

# A registry of registries? The US backs the idea for patients

Building on the success of ClinicalTrials.gov, a registry of nearly 100,000 federally and privately funded clinical trials around the world, the US government is now planning to build a registry of patient registries. The ultimate goal of the effort is to create a one-stop shop where physicians, patients and researchers can find these lists of individuals who have made themselves available for observational medical studies.

The ‘metaregistry’ will be searchable, and each entry will contain contact information for the person running the registry. At least initially, the catalog will not contain patient-specific information, but researchers could contact a given registry owner to obtain that data. The goal is that the database would serve patients and physicians looking for specific disease registries, researchers investigating a particular disease and drug developers.

The database could also be used to monitor outcomes and study best practices. “It’s a significant need in the US healthcare system,” says Tad Funahashi, the chair of national implant registries for the health care provider Kaiser Permanente.

The project is being funded by the American Recovery and Reinvestment Act for \$5 million over the next three years, and the US Agency for Healthcare Research and Quality (AHRQ) recently selected the Cambridge, Massachusetts-based company Outcome Sciences to design the database.

Currently, a large number of patient registries exist, but because there is no central database, no one knows exactly how many there are. ClinicalTrials.gov contains over 800 patient registries, for instance, but Elise Berliner, who heads AHRQ’s technology assessment in Rockville, Maryland, says that those probably represent just the “tip of the iceberg.” The metaregistry would build on the ClinicalTrials.gov model and possibly even link to that site.

Access to registries can provide fresh opportunities for data analysis. Funahashi, for example, recently coauthored a study in which he and his colleagues used Kaiser’s registry of joint replacements, analyzing 80,000 total joint replacements and 5,000 anterior crucial ligament reconstruction procedures and were able to determine risk factors that led to the procedures failing (*J. Bone Joint Surg.* 92, 117–132, 2010). Kaiser’s doctors are now implementing these findings in their surgical procedures.

Berliner says that a metaregistry could also be useful for monitoring outcomes of

patients who receive devices such as stents or implantable cardiac defibrillators.

Additionally, for rare diseases for which little is known, a metaregistry could help aggregate data and information, speeding up research on those diseases and ensuring that research projects are not redundant. Drug developers could also use the metaregistry to “find out real-world information about what’s happening to patients with that disease,” says Richard Gliklich, president and chief executive of Outcome Sciences.

Ideally, even after a specific trial ended the data on that registry would be archived, says Berliner. However, details on how to store data have not been worked out. “There are so many logistic issues that need to be considered, such as funding for the continuation of the registry, governance, data ownership and, of course, the ethical and legal rights of patients,” she says.

## Sizing up the situation

The size of patient registries can vary dramatically. Those relating to rare diseases may contain less than 100 people, says Gliklich. Meanwhile, large registries maintained by professional societies such as the American Heart Association or the Society of Thoracic Surgeons contain several million individuals each. Then there

are mega-registries such as the National Program of Cancer Registries, which pools data on people with cancer that states are required to collect.

Creating a centralized repository that would collect data from all these disparate registries is no small feat. Registries large and small will all be encouraged to participate, initially on a voluntary basis.

“Ferreting out the policies, procedures and incentives that will make it valuable to so many stakeholders so that everyone wants to participate in it” will be the biggest hurdle, says Gliklich. Everybody seems interested in being able to find other registries, but not necessarily in putting their own data into the registry, he adds.

Another hurdle will be standardizing the language—for example, by ensuring that myocardial infarction means the same thing across the board, says Berliner.

Then there are issues about privacy, as well as determining who owns the data. That’s why initially the database won’t contain subject-specific information but will simply be more of a search tool to find out whether a certain registry exists, with contact information for the researcher in charge. Eventually though, Gliklich says it will be valuable to include more detailed information.

*Monica Heger*

## New York Academy of Sciences launches angel investment network

NEW YORK—New York City’s burgeoning bioscience industry got a boost on 18 November when the New York Academy of Sciences launched a new network to connect private investors with fledgling life science companies looking for funding. The network, which is comprised of angel investors—wealthy individuals who risk their own money—will finance companies working to commercialize drugs, medical devices and other healthcare products. The goal is to bridge the funding gap between academic technology transfer offices and late-stage investors such as big corporations and venture capital firms.

To be eligible for funding, inventors must submit an application and business plan to the Life Science Angel Network’s

(LSAN) screening committee, a panel of scientists, physicians, venture capitalists and other technology development experts tasked with vetting proposals. The most promising applicants will have the opportunity to present their idea to the entire network.

LSAN’s director, Milena Adamian, points out that the need for such a network in New York is great. “I actually saw companies from this area coming to California to look for money,” she says. According to Adamian, start-ups selected for LSAN funding will probably receive investments ranging from several hundred thousand dollars to more than a million dollars.

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