EDUCATING PRACTITIONERS AND PATIENTS
IN A NETWORKED WORLD

SOCIAL MEDIA FOR NURSES

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Social Media for Nurses

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The value of Health 2.0 is created by nurses, other health care providers, patients, families, and significant others through their telepresence and information sharing. This book is dedicated to these contributors as they shape the next generations of Health 3.0, 4.0, and so on.

Co-Authors

As one of the co-authors of this book, I also dedicate this book to my grandchildren: Mackenzie Elizabeth and Hope Elizabeth Hollis. They are today's joy and tomorrow's hope.

Ramona Nelson

I dedicate this book to my husband, Brian, for his understanding and support in all I do and for his hours of editing work, and to our son, Brian, for his editing work (I knew his writing degrees would be helpful) and for his critique of the social media concepts and exercises.

Irene Joos

As a reflection of the love and support my family has given me, I dedicate this book to them. To my husband, Ken, for his patience and support throughout my professional career, to my children, Carrie, Stephanie, Colin, Jeff, and Matt, who inspire me daily, and, lastly, to my father Angelo, who has always taught me to be loving, caring, considerate, and aware of those around me who are in need.

Debra M. Wolf

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Preface

The use of Web 2.0 applications in the delivery of health care is creating an online health care delivery world where nurses and other health care professionals must establish a telepresence if they are to meet the health-related needs of the community. By understanding and using Health 2.0 applications and technology, nurses have the opportunity to extend their services and professional practice to this new online environment with the goal of improving the health of individuals, families, significant others, and communities.

The authors of this book believe nurses and other health care professionals are responsible for educating patients and consumers to effectively use Health 2.0 tools in managing their health and health care. This belief stimulated us to write a text that would assist nurses in maximizing the use of social media, the Internet, and electronic devices to inform, support, and empower the consumer in adhering to a healthier lifestyle. Just imagine the extent to which a nurse working in all settings can support patients through online educational sessions, blogs, wikis, or telehealth services by sharing accurate and pertinent information that further empowers those patients to play an active and informed role in addressing their health care needs. Just imagine the number of health care consumers that can be reached, assessed, treated, or supported using the technology that is currently available. Just imagine what we can learn from our patients by partnering with them in working to improve health and health care.

Patients are more likely to experience positive health outcomes if they have the opportunity to be informed, engaged, and serve as a true partner in working with their health care team. Consumers are more likely to avoid health care problems and experience good health if they are informed and actively engaged in managing their health. Health care professionals are more likely to achieve excellence in the delivery of health care if they are continuously engaged in the improvement of their knowledge and skills. Web 2.0 and, in turn, Health 2.0 provide a new range of tools and applications for achieving these goals. However, with this opportunity comes responsibility. Health care providers are responsible for the effective and professional use of these applications in the delivery of health care.

This book introduces health care professionals to the knowledge and skills needed to effectively and professionally use Health 2.0 applications. Each chapter begins with clear and concise learning objectives and a list of related terms that may be new to the reader. Each term is discussed in the chapter and defined in the Glossary. Each chapter then provides a theoretical foundation for understanding the concepts presented in that chapter. The reader is presented with resources that support additional in-depth learning through URLs or website names. Each chapter incorporates discussion questions that stimulate the use of critical thinking skills in dealing with the issues presented. This content is followed by exercises that reinforce the development of Health 2.0-related knowledge and skills presented in the chapter. The book concludes with an Appendix that lists several additional resources that can be used to further support the needs of nurses, other health care professionals, and consumers.

Ramona Nelson
Irene Joos
Debra M. Wolf

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CHAPTER 1

An Introduction

Social Media and the Transitioning Roles and Relationships in Health Care

Ramona Nelson and Irene Joos

LEARNING OBJECTIVES

At the completion of this chapter the reader will be able to:

1. Analyze historical trends and driving forces impacting the utilization of social media in health care.
2. Define social media related literacies and explain their interrelationships.
3. Apply appropriate criteria to assess the credibility of health information on social media websites.
4. Analyze social media and the transitioning role of nurses and other health care professionals.

TERMS

- Computer literacy/fluency
- Consumer health informatics
- Consumer informatics
- Crowd-sourcing
- Criteria
- Digital literacy
- Digital native
- eHealth
- Engaged consumer gray literature
- Health 2.0
- Health literacy
- Health care consumer
- Informatics for consumer health (ICH)
- Information literacy
- Patient Empowerment 2.0
- Social media
- Web 1.0
- Web 2.0
- Wisdom of crowds

In April 2012 the PricewaterhouseCoopers Health Research Institute reported that one-third of consumers are using social media sites to seek medical information, discuss symptoms and express their opinions about doctors, drugs and health insurers. When these same consumers were asked how the information they found within these sites could affect their health-related decisions:

- 45 % said it would affect their decision to get a second opinion;
- 41 % said it would affect their choice of a specific doctor, hospital or medical facility;
- 34 % said it would affect their decision about taking a certain medication; and
- 32 % said it would affect their choice of a health insurance plan (PriceWaterhouse-Coopers Health Research Institute, 2012).

As these statistics demonstrate social media is changing the conversation between health care systems and the communities they serve. Web 1.0 opened up the world of health-related information to provider and patient alike by providing open, easy and rapid access to a wealth of new information. In 1997, free online Medline searching was opened to the public. For the first time both the patient and the health care provider had access to the same health care literature. Information found on the web or via the Internet can be invaluable or inaccurate or even dangerous. For example, a patient can find detailed information on options for treating back pain from top academic medical centers as well as options for "snake oil" that online scams may offer. The challenge for health professionals is to teach patients how to determine the difference.

Web 1.0 refers to static websites that the user views without interactive involvement between the user and the website. Communication is in one direction, meaning Web 1.0 does not offer a dialog with a person who actually tried different treatments for back pain. Social media are web-based and mobile technologies that turn this one-way communication into interactive dialogues. "The engaged consumer is seeking an ongoing dialog on health—not a one-way, 30-second broadcast" (Sarasohn-Kahn, 2008, p. 10). Changing the knowledge base and the communication patterns among individuals as well as between groups changes not only the content of the dialog, but also changes the relationships of the people and groups involved in that communication. In other words, social media will forever change the patient-provider relationship.

This book explores the opportunities and challenges nurses and other health care providers may experience when using social media to dialog with colleagues, patients/consumers, friends and families. The various types of social media are examined while analyzing the impact of social media on the practice of health care delivery. This chapter begins by examining the historical events and driving forces that are impacting how social media is now being used in health care.

HISTORICAL EVENTS AND DRIVING FORCES

Over the last several decades, the role of the patient has been evolving from passive recipient of health care to informed, empowered, and engaged patient/consumer. Underlying and paralleling this changing role of the patient has been the development of communication technologies. These new technologies have increased the opportunities for individuals to function as cohesive groups as well as provide increased access to information and knowledge. The ongoing development of an informed, empowered and engaged patient/consumer is part of a larger movement creating an informed and engaged citizen participating in all aspects of society and not just health care. Table 1.1 demonstrates this process through examining highlights in the history of *Consumer Reports*. It demonstrate emerging trends within the larger consumer movement (Consumers Union of U.S., 2012) as well as health care.

Several parallel, interrelated, and overlapping themes from health care can be identified within this larger consumer movement. These include efforts to control and shift health care costs; the evolution of the empowered health care consumer and the emergence of well-informed, empowered, and engaged patients; the establishment of consumer informatics as a branch of health care informatics and the development of Web 2.0.

Table 1.1 *Highlights and Implications of the History of* Consumer Reports

Year	History of *Consumer Reports* (Consumers Union of U.S., 2012)	Consumer Trends	Implications for Health 2.0
1936	Colston Warne, an Amherst College economics professor, announced the founding of Consumers Union during a speech with the statement, "There is in New York City now a consumers' laboratory which tests products, and rates them as to their quality. It is owned and controlled by organized consumers." Warne, one of the founders of Consumers Union, chaired its board from 1936 to 1979. The first *Consumers Union Reports* was published with articles on Grade A and Grade B milk, breakfast cereals, soap, and stockings.	Consumers are in control. A research method is used to determine the quality of products with experts directing the process of determining quality. Information is easily available to the public.	The patient as consumer is in control. This approach is consistent with using the credentials of an individual or organization to evaluate the quality health care information posted on the web. To be empowered, a patient/health care consumer must have full access to information.
1940	*Consumers Union Reports* starts asking its readers about their experiences with various products on its Annual Questionnaire.	Consumers as individuals share valuable information on the quality of products they have used.	Using crowd-sourcing patients can create valuable knowledge that is not available from other sources. Experiential knowledge is as valuable and informative as theoretical knowledge.
1942	Consumers Union changes the name of its magazine to *Consumer Reports* to make it clear that it serves all consumers, not just union members.	Emphasizes the importance of easily available information for all consumers.	Demands access to one's personal health information as well as information about health that is stored in resources such as MEDLINE.
1953	*Consumer Reports* publishes a series of reports on the tar and nicotine content of cigarette smoke and health hazards of smoking. "Information on exactly what cigarettes contained was available from no other source at the time."	Health care and health-related information is a product that can be evaluated.	Changing the health of a population requires that health-related lifestyle information is easily available to the public.

