Focus on Consumer Health Informatics

White Paper ■

Developing Informatics Tools and Strategies for Consumer-centered Health Communication

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A b s t r a c t   As the emphasis on individuals' active partnership in health care grows, so does the public's need for effective, comprehensible consumer health resources. Consumer health informatics has the potential to provide frameworks and strategies for designing effective health communication tools that empower users and improve their health decisions. This article presents an overview of the consumer health informatics field, discusses promising approaches to supporting health communication, and identifies challenges plus direction for future research and development. The authors' recommendations emphasize the need for drawing upon communication and social science theories of information behavior, reaching out to consumers via a range of traditional and novel formats, gaining better understanding of the public's health information needs, and developing informatics solutions for tailoring resources to users' needs and competencies. This article was written as a scholarly outreach and leadership project by members of the American Medical Informatics Association's Consumer Health Informatics Working Group.

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Introduction

Consumer health information resources provide health information to lay users, hopefully to empower patients, caregivers, families, and consumers; improve decisions; and ultimately foster better public health outcomes. Although the number of consumer-oriented resources keeps growing, their effective use requires significant lay knowledge and skills in areas ranging from health terminology knowledge to effective use of electronic media. Competency deficiencies among those who most require such capabilities result in a digital divide, or a growing gap between persons who can and cannot benefit from the proliferation of online health information. The field of consumer health informatics has the potential to assist developers with tailoring resources to consumers, which reduces gaps between the knowledge and skills required by the resource and possessed by its users. The goals of this article are: (1) to review existing theory and informatics tools in the field of consumer E-health communication, and (2) to identify existing challenges and make recommendations for further research agenda. The approaches discussed in this article include, but are not limited to: work on the development of consumer health vocabularies, implementation of tools for information retrieval and readability support, integration of user needs and usability concerns into the design of consumer health information resources, and assessment of users' health literacy as well as the quality of information resources. Although health information can be delivered to consumers via a variety of media types (e.g., audio and video programs, podcasts, CD-ROMs), the usage of "consumer health informatics" throughout this article primarily refers to the provision of health information resources to consumers via the Internet.

The article is divided into four sections. Section one discusses the theory and trends in digital health communication. It includes an introduction to the conceptual dimensions that

influence informatics health intervention and outlines a variety of consumer E-health applications in public health, the health care delivery system, and patient care. Section two reviews barriers to designing effective resources for communicating with health consumers. These barriers include issues of access and user competencies, as well as designers' limited insight into users' information needs. Section three reviews selected informatics research on tools and strategies to overcome health communication barriers, including developing improved consumer health vocabularies, optimizing information retrieval and readability, evaluating information quality, incorporating user needs plus usability concerns into systems' design, and assessing users' health literacy. Section four, which is the conclusion, provides broader challenge and recommendations for future research.

This article originated from a round-table discussion during the 2007 AMIA Spring congress, when over 30 attendees with an interest in consumer health informatics expressed their views on the current state and research priorities of the field. The transcript of the discussion was instrumental in defining the topics covered in this manuscript. The manuscript was then reviewed and adopted by AMIA's Consumer Health Informatics Working Group, and endorsed by the AMIA Working Group Steering Committee on January 28, 2008. This article is intended to raise intraprofessional awareness, outline research priorities, and advance scholarly outreach and leadership. It does not provide a comprehensive literature review.

Theory and Trends

Conceptual Dimensions of Consumer Health Informatics

Although mass media–based public health campaigns have been common within the United States for almost 3 centuries,[1] it was not until the 1970s that health campaigns developed a formal literature.[2] In a discussion of consumer health informatics' formative direction, Napoli[3] suggested its disciplinary advancement could be accelerated by integrating the conceptual frameworks derived from the 30+ year legacy of health campaign research.

Logan and Tse[4] recently combined the conceptual history of health campaign and information-seeking process (ISP) research into an integrated conceptual framework of consumer health informatics and health communication to the public. This conceptual framework attempts to bridge the conceptual gaps between health campaign, health communication, and consumer health informatics research. The conceptual framework integrates the ISP, which is a dynamic, iterative series of cognitive processes, with four additional dimensions advanced by the health campaign research literature.

The first dimension includes consideration of: (1) the source of health messages, (2) the content of health messages, (3) the media delivery channel of health messages, (4) the receiver's (individual) postexposure to health messages, and (5) the destination of health messages.[5] Within this dimension, the focus on the content of health messages conceptually includes issues such as the ability of the content to match the target audience's written, visual, or media literacy.[5] The focus on the receiver partially conceptually encompasses

individual characteristics of health information seeking and includes the convergence of a person's prior interest in health, some cognitive skills, and access to information, which often are addressed in traditional consumer health informatics research.[4] Logan and Tse[4] note a core difference between traditions in health information seeking and health campaign research: the latter field consistently asserts that personal health information seeking and the match between a person's cognitive skills and content are just two elements within a broader environment in which a person is exposed and responds to health information.

