

# Genetic Counsellors' Preferences for Preimplantation Genetic Diagnosis: A Discrete Choice Experiment

## Long Abstract

Preimplantation genetic diagnosis (PGD) is a way of testing for a genetically affected embryo created through *in-vitro* fertilization (IVF) and provides an alternative to prenatal diagnosis for individuals who are at high risk for having a child affected with a genetic disorder and who choose not to undergo pregnancy termination. There are differences in PGD coverage across jurisdictions in Canada as well as ambiguity around the scope of testing that can be offered to patients and the inclusion criteria of the patients who could be chosen for public coverage. These key policy issues create a lack of clarity in the policy options under which PGD could be publicly covered. Clinical practice is guided by front line providers, especially genetic counsellors (GC), the health-care professionals who counsel these high-risk couples. A discrete choice experiment (DCE) was undertaken with Canadian GC to quantify their stated preferences for public coverage of PGD, considering the following attributes: PGD indication, risk of the condition, fertility status, family history and number of cycles covered. A total of 126 genetic counsellors completed the survey for a completed response rate of 41%. Multinomial logit regression was used to estimate part-worth utilities and importance scores. Key demographic and practice characteristics were considered as influences on preference. Risk of the genetic condition was the most important attribute with an importance score of 41.4%. Exploratory analysis suggests that those GC with more than 10 years experience were more supportive for coverage of conditions with decreased genetic risk and later onset. In general, GC preferred criteria related to scope of testing rather than patient inclusion criteria, which is consistent with their clinical expertise. This is the first study to quantify preferences of genetic counsellors

related to recommended PGD coverage. This study provides some insight into the conditions under which PGD might be covered or publicly subsidized. This knowledge contributes to evidence that may help to promote discussion and shape national PGD policy and regulation.