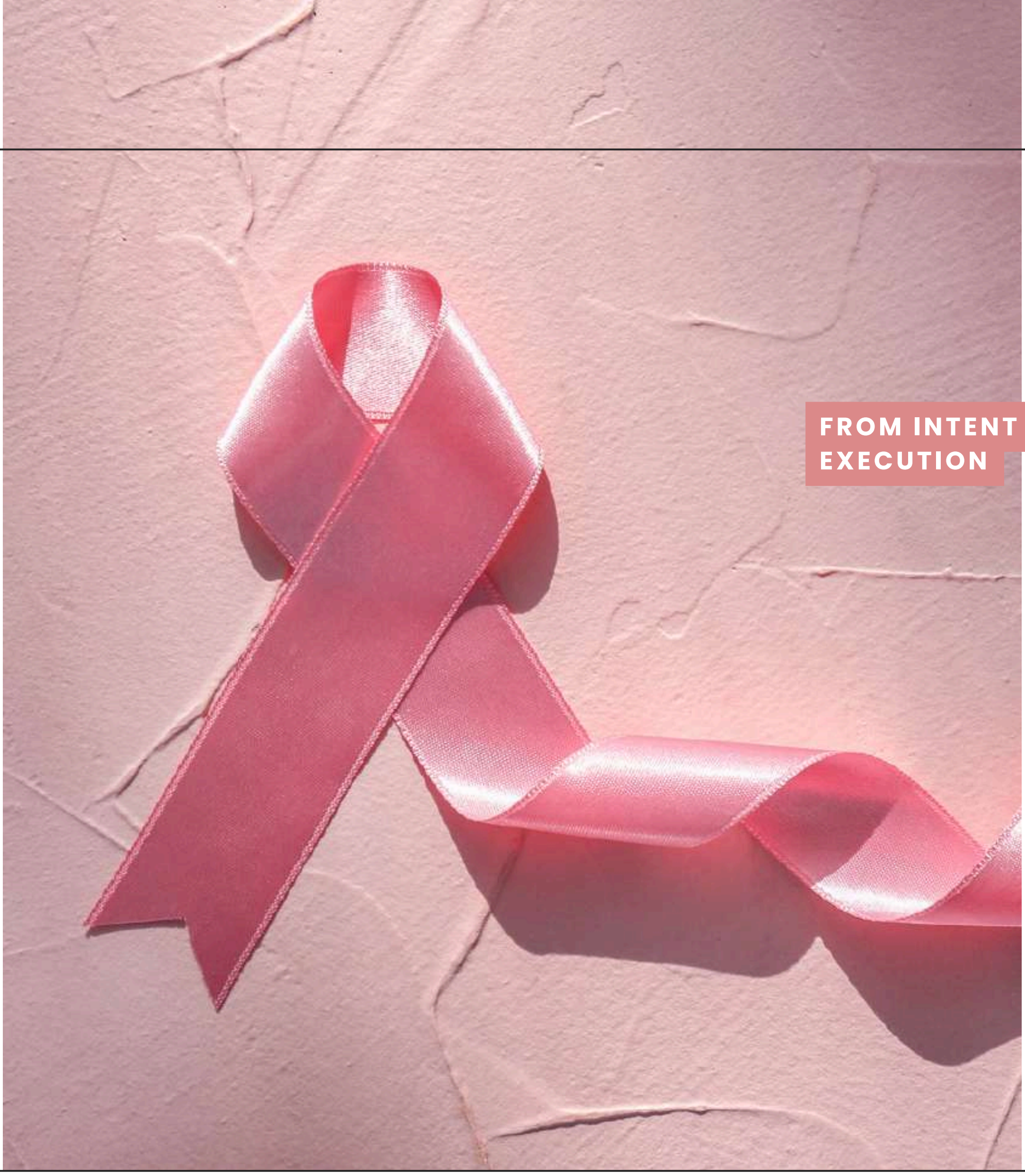

REPORT

ON

THE ROUNDTABLE ON NEW THRUSTS IN BREAST CANCER TREATMENT AND MANAGEMENT IN INDIA

CONDUCTED ON 9TH NOV 2024	BY PAIR ACADEMY	SHANGRI-LA NEW DELHI, INDIA

Patient Academy
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EXECUTIVE SUMMARY