Within this broader environment, the second dimension includes a consumer's environmental and affective context (e.g., emotions, feelings, instincts, broad non–information seeking interests, and motivations); the possibility of multidimensional, situation-based responses; and the probability that health information seeking and media use reflect both cognitive "uses" (such as information gain) as well as emotional "gratifications."[6,7] The third dimension includes: (1) assessing a consumer's immediate social influences, social milieu, and behavioral adaptability, such as the influences of peer pressure, community influences, and commercial advertising on health information seeking and behaviors[8–10]; (2) a more sophisticated understanding of individual cognitive behavioral factors, such as a person's problem solving and decision-making skills,[8,9,11] and (3) the degree a consumer's commitment to a specific health behavior is matched by other relevant skills or abilities to successfully adapt a health or medical intervention, including health status.[9,12] All three dimensions reflect an important research-derived understanding that a consumer's affective response, setting, lifestyle, and skills are as integral as cognitions (e.g., prior knowledge and information seeking habits) and health status to conceptually frame the dynamics of how persons seek health information.[2,7]

A fourth dimension emphasizes macro forces, such as a nation's or region's health resources, its global or national context (e.g., developing versus industrialized, cultural, and religious heritage) its economic prosperity and geopolitical factors.[13]

The linking of traditions in information science and health campaign research provides: (1) an integrated multidimensional conceptual framework, and (2) a convenient launching point for multidisciplinary efforts to better assess, explain, and model consumer motivations to seek, retain, and relish health information resources on the Internet. The integrated framework strongly suggests that a consumer's information-seeking process is impacted by affective, community, sociological, demographic, and individual skills, macro and micro cultural realities, as well as the possibility that the purpose of seeking health information and using health resources on the Internet is not always to gain information.[6,14] The integrated framework also suggests that the process of health communication is horizontal and multidirectional. Many of the conceptual dimensions and issues outlined here are discussed throughout the article.

New Trends in Health Communication and the Emergence of E-Health

Health communication via electronic media has roots in more traditional media. Books, encyclopedias, and take-

home patient brochures were among the first available mass media to share health information. Mass-printed media, such as newspapers and magazines, and television also have been used to deliver information. However, the power and popularity of the Internet significantly increased the types of available media resources, changed the mechanics and economics of the mass delivery of health information, the potential for increased consumer access to health information, and the modalities by which persons seek health information.

Three groups participate actively in the E-health information exchange: health care providers (clinical and other), patients and their immediate caregivers, and others, including healthy persons who wish to stay well. The Internet has provided numerous opportunities for health care professionals to interact with their patients and with each other. For example, telemedicine has made it possible to diagnose from a geographically different place and time, e-mail is used to provide advice, and pharmacies encourage electronic request for refilling of medication. Health care professionals also can consult each other using listservs or in online communities of practice. In a study of an advanced practice nurses' listserv, Hara and Hew[15] found the majority of activity (more than 80%) consisted of knowledge sharing or information solicitation. Finally, health care professionals together with hospitals, insurance companies, nonprofit and for-profit health care organizations/institutions and the news media, provide health information via websites, electronic newsletters, or e-mail.

Patients and others can educate themselves by reading about general disease and health information, such as provided by WebMD.com or MedlinePlus.gov, clinical trials information, such as provided on ClinicalTrials.gov, and product information (evidence-based or not), such as provided on pharmaceutical advertisements or drug labels. The Internet and the increased availability of technology also encourage a more active partnership between health care professionals and patients plus caregivers. Although many of these efforts are in trial phases, professionals and patients can use software products to help manage chronic diseases and conditions. For example, blood glucose meters can be combined with software to visualize glucose levels before and after meals for extended periods of time. Body mass index calculators are often available as a free download, or on highly accessible, free websites. Patient-accessible electronic health records are sometimes sponsored by hospitals, in addition to their electronic medical records, or they are initiated by individual consumers. Family health record keeping systems are available through Internet resources, such as the U.S. Surgeon General's Office. These sources of patient input collect additional, and often missing, information that is important in clinical decision making. Wuerdeman et al.[16] found consumer-generated data is reasonably accurate when consumers characterize the overall findings of medical tests, but self-reports are less reliable for precise measures, such as a blood pressure measurement.

