Accessing and Sharing Genomic Data

We live in the age of Big Data at a time when the access, sharing, collection, storage, analysis and use of information has become a major strategic challenge. The field of genomics research is no exception to this trend.

THE POWER OF RESEARCH

Genomics research has led to major medical breakthroughs. For instance, the results of genome sequencing, when combined with information from medical records, generate massive amounts of large datasets from many people. Researchers use these datasets to find specific treatments and/or target prevention and treatment strategies to an individual's unique features. This is known as personalized medicine.

But these datasets are expensive to produce and store. Given that a significant share of genomics research funding comes from public sources, it is vital to ensure the optimal use and sustainability of this resource. The access and sharing of data for future use is a simple, efficient and cost-effective way to make the most of existing genomic and health-related data. In fact, the cost of analyzing genomic data that has already been collected is far lower than the cost of collecting new data or sequencing new genomes.

OBSTACLES TO DATA SHARING

Currently, the obstacles and challenges associated with accessing information hamper the activities of the research community in Québec. For example, it can be difficult for researchers to share research data with one another. Datasets from research contain personal and confidential information from volunteers who agreed to participate in research by providing their DNA. In doing so, participants face a risk related to the potential invasion of their privacy or a breach of their personal information. When taking part in research, participants always give their consent, which must include the purpose for which data will be used and the manner in which they will be protected. If the research involves the linkage of data to other sources of information, this too is to be included in the consent process. The Commission d'accès à l'information (CAI) stipulates that for consent to be valid, it must be explicit,

free, informed, specific and time limited. However, the CAI never recognizes broad consent as valid, even when approved by a competent research committee.

It can also be very complicated to access patient information in medical records held by public bodies for the purpose of linking them with genetic information obtained through research. In Québec, the CAI's mission is to protect personal information held in the private and public sectors, but not to optimize the use of the information for research purposes.

An additional obstacle exists: the statistical power needed to analyze certain research questions in genetics requires a number of participants that often exceeds a single province or country. However, the interprovincial and international sharing of data is complicated due to legal restrictions on the storage period and location of information, the differences in terminology used and the mechanisms governing access to certain personal data (for example, information in medical records and administrative data, etc.). Indeed, the multitude of administrative approval processes in different jurisdictions often constitutes an operational obstacle that makes it difficult to share personal data internationally.

POSSIBLE SOLUTIONS

In Québec, genomics research is hampered by administrative rather than scientific barriers. But according to the Centre of Genomics and Policy (CGP) of McGill University, the situation could be improved by eliminating just a few legal barriers. For instance, consent mechanisms and communication with participants should include information on the access and/or linking of personal data and details on any subsequent sharing of the data for research in genomics even if the specific project objectives and modes have yet to be determined. By recognizing the validity of broader consent, research in Québec will be able to move forward.

According to the CGP, legal restrictions on the storage mode and retention period of information obtained from public bodies should also be eliminated, and access to the information they hold should be streamlined.

It goes without saying that these changes must be made with care to ensure balance between protecting the privacy of participants who have consented to contribute their genetic information and, fostering innovative research.

To learn more about the subject, consult the policy brief prepared by the Centre of Genomics and Policy of McGill University commissioned by Génome Québec.

Note : In response to criticism in connection with the situation in Québec, the Québec Economic Plan of March 2018 allocated $18.5 million to promote access to certain data for research purposes through the implementation of a one-stop access point by the Institut de la statistique du Québec. The implementation of this one-stop access point could help accelerate access to data; however, the Economic Plan stipulates that only anonymous data will be accessible, which greatly diminishes their usefulness in research and limits their value in a context of personalized medicine.

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