

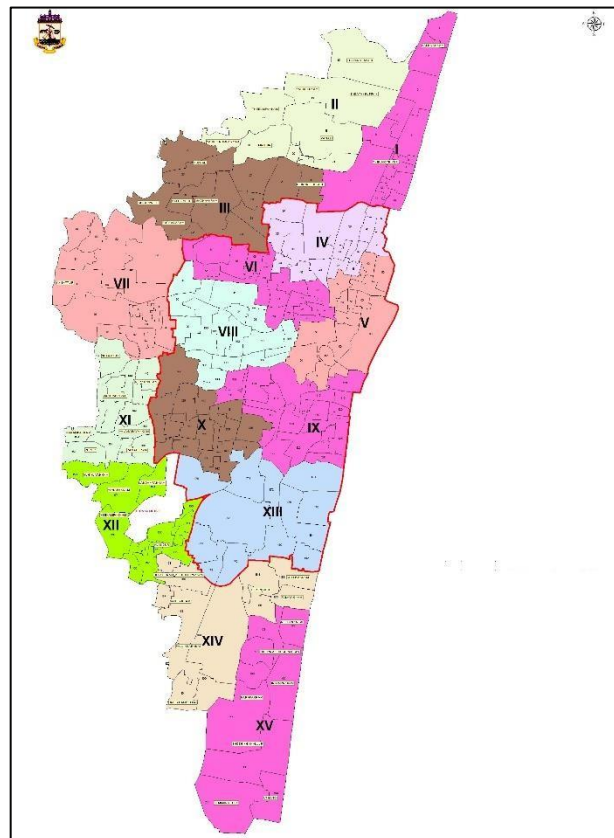


CANCER INSTITUTE (WIA)



Chennai Population-Based Childhood Cancer Registry (PBCCR) - First Report of High-Resolution Data.

Pediatric Cancer Incidence in Greater Chennai Corporation (GCC), Tamil Nadu, India: 2022



CANCER INSTITUTE (WIA)

ADYAR, CHENNAI - 600020

2025

Population-Based Childhood Cancer Registry (PBCCR) Report



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Chennai Population-Based Childhood Cancer Registry (PBCCR) Team

Cancer Institute (WIA), Adyar, Chennai.

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Abbreviations. HOD: Head of Department

LIST OF COLLABORATING HOSPITAL STAFF DETAILS FOR CHENNAI PBCCR

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Mr Antony	Dr Rela Institute and Medical Centre, Chennai	Medical Records Incharge
Dr. Harish	Gleneagles Health City, Chennai	Pediatric Medical Oncologist
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Abbreviations. ICMR: Indian Council for Medical Research; HBCR: Hospital-Based Cancer Registry

ABBREVIATIONS

Abbreviation	Expansion
ASpR	Age Specific Rate
ASR	Age Standardized Rate
CFIR	Consolidated Framework for Implementation Research
CIR	Crude Incidence Rate
CNS	Central Nervous System
CR	Cumulative Risk
EMR	Electronic Medical Records
GCC	Greater Chennai Corporation
GICC	Global Initiative for Childhood Cancer
HBCR	Hospital Based Cancer Registry
ICCC-3	International Classification of Childhood Cancer version 3
ICD 10	International Classification of Diseases, tenth revision
ICD-O	International Classification of Diseases for Oncology
ICMR	Indian Council of Medical Research
IICC-3	International Incidence of Childhood Cancer version-3
LMICs	Low- and Middle-Income Countries
MMTR	Madras Metropolitan Tumor Registry
MOU	Memorandum of Understanding
MRD	Medical Records Department
NGO	Non-Government Organization
PBCCR	Population Based Childhood Cancer Registry
PBCR	Population Based Cancer Registry
TNCRP	Tamil Nadu Cancer Registry Project
WHO	World Health Organization



FOREWORD

Cancer in children, though less common than in adults, poses unique challenges that extend beyond clinical care. The need for accurate, high-resolution data is paramount—not only for understanding the burden of disease but also for improving early diagnosis, optimizing treatment pathways, and ultimately enhancing survival rates. In this regard, the Chennai Population-Based Childhood Cancer Registry (PBCCR) is a groundbreaking initiative that strengthens our ability to combat childhood cancer through data-driven strategies.

At Cancer Institute (W.I.A.), we have long recognized the power of cancer registration in shaping public health policies and resource allocation. Our institute has played a pivotal role in India's cancer registry movement, and PBCCR is a natural progression of this commitment—tailored to the unique epidemiology of childhood cancers. This registry is not merely a database; it is a tool for advocacy, research, and system-wide improvements that will benefit children across Chennai and, in time, the nation.

This inaugural report highlights the incidence, treatment outcomes, and survival patterns of childhood cancers in Greater Chennai. It provides a scientific foundation for further strengthening pediatric oncology services, closing gaps in care, and ensuring that no child is left behind in the fight against cancer. The collaborative approach taken by PBCCR—bringing together hospitals, government agencies, research institutions, and global partners—demonstrates the impact of multi-sectoral teamwork in public health innovation.

I commend the PBCCR team, our institutional partners, and every contributor who has worked tirelessly to bring this registry to fruition. Their dedication has paved the way for a new era in childhood cancer surveillance in India. As we move forward, this registry will undoubtedly inspire similar efforts across the country and contribute to global pediatric cancer control initiatives.

Together, we stand committed to transforming childhood cancer care through knowledge, action, and compassion.

Dr. Kalpana Balakrishnan

Director,

Cancer Institute (W.I.A.), Adyar.



FOREWORD

To address childhood cancer as a public health issue, it is mandatory to measure its occurrence, outcome, and other parameters. A cancer registry is designed to assess the burden of the disease in a systematic way, as well as to design and monitor control strategies.

On a global scale, cancer statistics are known for a small fraction of the population. In addition, childhood cancer data are often presented without considering the specific characteristics of this group of diseases.

These premises make the Chennai Population-based Childhood Cancer Registry an exemplary flagship project. Combining the expertise developed within the long-standing Madras Metropolitan Population-based Cancer Registry with the vision for the development of pediatric oncology in Chennai sets this project for success.

This first report describes childhood cancer incidence and survival, the extent of early diagnosis, treatment abandonment, and other determinants. The reported 2-year survival of 70% represents a stepstone on the way towards 60% survival at five years from diagnosis, which is the 2030 global target of the WHO Global Initiative for Childhood Cancer.

The output reflected in this report is an achievement attributable to the registry leaders and all their collaborators. It is an admirable example of progress, which shows the way within India and serves as a bright example for other medium-income countries wishing to tackle cancers arising in their children.

Eva Steliarova-Foucher

Scientist

Cancer Surveillance

International Agency for Research on Cancer (IARC), France



PREFACE

Cancer Institute (W.I.A) is a pioneer in systematic population-based cancer registry surveillance in Tamil Nadu. The Madras Metropolitan Tumour Registry (MMTR) and the Tamil Nadu Cancer Registry Project (TNCRP) served as the basis for understanding the common cancer incidence pattern and trend in the state. Situational analysis of routine data on childhood cancers reiterated an imminent need for collecting more information for a better understanding. A childhood cancer registry was mounted on MMTR operations with extended data collection in 2012 but only met with limited success.

This prompted a novel approach of conceiving a special cancer registry for childhood cancers with emphasis on high-resolution data collection. The lead was taken by the institute to form a network of interested oncologists/clinicians as partners. This has culminated in establishing the Chennai Population-Based Childhood Cancer Registry (PBCCR), the only one in the country.

It is exciting to see the first report of PBCCR filled with high resolution data on referral status, disease stage, cancer directed treatment, outcomes and vital status. It is noteworthy that this information is available for more than 70% of all childhood cancers diagnosed among the residents of Greater Chennai Corporation limits.

My best wishes for the expansion of the Chennai PBCCR network into Tamil Nadu PBCCR in future.

Dr. R. Swaminathan MSc PhD (Statistics) PhD (Epidemiology)

Co-Principal Investigator Chennai PBCCR

Professor and Head

Department of Epidemiology, Biostatistics and Cancer Registry

Associate Director,

Cancer Institute (WIA)



MESSAGE

As the Principal Investigator of the Chennai Population-Based Childhood Cancer Registry (PBCCR), I am proud to present this pioneering effort in pediatric oncology surveillance. This report represents a significant milestone in our commitment to addressing the unique challenges of childhood cancers in low- and middle-income countries (LMICs). The PBCCR's establishment is not merely an academic or institutional achievement; it is a testament to the collaborative spirit of stakeholders across hospitals, government agencies, and international partners.

