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July 4: Data Independence Day



GetMyHealthData

Knowledge is Power.

This year's Fourth of July celebration has taken on a new meaning for supporters of the "Get My Health Data" movement, which is pushing for better patient access to health data. They are eager to raise awareness for their cause by holding "Data Independence Day" on the 4th of July.

Organisers are hoping that the one-day event will actually spur a larger movement with consumers demanding access to their health data. The aim is to demonstrate to lawmakers, healthcare providers, and other decision makers that people do care about electronic access to their health information.

The difficulty in getting information is "a tax on everything we do," said Dr. Farzad Mostashari, former National Coordinator for Health IT, who helped organise the Get My Health Data movement. Consumers are being encouraged to visit getmyhealthdata.org and to contribute money, apps or technology skills.

In addition, Get My Health Data is looking for patients to serve as "tracers" by requesting access to their records and reporting on the response. "We want to get as much information from tracers" to show that there is demand, said one movement leader, Christine Bechtel, former vice president of the National Partnership for Women & Families, and still an adviser to that organisation.

Bechtel, who chairs the consumer workgroup of the federal government's Health IT Policy Committee, described Get My Health Data an "informal collaboration among like-minded folks."

The movement has three core strategies: give consumers tools to request their information; support innovation; and seek policy advancements.

The goal, according to Bechtel, is to make data access "ubiquitous" for patients. "When I leave my doctor's office, I expect that I will receive a data feed," added Bechtel.

For his part, Dr. Mostashari called consumer access to their health records the "unlocker" to change healthcare for the better.

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