(*Continued*)

Table 1.1 *Highlights and Implications of the History of* Consumer Reports *(Continued)*

Year	History of *Consumer Reports* (Consumers Union of U.S., 2012)	Consumer Trends	Implications for Health 2.0
1970	With the recommendation of *Consumer Reports*, The National Commission on Product Safety is established, in part because of all the products that were unsafe.	Federal policy and, in turn, federal agencies support the consumer movement.	Health policy and government agencies must support the development of and provide regulation for Health 2.0 if the full benefit of this movement and related technology is to be achieved.
1987	*Consumer Reports* becomes available online.	Consumer information is available by Internet, thereby increasing access to this information.	Health care information is available via mobile electronic devices through Wi-Fi connections, thereby increasing access to this information for consumers on the move.
1989	First *Consumer Reports* health newsletter is published.	Health care is increasingly seen as a product requiring a quality type assessment that is available to the public.	Health care is increasingly seen as a product requiring a quality type assessment that is available to the public.
2007	ConsumerReportsHealth and the Consumer Reports Health Ratings Center are launched to meet consumers' demand for health information from a trusted source.	Increased emphasis on the quality of health-related information on the Internet.	Increased emphasis on the quality of health-related information and applications available through a variety of technologies.
Future?	A number of online stores now include reviews from consumers. As the number of reviews for each product offered via the web increases, how will access to this information impact the current role and activities of non-profit independent organizations such as Consumer Reports or government agencies such as the U.S. Consumer Product Safety Commission (http://www.cpsc.gov/about/about.html)?		

Source: Information for columns 1 and 2 from Consumers Union of U.S., Inc. (2012).

Efforts to Control and Shift Health Care Costs

The label "patient" and the label "consumer" carry very different connotations. A patient is someone who receives care that is provided by a health care provider. The phrase "patient-health care provider relationship" indicates that professional services are being provided in a caring manner by the health care provider to the patient and there is a special type of relationship between the receiver and the giver of the services. Evidence of this relationship is the tendency for a patient to say thank you at the end of an office visit with their health care provider. Even though the patient pays for the service either directly or indirectly, the emphasis is on the service. A review of several dictionaries demonstrates that the definition of the word patient does not include the word "cost" or suggest that money is exchanged for this service.

In contrast, a consumer is someone who purchases or takes in a product. The product may be a health care-related service, but the emphasis with the label consumer is on the fact that the service is not free. It is not a gift. The consumer pays for the service directly as an out-of-pocket cost or indirectly through a third party, such as their insurance company. Sometimes a non-profit agency or government program such as Medicare assumes the cost. In each case, cost is implied in the term "health care consumer." A health care consumer is defined as anyone who receives or has the potential to receive health care services, regardless of whether the individual pays for those services directly or indirectly (Guo, 2010). With this definition, the consumer of health care services can be identified as the key to controlling the ever expanding cost of health care for a number of reasons, including:

- Third-party payers for health care services isolate patients from information about actual costs and provide little to no motivation for controlling that cost.
- Providers and institutions paid on a fee-for-service basis have no motivation to provide fewer services. The more service provided, the more income produced with a fee-for-service model.
- Insurance companies that control cost by limiting access to health care services function in a conflict of interest environment. One can question if their decisions are in the best interest of the patient or are based on their profit margin.
- A significant proportion of health care costs are driven by chronic disease, which can be prevented or at least limited by lifestyle choices (Thompson & Cutler, 2010).

By providing health care consumers with larger financial incentives to control cost as well as information on prices, quality, and treatment alternatives, they can take more responsibility for their health by deciding what health care services to purchase. One particular approach to designing health benefits based on this definition of consumerism is called consumer-directed health plans (CDHPs), which include large deductibles and a tax-preferred savings account (Guo, 2010). With this model the consumer is encouraged to save money for future health-related costs and to decide if and when those savings might be spent. “However, there are still many gaps in the typical consumer models” (Thompson & Cutler, 2010, p. 26). The ideal situation is that patients/consumers would become more involved in controlling both their health and their health care costs, thereby improving the health of the community while creating a cost effective health care system. However, there are a number of factors that limit this ideal situation.

- Health care information is complex. Consumers may have difficulty understanding their options when faced with a health-related decision. In 2003, approximately 36% of the adult population in the United States demonstrated limited health literacy. These rates were higher in certain population subgroups (Berkman et al., 2011). In many cases, there is no one right or wrong answer for treating a specific health problem, but rather several options. This reality is demonstrated when patients are encouraged to get second or even third opinions. Questions of cost versus quality adds to the complexity. A recent study by Hibbard, Greene, Sofaer, Firminger, and Hirsh (2012) demonstrated that consumers are more interested in the quality of health care than in its cost, even when paying the cost out of pocket. In addition, a substantial minority of the respondents associated increased cost with increased quality. Interestingly, the researchers did find that “presenting cost data alongside easy-to-interpret quality information and highlighting high-value options improved the likelihood that consumers would choose those options” (p. 843). However, this kind of information is not often available.
- Funding prevention is a long-term investment. It is easy to delay these interventions if money and/or time are limited and there are no signs of impending health problems. Changing lifestyle choices across a population can take years and require a variety of approaches. For example, adult smoking prevalence declined from 42.4% in 1965 to 20.6% in 2009 (CDC, n.d.) as a result of multiple approaches. However, a

survey of employers conducted by PricewaterhouseCoopers found that 70% of surveyed employers include wellness initiatives in their personnel and benefit strategy, but only 15% of their employees participated (2012). In addition, many individuals, for a number of reasons, change their insurance companies several times over their lifetime. For example, some employers change their health insurance company options and some individuals change jobs, retire, or relocate. This reality does not encourage the insurance companies to fund preventative care since they are unlikely to be the insurer years later when illnesses develop.

- Some employees do not participate in prevention programs because they fear that completing a health risk appraisal, thereby revealing their poor health habits to the insurance company, will influence their job status or insurance premiums.
- Both patients and providers often avoid discussions of quality and cost. Many patients are uncomfortable questioning a highly educated health care professional. A feeling that the health care provider is rushed, as well as cultural, age and gender differences can accentuate this discomfort. For example, patients will often not mention to a physician that they would like a second opinion, because they do not want to leave the impression that they would doubt or question in any way the opinion of the first physician. In addition, health care professionals may not be knowledgeable or comfortable discussing health care options in terms of their costs. In many cases, both the patient and the provider would prefer to consider health care in terms of the caring relationship between them and not as a business decision between a consumer and a seller.

The Emergence of the Empowered Health Care Consumer

A search of the OVID Medline literature database (1946 to 2012) for articles that included *consumer* in the title returned 5,511 results (articles). A review of these results demonstrated that the term consumer began to be included in the title of articles during the 1960s. For example, in 1967, the *Journal of the American Dental Association* published an article titled "Consumer Attitudes Toward Prepaid Dentistry" (Simons, 1967). However, a search of this database using the same time period found only two articles that included the phrase "empowered consumer" in the title of the article (Anonymous, 1999; Weber, 1997). Both articles suggested that with the introduction of the Internet patients are becoming consumers with demands. Use of the term "empowered consumer" as a keyword in this same database produced a total of 4 results. In contrast, an Internet search using the search strategies ("empowered consumer" and "health care") in Google resulted in about 50,000 hits. This would suggest the concept that the empowered health care consumer is developing outside the traditional health care literature and maybe even outside the world of many health care providers.

The concept of an empowered consumer, in contrast to the concept of consumer as buyer, suggests that the consumer is not just making choices from predetermined options, but is in the driver's seat and in *control* of his or her health care decisions. The concept of the empowered consumer also suggests that by working in groups the consumer is able to impact and change the health care system.

A significant force in the development of the empowered consumer concept is the mental health consumer movement beginning in the 1960s and 1970s. During this time period, social change movements were part of the American culture. Mental health consumers were inspired by the African American civil rights movement, women, gays and lesbians, and people with disabilities who organized for social change. Large state hospitals across the country closed and new laws limiting involuntary commitment were being instituted. Former patients began meeting together in groups. Initially, these groups expressed anger at their treatment and demanded change. In 1978, the landmark book *On Our Own: Patient Controlled Alternatives to the Mental Health System* was authored by Judi Chamberlin, a psychiatric survivor and a long time activist. Over the next decades, the tone of this movement changed from a confrontational approach demanding change to collaboration and mutual respect as each side continues to work toward improving mental health services for all (Zinman, Budd, & Bluebird, 2009).

The Evolution of Well-Informed, Empowered, and Engaged Patients

Several key individuals, along with the development of the web, played a major role in leading the empowered consumer movement forward to the well-informed, empowered, and engaged patient movement. Table 1.2 provides a sample of health care professionals who are leading this movement on a national and international level. Selected accomplishments demonstrate how these leaders are using social media to change both the patient and provider roles in the health care system.

