

THE PROMISE OF

Electronic Health Information Exchange:

A LIVESTRONG REPORT

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ACKNOWLEDGEMENTS

LIVESTRONG wishes to thank the more than 10,000 individuals who participated in this online survey and shared their perspectives on electronic health information exchange.

LIVESTRONG also wishes to thank Dr. Susan Love's Army of Women and the Cancer Support Community for helping to share the word about this survey.

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Background
and Methods

The old ways of maintaining health records are changing. Soon, individuals' records will be stored and updated electronically. But who decides how these records will be used? What are the safest ways to store this information? Can safe, electronic health records improve individual health, and the health of the nation as a whole?

Decisions are being made now about how electronic health information is stored and shared. At **LIVESTRONG**, we believe that the safe and effective adoption of electronic health records and the electronic exchange of health information can have tremendous potential to enhance the quality of care, engage patients in clinical decisions, and facilitate research for improved health outcomes.

Individuals affected by cancer could benefit greatly from electronic health information exchange because of its capacity to improve care coordination and increase quality of care. Take, for example, the experience of one **LIVESTRONG** constituent:

My mother died of breast cancer after a six-year battle . . . It often seemed that no one would take responsibility for her care and many times seemed that people didn't bother to go through her lengthy history before coming in to see her. I think having all of her history in one place, organized and easily accessible by all involved, may have helped. It also would've been nice to be able to get all of her test results, etc. in one place for my aunt, my sister and me to have and refer to.

The situation described above is not unusual: Cancer care is often complex, involving multiple providers and the introduction of new and different treatments over time. **LIVESTRONG** believes in the promise of electronic health information exchange to help improve such multifaceted care. We believe that people affected by cancer should be empowered to make well-informed decisions based on facts and data. That is the foundation of patient-centered care, and it is why ongoing debates about electronic health information exchange are so critical to us. As other companies, government agencies, and groups are exploring how best to adopt electronic health records, we want the voices of people affected by cancer to be heard. To better understand what people affected by cancer think about electronic health information exchange, **LIVESTRONG** fielded a survey from April until August 2010.

The survey instrument included relevant items from the National Cancer Institute's 2007 Health Information National Trends Survey (<http://hints.cancer.gov>), the Centers for Disease Control and Prevention's 2010 Behavioral Risk Factors Surveillance System (<http://www.cdc.gov/brfss>), and questions developed by **LIVESTRONG** researchers. The online survey was advertised and fielded via **LIVESTRONG** Facebook, Twitter and email; Dr. Susan Love Research

Foundation's Love/Avon Army of Women Program; and the Cancer Support Community.

The survey included both qualitative and quantitative questions that addressed the value attached to electronic health information exchange and access, perceptions of privacy and safety related to electronic health information, the importance of different functional capabilities for Electronic Health Records (EHR) and Personal Health Records (PHR), and opinions about the effect of electronic health information exchange on quality of care. For the purpose of this survey, an EHR was defined as a real-time patient health record that provided doctors and other health care providers with access to evidence-based tools that can be used to support clinical decision making. A PHR was defined as an electronic application through which an authorized individual can maintain and manage personal health information in a private, secure, and confidential environment (Office of the National Coordinator for Health Information Technology, 2010).

LIVESTRONG has shared the results of this survey with the clinical oncology community, members of the cancer research community, policymakers, and other key stakeholders. Specifically, presentations have been made at the 2010 American Society of Clinical Oncology Annual Meeting, the 2010 Biennial Cancer Survivorship Research Conference, and the Institute of Medicine's *Electronic Infrastructure for the Learning Healthcare System* workshop. The intent of this report is to provide a public summary of the results for people affected by cancer and other interested parties. We plan to continue to analyze and share the data through other mechanisms in the future as well.

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Results

Between April and August 2010, 10,810 individuals started the survey and 8,371 who have some connection to cancer finished the survey. The latter group was used for the analysis in this report.

Please note that the survey respondents are not necessarily representative of the general cancer population, as this sample was drawn largely from the voluntary constituents of nonprofit organizations and the survey was administered entirely online.

