Abstract - People need health information to attain good health and make health care decisions. This paper discusses the transition from print-based to new modes of electronic dissemination of multimedia-based consumer health information. Developed in the context of the federal national information infrastructure initiative, issues presented in this paper relate to the entire enterprise of public and private consumer health information production, delivery and use.¹

1. INTRODUCTION

The Consumer Health Information Subcommittee of the Committee on Applications and Technology, a part of the Clinton Administration's Information Infrastructure Task Force has proposed the following definition of Consumer Health Information:

"CHI is any information that enables individuals to understand their health and make health-related decisions for themselves or their families. This includes information which supports individual and community-based health promotion and enhancement, self-care, shared (professional-patient) decision making, patient education and rehabilitation, how to use the health care system and select insurance or a provider, and peer-group support. From the perspective of the consumer, CHI can be actively sought or it can be provided to them through public or private education campaigns which target specific health issues (e.g., media efforts aimed cholesterol reduction). CHI encompasses a wide range of information, essentially the "who, what, how, why, where, when and how much?" of health information. The nature of CHI can be economic, technical, logistical and/or qualitative. It is available in health care settings as well as such locations as homes, schools, libraries, work-sites, stores and other arenas open and accessible to all.

To be effective, CHI must be tailored to the interests, literacy, language, cultural background, emotional state and desires of its user. From the standpoint of providers of CHI, effectiveness may be measured both by how rapidly and completely desired messages are communicated and by how completely changes in behavior occur. Ultimately, for both producers and consumers of CHI effectiveness will be measured by individual and population improvements in health status and quality of life."

¹ This paper does not necessarily represent the policy of the US Public Health Service, the Office of Management and Budget, or the Advanced Research Projects Agency.

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That an informed consumer is essential to an improved health care "system" is based upon several principles and assumptions:

• **Personal behaviors are an essential component of health promotion and disease prevention.**

Of the many factors which influence individual health status (genetics, environment, behavior, medical care) one of the most -- and in many circumstances the most -- important is personal behavior. These include behaviors such as eating habits; physical activity or inactivity; alcohol, tobacco and other drug use; risky sexual practices; and activities which place one at risk for accidental injuries. This also includes behaviors taken while healthy to intentionally reduce the likelihood of illness. For example, immunization to prevent disease, wearing protective helmets while bicycling, getting periodic screenings for cancer. While a complex set of social, economic and cultural factors influence these behaviors, all are (theoretically, at least) amenable to some improvement based upon the decisions of an informed individual and/or his or her community policy makers.

• **Consumer health information is necessary for self-care.**

Minor illness or injury is much more common than more serious illness or injury. How an individual or family member manages these problems through self-care can often mean the difference between simple resolution of the problem or progression towards more serious illness requiring professional intervention. Some self-care is quite simple (cleaning off a minor wound sustained while gardening). Other self-care is more complex (the management of a baby with a high temperature - and making the decision when to go to the doctor). Some of the information for self-care is acquired before an injury or illness happens. Other information is obtained at the time of the event. Optimal self-care is dependent upon sources of accurate and timely information tailored to personal needs.

• **Consumer health information is necessary for improved quality and cost of care**

One recognized failure of the health care market is inadequate information on comparative cost and quality of services and providers. Individuals are regularly faced with decisions about insurance plans, providers, facilities and treatment regimes. Improved access to such information will help support individual decision making and enhance market forces that can lead to more efficient care.

• **Professional management of health and medical problems requires the availability of CHI.**

When an individual needs to obtain professional advice for a health problem, the need for CHI can increase substantially. Information is needed about where to go for health care. Once seen and treated, information may be needed to return to optimal health status as quickly and efficiently as possible and to minimize the likelihood that the problem will recur. Sometimes information is needed to understand the implications of a newly diagnosed chronic or severe illness. Or information is needed to plan for changes (temporary or permanent) in work, school or other living arrangements. Some of this information is best provided through peer groups of individuals with similar characteristics, e.g., those with breast cancer or HIV disease. Sometimes the most important issues relate to what questions to ask health care providers in the context of a visit. In many circumstances, the need is great for ongoing, comprehensive and attainable information to use for decision making and for coping.

