

Navigating the Genetic Frontier: Establishing Genetic Clinics for Comprehensive Hereditary Cancer Management in Resource-Limited Settings

Akhil Kapoor¹  Ankita Rungta Kapoor² Archi Rungta³ Bal Krishna Mishra¹  Anuj Gupta¹
 Bipinesh Sansar¹ Amit Kumar⁴ Zachariah Chowdhury⁵  Shashikant Patne⁵ Satyajit Pradhan²
 Rajiv Sarin⁶ 

¹ Department of Medical Oncology, Homi Bhabha Cancer Hospital and Mahamana Pandit Madan Mohan Malaviya Cancer Centre, Tata Memorial Centre, Homi Bhabha National Institute, Varanasi, Uttar Pradesh, India

² Department of Radiation Oncology, Homi Bhabha Cancer Hospital and Mahamana Pandit Madan Mohan Malaviya Cancer Centre, Tata Memorial Centre, Homi Bhabha National Institute, Varanasi, Uttar Pradesh, India

³ Department of Cancer Genetics, Tata Memorial Hospital, Tata Memorial Centre, Homi Bhabha National Institute, Mumbai, Maharashtra, India

⁴ Department of Medical Oncology, Homi Bhabha Cancer Hospital and Research Centre, Tata Memorial Centre, Homi Bhabha National Institute, Muzaffarpur, Bihar, India

Address for correspondence Akhil Kapoor, MBBS, MD, DM, Department of Medical Oncology, Homi Bhabha Cancer Hospital and Mahamana Pandit Madan Mohan Malaviya Cancer Centre, Tata Memorial Centre, Homi Bhabha National Institute, Varanasi 221005, Uttar Pradesh, India (e-mail: kapoorakhil1987@gmail.com).

⁵ Department of Pathology, Homi Bhabha Cancer Hospital and Mahamana Pandit Madan Mohan Malaviya Cancer Centre, Tata Memorial Centre, Homi Bhabha National Institute, Varanasi, Uttar Pradesh, India

⁶ Radiation Oncology, Tata Memorial Hospital, Tata Memorial Centre, Homi Bhabha National Institute, Mumbai, Maharashtra, India

Ind J Med Paediatr Oncol

Abstract

This review article explores the vital role of genetic clinics in the management of hereditary cancers, emphasizing their significance in early detection, tailored treatment, and family screening. It presents analysis of the prevalence of hereditary cancers in India, including breast, ovarian, prostate, colon, and kidney cancers, stressing the necessity for effective genetic testing and counseling services.

The manuscript synthesizes available prevalence data, outlines key components and challenges of clinic establishment, and provides strategies for improving public acceptance, access, and workforce capacity. It also focuses on importance of early detection, family screening, and targeted therapies for patients with inherited genetic mutation.

In conclusion, the article emphasizes the need for a patient-centered approach, increased access to genetic clinics, exploration of future genomics and technology advancements, and the evaluation of genetic clinics' impact on patient outcomes. By addressing challenges and capitalizing on opportunities, genetic clinics can continue to improve patients' and their families' lives, ultimately contributing to the battle against hereditary cancers.

Keywords

- genetic clinics
- hereditary cancers
- genetic testing and counselling
- cancer prevention and management
- awareness and acceptance

DOI <https://doi.org/10.1055/s-0045-1811249>.
 ISSN 0971-5851.

© 2025. The Author(s).

This is an open access article published by Thieme under the terms of the Creative Commons Attribution License, permitting unrestricted use, distribution, and reproduction so long as the original work is properly cited. (<https://creativecommons.org/licenses/by/4.0/>)

Thieme Medical and Scientific Publishers Pvt. Ltd., A-12, 2nd Floor, Sector 2, Noida-201301 UP, India

Introduction

The growing burden of hereditary cancers in India has highlighted the need for a comprehensive approach to their management, detection, and prevention. Hereditary cancers result from inherited gene mutations that significantly increase an individual's risk of developing cancer. These mutations are responsible for a considerable proportion of cancer cases in India, including breast (5–10%), ovarian (15–20%), prostate (5–9%), colon (2–6%), and kidney (5–8%) cancers.¹ Despite the substantial impact of hereditary cancers, limited work has been done to address this issue in India.

