumers understand and interpret health science. Understanding how to interpret relevant scientific discoveries will be increasingly important as individuals assume more responsibility for health-related decisions. To gain that capability, training might be needed in areas such as critical thinking, judgment, risk communication, understanding of bias, or levels of evidence. A long-term strategy must include elementary and secondary education programs in such subjects. But a more short-range strategy could include community education programs as well as continuing education programs offered through health care providers and on the Web.

9. A <u>labeling system</u>. A labeling process could be developed and widely deployed, requiring that all interactive electronic communication technologies purporting to help people prevent or cope with illness or injury, prominently display (e.g., through a paper or electronic package insert) certain data about the program. Essential data might include: target audience, target health issues; identification, affiliation, and credentials of the authors; content sources; disclosure of program ownership, sponsorship, commercial funding, potential conflicts of interest; dates when content was posted; types of evaluations conducted, results including side-effects to date. Additional details (populations studied, sample size, recency of data, base rates) of the

evaluation could be filed with the consumer reports service and be available through a Web site.

Interactive Health Communication applications hold potential for dramatically improving the quality-of-life and reducing the total burden of illness. The panel hopes this article will contribute to the discussion on how consumers can make more informed choices among IHC applications and help those consumers make more effective use of the applications they adopt.

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