COMMUNICATIONS POLICY AND PRACTICE

BENTON
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NETWORKING FOR BETTER CARE:

Health Care in the Information Age

WHAT'S GOING ON

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The "What's Going On" series is published through the Benton Foundation's Communications Policy and Practice program. *Networking for Better Care: Health Care in the Information Age* is made possible by a generous grant from the Robert Wood Johnson Foundation, Princeton, NJ. Additional support for the series and for our work comes from the John D. and Catherine T. MacArthur Foundation, the W.K. Kellogg Foundation, and the Charles Stewart Mott Foundation.

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DESIGN: SUPON DESIGN GROUP, WASHINGTON, DC. PHOTOS: PHOTODISC

NETWORKING FOR BETTER CARE:

Health Care in the Information Age

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PRINTED IN MARCH 1999.

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Information and Health:

People have instant access today to vast stores of health care information in their homes, workplaces, schools, libraries, and anywhere else one finds computers with Internet access. Estimates of the number of health-related Web sites run as high as 10,000 or more. And that figure only begins to tell the story. Consider what can be found on just three sites:

- The National Library of Medicine's Medline contains more than 15 million citations and abstracts from more than 3,900 biomedical journals.

- healthfinder, the official government gateway to consumer health information and referrals, maintains a database of 4,600 health-related publications, online resources, and government offices.

- NetWellness, an online health information service sponsored by the University of Cincinnati, Ohio State University, and Case Western Reserve University, offers 25 electronic books and 340 health magazines and journals, as well as original features produced by faculty at the three institutions.

Services like these clearly are responding to an enormous desire among Americans to know more about health. The Emerging Technologies Group of the research firm Find/SVP found in a 1997 survey that more than one-third of all Internet users go online for health-related information. Medline, which only became available to the public free of charge in 1997, currently handles an estimated 300,000 searches per day. The Virtual Hospital Web site, an information service for health professionals and patients run by the University of Iowa, gets about four million "hits" per month.

But is this flow of digital data really making us healthier, or is it merely overwhelming us? A growing number of policymakers, health care providers, and consumers believes information resources hold the key to improving the health care system. These advocates say that judiciously collected and effectively communicated information can help professionals provide better care, turn patients into enlightened consumers of health services, and ultimately enable individuals and communities to address some of the root causes of illness before professional intervention is required.

But much hard work remains to be done if we are to realize these goals. Among the issues we must address are the following:

- **Content:** Information for information's sake is of little value. Health care professionals and consumers need well-crafted information that is both relevant to their needs and reliable.

- **Changing Professional Roles:** As health information moves out of the cloistered halls of medical libraries and doctors' offices and into the public square, the role of the health professional is changing. To take full advantage of the opportunities the information revolution is creating, we must help health care providers redefine how they relate to their patients and the public at large.

- **Help for Consumers:** Policymakers increasingly are relying on consumers, armed with information, to use their leverage as purchasers of health services to induce improvements in the quality of care. But market forces alone may have little effect unless government, employers, and nonprofit institutions educate and support consumers to play this role, and fill in gaps where consumers still lack clout.

- **Equity:** As information technologies enable some people to become increasingly well-informed and self-reliant, others who lack access to information resources will find themselves at a disadvantage. New strategies will be needed to ensure that all Americans can reap the benefits of the Information Age health care system.

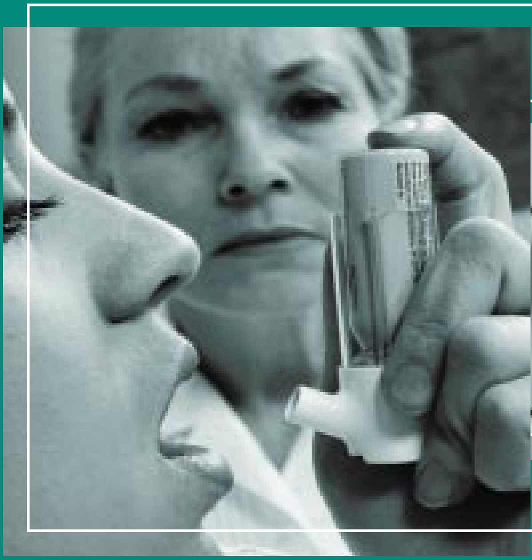
- **Community-wide Collaboration:** Americans have known for some time that prevention, screening, and education concerning healthy behaviors and other "wellness" strategies can dramatically improve health. We also recognize that such efforts are most effective when entire communities, not just the medical establishment, are engaged in them. Information technologies can help communities identify and act on their health needs; they can also enable health care providers, community institutions, and individuals to collaborate on health-enhancing projects.

These are challenges not only for the health care sector, but for institutions and individuals outside the health arena as well. This report describes some of the ways that new information tools could produce systemic changes in the health care arena. Its goal, in part, is to serve as a bridge between the health care sector, where many of these issues are well known, and the broader public—including people involved in building and using information networks—who may be much less familiar with them.

The report begins by describing in Section 1 why a growing number of policymakers, health care providers, and consumers believe that information-based strategies offer the best hope of addressing concerns about cost, quality, and access to health care. Section 2 explores some of the barriers that stand in the way of achieving information-driven improvements in health care. Section 3 describes the various steps that need to be taken to meet these challenges. Section 4 offers a glimpse at what the long-term future may hold for information technology and health. Finally, Section 6 suggests some resources for further study of this complex issue.

1

Challenges and Opportunities



1

Challenges and Opportunities

When Glenn Fleishman was first diagnosed with Hodgkin's disease in 1996, his doctor asked him to hold his questions until he could see a cancer specialist. But, said Fleishman, "With no real knowledge at hand, and my stomach dancing the fandango, I found it impossible to wait for answers."

So he turned to the Internet, where a quick search led him to the University of Pennsylvania's Onco Link, a respected source of information on cancer. He soon was thoroughly versed on the disease, knowing not only which chemotherapy regimen he preferred, but the wholesale prices for the medications involved. Later, he used the electronic Hodgkin's Disease Mailing List to commiserate with other people undergoing the rigors of chemotherapy, and he collected some information his doctor never mentioned (such as why his urine suddenly turned red—a harmless side effect of chemotherapy) from Web sites like "Mike's Lymphoma Resource Pages."

Six months later, the saga ended happily. An MRI scan showed he was in full remission. And there was a bonus. Fleishman, who hadn't even known where his liver was when he first became ill, now knew a lot more about health. "When I padded out of the magnetic resonance imaging machine in my socks and a hospital gown, and the imaging technician pinned up the image of my insides—my cancer-free insides—I could point to the liver without any hesitation," he proudly recalls in a personal account he wrote for the *New York Times*.[1]

Increasingly, people like Fleishman are taking charge of their own health care. Armed with the latest information on advances in medicine, empowered consumers are collecting tips on how to care for themselves, developing a better understanding of their diagnoses, and making more informed choices about their treatment options. With email and electronic bulletin boards, they are finding peers to share both emotional support and practical advice. Some even are going online to check the qualifications of their health care providers.

This is more than an enjoyable pastime. Electronic health information may help Americans address three sets of problems that have plagued our health care system for years: high costs, uneven quality, and gaps in access.

The cost problem is well known: Americans spent $1.1 trillion on health care in 1997, an amount equal to 13.5 percent of the Gross Domestic Product, according to the Health Care Financing Administration. Per capita spending for personal health services totaled $3,925—about $1,000 more than would be expected on the basis of income alone, judging from comparisons with other countries, according to the *New England Journal of Medicine*.[2]

The quality of health care is more difficult to measure, but on that score too, Americans may not be getting their money's worth. Summarizing exhaustive research, the President's Commission on Consumer Protection and Quality in the Health Care Industry in 1997 said that the United States suffers serious underuse of some services and overutilization of others. Almost one in four children does not receive appropriate immunizations by 18 months of age, for instance. One-third of all women over age 18 have not received pap smears in the previous three years, while 16 percent of women undergo clinically inappropriate hysterectomies. Between 10 percent and 35 percent of hospital admissions are inappropriate, according to the report.[3]

For the past 20 years or so, insurers, employers, and policymakers have all looked to managed care to find the right balance between cost and quality of medical services. But many Americans have come to believe that health maintenance organizations and other forms of managed care plans have sacrificed quality to control cost. As a result, numerous legislative proposals are springing up to dictate what services health plans must cover—requiring minimum hospital stays for new mothers or for women who have had mastectomies, for instance.

This backlash against managed care could have unintended consequences: if regulatory proposals force health plans to raise their rates, many employers would drop health benefits; that, in turn, could swell the ranks of the uninsured. Already, some 43.4 million Americans, or 16.1 percent of the population, lack health coverage. The Lewin Group, a consulting firm, estimates that a one percent increase in employer health insurance premiums would result in 400,000 people losing their coverage, according to an analysis by the Employee Benefit Research Institute (EBRI), a Washington-based think-tank. [4]

Information strategies may offer a solution to this dilemma. By collecting new types of data and providing it to the myriad participants in the health care system—everyday citizens as well as professionals—we may be able to improve the quality of care without increasing costs or increasing the ranks of the uninsured. This pleasant prospect arises from three distinct trends, all of which involve information. First, medical researchers are producing information that promises to improve the quality of care. Second, policymakers are looking to inform consumers to use their buying power to produce a more responsive and effective health care system. And third, consumers themselves are using information to assume more direct responsibility for their own health.

More Effective Medical Care

Almost daily, the news media bring reports of wondrous advances in medical research and genetics. But an equally important transformation in health care has received far less notice. "Owing more to laptops than lab coats, it is an information revolution, driven by the goal of finding the most appropriate and effective therapy for each individual patient," says Michael Millenson, a senior analyst in the health and welfare consulting practice at William M. Mercer, Inc.[5]

"Evidence-based medicine" or "outcomes research," as the movement is known, seeks to develop and use information to make the daily practice of medicine more of a science and less of an art. Its tools range from randomized clinical trials to statistical analysis of outcomes of different medical treatments. Already, it has profoundly affected the health care system. It has demonstrated, for instance, that preventive care such as immunizations and early screening procedures for chronic illnesses leads to better health and lower long-term medical costs at the same time.

Surprisingly, outcomes research is still relatively new. As recently as 20 years ago, Millenson notes, fewer than half of all medical treatments had been validated by clinical trials. Even today, there is little hard evidence about the implications of many treatments. No completed clinical trials have determined, for instance, whether men with prostate cancer have better prospects for survival if they undergo radiation or surgery rather than engage in simple "watchful waiting," according to the Center for the Evaluative Clinical Sciences at Dartmouth Medical School.[6]

Partly because of insufficient outcomes research, medical practices vary widely and inexplicably from region to region. Surgery rates for early-stage prostate cancer, for instance, vary more than ten fold between different parts of the country. In Sun City, Arizona, eight percent of all Medicare patients are admitted to intensive care units at some point during their last six months of life, compared to 47.6 percent of Medicare patients in Sun City, California.[7]

Such variations appear to be unrelated to the actual needs of patients, says John Wennberg, director of the Dartmouth center. Instead, they reflect differences in the availability of specialists and facilities, as well as the varying assumptions, priorities, and unscientific attitudes of physicians and health plans. "Doctors often form opinions based on hunches and professional interests," says Dr. Wennberg. "In health care, geography is destiny."

Today, though, a growing number of studies are helping to put decisions about medical treatment on a more solid scientific footing. The President's Commission on Consumer Protection and Quality in the Health Care Industry reports that the average number of Medline citations on randomized controlled trials increased from 509 annually between 1975 and 1980 to 8,636 a year from 1993 through 1997. These studies, in turn, have led to a dramatic proliferation of practice guidelines spelling out the most appropriate treatment for various medical conditions. Some 454 guidelines were published annually between 1993 and 1997, compared to just one a year between 1975 and 1980. The American Medical Association (AMA) lists 1,700 separate guidelines in its Directory of Clinical Practice Guidelines.