• **The need for CHI for community health.**

Many issues related to health happen at the population level, e.g., the spread of communicable disease or the impact of temporary environmental hazards. Individuals need to be as informed as possible about these issues and often need this in a timely and universal way. Because of the environmental, social and behavioral determinants of health, information that can help improve or maintain health is much broader than information solely about medical issues. Information on services that support healthier lifestyles such as exercise programs, work safety programs, or social service programs that help individuals and families gain access to housing, jobs, or child care can improve both mental and physical health. An individual's ability to readily obtain and use information in this broader spectrum of human needs must also be recognized as critical to health.
2. PROVIDERS OF CONSUMER HEALTH INFORMATION

A diverse array of CHI producers and disseminators exist including:

- **Health-related Organizations** - Hospitals, doctors and dentist offices, health maintenance organizations, insurers, demand management services, the pharmaceutical industry, occupational clinics, school and college health centers, nursing homes, pharmacies and others involved in the provision of, and payment for, health and medical care and their supporting services. This includes professional societies and accrediting organizations now increasingly involved in quality improvement strategies for healthcare.

- **Libraries** - Local, county, state, academic and other libraries generally providing open and free or low-cost access to CHI.

- **Health Voluntary Organizations** - American Heart, American Cancer, American Lung and upwards of 6000 other health-interest societies. The National Health Council estimates that the 40 largest of these organizations spent $623 million in CHI in 1991.

- **Broadcast and Print Media** - Television, radio, newspapers, magazines, medical and health publishers all provide substantial amounts of information on health.

- **Employers** - Most people get information on insurance choices from employers. Many also get health promotion and worksite health related information in these settings.

- **Governmental Agencies** - numerous federal, state and local government agencies have health and health-related information programs and clearinghouses. The Department of Health and Human Services alone spent an estimated $2 Billion in 1991. Estimates of state and local expenditures are difficult to obtain but may parallel the roughly 50-50 distribution between federal and non-federal investments in public health expenditure overall.

- **Community-based Organizations** - Separate from health-related organizations are churches, YMCAs, agencies for the aged and other special interest organizations which often engage in the distribution of CHI. Information and referral services provided by these organizations are substantial.

- **Networked CHI providers** - Internet and non-Internet Bulletin Board Service (BBS) providers of CHI are evolving that are, in essence, hybrids of voluntary and community based organizations: health voluntary and/or self-help groups are creating "virtual" communities of individuals with similar interests and needs. The rapid growth of these, and their likely continued growth and importance as technology advances, suggests that they may become one of the predominant players in the future CHI marketplace.

3. MEANS OF CHI PROVISION

Methods of CHI dissemination and access range from the simple to complex, from print to electronic, from one-way broadcast to interactive, and from individual "word of mouth" advice from friends and trusted advisors to community-wide campaigns. The following comprise the predominant means of CHI dissemination at present:

- **Informal channels** - Friends, trusted non-professional experts, family members, or someone else recently known to have had the same concern. This is often the first -- and sometimes the most important -- source of CHI.

- **Printed text** - Books, brochures, pamphlets, magazine articles and other material provided through libraries, newsstands, bookstores, health facilities and so forth.

- **Broadcast electronic media** - TV, radio or cabled programming of any sort broadcast from one to many individuals.

- **Dial up services (paid or toll free)** - Provided by governmental, voluntary or other organizations, these can serve as the way in which specific CHI is obtained or located (e.g., advice might be referral rather than definitive). An example of this is nurse telephone health counseling for either triage or for assistance with self care. Technology now
enables either a live or substantial voice-menu to be accessed and is often combined with a "fax-back" feature that allows printed information to be faxed by request.

- **Non-networked computer-based information** - Computer software, CD-ROM, CD-i, Laser disc, most Kiosk technology, and other forms of non-networked interactive media are available for an ever-increasing home, school, clinic, worksite, library (etc.)-based series of platforms. One of the most advanced in this category is the shared decision making software developed to support more informed decision making by patients in consultation with their practitioner. Intended to be used simultaneously by clinician and patient, this software enables complex decision making under situations of uncertainty. It enables patients to incorporate their preferences on such issues as quality of life and outcomes of medical treatment into the medical decision making process.

- **Networked interactive computer-based information** - This includes Internet based processes such as BBS, one-to-one e-mail, Gopher, World Wide Web servers, Wide Area Information Service (WAIS); some public Kiosk technology; and other increasingly sophisticated means of obtaining information predicated upon computer processing capability at two or more points on a network (wired or wireless) and capable of transmitting text, sound, graphics and/or video.

4. **LIMITATIONS OF CHI AT PRESENT**

- **Timing relative to need** -- Often times information is broadcast at a time when most individuals do not need, and therefore can't use, the information. Experienced teachers describe the "teachable moment" as the time when something is most likely to be learned. If the information is not in a form that is easily retrievable it does not have the desired affect. And often CHI is needed at the time of illness or injury -- an unpredictable event for most.

- **Single direction of most broadcasts** -- The difficulty of following up, clarifying and understanding broadcast information can also render it ineffective, particularly if unique individual characteristics require specialized messages.