The data and insights derived from the PBCCR aim to bridge critical gaps in understanding the epidemiology of childhood cancers in Chennai and beyond. Through this initiative, we strive to improve the diagnosis, treatment, and survival outcomes for children facing cancer, aligning with global objectives such as the WHO's Global Initiative for Childhood Cancer.

This report would not have been possible without the dedication of our team, the support of participating hospitals, and the trust of the families whose experiences contribute to this vital dataset. As we move forward, let this registry inspire further research, collaboration, and innovation in pediatric oncology, both nationally and internationally.

Dr. Venkatraman Radhakrishnan
Principal Investigator Chennai PBCCR
Professor and Head
Department of Medical Oncology and Pediatric Oncology
Cancer Institute (WIA)



MESSAGE

Childhood cancer is not preventable but is curable. Generating data to support policy-level decision-making and monitor the impact of local interventions is a key priority for the global childhood cancer control. How to effectively achieve this goal, however, has remained elusive worldwide. Far too few children are covered by PBCCRs, often leaving this population invisible.

It is within this context that we recognize the global importance and contribution of the Chennai PBCCR. The achievements of the team cannot be overstated. First and foremost, these data will provide critical information to support both health policy and quality improvements initiatives aimed at reducing the burden of cancer among the children of Chennai. Yet, the impact of this work is not just local but expands beyond the borders of the city. The team has demonstrated to policymakers and data monitoring teams worldwide that it is not only possible to work collaboratively, across multiple sectors and disciplines, to successfully conduct surveillance among large populations, but also to do so at a high level of quality and resolution.

On behalf of St. Jude Global and our global childhood cancer community, I congratulate the Chennai PBCCR team and all local collaborators on their hard-fought achievement. I have witnessed first-hand the passion and sense of mission that drove this effort and wish the team well for the many more years of data collection and action to come.

Dr. Nickhill Hitesh Bhakta

Associate Member, Director Disease Burden and Simulation Unit

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St. Jude Children's Research Hospital

Memphis, TN, USA



MESSAGE

Registration of patients is the starting point for understanding disease burden. This is best exemplified by cancer registries, which provide valuable information on cancer control efforts. Population-based cancer registries (PBCR) provide further information on cancer incidence. Although cancer registries capture information on childhood cancer as well, this data has deficiencies in comprehensiveness, quality, and detail. Reasons include children often being treated in pediatric rather than oncology departments, childhood cancer classification being morphology rather than site-based, the conventional TNM staging does not apply to childhood cancer, etc. Due to these challenges, high-resolution population-based data on childhood cancer, even today, is not widely available, and where available, almost exclusively in high-income countries. In the most recent International Incidence of Childhood Cancer Report (IICC-3), the majority of datasets were provided by general PBCRs, whereas only 19 pediatric cancer registries provided population-based data.

In such a context, the development and publication of the first report of the Chennai Population-Based Childhood Cancer Registry (PBCCR) is a true milestone in India and globally. The entire team led by Dr. Venkatraman Radhakrishnan and Dr. Rajaraman Swaminathan have to be congratulated on their efforts. Executing such initiatives requires navigating the logistical, regulatory, and operational hurdles besides the focus on the scientific aspect. It is heartening to know that not only is this project going to continue and mature, but it is now going to expand to the entire state of Tamil Nadu. This would expand the PBCCR coverage from 0.4% of the Indian population to approximately 5% in the future. The magnitude of this cannot be understated.

I extend my personal gratitude and congratulations to the Chennai PBCCR team and their supporting collaborators. I wish them all the best for the future.

Dr Ramandeep Singh Arora

Visiting Consultant, Pediatric Oncology, Max Super Speciality Hospital, New Delhi

Director, Indian Pediatric Hematology Oncology Group (INPHOG)

Member, Governing Council, Indian Childhood Cancer Initiative (ICCi)

Independent Contractor, St Jude Global



MESSAGE

The Chennai Population-based childhood cancer registry has been a work of sheer love, passion, and perseverance. The coming years will slowly reveal the results of the data built brick by brick. We will then be able to make recommendations to the government, non-governmental organizations, and funding agencies regarding interventions required to help our local community. Congratulations to the entire team on laying down the foundations for this amazing work, and I am sure that future generations will appreciate the work being done.

Dr. Revathi Raj
Senior Consultant
Pediatric Haematology Oncology
Apollo Cancer Centre

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MESSAGE

In India, including cities like Chennai, pediatric cancer is an emerging health concern, but there is a significant gap in data collection and registry systems. The lack of a comprehensive pediatric cancer registry impedes efforts to understand the true incidence, trends, and types of cancers affecting children. In LMICs, accurate cancer data is essential for several key reasons, like tracking trends, resource allocation, and policy making. Standardizing care based on data-driven insights is crucial in improving survival rates.

A national pediatric cancer registry would not just be a record of statistics but a valuable repository of information that can drive innovations in cancer treatment, policy, and research. With a comprehensive registry, India could contribute to international clinical trials, improving access to cutting-edge treatments for children.

The establishment of the first dedicated Population-Based Childhood Cancer Registry (PBCCR) in Chennai is a monumental step forward and will undoubtedly pave the way for better cancer care. Our institute is immensely proud and happy to be part of this valuable registry and contribute data. By participating in this endeavor, we are not only advancing the science and treatment of pediatric cancer but also contributing to a larger, collective effort to improve the health and well-being of children across the nation. I wholeheartedly congratulate Dr. Venkatraman Radhakrishnan, Dr. Swaminathan, Dr. Punitha Selvam, and their whole team at the Cancer Institute (W.I.A) for taking up the challenge of establishing this much-needed pediatric cancer registry.

Dr Arathi Srinivasan

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The funders of the study had no role in the study design, data collection, data analysis, data interpretation, or writing of the report. Data was not shared with any funders. The funding supported the purchase of equipment (computers, servers, etc.) and the salaries of registry staff.

HIGHLIGHTS

- The Chennai Population-Based Childhood Cancer Registry (PBCCR) is the first dedicated population-based cancer registry for childhood cancer in India.
- The registry was established in October 2022 under the Madras Metropolitan Tumor Registry (MMTR), a general population registry that has been collecting data since 1981.
- The Chennai PBCCR collects additional data for children aged 0–19 years who were not captured by the MMTR. This includes sociodemographic features, the International Classification of Childhood Cancers, Toronto staging, treatment details, follow-up, outcomes, and benign brain tumors.
- Data is recorded using a structured Case Record Form and electronically stored in a secure REDCap database server at the Cancer Institute (W.I.A).
- A total of 17 hospitals contribute data to the Chennai PBCCR. Data is actively collected from these hospitals through frequent visits.
- In 2022, 241 cases were recorded, which included 139 boys and 102 girls. In the same year, 170 cases were captured by the Chennai PBCCR for high-resolution data, and 71 cases were taken from TNCRP.
- For the 71 cases where high-resolution data could not be captured, efforts were made to ascertain follow-up status by telephonically contacting the families.
- The mean age of diagnosis in the high-resolution data was 8.6 years.
- The most common reason for not capturing high-resolution data was the lack of case records.
- The age-standardized incidence rate for pediatric cancer in Chennai was 136.3 per million population.
- The most common malignancies in both sexes were leukemia, lymphoma, and soft tissue sarcoma.
- The Institute of Child Health and Hospital for Children, Egmore, had the highest contribution to PBCCR, accounting for 104 (43%) out of 241 cases in 2022.
- Among the 72 lymphoma and solid tumors analyzed in the high-resolution data, 63 (88%) presented with localized disease, 2 (3%) had locoregional disease, and only 7 (9%) had advanced disease.
- The median time from symptom onset to cancer diagnosis was 12.5 days, while the median time from diagnosis to the start of treatment was 2 days.
- At the 2-year follow-up for all cases, 143 out of 241 cases (59.3%) were alive, 40 out of 241 cases (16.5%) were deceased, and the status was unknown for 58 out of 241 cases (24%).
- At the 2-year follow-up for high-resolution data, 120 out of 170 cases (71%) were alive. Among these:
 - 97 out of 120 cases (81%) were disease-free,

- 15 out of 120 cases (13%) had not achieved remission,
 - 5 out of 120 cases (4%) had relapsed, and
 - 3 out of 120 cases (2%) had an unknown disease status.
- Among the 38 out of 170 cases were deaths in the high-resolution data (22%):
 - 32 out of 38 cases (84%) were not in remission,
 - 5 out of 38 cases (13%) were in remission, and
 - 1 out of 38 cases (3%) had relapsed.
- Survival status at the 2-year follow-up in the high-resolution data was unknown for 12 out of 170 cases (7%). Of these, during the first-year follow-up:
 - The disease status was unknown for 12 out of 12 cases (100%).

