Genomic data sharing is critical to improving genetic health care

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There are an estimated 5,000 - 7,000 rare genetic diseases, each of which can vary dramatically and be caused by a multitude of different genetic changes. Even common diseases with genetic influences may also have rare variants that influence the risk of disease or how severe the disease might be. How can a single provider, laboratory, medical center, or even state possess sufficient knowledge about genetic conditions in order to deliver the best care possible for patients in need of care? How can we harness the massive amounts of genetic data that are currently being produced to improve patient care, continue to improve critical genetic testing and further the promise of personalized medicine?

The American College of Medical Genetics and Genomics (ACMG) tackles these extremely complex questions in its new position statement, "Laboratory and Clinical Genomic Data Sharing is Crucial to Improving Genetic Health Care." The new position statement says, "In order to ensure that our patients receive the most informed care as possible, ACMG advocates for extensive sharing of laboratory and clinical data derived from individuals who have undergone genomic testing. Information that informs healthcare service delivery should neither be treated as intellectual property nor as a trade secret when other patients may benefit from the knowledge being widely available."

"The only way that the medical community is going to be able to make sense of the massive amount of genetic information that is now being generated is through broad and responsible sharing among researchers, clinical laboratories and the clinic. If we do it in the way that the ACMG statement lays out, genomic medicine can be harnessed to benefit the health of all," said James P. Evans, MD, PhD, co-author of the new ACMG Position Statement.

Information about genetic diseases is accumulating rapidly and information science is empowering the use of 'big data' with the goal of improving patient care and advancing personalized medicine. The ACMG Statement advocates for responsible sharing of data, which will provide both a resource for clinical laboratories and treating physicians who interpret test results and also clinical validity data that can benefit laboratories and manufacturers who are developing new tests and testing platforms. Contributing research and clinical laboratory data to public databases for clinical curation is necessary before advances can make it to patients.

"Ultimately, Genomic Data Sharing is going to be critical to advancing what we know about the genetic aspect of both rare and common diseases. Responsible sharing of genomic variant and phenotype data will provide the necessary information to improve patient care and to empower those who are developing tests and treatments for patients to continue to improve genetic testing. ACMG believes everyone should have access to the best medical information and that it shouldn't be held as intellectual property or a trade secret," said Michael S. Watson, PhD, executive director of the ACMG.

It's essential to note that Genomic Data Sharing will not comprise an individual's privacy. Importantly, broad data sharing is compatible with the critical imperative of protecting the privacy of individual healthcare information and the security of data systems holding that information. ACMG believes that in order for data sharing to be done in a way that doesn't result in the compromise of privacy for patients and providers, systems are required that: ensure the security of databases, whether centralized or federated; ensure the privacy of patient and family medical information; and provide transparency in the documentation of data sharing transactions.

More information: undefined ACMG Board of Directors. Laboratory and clinical genomic data sharing is crucial to improving genetic health care:

a position statement of the American College of Medical Genetics and Genomics, *Genetics in Medicine* (2017). DOI: 10.1038/gim.2016.196

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