To help medical practitioners keep ahead of the enormous growth in information, the federal Agency for Health Care Policy and Research joined hands with the AMA and the American Association of Health Plans to create a National Guideline Clearinghouse, which publishes various clinical guidelines on the Internet, along with abstracts, summaries, and comparisons.

Enlightened Consumers

As promising as these undertakings are, another relatively untapped resource—patients themselves—may prove even more important for health care in the Information Age. Policymakers increasingly hope that educated consumers will become a driving force for improvements in the quality of health care.

If consumers are equipped to choose between competing health plans and providers, the theory goes, they will flock to those who provide the best care at the lowest price. Banking on this proposition, a number of large employers—including the federal government, the California Public Employees Retirement System (CalPERS), General Motors Corp., and GTE Corp.—now offer employees a choice of health plans. At the same time, the Health Care Financing Administration is moving to ensure that Medicare recipients are offered an array of health plan options. And numerous health plans themselves, responding to demands from consumers (and in some cases pressures from doctors), are expanding the choice of doctors and hospitals available to their customers.

"Retail health plan competition—the holy grail of public policy and market theory in the 1990s—creeps ever closer," writes Robert Cunningham, editor of Faulkner & Gray's *Medicine and Health Perspectives*.[8]

For the market mechanism to work, consumers must have reliable information comparing health plans and service providers. As the Institute of Medicine stated in a 1996 report on federal efforts to expand choices for Medicare recipients, "Without adequate, comparable and timely information, it is not possible to exercise informed choice."[9]

In fits and starts, Americans are developing an information system to meet this need. The Agency for Health Care Policy and Research, working with the RAND Corp., Harvard Medical School, and Research Triangle Institute, has developed the Consumer Assessment of Health Plans Study (CAHPS), a survey instrument used to gauge customer satisfaction with different health plans.

The National Committee for Quality Assurance, an industry-supported, nonprofit group based in Washington, DC, created the Health Plan-Employer Data and Information Set (HEDIS), a database that shows how health plans compare on such performance measures as their rates of immunizations, well-baby visits, prenatal care and post-delivery check-ups, screening for breast and cervical cancer, use of beta-blockers for heart attack victims, eye exams for diabetics, and more.

Another accreditation organization, the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), reviews hospitals, nursing homes, and other health care facilities using a variety of standards relating to patient care and management. A number of private consulting firms also rate health plans on behalf of large employers.

Some tools also help people assess individual providers. The American Medical Association maintains a database on the training, specialties, and board certification of many doctors. Similarly, the American Board of Medical Specialties informs consumers on its Web site and via a toll-free telephone number whether a doctor is board certified.

Public disclosure of quality measures can make a difference. Within one year of the time the Missouri Department of Health published a consumer report on obstetrical services, for instance, half of all hospitals in the state had taken action to reduce their rate of Cesarean-section births and address other issues. Three years after the National Institutes of Health issued guidelines recommending use of anti-inflammatory therapy for treatment of persistent asthma, 82 percent of physicians began promptly prescribing corticosteroids for patients with asthma, compared to 21 percent previously. And the in-hospital death rate for patients undergoing coronary-bypass surgery fell more than 30 percent in the seven years after the State of New York started gathering hospital performance data in 1989.[10]

Increased Self-Reliance

Many people want to be more than passive consumers of health services. They want to be active participants in their own care.

This became evident to Michael D'Allesandro, a pediatric radiologist, shortly after he inaugurated the University of Iowa's 35,000-page Virtual Hospital Web site. D'Allesandro and his associates designed the site to serve two distinct audiences. For health care professionals, the site provides an array of videoclips, multimedia textbooks, case studies, and technical descriptions of hundreds of medical afflictions. For consumers, it offers tips on such topics as when to be immunized or screened for cancer, what to expect before and after surgery, how to conduct a breast self-examination, and what should be included in a proper diet.

Soon after the service opened its electronic doors, the distinction between the professional and patient realms of information started to break down. "We found that patients would read the patient information, and then they would read the provider information too," says D'Alessandro.

As this example illustrates, the boundaries between experts and lay people are starting to blur. Today's Internet-savvy patients are coming to their doctors' offices armed with more information and better questions than the passive patients of the past. Occasionally, patients even tell their doctors about new research findings and experimental treatments, rather than the other way around. "A typical doctor may need to know about 500 different diseases," D'Alessandro explains. "A patient has to know only one. It's amazing what patients can learn."

There is nothing really new about patients playing a leading role in their own care. In the early days of the American nation, family members—especially women—were primarily responsible for caring for the sick; if families needed help, they turned to networks of kin and community, according to social historian Paul Starr. In his landmark study, *The Social Transformation of American Medicine*, Starr says the "sovereign profession" of medicine did not emerge until the 20th century.[11]

Even today, most health decisions are made outside the doctor's office, clinic, or hospital. Dr. Tom Ferguson, author of the book *Health Online* and the electronic journal *Healthworld Online*, and a leading proponent of self-help, lists some of the evidence. A U.S. study of 1,200 healthy adults concluded that the average person faces 117 health issues per year, but sees a doctor only once or twice. A British study conducted during the 1970s found that people deal with 79 percent of all their medical problems entirely on their own. Another study reported that 96 percent of patients interviewed in a doctor's waiting room had sought information or advice, or used self-care, before coming to see the doctor.[12]

Several other factors are contributing to the increased importance of patients as decisionmakers. The growing emphasis on prevention and early screening requires that patients be well informed and responsible. What's more, well-informed patients can significantly enhance the treatment of many major illnesses, such as heart disease, stroke, diabetes, hypertension, and arthritis.[13]

But self-care is not just for individuals. Self-help groups are springing up everywhere, addressing issues ranging from gambling addiction to Tourette's Syndrome. Many, such as the National Association of People With AIDS or the Huntington's Disease Society, focus on particular illnesses and disabilities. Others, such as Families of the Mentally Ill or Survivors of Suicide, address the needs of caregivers and families of the afflicted. Often formed by everyday citizens, these groups offer both patients and caregivers a way to overcome the sense of isolation and depression that often accompanies illness. Participants exchange information, compare experiences, and share coping techniques. They also vent their frustrations, and help others. As a result, they instill a sense of hope where once there may have been fear and anger.

Support groups make a measurable difference. Studies cited by the Self-Help Network of Kansas show, among other things, that chronic arthritis patients who join groups control pain more effectively. Women with metastatic breast cancer report milder mood swings and reduced pain—and survive twice as long, on average, as control-group patients. Support groups have also been shown to cut the rate of heart attacks among men, ease anxiety and depression arising from traumatic experiences, and reduce demand for medical services and medication among people suffering chronic mental illness.[14]

Electronic communications present new opportunities for the self-help movement, according to Edward Madara, head of the American Self-Help Clearinghouse. Electronic chat groups, bulletin board systems, and online forums are easier to attend than face-to-face meetings, so people can participate even if they lack transportation, have scheduling problems, are disabled, or have 24-hour-a-day caregiver responsibilities. Some online groups also offer participants the option of remaining anonymous even while sharing sensitive information. And electronic meeting places may represent the only opportunity for people with rare disorders to surmount their isolation in their own communities and find similarly situated peers.

2

Barriers

2

Barriers

For all their promise, information technologies cannot automatically transform the health care system. A number of barriers must be addressed before the full potential of these new tools can be realized. First and most fundamentally, many people still do not have access to these tools or lack the abilities to use them effectively. Second, information that is reliable and relevant to users' needs is not always easy to find. Third, health care providers face challenges in redefining their role in a world where information is widely available to nonexperts. And fourth, consumers often lack the opportunity or the motivation to make informed choices among health care providers and options.

Lack of Access or Information Skills

Although Americans continue to go online in increasing numbers, many people still do not have access to the basic tools of the information age. Just 26 percent of households earning less than $35,000 a year have online access at home, for instance, while twice as many urban families earning more than $75,000 do, according to the National Telecommunications and Information Administration. What's more, the gap between those who have access and those who do not is growing wider, the NTIA says.[15]

As responsibility for health care shifts away from doctors' offices and hospitals and toward homes and communities, differences in access are becoming increasingly worrisome—especially since disadvantaged groups already suffer certain health problems disproportionately. African Americans, for instance, are more likely than whites to have high blood pressure, making them more prone to strokes, kidney failure, and heart disease, according to Janice G. Douglas, chief of the Division of Hypertension at Case Western Reserve's Department of Medicine, and Kenneth Davis, associate professor of surgery at the University of Cincinnati College of Medicine. Glaucoma develops earlier in African Americans and progresses more rapidly than in whites. Asthma death rates for African American men are three times greater than for white men. About half of Hispanic women and African American women are overweight—a risk factor for diseases such as high blood pressure and diabetes. And African Americans currently account for 57 percent of new HIV infections each year.[16]

Addressing the access problem will require more than installing hardware. Even many people with access to online resources lack the skills to use health information proactively. People who use the Internet to gather information about health have higher incomes and are better educated than most Internet users, let alone the population at large, according to a 1997 survey by the Emerging Technologies Group of Find/SVP. They also are more likely to visit the Web on a daily basis and to use search engines and email. [17]

For the millions of people who are not as deft with the Internet, today's information-intensive health care system can be confusing and frustrating. Electronic health care information can be poorly organized, difficult to understand, and impossible to evaluate. Marc Fisher, a *Washington Post* reporter who ventured into cyberspace to learn about a rare disorder afflicting his son, was overwhelmed by "vast electronic archives of medical arcana." Search engines, he said, were as likely to direct one to "a fellow sufferer's recitation of home remedies, a pharmaceutical company's stealth advertisement, (or) an out-and-out scam" as to legitimate educational resources. What's more, Fisher found little comfort in support groups, which he said offered "an utterly unscientific, irrational collection of tales of woe."[18]

Unreliable Information

The success of Information Age health care will depend to a large extent on whether the information becoming available over emerging electronic networks is both accurate and responsive to the needs of everyday people. Substantial gains have been made on this score, but more work needs to be done.

On the World Wide Web, information presented by prestigious research institutions exists side by side with self-serving commercial sites and outright scams. A search for information on Attention Deficit Hyperactivity Disorder (ADHD), for instance, might lead to the National Institute of Mental Health (NIMH), which offers a highly informative, 44-page booklet explaining the nature of the affliction, the challenges involved in diagnosing it (and avoiding incorrect diagnoses), and the admittedly imperfect strategies for treating it. But the search also might lead to the Feingold Association of America, which blames the problem on salicylates, artificial colors, and artificial flavors in foods. Without offering a scientific justification, the association also links these substances to numerous other disorders, including poor self control, workaholic habits, nervousness, inability to follow directions, seizures, ear infections, asthma, bedwetting, nightmares, and more.[19]

The NIMH booklet says the cause of ADHD is not known and drugs can treat symptoms but not cure the condition. The Feingold Association, however, offers—for a price—to tell customers how to modify a suffering person's diet to avoid the substances it asserts are at the root of their problems. Unfortunately, while the NIMH report may not be exactly what a worried parent would want to hear, critics claim the Feingold diet has no scientific basis. "Carefully designed experiments fail to support the idea that additives are responsible for such symptoms," asserts Steve Barrett, a doctor and author of the Web site Quackwatch.[20]

As the name of his Web site suggests, Barrett takes aim at what he considers outright quackery. There may be no end to his potential targets. Last year, in the first "International Health Claim Surf Day," 80 agencies and organizations explored the Internet and found 1,200 sites proclaiming mechanical devices that miraculously treat the pain of arthritis, herbal remedies that ward off AIDS, mysterious elixirs that cure cancer, and other potentially false or deceptive advertising health claims. All received warnings from the Federal Trade Commission that advertisers must have reliable scientific evidence to back up their health claims, and that Web site designers may be liable for making or disseminating deceptive or false claims.[21]

Even generally credible sources can convey misleading information. A growing number of health researchers, for instance, rush to publish their findings on the Internet without first undergoing peer review. "Investigators sometimes may be overly enthusiastic about the importance of their observations and even extend their significance beyond what normally would be concluded from the data," the Mayo Clinic warns. "The Web allows rapid dissemination of scientific data, but it cannot replace the value of objective review."[22]

Bad information can keep people from receiving needed treatment, or worse. "A search under depression may lead you to Web sites that list ways of committing suicide," the clinic warns. "Some sites selling herbal remedies suggest throwing out all prescription medications, which, for some conditions such as high blood pressure, may be life-threatening advice." Even if deceptive information does not harm people's health, it can hurt them in their pocketbooks. Americans spend billions of dollars annually on worthless treatments, according to the National Council Against Health Fraud. The council's Web site includes a form people can use to report suspected fraud electronically.