EXECUTIVE SUMMARY

Establishing the Population-Based Childhood Cancer Registry (PBCCR) in Chennai, India

The Population-Based Childhood Cancer Registry (PBCCR) was established in Cancer Institute (WIA) on 4th October 2022 as India's first dedicated registry for childhood cancers. This initiative builds on the foundational work of the Madras Metropolitan Tumor Registry (MMTR), launched in 1981, to address the critical need for accurate, high-resolution data on childhood cancer incidence and outcomes. By systematically documenting pediatric cancer cases for individuals aged 0–19 years within Greater Chennai Corporation limits, the PBCCR aims to fill significant data gaps and improve treatment outcomes in line with the objectives of the World Health Organization's Global Initiative for Childhood Cancer (GICC).

Rationale and Methodology

Childhood cancers require specialized data collection due to their distinct epidemiology and treatment pathways. General population-based cancer registries often lack the detailed data needed to analyze childhood cancers effectively. The PBCCR collects comprehensive data, including Toronto staging, treatment adherence, socioeconomic factors, and referral patterns, through collaborations with 17 hospitals and other sources, including the Tamil Nadu Cancer Registry Program (TNCRP). Data is managed using REDCap software with stringent quality control measures.

Key Achievements in 2022

- **Stakeholder Engagement:** Ethical clearances and Memorandums of Understanding (MoUs) were established with collaborating hospitals to ensure seamless data collection. A dedicated team of trained registry staff coordinated with pediatric oncologists and social workers for case identification and data accuracy.
- **Training:** Registry staff received extensive training in cancer registration, data abstraction, and the use of staging systems through the Cure4Kids and IARC ChildGICR courses.
- **Data Collection:** In 2022, the PBCCR registered 241 cases, including 139 boys (57.7%) and 102 girls (42.3%). Of these, 170 (70.5%) cases were high-resolution data, and the remaining were routine data included from TNCRP.

- **High-Resolution Data:** Detailed abstraction was performed for 170 cases, with specific insights into diagnostic pathways, treatment timelines, disease-specific staging, and follow-up data. Acute Lymphoblastic Leukemia (ALL) was the most common cancer type, accounting for 63 (37 %) of cases.
- **Diagnostic and Therapeutic Timelines:** Among 170 counts of 241 with high-resolution data, the median time from symptom onset to diagnosis was 12.5 days, and the median time from diagnosis to treatment initiation was two days, highlighting efficient care delivery.

Findings

- **Cancer Incidence:** The age-standardized rate for pediatric cancer in Chennai was 136.3 per million population, 152.7 per million boys and 118.5 per million girls. Leukemia was the most common cancer type in both genders, followed by lymphomas, soft tissue sarcomas, Germ cell tumor, bone and CNS tumors.
- **Treatment Patterns:** Among the high-resolution cases, 81.2% received curative treatment, with chemotherapy being the most common modality. 84.7% of cases were treated according to therapeutic protocols, while 18.8% of cases were untreated due to various reasons.
- **Survival Outcomes:** At the 2-year follow-up for all cases, 143 out of 241 cases (59.3%) were alive, 40 out of 241 cases (16.5%) were deceased, and the status was unknown for 12 out of 170 cases (7 %) with High-resolution data and 46 out of 71 (64 %) with routine data.
- **Challenges:** Significant barriers include inconsistent record-keeping and difficulty in accessing both outpatient and in-patient data in a multi-speciality hospital setting. Recommendations include establishing Hospital-Based Childhood Cancer Registries (HBCCRs) for more robust data collection including follow-up.

Comparative Analysis

The PBCCR's results align with trends observed in other low- and middle-income countries (LMICs). Comparisons with international registries underscore the need for improved diagnostic and therapeutic infrastructure to enhance survival outcomes. The age-standardized rates (ASR) were comparable to those reported in Asian LMIC registries. However, survival rates were lower compared to high-income countries, highlighting the need for strengthened healthcare systems. Among Indian population-based registries, Chennai had the second-highest ASR for boys, following Delhi. For girls, Chennai ranked third, behind Thiruvananthapuram and Delhi.

Impact and Future Directions

The PBCCR's findings provide critical insights into the epidemiology of childhood cancers in Chennai, guiding policy decisions and resource allocation. Future efforts will focus on:

- Scaling up the registry model to other regions.
- Enhancing high-resolution data collection methods to cover more sources including electronic health records integration.
- Strengthening collaborations with international agencies and healthcare providers.

This pioneering effort marks a significant step toward improving childhood cancer care and outcomes in India, aligning with global standards and addressing the unique challenges in LMICs.

1. THE NEED FOR A DEDICATED POPULATION - BASED CHILDHOOD CANCER REGISTRY (PBCCR)

Enhancing the survival rates of children with cancer in low- and middle-income countries (LMICs) and achieving the objectives outlined by the World Health Organization (WHO) in its Global Initiative for Childhood Cancer (GICC) requires accurate measurement of childhood cancer incidence and outcomes. This critical goal can be achieved through data collected by a population-based cancer registry. Considering the unique characteristics and epidemiology of childhood cancers, establishing a specialized population-based childhood cancer registry (PBCCR) is an effective strategy to generate high-quality data specific to this population.

The primary aim of a PBCCR is to systematically document all newly diagnosed pediatric cancer cases within a defined geographic area with an emphasis on high-resolution data. Data is sourced from diverse and comprehensive channels, such as hospitals in public and private sectors, pathology labs, and government vital statistics. This information provides insight into the incidence and patterns of childhood cancer within the population. However, in many LMICs, including India, there is a significant lack of reliable data to facilitate detailed analyses of childhood cancer incidence and survival rates. This gap exists due to several challenges.

General population-based cancer registries typically record cancer cases across all age groups but often do not prioritize or maintain the detailed data necessary for studying childhood cancers, such as morphology type-specific statistics or disease-specific staging information. Consequently, relying on these general registries for understanding childhood cancer epidemiology is frequently insufficient. Despite these limitations, childhood cancers are highly curable when detected early and treated with appropriate anti-neoplastic therapies. Accurate and comprehensive reporting can significantly improve outcomes for children with cancer.

To address the need for a specific focus on childhood cancer in Chennai, we established the first dedicated PBCCR in India was on 4th October 2022 This initiative builds on the Madras Metropolitan Tumor Registry (MMTR), a general Population-based cancer registry established in 1981, which collects data on cancer cases across all age groups within the Chennai old Metropolitan limits.

The Chennai PBCCR is designed to gather detailed, high-resolution data on pediatric cancer cases for patients aged 0–19 years residing in Greater Chennai Corporation. In contrast to MMTR, the PBCCR includes additional data points such as Toronto staging, treatment details, socioeconomic factors, treatment adherence, and referral patterns. Findings from the PBCCR will be disseminated through annual reports and shared with participating institutions and other interested researchers, the National Cancer Registry Program of India, and the International Agency for Research on Cancer. These efforts aim to guide policy decisions and enhance childhood cancer outcomes.

Table 1.1: Comparing General PBCR and Specialized PBCCR High-Resolution Data

	General PBCR	Specialized PBCCR High-resolution data
Socio-Demographic Details	Name, Address with Pincode, Hospital Registration Number, Phone Number, Age (in years), Sex, Name of Father/Mother	Name, Date of Birth, Sex, Medical Record Number, National ID, Address with Pincode, Race, Ethnic group, Parent/Primary Caregiver name and Highest Education, Phone Number, E-Mail ID
Diagnosis	Date of Diagnosis, Most valid basis of Diagnosis, Anatomical site, ICD-O-3 Topography, ICD-O-3 Morphology, Site of Tumor (ICD 10), Sequence of cancer	Date of initial onset of cancer-related symptoms, Date of First Medical Assessment for cancer symptoms, Date of Diagnosis, Most valid basis of diagnosis, ICD-O-3 Topography/Site, ICD-O-3 Morphology: Type and Behavior code, ICCC-3, Laterality of primary site and sequence, HIV Status, Referral source and Address
Stages	Clinical extent of disease TNM/FIGO/etc. optional	CNS Involvement (For Leukemia), Toronto Tier 1 Toronto Tier 2
Treatment	Type of Treatment	Date of referral to treatment institution, Treated with curative intent or not, Date of curative treatment given, Treatment in therapeutic protocol and Protocol ID, Type of Treatment, Chemotherapy drugs, Radiation Site, Surgery types, Hematopoietic stem cell transplant details, The reason for curative treatment not being given,

		Treatment entirely or partially at other sites details and address. Palliative treatment type.
Follow-Up Details For 5 Years	-	Date of Remission, Date of Relapse, Treated with curative intent or not, Date of curative treatment given, Treatment in therapeutic protocol and Protocol ID, Type of Treatment, Chemotherapy drugs, Radiation Site, Surgery types, Hematopoietic stem cell transplant details, The reason for curative treatment not being given, Treatment entirely or partially at other sites, details and address of the hospital, Palliative treatment type. Need of updation in the patient information.
Vital Status	Alive/Death, Date of Death, Date of last contact	Last known vital status, Alive/Death/Unknown/Not seen Last follow-up, source of vital status, Date of last follow-up, Date of Death, Causes of Death, place of death

Abbreviations: ICD-O-3 - International Classification of Diseases for Oncology Version 3, ICD 10 - International Classification of Diseases, tenth revision, ICC-3 - International Classification of Childhood Cancer version 3, FIGO - International Federation of Gynaecology and Obstetrics, TNM – Tumor size, Lymph node, Metastasis, HIV - Human Immunodeficiency Virus.