In addition, E-health technology enables consumers to form relationships and communities online, thereby transcending time and geographical barriers. In these communities, consumers share stories, give advice, and support each other. For example, some multiple sclerosis patients assist each other online during painful self-injections.[17] Information exchange in online communities is often not moderated by health professionals. However, an analysis of postings to a breast cancer support group found that only a very small proportion of posts contained inaccurate information and that most inaccuracies were rapidly corrected by other participants.[18] E-health technology also has significantly changed how patients and caregivers interact. More health information has become available (such as public access to Pub Med) and more patient–caregiver interaction is possible because remote and anytime interpersonal communication is now possible via e-mail. The information exchange itself is potentially faster and can include a wider range of information that is easy to forward from the Internet. Finally, whereas the transmission of clinical information formerly emphasized a one-way, downward, interpersonal flow from provider to patient, E-health's information flow is horizontal, involves additional participants, and moves in multiple directions, as the conceptual framework outlined in the previous subsection suggests.[4,6]

Barriers to Effective Consumer E-Health Communication

Access, Competencies, and Digital Divide Issues

The opportunities afforded by E-health are not equitably available to everyone. Because E-health's inception, researchers, policy makers, and consumer health information product developers have been concerned about outreach to medically underserved audiences and the link between health disparities and Internet access. Ratzan and Parker[21] find those who most need health information lack the means, knowledge, and skills necessary to benefit from Internet health resources.

One significant barrier to the use of Internet health resources is consumer access. Pew Internet and American Life Project found in 2006 that 27% of U.S. adults had no online presence, and most Americans used a slow-speed connection.[19] Nonusers were more likely to be poor, less educated, over the age of 65, disabled, members of ethnic minorities, and nonnative English speakers.[20]

Although the access gap may be narrowing, health literacy has emerged as a more fundamental barrier to providing Internet and other health resources to medically underserved and other audiences.[21] Health literacy also is now perceived as a primary obstacle to reducing health disparities.[21] Health literacy is "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions."[21] It is useful to think of health literacy in terms of the core competencies required to retrieve and process various kinds of consumer heath information online. A number of conceptual models and frameworks identify somewhat different but largely overlapping sets of instrumental skills.[22,23] These include general literacy skills (reading ability, oral and written communication), numeracy skills (estimation, computation, understanding probabilities), conceptual knowledge, health vocabulary knowledge, document literacy (understanding format and function of specific health-related forms), technological fluency (ability to manage information technology devices), and information seeking skills and rhetorical skills (advocacy, making

requests and complaints). An individual's propensity to exercise health literacy skills is related to perceived cognitive abilities, health/physiological status, mass media familiarity, perceived self-efficacy, as well as social and cultural norms (similar to the conceptual overview discussed in the first section).

Further, about 50% of U.S. adults do not possess adequate health literacy skills required for many health communication and management tasks.[24,25] Similar to Internet access, health literacy skills are disproportionately low among economically disadvantaged people, seniors, and ethnic minorities[26,27] Problems with understanding health information can often be related to inadequate general literacy skills. For example, 43% of U.S. adults have difficulty with moderately challenging prose literacy activities, such as drawing on two separate statements in a text to make an inference.[28] To address this problem, many guidelines recommend writing consumer health materials at the 6th to 8th grade level, as measured by existing general readability formulas. Actual readability of material varies, but most assessments report that at least 50% (typically, more) of the reviewed materials were written above the 8th grade level.[29] In addition, health understanding also can be difficult even for persons with higher-than-average English or other language proficiencies. The Institute of Medicine found that above-average language skills are not necessarily associated with the public's functional understanding of health messages, or medical information.[21] The Institute of Medicine added that health education and literacy are not necessarily addressed by the same strategies used to bolster general education and language skills. Hence, improving health literacy is more challenging than general literacy and successful public communication strategies are not necessarily predicted by audience demographics or educational backgrounds.

Much research attention has been given to consumers' limited understanding of probabilities and difficulty reasoning about risk. Studies suggest that individuals across all education levels have difficulty interpreting probabilities, understanding the equivalence between percentages and proportions, converting the data from one representation into another (e.g., 1 in 500 to 0.002) and taking baseline risks into account.[30] These difficulties, from which even health professionals are not exempt, are likely to complicate reasoning through many important decisions (e.g., selecting a treatment option). Computational skills present another quantitative barrier to interpreting health information: 55% of U.S. adults have below basic or basic quantitative literacy level, and can only deal with simple numerical operations.[28]

Recent evidence suggests that inadequate health literacy negatively impacts health behaviors (e.g., medication adherence and compliance with physician instructions) and broader clinical outcomes.[27,31] Although the field of consumer health informatics cannot remedy all the challenges raised by health literacy, it can reduce the gap between user health literacy and consumer E-health resource health literacy requirement. This can be accomplished by providing ways to assess or estimate users' health literacy and appropriately tailor the presentation of health information.

