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The Contribution of Genetic Modulators of Disease Severity in Cystic Fibrosis to other Diseases with Similarities of Clinical Phenotype

Integrated GE³LS Research

Reporting genetic research results: Perspectives of study participants and researchers

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Summary

Several recent commentaries argue that researchers bear an obligation to report genetic research findings to study participants. The nature and scope of this obligation remains disputed and unresolved. While the principles of respect for persons, reciprocity, and beneficence are fundamental to the research enterprise, they may neither be well served if results are disclosed nor denied if they are not disclosed. This integrated GE³LS research examines study participants' and researchers' perspectives on how to manage genetic research results with respect to this putative obligation.

Phase 1 of this research surveyed research participants from the Canadian Consortium for Cystic Fibrosis research regarding the meaning ascribed to a recent gene modifier finding reported in the academic literature. One key finding was that study participants expect researchers to share genetic research results with them. Phase II of this research involves a complex experimental design that aims to understand the factors influencing researchers' judgments regarding reporting results. Using a cross sectional factorial survey design that includes vignettes presenting hypothetical scenarios involving genetic research findings to investigators engaged in cystic fibrosis and autism genetics research, this research aims to better understand the factors that influence researchers' judgments about (a) informing individuals about genetic research findings, (b) the clinical significance of a hypothetical research finding, (c) the nature of a research obligation to re-contact study participants with updated information about a particular finding, and (d) the nature of a clinical obligation that may/may not ensue from reporting research findings. Taken together, findings from this integrated research will inform the governance of this important research ethics issue.