The lack of awareness and knowledge about hereditary cancers in both the general population and the health care community has led to inadequate genetic testing and counseling services.² This shortfall contributes to a delayed diagnosis, less effective treatments, and missed opportunities for early intervention and prevention. Furthermore, the limited availability of genetic clinics, trained cancer genetic counsellors, and the high cost of genetic testing services have made access to these essential services challenging for many individuals and families.³

In recent years, however, there has been a growing recognition of the importance of genetic clinics in addressing the burden of hereditary cancers in India. Genetic clinics play a crucial role in providing comprehensive care by offering genetic testing and counseling services that enable early detection, personalized treatment, and family screening. Establishing genetic clinics in new cancer centers can significantly improve the management of hereditary cancers and enhance the overall quality of care for patients and their families.⁴

By shedding light on the current state of hereditary cancer management in India and outlining strategies to improve access to genetic clinics, this article aims to contribute to the ongoing efforts to combat hereditary cancers and improve patient outcomes. ►Table 1 provides an overview of the available data on hereditary cancers in India.

Importance of Genetics Clinic

Genetics clinics play a vital role in the management of hereditary cancers. They provide numerous benefits, including:

Early Detection and Prevention

Genetic testing enables early identification of individuals at risk for hereditary cancers. It allows for the implementation of appropriate screening programs and prophylactic interventions, reducing morbidity and mortality rates.

Therapeutic Benefit

Genetic testing can identify specific mutations that may be targeted by personalized therapies. For example, patients with BRCA1/2 mutations may respond well to poly (ADP-ribose) polymerase (PARP) inhibitors, improving their prognosis.⁵

Family Screening

Screening relatives of patients with hereditary cancers can help identify at-risk family members, enabling early interventions and better management of the disease.

Steps in Setting Up a Genetic Clinic in a New Cancer Centre

Establishing a genetic clinic involves several crucial steps (►Table 2):

Define the Scope

Identify the types of services offered, such as genetic counseling, testing, and personalized treatment planning.

Create a Multidisciplinary Team

Assemble a team of experts, including trained cancer genetic counselors, oncologists, surgeons, and laboratory personnel.

Develop Standard Operating Procedures

Develop and implement standard operating procedures for genetic testing, counseling, and management of patients with hereditary cancers.

Obtain Necessary Equipment and Resources

Acquire the necessary equipment for genetic testing, such as next-generation sequencing platforms, and ensure proper training of laboratory staff.

Establish Partnerships

Collaborate with other cancer centers, academic institutions, and research organizations to share resources and knowledge.

Table 1 Prevalence of hereditary cancers in India

Cancer type	Percentage of hereditary cases	Linked genes	Suggested solutions for early detection
Breast	5–10%	BRCA1, BRCA2	Genetic testing, mammography, MRI
Ovarian	15–20%	BRCA1, BRCA2	Genetic testing, ultrasound, CA-125 test
Prostate	5–9%	HOXB13	Genetic testing, PSA test, DRE
Colon	2–6%	APC, MUTYH	Genetic testing, colonoscopy, FOBT
Kidney	5–8%	VHL, MET	Genetic testing, CT scan, MRI

Abbreviations: CT, computed tomography; DRE, digital rectal exam; FOBT, fecal occult blood test; MRI, magnetic resonance imaging; PSA, prostate-specific antigen.

Table 2 Steps in setting up a genetic clinic

Step #	Description	More details
1	Define the scope	Identify target population, services offered
2	Create a multidisciplinary team	Include genetic counselors, physicians, etc.
3	Develop standard operating procedures	Create guidelines for genetic testing, follow-up
4	Acquire necessary resources	Secure funding, equipment, and space
5	Establish partnerships	Collaborate with hospitals, research institutions

Table 3 Challenges associated with genetic clinics

Challenge #	Description	Suggested solutions
1	Limited awareness and acceptance	Educational programs, community involvement
2	Financial constraints	Seek funding, collaborate with stakeholders
3	Ethical concerns	Develop ethical guidelines, informed consent

Challenges Associated with Setting Up a Genetic Clinic

Several challenges need to be addressed when establishing a genetic clinic (►Table 3):

Limited Awareness and Acceptance

In many communities, there may be limited awareness and acceptance of genetic testing. It is essential to develop strategies to educate patients and the public about its benefits.

Financial Constraints

One of the biggest barriers to the uptake of genetic testing is its cost. Many patients cannot afford the initial genetic test, and if found to be mutation carriers (previvors), they often face the additional financial burden of regular, lifelong cancer screening and preventive interventions. These may include annual magnetic resonance imaging, mammograms, colonoscopies, or even risk-reducing surgeries—all of which are expensive and rarely covered by insurance in low- and middle-income countries (LMICs). This creates a significant equity gap, where only a small fraction of the population can access the benefits of personalized cancer prevention.

