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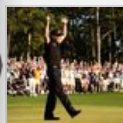
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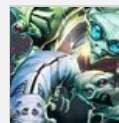
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APRIL 13, 2010

## My Data, Your Data, Our Data

*A bold project hopes that getting scientists to share information can deepen their understanding of diseases*

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By **AMY DOCKSER MARCUS**

In the age of Facebook, Twitter, and Wikipedia, it is hard to believe there is still one group that prefers to be more circumspect about sharing: scientists.

### Journal Report

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Scientists worry that if they share data before publishing their findings, someone else might claim credit for a discovery they made. And even after they mine information

for themselves, they frequently cling to the notion that more may be discovered, and so continue to hoard the data.

"Data is what scientists use to establish their reputation," says Thomas A. Finholt, a research professor and associate dean for research and innovation at University of Michigan. "There is no incentive for opening up access."

Now an ambitious project has been launched to try to change this traditional approach. Sage Bionetworks, a nonprofit with offices at the Fred Hutchinson Cancer Research Center in Seattle, is driving an effort to build an open-source collaborative effort it calls Sage Commons, a place where data and disease models can be shared in the hopes of deepening scientists' understanding of disease biology. To succeed, its founders acknowledge, will require not just data, but a huge cultural shift.

### Why Drugs Fail



The project got under way late last year, when Stephen Friend, the founder of Rosetta Inpharmatics and a senior vice president of cancer research at Merck & Co., left the pharmaceutical company to establish Sage. Dr. Friend says his experiences at Merck made him realize many drugs fail because scientists don't have a full enough understanding of disease biology. Drugs intended for one problem in the body often have unexpected consequences elsewhere.

Dr. Friend, along with staff and advisers including former researchers at Merck, a Nobel prize winner, mathematicians and physicists, hopes to build better models of disease. To do that, scientists need more genomic data as well as

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Susan Alderfer

Stephen Friend's vision of an open-source network on diseases and drugs will require a cultural shift among scientists.

detailed clinical information about how patients fared. Generating and analyzing the amount of information required is too expensive and complex an enterprise for any one person, lab or drug company to do on its own, Dr. Friend says. Sage's vision is an open-source network where different groups gain access to what others are doing in exchange for sharing their own data. The advantage: faster, cheaper, more effective ways of figuring out what is going wrong when someone gets sick.

There has been a real push lately to get scientists to collaborate more. Many foundations and government funding agencies require or favor grant proposals that involve multiple institutions. Some scientific disciplines have taken more readily to sharing than others. Physicists have been working together for decades, in part because they rely on hugely expensive equipment that generates massive and complex data sets.

The Sage network, however, requires contributions from groups whose interests often diverge: pharmaceutical companies attuned to the bottom line, academic centers where advancement depends on publishing and winning grants, and patient groups who require immediate treatments. Still, Sage got early and important backing from prominent groups. Quintiles, a biopharmaceuticals-services company, and nonprofits CHDI Foundation and the Canary Foundation put up some of the initial funding, which is now over \$18 million. Merck donated data sets that cost more than \$150 million to develop.

John Quackenbush is a professor of biostatistics and computational biology at Dana-Farber Cancer Institute in Boston who is building integrated databases and developing tools to leverage the information toward understanding disease. He says that people working in the field recognize that data integration is essential for moving science forward. But even major public archives are struggling to keep up with the volume and complexity of the data, he says.

Many groups have set up their own data-storage systems over the years, and there's no standardization. The National Institutes of Health and many scientific journals require researchers to put data accompanying published papers in public databases. But when Dr. Quackenbush went through tumor samples and other data stored in those public repositories, he found many scientists "live up to the letter of the law but not the spirit." He says data were annotated with the minimum information to get into the database, making it very difficult to use.

### Better Results?

There is still debate over whether scientific collaboration leads to better results. Jonathon Cummings, an associate professor of management at Duke University, and his colleagues got a grant from the National Science Foundation to look at 491 research collaborations funded by the foundation. They discovered something unsettling: Collaborations of more universities fared worse than projects primarily executed at a single university. More collaborators meant fewer patent applications, fewer published papers, and less chance of the group seeking additional funding to keep projects going.