- **Timeliness/relevance of information** -- If the information needs to be updated regularly certain forms of information e.g., verbal, written, and one-way multimedia can be very costly. It can also be potentially confusing and counter productive if outdated information is available alongside newer better information.

- **Limited nature of each information effort** -- Single message campaigns such as "get your flu shot this month" can make the initiatives very expensive and do not necessarily lead to coordinated messages that make sense to the receiving public.

- **Conflicting nature of many of the broadcast messages.** With non-interactive media there is no ability to reconcile the often different messages that pertain to the same subject. "Should I have a mammogram or should I not?" "What is the meaning of this recommendation to me?" "My neighbor had that done and ended up in the hospital; why wouldn't I?" Compounding this problem is the uncertainty in medical care and the fact that recommendations change over time. Discerning the "best" health recommendation can be difficult for even the most informed consumers.

- **Broadcast messages are not unique to the individual.** It is prohibitively expensive to customize broadcast messages to the unique cultural, social, economic and attitudinal needs of each individual. While some broadcast environments do address unique ethnic groups, many are still left out of the information chain because of the lack of precise match of medium to recipient.

- **Much current CHI is predicated upon the ability to read -- even at a low literacy rate.** The ability of some people to grasp information presented in written form varies. Additionally, we know the importance to learning of graphic and video presentation of information as an adjunct for even those with high literacy levels.

5. **VISION FOR THE FUTURE**

National Information Infrastructure (NII) capabilities in the near future will enable interactive information flows and rapid transmissions of information. More and more communities are becoming part of local and wide
area health information networks, often called Community Health Information Networks. These networks can make transmission of and access to CHI much easier. Open and interoperable communication channels will exist instead of the "stove-pipe", one-approach-doesn't-communicate-with-the-other methods of the past. Reusable dissemination channels will avoid the need to recreate new ones each time information is disseminated. Multi-user list server technologies will allow information sent to a single location to go to all entities on the list, expanding broadcast capabilities, allowing timely amendments to information, and enabling everyone on the list to be a "broadcaster."

Use of bulletin boards in combination with multiple recipient electronic mailing strategies will revolutionize the way information is disseminated and the ability to have follow-up communication and dialogue.

The long term vision is that every individual will be able to access, through computer, interactive TV, or phone, any information that he or she needs. Information exchange will be through multimedia using the combination of words, sounds and pictures. The technology available will include health-oriented point-to-point and distributed virtual reality-based simulation models and environments, i.e., synthetic environments that can show individuals or their family what the outcome of an operation could achieve e.g., mobility after orthopedic surgery, or what future health status would be like given current health behaviors.

Importantly, enhanced access to this information also will facilitate access to expert intermediaries -- real people -- as desired and necessary. Such intermediaries, expected to come from commercial and non-profit will have access to the full array of health information through the same channels. Ultimately the individual, or his or her intermediary, will be able to interact with information through the use of expert software that searches for information based upon the unique characteristics of that specific individual, renders that information in comprehensible terms, clarifies and modifies the "dose" of information to match current needs, and learns from the individual his or her habits and desires for subsequent information search and use.

It bears repeating: first, these tools, like other new technologies such as telephone answering machines or fax machines, will enhance the ability of two or more people to communicate. With time, they will enhance the means by which the knowledge stemming from such communication becomes individualized and meaningful.

Scenarios . . .

** A 26 year old woman carrying her first pregnancy seeks prenatal advice, wanting to know her risks, any community risks, who is an appropriate provider, the pros and cons of giving birth at home or a birthing center, where to find Lamaze classes, support groups for new mothers etc. She is interested in considering all the options available to her -- which doctor to see, what her health plan will cover, how long she will need to plan on being away from work, and so forth. She turns on her interactive television to the health information listings. She identifies the types of information in which she has an interest i.e., general information, about possible options and their implications, video displays of alternative birthing options, information about and teleconference links with the available local services.

She is either assigned a case-manager through her health plan or directed to a health professional within the community who assists her in locating a doctor for her and her baby who is close to her home and arranges for visits following the birth. She also finds out that there is a local pregnant women's support group that has a question and answer forum on the internet. She is also able to consult with her chosen health care practitioner through the local network and can contribute information to her medical record through the networked information system. This becomes particularly useful to her and her provider when she experiences something unusual in her pregnancy and needs to determine if an appointment is necessary.

If this women does not own a television she can access much of the same information via the telephone, by calling any of the local social service offices or by going to her local library and using the public kiosks. Assistance with this process can be provided by culturally sensitive and well trained professionals. These professionals can provide coordinated, seamless service to her through use of the Community Services Network (CSN). CSN workstations sit on the desks of virtually all health and human services providers in her community, interoperate with one another and enable the
exchange of information needed to develop, implement and evaluate care plans such as the one outlined for this individual. From the perspective of the consumer, they also avoid the "hassle" of having to physically go to many different locations for services.