Limited Understanding of the Public's Health Information Needs

Paradoxically, there is voluminous literature on the information needs of health care professionals but very little on those of patients and little about the needs of the general public. In practice, systems design is typically guided by the providers' perception of patients' information needs, rather than by actual needs assessment.[32]

Most research about the public's health information needs focuses on needs that are related to a specific disease or condition, on needs of specific demographic groups, and on stages of disease and treatment. Disease-specific, lay health information needs research usually focuses on patients, and less frequently on nonpatients. Patient-oriented studies have been conducted in a wide range of domains,[33,34] with cancer patient studies contributing a significant portion of the literature.[35] Nonpatient studies have assessed the information needs of caregivers, primarily focusing on family members, but occasionally this research includes friends and peers of patients.[36]

Our conceptualization of health decision making as a social process (that includes consumer convergence and the uses and gratifications derived from health information) leads us to believe that information needs of caregivers, family members, and peer groups should be given greater research attention. The contribution of ethnicity to information needs also deserves more study, as group differences have been found in information preferences.[37] Research that contextualizes needs within disease and treatment stages also suggests how information needs of patients change with time. For example, Echlin and Rees[38] argue for an understanding of a continuum of treatment in relation to information needs, not just what is needed but when it is needed for the particular population studied, encompassing pretreatment, in process, and posttreatment.

Research about the information needs of clinicians and patients/consumers typically has been performed with little attention to their similarities and differences. Timmins and Kaliszer[39] are among the few researchers who examine differences between patient and practitioner perceptions of information needs. These investigators found significant differences between rankings of postmyocardial infarction patients' information needs and nurses' perception of those same patients' information needs. From 37 information items categorized in seven types, nurses and patients were found to agree on only a few highly ranked information items including, "what to do when in chest pain," "what are the symptoms of a heart attack," and "what to do to reduce the chance of another heart attack." However, items such as "when to resume driving," "when to resume sexual activity," and "when to resume work" were rated by nurses as very important but by the patients as unimportant. To empower health consumers, information content and presentation should be dictated by consumer agendas and information needs. Before health informatics researchers can meet these needs, we need to understand lay audiences more thoroughly. One potentially promising way of gaining an insight into lay health information needs without direct questioning is by analyzing the popularity of various health information websites (assuming that popularity correlates with relevance).[40]

Five Other Consumer E-Health Communication Barriers

Besides the systematic obstacles outlined above, there are at least five other operant barriers in consumer health informatics research that seeks to optimize how health information resources are provided to the public, patients, and providers. First, although informatics has demonstrated potential to improve health communication to the public, the field faces challenges similar to those faced by health communication researchers, such as a need to serve diverse demographic and psychographic audiences within a variety of communication contexts. Because health care consumers are a heterogeneous group with varied cultural, educational, and social backgrounds (who engage in horizontal, multidirectional health communication within an array of contexts), the resulting diversity makes it difficult to develop general informatics solutions.

Also, although groups of clinicians and scientists using a professional resource typically share similar education backgrounds and often handle similar tasks (e.g., a literature search on a well-defined topic), for patients and caregivers, there is little training and predictability in information-seeking patterns. Although a consumer health website can use a built-in health literacy assessment tool to match the user to a desired readability level, optimal information presentation sometimes depends on the English fluency of the recipients, other health literacy competencies (such as a user's health information seeking proclivities), as well as a host of interactive factors that include user motivation, prior knowledge of the specific topic, and the context (e.g., the diagnosis, emotional state). Overall, the multidimensional nature of a consumer or an audience's converging on health information resources, which was outlined in the article's first subsection, poses a significant challenge in developing tailored consumer E-health resources on the Internet.

The complexity of communicated information presents a second challenge. For example, many consumer-generated, straightforward health questions, such as "Does hormone replacement therapy cause cancer," lack a simple answer. To comprehensively respond, one might discuss increased and decreased risks for different types of cancers, absolute versus relative risks, personal versus population-level risk prediction, and different types of hormone replacement therapies. In other words, adding a context to increase understanding can be detrimental to its comprehension by some health information consumers.

Third, some routine lay communication scenarios, such as informed consent, present externally imposed barriers that challenge researchers, providers, patients, caregivers and communicators who seek to make health information understandable. Informed consent forms serve a dual purpose: although the primary purpose is to help potential participants in clinical trials to make informed decisions, the secondary one is to limit liability. Yet, it is difficult to simultaneously simplify content and provide an effective legal defense. In this common example, the best of intentions to make language understandable may be eclipsed by external requirements, which can divert attention from a user focus, or result in more attention to the format in which information is presented instead of its content. While content might follow function in informed consent, the overriding issue in health communication creates scenarios where a range of optimal communication options may be unavailable.

Fourth, because communication is a horizontal, multidirectional process, the complexity of the information provided by consumers certainly must be taken into consideration. Patients' accounts of their health history may involve intricate narrations, concerns, and reasoning patterns. Whereas historically such information was often not well documented, the new emphasis on shared record keeping increases a need to devise accurate and efficient ways to represent and integrate patient-generated information.

Fifth, besides providing understandable information, measuring the clinical and cost-effective impact of health communication may be problematic in consumer health informatics research. In traditional mass media–based health campaigns, information is typically provided to either promote or discourage a behavior. Such behavior changes (e.g., smoking cessation) can then be measured as the outcome of the campaigns. However, consumer health informatics applications, such as information retrieval and decision support tools, often do not directly target immediate, measurable behavioral changes. Although consumer informatics researchers assume that well-informed patients make better self-care decisions and in the long run have better health, the inability to focus on a specific behavior undermines the demonstration of a specific, therapeutic, health-related outcome. While a higher level of patient satisfaction (e.g., a patient feels more confident about the decision to undergo a procedure) represents a positive outcome, informaticians should think about improving the accountability and outcome measures in consumer health informatics initiatives.

