Scientists Seek to Build Patient Trust

A recent article in Science magazine declares “Scientists can no longer guarantee patients’ privacy” so “They’re looking for new ways to build trust.” As the writer notes, “It’s now widely accepted that if someone can read your DNA, they might figure out who you are, either now or into the future, as technology marches ahead.”

But a survey of nearly 2,400 people found patients less worried about being identified than about how their data is used. In fact, 81% were not happy with researchers parsing through their de-identified data without their consent.

So researchers are reverting to informed consent, even for the use of de-identified data – and they’re letting participants be involved in how it’s used.

“TRUST ME, I’m a Medical Researcher,” Jennifer Couzin-Frankel, SCIENCE, January 30, 2015.