Professional Resistance

Although a growing number of health care providers have started using information tools, the industry as a whole has been slow to adopt computer-networking technology. "The health care industry has barely begun even to grasp its possibilities," *The Economist* wrote in February 1998. In part, the magazine blamed outdated laws, including state licensing of physicians, which it said hinder efforts by doctors to use electronic networks to practice medicine across state lines. Others suggest that health plans are discouraged from investing in information technology because employers insist on short-term savings on employee health benefits.[23]

In addition, technology advocates say, medical schools generally do not use information tools effectively themselves, or teach students how to use them. Computer networks that deliver the latest medical information into clinical settings could enable students to develop basic knowledge, tap into the most up-to-date research findings, and develop clinical skills all at the same time—an approach that many educators believe would lead to deeper and more long-lasting learning. But medical schools usually teach basic, factual knowledge separately from clinical knowledge and skills; students usually spend their first two years in classrooms learning the former, and only then begin their clinical training. As yet, medical schools lack "a solid core of educational ideas about how to use the new media to help people learn," concludes Joseph V. Henderson, director of the Interactive Media Laboratory at Dartmouth Medical School.[24]

Lacking training and basic familiarity with information tools, many physicians have a common reaction to the so-called "information revolution." They are overwhelmed. Earlier in this century, doctors reasonably could be expected to hold all essential medical information in their brains, but that is no longer true, suggests Richard Rockefeller, president of the Health Commons Institute. "If you read two medical journals a night all year, you'll end the year needing 800 more years to catch up on everything that was published since," Rockefeller observed during the 1997 Partnership for Networked Consumer Health Information Conference, which was sponsored by the U.S. Office of Disease Prevention and Health Promotion. The Health Commons Institute, which is based in Maine, promotes the use of computerized information tools in clinical care.[25]

The increased public availability of unfiltered information also can complicate doctors' relationships with patients. Some physicians complain, for instance, about patients coming into their offices armed with misinformation and cockeyed ideas they picked up in chat rooms and obscure Web sites. Lanyard K. Dial, a family physician in Ventura, California, told the *Wall Street Journal* about a 65-year-old patient with a history of heart problems who came into the office one day convinced by downloaded information that he wanted to substitute nutritional supplements for his blood-pressure drugs.[26]

Constraints on Consumers

Consumer-driven reform of the health care system remains more an ideal than a reality. While public disclosure of information on the performance of health providers has proven to be a powerful lever in some cases, market forces generally have been ineffective in producing overall improvements in the quality of care.

In part, that reflects inadequacies in the information available to measure performance. Gaps and inaccuracies are commonplace in the Health Plan-Employer Data and Information Set data, which health plans supply voluntarily and generally are not audited. More fundamentally, experts remain far from certain which measures are the most meaningful indicators of quality. "We have a lot more data than we ever had," says Shoshanna Sofaer, a professor in the School of Public Affairs at the City University of New York's Baruch College. "But we haven't figured out yet what subset of measures tell you the most about the quality of a plan."[27]

In addition, relatively little of the information currently collected actually reaches consumers. Much of the data collected on health-plan performance currently are never disclosed. Of the roughly 650 managed-care plans in the United States, the National Committee for Quality Assurance last year received HEDIS data from fewer than 450 plans, and fewer than half of all plans authorized public release of information. Some plans may be eager to suppress embarrassing information, but others have serious questions about whether existing measures accurately reflect their performance. Particularly vexing is the fact that information specialists have not yet refined techniques for adjusting performance measures to reflect differences in the underlying health of populations that plans serve. Without adequate risk adjustment, quality data could unfairly cast plans that serve groups with more severe health problems in an unfavorable light.

What's more, employers and individual consumers make scant use of the performance data they do have. Only about 40 percent of individual consumers with employer-sponsored health insurance even have a choice of health plans or have seen quality comparisons. And even those who have a choice often do not use performance data in selecting plans. More than half of health consumers, for instance, say they follow the advice of friends and family rather than relying on information from independent organizations like NCQA, according to surveys conducted for the Robert Wood Johnson Foundation Employer Health Insurance Survey, the Kaiser Family Foundation, and the Agency for Health Care Policy and Research.[28]

It may be little wonder, given the lack of stronger incentives, that health providers have been slow to heed performance data. At present, "eighty percent or more of senior managers and physician/nurse providers in the health care sector have accepted the concept of health outcomes measurement as being essential to their operations, but only a small percentage—1 percent to 3 percent—actually use health outcome measurements at the present time," estimates Al Tarlov, president of the Medical Outcomes Trust, a private group that promotes the use of outcomes research.

3

What's Needed

3 What's Needed

A concerted effort will be required to ensure that the information revolution truly produces a health care system that is more effective and equitable. Information specialists, health care professionals, consumers, policymakers, employers, business, the nonprofit sector, community leaders, and others are hard at work addressing the challenges, but they need help.

Trustworthy Information

Numerous efforts are under way to help Internet users find health information that is reliable, and avoid information that is misleading or deceptive. Peer review, generally considered the "gold standard" for ensuring the quality of health care information, is finding its way into some materials aimed at non-experts. The Virtual Hospital, for one, notes pages that have been peer reviewed, and identifies the reviewers by name. But there simply are not enough expert reviewers to keep pace with the enormous and constantly changing supply of information available over the Internet.

One solution is to create trusted gateways to information. The U.S. Department of Health and Human Services, for instance, sponsors healthfinder, a Web site that gathers links to government health agencies, public health and professional groups, universities, medical journals, support groups, and news sites. Relying on gatekeepers is not risk free, however. A 1998 study published by the *Journal of the American Medical Association* identified 47 different online rating services, but it said only 14 disclosed their rating criteria. A 1999 review found an emerging consensus on criteria, however, suggesting that more uniform standards may be possible.[29]

The Health On the Net Foundation, a Switzerland-based nonprofit organization sponsored by Sun Microsystems, the Swiss Institute of Bioinformatics, and the State of Geneva, seeks to raise standards for Web site developers. Its "HON" code commits developers to state the qualifications of people giving advice on their sites, pledge to avoid disrupting existing relationships their visitors have with physicians, maintain confidentiality, cite source material, support any claims with evidence, provide contact addresses for people seeking further information, disclose how their sites are financed, and clearly distinguish between advertising and original material created by site operators. Sites that adhere to the code can display the HON logo, although critics note that the foundation does not actively identify or monitor sites that use its logo.

Concerned that those principles are still too general, the Health Summit Working Group, a gathering of health care professionals, has developed a far more detailed set of criteria for evaluating Web sites. Its approach calls for judging sites according to their credibility, content, disclosure, links, design, interactivity, and whether they include "caveats" reminding users about the potential pitfalls of relying exclusively on the Internet. The group has built its standards into a simple tool that individuals can use to evaluate Web sites themselves. In preliminary tests, volunteer evaluators using the tool ranked Web sites the same as peer reviewers did. The working group hopes to enforce its standards through an army of volunteers, whose ratings it will store in a centralized database. As more and more developers use the tool in deciding about linking to other sites, "poorer sites will fall out," says Helga Rippen, director of the Health Information Technology Institute.

Still, the sheer size and dynamism of the Internet may make it impossible to rely on external ratings of sites. There is increasing interest in an approach that emphasizes disclosure, modeled on the standardized "nutrition label" used on foods. The U.S. Office of Disease Prevention and Health Promotion convened a Science Panel on Interactive Communication and Health to assess opportunities for improving the quality and effectiveness of both stand-alone and Web-based applications. The panel identified specific issues for consumers, developers, policymakers, and health care providers, and prepared a draft evaluation template to promote disclosure of key elements in the design of a given application or site. The panel's report will be published by the government this spring.

Ultimately, the best protection against inaccurate, misleading, and self-serving sources may be in educating users how to judge information for themselves. On this front, librarians, schools, and nonprofit organizations all have important roles to play. Librarians Jan Alexander and Marsha Tate at Widener University, to cite just one example, have developed a useful technique for evaluating Web sites. NetWellness is working with a number of schools to enlist high school students in developing health information for teens—a program that could simultaneously increase knowledge about both health and the nature of Internet-based information services. And the SPRY Foundation has worked with the Department of Health and Human Services and the National Institutes of Health to train senior citizens in information literacy and how to use Internet-based health resources.[30]

Increasing information literacy may not be as difficult as it sounds. One of the only documented studies of patient-to-patient communication on the Web found that people already approach Internet-based information with healthy skepticism: 78 percent of participants said they assumed that 25 percent or more of the information they received through an online epilepsy forum was inaccurate. In fact, the researchers found that only about 6 percent of the messages posted in the forum included "grossly inaccurate" information.[31]

New Roles for Professionals

It will be difficult to realize the full potential of information technologies unless professionals learn new ways of relating to patients and the public.

First, physicians and other professionals must recognize that the days when physicians had exclusive control over health information and could parcel it out to passive patients are over and are unlikely ever to return. With or without professional help, patients increasingly use the Internet to gather information about their health problems. Despite the highly technical nature of many of the articles contained in Medline, for instance, officials at the National Library of Medicine estimate that nonprofessionals conduct about one-third of all searches on the system. Virtual Hospital, which is a bit more user friendly, estimates that as many as 70 percent of its online visits are made by patients, rather than experts. Patients receive information from other sources as well. In 1996, for instance, pharmaceutical companies spent almost $600 million advertising prescription drugs directly to patients.

In this new environment, physicians must develop their own information skills. "Health is a basic human urge, and people thirst for information about their bodies," writes John Gartland, a physician. "If doctors don't satisfy that thirst, people look to newspapers, books, the Internet, and television ads for their information."[32]

Fortunately, the same tools that helped create this challenge offer ways to meet it. They enable health care institutions to corral health information so that doctors and other health care providers can use it to do their jobs more effectively. Massachusetts General Hospital, for instance, has given its neurology residents "Palm Pilots" to carry on their rounds. Doctors use the portable computers to carry patient data, drug references, lab numbers, and other information. And in one of the most comprehensive efforts to bring medical care into the Information Age, Kaiser Permanente, the nation's largest health maintenance organization, plans to spend $1 billion over five years to build a computer network electronically linking its 10,000 doctors and nurses to each other and to the Internet. Besides creating standardized medical records for its nine million members, the system will enable doctors to conduct Medline searches and review the contents of medical textbooks, order tests and prescribe drugs, and provide patients with printouts detailing their treatment plans.[33]

Providing information to professionals at the point where they make important treatment decisions can improve the quality of care delivered. In a 1994 study, medical librarians performed literature searches and forwarded relevant citations to doctors at the time their patients were admitted to three Detroit hospitals. The patients on average had 65 percent shorter hospital stays—and comparably lower hospital bills—than patients in a test group.[34]

"Clinical decisions frequently are made at the point of service," says Michele Klein, director of library services for Children's Hospital of Detroit and one author of the study. "So you have to get the information to where the decisions are made."

More broadly, professionals must help patients make sense of the often-conflicting information they are receiving. In the Information Age, Gartland says, doctors should accept their roles as "patient educators, including helping patients understand the differences between evidence and opinion, science and hype." That may seem inconsistent with the professional self-image of many doctors, but it hearkens back to the medical profession's roots. The word *doctor*, after all, comes from a Latin root, *docere*, which means "to teach."