Dr. Cummings says it appears that the amount of coordination required to make progress on research—everything from setting up meetings to integrating knowledge among group members—outweighed the potential benefits of collaboration. In the wake of the study, he says, the science foundation now requires grant applicants for some programs to detail how they expect to manage the collaboration.

At Sage, meanwhile, Dr. Friend acknowledges these are early days. About 20 people are working full time. They've begun some pilot projects as a way to test the concept and demonstrate that they can get results.

Robi Blumenstein, president of CHDI Management Inc., which works with nonprofits dedicated to Huntington's disease research, says that participating in the Sage Commons has already given his researchers access to data they didn't have, such as data from studies done on the brains of patients who died of Alzheimer's disease. In the studies, the brains of patients who died of Huntington's were used as controls. There was a significant amount of data available that had never been mined for clues into Huntington's disease, he says. "Sage is an experiment," Mr. Blumenstein says. "But it's an experiment worth trying."

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Sage also signed a research partnership with [Pfizer Inc.](#) in which Sage will analyze data sets from the company to try to find potential new targets for drugs and better ways to determine which patients will respond to cancer therapies. Pfizer agreed to put the data and models that are generated from the partnership into Sage's public database—but only a year after the partnership ends. The delay gives Pfizer a competitive advantage, and indicates how challenging it will be to totally change the culture of science.

Neil Gibson, chief scientific officer of Pfizer's oncology research unit in La Jolla, Calif., says his company appreciates the sophisticated analysis that the Sage team provides. "We are now at a stage in science where nearly everyone can generate this type of data," says Dr. Gibson. What companies need is a better way to make sense of it, he adds. Pfizer is paying Sage for this work, but the company declined to say how much.

In another project, Sage is trying to identify tumor specimens already collected from patients with different kinds of cancer. By collecting both clinical and genomic information, the scientists hope to figure out what is genetically distinct about patients who respond to certain therapies compared with those who do not.

Richard Schilsky, who is co-chairing that project with Dr. Friend, says they want access to data banks compiled from recent clinical trials funded by the National Cancer Institute. But Dr. Schilsky, who just completed 15 years as chairman of a cooperative that formed one of those data banks, says getting access will be tricky even for him. "The number of specimens is finite, so people who will be asked to give up specimens want assurance the specimens will be used for strong scientific purposes."

### *Who Gets Credit*

There is also the issue of who gets credit for any findings that emerge. Dr. Schilsky, chief of hematology/oncology at the University of Chicago, says researchers who have invested time and effort in collecting specimens can't be expected to simply hand them over. "We want to contribute scientifically to the process and get recognition for that," he says.




Kathy Giusti, founder and CEO of Multiple Myeloma Research Foundation and one of the co-heads of the myeloma piece of the project, says her foundation has nearly 3,000 bone-marrow samples and 2,500 matched peripheral blood samples. She is willing to share the data but will need resources to help fill requests, she says. Otherwise, well-intentioned projects "drag on for years and years."

Dr. Friend says some of these issues will be addressed later this month when Sage holds its first congress. He thinks eventually scientists will have to agree with him: "It is an absurd way to generate information if you start from scratch each time saying, 'I am going to do it better or different,' instead of saying, 'I will put my layer of information on top of what others have done and have a bigger insight.' "

Many of the of the scientists agree it will be increasingly difficult for their colleagues to resist cultural forces that insist on more sharing. "My son is 4. By the time he's 15, his genomic data will probably be on Facebook," Dr. Quackenbush says. "The way people handle their own data in their private lives will change the way researchers share data. If patients demand their data be shared, scientists almost have no choice."

Ms. Dockser Marcuse is a staff reporter for The Wall Street Journal in Boston. She can be reached at [amy.marcus@wsj.com](mailto:amy.marcus@wsj.com).

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