One of the earliest and most effective leaders was Tom Ferguson, MD. “Dr. Ferguson virtually led the movement to advocate informed self-care as the starting point for good health, and to promote a new kind of relationship between knowledgeable medical consumers and medical professionals. His goal was to encourage medical professionals to treat clients as equal partners in achieving better outcomes and change the entrenched practices of the traditional top-down hierarchy of the doctor-patient relationship. With the advent of broad access to the Internet, Dr. Ferguson’s long history of advocacy of information-empowered medical consumers positioned him to be a leading proponent of online health information resources” (Austin American-Statesman, 2006, para. 4).

Table 1.2 *Select Leaders in the Health 2.0 Movement*

Leaders	Examples of Achievements
“e-Patient Dave” Dave deBronkart (http://epatientdave.com/about-dave/#bios)	Diagnosed with stage IV cancer in 2007, Dave went on to become a well-known advocate to e-patient, who takes an active role in managing his own health. He is a blogger, keynote speaker, and health policy advisor.
Daniel Z. Sands, MD, MPH (http://www.linkedin.com/in/dannysands)	Wrote the first official guidelines for physicians using email with patients. He is the President and a founder of the Society for Participatory Medicine.
Matthew Holt (http://www.matthewholt.net/)	Established the Health care blog (http://thehealth care-blog.com/about/) and co-established the Health 2.0 Conferences (http://www.health2con.com/).
Patricia Flatley Brennan, PhD, RN (http://www.projecthealthdesign.org/about/npo/brennan)	Established *ComputerLink* in the 1980’s, one of the earliest online network of patients and caregivers. She is program director of Project HealthDesign, a Robert Wood Johnson Foundation program for personal health records.
Susannah Fox (http://pewinternet.org/Experts/Susannah-Fox.aspx)	Her research conducted as part of the Pew Internet & American Life Project has become a major resource for understanding how society is using the Internet in managing their health care challenges and problems.
Gunther Eysenbach, MD, MPH (http://www.linkedin.com/in/gunthereysenbach)	He founded one of the first research groups on cybermedicine and eHealth at the University of Heidelberg. He is Editor-in-Chief of the *Journal of Medical Internet Research* and established the Medicine 2.0 Conference series.

Tom Ferguson, MD, died April 14, 2006 while undergoing treatment for multiple myeloma, an illness he had battled for 15 years. But the impact of his advocacy continues today. In 2007, his final publication and a classic paper in this field titled *e-patients: how they can help us heal health care* was posted on the Internet at http://e-patients.net/e-Patients_White_Paper.pdf (Ferguson, 2007). This publication was co-authored by a group he called the e-Patient Scholars Working Group. This group, along with other leaders in this field, went on to establish the Society for Participatory Medicine in 2009. Additional information about the Society for Participatory Medicine and their current work in leading Health 2.0 can be viewed at http://participatorymedicine.org.

The Establishment of Consumer Health Informatics

Overlapping the evolution of the well informed, empowered, and engaged patient is the development of consumer health informatics as a branch or sub-specialization within the discipline of health care informatics. The phrases "consumer health informatics" "consumer informatics," and "informatics for consumer health" (ICH) are often used interchangeably in the literature. Health care informatics, which began in the late 1960s, initially focused on using computers and a variety of automated applications to assist in the management of data and information within the health care system. However, in 1990, well before the development of the first graphic interface browser, Patricia Brennan demonstrated that patients and caregivers would use a computer to access information and peer support. She did this by placing a computer terminal in the patient's home, where they could communicate via the mainframe (Brennan, Moore, & Smyth, 1991).

The term "consumer health informatics" was first used in the professional literature indexed by CINAHL as well as Medline by Tom Ferguson (Ferguson, 1995). Five years later, Gunther Eysenbach identified consumer informatics as a branch of medical informatics and provided one of the earliest definitions. "Consumer health informatics is the branch of medical informatics that analyses consumers' needs for information; studies and implements methods of making information accessible to consumers; and models and integrates consumers' preferences into medical information systems. Consumer informatics stands at the crossroads of other disciplines, such as nursing informatics, public health, health promotion, health education, library science, and communication science, and is perhaps the most challenging and rapidly expanding field in medical informatics; it is paving the way for health care in the information age" (Eysenbach, 2000, p. 1713). The impact of this definition can now be seen in the American Medical Informatics Association (AMIA) definition of consumer informatics located at http://www.amia.org/programs/working-groups/programs/consumer-health-informatics. Much of the same language is used in both definitions (American Medical Informatics Association, n.d.). In addition to the Society for Participatory Medicine, other examples of national groups and associations supporting consumer informatics include:

- Informatics for Consumer Health (ICH)—http://informaticsforconsumerhealth.org/
- AMIA Working Group for Consumer Health Informatics—http://www.amia.org/applications-informatics/consumer-health-informatics
- Partnership for Patients: A Common Commitment—http://www.healthcare.gov/compare/partnership-for-patients/about/index.html

Along with the emerging definition and support for consumer informatics was the movement from Web 1.0 to Web 2.0 and Health 2.0 that takes advantage of the developing technologies and interactive nature of the Internet.

Moving From Web 1.0 to Web 2.0 to Health 2.0

In 2004, Tim O'Reilly coined the term Web 2.0 to describe the changing nature of the Internet after the dotcom bust. Combining the symbol 2.0 with the word web suggested a new and updated version of the web. He defined Web 2.0 as a set of economic, social, and technology trends characterized by user participation, openness, and networking. In explaining the difference between Web 1.0 and Web 2.0, O'Reilly provided several examples. Britannica Online, representing Web 1.0, is a reference written by experts and depends on the knowledge of these experts to ensure its accuracy. Wikipedia (http://www.wikipedia.org/), representing Web 2.0, is written by the public and depends on end-user edits to ensure its accuracy.

Another example of the differences between Web 1.0 and Web 2.0 is the concept of indexing. With Web 1.0, one thinks in terms of a taxonomy represented by a standard language with a specific term and definition for each item or concept. With Web 2.0, one thinks in terms of tagging where each person selects the term they would use to label the item or concept (O'Reilly, 2005). In each of these examples the theme with Web 2.0 is collaboration to create user-generated content. The development of user-generated content through a process of collaboration synergistically opens up new doors to knowledge and questions about the accuracy of that knowledge.

The trend to Web 2.0 most likely began around the turn of the century, picking up momentum over the decade. In 2010, Facebook bypassed Google as the most visited site on the Internet. This was seen by many as the passing of the flag from Web 1.0, based on searching for information, to Web 2.0, based on creating and sharing information. Table 1.3 identifies the beginning date for several well-known social media applications.

Table 1.3 *Development of Social Media Applications and/or Device*

Year	Device and/or Application
1978	Computerized Bulletin Board
1998	Blogger
2000	Friendstar
2002	My Space
2003	Linkedin and Facebook
2005	YouTube
2007	iPhone
2009	Twitter
2010	iPad and Pinterest

Source: Adapted from Bennett, S. (2012).

Wisdom of Crowds

In 2004, Surowiecki published *The Wisdom of Crowds: Why the Many Are Smarter than the Few and How Collective Wisdom Shapes Business, Economies, Societies and Nations*. Surowiecki proposed that the aggregation of information in groups can produce decisions that are often better than that made by an individual. This would suggest that when examining group efforts at problem-solving, the problem solving ability or the intelligence of the group is greater than that of any individual in the group.

However, additional research has demonstrated that using the collective wisdom of groups is not a panacea for solving all types of problems. The "wisdom of a crowd" approach can be very effective for well-defined problems, where each member of the group provides his or her input independent of the other members. A well-defined problem is a problem that has one correct solution. For example, how many pieces of candy are in a jar? If each person in a group were to guess the answer, several people could be way off base, but the correct answer is very likely to be close to the average of the individual scores. However, if the group is permitted to discuss the problem and achieve a consensus, they are less likely to achieve the correct answer. In other words, the wisdom of the crowd is usually inaccurate when well-defined problems are solved by group consensus.

In health care, many if not most problems are ill-defined. Ill-defined problems are problems that can be managed via several different options, none of which are perfect. Research on how groups manage ill-defined problems is limited. Two studies conducted at Massachusetts Institute of Technology (MIT) and Carnegie Mellon University (CMU) found converging evidence that groups participating in problem-solving activities demonstrate a general collective intelligence factor that explained the group's performance on a wide variety of tasks. "This '*c* factor' is not strongly correlated with the average or maximum individual intelligence of group members, but is correlated with the average social sensitivity of group members, the equality in distribution of conversational turn-taking, and the proportion of females in the group" (Woolley, Chabris, Pentland, Hashmi, & Malone, 2010, p. 686). "A group's interactions drive its intelligence more than the brain power of individual members" (Marshall, 2010). Certain characteristics of the individuals within the group and the group's ability to work together as a whole can influence the effectiveness of the group, whether they are online or face-to-face. These findings are important to nurses working with both online and in-person support groups.