A 31-year-old mother, an engineer, is concerned about recurring ear infections in her 6-month old son, and phones her pediatrician for advice. The pediatrician, after accessing the AHCPR-supported clinical practice guideline on Otitis Media with Effusion in Young Children through an electronic version of the Quick Reference Guide for Clinicians available from Physicians' On-line, consults his copy of the Online Access to Clinical Practice Guidelines and suggests the mother obtain the consumer version on the Internet through the National Library of Medicine's free HSTAT electronic service using her commercial subscription to Prodigy. The pediatrician feels this information will help the mother understand the benefits of watchful waiting versus the risks of antibiotics or surgery. Farther into the future, the mother may buy or rent an ear scope that can be plug into the TV and relay the inner ear image to the practitioner who in turn makes a diagnosis and can order a prescription, if appropriate, without an office visit.

6. CRITICAL ISSUES SUPPORTING THE VISION

As health care restructures itself, and as the information services sector of the economy continues to grow, producers and consumers of CHI will grow in sophistication and number.

The challenge for any disseminator of CHI is how to use the evolving interconnected networks in ways that improve the efficacy, effectiveness and impact of information delivery. One significant challenge in the short term is to recognize that the information has to be adaptable to the full spectrum of existing information dissemination modes, i.e., verbal, written, networked, and multimedia. As we develop information and make it available in networked form we must acknowledge that the use of these new media raises many important issues.

• Assurance of Privacy and Confidentiality

In the evolving information infrastructure, assurance is necessary that CHI "systems" are not used as tools to breach issues of patient confidentiality and privacy. The public should be able to access CHI in completely anonymous (e.g., at home or privately in libraries) or confidential (clinical practice settings) ways. While existing safeguards may be sufficient, as these systems evolve, unique challenges to the maintenance of confidentiality and privacy may arise.

• Assurance of availability of information critical to public health

As we move into a more information-rich society, the importance of the timely availability of information critical to the health and well being of individuals and communities may increase. This might include information deemed worthy of national-scale health promotion and/or disease prevention efforts such as those associated with major environmental health issues or wide-spread communicable disease challenges.

• Research, Development & Evaluation

The key issues here relate to both the basic and applied research necessary to the development and deployment of CHI technologies. These include:

> What is the ultimate impact on health outcomes of CHI information initiatives? Who uses it and who doesn't? How is this best measured?

> What kind of performance measures should be developed and used to assess CHI projects? Should the cost-effectiveness of CHI efforts be compared to direct care interventions? If so how?

> What types of media, interface designs and information platforms work best for what kinds of messages and what types of populations?

> From the consumer's standpoint, what means of coordinated delivery work best?

> How can CHI systems be developed to minimize redundancy, confusion and overlap of purpose and to maximize utility?

> What about "information overload"? How may new technologies incorporate "intelligent systems" that help people find the information they need when they need it while at the same protecting them against massive information overload?
> What methods of CHI provision most effectively address equity of access issues?

- **Uniform standards of transmission, support of common frameworks and unifying language structures**

An issue that relates to all of the national information infrastructure and all health information is the difficulty of communication due to the absences of common language, taxonomies, and electronic data exchange standards. Substantial standardization efforts are underway to facilitate administrative data exchange and medical record exchange, however, it is not clear that these efforts will facilitate the exchange of CHI.

- **Information validity and integrity**

Should the treatment of CHI information, particularly in an electronic networked environment be consistent with existing regulatory responsibilities and the legal treatment of speech and the press? Many health professionals are concerned that the emerging electronic environment will have the ability to disseminate vast amounts of misinformation without any ability to easily correct the information or identify what information is or isn't valid. Free speech proponents believe that electronic media should be treated no differently than speech or the press and that information on networks is self correcting through interactive dialogue. What mechanisms could be developed that address this concern without regulating information flow?

- **Assured telecommunications infrastructure**

As CHI moves to encompass increasingly sophisticated techniques, if these are demonstrated to be essential for individual or community health, then assurance of some level of "minimal" information infrastructure available to all Americans may become necessary. This could mean the assurance of adequate bandwidth (electronic carrying capacity) to schools, libraries, clinics and, ultimately, homes to enable multimedia health programming. The demonstrated need for this is not now present, but may well be in the future. Who will perform this assurance function?

7. CONCLUSION

The future of networked CHI holds great promise as a means by which individuals can play an active role in maintaining and improving their health. However, several important issues must be addressed before we can get "from here to there" in the development of a robust and effective CHI enterprise.