Breast cancer remains a significant public health concern in India, accounting for over a quarter of all female cancers. Female breast cancer (BC) is the leading cause of cancer incidence and mortality in India and accounted for 13.5% of new cancer cases and 10% of cancer-related deaths in 2020[1]. While the management of breast cancer has grown leaps and bounds with innovations in several areas, implementation of these management protocols has not grown at the same pace, especially within the public health sector, leaving patients with poorer quality of life and less chance of surviving than the global average. ESMO published updated ABC (Advanced Breast Cancer) guidelines in 2021, and a pan-Asian version representing oncology societies from 10 nations was formulated in 2023[2]. For India, practical consensus recommendations on the management of triple-negative metastatic breast cancer were developed in 2018[3]. India has just 10% of the total requirement of 5000 radiation therapy units indicating a shortfall of > 4500 machines. The World Health Organization recommends at least one teletherapy unit per million population, and there is a shortfall of 700 teletherapy units[4]. If we look at the treatment infrastructure, at least half of patients with cancer will be judged to need radiotherapy at some point. Nearly 40% of hospitals in India are not adequately equipped with advanced cancer care equipment. Very few centers in the country provide integrated surgical and chemoradiation for BC. Nearly 75% of the patients in the public sector do not have access to timely radiotherapy[5].

With challenges such as limited awareness, gaps in treatment access, and weak post-treatment care, there is an urgent need for a multifaceted approach to address the disparities in breast cancer management.

On November 9th, 2024, a roundtable discussion was convened by PAIR Patient Academy for Innovation and Research (PAIR), bringing together healthcare professionals from the public and private sectors, patient advocates, representatives from over 10 patient organizations from across India, and other stakeholders to explore innovative solutions to address challenges in awareness, accessibility, and survivorship care. The discussions underscored the urgency of fostering multi-pronged approaches to strengthen breast cancer care in India. This report serves as a roadmap to advocate for policy reforms and collaborative actions, ensuring that breast cancer care is both accessible and comprehensive across India.

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[1] Breast Cancer Res Treat. 2024 Mar 4;205(2):323–332. doi: 10.1007/s10549-024-07264-3
[2] https://www.sciencedirect.com/science/article/pii/S2059702923007676
[3] https://www.scopus.com/record/display.uri?eid=2-s2.0-85097392939&origin=inward&txGid=3d3943cc4918959e672468e681477ca4
[4] https://pubmed.ncbi.nlm.nih.gov/28325242/
[5] https://pubmed.ncbi.nlm.nih.gov/33528692/

LANDSCAPE OF BREAST CANCER IN INDIA

Breast cancer is the most common cancer in India, accounting for 28.2% of all female cancers, with an estimated 216,108 cases by 2022. Descriptive epidemiology in India has demonstrated that breast cancer is on the rise, with a particularly sharp increase between ages 25 and 59 years, attributable to generational shifts in risk factors.

A recent SURVCAN-3 study (Cancer Survival in Countries in Transition) published in 2023 found that the 3-year median survival for breast cancer across countries is 84%, whereas, in India, it is 68%. These data can be largely attributed to policy gaps, owing to the ever-evolving population and healthcare system within the country.

THE NEED FOR A DIALOGUE

India has a variety of programs addressing NCDs broadly, and cancer is included in the National Program. As of 2024, several government health initiatives in India under the National Programme for Prevention and Control of Non-Communicable Diseases (NP-NCD) are active, focusing on various aspects of NCDs as a whole. The program covers community-based screening for oral, breast, and cervical cancers through the health and wellness centers. 5-year overall survival rates in India for Breast Cancer are not promising. A study reported it to be 95% for stage I patients, 92% for stage II, 70% for stage III, and only 21% for stage IV patients[9]. The survival rate of patients with breast cancer is poor in India as compared to Western countries due to earlier age at onset, late stage of disease at presentation, delayed initiation of definitive management, and inadequate/fragmented treatment. A dedicated national policy catering to Breast Cancer management could significantly enhance awareness, screening, early detection, and comprehensive treatment access across all demographics.

Notably, India has a strong patient voice and several patient organizations working on cancer, especially breast cancer. However, most organizations are focused on service delivery and awareness generation once the patient reaches the healthcare facility. Awareness on advances in therapy, availability of clinical trials and access to various programs are seldom disseminated as the patient organization's lack the information and the resources to provide this kind of information. Keeping this in mind, there is an urgent need for a multi-step process to propel stakeholder discussions for the way forward.

