

GOVERNMENT OF INDIA
MINISTRY OF SCIENCE & TECHNOLOGY
DEPARTMENT OF BIOTECHNOLOGY

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UNSTARRED QUESTION No. 447

ANSWERED ON 06.02.2025

Genome India Project

447 Shri Sanjeev Arora:

Will the Minister of Science and Technology be pleased to state:

- (a) the percentage of the Genome India Project samples collected from rural, urban and tribal populations separately;
- (b) the challenges faced in ensuring equitable representation of these populations; and
- (c) the steps being taken to overcome these challenges?

ANSWER

MINISTER OF STATE (INDEPENDENT CHARGE) FOR THE MINISTRY OF SCIENCE
AND TECHNOLOGY & EARTH SCIENCES

(DR. JITENDRA SINGH)

(a) Approximately, 36.7% of the samples were collected from rural, 32.2 % were from urban and 31.1 % were from the tribal populations.

(b) In the GenomeIndia project, equitable representation from rural, urban and tribal population was ensured. However, to achieve this goal, the researchers involved in GenomeIndia project faced some challenges, as outlined below.

- **Geographic Accessibility:** Reaching tribal remote regions to collect samples and gather data from these populations was difficult task.
- **Cultural and Socioeconomic Barriers:** Overcoming socioeconomic and cultural barriers and convincing such populations for their participation in the project was challenging.

- **Lack of Awareness and Education:** Rural and tribal populations are not having sufficient awareness of the benefits of genetic research, that led to misunderstandings about its purpose and value. Educating and convincing such populations was hard.
- **Data Representation and Bias:** Rural and tribal populations were not easily accessible and on the contrary, urban populations were often more accessible and had greater awareness. Hence, removal of bias by ensuring participation of appropriate proportions of all types of populations was important.
- **Logistical Constraints:** Insufficient accessibility to state-of-art healthcare infrastructure, laboratories, and skilled professionals in isolated regions made it challenging to collect samples and conduct blood parameter assessments.

(c) Under GenomeIndia project, a reference genome for the Indian population with equitable representation from rural, urban and tribal population has been developed. The GenomeIndia Team followed pre-planned strategies to overcome the above challenges. Nearby logistics hubs were established for sample transportation, and laboratories were approached in advance to prepare resources for handling a higher number of samples. Additionally, partnerships with local healthcare institutions were formed to streamline data collection and improve accessibility. Involvement of local leaders and community representatives in interactions with rural and tribal populations helped to mitigate cultural and socioeconomic barriers, to build trust and promoted a greater participation by rural and tribal populations. Outreach programs and community engagements, making the populations aware about the importance of genetic studies and to assure them on data confidentiality made to dispel myths and clarify the goals of the GenomeIndia project. Moderated campaigns were organized to ensure a balanced inclusion of diverse groups. Logistic constraints in isolated regions were handled with systematic planning.
