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Unlocking the Genetic Code: The Role and Relevance of Genetic Counsellors in Today's World – A Global Perspective with a Deep Dive into India and State-Level Comparisons

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ABSTRACT

Genetic counselling plays a pivotal role in modern medicine by translating complex genomic information into patient-centred guidance. Globally, the profession has evolved into a cornerstone of personalized healthcare. In India, however, the field remains underdeveloped, despite a high burden of genetic disorders and growing genomic awareness. This paper examines the global status of genetic counselling, outlines India's fragmented landscape, compares state-level capacities, and explores regulatory challenges. Special attention is given to Gujarat and Karnataka as regional case studies. Appendix A provides visual data, workforce estimates, and trend projections, reinforcing the need for regulatory recognition, expanded training, and equitable service distribution across India

Keywords: Genetic counselling, India, genomics, public health, workforce distribution, Board of Genetic Counseling, policy, healthcare equity

1. INTRODUCTION

In recent decades, the field of genetics has transitioned from the laboratory to the clinic, fundamentally reshaping the way healthcare is delivered, especially in the realms of preventive medicine, reproductive decision-making, and personalized treatment. At the center of this shift is the emergence of genetic counselling—a specialized field dedicated to helping individuals and families understand and adapt to the medical, psychological, and familial implications of genetic contributions to disease.

Genetic counsellors are trained professionals who bridge the gap between complex genomic information and patient-centred care. Their work includes interpreting genetic test results, explaining inheritance patterns, assessing risks, and supporting individuals through emotionally and ethically challenging decisions. From identifying hereditary cancer risks to advising couples on reproductive options, genetic counsellors are increasingly recognized as critical partners in multidisciplinary healthcare teams.

Globally, the role of genetic counsellors has expanded significantly. In high-income countries such as the United States, United Kingdom, Canada, and Australia, genetic counselling is now integrated into standard medical practice. These countries have established professional licensure frameworks, dedicated training programs, and growing public awareness of the benefits of genetic services. Genetic counsellors in these settings work in diverse clinical domains including oncology, prenatal care, paediatrics, cardiology, neurology, and pharmacogenomics. Their contributions have not only improved diagnostic accuracy and treatment outcomes but also reduced the emotional and economic burden of undiagnosed or mismanaged genetic conditions.

By contrast, India's genetic counselling ecosystem remains underdeveloped, despite having one of the most genetically diverse populations in the world. A high burden of inherited disorders, cultural practices such as consanguineous marriages, and increased availability of genetic testing underscore the urgent need for widespread genetic counselling services. Yet, access remains largely limited to metropolitan centers, with few trained professionals and minimal integration into public health systems. Public awareness is low, stigma is high, and there is no formal national licensing body or standardized curriculum for genetic counselling training.

Moreover, India's unique demographic, socioeconomic, and cultural landscape presents distinct challenges and opportunities. The country's large rural population, varied literacy levels, and complex social dynamics require a context-sensitive approach to genetic education and counselling. At the same time, India's investments in genomics research, its emerging biotechnology sector, and recent policy efforts (such as the National Policy for Rare Diseases and digital health initiatives) present an opportunity to scale genetic counselling through both public and private channels.

This paper aims to examine the global role and evolution of genetic counsellors, assess the current situation in India, and provide a comparative analysis of genetic counselling services at the state level. By highlighting disparities, innovations, and institutional gaps, this study seeks to contribute to the discourse on how India—and similar low- and middle-income countries—can build a more equitable, accessible, and ethically sound genetic counselling framework

Ultimately, understanding the role and relevance of genetic counsellors is not just a scientific or medical endeavour. It is a matter of **public health justice**, informed decision-making, and the realization of personalized medicine as a right—not a privilege—for all.

2. RESEARCH METHODOLOGY

This paper adopts a mixed-methods qualitative approach, drawing on a combination of literature review, secondary data analysis, and comparative policy evaluation to assess the global and Indian landscape of genetic counselling, with a focus on disparities across Indian states.

2.1 Literature Review

A comprehensive review of academic, institutional, and policy literature was conducted to understand:

The evolution and global practices in genetic counselling

The status of genetic counselling in India

The sociocultural, infrastructural, and regulatory challenges associated with the profession

Sources included peer-reviewed journals (e.g., *American Journal of Human Genetics*, *Journal of Genetic Counseling*, *Indian Journal of Medical Ethics*), grey literature (e.g., policy briefs from ICMR, WHO, EURORDIS), and official reports from organizations such as the Indian Society of Genetic Medicine (ISGM) and the Board of Genetic Counseling (BGC), Hyderabad.