Although all five aforementioned challenges are common in consumer health informatics research, the point is for researchers to remain mindful of them in study design and execution. The ability to address each challenge is an opportunity to advance how informatics provides health information to intended audiences and advances communication among them.

Informatics Tools and Strategies to Eliminate Health Communication Barriers

Developing Consumer Health Vocabularies

As previously mentioned, a significant element of the multidirectional E-health communication between consumers and providers is text-based, and vocabulary is an essential component of all textual messages. Education materials, medication labels, informed consent forms, personal health records, patient e-mails, news group postings, and Web queries all require adequate vocabulary knowledge for both machine processing and human understanding. This raises two issues: first, many consumers have difficulty comprehending medical jargon. Second, computer systems may not recognize lay health terms if they are not included in a controlled vocabulary such as Unified Medical Language System (UMLS).

Health communication researchers have partially explored the lay-professional vocabulary barrier. More health education for consumers and increased communication education

for providers are two potential solutions, but both will take decades and a massive investment in adult, child, adolescent, and professional education to accomplish. In the interim, the authors believe informatics can and should provide much-needed assistance (although it will not provide a total solution) to both health consumers and providers.

To address the critical need of vocabulary support for consumer health application, both for-profit and nonprofit organizations have developed consumer health vocabulary (CHV) products. Three commercial entities (Intelligent Medical Objects, Apelon, and WebMD) created CHV and/or CHV tools between the late 1990s and early 2000s. The content of the Intelligent Medical Objects and WebMD products are proprietary. Apelon's product has been proprietary, although it might move to open source in the near future.

There are two early CHV-related developments in nonprofit settings: the Planetree Classification System (www.planetree.org) and women's health thesauri, for example, those developed by the former Boston Women's Collective (www.ourbodiesourselves.org) and the Canadian Women's Health Network (http://www.cwhn.ca). These are lay-friendly categorization schemes for health content, although not extensive representations of lay vocabularies. The Planetree system has been used by a number of consumer health libraries and on-line sites.[41,42] The Canadian Women's Health Network's health information center uses the Canadian Women's Health Network thesaurus, consisting of more than 4,000 keywords, to catalog its online topic pages. Since the early 2000s, a number of informatics researchers have analyzed consumer-authored texts and found discrepancies between the health terms and concepts used by consumers and professionals.[43–48] Based on these studies, a Consumer Health Vocabulary Initiative (www.consumerhealthvocab.org) was formed and an Open Access Collaborative (OAC) CHV has been developed.[49] There is a plan to submit OAC CHV to the National Library of Medicine in 2008 for incorporation into the UMLS. Overall, the CHV research and development has taken an audience-inspired and data-driven approach and has the potential to provide valuable tools for addressing the lay-professional language barrier in consumer E-health applications.

Optimizing Information Retrieval and Text Readability

Health domain–specific portals are available and popular. For instance, MedlinePlus.gov and WebMD received top rankings by Alexa Web Information Company based on visits in the health category (October 2007, www.alexa.com). Consumers reading this type of information are influenced by it, so misunderstandings may lead to poor decisions. Hence, it is important to facilitate the retrieval and understanding of accurate, precise, patient-specific, and actionable information.

Despite this evident need, improving information retrieval with consumer-friendly tools remains surprisingly uncommon and is limited to a few research projects, such as term suggestion tools to enhance the retrieval of appropriate information. The good news is that some term suggestion tools report significantly increased success rates in helping consumers find relevant documents.[49] Yet, once the infor-

mation is found, consumers still need help evaluating the validity of the information they find, especially for unknown and new sources. More research and development are needed in this area, as discussed in the subsection below. Then, to facilitate consumer understanding of retrieved information, all text and graphics need to be presented so they are understandable to lay audiences. Several groups have developed guidelines for writing text for the public, e.g., the National Institutes of Health Plain Language Initiative or the California Health Literacy initiative. These guidelines usually suggest using readability formulas, which assign grade levels to English text; some advocate a maximum as low as 6th grade level. A vocabulary-based evaluation can compliment such formula-based evaluations.[50] However, this approach is not ideal for three reasons. First, it is impractical to rewrite all existing online information. Second, it is impossible to enforce adherence to the guidelines for new text, and third, not all biomedical topics can be explained at a very low grade level and provide actionable knowledge for readers.