To overcome this, public cancer centers must advocate for state-funded testing programs for high-risk groups, collaborate with nonprofit foundations to sponsor testing and screening, and push for integration of genetic services into national health insurance schemes. Examples from other LMICs suggest that cost-sharing models, means-based subsidies, or donor-funded screening programs can improve accessibility. Public hospitals can collaborate with government schemes (e.g., Ayushman Bharat), nongovernmental organizations, and insurance companies to subsidize costs.

Shortage of Skilled Personnel

There may be a limited number of trained cancer genetic counselors and other specialists available to run a genetic clinic. Training programs and partnerships with academic institutions can help address these challenges.

Ethical Aspects of Genetic Clinics

Ethical considerations are an integral part of genetic clinic operations:

Informed Consent

Obtaining informed consent from patients before genetic testing is essential to ensure they understand the implications, risks, and benefits.

Confidentiality and Privacy

Protecting patients' genetic information is critical to maintain their privacy and prevent potential discrimination. Implementing strict data security measures is necessary.

Strategies for Improving Acceptance of Genetic Testing

To enhance the acceptance of genetic testing in society, various methods can be employed:

Public Awareness Campaigns

Utilize mass media, social media, and community outreach programs to raise awareness about the benefits of genetic testing.

Collaboration with Primary Care Providers

Collaborate with primary care providers to identify at-risk patients and refer them to genetic clinics for further evaluation and testing.

Financial Assistance Programs

Establish programs to help patients cover the cost of genetic testing and related services.

Enhancing Access to Genetic Clinics

Improving access to genetic clinics is vital for ensuring that a broader population can benefit from their services. Some approaches to achieve this goal include the following:

Table 4 Benefits of genetic testing

Benefit #	Description	Implications for patients and families
1	Therapeutic benefits	Tailored treatments based on genetic profile
2	Early detection	Timely interventions, better prognosis
3	Family screening	Identify at-risk family members, prevention

Telemedicine and Remote Genetic Counseling

Leveraging telemedicine and remote genetic counseling can help reach individuals in rural or remote areas where access to genetic clinics may be limited. This approach may also be useful in providing services to patients with mobility or transportation challenges.

Mobile Genetic Clinics

Establishing mobile genetic clinics that can travel to underserved areas can increase access to genetic testing and counseling for individuals who might otherwise not receive these services.

Collaboration with Community Health Centers

Partnering with community health centers can help to identify individuals at risk for hereditary cancers and facilitate appropriate referrals to genetic clinics.

Discussion

Genetic clinics are essential for the management of hereditary cancers, offering numerous benefits such as early detection, therapeutic benefits, and family screening (►Table 4).

The process of setting up a genetic clinic within a cancer center can be met with several challenges.^{4,6} One such challenge is ensuring access to high-quality genetic testing services that provide accurate and reliable results. Moreover, the lack of well-established guidelines for genetic testing and management of hereditary cancer syndromes in India further complicates the process.⁷

In addition to technical challenges, financial constraints can pose significant barriers to establishing a genetic clinic. The high cost of genetic testing and limited funding opportunities for research and service development contribute to

these challenges. Additionally, there is a need to train health care professionals in the field of cancer genetics, which requires resources and infrastructure.

Implementing multidisciplinary care models that include oncologists, cancer genetic counselors, and other health care professionals can improve patient outcomes.⁸ However, a shortage of trained genetic counselors and other professionals can hinder the formation of these multidisciplinary teams. Moreover, the lack of awareness about the importance of genetic counseling and testing among health care professionals further exacerbates the problem.

Ethical considerations also play a critical role in the establishment of genetic clinics. Issues such as informed consent, patient confidentiality, and the disclosure of genetic information to family members must be addressed. Genetic counseling should be sensitive to cultural and religious beliefs, as well as the psychological impact of genetic testing on patients and their families.⁹

Public awareness of the benefits of genetic testing and counseling is vital for its acceptance and utilization. Social media can be an effective tool for disseminating information and promoting awareness about the importance of genetic testing. Studies have shown that social media interventions can improve patient well-being and facilitate social support. Furthermore, social media can be used to engage with diverse populations and promote health behavior changes.¹⁰

Mass media campaigns have also been proven effective in promoting health behavior change and reducing the incidence of cancer. Tailored interventions targeting specific populations can further improve the efficacy of these campaigns. By leveraging new technologies, health care providers can enhance the prevention and management of chronic conditions, including hereditary cancers.¹¹

Outreach and integration programs can promote family communication and participation in genetic counseling and testing among low-income and underserved populations. These programs can be especially beneficial for minority groups who may have limited access to genetic services due to cultural, linguistic, or financial barriers.² By addressing these challenges and fostering an environment that encourages genetic testing and counseling, cancer centers can harness the potential of genetic clinics to improve cancer prevention and management (►Table 5).

