The Next Social Media Revolution Will Occur In...Personalized Medicine?

by Dan Vorhaus

Social media – including Facebook, Twitter and other social networking platforms – are widely credited with fundamentally altering the nature of political discourse and, in some instances, credited as catalysts of political revolution. But social media’s ability to affect change need not be limited to politics, as recent developments in the arena of personalized medicine and consumer genomics continue to demonstrate.

Social Media as a Research Tool. Last month, PatientsLikeMe, an online patient community, made headlines with a study published in Nature Biotechnology in which the company analyzed self-reported data from nearly 600 patients to demonstrate that the use of lithium had no effect on the progression of amyotrophic lateral sclerosis (ALS, also known as Lou Gehrig’s disease).

The study’s findings are valuable for ALS patients, who frequently experiment with unproven treatments in an attempt to slow progression of the degenerative disease for which there is not yet an effective therapy. But the long-term impact of the study’s methodological approach, which suggests “that data reported by patients over the internet may be useful for accelerating clinical discovery and evaluating the effectiveness of drugs already in use,” should be felt far beyond the ALS community.

PatientsLikeMe was formed after the brother of two of the company’s co-founders was diagnosed with ALS. The company, which initially sought effective treatments for ALS, has broadened its focus in recent years. PatientsLikeMe now seeks to help patients representing a range of diseases manage those conditions and to help medical researchers and companies improve the way they develop treatments, including by involving both patients and social media.

The Nature Biotechnology publication is a validation of the company’s efforts and, while not a substitute for traditional clinical trials, the PatientsLikeMe approach does demonstrate that social media tools, including networks of like-minded individuals (in this case ALS patients) “can provide supplementary data to support effective decision-making in medicine and discovery.”

Or, as PatientsLikeMe Chairman and Co-Founder Jamie Heywood told Health Business Blog, the study affirms that “there is tremendous value in reconnecting researchers to the patients they are working hard to serve by changing the norm from doing research ON patients to doing research WITH patients.”

Joining the Revolution in Progress. The PatientsLikeMe study, while impressive, is just the latest development in an ongoing and increasingly widespread effort to change how personalized medicine is pursued.

Consider, for example, Hugh Rienhoff, who launched a search to find the cause of his daughter’s mysterious genetic condition and, along the way, created a non-profit company to help others tackle similar problems. Or Genomera, a Bay Area start-up which aims to provide tools to help individuals design and carry out their own, personalized research projects.

Or 23andMe, the most prominent direct-to-consumer (DTC) genetic testing company in the market today, which has already demonstrated its ability to use social media and customer-driven data to identify novel genetic associations. While those particular associations are of admittedly limited utility, 23andMe is employing the same approach to identify the causes of – and potentially a cure for – Parkinson’s disease, a disease for which Sergey Brin, the Google co-founder and the husband of 23andMe co-founder Anne Wojcicki, carries a genetic predisposition.

23andMe also recently opened recruitment for a new study, in conjunction with researchers at Stanford University, to examine how social networking impacts health behavior and research.

And there are plenty of other projects seeking to expand the role individuals and social media play in scientific and medical research, including the Personal Genome Project, Sage Bionetworks, CollabRx, Genetic Alliance and DIYgenomics, to name just a few.

A Revolution Hiding in Plain Sight. While companies like PatientsLikeMe and 23andMe have successfully leveraged social media tools to demonstrate alternative pathways for personalized medicine research, social networking alone would be insufficient to produce a true revolution in personalized medicine. Another key factor has been the dramatic increase in availability of personalized health data, particularly genomic data.

Over the past year, a spate of articles has appeared in mainstream media publications describing the alleged failure of the Human Genome Project (HGP) to live up to the lofty expectations it set for itself a decade earlier. Last fall, for example, The New York Times’ Nicholas Wade lamented that “ten years after President Bill Clinton announced that the first draft of the human genome was complete, medicine has yet to see any large part of the promised benefits.” Francis Collins, then one of the leaders of the HGP and now the head of the NIH, opined in the journal Nature that “while the promise of a revolution in human health remains quite real...it is fair to say that the [HGP] has not yet directly affected the health care of most individuals.” And Matt Ridley criticized the HGP and its successors in the pages of The Wall Street Journal for “underdelivering useful medical knowledge and overdelivering other stuff.”

Yet by focusing solely on more easily quantifiable scientific and medical advances, and dismissing all of the “other stuff,” Wade, Collins, Ridley and others have largely overlooked a crucial legacy of the HGP: the rapid and continued democratization of genomics. Over the past ten years, technological advances have made it possible for increasingly large numbers of researchers, clinicians, patients and consumers to access personal genomic data. What was once a decade-long, multi-billion dollar, public-private collaboration to obtain a single human genome now requires nothing more than a credit card, a saliva sample and a few weeks.
While there can be no doubt that the ultimate goal is an improved understanding of the mechanisms of human disease and, as a result, an improved ability to effectively and efficiently treat those diseases, we should not lose sight of the tremendous progress we have made over the past decade in democratizing genomics and changing how personalized medicine is pursued.

Last fall, in “The Failed Promise of Genomics,” Matt Ridley wrote that “…personalized genomics will struggle to say anything at all, for the simple reason that it will be too personal.” That argument never made much sense to me in large part due to one simple fact, which was beautifully articulated by Joe Pickrell of Genomes Unzipped in a post explaining why DTC genetic testing is good for research. Wrote Pickrell, “all research is driven by curiosity, and the people most curious about a disease or trait are those who have it.”

The dramatically increased personalization of many aspects of health and medicine, especially genomics, is one promise the HGP has delivered in spades. As for Ridley, after initially worrying that personalized genomics was somehow too personal, he finally decided to see for himself. Apparently prompted by the threat of FDA regulation of DTC genetic tests, Ridley recently opted in to the personalized genomics movement and appears to have come away a changed man.

Last month, writing again in The Wall Street Journal, Ridley argued that the promised genomic revolution may indeed be realized, but only if it is embraced by the masses. “Genetic knowledge, whether the high priests like it or not, is going to be a crowd-sourced phenomenon,” Ridley wrote.

Of course, as the work of PatientsLikeMe, 23andMe and others continues to demonstrate, the revolution has been ongoing for some time now. Ridley is right that it will take many more doctors, researchers, consumers, patients, policymakers and, yes, even pundits before the active involvement of individuals in personalized medicine research becomes commonplace. And he is right that the revolution will occur whether or not personalized medicine’s “high priests” – including groups like the American Medical Association – are ready for it. What Matt Ridley failed to grasp is that the revolution is already here, and now he is a part of it.

Welcome to the Revolution, Matt.