Ironically, most information technology research has not focused on consumers but on providing clinicians and researchers with tools to extract information from medical records or visualize research findings. The greater need would seem to be more for research targeted to assist consumers: information technology is needed to evaluate documents automatically, provide consumers with vocabulary help, and add structure and visualization to increase understanding.[51,52] Different approaches need to be tested, especially because preliminary evidence suggests that providing dictionary support alone may not be effective when texts lack lexical cohesion and logical organization.[53] For example, an overview of information, such as a visual table of contents,[54] can help consumers focus on relevant text snippets, which is important for those with low reading skills.

Increased understanding can be accomplished by enhancing text readability; by facilitating precise information retrieval with optimized, domain-specific search engines; with query assistance; with information validation; and with optimal results presentation. Potential solutions such as automated translation to easier text, visualization, and animation require additional research. Yet, readability challenges and the optimal format for information presentation (such as the utility of accompanying graphics) remain underexplored areas.

Evaluating and Ensuring Information Quality

The evaluation of the quality of online health information has been a concern since the Internet became widely available to consumers. The medical literature began to address the problem in 1997, following Impiccatore et al.'s disturbing findings on uneven official recommendations for pediatric fevers.[55]

The 1997 Mitretek report[56] outlines seven core criteria of quality: credibility, content, disclosure, links, design, interactivity, and caveats. The (2007) *MedlinePlus Guide to Healthy Web Surfing* (www.nlm.nih.gov/medlineplus/healthywebsurfing.html) makes similar suggestions. It encourages users to:

- Use "recognized authorities" (about us page, contact information)

- Focus on quality (editorial board members, credentials of members, posted selection policies)
- Be a cyberskeptic (sensitivity to potential quackery demonstrated by unreasonable health claims, obscure language, miraculous results, etc.)
- Look for the evidence (author identification, author credentials, contact information)
- Check for currency (dates on documents, current links, update information)
- Beware of bias (site sponsorship, clear identification of source of content)
- Protect their privacy (posted privacy policy)

A complete listing of quality criteria found in various instruments can be found in Jadad and Gagliardi.[57] "Indirect" indicators, such as "impact factor" derived from Medline citations to cited authors, as a proxy for "credentials" also have been explored.[58]

As health information quality received more attention, policy statements and codes multiplied. Similar to MedlinePlus's aforementioned guidelines, others have incorporated quality criteria and packaged them for easy consumer application. For example, the Health on the Net Foundation (www.hon.ch), a nongovernmental organization that began after an international conference in Switzerland in 1995, provides consumer-friendly quality guidelines. The DISCERN tool, an outcome of the DISCERN On the Internet Project funded by the British National Health Service, (www.discern.org.uk/index.php) is designed to be used online, and features 15 questions that generate a rating of quality, based on the assessment of reliability, trust, and specific details about the information presented.

However, some researchers have questioned the reliability and validity of some widely used quality indicators. Bernstam et al.[59] found that many commonly cited quality criteria (e.g., disclosure of ownership, disclosure of advertising) could not be reliably assessed by individuals with medical informatics training, thus raising the issue of their usefulness for an average consumer. Fallis and Fricke[60] found little correlation between the indicators found in published guidelines and the accuracy of the information on a health website. In a study of 47 rating instruments purporting to evaluate health information online, Jadad and Gagliardi found none provided reliability and construct validity.[57] In a recent update of the same study, the investigators found the number of rating instruments grew to 98.[61] Although most of the originally surveyed 47 instruments were no longer functioning, 51 new instruments were found. Of these, 11 proved to be produced by defunct organizations, 35 provided no information about their quality criteria, and only five that revealed their criteria remained to be assessed in the follow-up study. Not one of the latter five reported reliability or validity data.

Because Healthfinder.gov currently lists many of these instruments as recommended evaluation tools for the consumer, a renewed effort to provide grounded guidelines for consumers to determine quality health information is a research priority. Innovative approaches to quality assessment would also be beneficial. For example, the work of Dutta-Bergman[62] calls for a segmented approach to consumers, an approach that appreciates the demographic differences between respondents who trust a particular online

source and those who do not. Mechanic[63] calls for physicians to "sharpen their own communication skills" and work on strategies for new kinds of partnerships with consumers; he cites innovations like "training in communication skills; creative uses of the Internet and videotape technologies; improved 'customer service' programs; critical pathways for patients; and special educational aids." In addition, community expertise, as opposed to individual expertise, is assuming more dominance in the conversation. For example, Eysenbach[64] postulates that in the age of Web 2.0, the opinion of influential peers/leaders in online communities becomes the key conveyor of source credibility. This points to the potential of community/user feedback as a contributor to a quality metric (although of course the ability to distinguish between quality and popularity is essential). The role of the health care provider as evaluator and gatekeeper of these metrics as well as the information they assess cannot be underestimated here; Cullen[65] found that the medical specialist assumes an important role not only in the dissemination but also in the establishment of information quality, and not only for consumers but also for generalist practitioners. Finally, it is important to address the distinction between information completeness, accuracy, and quality. Although we (and many guidelines) treat accuracy as a prerequisite for quality, it is possible for quality information to be incomplete, and for accurate information to be of low quality. However, each of these three indicators is essential in order for the information to be actionable.

