

From Genomic Data to Genomic Governance: Why Pakistan Needs Responsible Data Sharing?

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The rapid development of genomics has transformed the biomedical research and healthcare. Advances in next-generation sequencing (NGS), bioinformatics and computational biology have made it possible to generate and analyze genomic information at a scale that was difficult to imagine only a few decades ago. Genomic technologies are increasingly contributing to the diagnosis of rare diseases, understanding disease susceptibility, infectious disease surveillance, pharmacogenomics and precision medicine.^{1,2} For Pakistan, where inherited disorders and other complex health conditions represent important public-health challenges, genomics offers considerable opportunities for improving disease prevention, diagnosis and treatment. However, the increasing ability to generate genomic information has created a corresponding need to consider how such data should be governed.

Unlike many conventional health records, genomic information is inherently sensitive and connected not only to biological relatives but in some conditions to a wider group of population. Genomic data may retain a potential for re-identification when combined with other datasets even after removal of direct identifiers.³ Sharing of genomic data across institutional and national borders adds more complexity to these challenges. International collaboration and access to global genomic data is important for research progression, especially for the populations that are less represented in genomic studies, but at the same time, it raises questions regarding informed consent, data access, use of secondary data, data security,

benefit sharing and the responsibilities of researchers and institutions receiving the data.⁴ The ethical question therefore is not sharing of genomic data, but under what conditions they should be shared responsibly?

In 2024, the World Health Organization (WHO) issued guidance establishing principles for the collection, access, use and sharing of human genome data.⁵ Similarly, the Global Alliance for Genomics and Health (GA4GH) have also emphasized the appropriate sharing of genomic and health-related data by governance structures that balance scientific usefulness with human and social needs.

A major phase in this approach is set to begin in Pakistan. The Ministry of National Health Services, Regulations and Coordination (MNHSR&C) conducted a national consultation on Pakistan's proposed National Genomic Policy in June 2026, reflecting the increasing recognition of genomics as a crucial element of precision medicine, health security, and disease prevention.⁶ The National Genomic Surveillance Strategy (Pakistan) 2026 has also been incorporated into national plans by the National Institutes of Health (NIH). These achievements demonstrate the growing importance of genomic capacity in Pakistan's health policy. Additionally, they turn genetic data governance from a distant issue to an urgent governmental concern. However, developing a national genomic policy and boosting sequencing capacity are only two aspects of Pakistan's readiness for the demands of the genomic age. Additionally, a strong local ethical and legal framework is required.⁷

The National Bioethics Committee (NBC) of Pakistan took a major step toward building this infrastructure as it started registering institutional Review Boards (IRBs) and Ethical Review Committees (ERCs) with the NBC in July 2026. The effort aims to increase institutional ethical monitoring as part of the national research governance framework.⁸ The notion is especially important to genetic research, where ethical issues

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Received: 20 August 2026, **Accepted:** 24 September 2026

Published: 27 October 2026

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may affect families, communities, and populations beyond individuals. But rather than being an objective in itself, registration should be seen as a starting point. Appropriately formed committees, standardized protocols, ongoing training in cutting-edge fields like genomic data and secondary usage, quality control, and efficient coordination between institutional ethical committees and national oversight mechanisms are all necessary for sustainable supervision.

The NBC has published several national guidelines and frameworks including those on human biological materials (HBM), stem cells, human organ transplants, ethical review (NBC-ERC), and ethical healthcare decision-making during outbreaks covering areas such as the collection, use, storage, and transfer of biological materials.^{9,10} These frameworks offer a key foundation for creating more specialized governance systems for biological materials and genetic data.

The objective should not be to create unnecessary barriers to scientific collaboration. Excessively restrictive systems may limit research and disproportionately disadvantage researchers and populations in resource-constrained settings. Inversely, unrestricted sharing of data without appropriate safety measures may weaken the public trust. Responsible governance should therefore seek an appropriate balance between scientific openness and protection of rights.

Pakistan now has an opportunity to establish a framework based on the principle of responsible genomic data sharing. The future of genomic medicine in Pakistan will depend not only on our ability to sequence genomes, but also on our ability to govern the information generated from them. Strengthening institutional ethics oversight alongside national genomic policy and data-governance mechanisms can enable Pakistan to participate more effectively in international genomic research while protecting the privacy, dignity, rights and interests of its population.

Conflict of Interest: None declared.

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