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Structural and Functional Annotation of the Human Genome for Disease Study

Integrated GE³LS Research The meanings and understandings of terms used in genomics research

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Summary

In order to ensure optimal data collection and informed choice, the GE³LS project team's over-arching goal is to investigate how the understandings of terms used in genomics research by scientists, when translated into the scientists' meanings on consent forms, information letters, surveys, and demographic forms, may or may not be consistent with the understandings of research participants and their meanings when they respond to such documents. The team will:

- perform a textual analysis of research grants, information letters and consent forms that are being used in clinical studies of this Genome Canada grant and others funded in the last Genome Canada competition. With interview 'prompts' from the results of this research, research participants and researchers involved in the clinical Themes of this Genome Canada grant will be interviewed to provide further insight into the meanings and understandings of terms used in genomics research, particularly related to copy number variations (CNVs);
- survey other key stakeholders' views of genomic research (particularly related to CNV), such as health professionals' (medical geneticists and counselors, physicians) perceptions of the clinical meaning of CNV results (what kinds of results should provoke duty to warn, and child protection obligations);
- examine the views and experiences of patients and their families as research participants towards furthering informed choice to participate in CNV research;
- explore the meanings and understandings of terms used in CNV research by studying issues revolving around the interpretation, management and communication of whole genome scanning (WGS) results to patients and their families; and
- consider the legal issues that are emerging from the methodologies of the aforementioned studies that explore the meanings and understandings of terms used in CNV research, including qualitative content analysis, interviews of researchers and research participants, and electronic surveys.