Incorporating Information Needs and Usability Concerns in Systems Design

Effective E-health resources anticipate users' needs and actions and present clear pathways to desired information; problems with interface design and the underlying information structure can severely limit their usefulness to consumers. Designing usable websites is especially challenging if target users have limited levels of health literacy, lack computer experience, or suffer from disabilities that complicate resource use.[66]

Evangelista et al.[67] assert that usability starts with needs assessment and "the most important issue when developing a health information system is that its design and content are anchored in what consumers really want and need." The guidelines for a website development site such as Usability.gov typically state that a user or audience's needs should be considered from the outset of the website creation process. Guidelines also suggest employing usability testing throughout the design cycle, as usability problems are most easily prevented when developers of the resources keep their users in mind throughout the design cycle. Usability.gov recommends the techniques of usability testing ranging from interviews to card sorting.[68]

In reality, attention to actual users varies. Some articles cite, in passing, the use of "frequently asked questions" of library patrons or website visitors in design or redesign of information-oriented publications and websites. Chason[69] describes a published directory of Florida psychiatrists that was created by the staff of a mental health facility library because this resource was frequently requested. Ritter et al.[70] performed task analysis of user groups and examined documentation of their work productions (e.g., search engine

logs), to assist in building academic department websites. The National Cancer Institute reports using a multifaceted approach to assessing audience needs and gathering feedback from users via its CancerNet website.[71] Cole et al.[72] also developed an information retrieval system using a differential diagnosis model. User need was measured according to its fit with Kuhlthau's six discrete stages of the information search process: task initiation, selection, exploration, focus formulation, collection, and presentation.[73]

Although the problem of user needs assessment and usability is not unique to health websites, the latter frequently often share some common challenges and characteristics. Health websites are designed for widely diverse audiences (where user needs differ), and there is large variance in user background knowledge and computer experience. For example, ClinicalTrials.gov, the largest existing database of clinical trials, provides information to patients and caregivers, the press, clinicians wishing to make a recommendation, academic researchers conducting systematic reviews, medical journal editors, and policy makers.[74] Health information resources also can provide scientifically complex and detailed information to individuals who may lack the cognitive skills and vocabulary necessary for effective navigation. As a result, designers need to carefully provide opportunities for both searching and browsing, and offer several hierarchical structures for browsing the data (e.g., grouping diseases both by bodily systems and by demographics groups they affect).[75] Similar to the challenge of health literacy, consumer health informatics can improve the usability of consumer health resources by assessing or estimating relevant user demographics, and then provide tools to tailor the interface to different audiences.

Overall, the literature suggests that patients, family, and caregiver opinions on what information they need deserves more attention in systems design.[67] Greater attention also is needed to usability issues that are specific to consumer E-health resources for diverse audiences.

Assessing Health Literacy for Information Tailoring

Health literacy measures can be subdivided into three categories: (1) health literacy screening measures, (2) large-scale national surveys of general adult literacy, and (3) research studies' tasks measuring specific, narrow components of health literacy (which are outside the scope of this review). Two frequently used health literacy screening measures include Rapid Estimate of Adult Literacy in Medicine (REALM)[76] and the Test of Functional Health Literacy in Adults (TOFHLA).[77] These measures do not provide comprehensive assessment, but assess competency in selected domains that are supposed to be representative of overall health literacy. The REALM is a vocabulary test that requires reading and pronouncing 66 health-related terms of increasing difficulty. The TOFHLA includes a 50-item reading comprehension section that employs modified Cloze (sentence completion) procedure for measuring prose literacy plus a 17-item long multiple-choice "numeracy" section based on real medical documents. The advantages of these tests are a relative ease of administration and some intuitively appealing scoring categories (e.g., grade levels). Both measures also exhibit good psychometric properties, and are highly correlated with each other and with general vocabulary tests.[23]

However, the Institute of Medicine notes "neither the REALM nor the TOFHLA capture the full complexity of the construct of health literacy."[25] Although these measures may be good screening tools, they cannot identify specific areas of health literacy where an individual might need support (e.g., health concepts that need to be taught).[23]

The second category of health literacy assessment involves large-scale national surveys of general adult literacy, which often include tasks that are situated within health contexts. The National Adult Literacy Survey (NALS) measures three aspects of literacy: prose literacy, document literacy, and quantitative literacy.[78] The NALS assessment is based on tasks of increasing difficulty that are taken from texts and documents drawn from six everyday contexts. The easiest tasks require locating information, and the most difficult involve generating inferences and formulating/performing required numerical operations. Participant raw scores on each subscale are categorized into Levels 1 through 4. Health-related NALS activities provided a basis for the compilation of the Health Activities Literacy Scale (HALS).

