

How the MySpace mindset can boost medical science

15 May 2008

By Peter Aldhous

IT CAN create a buzz around an up-and-coming rock band, and is great for reuniting with friends from college. But can it help investigate the causes and treatment of serious diseases? That's the question surrounding attempts to use online social networking to recruit volunteers for clinical research.

"Social networking sites could transform the way in which clinical research takes place"

The MySpace mindset is already meeting medical science on the website [PatientsLikeMe](#). For the past two years it has enabled people with the degenerative neurological disease amyotrophic lateral sclerosis (ALS) to share information about symptoms and treatments. PatientsLikeMe has also expanded to build communities of people with other conditions, and has launched a number of projects analysing clinical information provided by the site's users.

Now online social networking is moving into genetics research. In a pilot project, personal genomics firm [23andMe](#), based in Mountain View, California, is building a site for people with Parkinson's disease. Using a grant from the Michael J. Fox Foundation for Parkinson's Research (MJFF) in New York, the company will scan the genomes of up to 150 people with Parkinson's for genetic variants associated with susceptibility to the disease. The patients will also be asked about their symptoms, medication and factors such as exposure to pesticides and use of alcohol and tobacco via online questionnaires developed by the Parkinson's Institute in Sunnyvale, California. These patients have previously been examined in person on behalf of the institute, so by comparing the two forms of assessment, the study hopes to discover whether clinical information gained from a web-based patient community can provide a reliable means of investigating the genetic and environmental factors that can trigger Parkinson's.

If the online approach proves viable, it could overcome two major constraints on scientific progress in clinical research: gaining access to enough people to obtain reliable results, and doing so without running up huge costs. "The slowest part of the research is recruiting the patients," says Todd Sherer, MJFF's vice-president for research. Many willing volunteers live far away from clinical research centres, and even if they can make the trip, getting their symptoms assessed by a specialist is expensive.

*This article has been posted with permission from
New Scientist © Reed Business Information*

"One of the fundamental reasons why we started this company was to accelerate the pace of research," says 23andMe co-founder Anne Wojcicki. By empowering patients with information about themselves and building an online community, "we can transform the way research is done", she says.

PatientsLikeMe, based in Cambridge, Massachusetts, has a similar ethos. The site's communities now include more than 5000 people with multiple sclerosis, 2000 with mood disorders, 2000 with ALS, 700 with HIV and 1600 with Parkinson's. Patients who would otherwise rely on their doctors for information on treatments can see charts detailing what drugs other patients are taking, and how their symptoms are progressing.

Once patients are able to share this information, more ambitious research becomes possible. For instance, 187 members of PatientsLikeMe's ALS community have joined forces to investigate whether [lithium](#), generally used to treat bipolar disorder and depression, may slow progression of the disease. The driving force behind this project is Humberto Macedo, a systems analyst in Brasília, Brazil, who was diagnosed with ALS last year. Having learned about a small Italian study on lithium as a treatment for ALS, he decided to try it himself and work with others taking the drug to track the results. Macedo argues that the participants have nothing to lose, and everything to gain. "At least we won't be sad, right?" he jokes.

Patients like Macedo use the website for free, and he clearly feels empowered by the ability it has given him to initiate research. But PatientsLikeMe is also a commercial operation that aims to sell its users' data to companies that make drugs and medical devices. "We take information patients share about their experience with the disease, and sell it in a blinded, aggregated and individual format to our partners," the website explains.

23andMe's business model is more complex. Participants in its pilot research into Parkinson's disease will have their genome scans paid for by MJFF. But the company also offers scans to anyone for \$999, and in the long term also hopes to get paying customers involved in research. 23andMe's other co-founder, Linda Avey, insists it will not sell its customers' data. Instead, it plans to charge an introduction fee for organisations wanting to recruit volunteers for research.

Mark Rothstein, a bioethicist at the University of Louisville in Kentucky, is concerned that disease-based social networking sites will become vehicles for advertising drugs and medical devices to their users. "That's an area we're going to look into carefully and see what our customers are OK with," says Avey.

Another worry is that patients may be lured into providing personal data that might come back to haunt them. Many users of PatientsLikeMe are already

divulging detailed medical information, often without concealing their identities. Rothstein points out that there is pressure on users to provide as much information as possible, as those who do so enjoy prominent billing on the site.

23andMe's customers can control how much genetic information to reveal and who is able to see it, but unlike the hospitals and academic institutes where clinical research has traditionally been run, PatientsLikeMe and 23andMe are not covered by US federal regulations intended to protect personal health information. "The only thing that binds them is the policies they adopt. These can be changed at will," says Bob Gellman, a privacy consultant based in Washington DC.

Avey counters that 23andMe has a strong commercial motivation to protect its customers' information, and points out that regulations may not always prevent privacy breaches at academic medical centres. A former staff member at the University of California, Los Angeles, was indicted in April on charges of selling the medical information of celebrities being treated there.

PatientsLikeMe carries this warning about the potential dangers of sharing clinical information online: "Medical and life insurance companies have clauses that exclude pre-existing conditions. Employers may not want to employ someone with a high-cost or high-risk disease." PatientsLikeMe's chairman James Heywood insists that the benefits will outweigh the risks. "Some day someone may be harmed, but it's more likely that a lot of lives are going to be improved," he says.

That will depend on the quality of the research, and some experts fear the data provided by patients will be unreliable. "If it turns out to be useful, I will be very surprised," says Kari Stefansson, CEO of Decode Genetics in Reykjavik, Iceland.

This is where 23andMe's pilot study comes in. While thousands of volunteers will eventually be needed to reveal the environmental and genetic triggers of Parkinson's disease, the initial project will at least reveal whether web-based questionnaires can be a reliable tool. If it pans out, the stage will be set for social networking sites to change the way in which clinical research takes place, says Katie Hood, CEO of MJFF. "This is a completely new frontier."

From issue 2656 of New Scientist magazine, 15 May 2008, page 26-27