

06700 eHealth Initiative

Verbatim Summary

Q3 And if a friend or neighbor asked you to describe to them what the term secure electronic health information exchange means, what might you tell them?

There remains some confusion with respect to the meaning of the phrase “secure electronic health information exchange.” The majority of respondents made an educated guess at describing what they thought it meant, while some respondents felt uninformed and did not try to describe it.

Among those who tried to explain the meaning, most correctly identify “secure electronic health information exchange” as medical records being stored online/on the Internet/in a database and could be accessed by patients/doctors/hospitals/insurance companies. For some, they viewed the system as being a way for them to access their own information, while others thought it would be for health care providers to exchange information/access records.

Some respondents mentioned that it was a way to keep records private. Others expressed concern about keeping the records “secure” if they were stored electronically. Many talked about how hackers can get all sorts of information that is stored on the Internet and they would fear for the security of their health records.

Some respondents thought the phrase was referring to HIPAA.

Q4 Please tell me some of the reasons you rated the term secure electronic health information exchange (Q2)?

Respondents rating the exchange above 50 were generally positive about the concept and felt that it would be good for doctors to share medical data and have it be secured online or in an electronic database. Although these respondents were positive, several expressed concern about the data actually be secure and not easily hacked.

Respondents rating the exchange lower than 50 generally expressed concern about how secure their medical information would be. They were very skeptical that if their health information was stored electronically could it actually be secure, fearing that hackers could get into the database and steal personal health information.

Those who offered a neutral rating of 50 mostly said they did not know enough about health information exchange to give it a positive or negative rating. Some said they did not know what the phrase meant, or they simply needed further explanation before deciding how they truly feel about it.

Q12 Please tell me some of the reasons you gave a rating of (Q11)?

Q14 And please tell me the reasons you would (FAVOR/OPPOSE) the creation of this type of nationwide health information exchange or network?

Respondents were read the following description of the exchange:

Health information exchange is a way to electronically move your personal health and medical information securely between your doctors, hospitals and other health care providers when it is needed for your care. With your consent, your health information will be protected and exchanged under current medical privacy and confidentiality standard procedures. Secure electronic health information exchange allows you to make sure your health information is available when and where you need it while seeking medical care or treatment.

Then, one-quarter of respondents were asked again to rate it on the thermometer scale and one-quarter were asked if they would favor or oppose the exchange being made available in the Gulf States region:

Those who rated the exchange positively (51 or higher on the thermometer or favored it being made available in the Gulf States region) gave the following reasons:

- ✓ It would be great to have doctors and hospitals exchanging the information (some respondents mentioned personal experiences where they have had trouble moving medical records around in the past);
- ✓ It would be very useful and timely in an emergency - some people die because their records are not available and/or they get mis-diagnosed;
- ✓ If you are traveling or in a different state it makes it easier to get medical help;
- ✓ It would be convenient, speed up the process and save paperwork;
- ✓ It makes it easier to transfer records;
- ✓ It may reduce health care costs; and,
- ✓ A handful of respondents in Louisiana and Mississippi noted that if such an exchange had existed during Hurricane Katrina, many medical problems might have been averted.

Although these respondents were generally positive about the exchange several continued to express concern over how secure the system would be.

Overwhelmingly, respondents who opposed the exchange or rated it as 50 or below on the thermometer after hearing the definition were concerned about security and privacy. Over and over respondents say they are concerned about hackers getting access; they do not believe that any information stored electronically or online is truly secure. Some people cited the recent Veteran's Administration incident where a laptop containing the names and personal details of thousands of veterans went missing.

A few respondents were simply agnostic about the exchange. They just did not care about the topic or see no need for it as they are healthy and do not seeing doctors/hospitals.

A handful of respondents seem to have the impression that the exchange would be run/controlled by the government and this makes them skeptical of their right to privacy.

Q16 Please tell me some of the reasons you said you would be (Q15) to access your medical records and personal health information online?

Those who said they would be likely to access their records online offered the following reasons:

- ✓ Curiosity/just to know what's in there;
- ✓ To check the accuracy of the information;
- ✓ To make sure the information is up-to-date;
- ✓ To understand and know more about your health condition;
- ✓ As a convenient reminder for what the doctor has said/what medications he/she may have prescribed and instructions for taking them; and,
- ✓ They are used to doing things online, so why not review their own medical records online as well?

Respondents who say they would not be likely to access their records online gave the following reasons:

- ✓ They worry about security/privacy of the information being online;
- ✓ They already know what's in their records;
- ✓ They are not sick so they do not need to review it;
- ✓ They would rather talk to the doctor in person about whatever is in their medical records; and,
- ✓ The concern that this would not be available to everyone because some people do not have the right equipment to be able to access the information.

Q19 What do you believe are some of the benefits of secure electronic health information exchange?

- ✓ Speed - very fast access to the information;
 - ✓ Easily available/convenience of availability;
 - ✓ Very helpful when traveling;
 - ✓ In an emergency, regardless of where you are, doctors/hospitals can immediately get your information;
 - ✓ Efficient/cost effective;
 - ✓ Ability to access your own information (from anywhere);
 - ✓ Accurate and up-to-date; and,
 - ✓ More clear/legible information than trying to read your doctor's handwriting.
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Q20 What are some of your hesitations or concerns about secure electronic health information exchange? What do you think are the barriers to the development of secure electronic health information exchange?

- ✓ Security/privacy/confidentiality;
 - ✓ Fear of people hacking into the records/system;
 - ✓ Fear of records being lost/misplaced (VA incident mentioned again);
 - ✓ Accuracy - the information is only as accurate as the human being entering the data;
 - ✓ Possible misinterpretation of information resulting in improper care/mis-diagnosis; and,
 - ✓ Fear of government involvement.
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Q32 Now, I noticed you changed your rating for secure electronic health information exchange. Please tell me some of the reasons you just gave it a rating of (Q32) but earlier you gave it a rating of (Q11)?

Q34 Please tell me the reasons you changed your opinion of secure electronic health information exchange.

Respondents who moved five points or more towards 100 on their thermometer rating (64%), or moved to favor the exchange at the end of the survey (12%) offered the following reasons for feeling more favorably towards it:

- ✓ The system would help doctors and pharmacists better manage their health care;
- ✓ It would be very useful and could save lives in emergency situations - especially if something happened out of state;
- ✓ It would be useful when traveling or in another state;
- ✓ It would be useful in the event of a natural disaster. (A handful of respondents said they had not thought of it in the context of the hurricanes, but now they heard more about it in the survey and it made sense);
- ✓ It sounds convenient;
- ✓ It would be great to have access to medical records at any time, from anywhere; and,
- ✓ It may help reduce the death statistics and be useful for the elderly.

Respondents who moved five points or more towards one on their thermometer rating (16%), or moved to oppose the exchange at the end of the survey (3%) offered the following reasons for feeling more negatively towards it:

- ✓ Still have concerns about security/privacy/confidentiality;
 - ✓ Fear of hackers getting into the records;
 - ✓ Skepticism over whether it would actually reduce costs or paperwork;
 - ✓ Concern over accuracy of information - it's only as good as the human inputting the data;
 - ✓ Concern about who maintains the information and how often it is reviewed/updated;
 - ✓ What happens if the computers crash or the data is lost - often it cannot be retrieved if it is only stored on the computer; and,
 - ✓ How would the system work in rural areas?
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