The term Health 2.0 began to appear in the online and published literature around 2007. The term Health 2.0 extends the definition of Web 2.0 and concepts associated with Web 2.0 to health care, such as the power of collected wisdom. In 2008, the California Health Care Foundation published a report, titled *The Wisdom of Patients: Health Care Meets Online Social Media*. In this report, Health 2.0 is defined as "the use of social software and its ability to promote collaboration between patients, their caregivers, medical professionals, and other stakeholders in health" (Sarasohn-Kahn, 2008, P.2). Other related terms such as eHealth, Patient Empowerment 2.0, Health Care 2.0, Medicine 2.0, and Nursing 2.0 also begin to appear, along with a discussion concerning which of these is the more inclusive term (Van De Belt, Engelen, Berben, & Schoonhoven, 2010). Van De Belt et al determined, for their purposes, Medicine 2.0 was the more inclusive term and that Health 2.0 was included as part of Medicine 2.0. In 2010, Van De Belt et al searched both the peer-reviewed professional literature and the gray literature, finding 46 unique definitions. An analysis of these definitions identified 7 themes:

1. Patient and Consumer
2. Web 2.0
3. Professional
4. Social Networking
5. Change
6. Collaboration
7. Health Information of Content.

In this book we have selected Health 2.0 as the more inclusive term. The term Health 2.0 refers to the use of social media, via electronic devices, electronic health information exchange platforms, and mobile applications to promote collaboration among stakeholders and health care providers. This collaboration includes the empowered patient/consumers within the health care system, with the goal of improving the health and quality of life for individuals, families, and communities. Achieving this goal requires, at a minimum, stakeholders that have achieved digital literacy.

LIERACY IN THE WORLD OF SOCIAL MEDIA

There are a number of different types of literacies that have been identified in the literature. Some examples include emotional literacy, numeric literacy, scientific literacy, and health literacy. In this chapter the discussion is limited to basic literacy and those literacies that relate directly to the use of social media. Successful use of social media tools to achieve the goals of Health 2.0 is dependent on basic literacy, computer literacy, information literacy, digital literacy, and health literacy. These specific literacies are both overlapping and interrelated, as demonstrated in Figure 1.1.

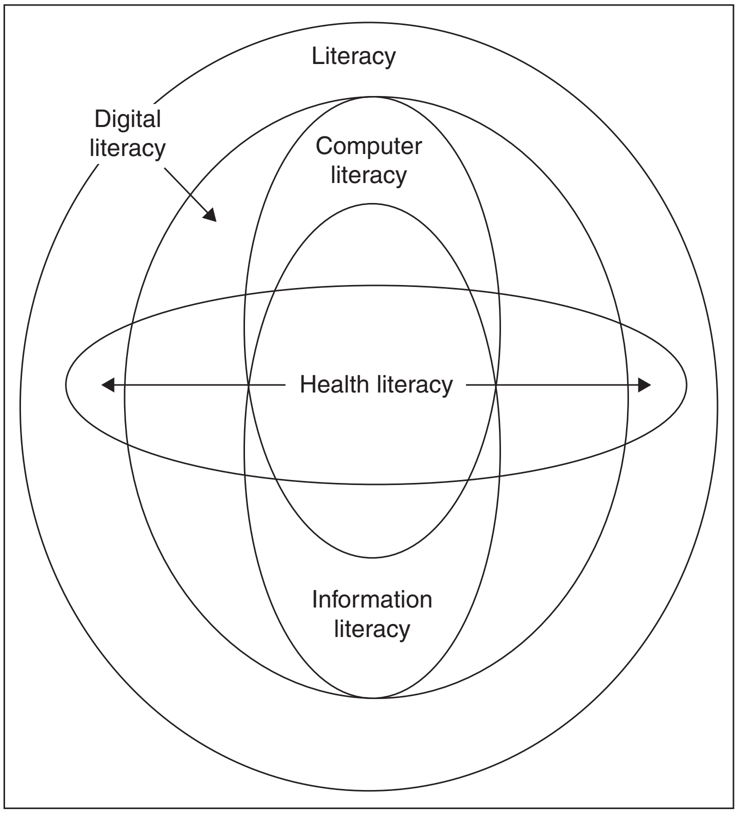


Figure 1.1 Interrelationships of literacies required for Health 2.0.

In each of these types of literacy, basic literacy is the foundational skill. Without a basic level of literacy the other types of literacy become impossible and irrelevant. The assessment of a consumer/patient's potential to benefit from social media tools begins with an assessment of basic literacy.

A Definition of Basic Literacy

An international effort to address the need for a literate population was initiated in 1946 with the formation of the United Nations Educational Scientific and Cultural Organization (UNESCO). As part of this effort, UNESCO offered one of the first definitions of literacy and one that is still quoted today. "A literate person is one who can, with understanding, both read and write a short simple statement on his or her everyday life" (UNESCO Educational Sector, 2004, p. 12). As the needs of society changed, the UNESCO definition evolved, and in 2003 UNESCO proposed an operational definition that attempted to encompass the several different dimensions of literacy. "Literacy is the ability to identify, understand, interpret, create, communicate and compute, using printed and written materials associated with varying contexts. Literacy involves a continuum of learning in enabling individuals to achieve their goals, to develop their knowledge and potential, and to participate fully in their community and wider society" (UNESCO Educational Sector, 2004, p. 13). UNESCO points out that this definition requires careful thought in order to incorporate it into the various circumstances in which individuals lead their lives. When considering Health 2.0, one of the primary aspects of how people lead their lives is how they live their online lives.

In the United States, the U.S. Department of Education, Institute of Education Sciences, National Center for Education Statistics conducts the National Assessment of Adult Literacy (NAAL), which is a nationally representative and continuing assessment of English language literary skills of American adults. The NAAL definition of literacy includes both knowledge and skills and assesses three types of literacy—prose, document, and quantitative. A description of each can be seen in Exhibit 1.1.

The focus of both the national and international definitions is the ability to take in and understand information that is presented in printed or written format. The assumption is that this includes the ability to understand both text and numeric information. If one can read information in printed format, it could be expected that this individual could read and understand the same information on a computer screen. However, computer literacy involves much more than the ability to read information from a computer screen. In fact, the term computer literacy, with its limited focus, is becoming outdated.

Exhibit 1.1 ***National Assessment of Adult Literacy—Three Types of Literacy***

Prose literacy
The knowledge and skills needed to search, comprehend, and use continuous texts such as editorials, news stories, brochures, and instructional materials.

Document literacy
The document-related knowledge and skills needed to perform a search, comprehend, and use non-continuous texts in various formats, such as job applications, payroll forms, transportation schedules, maps, tables, and drug or food labels.

Quantitative literacy
The quantitative knowledge and skills required for identifying and performing computations, either alone or sequentially, using numbers embedded in printed materials such as balancing a checkbook, figuring out a tip, completing an order form, or determining the amount.

Source: National Assessment of Adult Literacy (NAAL; 2003).

Definition of Computer Literacy/Fluency

The National Academy of Science has coined the term FIT Persons to describe people who are fluent with information technology. These people go beyond proficiently in using a computer and are able to express creatively, reformulate knowledge, and synthesize new information using a wide range of information technology. FIT Persons possess three types of knowledge.

- Contemporary Skills—the ability to use current computer applications such as word-processors, spreadsheets, or an Internet search engine. This means using the correct tool for the right job. Spreadsheets when manipulating numbers; word processors for manipulating text, and so on.
- Foundational Concepts—underlie the how and why of information technology. This knowledge gives the person insight into the opportunities and limitations of social media and other information technologies.
- Intellectual Capabilities—the ability to apply information technology to actual problems and challenges of every life. An example of this knowledge is the ability to use critical thinking when evaluating health information on a social media site (Committee on Information Technology Literacy, National Research Council, 1999).

While these three types of knowledge might be easily conceptualized in a formal curriculum, it is more of a challenge to apply these types of knowledge and skills to the assessment and education of a patient/consumer. This is the challenge for health care providers as we work to educate and, in turn, empower patients/consumers.

Definition of Information Literacy

The American Library Association (ALA) has supported the development of information literacy standards since the 1980's. As part of this effort they have established standards of information literacy for higher education, high schools, and even for a personal digital assistant (PDA). The ALA defines information literacy as "a set of abilities requiring individuals to recognize when information is needed and have the ability to locate, evaluate, and use effectively the needed information" (Library Association, 2000, p. 2). This definition has gained wide acceptance. However, with the extensive growth of social media, there are increasing calls for revising the definition as well as the established standards from over a decade ago. "Social media environments and online communities are innovative collaborative technologies that challenge traditional definitions of information literacy … information is not a static object that is simply accessed and retrieved. It is a dynamic entity that is produced and shared collaboratively with such innovative Web 2.0 technologies as Facebook, Twitter, Delicious, Second Life, and YouTube" (Mackey & Jacobson, 2011, p. 62).

For example, what are the different types of knowledge and skills needed to evaluate information posted on Facebook, versus Wikipedia, versus a peer-reviewed article posted online before publication, versus a peer-reviewed published article. Are different writing skills needed when participating in an online dialog as opposed to preparing a term paper? Are there standards that apply to text messaging, especially if the message is between health care colleagues or being sent to a patient? These questions are the challenges facing health care providers in the world of social media.

