NETWORKING MEDICINE

Although fully organized patient-run trials are still few and far between, patients are taking a more active role in clinical research. Now, more than ever before, patients have access to scientific knowledge as it’s reported, and advocate communities are flourishing, thanks to the wide-ranging, faster, and more accurate communication provided by the Internet. This increasing patient activism, and an accompanying willingness to share personal stories, has resulted in a veritable deluge of patient data.

“When you have gigabytes of data, perhaps hundreds of gigabytes, for each patient, that’s more data than has existed in all clinical trials combined up until a couple of years ago,” says Marty Tenenbaum, who in 2010 founded Cancer Commons, a database that collates real-time patient data and up-to-the-moment basic medical research to inform cancer treatment.

The online networking site PatientsLikeMe, for example, has accumulated more than 175,000 users who are recording information about hundreds of diseases, treatments, and outcomes. Of the 200,000 customers of direct-to-consumer genetics company 23andMe, some 85 percent have contributed their genomic and phenotypic information to research—totaling more than 80 million phenotypic data points for more than 60 conditions. And the Personal Genome Project, launched by Harvard Medical School’s George Church in 2006, has accumulated about 200 full genomes and 400 partial sequences, with some 1,500 additional volunteers who have already made trait data available online and are willing to share their whole genomes.

But the availability of such data is only one side of the coin. Without expert analysis, patient-generated data would be useless to the drug development community. Fortunately, initiatives and companies are cropping up left and right to support and take advantage of this movement.

Among the benefits of such stockpiles of data is the ability to sift through the challenging heterogeneity of patients, their diseases, and their case information. “Clinical trials, especially as they’ve been traditionally constituted—large randomized trials—just are a disaster in cancer, because of the nature of the disease,” says Tenenbaum. “Every tumor is unique at some level.” Databases that collate genetic data, such as patient genomes or the genomes of their tumors, could facilitate the identification of biomarkers to help differentiate responders and nonresponders, speeding a drug’s path to the clinic. “It could literally slash years, if not decades, off the normal process,” Tenenbaum says.

Platforms that support patient input can also help researchers develop better benchmarks for assessing disease progression and more accurate measures of patient health, as well as point to novel indications for existing drugs and promising drug combinations. “We’re enabling a new partnership between the patients and the physicians,” says Jamie Heywood, cofounder and chairman of PatientsLikeMe, “and that new partnership should produce outcomes at lower costs with lower risks and better innovation.”

WHERE THE DATA COME FROM

PATIENT-CONTRIBUTED

PARTIALLY PATIENT-CONTRIBUTED

NOT PATIENT-CONTRIBUTED

Genetic Alliance
Collects patient blood and tissue samples and stores them in disease-specific biobanks, while serving as a networking organization for patient advocacy groups, universities, companies, and more.

CureTogether
Gathers survey data from patients about symptoms, treatments, and outcomes, then allows users to compare themselves to others. (Note: 23andMe bought CureTogether in July 2012.)

PatientsLikeMe
Users share personal health information, which company researchers analyze for potential trends, or sell to interested parties.

Genomera
Provides an online platform for users to launch their own crowdsourced health studies; organizers come up with the questions, develop protocols, and invite other Genomera users to take part.

NextBio
Provides a platform for biopharmaceutical clients to search databases of clinical and molecular profiling data collected by hospitals, contract research organizations, and public databases.

Sage Bionetworks
Collects data from patient networks and clinical studies and combines them in a platform that allows researchers to run their own analyses. Also allows patients to donate data, in the form of photographs of their melanomas, for example, or lab reports from their doctors.

Cancer Commons
Hopes to track genomic data from cancer patients and use rapid-learning algorithms to generate regularly updated models of cancer progression and response to treatment. (Full disclosure: Cancer Commons’ executive director is The Scientist’s former editor-in-chief, Sarah Greene.)

C3N Project
The Collaborative Chronic Care Network (C3N Project) combines data from medical registries and patient records—and hopes to soon supplement with patient-contributed data on diet, exercise routines, etc.—and makes those data available to the patients’ doctors.