Health literacy surveys are grounded in more complex literacy constructs than REALM and TOFHLA, and are more likely to generate the information needed for successful interventions. However, health literacy surveys also have important limitations that should be addressed in the next generation of health literacy assessment tools. For example, health literacy surveys do not encompass the multidimensional dynamics of how persons engage, understand, and act on health information, especially if one considers the conceptual framework raised in the first subsection of this article. Current measures are not based on an explicit theoretical health literacy framework, and fail to measure several important aspects of health literacy, such as oral literacy skills, conceptual understanding of health-related constructs, health vocabulary knowledge, and cultural beliefs. In addition, current measures do not provide a comprehensive assessment of health-related quantitative skills (or numeracy), are very dependent upon reading skills, and often cannot distinguish between health and general literacy. Finally, current tests do not evaluate basic technical competencies, which are essential in today's technology-driven health care environment.

Consumer health informatics creates the promise to ease the task of comprehensive assessment via adaptive testing techniques and making health literacy–based approaches more audience tailored, multidimensional, and pragmatic. However, health literacy needs additional operationalization and specificity to reach its potential as a robust independent or dependent variable in both consumer health informatics and clinical outcomes research.

Conclusion: Recommendations and Directions for Future Research

In an era in which the public is asked to play an increasingly active role in their health care, consumer health informatics seeks to bridge the digital divide and support more consumers' ability to understand and author health information. However, this promise is ripe with challenges and potential

pitfalls, as this article attests. Fortunately, the same challenges present an exciting time for the field, with a surplus of interesting theoretical and applied research problems to address.

Throughout this article, we discussed the potential of informatics to support consumers by bridging two gaps: (1) between user needs and the content of information resources, and (2) between user competencies and resource complexity. With respect to user needs, novel methods to map how persons converge on health information resources need to be developed. In doing so, it is important to be mindful of the aforementioned current emphases on horizontal communication from health authorities to consumers, from consumers to health professionals, and among consumers, as well as among all possible participants in the creation of the public's health information and health care policy environment. A related issue is to explore ways to employ informatics tools to assess the quality and gently moderate consumer-generated content in venues such as online discussions and personal health records.

The authors believe informatics support has the potential to enable developers to match user competencies and resource complexity. However, the devil is in the details—significantly more work needs to be done to ascertain the demographic and situational characteristics that affect information needs and processing. One potentially promising technique is log analysis, frequently used in market research consumer segmentation. An underlying architecture of resources that permits customization is another interesting approach that merits consideration. In addition, the authors believe the field needs advances in the areas of consumer health vocabulary development and readability measurement.

Yet, there are no shortcuts to encompass the dimensions of health communication that are outlined in the article's opening subsection. Mindful of the challenges, the authors make the following specific recommendations to consumer health informatics researchers and designers:

1. Consumer health informatics research and design should focus on drawing upon communication and social science research that addresses the social and emotional aspects of information seeking and acquisition behaviors. The understanding that health communication is horizontal and multidirectional (not top-down or unidirectional) needs to be a conceptual lynchpin of consumer health informatics research.

2. In reaching out to health consumers, the field should make use of a wide range of traditional and novel health information resources, from static informational Web pages to patient forums and virtual reality environments. A wide range of tools and resources should also be used to educate consumers about health issues and improve health literacy. These may include traditional informational pages and portals, as well as dictionaries, encyclopedias, tutorials, risk calculators, and information visualization tools.

3. Patients' and consumers' information needs and usability concerns should be given more consideration. Additional research is needed to understand the public's information needs as they pertain to health.

4. In order to support users with limited health literacy and bridge the digital divide, resources should aim at tailoring information content and presentation to intended users, or targeted audiences. This requires systematic research into the effect of various user characteristics on information behavior, and better tools for assessing the known facets of health literacy.

5. Reaching health consumers with the appropriate information can be improved via further development effort in the areas of consumer health vocabularies, information retrieval, and readability. Research in this areas can benefit from drawing on large amounts of existing data recorded by consumer E-health communication applications (e.g., queries, e-mails, and usage logs).

6. More accurate, well-publicized information quality indicators will benefit health consumers. These resources also need to be better maintained over time.

7. Greater research attention needs to be given to health information needs of caregivers, family members, and peer groups. Additional research is also needed into health information needs and information-seeking patterns of special populations (e.g., ethnic minorities, individuals with disabilities).

Consumer health informatics practitioners and researchers sometimes disagree on whether the primary goal of health communication and providing health resources is to provide clear, usable information or to promote behavioral change. In either case, all might agree that it is desirable to motivate educated consumers. Although many health educators are concerned about the clarity of their message, fewer worry about the "attractiveness" of the message to people whose health is not immediately affected (e.g., healthy smokers). This is yet another area where informatics can benefit by adopting techniques from marketing, entertainment, and the news media. The opportunities for research and application are numerous, as are the challenges. The field of consumer health informatics is at an exciting point, where new developments can bring innovative solutions to the challenge of effective communication with health consumers.

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