A Roundtable with Breast Cancer Patient Advocacy Groups and other government and non-government stakeholders was conceptualized with the objective of exploring New thrusts in Breast Cancer Treatment and Management and find solutions to address key gaps in the awareness and accessibility of treatment choices in India.

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[9] https://www.sciencedirect.com/science/article/pii/S0923753419517513

TOPICS OF DISCUSSION

ROLE OF HEALTH SYSTEMS: CURRENT POLICIES AND FRAMEWORK FOR BREAST CANCER MANAGEMENT IN INDIA

- Rising trends of breast cancer in India
- India's approach to screening and prevention
- Health system preparedness for early detection and treatment
- Awareness and health literacy around breast cancer in India
- ABY and its provisions, any other schemes by central and state governments

VALUE OF INNOVATION TO STRENGTHEN STANDARD OF CARE IN BREAST CANCER TREATMENT

- Personalized treatment approaches to Breast Cancer
- Role of innovative drug development and affordable therapeutics in improving access
- Improving clinical trial participation using digital technology
- Financial support for innovations to improve access to advanced treatments

PATIENT'S CHOICE TO QUALITY TREATMENT AND SAFETY

- How can the patient voice be improved in India? What can patient advocates and patient organizations do to elevate the patient's voice?
- Does the patient have a choice in his/her treatment? Barriers to choice- lack of knowledge/ limited treatment options/ financial constraints. How can this be improved?

KEY CHALLENGES

1 CHALLENGES IN ACCESS TO TREATMENT

Insurance Gaps and Limited Coverage: Health insurance in India often does not fully cover the cost of advanced cancer treatments, leaving patients to bear significant out-of-pocket expenses. Additionally, coverage may exclude certain targeted or advanced therapies, further limiting access. Existing government schemes provide basic coverage and do not cater to advanced treatments due to cost constraints. In India, the cost and OOP for breast cancer treatment are high, and reimbursement for the treatment flows from multiple sources. Though many of the patients receive some form of reimbursement, it is insufficient to prevent high OOP. Hence both wider insurance coverage as well as higher caps of the insurance packages in the health insurance schemes will be required to improve affordability[6]

Inconsistent Availability: Advanced medications are often available only in larger cities and specialized oncology centers, creating geographical barriers. Public sector hospitals face challenges of procurement and are unable to provide customized treatment protocols based on the needs of patients. Tumor boards are limited by the treatment choices available to them and often patients are provided the best option available within the basket even though the treatment options available outside the basket may offer better outcomes.

Regulatory and Procurement Challenges: Import restrictions, lengthy regulatory approval processes, and supply chain issues delay the availability of newer drugs. Even after approval, logistical hurdles may hinder timely distribution to smaller towns and remote areas.

Lack of qualified human resources: For a large country like India there are only 2000 medical oncologists and fewer radiation and surgical oncologists. Cancers require a multidisciplinary management approach, but most tertiary hospitals lack the critical manpower required to have a full team. Most doctors are overstretched and struggle to provide appropriate care within the limited resources available to them.

Lack of appropriate infrastructure: Many hospitals in the public sector lack the infrastructure required for a multidisciplinary approach. Critical investigations like MRI and CT scan are sometimes lacking and patients have to get this done out of pocket.

Limited Clinical trials: Advanced therapies are unavailable as limited clinical trials are offered in the country. Information on available trials is limited, and enrollment is difficult. The clinical trial database is not user-friendly and patients have difficulty accessing data n ongoing clinical trials.

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[6] https://www.thelancet.com/journals/lansea/article/PIIS2772-3682(23)00206-8/fulltext

INSUFFICIENT KNOWLEDGE OF AVAILABLE TREATMENT OPTIONS

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Lack of Awareness Among Providers and Patients: Healthcare providers in smaller facilities and rural areas may not be fully aware of the latest treatment protocols or advancements, which limits their ability to offer these options to patients. Similarly, patients are often unaware of the existence of these therapies or the pathways to access them, such as financial aid programs or clinical trials. While some private sector hospitals offer information, patients are unable to choose due to financial constraints. Information on advanced treatments is often unavailable to specialties other than medical oncologists as there are no ongoing clinician upgrade programs.

