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Editorial

Evaluating the Legal Framework for Thalassaemia Prevention and Control in Pakistan

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Thalassaemia, a preventable genetic blood disorder, continues to impose a significant burden on Pakistan's healthcare system.[1] Despite advances in medical science and the availability of cost-effective preventive strategies, the country continues to report new thalassaemia major births each year.[2] In response to this public health challenge, the provinces of Sindh (2013),[3] Balochistan (2015),[4] and more recently Punjab (2025)[5] have enacted legislation aimed at the prevention and control of thalassaemia. While these legislative frameworks represent a commendable policy shift, a critical appraisal reveals several structural, operational, and implementation gaps that must be addressed to ensure real-world impact.

The existing provincial laws share a common framework in terms of objectives and key provisions. All three Acts emphasize public education, premarital screening, antenatal testing, and the establishment of institutional structures to oversee implementation. The legislation in Sindh and Balochistan, for instance, mandates the formation of dedicated Boards or Foundations to centralize control and disburse funds, whereas Punjab has taken a more direct regulatory approach without yet establishing an oversight authority.

One of the key strengths across all three legislations is the explicit requirement for premarital screening and genetic counseling, particularly among high-risk groups such as blood relatives of known thalassaemia patients. However, this is mandated without properly taking into consideration the peculiar dynamics of thalassaemia in Pakistan (nonrandom distribution of thalassaemia genes) and the current state of the primary and secondary health-care systems.

The laws also allow non-governmental organizations (NGOs) to participate in service provision, thereby opening the door for collaboration with civil society and private sector stakeholders.

Another notable feature is the mandate to allocate a percentage of budgetary resources (10%) by NGOs for the development of diagnostic and prenatal services. This is a proactive step that ensures sustainable investment in prevention infrastructure.

Despite these legislative advances, the operationalization of these laws remains inadequate. First, none of the Acts outline clear timelines, performance indicators, or monitoring frameworks to assess the implementation status. This absence of accountability structures has resulted in sporadic and inconsistent enforcement, particularly in rural and underdeveloped areas. Secondly, while the Sindh and Balochistan Acts establish Boards or Foundations, their roles are vaguely defined, and governance structures are left to be determined by later notifications. The Punjab legislation, although more recent, does not establish any similar institutional oversight body, relying instead on directives to existing healthcare facilities. This lack of a centralized authority in Punjab could hinder coordination, data collection, and policy adaptation.

Moreover, financial provisioning and resource mobilization remain largely aspirational. Although the Sindh and Balochistan Acts speak of funding mechanisms, they do not provide clarity on actual budgetary allocations from the provincial exchequers or the specific financing models to be adopted.

All three laws underscore the importance of informed consent for genetic and antenatal testing, a crucial element in protecting individual autonomy and aligning with ethical standards. However, the

practical implementation of informed consent processes remains weak, particularly in lower-literacy populations where understanding of genetic risks is limited.

The penalties outlined for non-compliance are relatively mild and focused predominantly on health care facilities, with little attention to systemic failures such as the non-availability of diagnostic services or the lack of training for healthcare providers. Moreover, there is minimal focus on community-based education and engagement strategies that are essential in culturally sensitive areas where genetic disorders are often stigmatized.

Health being a devolved subject under the 18th Amendment, provinces have moved independently with varying levels of commitment and capacity.[6,7] Therefore, perhaps the most glaring gap in Pakistan's thalassaemia legislative landscape is the absence of a harmonized, nationwide framework. However, thalassaemia prevention requires cross-border coordination, standardization of testing protocols, central data registries, and unified public messaging. The lack of a National Thalassaemia Policy is a critical shortcoming.[8] Despite the magnitude of the disease burden and repeated calls by medical professionals and patient advocacy groups, no federal-level strategy or guideline currently exists to define long-term goals, align provincial efforts, or ensure uniform standards of care and prevention. In the absence of such a policy, initiatives remain fragmented, reactive, and heavily dependent on provincial priorities and donor interest. The absence of a National Thalassaemia Registry or a federally endorsed screening policy further exacerbates the issue, leading to duplication of efforts, data silos, and missed opportunities for epidemiological surveillance.

Furthermore, provincial disparities in legislative design may lead to healthcare inequities, where access to diagnosis and counseling varies drastically based on geographic location. For instance, a resident in a major city may have access to well-funded thalassaemia centres, while a rural inhabitant may be unaware of their carrier status due to inadequate outreach and diagnostics.

To make meaningful progress, the it is vital to have strategic directions and policy decisions. These include, (1) formulating a National Thalassaemia Policy, offering technical guidance, financial support, and data governance to all provinces;[9] (2) constituting a Federal-Provincial Task Force on Thalassaemia Prevention to harmonize policies, standardize practices, and ensure equitable implementation across all regions; (3) institutionalizing autonomous Boards or Authorities in provinces with defined powers, responsibilities, and performance indicators to oversee the respective Act's enforcement; (4) evolving towards a model where premarital thalassaemia screening is not merely recommended but mandatory, supported by subsidized testing and robust counseling services; (5) expanding genetic counseling and diagnostic infrastructure particularly in underserved districts. Integration with existing maternal and child health programmes can provide cost-effective solutions; (6) launching a nationwide awareness campaigns using media, schools, religious institutions, and health workers, to reduce stigma and promote voluntary compliance; (7) creating a national thalassaemia carrier registry to map carrier prevalence, monitor trends, and inform future policy planning; and (8) integrating education on genetic diseases and the importance of screening into biology and health science curricula at the high school level.

Pakistan's legislative intent to combat thalassaemia is evident from the three provincial laws already in place. However, legislation alone is not sufficient. Effective prevention requires institutional clarity, financial commitment, community engagement, and interprovincial coordination. The introduction of the 'Islamabad Capital Territory Compulsory Thalassaemia Screening Bill, 2025' and the 'Khyber Pakhtunkhwa Prevention and Control of Thalassaemia Bill, 2025' presents a timely opportunity to adopt a harmonized, evidence-based, and implementation-focused model, which can set the benchmark for other regions. Thalassaemia is preventable, with the right legal instruments and political will, Pakistan can dramatically reduce the disease burden and protect future generations.

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