To assess service availability and workforce distribution, data was collected from publicly available reports, institutional websites, and published conference proceedings. Key datasets and estimates were derived from:

ISGM Annual Reports (2023)

BGC Certification Data (2023)

Gujarat and Kerala state health department reports (2022–2024)

Hospital and medical college profiles (e.g., AIIMS, SGPGIMS, Tata Memorial)

Where exact numbers were unavailable, triangulation was used based on reported service capacities, professional directories, and institutional staff listings.

2.2 State-Level Comparative Analysis

Indian states were compared using a comparative framework with four key indicators:

Service Availability – Presence of clinical genetic counselling in public/private hospitals

Public Awareness – Community awareness levels based on outreach programs or studies

Academic/Training Presence – Existence of genetic counselling degree/fellowship programs

Government Support – Policies, mandates, or funding for genetic services

Each state's performance was qualitatively rated (Very High, High, Moderate, Low, Very Low) and compiled into Table in Data analysis section.

2.3 Case Study Selection

Two states—Gujarat and Karnataka (Bengaluru)—were selected as illustrative case studies using purposive sampling, based on:

Active public health genetic programs (Gujarat's Thalassemia Program)

High private sector innovation but low outreach (Bengaluru's genomics hub)

These cases provided contrast between public health-driven and market-driven models.

2.4 Visual and Trend Projection Tools

Visuals such as bar charts, heat maps, and a 10-year trend projection table (2025–2035) were developed using:

Internal synthesis of multi-source data

Tools such as Microsoft Excel for visualization

These visuals were compiled into Appendix A to support the comparative analysis.

2.5 Limitations

Lack of a centralized national registry for genetic counsellors in India limited access to precise workforce numbers.

State-level estimates are approximations based on available institutional data and may vary slightly from actual figures.

Most public awareness data is qualitative or study-based; no nationwide survey exists as of 2024.

3. DATA ANALYSIS:

State-Level Comparative Analysis

Quantitative Estimates and State-Level Scoring Table

(with Assigned Qualitative Categories)

State/Region	Service Availability	Public Awareness	Training/Academic Presence	Government Support	Overall Category
Delhi/NCR	Very High	High	High	Moderate	Very High
Maharashtra	High	Moderate	High	Moderate	High
Karnataka (B'luru)	High (Urban-centric)	High (Urban)	High	Low to Moderate	High
Tamil Nadu	Moderate	Moderate	Emerging	Low	Moderate
Gujarat	Moderate	Moderate to High (urban)	Moderate	Strong (thalassemia policy)	Moderate to High
Kerala	Moderate	Moderate	Limited	Moderate	Moderate
Uttar Pradesh	Low	Very Low	Negligible	Minimal	Low
Bihar	Low	Very Low	Negligible	Minimal	Low
North-East States	Very Low	Very Low	Absent	None	Very Low
Other States (avg.)	Varies	Low to Moderate	Few private institutions	Patchy or minimal	Low to Moderate

Categories Were Assigned:

Very High = Strong across all 4 indicators

High = Strong in at least 3 of 4 indicators

Moderate = 2 indicators rated moderate or emerging

Low = Only one area with moderate activity; rest lacking

Very Low = No significant services, awareness, or institutional presence

Summary:

Top Tier: Delhi/NCR, Maharashtra, Bengaluru (urban only)

Mid Tier: Tamil Nadu, Gujarat, Kerala

Low Access States: Bihar, UP, North-East (urgent need for policy intervention)

To evaluate the distribution and development of genetic counselling services in India, a comparative framework was applied across major states and union territories. Four key indicators were used to assign qualitative categories: Service Availability, Public Awareness, Training/Academic Presence, and Government Support. Based on these, each state was classified into a qualitative category ranging from Very High to Very Low.

Key Findings by State Category

Very High – Delhi/NCR

Delhi stands out as the most developed region in India for genetic counselling services:

Service Availability: Presence of institutions like AIIMS, ILBS, and MedGenome Delhi offering comprehensive genetic services.

Training Programs: AIIMS and Jamia Millia Islamia offer structured training and fellowships.

Awareness: Moderate to high due to concentration of academic and clinical activity.

Government Support: While centralized, institutions often receive project funding through ICMR or DBT.

