Policy advice by Ana Isabel Castillo Orozco

Nowadays, genetic tests (whether for ancestry or disease prediction) from private companies are becoming more accessible to the public through online resources. By the moment the payment is, and the DNA sample is sent, genomic information may be shared with authorities and further organizations for the establishment of databases/repositories and biobanks. Indeed, the sharing of genomic data has become critical for the stimulation of scientific research and improvement in diagnosis, treatment, and prevention of genetic disorders and chronic diseases.

However, lack of knowledge and awareness regarding the interpretations of the test results, as well as stakeholders implications as soon as the genomic data is available to the public, many individuals have become reticent in using such tests, hindering the progress of genomic medicine. To address these challenges, the following policy advice, which is featured by two primary measures, is shown below.

The following measures try to increase as much as it is possible the integrity of stakeholders around the use of genetic tests from private companies, as well as to safeguard the promotion of scientific research. Probably, consumers and students may still develop insecurity due to unsolicited or secondary findings obtained from those tests since these outcomes are most challenging to deal with, especially when establishing policy advice. However, this policy was designed to promote transparency and improve genetic literacy and thus, make a change in the values and interests of consumers that leads to the consolidation and implementation of precision medicine.

First of all, since online, genetic tests are inevitably increasing and eventually will become standard routine tests, a genetic counselor should be established to guide consumers throughout the service. Conventionally, after the sample is analysed, reports and graphics are sent back, and though these results bring a thorough analysis, consumers may be susceptible to misinterpreting information and unsure how to proceed regarding notification of relatives. For this reason, private companies should design particular online platforms to allow proper interaction between experts and consumers (potentially stakeholders). Indeed, genetic counselors may aid and significantly improve their understanding regarding incidental findings, adequate risk interpretation and how to deal with relatives.

As the second action, private companies should assign economic resources to address the relevance of sharing genomic data through cinematography and further cultural resources. Indeed, in the last decades, scientists have been able to communicate their advances and discoveries through these means and to express ideas with the use of living things to make art (bio art). Undoubtedly, this strategy is essential to influence people's decision and improve their thrust when using those kinds of test, as well as their consent in sharing genomic data.

Broadly, this policy advice takes into consideration the implications of stakeholders, as well as their engagement to align practice recommendations with social needs and expectations. Moreover, these measures are possible strategies, since private companies may have the financial means to give access to adequate platforms and production of required material for scientific dissemination and advances in genomic technologies.