Experts can play an important supporting role in self-help groups as well as in their relations with individual students. Roger T. Williams, a professor in the Health and Human Issues Department at the University of Wisconsin-Madison, suggests that professionals can serve as guides, enablers, teachers, facilitators, and coordinators. But, he emphasizes, they should not dominate groups. There are important medical, as well as philosophical, reasons for professionals to play a supportive, rather than leading role. Groups owe their success in large measure to the sense of mastery they give people over their illnesses. That advantage can disappear if professionals dominate them. "The process of empowerment lies at the heart of healing," Dr. Tom Ferguson says. "The key to empowerment is to offer tools, skills, information, and support for self-help."[35]

Professionals have much to gain personally from supporting self-help groups. Patients often express thoughts or ask questions in support groups they are reluctant to raise directly with professionals who can be busy and intimidating. John Mangiardi, chief of neurosurgery at Lenox Hill Hospital in New York, had no idea how much his patients were disturbed by unsightly incision scars until he began logging onto discussion groups and heard patients complaining among themselves. Since then, Dr. Mangiardi told the *New York Times*, he has tried to make incisions in less noticeable places.[36]

A new style of medical practice called "shared decisionmaking" illustrates the kind of collaborative relationship the information age can foster. As proponents explain it, shared decisionmaking requires physicians and other experts to explain the risks and trade-offs associated with different types of treatments, but patients themselves must choose which strategy to pursue based on personal priorities and attitudes about risk.

Shared decisionmaking itself is a product of outcomes research and the growing awareness of the limitations of an authoritarian approach to medical care. As various treatments are coming under closer scrutiny, it is becoming clear that often no single,"correct" treatment exists for many medical conditions. Surgery can ease urinary problems caused by benign prostatic hyperplasia, for instance, but it carries a risk of incontinence or impotence; when fully informed of this trade-off, a substantial number of men chose to forego the treatment and adapt a strategy of "watchful waiting." Similarly, hormone replacement therapy can reduce menopause-related discomforts and reduce the risk of osteoporosis and heart disease for women, but it also increases the chances of endometrial cancer, gallbladder disease, migraine headaches, and other side effects.

"There are risks and benefits, and people have to figure out what their priorities are," says Margery Gass, associate professor of obstetrics and gynecology at the University of Cincinnati College of Medicine. Dr. Gass offers advice to Web-based questioners as part of an "Ask an Expert" feature of the NetWellness Web site.

Issues concerning information reliability and shared decisionmaking all came into play when John Wennberg at Dartmouth Medical School launched the nonprofit Foundation for Informed Medical Decision Making. Dr. Wennberg's goal was to facilitate shared decisionmaking. Combining expert reviews of the latest findings of outcomes research with focus group findings on how people confront difficult medical decisions, the Foundation has produced a series of videotapes on which doctors and representative patients explain treatment options and their implications. Studies have shown that people who have viewed the videotapes make decisions about treatment more quickly than others. Because many opt for less invasive procedures, the tapes have reduced health costs. Yet surveys show that patients who use the tapes to make decisions are more satisfied with their care.

"We are moving from a paternalistic, inspect-and-control model to a patient-partner model," says George Bennett, president of Health Dialog Inc., a Boston-based company that markets the videos to health plans as part of a service that also includes a medical reference book for nonexperts and a 24-hour support line staffed by nurses. "It's ethically the right thing to do, and it will reduce costs more than any paternalistic model will." [37]

The idea is catching on. Health Dialog's growing customer base includes Fidelity Investments, the mutual fund company, and Blue Cross & Blue Shield of New Hampshire. Income from the sales will enable the Foundation to add about 40 new topics over the next three years to the 11 currently covered in its video series.

Help for Consumers

People cannot become effective health care consumers without better information to compare the performance of health plans. And even then, consumers may need powerful intermediaries to create an effective retail market for health services.

The federal government, as a major purchaser of health services, has an important role to play. Various federal agencies, including the Health Care Financing Administration, Office of Personnel Management, Defense Department, Veterans Administration, and others, have joined forces to prod health care plans to improve their ability to collect, report, and act on performance data. Chaired by Health and Human Services Secretary Donna Shalala and Labor Secretary Alexis Herman, the Quality Interagency Coordinating Task Force has established working groups to:

- Develop consumer information for patients;
- Identify key opportunities for clinical improvements;
- Determine which of the many emerging quality measures best serve the needs of professional health care providers and consumers;
- Improve the health industry work force in ways that will lead to higher quality service (this group will look specifically at ways to standardize the credentialing process, improve training, and modify working conditions in ways that improve the quality of care); and
- Study what data federal agencies should collect from health care providers and share among themselves to assess quality of care.

Separately, the Clinton administration has helped launch the Forum for Health Care Quality Measurement and Reporting, a private sector effort to standardize quality measurement and reporting. This group, staffed by the United Hospital Fund, is developing a strategy to ensure that comparative information on health care quality is "valid, reliable, comprehensible, and widely available in the public domain." The forum will seek to identify what core data should be used in standardized quality reporting by the health care industry, to propose research priorities, and to support further development of quality measures.

The U.S. Department of Labor also is encouraging development of a stronger consumer market for health coverage. In February 1998, the Department went on record stating that employers have a fiduciary obligation to consider quality as well as price in selecting health plans for employees. The Department also has assembled 70 public and private organizations to conduct a Health Benefits Education Campaign to inform employers and employees about health insurance and related issues.[38]

The private sector also must participate in such efforts. Three private sector organizations have formed a Consumer Health Education Council to inform consumers about the need for health insurance, and provide with them tools for choosing among health plan options.

States too can help improve the quality of consumer health care information. The Maryland Health Care Access and Cost Commission, for instance, audits Health Plan-Employer Data and Information Set data submitted by health plans operating in the state, and then presents its own report card on their performance. The President's Commission on Consumer Protection and Quality in the Health Care Industry has called on foundations and governmental grantmaking institutions to provide seed money for local consumer information initiatives as well.[39]

Employers may hold the key in creating a well-functioning health care market. Many employers currently are unable to offer employees a choice of health plans because of administrative costs, the complexity of plans, and the need to maintain large groups of participants for insurance purposes. But even if they cannot offer more than one option, employers themselves can and must start choosing health plans for their employees on the basis of performance as well as cost. Such efforts almost certainly will bear fruit. Consider the experience of General Motors, one of the few corporate practitioners of so-called value-based purchasing. GM offers its employees a choice of plans, and works hard to inform them about how to select plans on the basis of quality. In the last two years, the number of GM employees who chose plans that executives rated highest in quality rose about 30 percent, while the number participating in the poorest plans dropped 82 percent, according to Bruce Bradley, the company's director of managed care plans.

Still, GM is no believer in the unfettered marketplace. Rather than simply let employees choose among plans, the automaker gives its workers strong financial incentives to select the plans it believes offer the best care. "It is really tough to get consumers to want to understand it and act on it," Bradley explains.

Bradley wishes GM workers would show more interest in comparing plans on the basis of the quality of care they provide, but he sympathizes with their reluctance to trust independent evaluation organizations. In fact, GM itself does not evaluate plans solely according to HEDIS-type data.

Much of its assessment comes from face-to-face meetings with health plan managers, in which company officials make subjective judgments about plans' commitment to quality.

"I cannot put a score on that in a report, but it's really important," says Bradley. "I don't think information is enough."

Reaching the Disadvantaged

To use information technology to reduce rather than increase inequities, the nation needs to commit itself to making health information networks "a public highway," not a "private road," Thomas Eng, Andrew Maxfield, Kevin Patrick, Mary Jo Deering, Scott Ratzan, and David Gustafson argued in the October 21, 1998, *Journal of the American Medical Association.* Achieving universal access, they concede, will involve substantial costs, not only for communications lines, computers, and other hardware, but to develop appropriate software, train users, increase information literacy, and hire essential information helpers such as librarians. But much of the basic infrastructure already exists to deliver health information to people's homes or to public facilities like schools, libraries, community centers, and other public places.[40]

Eng and his co-authors argue that various institutions—employers and health plans, pharmaceutical and other health companies, government, public agencies, and charitable organizations—all should share the cost of achieving universal access. These institutions also could join forces with allied institutions outside the health care field—schools, universities, and economic development agencies—that also have a strong interest in building information networks and training people to use them.

Infrastructure alone won't bring disadvantaged communities into the new health information system, however. Communities and individuals themselves must see the value of the new information tools, and assume ownership of them. Several other strategies could help in this regard.

First, Internet publishers should redouble efforts to tailor health information to the needs of specific audiences. A partnership between NetWellness and the Health Foundation of Greater Cincinnati can serve as a model. The foundation has agreed to finance creation of a "minority health center" on the NetWellness Web site. The center will feature topics—including breast and prostate cancer, hypertension, heart disease, diabetes, and diet—recommended by a Minority Health Community Advisory Board. The center also will address head-on a legacy of distrust planted among African Americans by the infamous Tuskegee experiment, in which the U.S. Public Health Service allowed nearly 400 poor, black sharecroppers with syphilis to go untreated for 40 years. "Despite the tremendous lack of trust in the medical establishment that this experiment created, we must continue to seek ways to empower ourselves to obtain the highest quality health care available," NetWellness says. NetWellness plans additional centers for women, adolescents, seniors, and men.

Creating targeted information costs money, but such expenditures in many cases pay for themselves. Since 1996, Healthwise Communities, Inc., and a group of community sponsors have distributed self-care handbooks to 250,000 residents of a four-county area in Idaho. The project also features specially trained nurses, who provide counseling and in-depth medical information over a toll-free telephone line; additional health information via the Internet and kiosks in libraries, clinics, and community centers; and self-care workshops for health care providers and consumers.

The results are encouraging. A study by Oregon Health Sciences University found that nearly three-quarters of the target population said they had used a health or medical reference book "within the last few months." Of those, 62 percent avoided a visit to a doctor's office, and 33 percent avoided an unnecessary visit to a hospital emergency room. The resulting savings totaled somewhere between $7.5 million and $21.5 million.

In disadvantaged communities, outreach efforts should strive first to connect certain natural information leaders who could become networking advocates. A number of analysts have observed that certain people—sometimes people who work in the health field or in social service agencies, but often just trusted neighbors—serve as invaluable information sources. The late Eva Salber, a professor in the Duke University Department of Community Medicine and mentor to Health Online's Tom Ferguson, once surveyed a disadvantaged urban community of 4,000 residents. She identified about 39 neighbors to whom people repeatedly looked for advice on health matters. In fact, those "natural helpers" provided as many consultations as the doctors in the hospital's emergency room did.[41]

Others have sought to tap this valuable resource. Doctors in an HIV-prevention program in Baltimore map addicts' networks of relationships to identify what *New Yorker* writer Malcolm Gladwell describes as their "mavens." The doctors teach these leaders about HIV prevention information so that they will pass the information on to other addicts. "We need to worry less about asking influential high-profile people to become bearers of the message," says Gladwell. "The most influential groups in generating word of mouth act out of transparent good will, with no self-interested motivation for what they are trying to sell."[42]

The Internet has spawned a whole new breed of "natural helpers"—people like Linda Bowser of Jackson, Mississippi, who used her own painful experience with hip replacement surgery to create "Totally Hip," a Web site devoted to information, practical advice—even jokes—for people in similar situations. Some self-trained patient "experts" are so effective that John Renner, head of the National Council for Reliable Health Information in Independence, Missouri, has proposed creating a new "occupation"—the "board-certified patient."

Several projects sponsored by the federal Telecommunications and Information Infrastructure Assistance Program (TIIAP) are putting new information technologies into the hands of natural information leaders. One grantee, the West Suburban Hospital Medical Center, is installing WebTV units and Internet access in homes of 57 "citizen leaders" so they can obtain and distribute health and safety information to their neighbors.