DEMOGRAPHICS AND CONNECTION TO CANCER

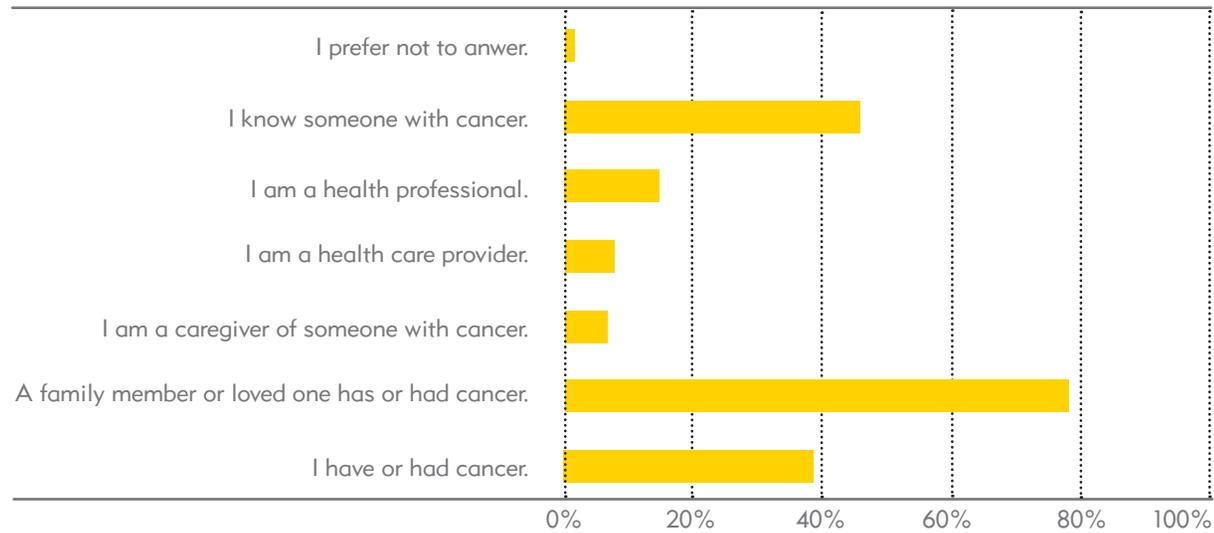
The majority of respondents were female (62%) and reported white race/ethnicity (91%). Most respondents (68%) were between 40 and 64 years old. Additionally, nearly all (94%) reported to have health care coverage (including health insurance, prepaid plans such as HMOs, or government plans such as Medicare).

The majority of respondents indicated that they have a family member or loved one who has or had cancer. Of the 3,177 individuals who indicated that they have or had cancer, the majority (74%) indicated that they have finished treatment for cancer (**Figure 1**).

USE OF ELECTRONIC INFORMATION

While more than two-thirds of respondents had used online tools for a specific health-related purpose (e.g., weight management), fewer than half had used the Internet to look for a health care provider, and only about one-third had used online functionalities typical of a PHR (such as keeping track of test results) (**Table 1**).

FIGURE 1: Connection to Cancer



Please note individuals were able to select more than one way that they were connected to cancer.

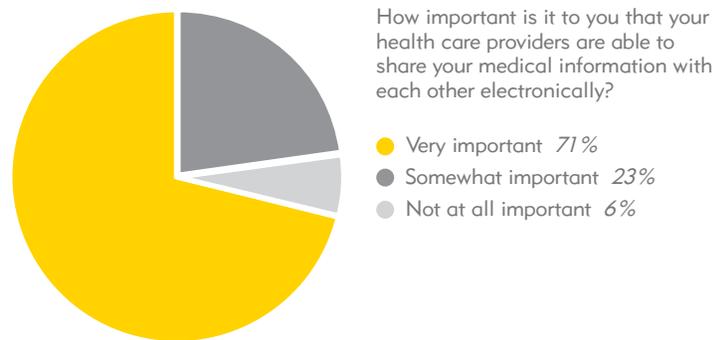
TABLE 1: Health-Related Internet Usage

In the past 12 months, have you done the following things while using the Internet?	
Used a website to help with your diet, weight, or physical activity?	67%
Looked for a health care provider?	44%
Kept track of personal health information, such as care received, test results, or upcoming medical appointments?	36%

IMPORTANCE OF SHARING MEDICAL INFORMATION ELECTRONICALLY

Though few respondents had engaged with electronic health information, the majority attached value to electronic health information exchange: 71% indicated that it is “very important” that health care providers are able to share medical information electronically (**Figure 2**).