2. INTEGRATION OF THE CHENNAI PBCCR INTO THE MADRAS METROPOLITAN TUMOR REGISTRY/TNCRP AND COLLABORATION WITH DATA SOURCES

The Cancer Institute (W.I.A.) is the first demographic cancer registration organization in the state of Tamil Nadu. Under the National Cancer Registry Program (NCRP) of the Indian Council of Medical Research (ICMR), Government of India, the institute has hosted the first population-based cancer registry (PBCR), known as the Madras Metropolitan Tumor Registry (MMTR) in Tamil Nadu, since 1981. The registry serves an exclusively urban population, covering the 170 km² Chennai metropolitan area.

In 2011, the Tamil Nadu Ministry of Health and Family Welfare was approached by the institute to request authorization for data collection from entire the state and to discuss the possibility of designating cancer as a notifiable disease. After careful consideration by senior officials of the Directorate of Public Health and Preventive Medicine (DPH&PM), a government order [G.O. (Ms.) 132 dated June 17, 2012] was issued, authorizing the Cancer Institute (W.I.A.), Chennai, to enhance registry operations by collecting information on all new cancer cases among Tamil Nadu residents. Subsequently, the Public Health Act facilitated the issuance of another government order [G.O. (Ms.) 66 dated February 22, 2018], officially designating cancer as a notifiable disease in Tamil Nadu.

The Population-Based Childhood Cancer Registry (PBCCR) was conceived as a collaborative study by networking with oncologists/ other clinicians in Chennai and integrated with the existing TNCRP residing in Greater Chennai Corporation limits to improve case-finding and supplement high-resolution data for the pediatric population. Ethical clearance for the project was obtained from the Institutional Ethics Committee of the Cancer Institute (W.I.A.), Adyar.

An official meeting was held with pediatric and medical oncologists from major source hospitals that had reported pediatric cancer cases to the TNCRP in previous years. The meeting proposed involving pediatric and medical oncologists in Chennai as co-investigators to address challenges and gaps in collecting high-resolution data.

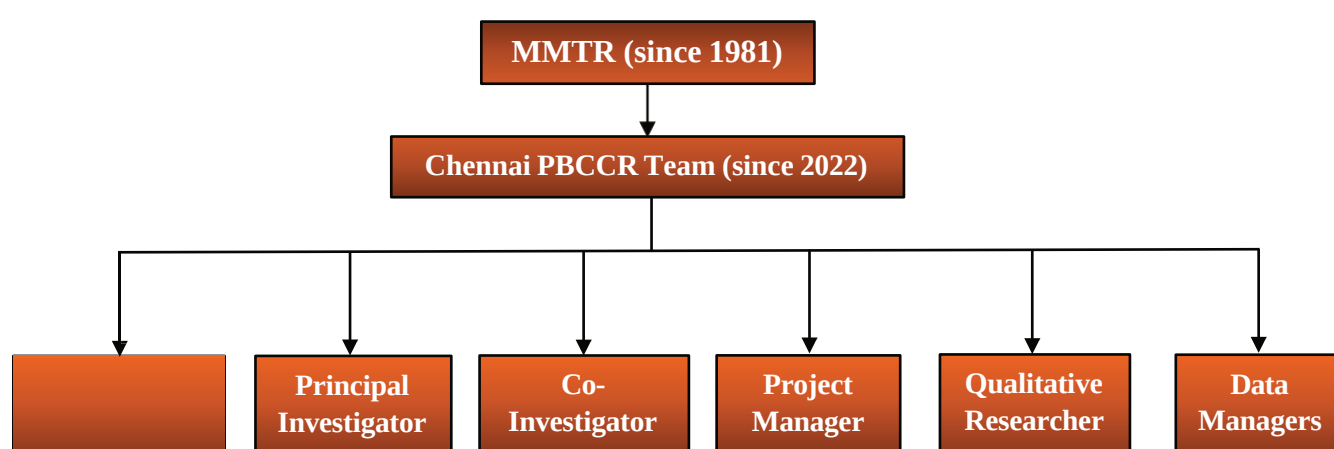
Collaboration letters and memorandums of understanding were signed between the principal investigators (PIs) of the Cancer Institute (W.I.A.), Adyar, and the co-principal investigators (Co-PIs) (pediatric/medical oncologists) from major pediatric cancer centers in Chennai to facilitate the collection of extended data for the PBCCR. In some centers, ethical committee approval was obtained from their respective institutions for extended data collection.

3. OPERATION OF CHENNAI PBCCR: MODUS OPERANDI

Staff Selection and Training

The Project Manager and Data Managers were appointed and trained in the cancer registry program at the Epidemiology, Biostatistics, and Cancer Registry Department, Cancer Institute (W.I.A), Chennai. They also received additional training in high-resolution data collection through the Cure4Kids website (SJ CARES Registry Course) and the IARC ChildGICR course. During the training, the staff were instructed on quality data abstraction from patient records, filling out Case Record Forms (CRFs), making online entries, and using childhood cancer staging systems.

Figure 3.1: Organization of the Chennai PBCCR



Case finding and data collection

Trained registry staff visited hospitals collaborating with the PBCCR in Chennai to collect cancer case data. The various sources of data collection are presented in Table 3.1.

Registry staff conducted regular visits—1 to 2 times per month—to gather data on cancer-diagnosed cases residing in the Greater Chennai Corporation area from 2022 onward. They obtained cancer case information from the Oncology Out-Patients Departments / medical records departments of the collaborative hospitals and collected detailed data, including diagnosis, stage, treatment, and follow-up details, from both manual and electronic case files. Missing information in case files was completed through interactions with the Co-Principal Investigators (Co-PIs) of the respective hospitals. Senior staff reviewed the completed data collection forms to ensure accurate and complete entries.

In hospitals where registry staff were unable to access medical records, social workers assigned by the Co-PI were responsible for data collection. These social workers, trained in cancer registration, data collection, and entry, gathered pediatric cancer patient data from their respective sources in Chennai and recorded it in the data collection forms. The completed forms were submitted to the Project Manager monthly.

During each visit, the registry staff identified new cases and verified collected data to avoid duplication across hospitals. The hospital where the first diagnosis of cancer was made was retained as the reporting institution for PBCCR for that case. They also collected/ updated patient details, including remission status, follow-up treatment, and follow-up status, on an annual basis.

For cases where follow-up details were missing, the registry staff contacted the patients' caregivers by phone to obtain vital status information, including reasons for missed follow-ups, such as receiving treatment at other hospitals, treatment refusal, or patient death. The collected details were then entered into the data collection form.