Similarly, "Making Healthy Music," a TIIAP-supported project in the "New Community" housing development in Newark, New Jersey, installed computers in the homes of a group of neighborhood "captains." The project reduced barriers between the neighborhood and the nearby University of Medicine and Dentistry of New Jersey, and school absenteeism fell as neighbors exchanged information and used the network to launch a number of community improvement projects.

But there are no silver bullets. Pilot projects must find ways to sustain themselves when their grant support ends. The Newark project has been struggling since loss of outside funding two years ago meant it no longer could afford to employ a facilitator. "Without a facilitator to maintain the computers, answer questions, and provide support the project cannot really function," says Pamela Morgan, a project coordinator in the Newark Public Schools.

Existing community networks can provide a cost-effective way to connect disadvantaged communities to online health information networks. The Eugene Freenet in Oregon provides a comprehensive list of resources on its health pages, including a link to White Bird, a program that offers a variety of services to low-income people in the community. Another widely praised community network, Charlotte's Web in North Carolina, also has links to both local and Internet health and human service organizations. Charlotte's Web frequently forms partnerships with local and regional organizations to disseminate information and foster communication. It currently is involved in a joint venture with a local AIDS organization to provide information to institutions, counselors, caregivers, and families of people living with the disease.

Community-Based Action

Ultimately, health is more than an individual concern. As support groups and informal networks demonstrate, individuals generally are healthier when they are part of nurturing communities. New health information networks can help build and sustain such communities, both because they enable communities to understand their health problems more clearly and because they help diverse organizations and individuals build relationships that allow collective action. Consider a few examples:

- In Lane County, Oregon, 30 social agencies are developing a common database that will enable them to piece together information on their disparate encounters with families. By seeing an entire mosaic, officials believe they will be able to identify children at risk of being abused—and get their families help before tragedies occur.

- In Dallas, officials at Parkland Memorial Hospital analyze the addresses of patients at three ambulatory clinics and an emergency room to see where health problems are occurring. Shortly after starting the project in 1986, they observed that a large number of patients came from the same suburban neighborhood. Census data and vital statistics showed the area has pockets of poverty and housing transience. The hospital decided to open a Community Oriented Primary Care clinic to help the neighborhood address its problems.[43]

- In New Jersey, the state Department of Health and numerous hospitals, clinics, and social agencies maintain a centralized immunization registry. Network participants can check the shared database to determine whether patients, many of whom are transient, are keeping up to date with immunizations. The system can generate phone calls or written reminders for families who fall behind their immunization schedule. Data collected from the project showed that up-to-date immunization records drop when children reach 15 months of age, a finding that led some providers to target outreach efforts at families with kids that age.[44]

- In Springfield, Pennsylvania, Crozer-Keystone Health System will provide WebTV technology to link 150 patients to medical and social service providers and to the Internet from their homes. Crozer-Keystone does not plan to use the system to provide medical services to patients in their homes. Instead, it hopes the seniors will be able to connect with a variety of public services so that they can remain healthy and independent—and out of nursing homes—for as long as possible.

Traditionally, public health agencies have led such community-wide, or "population-based" health efforts, providing immunizations, tracking communicable diseases, enforcing environmental health standards, inspecting public establishments such as restaurants, and conducting public education programs aimed at promoting preventive care, nutrition, and healthy lifestyles. All these activities require public agencies to collect data about their communities, organize it, and return it in ways that people can use to promote health. Today, public health departments need encouragement—and funding—to modernize their information systems so they can carry out these important tasks.

This is no easy job. Different constituencies have varying information needs. A multifaceted information system developed by the Missouri Department of Health offers a model for how a public health system can respond to the varying demands. The department maintains a detailed database known as the Missouri Strategic Architecture and Information Cooperative (MOSAIC), which public health nurses and other frontline care providers can use to check such information as whether particular children are up to date on their immunizations. For epidemiologists and research analysts seeking aggregate data upon which to base broad public health policies and strategies, the department maintains a "data warehouse," which brings together data from MOSAIC and other sources. And for community groups, it offers on its Web site a range of general health indicators, such as the frequency of certain health problems among different population groups and the most common reasons people are hospitalized in different communities. The Web site includes a tool called the Missouri

Information for Community Assessments (MICA), which schools, advocacy groups, neighborhood associations, and citizens can use to identify health problems in their particular communities.

One of the biggest information challenges for public health systems in the years ahead will involve obtaining useful data from private, for-profit health care providers. Currently, providers are reluctant to share their data for fear competitors will use it against them, says Nancy Milio, professor of health policy and administration at the University of North Carolina. And when they do share information, it often is either not comparable with data produced by other providers—or worse. "If they report at all, the reporting is incomplete, inaccurate, inept, and in some cases dishonest," Milio says. [45]

At least part of the solution to this problem will be to appeal to the enlightened self-interest of private health care providers. This may be a propitious time to make such an appeal. Several forces are prodding health plans to pay more attention to public health issues. For one thing, health insurers and large purchasers increasingly are expanding coverage for preventive services such as immunizations, mammograms, Pap tests, and counseling. In addition, "capitated" reimbursement arrangements are rewarding health plans that keep patients healthy rather than simply treat ones who are sick. And because Americans frequently change health plans when they change jobs, collaborative projects may offer the best means of delivering preventive care.

In 1994, the American Medical Association and the American Public Health Association launched a joint Medicine/Public Health initiative to encourage closer collaboration between the medical establishment, which traditionally has focused on treating illness, and the public health system, which concentrates on addressing population-wide health issues. That project led to the publication in 1997 of a lengthy monograph, "Medicine and Public Health: The Power of Collaboration," identifying numerous ways that the two sectors can and should cooperate. "Today, professionals and institutions in the two sectors need each other and can help each other—not only in addressing their patients' and populations' health problems, but also in promoting their own professional and economic health," wrote Roz Lasker, the report's author. [46]

According to Lasker, health care providers are learning at least one other lesson from the public health system—namely, that the best health results occur when patients have access to a variety of services, including home visits and referrals to relevant community services and programs, in addition to traditional medical care.

"Health care providers will continue to focus on treating acute conditions, but we are becoming increasingly aware of all the other factors that influence how people manage their health condition—security, nourishment, relationships, access to transportation," notes Edward Baum, vice president for community health at Crozer-Keystone Health System, which is working to connect seniors to the Internet. "Just as important as monitoring the biochemical status of the individual is creating linkages among all the providers of these services and bringing information about them into the homes of seniors."

Still, financial considerations will limit how far health care providers can go in offering a full range of "wellness" care, Baum acknowledges. "I'm sure this is the right thing to do," he says. "But it is probably one or two steps beyond what makes good business sense for us in terms of rapid return." In Crozer-Keystone's case, government is helping to fill the gap; the health plan's Internet-for-seniors project is getting off the ground with funding from the Commerce Department's TIIAP.

This demonstrates that community-wide health projects will require participation and support from community institutions, local governments, nonprofit groups, and charitable organizations. Many such projects already are under way across the country, with numerous groups conducting community assessments, mapping community health problems, and organizing their own health-improvement projects. The Coalition for Healthier Cities and Communities has created a Web site on this budding movement, full of case studies, best practices information, educational materials, links to more than 120 related Web sites, and more.

"The nation is beginning to see health as a byproduct of income, education, intimacy, the environment, and social cohesion—not just medical care," says the coalition's Tyler Norris. "Virtually every health care system has taken a fresh look at its mission and is re-examining what creates health in the first place. Public health is bolstered by a new wave of citizen partnership in their 150-year mandate. Faith communities are linking worship to service, and finding improved health status. Business leaders are recognizing the workplace productivity and economic development benefits of a healthier, more livable community." [47]

In the end, the success of collaborative efforts like these, arising within communities and consisting of numerous cross-cutting partnerships, may be the true test of the American health care system in the Information Age.

4

Afterword: A Foundation of Trust

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A Foundation of Trust

From the managed care revolution to the Internet, the American health care system has seen continuous change for 30 years. What will it look like 30 years from now?

In one vision, information technology will create a seamless system of care. Computerized medical records will carry all pertinent information on the health status of every individual. Doctors, hospitals, and health plans will be able to call up computerized medical records for any individual, ensuring continuity of care for a highly mobile population. Researchers will aggregate data from millions of individual records to produce comprehensive, "real-time" outcomes information for virtually every medical treatment. And the same computer networks that made it possible to create this information will speed it back to doctors and patients in homes and offices where important medical decisions are made.[48]

This future may not be so far away. In a concept paper presented recently to the U.S. Department of Health and Human Services, the National Committee on Vital and Health Statistics described a plan for building a comprehensive National Health Information Infrastructure. This system would serve multiple purposes, such as improving clinical care, monitoring public health, and educating consumers and patients. The human services agency currently is assessing approaches to building such an infrastructure.[49]

While advocates believe such a system holds great promise for enhancing the health of millions of people, Americans are understandably wary. Medical records contain intimate information about individuals' physical conditions, disabilities, mental health, dietary and drug use, recreational habits, sexual practices, and more. In the wrong hands, they could lead to embarrassment, job loss, or even ruined lives.

Diverse corporate entities already engage in "an increasingly complex pattern of health information traffic," according to the National Committee for Vital and Health Statistics. But, note University of Virginia Professors Reid Cushman and Don Detmer, "Given the incentives inherent in our private, risk-based system of health care finance, and the absence of adequate 'data protection' legislation, no country presents as unsafe an environment for health data as does the United States today."[50]

Despite the urgency of this issue, Congress so far has been unable to agree on privacy legislation. But pressures are mounting for action. The federal government will take a step toward addressing this later this year. If Congress has not acted on this issue by August 1999, the Secretary of Health and Human Services is required to issue her own regulations governing the privacy of electronic medical records.

Electronic privacy is a very complex issue, far beyond the scope of this report. Some observations are relevant, however. Substantial work is being done to address the challenge, both by increasing the technical security of computer networks themselves and by adopting audit procedures to prevent possible abuses by institutions and individuals with authorized access to computerized medical records.

But it is difficult to imagine full realization of the dream of a comprehensive health information system without one other element: public trust.

That's where the issues in this report come into play. The agenda described here and the good efforts of the many people and institutions working to achieve it, could lay a foundation of trust on which the information age health care system could be built. If Americans have faith in the information they receive about health, if they believe their health plans are committed to quality care, if the best health services the nation can provide are available to everyone regardless of race or income, and if the health care system is embedded in caring communities, then the promising next stage of the information age can become a reality.

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End Notes

5 End Notes

Endnotes

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6

Resources

6

Resources

This section links you with the sources, programs, and studies mentioned in the report, and suggests additional areas for exploration.

Overview

Bringing Health Care Online:
The Role of Information
Technologies
OTA-ITC-624, U.S. Congress, Office of
Technology Assessment
(Washington, DC: U.S. Government
Printing Office, September 1995)
GPO Stock # 052-003-01433-5
www.wws.princeton.edu:80/~ota/disk
1/1995/9507_n.html

This report discusses the synergy between information technologies and new trends in the health care delivery system as health care is brought online. It identifies some of the opportunities to improve health care delivery through increased use of information technology, and discusses some of the conceptual, organizational, and technical barriers that have made technologyÕs adoption so uneven. The report identifies key technologies and shows how they are being used to communicate clinical information, simplify administration of health care delivery, assess the quality of health care, inform the decision-making of providers and administrators, and support delivery of health care at a distance (telemedicine).

Creating a Health Information
Network: Stage Two of the
Health Care Revolution
David B. Kendall and S. Robert Levine
(Washington, DC: Progressive Policy
Institute, July 16, 1997)
www.dlcppi.org/texts/health/
hinfonet.htm

The authors of this paper argue that Òthe burgeoning use of information technology in health care is creating the opportunity for a smarter as well as a more cost-effective health care system.Ó They propose building a Òhealth information networkÓ in which everyone would have a Òhealth management accountÓ containing their electronic medical records and insurance coverage, performance information for choosing health care providers, and automated notification of new studies that could help with individual medical problems. Individuals could use their accounts through computer networks, toll-free telephone service centers, or printed statements.

