

Navigating the ethical clash between access to health information and proprietary databases

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Sharing medical information, including genomic data, has the potential to benefit public health. However, companies that generate that information have a legal right to protect it as a trade secret. Legal and ethical conflict exists between individuals' right to access their personal health information and the protection of these trade secrets, as examined

in *Science* by a group of ethicists from Baylor College of Medicine's Center for Medical Ethics and Health Policy.

As a case study, Christi Guerrini, Dr. Amy McGuire and Dr. Mary Majumder look at the complaint filed against Myriad Genetics, the once-exclusive provider of genetic tests to screen for the BRCA1/2 breast cancer genes, by four of its clients who received genetic testing.

"This case presents a fascinating clash between two important rights: the right of individuals to access their [health](#) information as it relates to their wellbeing and the right of innovators to protect their [trade secrets](#), which Myriad exercises in this case," said Guerrini, assistant professor in the Center. "Myriad has a legitimate commercial interest in protecting its algorithms and the huge amounts of data it amassed from BRCA1/2 testing, but its clients and the healthcare community have compelling personal and [public health](#) interests in accessing the information gathered from the tests."

The data gathered from these genetic tests can provide important insights when making an individual diagnosis or pursuing clinical treatments, thereby having a direct impact on patient care. On the other hand, if companies and innovators are able to keep certain pieces of data and their processes secret, they are more easily able to recover their investment in the project and use it to finance new diagnostic tests.

"As genetic testing continues to become more prevalent, we are going to see increasing challenges between the public and the companies doing the testing. Trying to mask protected health data, or information that can be individually identified to one person's health condition, under patents or trade secrets will result in more and more public backlash as the government figures out how to regulate genomic databases and client access," said McGuire, director of the Center.

But if clients were to exercise their data access rights and take back their genetic data, the question becomes how to interpret the data and amass it into a database that would be of value to others.

"This would be a legal win for the clients – for patients," said Majumder, associate professor in the Center. "However, these data are not user friendly, and the further step of assembling the data from lots of individuals into a database that rivals Myriad's will be a big logistical challenge."

In the end, the team at the Center envisions a partial win for both sides. A compromise will need to be reached between the data access right in HIPAA requiring these [genetic testing](#) companies to disclose parts, or all, of the requested information to clients, and the legal right of companies like Myriad to protect that [information](#) as a trade secret in order to stimulate competition and innovation.

More information: Christi J. Guerrini et al. Myriad take two: Can genomic databases remain secret?, *Science* (2017). [DOI: 10.1126/science.aal3224](#)

Provided by Baylor College of Medicine

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