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Identification and Characterization of Genes Involved in Common Developmental Brain Diseases

Integrated GE³LS Research

Considerations of providing individual genetic research results to participants: An Ethical Analysis

GE³LS Project Leaders

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Summary

Genetics studies are becoming increasingly prevalent, leading to a growing body of information on disease susceptibility with the potential to improve health care. Much of these data are characterized as exploratory, with little or no clinical utility. However, there is an international trend for research participants to be permitted access to their personal data if they so choose. Stakeholders are consequently confronting the issue of whether and how research participants might receive their individual results. Yet, few empirical data exist on the attitudes and needs of research participants in the context of research on neurodevelopmental diseases.

This integrated GE³LS research study aims to conduct a benefit-to-risk assessment in order to balance the potential positive vs negative consequences to participants, while maintaining the integrity and feasibility of conducting genetic research studies. To do this, researchers will carry out a review and analysis of (inter)national guidelines, as well as an empirical study of the attitudes and needs of study participants. Findings of these analyses may help inform the development of an ethical framework to assist investigators in providing research participants with the results of neurogenetics studies.

We expect to find major challenges in this context, given both the high expectations surrounding genetic research and the vulnerable state of some patients/research participants. We also expect that healthcare costs will constitute an important contextual issue, especially in the context of public healthcare systems where issues of resource allocation figure prominently in the delivery of innovative care in neurodevelopmental diseases.

<http://www.genomequebec.com/GQGenomiqueSociete/projets/maladiesCerebralesEn.asp?l=e>