Definition of Digital Literacy

The term digital literacy first began appearing in the literature in the 1990s, however, to date there is no generally accepted definition. Interestingly, there are a number of Digital Literacy Centers supporting the development of digital literacy. Some examples include:

- Syracuse University's Center for Digital Literacy, located at http://digital-literacy.syr.edu/
- University of British Columbia, the Digital Literacy Centre, located at http://dlc.lled.educ.ubc.ca/
- Microsoft Digital Literacy Curriculum, located at http://www.microsoft.com/About/CorporateCitizenship/Citizenship/giving/programs/UP/digitalliteracy/eng/default.mspx
- National Telecommunications and Information Administration Literacy Center, located at http://www.digitalliteracy.gov/

There are also a number of books published on digital literacy. A search of Amazon for books with "Digital Literacy" in the title produced 53 results. The American Library Association Digital Literacy Task Force posted a working definition on their online community. This definition describes digital literacy as "a broad term to encompass information literacy abilities requiring individuals to recognize when information is needed and have the ability to locate, evaluate, and use effectively the needed information, as well as competencies in creating content, reflecting on one's own conduct and social responsibility, and taking action to share knowledge and solve problems. Digital literacy also is associated with the ability to use computers and other devices, social media and the Internet" (American Library Association Digital Literacy Task Force, 2011, para. 1). The work of the task group is not yet complete and the final definition has not been presented to the larger organization for approval.

In a white paper commissioned by the Aspen Institute Communications and Society Program and the John S. and James L. Knight Foundation, "Digital and media literacy are defined as life skills that are necessary for participation in our media-saturated, information-rich society. These include:

- Make responsible choices and access information by locating and sharing materials and comprehending information and ideas,
- Analyze messages in a variety of forms by identifying the author, purpose, and point of view, and evaluating the quality and credibility of the content,
- Create content in a variety of forms, making use of language, images, sound, and new digital tools and technologies,
- Reflect on one's own conduct and communication behavior by applying social responsibility and ethical principles, and
- Take social action by working individually and collaboratively to share knowledge and solve problems in the family, workplace, and community, and by participating as a member of a community (Hobbs, 2010, pp. vii–viii).

As both these definitions demonstrate, except for basic literacy, digital literacy is a more comprehensive concept than any of the other social media-related literacies discussed in this section of the chapter. The definition goes beyond the comfortable use of technology demonstrated by the digital native. Digital literacy is not just about knowing how to use the tools; it's about understanding the implications of digital technology and the impact it is having, and will have, on every aspect of our lives. "Though most people think kids these days *get* the digital world, we are actually breeding a generation of digital illiterates. How? We are not teaching them how to really understand and use the tools. *We are only teaching them how to click buttons*. We need to be teaching our students, at all levels, not just how to click and poke, but how to communicate, interact, and build relationships in a connected world" (Murphy, 2011).

For the purposes of this book, digital literacy is defined as including:

- Competency with digital devices of all types, including cameras, eReaders, smartphones, computers, tablets, video games, and so forth. This does not mean that one can pick up a new device and use that device without an orientation. Rather, one can, using trial and error as well as a manufacturer's manual, determine how to effectively use a device.
- The technical skills to operate these devices as well as the conceptual knowledge to understand their functionality.
- The ability to creatively and critically use these devices to access, manipulate, evaluate, and apply data, information, knowledge and wisdom in activities of daily living.
- The ability to apply basic emotional intelligence in collaborating and communicating with others.
- The ethical values and sense of community responsibility to use digital devices for the enjoyment and benefit of society.

Definition of Health Literacy

While health literacy is concerned with the ability to access, evaluate, and apply information to health-related decisions, there is not a generally accepted agreement of the definition of this term. A systematic review, in 2011, of the literature that had been published on Medline, PubMed, and Web of Science identified 17 definitions and 12 conceptual models of health literacy. Definitions of health literacy from the American Medical Association, the Institute of Medicine, and the World Health Organization (WHO) were found to be cited most frequently (Sorensen, et. al., 2012). Current definitions from these organizations are provided in Exhibit 1.2.

The focus in each of these definitions is on an individual's skills in obtaining, processing, and understanding the health information and services necessary to make appropriate health decisions. While these definitions are not incongruent with Web 1.0, they do not address a networked world. In recognition of this deficiency, Norman and Skinner introduced the concept of eHealth as "the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained

Exhibit 1.2 ***Definitions of Health Literacy***

- American Medical Association defines health literacy as "a patient's ability to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (American Medical Association, 2004).
- The Institution of Medicine uses the definition of health literacy developed by Ratzan and Parker and cited in *Healthy People 2010*. 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" (Committee on Health Literacy Institute of Medicine, 2004, p. 4).
- The World Health Organization (WHO) defined health as "the degree to which people are able to access, understand, appraise and communicate information to engage with the demands of different health contexts in order to promote and maintain good health across the life-course" (Nutbean, 1998, p. 351).

to addressing or solving a health problem" (2006, p. e9). This definition acknowledges the need for computer fluency and the use of information literacy skills to obtain an effective level of health literacy. However, this definition is not especially sensitive to the impact of social media. For example, it does not address the individual as a patient/consumer collaboratively creating health-related information that could be used by others in making health-related decisions. Yet, there is increasing evidence that patients bring to the dialog a unique knowledge base for addressing a number of health related problems (Hartzler & Pratt, 2011). Creating a comprehensive definition and model for assessment of health literacy levels that includes the social media literacy skills necessary for Health 2.0 is now a challenge for health professionals.

While each of the social media-related literacies focus on a different aspect of literacy and have a different definition, they all overlap and are interrelated. Figure 1.1 demonstrates that interrelationship. In this figure, basic literacy is depicted as foundational to all other literacies. Digital literacy includes computer and information literacy as well as other social media-related knowledge and skills not currently included in the definitions of computer and information literacy. For example, using a Wii to play online games is not usually considered part of information or computer literacy, but clearly requires digital literacy. Health 2.0 requires both digital literacy and a basic knowledge of health, unrelated to automation. In other words, it overlaps digital literacy and basic literacy. All of the literacies require the ability to evaluate information.

EVALUATION OF ONLINE INFORMATION

As more and more consumers and health care professionals use the Internet to find information, it becomes critical for them to effectively evaluate the quality of that information. Remember, anyone can and does publish to the Internet; it is NOT a refereed source of information. This is especially critical when that information relates to health care decisions that could alter the life of the consumer.

Types of Health Care Information Sites on the Internet

There are three main types of health informational sites on the Internet:

- Static web pages,
- Web pages that request some personal information and provide a report back to the consumer based on the data supplied, and
- Consumer-generated information found on social media sites.

Web 1.0 provided the first type of health care information retrievable from the Internet—passive or static information. A web page with information about a specific condition is an example of this type of information. While the user searches for this information and reads the information found, the user does not interact with the website or input any information. Anyone can publish to these types of sites; some are by reputable organizations like the American Heart Association, some are government-sponsored sites, and some are consumer-published sites.

Do not confuse accessing information OVER the Internet with information published ON the Internet. Medline is a database of professional biomedical literature; it is a web-based searchable database. This is similar to the literature databases that one may have access to through a library. Most colleges/universities have arrangements to access these databases OVER the Internet. Many of them require a user-id and password. These databases point to peer-reviewed information. MedlinePlus, an example of information ON the Internet, includes a number of high quality health related resources written for patients, families, and other consumers. This database is published on the Internet and is free (http://www.nlm.nih.gov/medlineplus/). MedlinePlus contains carefully selected links to web resources as well as interactive health tutorials. Other Internet sites may not be peer reviewed or written by authoritative sources.

The second type of health informational site requires the patient to enter personal health information. Many of these sites are looking to market some type of health-related product to the consumer or organizations with a cause, like heart disease or cancer. Some of these sites offer an opportunity to enter personal information and receive feedback, such as a risk assessment. Examples of these sites include Harvard Pilgrim Health Care (https://www.harvardpilgrim.org/portal/page?_pageid=213,38394&_dad=portal&_schema=PORTAL), The National Cancer Institute (http://www.cancer.gov/bcrisktool/), and The American Heart Association (http://www.heart.org/HEARTORG/Conditions/Whats-Your-Risk-Find-out_UCM_306929_Article.jsp).

The third type of health informational site involves the use of Web 2.0 applications. Web 2.0 is an umbrella term referring to web-enabled applications that are built around user-generated or user-manipulated content. Some examples include wikis, blogs, podcasts, and social networking sites (see chapter 2 for more information on these tools). When these applications are used with health-related issues, they are included in the Health 2.0 movement.

Criteria for Evaluating Health Information

Traditional methods of evaluating the credibility of information on the Internet includes criteria related to a peer reviewed journal, the credentials of the author, and writing style of the publication (Standler, 2004). The standard for credibility was peer reviews or scholarly journals and the reputation of the publishing company. This, however, provides no protection against fraud, as there are incidences of fraud in medical research published in peer review journals. This also provides little or no help in the social media world, as most posts are not peer reviewed—more on this later. Next, one would consider the credentials of the author. The credentials of the author are also not of much help in the social media world, as one needs to either know the field in order to recognize the "experts" or trust what the author published about his/her credentials is the truth. The last traditional method is the writing style. While this may have some validity in the social media world, many posts on social media sites tend to be more informal and not scholarly in writing style.