Table 3.1: Institutes involved in the PBCCR Project

S. No	Institutions name	Place
1	Rajiv Gandhi Government General Hospital	Chennai
2	Government Royapettah Hospital	Chennai
3	Institute of Child Health and Hospital for Children	Chennai
4	Tamil Nadu Government Multi Super Speciality Hospital	Chennai
5	Sri Ramachandra Medical College and Research Institute	Chennai
6	Apollo Cancer Centers,	Chennai
7	Kanchi Kamakoti Childs Trust Hospital	Chennai
8	Rainbow Children's Hospital	Chennai
9	Dr. Mehta's Hospital	Chennai
10	Sankara Nethralaya Eye Hospital	Chennai
11	Kauvery Hospital	Chennai
12	Cancer Institute (WIA)	Chennai
13	Dr. Rela Institute and Medical Centre	Chennai
14	Gleneagles Health City	Chennai
15	SRM Institutes for Medical Science	Chennai
16	VS Hospitals	Chennai
17	Kumaran Hospital (Madras Cancer Care Foundation)	Chennai

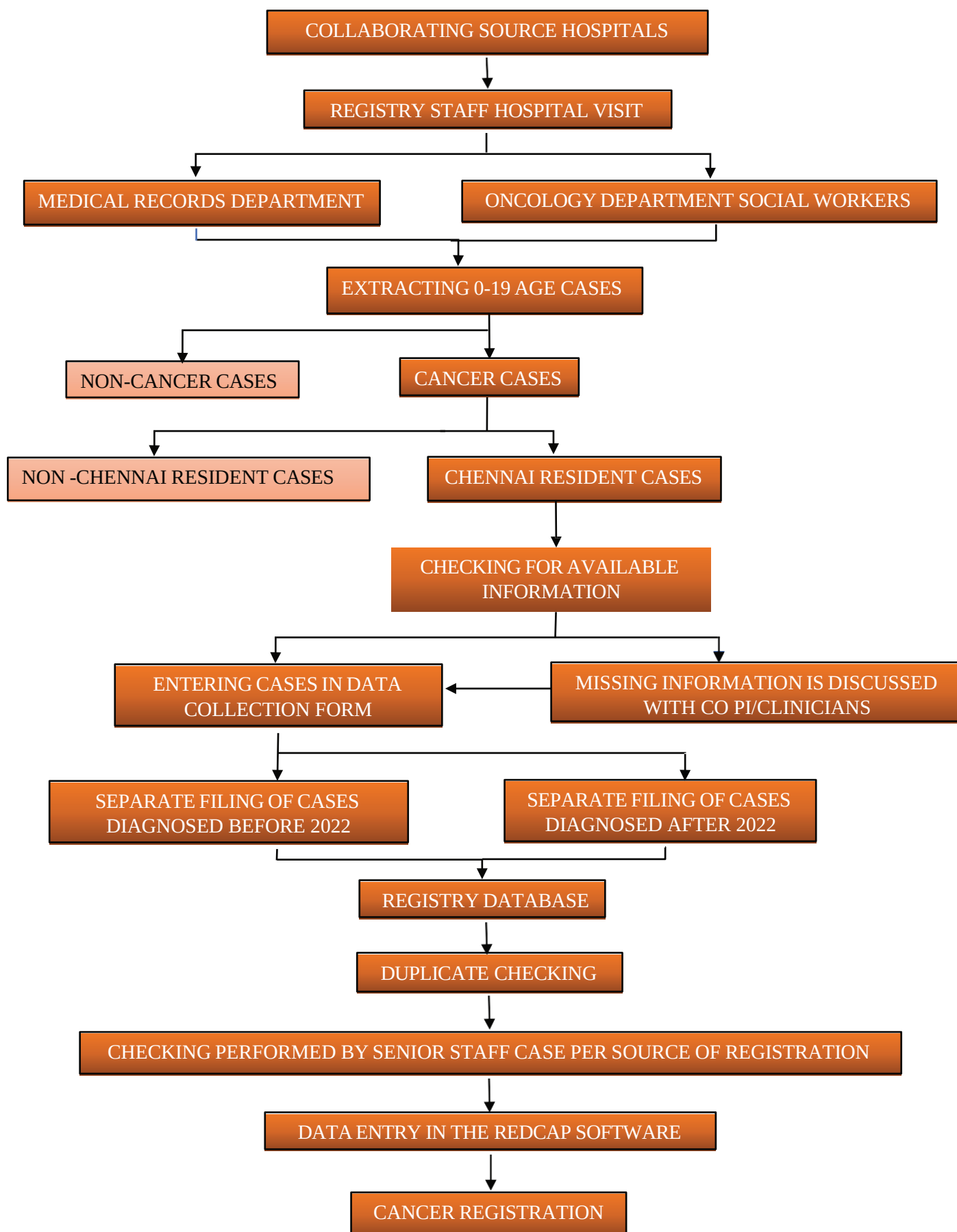
Cancer Prevalence Cases

During hospital visits, registry staff encountered cases diagnosed prior to 2022. For such instances, the staff collected information on these cancer cases from the medical records department using a data collection form and maintained the data in a separate database at the registry office. The registry staff also updated follow-up details and the current status of these cases during their regular visits, recording all updates in the data collection form for transmission to the MMTR/TNCRP database.

Data Checking and Entry

All cases collected by the registry staff from hospitals were thoroughly checked for duplication. In cases where the morphology was difficult to determine, discussions were held with clinicians to ensure accurate classification. After completing the duplication checks and implementing other quality control measures, the cases were registered in the database.

Data entry was performed using the REDCap software by the Cancer Institute (W.I.A), Adyar. A unique PBCCR ID was assigned to each case in the REDCap system. During the registration process, the ICCC-3 code was automatically generated based on topography and morphology. Additionally, the age at diagnosis was calculated using the patient's date of birth.

Figure 3.2: Cancer Registration Method for PBCCR High-Resolution Data Collection

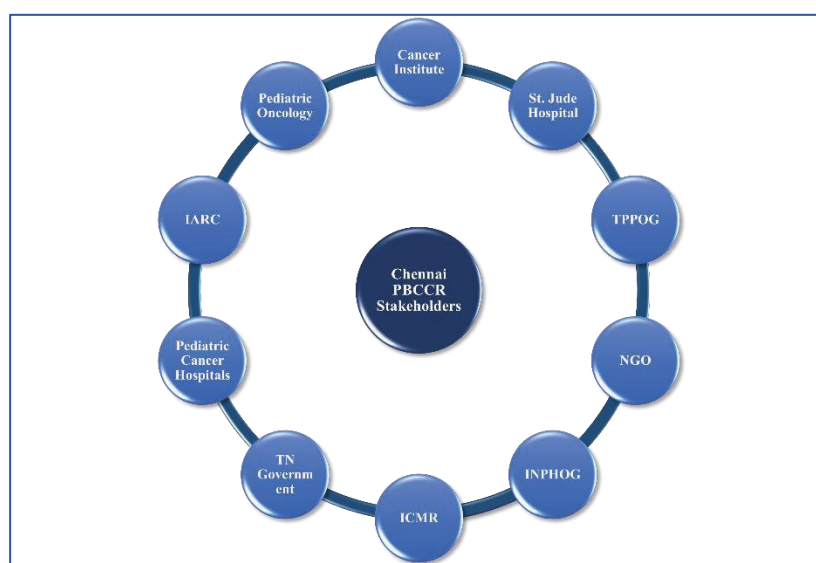
4. CHENNAI PBCCR STAKEHOLDERS

Collaboration from various stakeholders was necessary for the PBCCR to operate Hospitals in the public and private sectors: oncologists, the Health and Family Welfare Department of the Government of Tamil Nadu, the Indian Council for Medical Research (ICMR), the Indian Pediatric Hematology Oncology Group (INPHOG), the Cancer Institute (W.I.A.), the Tamil Nadu Puducherry Pediatric Oncology Group (TPPOG), the Pediatric Hematology Oncology Chapter of the Indian Academy of Pediatrics (IAP PHO), and non-governmental organizations (NGOs) dealing with childhood cancers, such as Cankids and St. Jude Global, were the main stakeholders in the Chennai PBCCR.

The registry staff interacted with various social workers, TNCRP social/field workers, ICMR HBCR staff, Cankids staff, and patients' caregivers to collect details about newly diagnosed cases and cancer-related deaths. The registry staff engaged regularly with these members during visits to gather detailed information about cancer cases registered at the hospital.

During the initial phase of cancer registration, the TNCRP social/field investigator oversaw the process of identifying cancer cases from the medical record department. In some private hospitals, social workers were assigned to extract cancer case data and conduct regular follow-ups. The project staff collected the completed forms once a month. In some government hospitals, where data in the medical records department was insufficient, Cankids social workers, who were already present in the hospitals, provided lists of registered cancer cases from regional centers. In instances where treatment details or follow-up information were missing, project staff directly contacted patients' caregivers over the phone to inquire about treatment follow-up and vital status.

Figure 4.1: Major Stakeholders for Chennai PBCCR



This interaction enhanced the completeness of details regarding the residence of the cancer cases and demographic details such as education, income, and religion. It also allowed the collection of follow-up information and updates on the vital status of cancer patients, which are critical for cancer survival analysis.

The Conquer Cancer Foundation of the American Society of Clinical Oncology (ASCO), USA, and St. Jude Children's Research Hospital, Memphis, USA, provided funding grants for infrastructure and staffing for the Chennai PBCCR. Additionally, the International Agency for Research on Cancer (IARC), Lyon, France, and St. Jude Children's Research Hospital, Memphis, USA, provided support to the Chennai PBCCR.

5. CASE RECORD FORM AND DATABASE FOR CHENNAI PBCCR

The Chennai PBCCR operates within the Department of Epidemiology, Biostatistics, and Cancer Registry at Cancer Institute (W.I.A). The Case Record Form (CRF) was adapted from the St. Jude Hospital SJCARES hospital-based cancer registry form (Appendix 1). Data is actively collected using paper CRFs, which are later transferred to the online CRF in the REDCap database presented in Figure 5.1.