Management of BC is multidisciplinary and has come a long way. In the past, the widely used treatment option was mastectomy followed by adjuvant chemotherapy for locally advanced BC, triple-negative breast cancer, and HER2neu-expressing tumors (human epidermal growth factor receptor 2). At present, it includes a loco-regional approach and a systemic therapy approach that targets the entire body. The systemic therapy includes endocrine therapy for hormone receptor-positive disease, chemotherapy, anti-HER2 therapy for HER2-positive disease, bone stabilizing agents, polymerase inhibitors for BRCA mutation carriers, and recently, immunotherapy. However, the majority of patients still undergo primary ablative surgical procedures. Gene expression profiling in hormone receptor-positive disease is also a promising option but has financial implications.

Radiation treatment of BC has evolved from 2D to 3D conformal radiotherapy and accelerated partial breast irradiation, aiming to reduce normal tissue toxicity and overall treatment time. The newer additions, viz. intensity-modulated radiation therapy and deep inspiration breath-hold, are still inaccessible to many. The same is the case with brachytherapy.

The outcomes with triple-negative breast cancer are poor, and the treatment options are mainly restricted to systemic chemotherapy. Immunotherapy, poly adenosine diphosphate-ribose polymerase inhibitors and antibody-drug conjugates have the potential to change the current scenario of BC treatment. The field of breast surgery has also evolved from total mastectomy to breast conservation therapy to oncoplastic breast surgery. The rapidly advancing field of oncoplastic breast surgery offers a pragmatic alternative to total mastectomy and breast conservation therapy.

Language and Literacy Barriers: Information on treatment options is often available only in English or major regional languages, leaving out those who speak fewer common dialects, impacting their ability to make informed decisions. Information is available on multiple channels and the authenticity of information is hard to establish.

Dependence on Traditional or Alternative Medicine: Due to a lack of knowledge or distrust of conventional medicine, some patients resort to traditional or alternative treatments that may not be effective.

Delay from the healthcare provider's side: On average, more than 12 weeks of delay is seen in diagnosis and treatment in 23% of patients[7]. A study examined provider delay (defined as the period between the first consultation and diagnosis) and observed that the mean provider delay was 80 days in rural areas and 66 days in urban areas[8]. More than half of the women were observed to have a delay of more than 90 days in seeking care. The patient-related delay was observed to be 6.1 weeks, and the system-related delay was 24.6 weeks with a mean total delay of 29.4 weeks in treatment.

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LIMITED AWARENESS AND EDUCATION

Low Public Awareness: Awareness about breast cancer signs, preventive measures, and the importance of regular screening is limited, especially in rural and semi-urban populations. This leads to a high rate of late-stage diagnoses.

Stigma and Cultural Beliefs: Social stigmas around cancer, particularly breast cancer, hinder open discussion and early detection efforts. Cultural beliefs sometimes contribute to delayed medical consultation and reluctance towards preventive screenings.

Lack of Education on Self-Examinations: Limited knowledge on how to perform regular self-examinations or recognize early warning signs further contributes to delayed detection.

WEAK POST-TREATMENT AND SURVIVORSHIP CARE

4

Lack of Rehabilitation Services: Post-treatment care, such as physical therapy and vocational rehabilitation, is limited, making it difficult for survivors to return to normal life.

Psychosocial Support Gaps: Breast cancer survivors often experience psychological and emotional stress, yet mental health support remains limited or inaccessible for many patients.

Absence of Follow-Up Protocols: Many patients lack access to regular follow-up care after treatment, leading to a risk of recurrence going unnoticed or untreated.

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[7] https://pubmed.ncbi.nlm.nih.gov/26658324/
[8] https://journals.sagepub.com/doi/10.1258/shorts.2011.011006

CONCLUSION AND KEY TAKEAWAYS

While there is a lot of progress made in improving awareness and access to treatment for Breast Cancer patients, much work still needs to be done. Some of the key takeaways are as follows:

IMPROVING ACCESS TO TREATMENT

- Work with policymakers and insurance companies to include advanced cancer treatments and newer therapies in both public and private sector health insurance plans.
- Improve procurement and distribution channels to ensure that medications are available.
- Streamline regulatory approvals for cancer medications and consider fast-tracking drugs for high-need areas. Collaborate with NGOs or the private sector to expedite procurement processes.