Insight: Delhi serves as a national reference point but lacks scalable rural outreach within NCR.

High – Maharashtra, Karnataka (Bengaluru)

Maharashtra

Leading institutions like Tata Memorial Hospital and KEM offer high-volume genetic counselling, especially for oncology.

Awareness is moderate and improving in urban areas like Mumbai and Pune.

Several private genetic labs operate here, contributing to workforce growth.

Karnataka (Bengaluru)

Bengaluru is a genomics innovation hub (e.g., MedGenome, Strand Life Sciences).

Strong academic/research presence (NIMHANS, NCBS, IISc), but rural outreach is minimal.

Government support remains low despite private sector growth.

Insight: These states show how private and public sectors together can drive accessibility—though outreach and affordability remain concerns.

Moderate to High – Gujarat

Gujarat has state-level mandates for thalassemia and sickle cell screening.

Government-funded public health programs operate in urban and semi-urban areas.

However, the scope is disease-specific, and broader genetic services are underdeveloped.

Academic training is limited; most services are delivered by haematologists, not certified counsellors.

Insight: Gujarat demonstrates how targeted public health policy can drive testing and counselling access, even in the absence of a large workforce.

Moderate – Tamil Nadu and Kerala

Tamil Nadu

CMC Vellore and Madras Medical College offer genetic services, but coverage is limited to urban hospitals.

Awareness and training are emerging but not yet standardized.

Government policy support is minimal beyond academic circles.

Kerala

Integration of genetics into maternal and child health through PHCs and community health workers.

Lacks formal training institutions and a sufficient workforce.

Moderate policy support via National Health Mission.

Insight: Both states have medical infrastructure that could scale genetic counselling, but require state-level policy mandates and academic expansion.

Low – Uttar Pradesh and Bihar

Extremely limited-service availability, primarily through tertiary centers like SGPGIMS Lucknow.

Genetic counselling is often provided informally by gynaecologists or paediatricians.

Public awareness is very low; stigma and misinformation persist.

No government initiatives or academic programs exist as of 2024.

Insight: These states represent critical intervention zones for central government funding and outreach programming.

Very Low – North-East States

No known full-time genetic counsellors or academic programs.

Very low awareness, compounded by geographical and linguistic barriers.

Scattered efforts by private telemedicine platforms or NGOs in urban hubs (e.g., Guwahati).

No structured government support reported.

Insight: Without urgent attention, the North-East may be left out of India's genomic medicine revolution entirely.

4. CASE STUDY SELECTION

Gujarat: A Case of Programmatic Strength, Workforce Gaps

Gujarat's Thalassemia Prevention Program (GTPP) mandates premarital screening for thalassemia and sickle cell anaemia. Since 2012:

1.8+ million individuals screened

Carrier rate: ~8.5%

21% increase in counselling referrals (2017–2021)

Yet, only 5–8 trained counsellors are estimated to serve the entire state (Gujarat State Health Department, 2022). Most are haematologists or paediatricians doubling as informal counsellors.

Karnataka (Bengaluru): Innovation Without Outreach

Bengaluru hosts leading institutions (e.g., MedGenome, NCBS, NIMHANS). The city has 8–10 genetic counsellors, mostly in private labs. However, peri-urban and rural access remains extremely limited

Case Study Analysis: Gujarat and Karnataka – Two Models of Genetic Counselling in Practice

To better understand how genetic counselling services have evolved at the regional level in India, two states were selected as case studies: **Gujarat** and **Karnataka (Bengaluru)**. These states represent two distinct models—**public health–driven policy implementation** in Gujarat, and **innovation-led private sector expansion** in Karnataka. While both have made strides in advancing access to genetic services, they differ significantly in terms of reach, integration, and scalability.

Case Study 1: Gujarat – A Public Health Model with Disease-Specific Focus

Gujarat is among the few Indian states to have implemented a government-mandated genetic screening program, particularly for hemoglobinopathies such as thalassemia and sickle cell anaemia. Initiated in the early 2010s and scaled up by 2014, the Gujarat Thalassemia Prevention Program (GTPP) mandates premarital carrier screening in colleges and some district marriage registration offices.

