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Atlantic Medical Genetics and Genomics Initiative

Integrated GE³LS Research Assessing economic, social, and ethical barriers to the implementation of genetic services

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Summary

The study of monogenic disorders is likely to yield clinically relevant results in the near term. Although specific therapeutics are probably several years down the line in most cases, the prospects for diagnostics are much more positive. Indeed it is likely that the current project will yield a number of diagnostic tests for a variety of conditions. As the number of genetic diagnostics continues to expand in succeeding years, difficult decisions will need to be made regarding both the social utility and economic practicality of adopting these new technologies.

The primary objective of the GE³LS component of this project is to provide systematic evaluation of selected existing and potential genetic screening programs in Atlantic Canada. The goal is to facilitate effective and efficient uptake of genetic services. More specifically, the aims are to:

- 1) Evaluate the economics of selected existing and potential genetic screening programs in Atlantic Canada in the short and long-term.
- 2) Identify the range of barriers and benefits relating to social utility and economic practicality of adopting these new technologies.
- 3) Understand the range of social, historical, cultural and economic barriers to access and use of genetic services from the perspectives of patients, physicians, populations/communities, and government policy makers.
- 4) Facilitate effective and efficient uptake of genetic services.
- 5) Identify needs and provide ethics training for genomics researchers.
- 6) Develop goals and strategies for transparent and open public debate in Atlantic Canada.
- 7) Create policy documents which will outline the steps and capital investment necessary to fulfill genetic testing needs of Atlantic Canada.