The Dartmouth Atlas of Health
Care in the United States
Center for Evaluative Clinical Sciences
Staff (editor)
(Chicago, IL: American Hospital
Publishing Inc., 1998)

This text examines regional variations in medical resources and treatment of various common diseases, and explores how outcomes research and shared decisionmaking between doctors and patients could produce a more rational and fair system. Research was financed in part by the Robert Wood Johnson Foundation. The Atlas is published in cooperation with the Center for Health Care Leadership of the American Hospital Association.

Demanding Medical Excellence:
Doctors and Accountability in
the Information Age
Michael L. Millenson
(Chicago, IL: University of Chicago
Press, 1997)

Millenson, a senior analyst in the health and welfare consulting practice of William M. Mercer, Inc. and former reporter for the Chicago Tribune, explores the emergence and implications of evidence-based medicine. Millenson also summarized many of his ideas in ÒBeyond the Managed Care Backlash: Medicine in the Information Age,Ó (Washington, DC: Progressive Policy Institute, July 1997) www.dlcppi.org/adobe/health.

The Future of the Internet in
Health Care: Five-Year Forecast
Robert Mittman and Mary Cain,
Institute for the Future
California HealthCare Foundation
(Oakland, CA: January 1999)
www.chcf.org/conference/forecast.cfm

This report discusses the driving forces pushing the Internet into health and health care, the barriers that will impede this development, and some of the leading-edge applications.

Health and the New Media:
Technologies Transforming
Personal and Public Health
Linda Harris, editor
(Rahwah, NJ: Lawrence Erlbaum
Associates, 1995)

This book focuses on health delivery, health information, health education, and takes a hard look at whether many of the potential health-promoting uses of new information media will soon be realized for all Americans. It also includes a glossary of computing and networking technology terms.

The Computer-based Patient
Record: An Essential Technology
for Health Care
Institute of Medicine, Elaine B. Steen
and Richard S. Dick, editors
(Washington, DC: National Academy
Press, 1998).

This slightly technical, but seminal work outlines the value of computerized medical data for health care delivery, education, and research.

Journal of the American
Medical Association (JAMA)
October 21, 1998: Vol. 280, No. 15
www.ama-assn.org/sci-pubs/journals/
archive/jama/vol_280/no_15/toc.htm

The Journal of the American Medical Association devoted an entire issue to exploring the way computers and the Internet are affecting medicine. Articles address various themes, including how new technologies affect the ways that physicians learn and communicate with their patients and with each other.

National Library of Medicine
(NLM)
8600 Rockville Pike
Bethesda, MD 20894
Tel: 888.346.3656
www.nlm.nih.gov

NLM is the worldÕs largest biomedical library. Home to MEDLINE, NLM has assumed a leadership role in fostering the development of computer, communication, and audiovisual technologies to improve the collection, dissemination, and utilization of medical information.

Consumer and Patient Information Online

American Board of Medical
Specialties (ABMS)
Public Education Program
47 Perimeter Center East, Suite 500
Atlanta, GA 30346
Tel: 800.776.2378
www.certifieddoctor.org

This service allows the public to search for and verify the board certification status, location by city and state, and specialty of any physician certified by the ABMS.

American Self-Help
Clearinghouse
Behavioral Health Services
Saint ClareÕs Health Services
130 Powerville Road
Boonton Township, NJ 07005-8701
Tel: 888.626.2111
www.cmhc.com/selfhelp

The American Self-Help Clearinghouse lists more than 800 self-help groups in its database. Its Self-Help Sourcebook OnLine (Northwest Covenant Medical Center, 1998) provides links to existing Òreal lifeÓ and online support groups. It also provides a manual for starting your own support group in your community or in cyberspace.

Better Health
170 Fifth Avenue
New York, NY 10010
Tel: 212.206.3190
www.betterhealth.com

Better Health is a supportive and helpful health community with 27 interactive community forums. Members can take the Better Health IQ test, seek support and advice at dozens of message boards, or chat about topics from addictions and allergies to sex and womenÕs health. The site also offers a weekly newsletter covering current health research.

CHESS
Center for Health Systems
Research & Analysis (CHSRA)
1120 WARF Building
610 Walnut Street
Madison, WI 53705-2397
Tel: 608.263.0492
chess@chsra.wisc.edu
chess.chsra.wisc.edu

This interactive, computer-based system to support people facing AIDS/HIV infection and breast cancer demonstrates the potential of new technologies to help people cope with health problems in todayÕs bewildering environment. CHESS, accessible from the safety and privacy of a patientÕs home via the Internet, has also been installed in community centers, health centers, college dormitories, and in the workplace. Participants in the CHESS project who do not have a computer are loaned one for up to a year. By providing information, referrals, support in making tough decisions, and networking to experts and others who face the same concerns, CHESS attempts to increase patient and family sense of control, and empowers patients to be more active participants in their clinical care.

Consumer Health Information
ÒWhite PaperÓ
Kevin Patrick and Shannah Koss,
Consumer Health Information Subgroup
Health Information and Application
Working Group
Committee on Applications and
Technology Information Infrastructure
Task Force
May 15, 1995
nii.nist.gov/pubs/chi.html

In order to better attain good health and make knowledgeable health care decisions, people need accurate and up-to-date health information. This White Paper discusses the appropriate transition to new technologies in consumer health information. In particular, it looks at how the federal government, a provider of a substantial portion of this information, can undertake the transition from predominately paper-based information strategies to the use of the full scope of existing and emerging information technologies. The paper also discusses the role of the federal government as it relates to the wider community of health information providers.

Evaluating Web Resources
Wolfgram Memorial Library,
Widener University
One University Place
Chester, PA 19013
Tel: 610.499.4591
Janet.E.Alexander@widener.edu
(Jan Alexander)
Marsha.A.Tate@widener.edu
(Marsha Ann Tate)
http://www.science.widener.edu/~withers/webeval.htm

Jan Alexander and Marsha Tate, reference librarians at the Wolfgram Memorial Library of Widener University in Chester, Pa., developed a methodology for evaluating Web sites for authority, accuracy, objectivity, timeliness, and thoroughness.

Health Benefits
Education Campaign
U.S. Department of Labor
Office of Public Affairs
200 Constitution Ave., NW
Room S-1032
Washington, DC 20210
Tel: 202.219.8211
www.dol.gov/dol/pwba/public/health.htm

In 1998, the Department of Labor brought together 70 public and private organizations in a campaign to educate American workers about health benefits. The department itself offers brochures on ÒTop 10 Ways to Make Your Health Benefits Work for You,Ó ÒChanges in Your Work Status May Affect Your Health Benefits,Ó and ÒLife Changes Require Health Choices-Know Your Options.Ó The ÒHealth Benefits Education CampaignÓ is modeled after an earlier department campaign to educate workers about pension rights. In both cases, the department was prompted to act by social and economic forces that are causing individuals to assume responsibilities for major life-planning decisions that once were shouldered more by employers.

healthfinder
Office of Disease Prevention and
Health Promotion (ODPHP)
Office of Public Health and Science
Office of the Secretary
U.S. Dept. of Health and Human Services
Hubert H. Humphrey Building
200 Independence Ave. SW
Washington, DC 20201, Rm 738G
Tel: 202.401.6295
Fax: 202.690.7054
healthfinder@health.org
www.healthfinder.gov

Launched April 15, 1997, this Web site is a gateway consumer health and human services information Web site from the U.S. Government. healthfinder provides links to selected online publications, clearinghouses, databases, Web sites, and support groups, as well as government agencies and not-for-profit organizations that produce reliable health-related information for the public.

HealthWeb
1135 East Catherine Street
Ann Arbor, MI 48109-2038
Tel: 734.936.1396
Fax: 734.763.1473
healthweb@umich.edu
healthweb.org

A collaborative project supported by the National Library of Medicine (NLM) and the University of Illinois at Chicago, HealthWeb provides links to noncommercial, health-related Internet-accessible resources. The links, selected by librarians and information professionals at leading academic medical centers in the Midwest, emphasize quality information aimed at health care professionals and consumers.

Healthwise Inc.
2601 N. Bogus Basin Road
P.O. Box 1989
Boise, ID 83702-1289
Tel: 800.706.9646 or 208.345.1161
Fax: 208.345.1897
moreinfo@healthwise.org
www.healthwise.org

Healthwise is a nonprofit producer of health information for consumers. Its electronic Healthwise Knowledgebase contains 28,000 pages of materials that individuals can use in partnership with health professionals to assess the severity and urgency of health problems and determine what level of care they need. In 1996, Healthwise and a variety of community partners launched the Healthwise Communities Project, which sought, in the words of Healthwise President Don Kemper, to Òprove to the world that, fully empowered and encouraged by doctors, patients can improve their health care and lower costs.Ó Self-care handbooks were sent to every home in a four-county area, and individuals also were given access to a nurse advice line, Internet access to health information, health information kiosks in libraries, clinics, and community centers, and self-care workshops for consumers and health care providers.

Healthworld Online
10751 Lakewood Blvd., Suite G
Downey, CA 90241
hwinfo@healthy.net
www.healthy.net

While most Web sites are extensions of existing health care institutions, health publisher Faulkner & Gray calls this Web site Òa new breed of Internet company...created for the sole purpose of using the Internet as a solution for existing problems or deficiencies within health care delivery as well as consumer and professional education.Ó The exhaustive site promotes what it calls Òself-managed care,Ó emphasizing the role of individuals in caring for themselves. It includes a wide range of information resources, products, and services on topics such as fitness, nutrition, alternative medicine, and more. A self-care section includes extensive archives of the writings of Dr.Tom Ferguson, one of the leading proponents of self-care.

HealthyWay
www1.sympatico.ca/Contents/Health/

SympaticoÕs HealthyWay is a good online health and wellness resource for Canadians (and others). HealthyWay has an expansive directory of 9,844 health sites and reviews. Their links include everything from consumer information sites to thousands of U.S. and Canadian governmental agencies and medical associations, and to more than 3,000 health-related newsgroups.

Massachusetts General Hospital (MGH) Neurology Chat Rooms
Massachusetts General Hospital
Department of Neurology
Fruit Street - VBK9
Boston, MA 02114
lester@helix.mgh.harvard.edu
neuro-www3.mgh.harvard.edu/interaction$/chat/index

Massachusetts General Hospital provides chat rooms and bulletin-board-type discussions (where posts are permanently stored on the server) about neurology-related topics. MGH Neurology chat rooms are remarkably easy to access and use, making it a good place for a beginner to start. MGH neurologists periodically host chat sessions on a particular neurological topic. Topics include Epilepsy, Fibromyalgia, Alzheimers Disease, Multiple Sclerosis, RSD (Reflex Sympathetic Dystrophy), and Tourette Syndrome Chat Rooms among many others.

Mental Health Net
570 Metro Place North
Dublin, OH 43017
Tel: 800.467.1482 or 614.764.0143
Fax: 614.764.0362
Webmaster@cmhc.com
www.mentalhelp.net

The oldest and largest online mental health community, Mental Health Net is a comprehensive guide to mental health, psychology, and psychiatry resources. Its index lists more than 9,000 referenced resources. The ÒDisorders and TreatmentÓ page houses an extensive list of support groups that address both physical and psychological conditions.

National Council
Against Health Fraud
c/o William Jarvis, Executive Director
P.O. Box 1276
Loma Linda, CA 92354
Fax: 909.824.4838
www.ncahf.org

The NCAHF is a nonprofit, voluntary health agency that focuses its attention upon health fraud, misinformation, and quackery. As with the Quackwatch site, the NCAHF displays an apparent bias against remedies or practices outside of Òwestern medicine.Ó

NetWellness
University of Cincinnati
2624 Clifton Avenue
Cincinnati, OH 45221
Tel: 513.556.6000
www.netwellness.org

A Web-based consumer health information service developed by the University of Cincinnati Medical Center and many partners, this site offers a wide range of online consumer health information. Health faculty from the University of Cincinnati Medical Center, Ohio State University Medical Center, and Case Western Reserve University School of Medicine develop original content and provide expertise for popular NetWellness features such as ÒAsk an Expert.Ó

Quackwatch
P.O. Box 1747
Allentown, PA 18105
Tel: 610.437.1795
questions@quackwatch.com
www.quackwatch.com

This consumer guide to health fraud and quackery (defined by Merriam Webster as the practices of a pretender to medical skill) provides resources for Òintelligent decision makingÓ on traditional and alternative health topics. The Quackwatch site highlights, researches, and documents misleading health information and advertising found on the Internet.