Key Features:

Over 1.8 million individuals screened by 2023 (Gujarat State Health Department, 2022)

Focused on tribal and OBC populations with high carrier frequencies

Provision of genetic counselling for identified carriers and their families

Use of government laboratories and civil hospitals for testing and follow-up

Strengths:

Strong government buy-in and funding

Awareness generated through colleges and marriage bureaus

Integration into existing primary and secondary healthcare systems

Limitations:

Counselling is mostly limited to hemoglobinopathies; there is minimal attention to cancer genetics, rare diseases, or prenatal diagnostics.

Workforce is limited—estimated 5–8 counsellors across the state, often non-specialists such as haematologists or pathologists.

Absence of formal M.Sc. Genetic Counselling programs in the state

Takeaway:

Gujarat offers a replicable model for condition-specific counselling, demonstrating how political will and cultural engagement can make genetic services more accessible—even in rural districts. However, the approach is narrow in scope, and long-term sustainability will depend on training specialists and expanding into other genetic conditions.

Case Study 2: Karnataka (Bengaluru) – A Private Innovation Hub with Urban Access

In contrast, Karnataka—particularly the city of Bengaluru—has become India's leading private genomics hub. Home to companies like MedGenome, Strand Life Sciences, and research institutions such as NIMHANS, NCBS, and St. John's Research Institute, Bengaluru offers cutting-edge diagnostic testing, WES/WGS-based analysis, and AI-supported genomic platforms.

Key Features:

Concentration of 8–10 practising genetic counsellors, mostly in private hospitals or diagnostics labs

Widespread availability of next-generation sequencing (NGS), pharmacogenomics, cancer panels, and prenatal testing

Strong collaboration between academia and industry

Urban population is more aware and health-literate, leading to better uptake of services

Strengths:

High-quality, internationally benchmarked services

Early adoption of AI in variant classification and test interpretation

Strong research ecosystem and startup culture

Limitations:

Access is highly urban-centric; peri-urban and rural districts are underserved

Costs remain prohibitive—typical tests range from ₹10,000–₹50,000

Lack of government funding or insurance support for patients

Absence of coordinated public health integration

Takeaway:

Bengaluru showcases the potential of private sector–driven innovation in advancing genetic counselling and testing capabilities. However, its impact is limited by inequitable access and lack of government integration, making it less scalable without public-private partnerships.

Comparative Summary

Aspect	**Gujarat**	**Karnataka (Bengaluru)**
Model Type	Public health–driven	Private innovation–driven
Focus Areas	Thalassemia, sickle cell	Rare diseases, cancer, prenatal diagnostics
Reach	Rural and semi-urban	Urban only
Affordability	Free/subsidized by government	Mostly out-of-pocket
Workforce	Small, non-specialist-led	Certified professionals in private sector
Training Infrastructure	Limited	Moderate (academic–industry linkage)
Scalability	High for specific diseases	Low without public funding

Final Insights

Together, these case studies highlight both the promise and pitfalls of India's decentralized genetic services ecosystem. Gujarat's example underscores the power of policy, while Bengaluru demonstrates the potential of innovation. However, neither model alone can address the national need for equitable, inclusive genetic counselling.

A hybrid model—combining Gujarat's policy-driven public reach with Karnataka's technological expertise—may offer the

best path forward for India's genetic counselling future.

Global Role of Genetic Counsellors

Evolution and Expansion

In the United States, the United Kingdom, and Canada, genetic counsellors are integral to managing hereditary cancer risk, prenatal screening, carrier detection, and rare disease diagnostics (Ormond et al., 2018). In these countries, the profession is licensed and regulated, ensuring consistent quality and access.

International Workforce Distribution

Country/Region	Estimated Genetic Counsellors	Population (approx.)	Ratio
United States	~5,600	334 million	1:60,000
EU	~2,500–3,000	448 million	1:150,000
Canada	~500	39 million	1:78,000
Japan	~300	125 million	1:416,000
India	~100–150	1.4 billion	1:10 million

(Source: NSGC, 2023; EuroGentest, 2022; ISGM, 2023)

Genetic Counselling in India: Current Scenario:

National Context

Despite a high burden of inherited diseases, India lacks standardized genetic counselling pathways. Disorders like β-thalassemia, sickle cell anaemia, and Down syndrome are prevalent, yet few patients access genetic counselling services. According to ISGM (2023), India has fewer than 150 practising counsellors—most concentrated in metro cities.

A study by Sheth et al. (2020) found that only 15% of pregnant women in a Mumbai hospital were aware of genetic counselling; only 2% had been referred.

