

The Power of Open Data

How large-scale sharing and collaboration are helping to solve medical mysteries.

By [David Bollier](#)

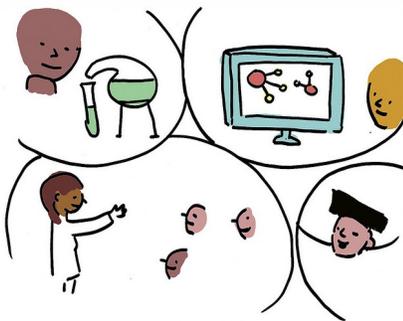


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Science has always recognized the power of sharing in developing new knowledge. But in the search for treatments and cures for diseases like Alzheimer's and Parkinson's, the sprawling bodies of highly diverse research data are not easily shared. Either they are considered proprietary resources for making money, or they are hidden in academic databases that others may not know about, often inaccessible because of incompatible software formats. No single researcher really has the resources or incentive to develop an overarching regime to enable cooperation and sharing. And so dozens of academics, nonprofits and pharmaceutical companies have continued their research in relative isolation.

"Companies were caught in a prisoner's dilemma," a research at the University of Pennsylvania recently told the [New York Times](#). "They all wanted to move the field forward, but no one wanted to take the risks of doing it."

But ten years ago, Dr. Neil S. Buckholtz, who oversees dementia research at the National Institutes of Health, realized that the sharing of research data was a collective action problem that might be solved through concerted leadership. He helped instigate a plan by which the NIH stepped up to serve as an "honest broker" between the pharmaceutical industry and academics. The goal was to ensure that all research would be shared openly and freely, and published on the Internet immediately, so that anyone could use it. You could publish a research paper and you could develop new treatments, but no one would own the data. Researchers would even be free to make mistakes or misguided interpretations — because who is to say at the outset that something is necessarily incorrect?

Seven years ago, the NIH persuaded scientists from the FDA, the drug industries, medical-imaging companies, academia and nonprofit groups to cooperate in an ambitious scheme to affirmatively *share* their findings with each other. As the *Times* reports (August 13, 2010), the sharing of data is now

starting to show results. Scientists studying Alzheimer's disease routinely share their findings about "biological markers" that indicate the progression of the disease. This has led to recent scientific papers suggesting the value of PET scans and tests of spinal fluids as ways to make early diagnoses of Alzheimer's.

The conventional business response to such radical ideas of "sharing" is that no company would have adequate incentive to invest in risky research unless they could be assured exclusive ownership of the results, in order to create a revenue-generating "product" (i.e., medical treatment or drug). But the drug industry has had to concede that diseases such as Alzheimer's are just too scientifically complicated for any single research entity to tackle; the most fruitful way forward is to pursue an "open source" approach that places the basic building-blocks of knowledge into the commons – while sanctioning the private patenting of more refined medical innovations that build on the fruits of the commons.

It's so common-sensical that it seems faintly ridiculous that a story of this sort should merit lead-story treatment in the *New York Times*.

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