A Proposed Definition for Genetic Discrimination

Background:

Genetic Discrimination (GD) is a multifaceted concern that can infringe upon human rights and fundamental freedoms.[1] Cognizant of the growing occurrence of GD in various contexts, scholars have proposed various definitions to better conceptualize the phenomenon. These definitions have largely focused on differential and unfair treatment. While current conceptualizations have promoted greater awareness of GD, a more dynamic definition is needed to better account for advances in genomic technologies, as well as the types of harms individuals and groups could face if GD is not regulated. This policy tool proposes a nuanced and inclusive definition, that better reflects the multi-faceted impact of GD, and that remains relevant in light of an evolving science:

> **Proposed Definition**: Genetic discrimination involves an individual or a group being negatively treated, unfairly profiled, or harmed, relative to the rest of the population, on the basis of actual or presumed genetic characteristics.

It is recommended that this definition be used as a tool by GA4GH members and the wider community of researchers, policymakers, and other interested parties, who are working on preventing and addressing matters of GD. Ultimately, we hope that this definition will facilitate the development of more coherent, international policy efforts to combat GD.

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[1] Otlowski, M., Taylor, S. & Bombard, Y. Genetic discrimination: international perspectives. Annu Rev Genomics Hum Genet 13, 433–454 (2012).