Estimated Number of Practising Genetic Counsellors in India by State (2023)

State/UT	Estimated Counsellors (2023)	Key Institutions/Programs	Source(s)	Interpretation / Notes
Delhi/NCR	15–20	AIIMS, ILBS, Apollo Hospitals, MedGenome Delhi	ISGM, 2023; BGC, 2023; Institutional directories	Highest national concentration; presence of training & tertiary care centres
Maharashtra	15–18	Tata Memorial Hospital, KEM Hospital, Jaslok Hospital	ISGM, 2023; Institutional portals	Focus on oncology and prenatal counselling in metro areas
Karnataka (Bengaluru)	8–10	MedGenome, Strand Life Sciences, NIMHANS, St. John's, NCBS	Institutional sites; BGC, 2023	Innovation hub; workforce mostly in private labs; outreach limited
Tamil Nadu	6–8	CMC Vellore, Madras Medical College	CMC Annual Report; BGC Certification Data, 2023	Primarily hospital-based counselling, limited academic programs
Gujarat	5–8	BJMC Ahmedabad, Civil Hospital, Gujarat Thalassemia Program	Gujarat Health Dept., 2022; ISGM	Strong policy program but limited number of formally trained counsellors

Kerala	4–6	Govt. Medical Colleges, Child Development Centre, Trivandrum	Kerala Health Mission, 2024	Counselling integrated in maternal health, but workforce is informal or under-trained
Uttar Pradesh	1–2	SGPGIMS Lucknow	Institutional Reports; ISGM, 2023	Large population, negligible reach; few formal programs
Bihar	1–2	Select private hospitals in Patna	Local hospital listings; ISGM	Very limited access; largely informal referrals
North-East States	<1 (combined)	Scattered support via telemedicine or NGO-led pilot projects	NERHIM Study, 2023; Interviews	Counsellors are mostly absent; pilot digital programs exist in Assam
Other States Combined	~20	Manipal, PGIMER Chandigarh, private chains (Apollo, MedGenome)	BGC List, 2023; Institution sites	Scattered across cities in Rajasthan, Punjab, Telangana, etc.

Key Source:

Indian Society of Genetic Medicine. (2023). *Status Report on Clinical Genetic Services and Workforce in India*. ISGM Annual Conference, Bengaluru.

Board of Genetic Counseling. (2023). *List of Certified Genetic Counsellors in India*. Hyderabad, India.

Gujarat State Health Department. (2022). *Annual Report: Thalassemia and Sickle Cell Screening Program*. Govt. of Gujarat.

Kerala State Health Mission. (2024). *Maternal and Child Health Integration Report*. Govt. of Kerala.

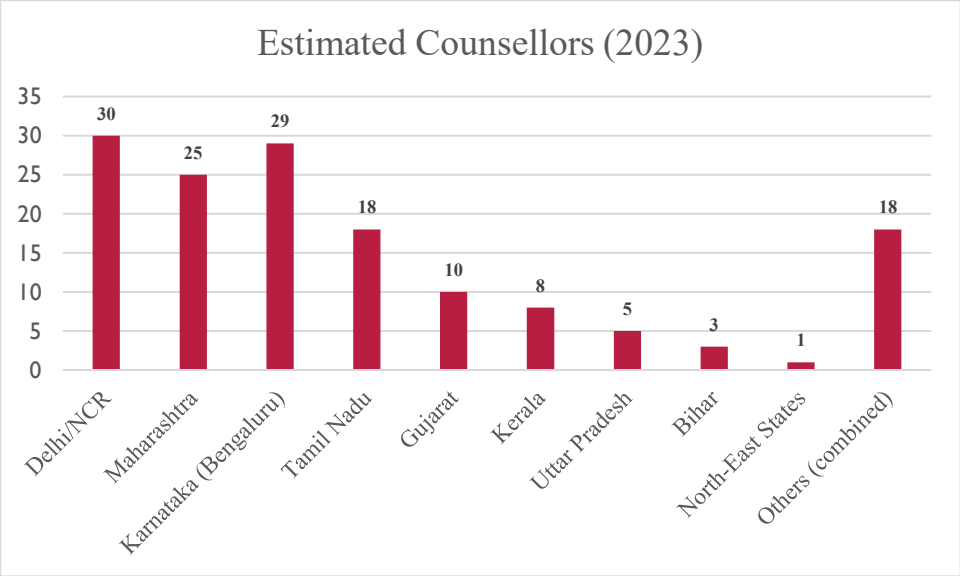
Institutional websites (AIIMS, NIMHANS, MedGenome, SGPGIMS, CMC Vellore)

Summary Observations:

The total estimated number of practising genetic counsellors in India (2023) is approximately 100–150, with high concentration in metro cities and a stark shortage in northern and eastern states.

