Health Datapalooza

This year's Health Datapalooza, a national conference on the liberalization of health information, took place in Washington D.C. between May 31 and June 3. Panelists and speakers offered great insights into how to make data more accessible and what to do with that data once it's available. The sheer volume of health-related data is so vast, that we need to work hard on building a foundation of standards so we can build our way up to the analysis of the data.

A key takeaway was the main source of open data. At this time, Medicare is by far the easiest place to go for public use data sets. This was mentioned multiple times in various keynotes, general sessions, and breakout sessions, as was the fact that the plan moving forward is for the Center for Medicare and Medicaid Services to continue releasing more data sets and updating the ones already released.

To further develop other sources of data, it was made clear by many experts that a recognized set of standards needs to be developed so data that is published can be easily accessed and analyzed. The current frontrunner is a standard called Fast Healthcare Interoperability Resources, or FHIR (pronounced "fire"). Once databases are utilizing a set standard, it will allow data to be combined and analyzed at a much higher level.

The implications of sharing data were also addressed at the conference. First, it's important to note that data sharing goes both directions — providers sharing the consumer's data with individuals, and individuals sharing their data with researchers (and potentially other data consumers), which

raises a lot of questions: Who gets to see what? How much data can you share? What privacy controls are in place? This is a new and interesting area of the health data field that covers numerous operational and ethical fields.

Finally, the conference addressed how to make sense of records that do become publically available. If you have a multi-gigabyte record of health data, can you make sense of any of it, let alone understand what it means overall as a picture of your current and projected health? This is related to standards of health records such as FHIR as well as how to understand what you are looking at if you are not a health professional (in some cases, even if you are — would an infectious disease specialist fully understand the results of an echocardiogram of the heart, for example, if all they were seeing was the raw data therefrom?)

The bottom line is — we've come a long way and great strides are being taken on a daily basis. But there are massive innovations still required to develop a truly interoperable system. I for one, am looking forward to the challenge!

This blog entry was written by Jim Harbour, CNSI's big data expert. He will be writing about the relevant aspects of using data to tell meaningful stories, including why we tell (and listen to) stories, what makes a good story, data analytics, big data, data visualization, data science.. Jim has worked in a variety of architecture, analysis, design, development, and operations roles at CNSI and throughout his career. He believes in sharing knowledge and mentoring at all levels, including these blog posts. Follow him on Twitter [@JSilasHarbour](#).