How does one protect him/herself from using poor information to make health care decisions? For Web 1.0, we traditionally looked at selecting sources more likely to be reliable, like NIH, Cleveland Clinic, WebMd, and so forth; evaluating that information based on a set of criteria, like authority/credibility, accuracy and currency, coverage and scope, objectivity, and reasonableness; and using evaluation checklists to make sure all criteria were considered (see Exhibit 1.3).

There are many evaluation checklists available. Most of them include the same points, but are expressed in different ways. In summary, these checklists consist of four to five main criteria one should use to critically evaluate the sources of the information. Here are two examples of such sets of criteria:

- Authority of author, Accuracy of content, Objectivity, Currency, and Coverage (Alexander & Tate, 2005).
- Credibility, Accuracy, Reasonableness, Support (Harris, 2010).

Exhibit 1.3 ***Evaluation of Information From the Internet***

Authority/Credibility:	Who wrote or is responsible for the content on the web page? What are the credentials of this person(s)? If it is an institution, what is the purpose of this institution? What is their reputation? Do they provide contact information?
Accuracy/Currency:	How current and comprehensive is the information? Is there a publication date listed? Is currency relevant to the topic area? Is it presenting a complete picture of the topic (both sides of an issue)? Does it contain generalizations with no supporting evidence or links? Are there references or citations? Can you corroborate the information with other sites? Is the grammar correct? Are words spelled correctly?
Coverage/Scope:	Is the content sufficient in extent and depth of coverage for the intended audience? Did it answer the obvious questions? Does it give enough detail on the topic? Did it make generalizations?
Objectivity/Reasonableness:	Does the site cover the content with fairness, objectivity (controlled bias), and consistency? Is there a hidden agenda, like trying to sell you a product? Is the writing slanted?

Note how authority can also refer to credibility; accuracy of content can refer to currency; and objectivity can refer to reasonableness.

Some of these same criteria, such as currency and accuracy, can also apply to social media sites. One must also consider websites from the perspective of the intent or purpose of the site. Some websites may be advocacy sites with a purpose of influencing the user toward a specific issue or cause. Two examples of these websites are ACLU (http://www.aclu.org) and the Democratic Party (http://www.democrats.org/). Social media sites can also fall into this category of websites. Other types of websites with their own aims or purposes include:

- Entertainment/gaming—The primary aim of these sites is to entertain, although sometimes they get caught up in enticing you to purchase a game or some other item. They have a variety of URL endings depending on the sponsoring organization. Three examples are http://games.yahoo.com, http://film.com, and http://kidshealth.org/kids/. The last site has games or word finds about health for kids to play.
- Informational—The purpose of these sites is to provide factual information. They tend to end in edu or gov. Three examples are http://usa.gov (formerly firstgov.gov), http://www.cdc.gov, and http://owl.english.purdue.edu/owl/.
- Marketing/Business—The purpose of these sites is to sell a product or service. Most of them end in com, but some of them now take on one of the new top-level domains (TLD), like pro. Some examples include http://www.amazon.com, http://www.microsoft.com, http://www.beltone.com, and http://smiles.pro.
- News—Most news sites end in com and serve to present current information or news about what is happening worldwide, regionally, and locally. Two examples in this group are http://www.cnn.com and http://www.nytimes.com.

Social Media and Health 2.0 Criteria

Another type of website that has populated the Internet over the past few years includes sharing and/or community sites. These websites have evolved from Web 2.0 tools. Each of these types of sites can provide quality information, misinformation, or biased information. Using traditional criteria for evaluating information on Web 1.0 sites may not be effective when applied to Web 2.0, Health 2.0, or social media sites. For example, is the patient who writes about their condition and treatment issues a credible source? They may have no health care provider credentials, but may be expert in how they are responding to treatment and what symptoms they present.

When using types of resources like Health 2.0, patients need guidelines on how to evaluate the information from these sites and how to apply the information to their health care decisions. Many of the sites that offer educational materials deal only with teenagers and issues of safety. An excellent resource for these types of materials can be seen at http://www.ftc.gov/bcp/edu/pubs/consumer/tech/tec14.shtm. However, there are several resources that have been developed to teach patients safe access to quality information. The data that can be applied to Health 2.0 sites is limited. The National Library of Medicine at NIH (Figure 1.2) provides access to examples of these types of resources at http://www.nlm.nih.gov/medlineplus/evaluatinghealthinformation.html, as does Evaluating Online Sources of Health Information from the National Cancer Institute (Figure 1.3) at http://www.cancer.gov/cancertopics/cancerlibrary/health-info-online/.

The best advice one can give consumers at this point is to use their own best judgment in deciding how far to explore these sites and what information to enter and share publically with others. With experience, individuals will develop "Internet street smarts" or a gut reaction to a site and how the site is designed. The following general questions will help guide that development:

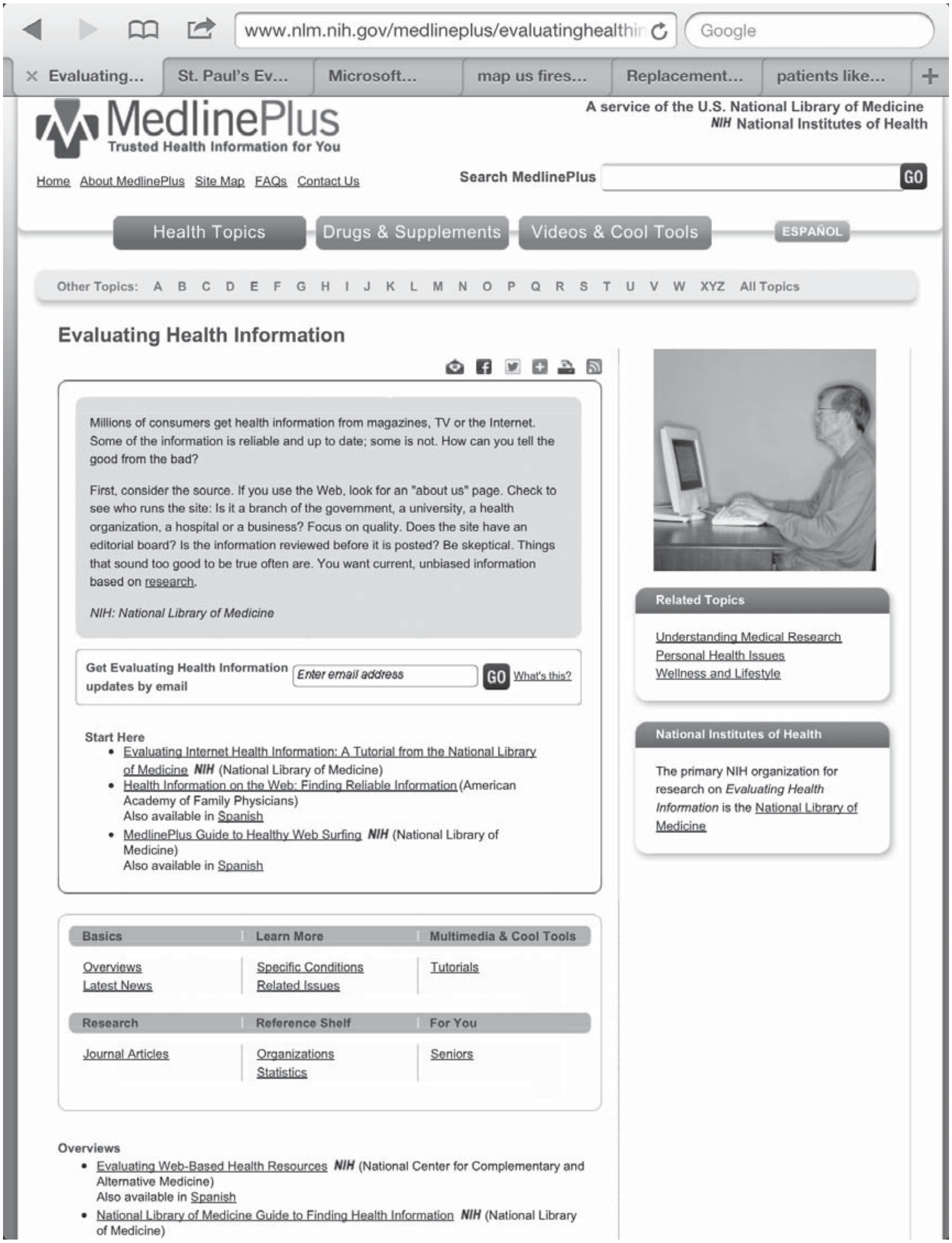
- Who is maintaining this site and why? Who is paying for this project?
- Can a cookie or other technology be used to track this information back to me? Is this a concern to me? How might this affect me?
- What is included in the disclaimer posted on the site?
- What are the Terms and Conditions to use this site?
- What is included in the privacy statement for this site?
- Do I trust they will follow their privacy statement or Terms and Conditions?
- Can I trust that the patients/consumers posting to this site are who they say they are? Can that be verified in some way?

In addition, some traditional criteria, such as how current is the information, may also apply. However, the best advice may be to pay close attention to where the information comes from and back up what you find with authoritative sources, such as recognized health sites and your health care provider. Health 2.0 sites involve not only the evaluation of information that is on these sites, but how one can and/or should participate in the creation of information. The following section discusses that issue.