AWARENESS

- Create and distribute materials in multiple regional languages to help patients understand their treatment options, funding sources, and financial aid programs.
- Partner with community leaders to launch campaigns on breast cancer awareness, focusing on early detection, regular check-ups, and the benefits of self-examination.
- Implement training and certification programs for healthcare providers on the latest treatment protocols, supported by both public health departments and private health organizations.
- Establish affordable, mobile screening units to reach underserved communities and provide access to early detection services.

POST-TREATMENT CARE

- Develop support groups and counseling services for accessible mental health resources
- Set up clinics that offer post-treatment services such as physical rehabilitation, and nutritional guidance.
- Create standardized follow-up care guidelines to ensure that patients have access to continuous care post-treatment. This could include telehealth options to monitor health remotely and regular screenings for recurrence.

IMPROVED INFRASTRUCTURE AND HUMAN RESOURCES

- Critical positions need to be filled, infrastructure investments need to improve and referral systems need to be strengthened

THE WAY FORWARD

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MULTISTAKEHOLDER COLLABORATION FOR HEALTH SYSTEM STRENGTHENING

- Initiate dialogue between governmental bodies, NGOs, private sector players, and patient organizations to pool resources and expertise.
- Create task forces to identify gaps in screening programs and implement corrective measures.
- Strengthen treatment protocols through consensus statements and patient inputs at National and state levels
- Engage community leaders and influencers to amplify awareness and reduce stigma around breast cancer.

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FOCUSED SESSIONS WITH EXPERTS TO BUILD CAPACITY AND ENCOURAGE MEANINGFUL ENGAGEMENT WITH PATIENTS

- Organize workshops for healthcare providers on early detection techniques, holistic patient care, and cultural sensitivity.
- Conduct patient engagement sessions led by oncologists, psychologists, and survivors to foster a supportive community.
- Develop toolkits and training modules for primary healthcare workers to identify symptoms and provide basic counseling.
- Leverage digital platforms for webinars and Q&A sessions, ensuring accessibility for rural and urban participants alike.

THE WAY FORWARD

3

CREATION OF AND ADVOCACY TOWARDS ROBUST REFERRAL PATHWAYS

- Map existing healthcare infrastructure to identify and address bottlenecks in the referral process.
- Train healthcare workers to recognize symptoms and provide clear referral instructions to patients and families.
- Develop patient journey maps to monitor referral tracking systems and identify intervention points.

4

INTEGRATION OF MENTAL HEALTH SERVICES INTO PATIENT CARE

- Develop specialized counseling sessions for newly diagnosed patients, survivors, and caregivers.
- Offer peer-support groups online, enabling patients to connect and share experiences in a safe space.
- Create easy-to-understand infographics on managing anxiety, stress, and depression associated with breast cancer.
- Provide resources on mindfulness techniques, coping strategies, and the importance of seeking help.
- Develop evidence-based mental health screening tools for patients to assess their emotional well-being.
- Include questionnaires addressing common issues like fear of recurrence, body image concerns, and treatment side effects.

AGENDA

TOPIC	**SPEAKER**	**DESIGNATION**
Context setting: Welcome & Introduction to the meeting	**Dr. Ratna Devi**	Director, Patient Academy for Innovation and Research
Role of health systems: Current Policies and framework for breast cancer management in India	**Dr. Pragya Shukla**	HOD, Clinical Oncology, DSCI
Value of innovation to strengthen standard of care in Breast Cancer treatment	**Dr. Priya Tiwari**	Head - Medical Oncology, Artemis Hospital, Gurgaon
Patient's choice to quality treatment and safety	**Ms. Vandana Mahajan**	Patient Advocate & Person with Lived Experience
Panel discussion: Way forward to establish new paradigm in breast cancer treatment and management	**MODERATOR**	**Dr. Ratna Devi**
	Dr. Pragya Shukla	HOD, Clinical Oncology, DSCI
	Dr. Priya Tiwari	Head - Medical Oncology, Artemis Hospital, Gurgaon
	Mrs. Satinder Kaur	Director, Sahyog, Indian Cancer Society
	Dr. Monika Puri	Chief Country Access and Policy Officer, Roche India
Q & A	**Dr. Ratna Devi**	Director, Patient Academy for Innovation and Research
Conclusion: The need for concerted action	**Dr. Ratna Devi**	Director, Patient Academy for Innovation and Research
Thank you note	**Mugdha Barik**	Program Manager, Patient Academy for Innovation and Research