

How India's National Biobank can power next frontier in healthcare

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For the healthcare industry, the National Biobank opens opportunities to co-create value

In 1996, the term biobank was first used by researchers Steffen Loft and Henrik Enghusen Poulsen to describe the use of human biological material in studying cancer risk factors. Since then, biobanking has evolved into a cornerstone of medical innovation worldwide, powered by advances in genomics, proteomics, metabolomics and the ability to analyze vast patient-linked datasets. Globally, it has emerged as one of the most powerful engines of discovery, accelerating drug development, strengthening diagnostics and enabling healthcare systems to move from reactive to predictive care.

India has now entered this frontier with the launch of the Phenome India National Biobank at the CSIR–Institute of Genomics and Integrative Biology (IGIB). Backed by the Council of Scientific and Industrial Research (CSIR), this initiative is designed to build a longitudinal health database that reflects India's vast ethnic, regional and socio-economic diversity. Inspired by the UK Biobank, but tailored to India's unique health landscape, it aims to collect genomic, clinical and lifestyle data from 10,000 individuals across the country.

The National Biobank is not just a repository of samples and stays as the foundation of a predictive and personalized healthcare ecosystem for 1.4 billion people. By generating India-specific datasets, it will help address questions that Western health models cannot, such as why diabetes manifests at lower body weights in Indians or why cardiovascular disease strikes earlier here than in other populations. These insights are vital for tackling India's distinct health challenges.

The potential impact, however, is far-reaching.

The Biobank will accelerate research into complex diseases such as cancer, cardiovascular disorders, diabetes and rare genetic conditions. It will enable early diagnosis and precision treatments while also supporting frontier technologies like AI-powered diagnostics, CRISPR-based therapies and disease-pattern mapping.

CSIR-IGIB, which has pioneered genomics in India through breakthroughs in genetic diagnostics, COVID-19 genome sequencing and rare disease research, is bringing its scientific leadership to the initiative. With its focus on indigenous, scalable solutions, the Biobank represents a major step toward healthcare self-reliance and future-ready personalized care systems.

At the same time, several critical challenges must be addressed to unlock the full potential of the National Biobank. For instance, while the Digital Personal Data Protection Act, 2023 (DPDPA) is a landmark step in introducing global-standard safeguards such as consent, purpose limitation, and the right to erasure, several gaps persist for biobanking.

The law gives individuals—called “data principals” the right to control how their genetic data is used, shared, or stored. However, the lack of biobank specific rules makes its application unclear for complex scientific practices. Similarly, DPDPA also permits cross-border data sharing to support international research, but this could expose Indian genomic data to privacy risks if not carefully regulated.

On the socio-ethical front, without robust legal and institutional safeguards, genetic data stored in biobanks could be misused by third parties such as insurance companies, employers, or commercial entities. This could result in denial of health coverage, employment discrimination, or even targeted advertising based on inferred health risks. The opacity of many data-sharing agreements only deepens these concerns.

Additionally, for a country like India where caste, class, and gender biases already shape opinions, the risk of genetic discrimination is particularly pressing. For instance, individuals whose genetic data indicates potential health risks such as cancer, cardiovascular disorders, or rare genetic conditions may face social exclusion, stigmatization, or economic disadvantage.

To counter such risks, community engagement will be equally vital. By fostering trust, addressing ethical concerns, and ensuring that research reflects social values and priorities, biobanking can secure both legitimacy and participation. This will require inclusive governance through advisory boards, open dialogue via public meetings and focus groups, and collaboration on research design to guarantee transparency and shared benefits.

Furthermore, our healthcare system must evolve, investing in new infrastructure and re-training healthcare professionals so they can integrate biobank-generated insights into clinical care. Sustaining this momentum will depend on consistent funding, progressive policy support, and active collaboration from the private sector.

For the healthcare industry, the National Biobank opens opportunities to co-create value. Industry players can help build the pipelines that translate discoveries into affordable diagnostics, therapies and digital health solutions. Collaboration between government, academia and industry will be essential to ensure that discoveries move beyond research papers and translate into real-world benefits for people. Its success, however, will not be determined by vision alone but by the collective commitment of all stakeholders to perfectly execute, scale and measure impact.

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