The REDCap CRF is hosted on a dedicated server of the Madras Metropolitan Tumor Registry (MMTR) and TNCRP at the Cancer Institute (W.I.A) with exclusive access rights. The data is also backed up on an additional server within the institute campus to ensure data security.

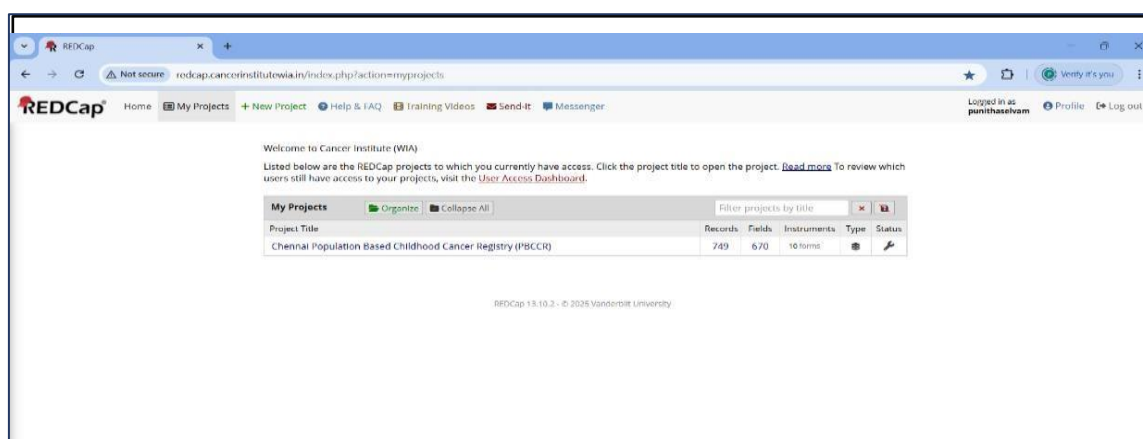
The PBCCR team collaborated with the informatics team to integrate the SJCARES-designed Data Collection Form into the REDCap software, using the SJCARES codebook guide for seamless compatibility.

Access to PBCCR data is restricted to the Principal Investigator and PBCCR staff, who utilize unique User IDs and passwords to ensure data confidentiality and security. Each case registered in REDCap is assigned a unique ID, and the age of patients at the time of diagnosis is automatically calculated based on their date of birth.

The REDCap CRF is designed to automatically generate coding for primary site and morphology using ICD-O, ICD-10, and ICC-3 codes based on the data entered. The software allows for updates and corrections to be made to registered data, ensuring accuracy and consistency. After completing data entry for each form, users can select "Complete" or "Incomplete" to save the form accordingly.

Data analysis is performed by extracting raw data from the software in Excel format for further processing and reporting.

Figure 5.1: Redcap Software



6. CHENNAI PBCCR QUALITY CONTROL

Quality Control of Cases

Quality control is a critical component of the registry, ensuring that the information collected by staff is accurate, precise, and adheres to established standards. Special training was provided to staff members on data collection methods. The registered cases were thoroughly reviewed by senior staff, focusing on the primary site, morphology, and treatment details.

Interaction with Clinician

During case abstraction, registry staff engaged with clinicians at the registration hospital to address difficulties or seek clarifications related to primary sites, staging, and treatment procedures. Based on oncologists' input, the abstracted data was modified and re-entered to ensure accuracy.

Re-Abstraction of Cancer Cases

After initial abstraction, registered cases were checked for duplication across other sources and reviewed for missing data and coding errors. If duplicate cases were identified, the information from the duplicates was updated in the original records. In cases of missing data, registry staff conducted re-abstraction to ensure completeness.

Cases Registered Based on Other Sources

Most cases in the registry were directly abstracted and entered by registry staff at source hospitals. In some hospitals, data managers trained in data abstraction were assigned by the source hospital to register childhood cancer cases. These entries were verified by the respective clinicians and shared with the registry staff. In some institutions, registry staff obtained outpatient and inpatient lists from Cankids social workers, tracked patient records, abstracted necessary information, and followed up regularly. The collected data was cross-checked with pediatric cases residing in Chennai and registered in TNCRP for 2022 and earlier years to identify missing data and older cases and avoid duplication. The exchange of data from TNCRP enhances the completeness of coverage and information on Childhood Cancer Cases.

Most Valid Basis of Diagnosis

Out of 241 total cases, four were diagnosed through imaging, 235 were diagnosed via microscopic verification, and two were from death certificates only. Among boys, 137 cases (98%) were confirmed microscopically, and 2 cases (2%) via imaging. Among girls, 98 cases (96%) were confirmed microscopically, 2 cases (2%) via imaging, and 2 cases (2%) from death certificates only. The high percentage of microscopic verification reflects the good quality of data in the report.

Basic Demographic Details

As PBCCR collects high-resolution data and monitors patient records for up to five years, obtaining basic demographic details such as the address and mobile numbers of caregivers is essential. This information allows registry staff to contact caregivers in cases of treatment withdrawal, loss of follow-up without intimation, or sudden deaths at home.

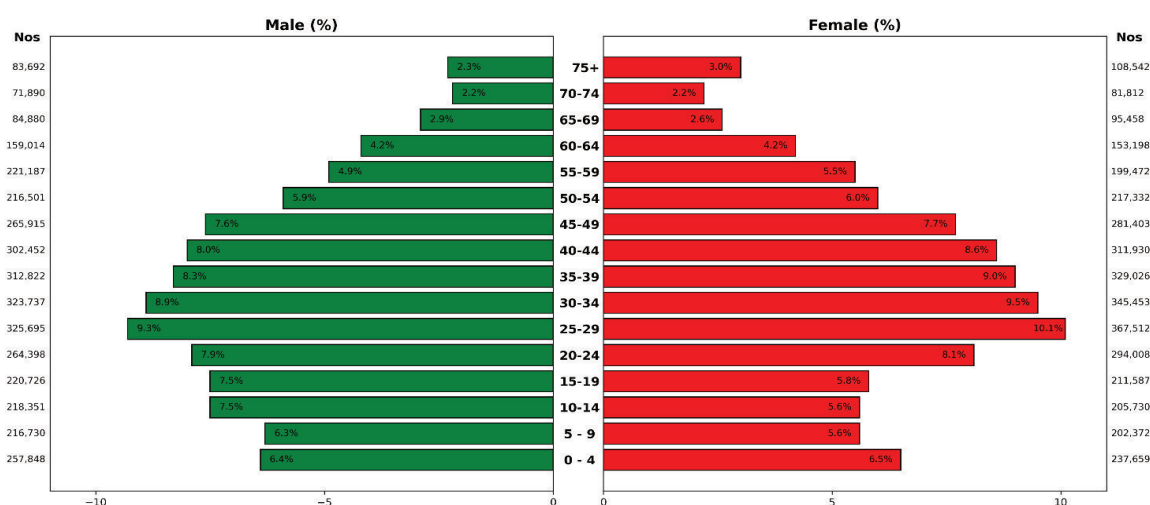
7. GREATER CHENNAI CORPORATION (GCC) PROFILE

Chennai, the capital of Tamil Nadu State, is a prominent district and one of India's four major metropolitan cities. It is located on the eastern coast of peninsular India, bordering the Bay of Bengal to the east. It is surrounded by the districts of Chengalpattu, Kanchipuram, and Tiruvallur on the remaining sides. Chennai plays a significant role in the nation's historical, cultural, and intellectual development and is often referred to as the "Gateway of South India".^{1,2}

Chennai is divided into four broad regions: North, Central, South, and West. North Chennai is primarily an industrial area, while South and West Chennai, previously predominantly residential, are rapidly transforming into commercial hubs, hosting a growing number of information technology firms and financial companies.¹