FIGURE 2: Electronic Health Information Exchange Among Health Care Providers

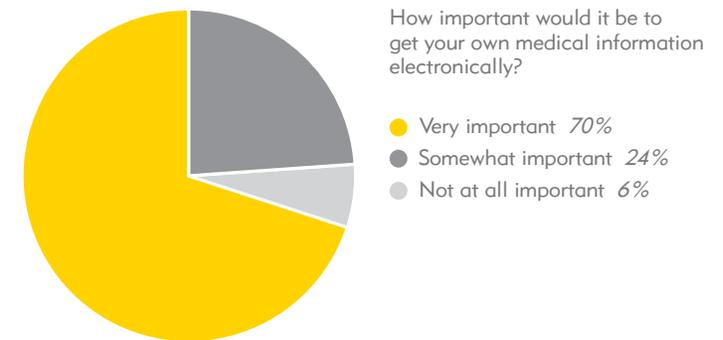


One respondent noted the potential importance of sharing information between providers, writing:

I am tired of filling out forms each time I go to another doctor. I think the doctor would have faster access to the patients' information. Too often it is buried in tons of tests, previous visits, etc. The average doctor today doesn't have the time to sift through all that paper. Things get overlooked. The electronic form could be organized and in an easy-to-read format for the doctor and the patient. Each doctor could see what the other specialist had suggested or prescribed.

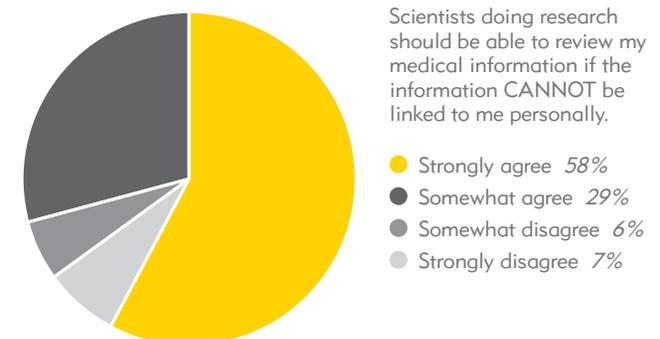
Similarly, the majority of respondents indicated that it is “very important” that they be able to access their own medical information electronically (**Figure 3**).

FIGURE 3: Personal Access to Electronic Medical Information



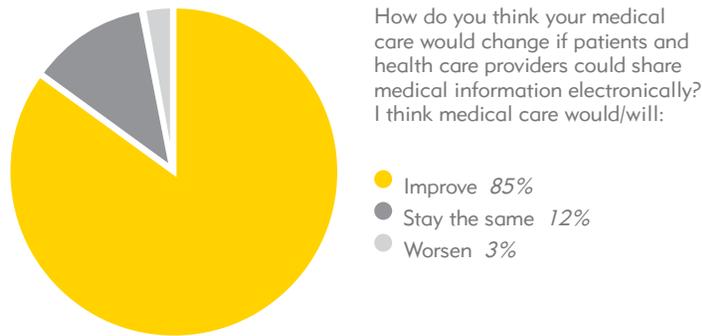
Additionally, the majority of respondents agreed that scientists doing research should be able to review their medical information—if the information cannot be linked to them personally (**Figure 4**).

FIGURE 4: Researchers' Access to Medical Information



Finally, most respondents believe that medical care would improve if information could be shared electronically (**Figure 5**).

FIGURE 5: Electronic Health Information Exchange and Quality of Care



The desire to share anonymous health information with researchers speaks to respondents' concerns about the safety and security of electronic health information. However, it is interesting to note that the number of respondents who feel that electronically-stored health information is safely guarded is greater than the number who believe that paper health records are safely guarded (**Table 2**).

TABLE 2: Security of Health Information

SURVEY QUESTION	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree
In general, I think that the information I give doctors is safely guarded when the information is stored on paper.	11%	48%	31%	10%
In general, I think that the information I give doctors is safely guarded when the information is stored in an electronic format.	15%	56%	21%	8%

COMPONENTS OF AN ELECTRONIC HEALTH RECORD (EHR)

Respondents were asked to select the functional components they thought an EHR should include; not surprisingly, privacy, security, and confidentiality rated at the top of the list. Respondents also favored more convenient information sharing, allowing multiple health care providers to share information, and the requirement of patient approval prior to any sharing of information. Finally, respondents indicated a desire to be a part of the electronic health information exchange process by having the capability to input their own assessment of their physical and emotional/mental health status into the EHR (**Table 3**).

