How much access to DNA databases should be shared with public?

The GLP aggregated and excerpted this blog/article to reflect the diversity of news, opinion and analysis.

After dozens of unsuccessful treatments, Eric Dishman started to suspect that his illness was due to something other than the rare kidney cancer he was diagnosed with in 1989. Five years ago, he had his whole genome sequenced, then gave the data to oncologists — and learned that he had a different type of cancer altogether.

Dishman now leads the health and life-sciences division of microprocessor giant Intel in Banks, Oregon. He is also a member of a working group run by the US National Institutes of Health (NIH) for the Precision Medicine Initiative (PMI) — a U.S. $215-million project to collect data on genomes, health records and physiological measurements from 1 million participants, to learn how genetics, environment and lifestyle influence disease risk and the effectiveness of treatments.

The group is expected to release a project plan, and observers are eager to learn its answer to a key question: how much information about disease risk, especially genetic data, will the project share with participants?

That issue is the subject of much debate. Dishman and others say that participants should at least have the option to see all their personal data so that they can investigate their own health, just as he did. But some specialists in the field say that showing participants their data is irresponsible, because the information is challenging for people to interpret and its significance is often uncertain.

Read full, original post: Giant study poses DNA data-sharing dilemma