

UCSF chancellor issues call-to-arms to patient advocates

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This is Susan Desmond-Hellmann. Credit: Elisabeth Fall/fallfoto.com

In November 2011, a National Academy of Sciences committee issued a report calling for the creation of a "Google Maps"-like data network intended to revolutionize medical discovery, diagnosis and treatment. Today, the co-chair of that committee, UCSF Chancellor Susan Desmond-Hellmann, MD, MPH, is issuing a call-to-arms to patient advocates to help make that idea a reality.

In her editorial, reported in the April 11 issue of [Science Translational](#)

[Medicine](#), Desmond-Hellmann calls on patient advocates to work with policy makers in the U.S. Congress and elsewhere to develop regulations that would more efficiently link patient information between research and clinical care settings, while continuing to protect patient privacy. The information is a key component of the proposed data network and could accelerate medical advances, she and her Academy co-authors say.

The so-called "Knowledge Network" would integrate emerging research on the [molecular makeup](#) of disease with clinical data from [patients](#), to drive the development of a more accurate classification, or [taxonomy](#), of disease beyond classification by organs and symptoms. The goal would be more diagnostics and treatments tailored to the individual patient – which the committee called "precision medicine," meaning both "accurate" and "precise."

The opportunity to create an entirely new way to classify—and therefore understand and treat—human disease "could bring us to the tipping point at which the remarkable scientific advances in biomedicine and engineering translate to concrete therapeutic benefits for humankind," Desmond-Hellmann wrote in her editorial.

Noting the role that patient advocates undertook around the HIV/AIDS epidemic of the 1980s, she said, the vision of the Academy report "is worthy of that kind of passion and leadership."

The Knowledge network would be centered on a dynamic, interactive data repository, or "Information Commons," that, like [Google Maps](#), would link layers of data to reveal patterns. Data on environmental exposures, signs and symptoms, genetics, epigenetics, microbial exposures and other types of patient information would be linked to data on individual patients. Content could be continuously refreshed with new basic and clinical research results and patient responses.

The opportunity posed by such a database is great, said Desmond-Hellmann, an oncologist by training and the former head of product development at Genentech, Inc. "Research findings can take years to trickle to doctors and patients, while wasteful health care expenditures are carried out for treatments that are only effective in specific subgroups. Meanwhile, researchers don't have access to comprehensive and timely information from the clinic. Opportunities are being missed to understand, diagnose and treat diseases more precisely, and to better inform health care decisions."

Two major impediments to implementing the envisioned network involve access to [patient information](#), she said. One is that less than 5 percent of the population participates in clinical trials. The other is the emphasis on patient privacy in research and clinical settings. The Health Insurance Portability and Accountability Act (HIPAA) promises penalties for anyone who breaches patient privacy, resulting, Desmond-Hellmann said, in an ever-increasing conservatism regarding access to and pooling of data.

"The most important requirement for the new knowledge network envisaged is that it be driven by patients," Desmond-Hellmann wrote in her editorial. "Patient advocacy can best ensure that policymakers in the U.S. Congress and elsewhere understand that well-intended efforts to guard [patient privacy](#) could impede the kind of data sharing required to accelerate the cures all are awaiting."

She concluded, "A unified group of patient advocates pushing government, academia, private industry and caregivers to create a new social contract in which patients both contribute and benefit would be a powerful force. I cannot imagine a more effective way to create the world we imagined in 'Precision Medicine'."

The National Academy of Sciences report, titled "Toward Precision

Medicine: Building a Knowledge Network for Biomedical Research and a New Taxonomy of Disease," [PDF] was the result of a one-year study conducted at the special request of Francis Collins, MD, PhD, director of the National Institutes of Health (NIH).

Keith Yamamoto, PhD, vice chancellor for research at UCSF who served on the National Academy of Sciences committee, has characterized the proposal as "the most important [National Academy of Sciences](#) Framework Analysis since that advisory body recommended that the United States go forward with the Human Genome Project."

Provided by University of California, San Francisco

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