Guidelines for Participating in Online Groups

Information and guidelines for participating in online groups can be divided into six topic areas. The topics provide a framework for what should be included in patient education programs. These topics are:

- Deciding why one wants to participate,
- Setting realistic expectations about the activity and what one will gain by participating,
- Finding an appropriate group,
- Joining and participating in a group, and
- Discontinuing participation in a group.



Evaluating Health Information

Millions of consumers get health information from magazines, TV or the Internet. Some of the information is reliable and up to date; some is not. How can you tell the good from the bad?

First, consider the source. If you use the Web, look for an "about us" page. Check to see who runs the site: Is it a branch of the government, a university, a health organization, a hospital or a business? Focus on quality. Does the site have an editorial board? Is the information reviewed before it is posted? Be skeptical. Things that sound too good to be true often are. You want current, unbiased information based on research.

NIH: National Library of Medicine

Get Evaluating Health Information updates by email *Enter email address* GO What's this?

Start Here

- Evaluating Internet Health Information: A Tutorial from the National Library of Medicine ***NIH*** (National Library of Medicine)
- Health Information on the Web: Finding Reliable Information (American Academy of Family Physicians)
  Also available in Spanish
- MedlinePlus Guide to Healthy Web Surfing ***NIH*** (National Library of Medicine)
  Also available in Spanish

Overviews

- Evaluating Web-Based Health Resources ***NIH*** (National Center for Complementary and Alternative Medicine)
  Also available in Spanish
- National Library of Medicine Guide to Finding Health Information ***NIH*** (National Library of Medicine)

Related Topics

Understanding Medical Research
Personal Health Issues
Wellness and Lifestyle

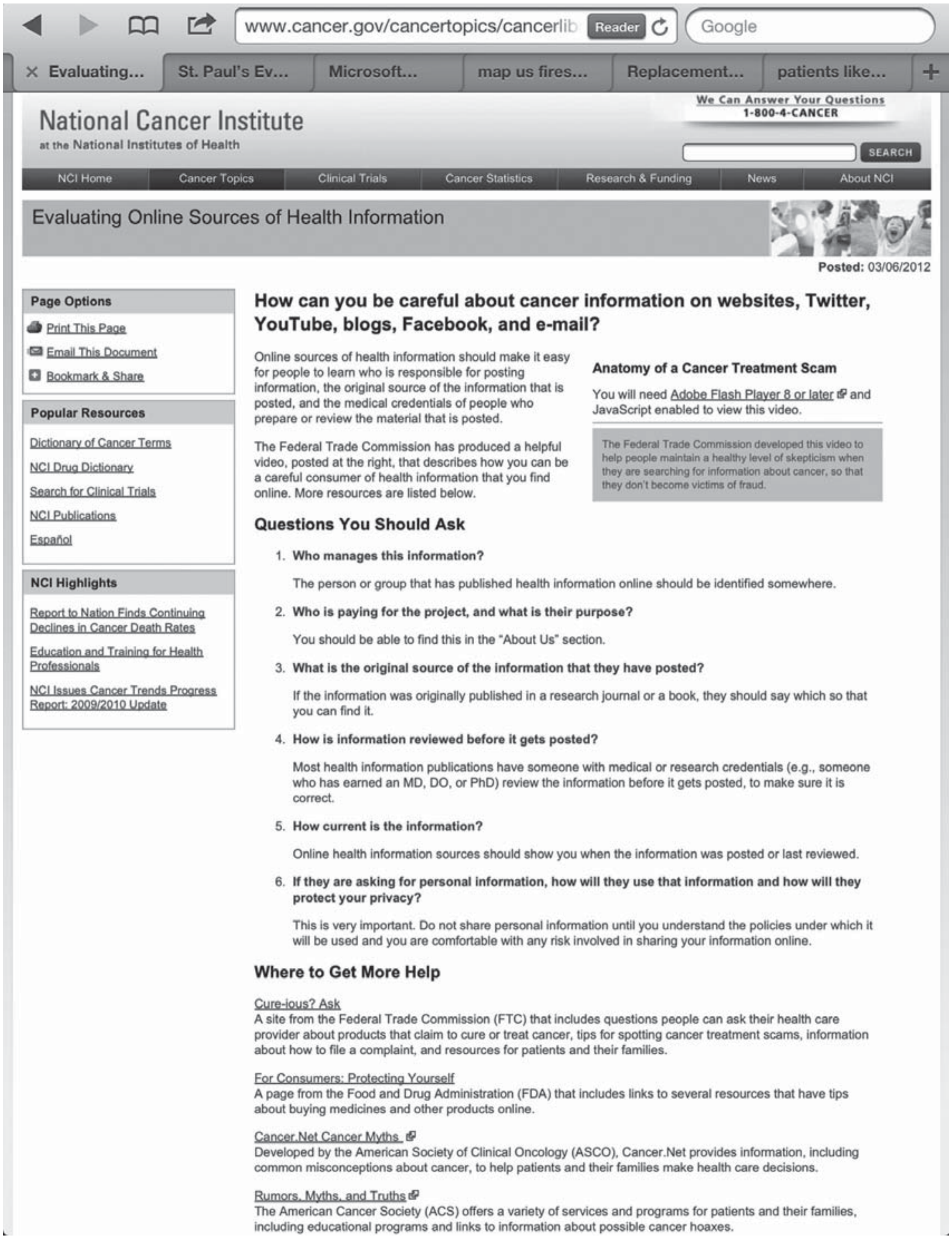
National Institutes of Health

The primary NIH organization for research on *Evaluating Health Information* is the National Library of Medicine

Figure 1.2 Medlineplus: Evaluating health information, main screen.

Table 1.4 lists common reasons why patients are interested in joining online groups and some of the cautions a nurse can share with patients in terms of these reasons.

When initially joining an online group, the new person is joining an ongoing discussion. It can be helpful to have realistic expectations. If the group has been interacting



Evaluating Online Sources of Health Information

Posted: 03/06/2012

How can you be careful about cancer information on websites, Twitter, YouTube, blogs, Facebook, and e-mail?

Online sources of health information should make it easy for people to learn who is responsible for posting information, the original source of the information that is posted, and the medical credentials of people who prepare or review the material that is posted.

The Federal Trade Commission has produced a helpful video, posted at the right, that describes how you can be a careful consumer of health information that you find online. More resources are listed below.

Anatomy of a Cancer Treatment Scam

You will need Adobe Flash Player 8 or later and JavaScript enabled to view this video.

The Federal Trade Commission developed this video to help people maintain a healthy level of skepticism when they are searching for information about cancer, so that they don't become victims of fraud.

Questions You Should Ask

1. **Who manages this information?**

   The person or group that has published health information online should be identified somewhere.

2. **Who is paying for the project, and what is their purpose?**

   You should be able to find this in the "About Us" section.

3. **What is the original source of the information that they have posted?**

   If the information was originally published in a research journal or a book, they should say which so that you can find it.

4. **How is information reviewed before it gets posted?**

   Most health information publications have someone with medical or research credentials (e.g., someone who has earned an MD, DO, or PhD) review the information before it gets posted, to make sure it is correct.

5. **How current is the information?**

   Online health information sources should show you when the information was posted or last reviewed.

6. **If they are asking for personal information, how will they use that information and how will they protect your privacy?**

   This is very important. Do not share personal information until you understand the policies under which it will be used and you are comfortable with any risk involved in sharing your information online.

Where to Get More Help

Cure-ious? Ask
A site from the Federal Trade Commission (FTC) that includes questions people can ask their health care provider about products that claim to cure or treat cancer, tips for spotting cancer treatment scams, information about how to file a complaint, and resources for patients and their families.

For Consumers: Protecting Yourself
A page from the Food and Drug Administration (FDA) that includes links to several resources that have tips about buying medicines and other products online.

Cancer.Net Cancer Myths
Developed by the American Society of Clinical Oncology (ASCO), Cancer.Net provides information, including common misconceptions about cancer, to help patients and their families make health care decisions.

Rumors, Myths, and Truths
The American Cancer Society (ACS) offers a variety of services and programs for patients and their families, including educational programs and links to information about possible cancer hoaxes.

Figure 1.3 National Cancer Institute: Evaluating online sources of health information.

for some time, the amount and depth of the information discussed can be overwhelming. The flow of information can appear disorganized. Different online groups may also have different personalities. Some groups will take the initiative in helping a newcomer, while others will suggest the new person spend some time reading the archives.

Table 1.4 *Reasons to Participate in Online Groups and Related Cautions*

Reason	Caution
I would like to talk to someone else who has this same problem.	Each person is different. Your symptoms and your personal situation may be very different from someone else with the same diagnosis.
I want to know if anyone else is having this same symptom, side effect, or problem.	It may be just a coincidence that someone else is experiencing the same symptoms, side effect, or problem, or it can be an early alert for a previously unrecognized problem. More information will be needed.
I can find out about other potential treatments from other patients who are also researching this problem.	Some of the treatments discussed may be experimental or even outdated.
Someone is always online 24/7.	Be careful, since the first response may not be the last or best answer to your question.
I can find out if there are several other people with this issue.	A group consensus is not always a corrent answer.