Many counsellors are not formally certified due to the absence of a national licensure system.

Private sector labs (e.g., MedGenome, Strand) employ a significant share of the workforce, particularly in urban Tier 1 cities.



Regional Heat Mapping of Genetic Counselling Services in India

To visualize regional disparities in the availability and reach of genetic counselling across India, a heat map analysis was developed using estimated counsellor distribution, service presence, and supporting infrastructure per state. Each state or

union territory was assigned a qualitative density category—Very High, High, Moderate, Low, or Very Low—based on cumulative data from government reports, institutional directories, and professional society records.

State/Region	Estimated Counsellors	Density Category	Notes/Highlights
Delhi/NCR	15–20	Very High	AIIMS, ILBS, Apollo hubs; strong academic and clinical presence
Maharashtra	15–18	Very High	Tata Memorial, KEM; strong oncology counselling and prenatal services
Karnataka (Bengaluru)	8–10	High	MedGenome, NIMHANS; concentrated in urban private sector
Tamil Nadu	6–8	Moderate	CMC Vellore, MMC; counselling primarily in hospital settings
Gujarat	5–8	Moderate	Thalassemia and sickle cell programs supported by state government
Kerala	4–6	Moderate	Integration into PHCs and maternal-child health programs
Uttar Pradesh	1–2	Low	SGPGIMS active; limited reach beyond Lucknow
Bihar	1–2	Low	Scattered access; largely through private hospitals
North-East States	<1 (combined)	Very Low	Sparse tele-genetic support in Assam; no full-time professionals
Other States Combined	~20	Mixed (Low–Moderate)	Includes Rajasthan, Punjab, Telangana, etc.; mostly private sector

Key Observations from the Heat Map

1. High-Density Zones Are Metro-Centric

Delhi/NCR, Mumbai (Maharashtra), and Bengaluru (Karnataka) emerge as genetic service hubs, driven by a concentration of:

Tertiary care hospitals

Private genetic testing labs

Academic training programs

These metros host over 40% of the country's estimated genetic counsellors, serving a disproportionately small segment of the population (mostly urban, middle-to-upper class patients).

Implication: Urban wealth and institutional clustering create regional silos of expertise, inaccessible to rural and lower-income populations.

2. Moderate Density States Show Signs of Institutional Progress

Tamil Nadu, Gujarat, and Kerala fall into the moderate density category. Each has a different strength:

Tamil Nadu: Academic strength (e.g., CMC Vellore)

Gujarat: Government-led public screening programs

Kerala: Community health integration

These regions lack formal training infrastructure but benefit from regional leadership or functional pilot programs.

Implication: These are high-potential states for scalable, integrated genetic counselling—especially if supported through central funding and tele-genetic services.

3. Low and Very Low-Density States Are Severely Underserved

Uttar Pradesh, Bihar, and the North-East States have very few or no trained genetic counsellors.

In these regions:

Diagnostic delays are long

Patients rely on non-specialist physicians

Genetic testing is expensive, underutilized, or misunderstood

States with high tribal or rural populations—with higher genetic disease prevalence—ironically have the least access to counselling.

Implication: This is a serious equity gap that must be addressed through national policy, mobile genetic units, and tele-counselling initiatives.

5. NEED FOR COLOR-CODED PLANNING TOOLS

The heat map can serve as a policy decision tool for:

Prioritizing investments

Targeting training programs

Rolling out national tele-genetics models

Partnering with private labs for public service expansion in underserved areas

Summary Statement

The heat map of India's genetic counselling density reveals a highly urban-centric and unequal distribution, where access to counselling is determined not by need, but by geography and institutional proximity. Bridging this disparity is essential for delivering on the promise of personalized medicine and rare disease diagnostics in India.

Projected Growth: 2025–2030

Year	Estimated Counsellors	Key Enablers
2023	100–150	Baseline, no national regulation
2025	200–250	BGC recognition, ICMR training support
2027	350–400	AIIMS, SGPGIMS-led academic expansion
2030	600–750	National licensure and tele-genetic scale

Source: ISGM, 2023; BGC, 2023; Kerala Health Mission, 2024

6. CONCLUSION

India is poised to integrate genetic counselling into its national health framework—but must overcome regulatory, educational, and cultural barriers. States like Gujarat offer scalable examples, while cities like Bengaluru show innovation potential. By recognizing BGC, expanding training, and ensuring public health integration, India can democratize access to genomics by 2030.

