

*Gathering and understanding the deluge of biomedical research and health data poses huge challenges. But this work is rapidly changing the face of medicine.*

BY ERIC BENDER

## BIG DATA IN BIOMEDICINE

# 4 BIG QUESTIONS

### QUESTION

**1** *How can long-term access to biomedical data that are vital for research be improved?*

### WHY IT MATTERS

Data storage may be getting cheaper, particularly in cloud computing, but the total costs of maintaining biomedical data are too high and climbing rapidly. Current models for handling these tasks are only stopgaps.

### NEXT STEPS

Researchers, funders and others need to analyse data usage and look at alternative models, such as 'data commons', for providing access to curated data in the long term. Funders also need to incorporate resources for doing this.

### QUOTE

"Our mission is to use data science to foster an open digital ecosystem that will accelerate efficient, cost-effective biomedical research to enhance health, lengthen life and reduce illness and disability." **Philip Bourne**, US National Institutes of Health.

**2**

*How can the barriers to using clinical trial results and patients' health records for research be lowered?*

'De-identified' data from clinical trials and patients' medical records offer opportunities for research, but the legal and technical obstacles are immense. Clinical study data are rarely shared, and medical records are walled off by privacy and security regulations and by legal concerns.

Patient advocates are lobbying for access to their own health data, including genomic information. The European Medicines Agency is publishing clinical reports submitted as part of drug applications. And initiatives such as CancerLinQ are gathering de-identified patient data.

"There's a lot of genetic information that no one understands yet, so is it okay or safe or right to put that in the hands of a patient? The flip side is: it's my information — if I want it, I should get it." **Megan O'Boyle**, Phelan-McDermid Syndrome Foundation.

**3**

*How can knowledge from big data be brought into point-of-care health-care delivery?*

Delivering precision medicine will immensely broaden the scope of electronic health records. This massive shift in health care will be complicated by the introduction of new therapies, requiring ongoing education for clinicians who need detailed information to make clinical decisions.

Health systems are trying to bring up-to-date treatments to clinics and build 'health-care learning systems' that integrate with electronic health records. For instance, the CancerLinQ project provides recommendations for patients with cancer whose treatment is hard to optimize.

"Developing a standard interface for innovators to access the information in electronic health records will connect the point of care to big data and the full power of the web, spawning an 'app store' for health." **Kenneth Mandl**, Harvard Medical School.

**4**

*Can academia create better career tracks for bioinformaticians?*

The lack of attractive career paths in bioinformatics has led to a shortage of scientists that have both strong statistical skills and biological understanding. The loss of data scientists to other fields is slowing the pace of medical advances.

Research institutions will take steps, including setting up formal career tracks, to reward bioinformaticians who take on multidisciplinary collaborations. Funders will find ways to better evaluate contributions from bioinformaticians.

"Perhaps the most promising product of big data, that labs will be able to explore countless and unimagined hypotheses, will be stymied if we lack the bioinformaticians that can make this happen." **Jeffrey Chang**, University of Texas.

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