Over time, the group can become inactive or drift off target, leaving some members to feel they are losing a friend or support network.

In selecting groups, patients should be encouraged to search for groups that are associated with known organizations, such as major medical centers. They should look for groups with easy to find information about who they are and why the group is being sponsored. They should use caution with groups that ask for personal health information in order to learn about the group; sites that have numerous advertisements, making it hard to read the content without reading the ads; and sites that stress how much they offer, with little or no information about who has established the site.

When participating in an online group, patients/consumers should:

- Use caution in establishing personal relationships since health problems, especially newly diagnosed health problems, can increase their vulnerability.
- Be careful not to isolate themselves from family and established friends.
- Avoid providing too much personal information, especially when tired and anxious.
- Think carefully about how much privacy they are willing to trade for information.

One of the things that can be difficult for patients who are active members of an online group is the loss of a member. If a patient decided to leave a group for any reason, they could indicate they are leaving the group. They are not obliged to give any explanation for their decision, but a brief good-bye as opposed to just disappearing can be reassuring to an ongoing group. Several other aspects of participating in online groups are discussed throughout this book.

SUMMARY

As consumers and health care professionals become more empowered with stronger levels of literacy, electronic devices, and web based platforms to access, share, and receive information a paradigm shift is occurring. This paradigm shift is moving patients/consumers and providers to a virtual world that requires new guidelines, standards, and health policies to ensure the safe and effective use of social media. This book is an introduction to the world of Health 2.0 and the wealth of opportunities offered by this new digitalized world.

DISCUSSION QUESTIONS

1. What specific literacy skills should be included as part of a baseline patient assessment for patients being seen for the first time in any health care establishment?
2. You are being assigned to a new unit in an acute care setting. The unit is designed for patients who have both a significant mental health and physical illness. To learn more about mental health from a patient perspective, you are interested in joining an online support group designed for patients with depression. Should you (a) contact the site before joining and explain your interest; (b) Sign in and then introduce yourself, including your professional background and reason for joining; (c) Sign in, lurk on the site, but never participate; or (d) Select another approach. Explain your selection and why you did not select the other options. Before you complete your answer, you may want to examine some of these sites to see if they provide any directions or check the additional resources located in the Appendix.
3. The hospital where you are employed is creating a new transparency policy, making more information about the institution available online. Currently, a number of quality measures including infection rates, patient satisfaction scores, employee turnover rates, and so on, are viewable via the Internet. Should unit-specific data and scores be posted on the hospital's website, open to the general public to see? Should hospital-wide data and scores be posted? Explain your answer. Share a list of data items you would and would not post. Discuss how you reached this conclusion about these items.
4. As a nurse educator, you have been asked to prepare a tutorial sheet as part of a patient education discharge packet on understanding and using health information on the Internet. List the key points you would include in this document. Share what format or manner you would use to create the document.
5. Please review the website located at http://www.cancer.gov/cancertopics/cancerlibrary/health-info-online and answer the following questions:
   - Is the website sensitive to the different types and levels of literacy?
   - Does the website prepare people to safely participate in online groups?
   - Does the criteria for evaluating information apply to both Web 1.0 and Web 2.0 type of sites?
   - What additional information would you include on this site?

EXERCISES

Exercise 1: A Rose by any Other Name—Is Maybe Not a Rose

Purpose: *The purpose of this exercise is to appreciate the implications of the terms used to describe the individuals, families, and groups utilizing health care services.*

Objectives

1. Analyze the different meanings for the terms used to identify individuals, families, and groups utilizing health care services.
2. Explore the implications of the terms used to identify individuals, families, and groups utilizing health care services.
3. Develop appropriate definitions for terms commonly used to describe individuals, families, and groups who use should be health care services.

Directions

Note: This activity can be done as a group exercise or as an individual assignment.

1. Use an Internet search engine to find three or more definitions for each of the following terms:
   Patient
   Client
   Consumer
   Community.
2. Using this information, create your own definition for each of these terms.
3. Use an Internet search engine to find three or more definitions for each of the following terms:
   Empowered
   Engaged.
4. Using this information, create your own definition for each of these terms
5. Use each of the terms in step 3 to modify the terms in step 1. This will create a list of phrases, starting with empowered patient and ending with engaged community.
6. Use your word processer to create a glossary that includes a definition for each of these phrases.

Exercise 2: Can You See Me Now?

Purpose: *To explore the difference in personal responses to virtual communication or voice communication versus an actual face-to-face (F-2-F).*

Objectives

1. Describe the difference in feelings or emotions that can be experienced in online versus F-2-F communication.
2. Analyze the difference in feedback loops associated with F-2-F communication versus online communication.

Directions

1. Select a former teacher who has had a major positive impact on your education
2. Create *but do not send an email* letting the person know the impact they have had on your education.
3. Create a script you would use to make a telephone call to this person.
4. Modify the script for you to use with an online video call (i.e., Skype) to this person.
5. Create a script of what you would say if you were able to invite this person to lunch
6. Modify the script, if needed, if the meeting was scheduled to take place in the person's office.
7. Set-up a role-play with a classmate where you can review your email and rehearse your scripts. Do *not have* the scripts in front of you during the role-play experience. Use your memory of what you wanted to say to talk in the F-2-F role-plays.
8. In a small group, discuss the overall experience. Explore how you felt during the actual events. For example, did you feel nervous, embarrassed, or pleased with the opportunity?

In which of the three situations did you have more control? How did the F-2-F conversation go when your classmate who was playing the role of the teacher began to respond to your comments? At any point did you get off topic? Did you cover all your points in your script?

9. As a group, create a list of key points to guide your online communication with both colleagues and patients.

Exercise 3: Patient Is Not a Third Person Word

Purpose: *The purpose of this exercise is to explore the role of the patient as perceived by the patient.*

Objectives

1. Analyze the level and type of communication a patient may expect when talking with their health care providers.
2. Contrast and compare the definition of an ePatient and the definition of a patient that you created in Exercise 1.

Directions

1. Watch the You Tube video located at http://www.youtube.com/watch?v=2vejkD0Rl3o.
2. It has been suggested that social media is a" game changer." As a small group online or in an F-2-F setting, discuss the implications of this video for your communication with patients/consumers.

Exercise 4: If Two Heads are Better Than One, are More Heads Even Better?

Purpose: *The purpose of this exercise it to consider the implications of research related to group process and the use of social media in health care.*

Objectives

1. Explain the concept of group intelligence as opposed to individual intelligence.
2. Discuss how access to group intelligence may impact the decisions individuals make about their health care.

Directions

1. It has been suggested that patients working together in social networks with access to the same information as health care providers are increasingly functioning as peers in the health care team. Watch the video located at http://www.nsf.gov/news/news_videos.jsp?cntn_id=117795&media_id=68461&org=NSF.
2. Now go to the website https://www.inspire.com/groups/lung-cancer-survivors/ and review some of the postings. Do not join this group unless you or a family member, close friend, or so forth, are dealing with lung cancer. Read the different comments.

3. Create a blog with your classmates. Discuss how individual patients and/or families are using this group as a resource in making decisions related to their health care. Is this an effective approach to making these decisions? Support your answer with your opinion and with data.
4. Should digital literacy be a job requirement for all professional nurses? Explain your answer.

Exercise 5: Did I Say that Clearly?

Purpose: *The purpose of this exercise is to explore the level of literacy required for understanding health-related information from different online resources.*

Objectives

1. Measure the level of basic literacy required to access different health-related information resources.
2. Analyze the relationship between basic literacy and an individual's decision to utilize different health care resources.

Directions

1. Go to http://www.nlm.nih.gov/medlineplus/ and search on the term lung cancer
2. Copy and paste a paragraph from each of the first five results.
3. Use Microsoft Word to measure the reading level required for each paragraph.
4. Calculate the average reading level of your sample.
5. Go to the website https://www.inspire.com/groups/lung-cancer-survivors/.
6. Copy and paste a paragraph from the first five postings.
7. Use Microsoft Word to measure the reading level required for each paragraph.
8. Calculate the average reading level of your sample.
9. Look over both sets of data for differences in style and tone.
10. Create a PowerPoint presentation outlining your findings and the implications of your findings for patient education concerning health related online resources.

Exercise 6: Is this Information Credible?

Purpose: *The purpose of this exercise is to explore a social media site and evaluate it using selected criteria.*

Objectives

1. Apply selected criteria to evaluating a social media site for content quality.

Directions

1. Find a social media site that addresses a health care issue and is not a .gov or .edu site. This should be a site from a health care consumer to other health care consumers—a site like http://laughingatmynightmare.1000notes.com/.

2. Select one of the traditional criteria for evaluating health care information from the Internet—credibility, accuracy, currency, authority, scope, or so on. In addition, answer the questions found in the section Social Media and Health 2.0 Criteria in this chapter.
3. Using the criteria from step 2 and those questions, evaluate the information on this site. Did the criteria work? Would you recommend a patient with this problem follow this site? Why or why not? What problems did you find in applying the criteria and answering these questions?
4. Create a PowerPoint with your findings and recommendation.

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