Genomics in India: The Emerging Need for Legal Frameworks

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Context

India does not have a complete set of laws to oversee the sequencing, analysis, and understanding of genomes, despite notable progress in genomics. Foreign companies have been able to sequence and analyse Indian genome samples without much regulation or supervision.

Challenges in Genomic Research and Healthcare

- **Rare Genetic Diseases in India:** This is a rough estimate, as no exact figures are available, but it is known that rare genetic diseases in India affect 70 million people across the country. The felt need was a centralised clinical registry, which clearly defines rare diseases and the conduct of a country-level national rare disease survey in India for the first time ever.
- **Ethical and Policy Issues:** Other drawbacks that come with genomic advancements are sensitive ethical and policy issues, including concerns for privacy, the right to research findings, and technology implications for gene editing.
- **Data Sharing and Equity in Genomic Studies:** The global genomics community is slowly moving its focus from equitable data sharing to include conversations about transparency and sovereign control by participants over their data. Equitable data sharing would, therefore, mean more participation in research and a greater outreach of its participants, ensuring, by default, better diversity in representations in genomics.

Importance of Genomics in India

- Work on human genomics had started in India with the sequencing of the first genome in the year 2009 and had reached up to 1000 genomes by the year 2019, recently completed to 10,000 genomes.
- Effort has brought valuable insight into the diseases and prevalence of conditions, therefore assisting in the research and decision-making.
- However, India needs to ensure that the benefits of genomics reach its large and diverse population.
- To achieve this, a well-designed legal and policy framework and involvement of the industry are necessary.

Need for Legal Framework

- **High Prevalence of Genetic Disorders in the Country:** One of the major burdens in the country is a large number of rare genetic diseases. It should be contained through the establishment of the clinical registry together with clear definitions and policies about the management of the disease. If proper legislation is not guaranteed and does not ensure proper coverage in the health programs, then there are chances that these rare diseases might be mismanaged and neglected.
- **Privacy and Ethical Issues:** With these genomics advances, more ethical dilemmas, particularly those related to privacy and predisposition to potential discrimination, will become more inevitable. Thus, India now needs to have legislation for the protection of individual genetic information from misuse, ensure consent by an individual, and deal with the ethical considerations involved in genetic testing and research.
- **Equity and Access in Genomic Research:** In the present world, genomic research has really turned out to be homogenous, and there has been much need for diversity. There should be equal participation in genomic studies for the Indian population, which has a huge genetic diversity. Laws need to be put in place that ensures it reaches every section of society, hence ensuring there is no disparity in access to genomic medicine and technologies.
- **Regulation:** The Indian legal framework has a more environmental and food safety-centric bias for genetically engineered organisms. In that perspective, what really is the need of the hour is a well-drafted comprehensive legal framework for use in genomics in healthcare, biobanking, and genetic research.

Conclusion

To effectively address the challenges of genomics in India, a strong legal framework is necessary. This framework should protect individuals, promote equal access to genomic advancements, address ethical and privacy concerns, and effectively manage genetic diseases. It is not only a regulatory requirement but also an important step towards the responsible and fair application of genomic science in India.

Source: The Hindu

Q.*Discuss the role of genomics in shaping healthcare, agriculture, and biodiversity conservation in India. Highlight the challenges and opportunities associated with the integration of genomic technologies into these sectors. How can policymakers facilitate the responsible and equitable deployment of genomics for the benefit of society?*