TABLE 3: Priorities for EHR Management

ELECTRONIC HEALTH RECORDS SHOULD...	Strongly Agree/ Agree	Disagree/ Strongly Disagree	No Opinion
Be private, secure, and confidential.	99%	1%	0%
Allow for different health care providers to access information about a patient that could help them to improve care for that patient. (For example, a cardiologist could view information about chemotherapy that was provided by the oncologist.)	97%	2%	1%
Make sharing information with health care providers more convenient for patients.	96%	3%	1%
Require approval from the patient BEFORE information is shared among health care providers.	91%	8%	1%
Allow patients to enter information about their physical health for health care providers to review. (For example, patients could provide information about how much pain or fatigue they experience.)	91%	6%	3%
Provide patients with a way to share their medical information with scientists doing research—as long as the information cannot be linked to them personally.	87%	9%	4%
Allow patients to enter information about their emotional or mental health needs and concerns for health care providers to review. (For example, patients could report how much sadness or worry they experience.)	86%	10%	4%

COMPONENTS OF A PERSONAL HEALTH RECORD (PHR)

Respondents were asked to select the functional components they thought a PHR should include. Again, privacy, security, and confidentiality rated at the top of the list. Other highly-rated components included viewing information in the same way as providers, allowing all medical information to be tracked, and storing information in one convenient place. Again, survey respondents indicate a strong overall desire to be a part of the electronic health information exchange process, both as consumers and donors of health information (**Table 4**). Additionally, nearly three-fourths of respondents (73%) indicated that they would be “very likely” to use a PHR provided by their health care provider.

TABLE 4: Priorities for PHR Management

PERSONAL HEALTH RECORDS SHOULD ...	Strongly Agree/ Agree	Disagree/ Strongly Disagree	No Opinion
Be private, secure, and confidential.	99%	1%	0%
Allow people to keep track of medical information such as care received, test results, and health care appointments.	96%	3%	1%
Allow people the ability to see their own medical information in the same way that health care providers do.	90%	8%	2%
Store all of an individual’s personal medical information in one place.	89%	8%	3%
Provide people with a way to share their medical information with scientists doing research—as long as the information cannot be linked back to them.	88%	9%	3%
Offer people a way to update personal medical information from their own health records.	87%	10%	3%
Include information about clinical trials that relate to an individual’s personal medical information.	84%	9%	7%
Allow people the ability to view a patient-friendly version of their medical information that contains less detail than what a health care provider would see.	74%	23%	3%
Allow people a way to share personal medical information with loved ones.	74%	19%	7%
Include links to articles, stories, and tools that relate to an individual’s personal medical information.	71%	16%	13%
Be accessible to people on any device that connects to the Web.	66%	25%	9%
Offer people the ability to download information to a portable device such as a cell phone, iPod, or PDA.	63%	24%	13%
Allow people a way to share medical information with others who have similar health experiences.	55%	32%	13%

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Summary

The individuals affected by cancer who participated in this survey seem to value the promise of electronic health information exchange to improve the quality of health care, and they want to be active participants in the process. They want access to their electronic health information, would like their health care providers to share information to coordinate care, and believe researchers should have access to their anonymous electronic health information. And while they require that their electronic health information be safe, secure, and confidential, they also have more confidence in the safety of electronic health information than they do in paper health records.

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While there is still a need for more education and awareness related to electronic health information exchange among individuals affected by cancer, some are already experiencing the reality of how electronic health information exchange can impact patient care. As one respondent noted:

I currently see several different doctors within the same medical group. It has helped tremendously for them to pull up my records

and see what has been done, by whom, confirm medications, see test results, etc. I feel that each health care provider has the information that is needed to be able to make a better recommendation for treatment.

LIVESTRONG believes that the preferences of people affected by cancer regarding EHR and PHR functional capabilities should serve as a roadmap for policymakers as decisions are

made about how to stimulate the use of electronic health information exchange across all components of health care. It is worth noting that the United States Department of Health and Human Service's Office of the National Coordinator for Health Information Technology has published criteria outlining the "meaningful use" of health information technology (Medicare and Medicaid Programs; Electronic Health Record Incentive Program Final Rule, 2010). While several of the meaningful use criteria address the preferences of people affected by cancer as shown in this report (e.g., an emphasis on privacy and security and timely patient access to electronic health information), there are no criteria that acknowledge the desire among people affected by cancer to donate their own health information to an EHR. We hope that the results of this survey will be considered as the policy guiding electronic health information exchange evolves, while guidelines continue to be developed for EHR and PHR products, and as providers and hospitals select tools for electronic health information exchange.

REFERENCES

Medicare and Medicaid Programs; Electronic Health Record Incentive Program; Final Rule, 75 Fed. Reg. 144 (Jul. 28, 2010) (to be codified at 42 C.F.R. pt. 412, 413, 422, and 495.)

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