The Virtual Hospital
200 Hawkins Drive
Iowa City, Iowa 52242
Tel: 319.353.7235
Fax: 319.353.6629
Librarian@vh.org
www.vh.org

This project of the University of Iowa is a model in Web-based health information services for professionals and lay people. Virtual Hospital claims to be the 250th Web site ever developed, and the second site (after the National Library of Medicine) devoted to health. The site contains some 35,000 pages and receives four million ÒhitsÓ per month, 20 percent of them from outside the United States.

Quality of Care

Agency for Health Care Policy and Research (AHCPR)
Executive Office Center, Suite 600
2101 East Jefferson Street
Rockville, MD 20852
Tel: 301.594.6662
info@ahcpr.gov
www.ahcpr.gov

AHCPR, part of the U.S. Department of Health and Human Services, is the lead governmental agency charged with supporting research designed to improve the quality of health care, reduce its cost, and broaden access to essential services. Established in 1989, AHCPR's broad programs of research bring practical, science-based information to medical practitioners and to consumers and other health care purchasers.

"America's Top HMOs"
U.S. News and World Report
Oct. 5, 1998, pp. 64-91
www.usnews.com/usnews/issue/981005/5hmol.htm

U.S. News ranked 271 managed care plans according to data released by the National Committee on Quality Assurance. Other stories in the issue praise some plans for offering particularly good services, and describe how some health plan company executives became so upset by previous U.S. News rankings that they decided against allowing public release of performance data. The Web site also describes in more detail the magazine's system for ranking plans.

Consumer Coalition for Quality Health Care
1275 K Street NW, Suite 602
Washington, DC 20005
Tel: 202.789.3606
Fax: 202.898.2389
www.consumers.org

This national, nonprofit membership organization of consumer groups is dedicated to protecting and improving the quality of health care for all Americans. To fulfill its mission, the Consumer Coalition advocates for consumer protection and quality improvement programs and policies in the public and private sectors.

National Committee for Quality Assurance (NCQA)
2000 L Street, NW #500
Washington, DC 20036
Tel: 202.955.5199
www.ncqa.org

NCQA is a private, not-for-profit organization dedicated to assessing and reporting on the quality of care. NCQA provides information to enable purchasers and consumers of managed health care to distinguish among plans based on quality, allowing them to make more informed health care purchasing decisions. Its Board of Directors includes employers, consumer and labor representatives, health plans, managed care plans, quality experts, policy makers, and representatives from organized medicine.

The National Forum for Health Care Quality Measurement and Reporting
United Hospital Fund of New York
Empire State Building, 350 Fifth
Avenue, 23rd Floor
New York, NY 10118
Tel: 212.494.0722
Fax: 212.494.0823
pbrooks@uhfnyc.org
www.uhfnyc.org/intro/qfpc.htm

The Clinton administration named the United Hospital Fund to direct the planning process for the formation of a new, private sector Forum that will guide the development of a common framework for measuring health care quality and ensure widespread availability of information on quality to the public.

National Guideline Clearinghouse
Agency for Health Care Policy and Research
6010 Executive Blvd.
Rockville MD 20852
Tel: 301.594.4042
Fax: 301.594.4027
info@guideline.gov
www.guideline.gov

A public resource for evidence-based clinical practice guidelines, the National Guidelines Clearinghouse is sponsored by the Agency for Health Care Policy and Research (AHCPR), in partnership with the American Medical Association and the American Association of Health Plans. The NGC site makes available evidence-based clinical practice guidelines and related materials.

President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry
www.hcqualitycommission.gov

President Clinton created this commission in 1997 to "advise the President on changes occurring in the health care system and recommend such measures as may be necessary to promote and assure health care quality and value, and protect consumers and workers in the health care system." The commission's final report, entitled "Quality First: Better Health Care for All Americans," (www.hcqualitycommission.gov/final) describes and documents in detail the quality issues facing the health care system, and proposes a detailed agenda for addressing problems. The Clinton administration has embraced many of its proposals.

Equity and Access

"Bridging the Barriers of Telehealth to Underserved Populations: Barriers and Opportunities"
Neal Neuberger, Louise Arnheim, John C. Scott, and Keith Krueger
Workshop report of the Center for Public Service Communications, Friends of the National Library of Medicine sponsored by the Robert Wood Johnson Foundation, July, 1998 www.fnlm.org/communications/underserved.html

This report examines the unique characteristics and risk factors among children and the elderly, minorities, inner city and rural poor, and persons with disabilities that argue for special consideration during the development and deployment of communications technologies. This workshop sought to identify several broad areas that must be addressed if telecommunications services are to reach these underserved populations in the near future.

National Coalition of Hispanic Health and Human Services Organizations (COSSMHO)
1501 Sixteenth Street, NW
Washington, DC 200036-1401
Tel: 202.797.4341
Fax: 202.797.4353
info@cossmho.org
www.cossmho.org

Focusing on the health, mental health, and human services needs of the diverse Hispanic communities in the United States, COSSMHO's membership consists of thousands of front-line health and human services providers and organizations. COSSMHO attempts to connect communities and create change to improve the health and well-being of Hispanics in the United States.

National Medical Association
1012 Tenth Street, Northwest
Washington, DC 20001
Tel: 202.347.1895
Fax: 202.842.3293
www.nmanet.org

Founded in 1895, the National Medical Association (NMA) is the collective voice of African American physicians. NMA is also a leading force for parity and justice in medicine and the elimination of disparities in health. To these ends, the NMA supports efforts that improve the quality and availability of health care to poor and underserved populations.

Office of Minority Health Resource Center
PO Box 37337
Washington, DC 20013-7337
Tel: 800.444.6472
Fax: 301.589.0884
www.omhrc.gov

The Department of Health and Human Services Office of Minority Health established the Office of Minority Health Resource Center in 1987. The OMH-RC serves as a national resource and referral service for minority health issues. OMH-RC maintains comprehensive databases on a wide variety of health topics affecting minority populations. One database includes extensive information on funding and grant resources that can help support minority health projects.

Tribal Connections in the Pacific Northwest
Tel: 206.543.8262
rs@u.washington.edu
(Roy Sahali, Project Manager)
www.tribalconnections.org

With special funding from the National Library of Medicine, the Regional Medical Library (RML) at the University of Washington has provided assistance to 16 tribes and Native villages in Alaska, Idaho, Montana, Oregon, and Washington. The goal of the project is connecting the tribes to the Internet with the aim of providing access to health information.

Community and Public Health

American Health Decisions
c/o Wisconsin Health Decisions
P.O. Box 35 Menomonee Falls, WI
53052-0035
Tel: 414.832 6702
Fax: 414.832 6767 att: Gretchen
Bambrick, Library #201
John.M.Stanley@lawrence.edu
(Jack Stanley, Ph.D., Chair)
www.ahd.org

American Health Decisions is a national coalition of citizens groups that seek to address ethical issues in health care and to empower individuals to participate in policy decisions and personal choices affecting their own health care. The coalition grew out of Oregon Health Decisions, a group that helped organize citizen deliberations that led to adoption of the Oregon Health Plan, which sets priorities for spending Medicaid funds within the state. A number of recent efforts to develop public ideas about health care have focused on end-of-life decisionmaking.

CareWeb
Syracuse University College of
Nursing
426 Ostrom Avenue
Syracuse, NY 13244-3240
Tel: 315.443. 4272
sumweb.syr.edu/nursing/careweb/

CareWeb is a school-based health care program designed to provide an integrated, coordinated system of health care for children and their families using the combined resources of school nurses, nurse practitioners, and pediatricians supported by information technology. Developed first in a group of pilot schools in Syracuse, New York, the system can be expanded to include the entire school district and is equally applicable in other urban and rural settings.

Charlotte's Web
119 E. Seventh St.
Charlotte, NC 28202
Tel: 704.332.1610
shsnow@charweb.org
(Steve Snow, Executive Director)
www.charweb.org

Charlotte's Web is a regional community network in Charlotte, North Carolina. In addition to affordable Internet access, the service provides low-cost community training courses, and local community information terminals. The Charlotte's Web site also has links to both local and Internet health and human service organizations and is currently involved with a joint venture with local AIDS organizations to provide AIDS information.

Coalition for Healthier
Cities and Communities
c/o HRET
1 North Franklin
Chicago, IL 60606
Tel: 312. 422.2618
Fax: 312.422.4568
www.healthycommunities.org

This Web site provides news, resources, tools, and numerous case studies about multi-sector initiatives seeking to improve community health. The Web site includes "Healthy Communities: A Guide for Community Leaders," which discusses how to build integrated health-improvement systems.

Community Tool Box
The Work Group on Health Promotion and Community Development
University of Kansas
4082 Dole Center
Lawrence, Kansas 66045
Tel: 785.864.0533
Fax: 785.864.528
ctb.lsi.ukans.edu/wg/

The University of Kansas Work Group on Health Promotion and Community Development prepared this wide-ranging collection of tools on leadership, strategic planning, community assessment, advocacy, and grantwriting aimed at promoting community health and development. The site includes numerous links to resources on funding, health, education, and community issues.

Crozer-Keystone Health System
Mr. Edward Baum
100 West Sproul Road
Springfield, PA 19064
Tel: 610.338.8234 or 800.560.2448
ebaum@crozer.org
www.crozer.org

Crozer-Keystone Health System, in partnership with three local senior service agencies, will pilot a telemedicine network for 150 elderly patients. Patients' homes will be equipped with WebTV technology linking them to medical and social service providers and to the Internet.

Engines of Empowerment: Using Information Technology to Create Healthy Communities and Challenge
Nancy Milio, Ph.D.
(Chicago, IL: Public Policy Health Administration Press, 1996)

This book shows how information technologies can be used to deliver health services and create healthier communities. Case studies involving different types of organizations and communities, populations, and purposes illustrate the possibilities and potential pitfalls of using information technology to deliver health care services. Included are recommendations for building a national technology policy that encourages healthier communities.

Every Block A Village
West Suburban Hospital Medical Center
Erie at Austin
Oak Park, IL 60302
Tel: 708.763.6905
doc.masc@wshmc.org (Mr. Christopher Masi MD, Project Coordinator)
www.wshmc.org

The West Suburban Hospital Medical Center will provide 57 "citizen leaders" with WebTV units and Internet access in their homes so they can obtain and distribute health and safety information to community residents. Other community members will also have access to a local Wellness Center home page (and the Internet as a whole) at the PCC Community Wellness Center.

For the Record: Protecting Electronic Health Information
Computer Science and
Telecommunications Board
National Research Council
(Washington, DC: National Academy Press, 1997)

For the Record explores ways of protecting the privacy and security of health information as it is increasingly recorded and used in an electronic form. The book addresses different privacy concerns and makes recommendations for steps that can be taken to help protect privacy, while ensuring adequate access to information for the purposes of care.

A pre-publication version of the book is available at www.nap.edu/readingroom/books/ftr.

Health and Medicine Resources, Eugene Freenet (EFN)
Oregon Public Networking
448 Charnelton St.
Eugene, OR 97401
Tel: 541.484.9637
useracct@efn.org
db.efn.org/community/health.html

This comprehensive list of local resources includes a link to White Bird, a program that offers a variety of services to low-income people in the community. There is also an extensive list of health and medicine Web sites. Because EFN makes the Internet accessible through local community centers, this site is a vitally important health resource for communities in Eugene.

