

From: Susan Israel [REDACTED]
Sent: Tuesday, March 10, 2015 9:27 AM
To: Tikoo,Minakshi
Subject: Fw: SIM & APCD privacy concerns

Hi Minakshi,

Perhaps my comments can be of help.
Thanks! Susan

This is my public comment to date. Perhaps many agree with me on these issues but many seem to want to overlook the elephant in the room in my view.

As for my personal medical privacy, I have none as I will soon be on Medicare and fortunately for my generation, anything we might not have wanted others to know has long since been shredded. I know not to divulge anything I wish to keep private and as a physician, I know what needs to be known and what can be withheld safely. Eventually, as people find out what is happening to their information, I will not be the only one withholding information from their providers.

Patient privacy protections must be the foundation for the policies and technology systems as the number one priority, not cutting medical costs and the expediency of providing care. Telling patients that they can have quality or their privacy needs to be a public discussion and a private choice, not a government policy of the ends justifies the means or we will do the best we can, and sorry if there will be some mishaps in the future. Government control and “need to know” are trumping individual liberty in all spheres with the current technologies.

Paper records, metal file cabinets and doctors’ hand writing kept records private. The HIPAA rules for the de-identification of data with the removal of 18 identifiers probably worked even 10 years ago. But with the internet, EHRs, hackers and multiple data bases to cross reference, privacy has become the hardest thing to preserve, but is a sacred trust of the medical profession, starting with the Hippocratic oath to do no harm. Public Health data is also gravely at risk with electronic communications. Your teenager’s lab record of a sexually transmitted infection is on file with the State, along with your tumor tissue.

The widespread Epic system was installed without the technology of segmentation, meaning without the ability of the patient to require that certain information be kept private or not sent over the internet. Thus very personal and intimate information is available to hundreds of authorized people, as our right of consent for treatment, payment and operations (tech support, quality control, etc.) was taken away by HHS in 2002 without Congressional approval. Further, the HIPAA provisions for business associates, covered entities, researchers and Federal and *State* oversight bodies extend the list of fellow citizens who have access to our personal medical records. SIM will be a giant umbrella for all of these groups.

It was said that the indexing of patient data from the EHR is to be done. How will the computer programs be set up? There will only be internet transmission and thus access to blood pressure readings or other single data sets only, not the rest of the record?

The plan to merge the APCD with the EHR is of particular concern. The APCD people are working very hard to make sure that no one sees identified and that no one has the ability to merge its data with other data bases for re-identification. So will the APCD data now be merged with the EHR? Even if that is done through the Master Patient Index number, privacy may be compromised depending on how it is technically done. If the MPI number is not kept hidden from providers, researchers, overseers, etc., it would be possible to match the MPI number with an individual patient by using their medical information in their EHR to identify them, even if the HIPAA 18 identifiers are removed from the record seen. Then that information could be used to identify the APCD data. With just the sex, date of birth and zip code, 87% of people can be found and identified, not to mention all of the data bases online that can be crossed reference to identify people. As just an example: One can use google or phone directories online to find out all the people associated with a given person, so how hard would it be to use family data from a medical record or insurance application data to identify someone?

Because of scorecards and quality control metrics for providers, will they be under pressure to disclose any identified data needed to explain and exonerate themselves? Patients' actions and medical conditions will need to be completely scrutinized by the oversight groups to ensure fairness and equity to the providers. So quality control necessitates that our lives will be under the microscope of government employees?

Please incorporate these concerns into your discussions and computer programs.

Thank you very much.

Susan Israel, MD