

# Assessing the Interest in Genetic Counseling within the Adoption Community

**Leann Bartomioli, Kira Apse, Deborah Bowen, and MaryAnn Whalen Campion**  
Boston University School of Medicine, Boston, Massachusetts

In the field of genetic counseling, it can be difficult to provide complete services to adopted individuals and their families due to lack of known personal or family medical information. As genetic counseling and genetic testing become more commonplace in medical management, it is important that these services and growing technologies are made available to all groups of people, including the adoption community. The goal of this study was to identify factors, in addition to lack of personal and family medical information, that may influence an adopted individual's or adoptive parent's interest in genetic counseling services. Participants were recruited through advertisement in adoption agency and advocacy group newsletters and online forums. In total, thirty participants (thirteen adoptees and seventeen adoptive parents) completed online surveys. The factors that influenced their interest in genetic counseling services included: 1) a doctor's recommendation, 2) family history of an inherited medical condition or the adoptee is affected with an inherited medical condition, and 3) access to records before or after the adoption. The participants' amount of knowledge about genetic counseling did not affect their interest in genetic counseling. The study results suggest that there is a desire for genetic counseling services within this population. These services can best be rendered when adequate and relevant information is collected from the birth parents and released to the adoptive parents and adult adoptees. This may be accomplished by adoption agency policy and law reform. If adoptees or their adoptive parents had access to sufficient medical information about the adoptee's family medical history, inherited conditions that could cause sudden death or major medical complications might be prevented and/or treated appropriately through the utilization of genetic services.