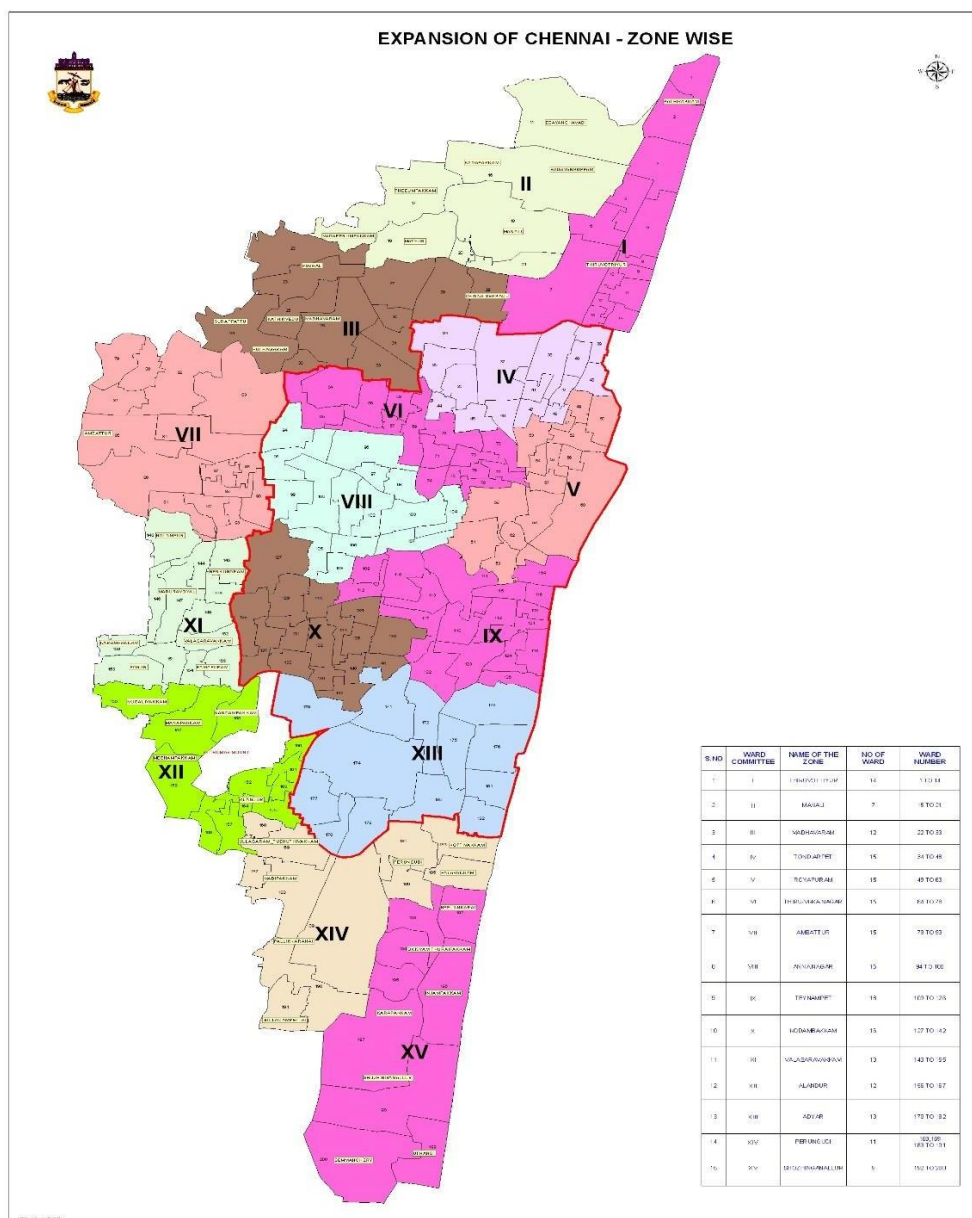
The city has been governed by the Greater Chennai Corporation (formerly the Corporation of Madras) since 1688. It is the oldest municipal corporation in India and the second-oldest in the world.¹

According to the 2011 Census of Tamil Nadu, the Chennai metropolitan area covered 176 square kilometers and had a population of 4,646,732, accounting for 6.44% of Tamil Nadu's total population. The Chennai district then had 155 divisions classified under 10 zones. It ranks first in terms of population within the state. Currently, Greater Chennai Corporation spans an area of 426 square kilometers with 200 divisions classified under 15 zones and a total population of 7,188,333. The male population is 3,545,840, and the female population is 3,642,493. The estimated population of Greater Chennai Corporation by 5-year age group and sex in 2022 is given in Figure 7.1. The Greater Chennai Corporation area by 15 zones and 200 divisions is given in Table 7.1. The map of the Greater Chennai Corporation area by 15 zones and 200 divisions is given in Figure 7.2.

Figure 7.1: Population Pyramid of Greater Chennai Corporation Estimated 2022**Table 7.1: Greater Chennai Corporation (GCC) by Zone and Divisions**

S No	Zone	Name of the Zone	Division Number
1	I	Thiruvotriyur	1 to 14
2	II	Manali	15 to 21
3	III	Madhavaram	22 to 33
4	IV	Tondiarpet	34 to 48
5	V	Royapuram	49 to 63
6	VI	Thiru Vi Ka Nagar	64 to 78
7	VII	Ambattur	79 to 93
8	VIII	Anna Nagar	94 to 108
9	IX	Teynampet	109 to 126
10	X	Kodambakkam	127 to 142
11	XI	Valasaravakkam	143 to 155
12	XII	Alandur	156 to 167
13	XIII	Adyar	170 to 182
14	XIV	Perungudi	168,169, 183 to 191
15	XV	Shozhanganallur	192 to 200

Figure 7.2: Map of Greater Chennai Corporation (GCC) Area by 15 Zones and 200 Divisions



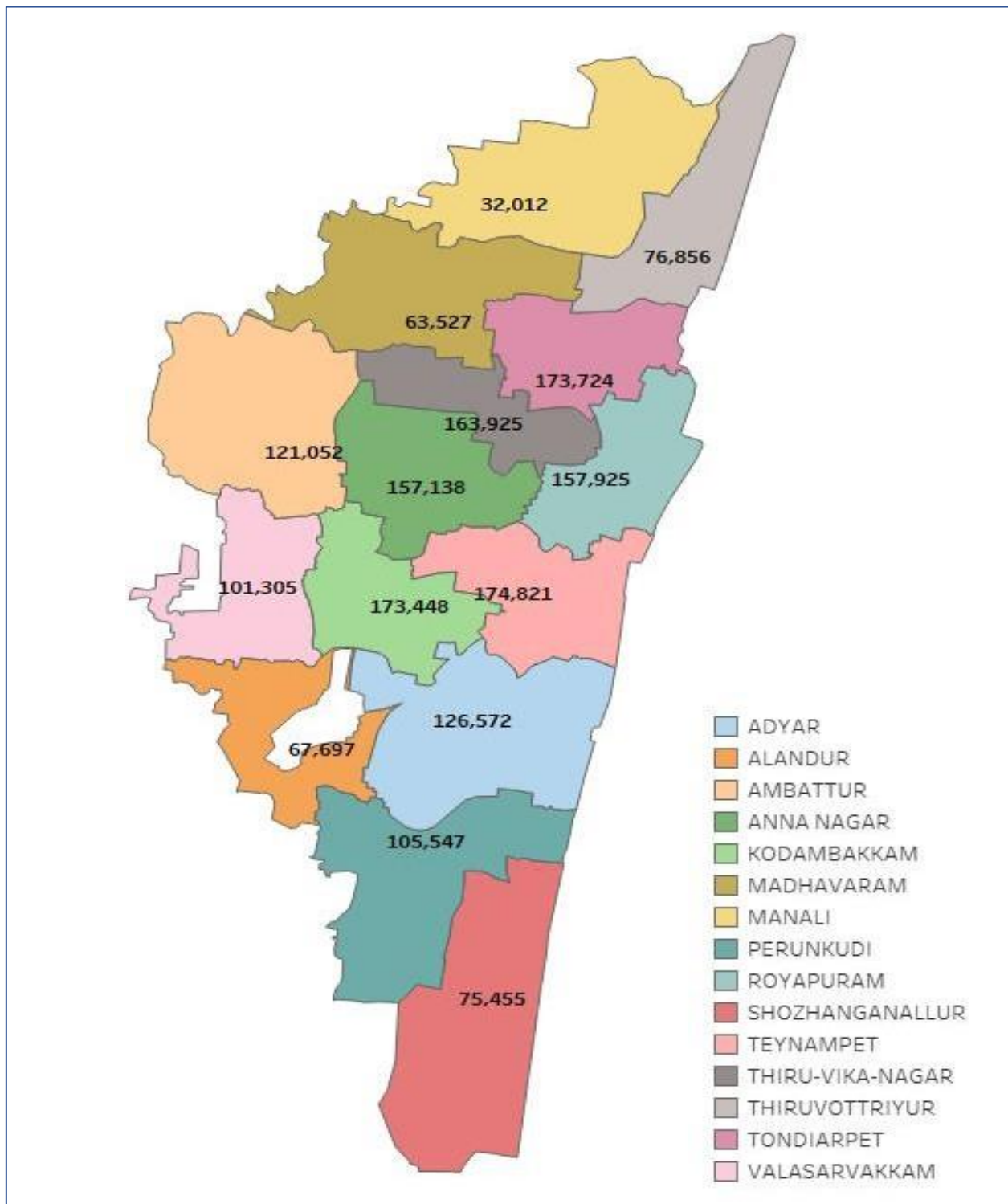
8. POPULATION COVERED BY CHENNAI PBCCR

Currently, the Greater Chennai Corporation area is divided into 15 zones and 200 divisions. The pediatric population aged 0-19 years in 2022 was estimated using the exponential growth method based on the 2001 and 2011 Census data and Population statistics presented by the health department of GCC.

