

Position Statement of the Network of Applied Medical Genetics (RMGA) on Genetic Discrimination

2016



The Network of Applied Medical Genetics (RMGA) of the Fonds de Recherche du Québec – Santé is a network of researchers seeking to facilitate both applied research in medical genetics in Quebec and the transfer of new knowledge useful to this population. The issue of genetic discrimination is an important concern for RMGA researchers because the fear of the population in this regard is likely to have a negative impact on participation in genetic research and health programs.

Scientific progress in genetics fosters improved knowledge of biological mechanisms and better understanding of the impact of genes on the health of the population. For several conditions, genetic tests are crucial for diagnosis and treatment. As a vector of translational research in human genetics, the RMGA maintains that individuals have the right to participate in research and clinical programs without being concerned that their data will be used in a discriminatory manner by third parties.

For this reason, the RMGA has adopted strict ethical rules for its members on confidentiality and the protection of the genetic information of research participants.

Nevertheless, there is currently no Canadian law that explicitly protects the population against genetic discrimination. Although, to date, the incidence of genetic discrimination is relatively low in Canada, this problem is a source of concern in the population and a cause of refusal to participate in both genetic research and clinical programs likely to bring about important health benefits.

Bill S-201, entitled “Genetic Non-Discrimination Act”, was recently introduced in the House of Commons. The RMGA is in favor of protecting citizens against discrimination based on genetic information and considers that Bill S-201 constitutes an important first step in this direction. We encourage the Quebec legislator to continue and extend this initiative in provincial fields of jurisdiction, such as insurance and employment. As a leading actor in Quebec in applied genetics, the RMGA will be actively involved in the provincial legislative process on this issue in order to defend the interests of researchers, research participants, patients and the general population.

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