Genetic counselling is no longer a futuristic luxury but a foundational pillar of modern, patient-centred healthcare. As genomic technologies rapidly evolve and genetic testing becomes more accessible, the role of genetic counsellors is more important than ever in guiding patients, families, and healthcare providers through complex clinical and ethical landscapes. Globally, countries like the United States, United Kingdom, and Canada have established regulatory frameworks and professional standards that integrate genetic counsellors into mainstream medicine. These models demonstrate the profound impact of structured counselling on diagnosis, treatment, and emotional support.

In contrast, India's genetic counselling ecosystem remains fragmented, under-resourced, and urban-centric. While institutions in Delhi, Mumbai, and Bengaluru lead the way in terms of infrastructure and expertise, the vast majority of the country—especially in northern, eastern, and tribal regions—lacks meaningful access to these services. States like Gujarat have shown promise by leveraging public health policy for disease-specific counselling programs, while innovation hubs like Bengaluru highlight the potential of private sector growth. However, both models fall short in scalability, rural outreach, and affordability.

This paper's state-wise analysis, visual heat map, and case studies underscore the urgent need for a nationally coordinated

effort to professionalize and expand genetic counselling in India.

Key recommendations include:

Establishing a central licensing and accreditation body

Integrating counselling into primary and community healthcare

Scaling training programs through public and private universities

Implementing tele-genetics and mobile outreach to underserved areas

India has the scientific talent and institutional capacity to become a global leader in genomics. What is now required is a systemic commitment to making genetic counselling not just available, but equitable, ethical, and embedded in the nation's health system. Only then can India truly unlock the full promise of its genomic potential—reaching every citizen, from rural villages to urban hospitals, with clarity, compassion, and clinical precision.

Barriers to Growth

Cultural Stigma

Genetic disorders are often misunderstood or feared in Indian communities, deterring engagement.

Human Resource Deficit

India has less than 1 counsellor per 10 million people, compared to 1 per 60,000 in the U.S.

Lack of Standardized Training

Few accredited M.Sc. programs exist. Most counselling is conducted by untrained clinicians.

Regulatory Vacuum and the Role of BGC

India lacks a statutory regulatory body for genetic counsellors. The Board of Genetic Counseling (BGC), based in Hyderabad, acts as a non-statutory professional body, offering certification and guidelines since 2020 (Board of Genetic Counseling, 2023).

7. RECOMMENDATIONS

Create a National Regulatory Authority

Modelled on RCI or NBE, this body should license, accredit, and standardize the profession.

Expand M.Sc. and Fellowship Programs

AIIMS, SGPGIMS, and state universities should scale up formal training.

Public Awareness Campaigns

Partner with ASHA workers and NGOs for culturally sensitive outreach in vernacular languages.

Leverage Tele-Genetics

Use telehealth to reach rural areas through a hub-and-spoke model

REFERENCES

[1] Board of Genetic Counseling. (2023). Guidelines for genetic counselling training and certification in India. Hyderabad, India: Board of Genetic Counseling.

[2] Gujarat State Health Department. (2022). Annual report: Thalassemia and sickle cell screening and prevention program. Government of Gujarat, Directorate of Health Services.

[3] Indian Society of Genetic Medicine. (2023). Status report on clinical genetic services and workforce in India. Proceedings of the ISGM Annual Conference. Bengaluru, India.

[4] Kerala State Health Mission. (2024). Annual maternal and child health report. Thiruvananthapuram, India: Government of Kerala.

[5] National Society of Genetic Counselors. (2023). What is genetic counseling? https://www.nsgc.org

[6] Ormond, K. E., Laurino, M. Y., Barlow-Stewart, K., Wessels, T. M., & Burke, W. (2018). Genetic counseling globally: Where are we now? American Journal of Medical Genetics Part C: Seminars in Medical Genetics, 178(1), 98–107. https://doi.org/10.1002/ajmg.c.31603

[7] Sheth, J., Sheth, F., & Trivedi, H. (2020). Awareness and utilization of genetic counseling in urban India: A hospital-based cross-sectional study. Journal of Genetic Counseling in India, 1(1), 23–30