The 1000 Genomes Project Can’t become a basis for discrimination

Eric Green, director of the US National Human Genome Research Institute, has played a key role in research aimed at decoding the human genome. He is now involved in the ‘1000 Genomes’ research project which collects, studies and profiles the genetic maps of several diverse population groups, this complex data’s destination being the public domain, Green spoke with Smita Panday about the genetic research project, the vital contributions it aims at and managing possible drawbacks around it:

What is the ‘1000 Genomes Project’?

The 1000 Genomes Project aims to study the genetic maps of 2,500 people from 27 populations around the world. The first phase was to sequence and genotype 1000 samples that were available. The goal is to find most human genetic variations, which will then be used to discover diverse genetic contributions to health and disease. The data will be helpful in determining which genes contribute to the diseases.

In the project, 300 of the samples come from populations with an ancestry from India, 100 come from Bangladesh and 100 come from Pakistan.

Have you needed to work closely with research institutes in India in order to access genetic data on populations of Indian origin?

Samples from people of Indian ancestry are coming from other countries, like the United Kingdom and the United States, to which these people migrated. Despite considerable efforts to convince Indian researchers to participate in the 1000 Genomes Project, they were unable to agree about how to collaborate in the endeavor.

Eric Green, director of the US National Human Genome Research Institute

How will the ambitious aim of putting genetic data in the public domain help the scientific community?

All researchers looking for genetic contributions to disease risk, protection from disease risk or response to therapies will be able to use the data for free. Researchers focusing on a specific disease will be able to compare the individuals in their study to this international reference catalogue of human genetic variants. This will accelerate research on all diseases and human traits.

Yet, so much personal data is being made public via the project. Doesn't the move hold the potential to create discrimination based on a person's genetic profile?

The 1000 Genomes Project is not collecting any medical or personally identifiable information on the people who came forward and donated blood samples. Therefore, the project itself cannot become a basis for discrimination based on genetic profiles. But countries will need to regulate the use of the genetic risk information, so that people can utilize it productively to improve their health, rather than being afraid to use it.

In the United States, a law called the Genetic Information Nondiscrimination Act of 2008 bars the use of genetic information for decisions about employment or health insurance coverage. But regulating the use of any information - medical or genetic or otherwise - is a sovereign right for individual countries.

This has been a loaded issue through history - can your research now end up stoking sentiments of racism based on popular understandings of superior or inferior genetic profiles?

There is no evidence of the 'genetic superiority' of any population. People within populations are diverse, so some people are at higher risk for some diseases and lower risk for other diseases. Some genetic variants conferring risk for particular diseases are more common in some populations while other populations have variants conferring risk for other diseases. In the end, the balance between risk-conferring and risk-protecting genetic variants averages out across populations, so none is genetically better than any other.