

## The Need for Comprehensive Cancer Registries in India: A Crucial Step Toward Improved Cancer Care and Outcomes

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### Introduction :

Cancer remains one of the leading causes of morbidity and mortality worldwide, and India is no exception. The burden of cancer in India has been rising steadily, with an estimated 1.5 million new cases each year<sup>(1)</sup>. The increasing incidence of cancer in India underscores the urgent need for comprehensive cancer registries to facilitate better management, prevention, and control of this disease.

### Why Cancer Registries Matter

Cancer registries are essential tools for collecting, storing, analyzing, and interpreting data on cancer cases. They provide vital information on cancer incidence, prevalence, survival rates, and mortality, which are crucial for understanding the epidemiology of cancer in a given population. In India, where healthcare resources are often limited, accurate and comprehensive data is critical for designing effective public health policies, allocating resources, and improving cancer care outcomes.

In addition to providing epidemiological data, cancer registries are instrumental in identifying risk factors, monitoring trends, and evaluating the effectiveness of cancer control programs. They also support research efforts aimed at understanding the etiology of cancer, developing new treatments, and improving patient care. Without reliable cancer registries, it becomes challenging to assess the impact of existing cancer control measures or to plan future interventions.

### Current Status of Cancer Registries in India

India has made significant progress in establishing cancer registries over the past few decades. The National Cancer Registry Programme (NCRP), launched by the Indian Council of Medical Research (ICMR) in 1982, has played a pivotal role in collecting cancer data across the country<sup>(2)</sup>. The NCRP includes Population-Based Cancer Registries (PBCRs) and Hospital-Based Cancer Registries (HBCRs), which together provide valuable insights into the cancer burden in different regions.

As of 2023, there are 38 PBCRs and 238 HBCRs under the NCRP, covering various parts of the country<sup>(3)</sup>. However, despite these efforts, the coverage of cancer registries in India remains limited, with large gaps in data collection, particularly in rural and remote areas. Many states and regions lack PBCRs, and the available registries often face challenges related to underreporting, incomplete data, and inconsistent quality.

### Challenges Facing Cancer Registries in India

Several challenges hinder the effectiveness of cancer registries in India. These challenges must be addressed to ensure that cancer data is accurate, comprehensive, and actionable:

- 1. Underreporting and Incomplete Data:** One of the major issues facing cancer registries in India is underreporting of cases. Many cancer cases go unreported due to a lack of awareness, limited access to healthcare, and the stigma associated with the disease. Additionally, data from many cancer registries may be incomplete or inconsistent, making it difficult to draw reliable conclusions.
- 2. Lack of Standardization:** There is a need for standardized protocols for data collection, coding, and reporting across different cancer registries in India. The lack of uniformity can lead to variations in data quality and hinder the ability to compare data across regions.
- 3. Inadequate Infrastructure and Resources:** Many cancer registries in India suffer from inadequate infrastructure, including a lack of trained personnel, insufficient funding, and limited technological support. These limitations can affect the accuracy and timeliness of data collection and analysis.
- 4. Limited Coverage:** The existing cancer registries in India cover only a fraction of the country's population. Rural and remote areas, where a significant proportion of India's population resides, are often underrepresented in cancer registries. This limited coverage results in an incomplete picture of the cancer burden in India.

5. Privacy and Ethical Concerns: Ensuring the confidentiality and security of patient data is essential for maintaining trust in cancer registries. However, there are concerns about data privacy and the ethical use of information collected by cancer registries, particularly in a diverse and populous country like India.

### The Way Forward

To address these challenges and improve the effectiveness of cancer registries in India, a multi-pronged approach is needed:

1. Expand Coverage and Improve Data Quality: There is a need to expand the coverage of cancer registries to include more regions, particularly rural and remote areas. Efforts should be made to improve the accuracy and completeness of data collection, including enhancing case ascertainment and reducing underreporting.

2. Standardize Data Collection and Reporting: The implementation of standardized protocols for data collection, coding, and reporting across all cancer registries in India is essential. This will enable better comparability of data and facilitate more reliable epidemiological analyses.

3. Strengthen Infrastructure and Training: Investing in infrastructure and human resources is crucial for the success of cancer registries. This includes providing adequate funding, improving technological support, and training healthcare professionals in data collection, coding, and analysis. Leverage Technology: The use of digital health technologies, such as electronic health records (EHRs) and data analytics, can greatly enhance the efficiency and accuracy of cancer registries. Integrating cancer registries with EHR systems can streamline data collection and improve data quality.

5. Promote Public Awareness and Education: Public awareness campaigns can help reduce the stigma associated with cancer and encourage timely reporting of cases.

Education programs for healthcare providers and the general public can also improve the quality and completeness of data collected by cancer registries.

6. Ensure Data Privacy and Ethical Practices Safeguarding patient privacy and ensuring the ethical use of data should be a priority for cancer registries. Robust data governance frameworks and strict adherence to ethical standards are essential for maintaining public trust and protecting patient rights.

### Conclusion

Comprehensive cancer registries are critical for understanding the cancer burden in India and for guiding effective cancer control strategies. While significant progress has been made, there is still much work to be done to ensure that cancer registries in India are comprehensive, accurate, and reliable. By addressing the challenges of underreporting, standardization, infrastructure, and privacy, India can build a robust cancer registry system that will ultimately lead to improved cancer care and outcomes for its population.

### References

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