Join Together
441 Stuart Street, 7th Floor
Boston, MA 02116
Tel: 617.437.1500
Fax: 617.437.9394
info@jointogether.org
www.jointogether.org

Join Together is a national resource for communities fighting substance abuse and gun violence. A project of the Boston University School of Public Health, it is funded by grants from the Robert Wood Johnson and Joyce Foundations. Join Together Online provides technical assistance designed to link people nationwide so they can share information and resources, and learn from one another in an effort to keep their communities free of drugs and violence.

Making Healthy MUSIC
Newark Public Schools
2 Cedar Street
Essex, NJ 07102
Tel: 201.733.8290
pamela@music.umdnj.edu
(Pamela Morgan, Director)
music.umdnj.edu

In 1994, the Newark Public Schools set out to install a computer network to link people who live in New Community with professionals at the nearby University of Medicine and Dentistry of New Jersey. Funds from the U.S. Department of Commerce's TIIAP grant program were used to install computers at a local school and in the homes of a group of neighborhood "captains."

Medicine and Public Health: The Power of Collaboration
Roz D. Lasker
(New York, NY: New York Academy of Medicine, 1997)
www.nyam.org/pubhlth/medpub.html

Since World War II, medical practice and public health have circled each other like alienated siblings, the former concentrating on serving individual patients and the latter on addressing the health needs of entire populations. Lasker, director of the Division of Public Health for the New York Academy of Medicine, describes how medical practitioners are starting to adopt more of the strategies of the public health system in response to changes in the financial structure of the health care system and the resulting emphasis on preventive care. This178-page monograph describes how greater cooperation across the two sectors will enhance health and offers numerous examples of collaborations. The report comes out of a Medicine/Public Health Initiative (www.sph.uth.tmc.edu/mph) launched by the American Medical Association and the American Public Health Association in 1994.

Missouri Information for Community Assessment (MICA)
Missouri Department of Health
920-930 Wildwood
P.O. Box 570
Jefferson City, Missouri 65102-0570
Tel: 573.751.6001
Fax: 573.751.6041
www.health.state.mo.us/MICA/nojava.html

A multifaceted information system developed by the Missouri Department of Health, MICA is a tool that schools, advocacy groups, neighborhood associations, and citizens can use to identify health problems in their particular communities. The Web site provides information on a range of general health indicators, such as the frequency of certain health problems among different population groups and the most common reasons people are hospitalized in different communities.

Models That Work
c/o PSA, Inc.
6066 Leesburg Pike, Suite 200
Falls Church, VA 22040
feedback@hrsa.dhhs.gov
www.bphc.hrsa.dhhs.gov/mtw/mtw.htm

The Health Resources and Services Administration of the Department of Health and Human Services conducts an awards program to recognize programs or health systems that document outcomes, accomplishments, or creative approaches to increasing primary-care access. This Web site lists winning programs and explains how they were developed, financed, organized, and carried out.

New York Online Access to Health (NOAH)
City University of New York
555 W. 57th St., 16th Floor
New York, NY 10019
Tel: 212.541.0340
Fax: 212.541.0357
kidbh@cunyvm.cuny.edu
www.noah.cuny.edu

NOAH brings health information to an underserved population of consumers, many of whom are Spanish-speaking. Resources about several different health topics, ranging from aging to tuberculosis are available in both English and Spanish. NOAH's bilingual service is available in 100 partner libraries throughout New York City's five boroughs and Westchester County, and from additional sites on the CUNY campuses.

Parkland Community-Oriented Primary Care Clinics
Parkland Memorial Hospital
5201 Harry Hines Boulevard
Dallas, TX 75235
spicke@parknet.pmh.org
www.swmed.edu/home_pages/parkland/copc/copc.html

The Parkland Memorial Hospital decided to decentralize and move its high-volume primary care practice to community-based centers called Community-Oriented Primary Care (COPC) clinics. The clinics were designed to assess and treat both the community and the patient. Key to the creation of effective COPCs was the analysis of population data: knowing a market, the health needs that could be addressed by clinical or community programs, and the clinical staffing requirements. The hospital employed such population sciences as demography, epidemiology, and sociology, among others, to analyze the effects of socioeconomic factors and health utilization on its clinical practice needs.

State Offices for Services to Children and Families Child Abuse Multidisciplinary Intervention (CAMI)
500 Summer Street, NE
Salem, OR 97310
Tel: 503.945.5691
richard_l_schoonover@state.or.us
www.scf.hr.state.or.us/famsermultidisciplin.htm

Oregon State's Offices for Services to Children and Families has implemented a statewide image communications system to transmit medical images over standard telephone lines. Using the system, health care providers in remote areas of the state can consult with qualified medical experts on suspected child abuse cases.

Statewide Immunization Information System (NJ) State of New Jersey Department of Health and Senior Services
CN 360, P.O. Box 369
Trenton, NJ 08625
Tel: 609.588.7512
Fax: 609.588.7431
jd3@doh.state.nj.us
www.state.nj.us/health/cd/vpdphome.htm

The New Jersey State Department of Health, along with numerous hospitals, clinics, and social agencies, maintains a centralized immunization registry. Network participants can check the shared database to determine whether patients, many of whom are transient, are keeping up to date with immunizations. The system can generate phone calls or written reminders for families who fall behind their immunization schedule.

Related Organizations

American Medical Informatics Association (AMIA)

4915 St. Elmo Avenue, Suite 401
Bethesda, MD 20814
Tel: 301.657.1291
Fax: 301.657.1296
www.amia.org

AMIA is a nonprofit membership organization dedicated to the development and application of medical informatics in the support of patient care, teaching, research, and health care administration. In addition to a bimonthly journal, AMIA publishes reports and studies that examine the development of modern medical information systems, offering background and perspective on persistent challenges in the field of medical informatics.

The Federal Telemedicine Gateway

www.tmgateway.org

Sponsored by the Department of Defense and developed by a collaboration of federal agencies engaged in telemedicine activites, the Federal Telemedicine Gateway contains: information on active, federally funded telemedicine projects throughout the United States, and links to other telemedicine resources, activities, and databases.

Health Care and the FCC

www.fcc.gov/healthnet

The Federal Communications Commission hosts this page of resources about federal communications efforts in health care. The FCC has information about telehealth and TV related health issues. Through the Universal Service Administration, the FCC is encouraging the growth of telehealth in rural areas by making telecommunications rates for public and nonprofit rural health care providers comparable to those paid in urban areas.

Healthcare Open Systems & Trials (HOST)

444 North Capitol St.
Washington, DC 20001-1512
Tel: 202.434.4771
Fax: 202.434.4766
info@hostnet.org
www.hostnet.org

HOST is a nonprofit consortium created in 1994 to promote the development of information technology to improve healthcare. HOST members cooperate on a variety of innovative projects. Goals include acceleration toward the adoption of computer-based patient records, encouraging the development of open architecture, and the promotion of movement toward community-wide networks for health care information.

Health Information Technology Institute (HITI)

Mitretek Systems
13526 George Road, Suite 200
San Antonio, Texas 78230
Tel: 210.479.0474
hiti@mitretek.org
hitiweb.mitretek.org

Mitretek Systems, a nonprofit information technology and environmental management organization, established HITI to seek innovative technology solutions to ensure quality health care. HITI was instrumental in convening the Health Summit Working Group (hitiweb.mitretek.org/hswg), whose 1997 paper, "Criteria for Assessing the Quality of Health Information on the Internet" (hitiweb.mitretek.org/docs/criteria.html) represents a comprehensive guide that Web site developers and evaluators can use in to ensure the reliability of Internet-based health information. HITI also developed IQ, or "Information Quality," a tool Internet users can use to assess the quality of health-related Web sites while viewing them.

Health on the Net Foundation c/o Health On the Net Foundation
1211 Geneva 14
Switzerland
Tel: 41.22.372.61.81
Fax: 41.22.372.61.98
Info@hon.ch
www.hon.ch

Health on the Net Foundation (HON) is a nonprofit organization headquartered in Geneva, Switzerland. Dedicated to realizing the benefits of the Internet, the Foundation's site facilitates access to support communities, medical resources, health care news, health databases, and other support systems for individuals, professionals, and health care providers. The HON Foundation has developed the HONcode, a code of conduct for medical and health Web sites, to help ensure the reliability and credibility of medical and health information on the Internet.

National Committee for Vital and Health Statistics
Office of the Assistant Secretary
for Planning and Evaluation, DHHS
Humphrey Building, Room 440-D
200 Independence Avenue, SW
Tel: 202.690.7100
Fax: 202.690.5882
aspe.os.dhhs.gov/NCVHS

This panel of 18 experts advises the Secretary of Health and Human Services on issues involving health data and privacy. Its paper, "Assuring a Health Dimension for the National Information Infrastructure," (aspe.os.dhhs.gov/NCVHS/hii-nii.htm) explores the potential of the new information infrastructure to improve clinical care, monitor public health, and educate consumers and patients. The panel asserts, however, that this potential so far is "largely untapped."

Partnership for Networked Consumer Health Information Conference
National Health Information Center
P.O. Box 1133
Washington, DC 20013-1133
nhicinfo@health.org
odphp.osophs.dhhs.gov/confrnce

The first conference on Partnerships for Networked Health Information for the Public, held in 1995, started the process of identifying parties who have an interest in networked health information. These meetings bring together leaders from government, industry, health, libraries, nonprofit organizations, and others who are involved in the delivery of health information. Transcripts of the conference proceedings are now available are online.

Robert Wood Johnson Foundation
Route 1 and College Road East
PO Box 2316
Princeton, NJ 08543-2316
Tel: 609.452.8701
mail@rwjf.org
www.rwjf.org

The Robert Wood Johnson Foundation, which provided funding for this report, seeks to improve the health and health care of all Americans. Among the specific goals of its grants programs are to assure that Americans of all ages have access to basic health care, and to help the nation address the problem of escalating health care expenditures effectively and fairly. About three-quarters of the Foundation's $170 million in annual grants take the form of national programs and organized, multisite efforts to implement proven strategies or develop new approaches to problems.

Science Panel on Interactive Communications and Health
Office of Disease Prevention and Health Promotion
U.S. Department of Health and Human Services
Room 738G
200 Independence Avenue, SW
Washington, DC 20201
scipich@health.org
www.scipich.org

The Office of Disease Prevention and Health Promotion of the U.S. Department of Health and Human Services convened this panel of 14 national experts on interactive technologies and health, including medicine, human-computer interaction, public health, communication science, educational technology, and health promotion. Its Web site includes a template for evaluating interactive health communications tools, as well as some useful tips for evaluating the reliability of Internet-based health information.

Telemedicine Information Exchange (TIE)
Telemedicine Research Center (TRC)
2121 SW Broadway, Suite 130
Portland, OR 97201
Tel: 503.221.1620
Fax: 503.223.7581
tie@telemed.org
tie.telemed.org

A comprehensive online source of information about telemedicine from the Telemedicine Research Center (TRC). TRC is dedicated to telemedicine research and education, as well as the creation, management, and dissemination of information about telemedicine and telemedicine-related activities.

TIIAP
Telecommunications and Information Infrastructure Assistance Program
Office of Telecommunications and Information Applications
National Telecommunications and Information Administration
U.S. Department of Commerce
1401 Constitution Avenue, NW, Room 4096
Washington, DC 20230
Tel: 202.482.2048
Fax: 202.501.5136
tiiap@ntia.doc.gov
www.ntia.doc.gov/otiahome/tiiap

The Telecommunications and Information Infrastructure Assistance Program (TIIAP) is a highly-competitive, merit-based grant program that brings the benefits of an advanced national information infrastructure to communities throughout the United States. TIIAP provides matching grants to nonprofit organizations such as schools, libraries, hospitals, public safety entities, and state and local governments. Grants are used to fund projects that improve the quality of, and the public's access to, education, health care, public safety, and other community-based services.

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