

MARKLE FOUNDATION

December 7, 2006

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AMERICANS SEE ACCESS TO THEIR MEDICAL INFORMATION AS A WAY TO IMPROVE QUALITY, REDUCE HEALTH CARE COSTS

Survey shows that consumers view personal health records as an important element in reducing medical errors and increasing quality of care

Key role for government in protecting privacy, setting guidelines for sharing data

Washington, D.C. — Americans overwhelmingly want to have electronic copies of their medical records and believe that having greater access to their information will reduce medical mistakes and costly repeat procedures, according to a new survey commissioned by the Markle Foundation.

But eight in 10 Americans are very concerned about identity theft or fraud and the possibility of their data being used by marketers without their permission – with three-quarters of those surveyed saying the government has a role in establishing privacy and confidentiality protections for electronic health information.

The findings will be released tomorrow at the *Connecting Americans to Their Health Care* conference in Washington, D.C. The second annual conference will focus on advances in personal health technology, with discussion of the critical role of patients and their families in efforts to modernize and reform health care.

“Americans understand that quality of care could improve and costs decrease when their health information is available over the Internet to them and those who care for them. And they are clearly ready to do their part to improve our health care system,” said Zoë Baird, president of the Markle Foundation, which funded the research. “But consumers also have significant privacy concerns which must be addressed if we are to have sufficient consumer confidence to support a national commitment to electronic health records. People expect the federal government to establish rules that protect electronic personal health information from being used inappropriately.”

The survey, conducted by bipartisan polling firms Lake Research Partners and American Viewpoint, shows that:

- 97 percent think it’s important for their doctors to be able to access all of their medical records in order to provide the best care;
- 96 percent think it’s important for individuals to be able to access all of their own medical records to manage their own health;
- Two in three Americans (65 percent) would like to access all of their own medical information across an electronic network. This interest spans demographic groups – with a majority (53 percent) of Americans 60 and older and high proportions of minority groups expressing interest;
- When given the scenario of changing doctors or moving to a different city, an even greater majority – 84 percent – said it would be important for them to have electronic copies of their medical records that they keep and control; and
- Three-quarters of Americans are willing to share their personal information to help public officials look for disease outbreaks and research ways to improve the quality of health care if they have safeguards to protect their identity.

The survey shows that large majorities of Americans see a number of benefits from accessing their medical information online. Consumers say they want access to their medical information in order to ensure that it's accurate, to improve doctor-patient communications and to help prevent medical errors.

- 91 percent say it's important to review what their doctors write in their chart;
- 88 percent say online records would be important in reducing the number of unnecessary or repeated tests and procedures they undergo;
- 82 percent want to review test results online; and
- 84 percent would like to check for errors in their medical record.

Americans also see ways in which they could gain more control over their health care by making use of personal health records:

- 90 percent say it would be important to track their symptoms or changes in their health online;
- 83 percent of parents would be interested in using a network to track their child's health, such as tracking dates for immunizations; and
- 68 percent say having their information available online will give them more control over their own health care.

"It is encouraging to see that so many Americans recognize the opportunity to improve their health care – and their own health – by accessing and using their health information," said Carol Diamond, M.D., managing director of the Markle Foundation Health Program. "People not only want to see their medical records, they want to use the information to communicate with their doctors and be more involved in managing their care."

While the survey notes high recognition of the benefits made possible by accessing personal health information electronically, most respondents express concern that their medical information could be misused:

- 80 percent say they are very concerned about identify theft or fraud;
- 77 percent report being very concerned about their medical information being used for marketing purposes;
- 75 percent say the government has a role in establishing rules to protect the privacy and confidentiality of online health information;
- 66 percent say the government has a role in establishing rules by which businesses and other third parties can have access to personal health information; and
- 69 percent say the government has a role in encouraging doctors and hospitals to make their personal health information available over the Internet in a secure way.

"Despite the overwhelming interest in being more active participants in their own health care, and having their medical information available online to themselves and their physicians, Americans have very serious concerns about the privacy and security of their medical information," said David Lansky, Ph.D., senior director of the health program at the Markle Foundation. "People want to have control over whether their data are used for non-medical purposes and expect the government to establish rules that will protect them."

Connecting for Health, a Markle-operated collaborative group of more than 100 organizations, also released a new white paper at the conference to stimulate national discussion on the use of information technology to meet the critical needs of consumers, patients, and their families. The report describes a networked health information environment in which consumers could establish secure connections with multiple entities that hold personal health information about them.

"It is difficult for a consumer to manage her personal health information since it is scattered among various organizations such as insurance companies, pharmacies, hospitals, etc.," Lansky said. "Several projects are currently underway to deploy personal health records, which are designed to help individuals manage their

electronic personal health information. But because our health care system is so fragmented, and your health information is typically held by many unconnected entities, these electronic applications today struggle to provide a convenient way for consumers to access all of their data."

The paper begins with a brief discussion of how consumer participation in networked environments has transformed other sectors, such as travel and finance. It contends that the health care sector would benefit greatly from a properly designed secure network that enables consumer participation.

To view today's research, go to www.phrconference.org or www.markle.org.

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The Markle Foundation (www.markle.org) works to accelerate the use of technologies to address critical public needs, particularly in the areas of health care and national security. The Markle Foundation Health Program is committed to accelerating the ability of patients and consumers to use information technology to improve their health and health care, while protecting patient privacy. The Markle Foundation envisions a time in the near future when individuals will be able to gain access to their own health information through nationwide electronic health information exchange, personal health records, and other emerging technologies, making it possible for patients to participate more fully in their own health care.