NWABR
Northwest Association for Biomedical Research

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What does IBM's supercomputer Watson have to do with research? Stockpiles of genetic metadata combined with the advanced capabilities of supercomputers may be the key to specialized disease treatments at the individual level. Ethical issues, however, add layers of complexity to genetic testing and reporting. Should companies be allowed to conduct genetic testing to report health risks directly to consumers, or should this service be limited to tests ordered by physicians?

Bioinformatics is a multidisciplinary field aimed at processing and analyzing biological information. New bioinformatics methods may be a gateway to specialized disease treatments tailored to patients' own genetic profiles. Ethical questions have come to the forefront of the debate as the collection of genetic data and bioinformatics processing requires the storage of large amounts of individual genetic data. As society continues to scrutinize the ethical implications, NWABR strives to educate and engage our community in dialogue around this issue and we want you to join the Conversation.

In NWABR's Introductory Bioinformatics curriculum, NWABR covers ethical questions about genetic testing and the application of bioinformatics in the field. The curriculum explores how bioinformatics tools such as BLAST and Cn3D are used to investigate the genotypic and phenotypic consequences of a mutation to the Breast Cancer Susceptibility 1 (*BRCA1*) gene, which increases risk for breast and ovarian cancer. Ethical questions covered in the curriculum continue to pose challenges for researchers. As the costs of genetic testing decrease, ethical concerns about consumer privacy, impact on family members, test usefulness, access to genetic information and more will continue to arise.

Take, for example, IBM's Watson computer. The British Broadcasting Company (BBC) recently highlighted the promise offered by the supercomputer to help fight common types of cancer. Data synthesis from Watson's artificial intelligence platform is already being used to inform lung cancer treatment on an individual basis at the Memorial Sloan-Kettering Cancer Center in New York (BBC, 2013). Watson is capable of mining and decoding genetic information and identifying patterns in metadata in mere minutes — a process that would take researchers weeks or months—. This type of analysis requires large quantities of genetic data to ensure that correlations in gene sequences can be identified with enough statistical significance to lead to personalized treatments.

NWABR's public outreach is also current. We recently presented a Community Conversation, "What Can Your Genes Tell You?," that explored the ethical implications of Food and Drug Administration (FDA) regulation of direct to consumer genetic testing kits (Link 3). The Conversation centered on the private genetic testing company 23andMe, which offers consumers a Saliva Collection Kit and Personal Genome Service for $99. When consumers submit a sample, 23andMe creates a report utilizing metadata from scientific studies about single nucleotide polymorphisms (SNPs) and their association with health risk, genetic traits, drug response, and ancestry.

In 2013, the FDA ordered 23andMe to stop marketing and reporting health-related services because the company was not in compliance with the FDA rule for medical devices under the federal Food, Drug, and Cosmetic Act. Participants in the Community Conversation focused on privacy, trust, and control of data as well as the commercialization of DNA; the need for access to and assistance interpreting reports; resistance from members of the medical community in applying consumer-acquired data; and the lack of ethnic diversity in the 23andMe database.

There is no simple path forward when it comes to the generation, interpretation and application of genetic information. Medical professionals are able to use genetic data, synthesized by a supercomputer, to develop customized treatments for cancer patients. Regulations dictate how companies like 23andMe may use and report direct to consumer genetic data, which could reduce access to potentially valuable information.

NWABR wants to continue these Community Conversations, and has created a secure forum for your online dialogue. Start us off by sharing your thoughts. Here are a few questions to ponder: How can we manage the vast amounts of genetic data that are becoming available, and what can we do to protect privacy? What does genetic testing mean for sample donors, investigators, biorepositories and bioinformatics? What levels of clinical validity and transparency should be required when reporting disease risk, whether through tests ordered by a physician or by a consumer? What are the tradeoffs between FDA regulation and personal empowerment through access to genetic information?

To join the discussion email Troy Chapman at membership@nwabr.org.

For additional information follow the links below.

Resources

Community Conversation program page. *http://www.nwabr.org/communityconversation*

NWABR blog post on the Community Conversation by Ken Gordon, March 19, 2014.
http://nwabr.wordpress.com

"FDA orders 23andMe to halt sales," Nov. 26, 2013 (radio program). www.kqed.org

Genomics Law Report blog posts from Dec. 3, 2013. www.genomicslawreport.com

"Should the FDA stop you from scaring yourself with 23andMe's DNA test?" Washington Post.
http://www.washingtonpost.com/blogs/wonkblog/wp/2013/12/06/should-the-fda-stop-you-from-scaring-yourself-with-23andmes-dna-test/

The Spitoon, the 23andMe blog, posts from November and December 2013. http://blog.23andme.com