By integrating culturally sensitive approaches and addressing disparities, health care professionals can ensure that a diverse population can benefit from the advancements in genetic testing and counseling.¹²

Table 5 Strategies for enhancing genetic testing acceptance

Strategy #	Description	More details
1	Educational programs	Public campaigns, health care provider education
2	Community involvement	Health fairs, workshops, patient advocacy
3	Addressing cultural sensitivities	Develop culturally appropriate resources, counseling

Limitations

This review has several limitations. First, much of the data on the prevalence and uptake of genetic testing in India and other LMICs remain sparse or institution-specific, limiting generalizability. Second, the recommendations provided may not be uniformly applicable due to variability in health care infrastructure, resource availability, and sociocultural dynamics across regions. Third, while international practices and models are referenced, contextualizing them to Indian or LMIC settings may require further field validation. Finally, a lack of patient-centered outcome data hinders the ability to fully quantify the impact of genetic clinics on long-term health outcomes and cost savings.

Conclusion

Genetic clinics are pivotal in the era of personalized medicine, particularly for hereditary cancer prevention and management. Their role in early detection, therapeutic decision-making, and cascade testing has far-reaching implications for reducing cancer incidence and mortality. However, the success of such clinics in LMICs hinges on overcoming structural, economic, and sociocultural barriers. By investing in infrastructure, workforce training, community engagement, and inclusive policy development, LMICs can unlock the full potential of genetic clinics. Moving forward, tailored implementation strategies, continuous evaluation, and stakeholder collaboration will be essential in ensuring sustainable and equitable access to these critical services.

Data Availability Statement

Data sharing is not applicable to this article as no new data were created or analyzed in this study

Patient Consent

No patient data was collected as informed consent was not required.

Funding

None.

Conflict of Interest

None declared.

References

- 1 Sathishkumar K, Chaturvedi M, Das P, Stephen S, Mathur P. Cancer incidence estimates for 2022 & projection for 2025: result from National Cancer Registry Programme, India. *Indian J Med Res* 2022;156(4 & 5):598–607
- 2 Hann KEJ, Freeman M, Fraser L, et al; PROMISE study team. Awareness, knowledge, perceptions, and attitudes towards genetic testing for cancer risk among ethnic minority groups: a systematic review. *BMC Public Health* 2017;17(01):503
- 3 Kwong A, Tan DS, Ryu JMACROSS Consortium. Current practices and challenges in genetic testing and counseling for women with breast and ovarian cancer in Asia. *Asia Pac J Clin Oncol* 2025;21(02):211–220
- 4 Sharma HS, Singh KP. Genetic clinic: need of the hour. *J Med Soc.* 2024;38(02):83–84
- 5 Ledermann J, Harter P, Gourley C, et al. Olaparib maintenance therapy in platinum-sensitive relapsed ovarian cancer. *N Engl J Med* 2012;366(15):1382–1392
- 6 Ramos E. Genetic counseling, personalized medicine, and precision health. *Cold Spring Harb Perspect Med* 2020;10(09):a036699
- 7 Pederson HJ, Narod SA. Commentary: why is genetic testing underutilized worldwide? The case for hereditary breast cancer. *BJC Rep* 2024;2(01):73
- 8 Litton G, Kane D, Clay G, Kruger P, Belnap T, Parkinson B. Multidisciplinary cancer care with a patient and physician satisfaction focus. *J Oncol Pract* 2010;6(06):e35–e37
- 9 White MT. Making sense of genetic uncertainty: the role of religion and spirituality. *Am J Med Genet C Semin Med Genet* 2009;151C(01):68–76
- 10 Moore RA, Matthews AL, Cohen L. How might the genetics profession better utilize social media. *J Genet Couns* 2018;27(02):493–504
- 11 Melhem SJ, Nabhani-Gebara S, Kayyali R. Leveraging e-health for enhanced cancer care service models in middle-income contexts: qualitative insights from oncology care providers. *Digit Health* 2024;10:20552076241237668
- 12 Wang Y, He Y, Shi Y, et al. Aspiring toward equitable benefits from genomic advances to individuals of ancestrally diverse backgrounds. *Am J Hum Genet* 2024;111(05):809–824