The Estimated pediatric population of Chennai in 2022 was 1,771,030, comprising 913,655 boys (52%) and 857,348 girls (48%), and the sex ratio was 938 girls for 1000 boys. The estimated average population for 2022 by 5-year age group and sex is given in Table 8.1. The map of the 2022 population by zone is given in Figure 8.1.

Table 8.1: Estimated average population of Chennai district in the Age Group: 2022

Age Group (In years)	Male		Female		Total	
	Number	%	Number	%	Number	%
00-04	257848	28	237659	28	495507	28
05-09	216730	24	202372	24	419102	24
10-14	218351	24	205730	24	424081	24
15-19	220726	24	211587	25	432312	24
Total	913655	100	857348	100	1771003	100

Figure 8.1: Pediatric Population Distribution by Zone

RESULTS

9. CANCER NOTIFICATION

Cancer Notification Status in the Year 2022 and 2023 for PBCCR

The notification status of the cancer cases from each of the 16 PBCCR collaborating centers of Chennai district in the years 2022 and 2023 are listed below in Table 9.2. In 2022, 188 cases were notified, and the total incidence after the duplication check was 170. In 2023, 130 cases were notified, and 127 were the total incident cases.

Figure 9.1: Year-Wise Notification of Cancer Cases and Incidence

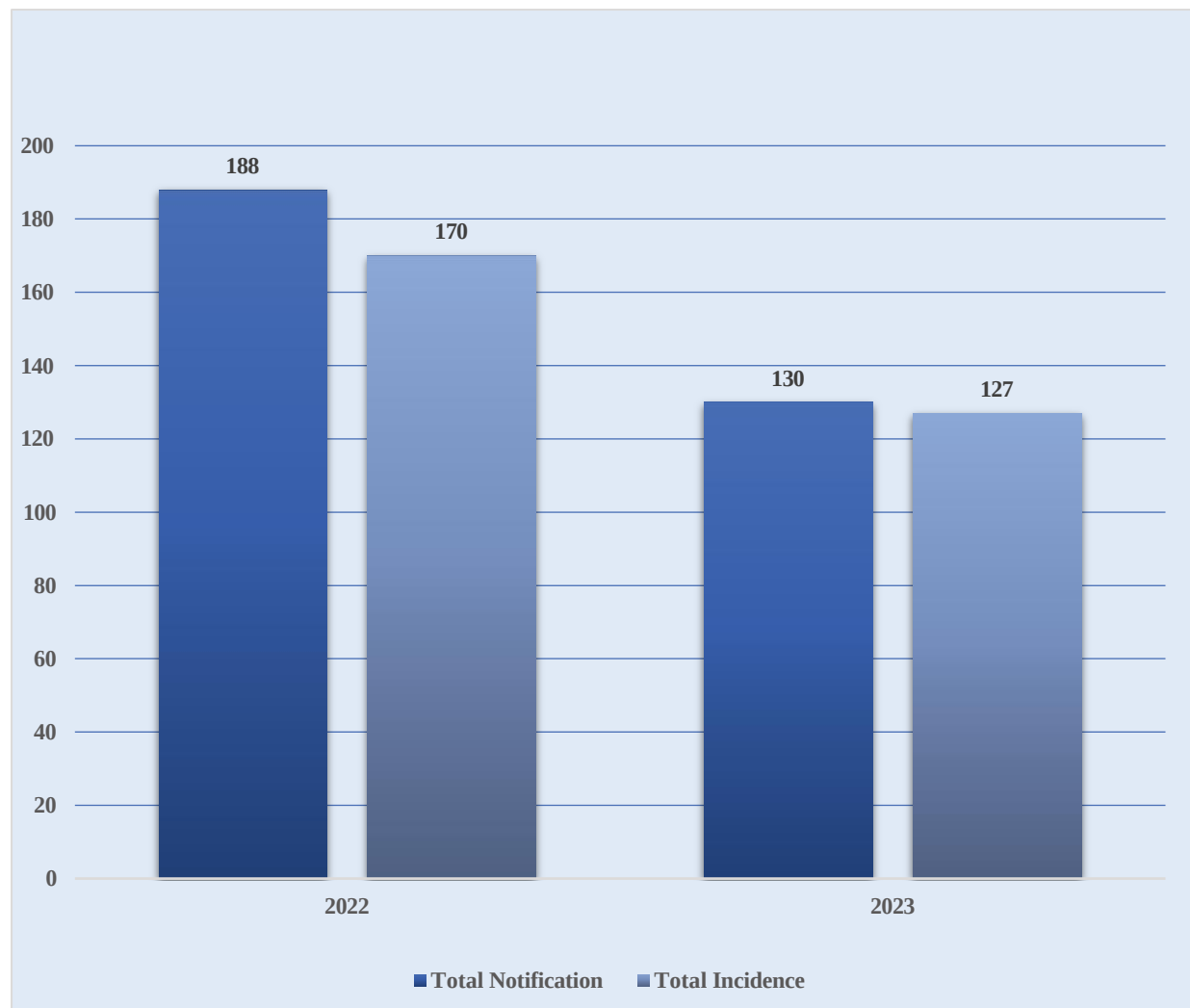


Table 9.1: Number of Cases Notified vs. Total Cancer Incidence Cases in 2022 and 2023 by Registration Hospital

S. No	Source of Registration	2022		2023	
		Total Notified Cases	Total Incidence Cases	Total Notified Cases	Total Incidence Cases
1	Institute of Child Health and Hospital for Children, Chennai	62	59	33	32
2	Cancer Institute (WIA), Adyar, Chennai	29	25	26	25
3	Kanchi Kamakoti Childs Trust Hospital, Chennai	18	17	10	10
4	Apollo Cancer Centers, Chennai	22	19	15	14
5	Rajiv Gandhi Government General Hospital, Chennai	13	12	8	8
6	Sri Ramachandra Medical College and Research Institute	9	9	3	3
7	Dr Rela Institute and Medical Centre, Chennai	9	9	7	7
8	Government Royapettah Hospital, Chennai	5	5	11	11
9	Gleneagles Health City, Chennai	3	3	6	6
10	VS Hospitals, Chennai	3	2	1	1
11	Dr Mehta's Hospital, Chennai	5	3	5	5
12	Kauvery Hospital, Chennai	2	2	3	3
13	Kumaran Hospital (Madras Cancer Care Foundation), Chennai	2	2	0	0
14	SRM Institute of Medical Science, Chennai	2	2	0	0
15	Sankara Nethralaya Eye Hospital, Chennai	4	1	2	2
16	Tamil Nadu Government Multi Super Speciality Hospital, Chennai	0	0	0	0

10. CANCER REGISTRATION

Source Of Registration for TNCRP and Chennai PBCCR

Population-Based Childhood Cancer Registry collects high-resolution data from 16 hospitals, and routine TNCRP data is integrated from 8 other sources. The list of hospitals is given in Table 10.1. In total, 241 childhood incident cancer cases were registered in the district of Chennai in the year 2022, out of which 170 cases were directly registered and high-resolution data abstracted by the PBCCR staff from 16 collaborating hospitals, and 71 remaining cases were registered from 8 other sources from TNCRP routine data.

Table 10.1: Source of Incidence Cases Registered in PBCCR per Hospital

S.NO	Registration Hospital	Chennai PBCCR (High-Resolution Data)	TNCRP (Routine data)	Total
1	Institute of Child Health and Hospital For Children, Chennai.	59	45	104
2	Cancer Institute (WIA), Chennai.	25	0	25
3	Apollo Cancer Centers, Chennai.	19	0	19
4	Kanchi Kamakodi Child Trust Hospital, Chennai.	17	3	20
5	Rajiv Gandhi Government General Hospital, Chennai.	12	0	12
6	Dr Rela Institute and Medical Centre, Chennai.	9	1	10
7	Sri Ramachandra Medical College and Research Institute	9	2	11
8	Government Royapettah Hospital, Chennai.	5	1	6
9	Dr.Mehta Hospitals, Chennai.	3	1	4
10	Gleneagles Health City, Chennai.	3	0	3
11	SRM Institute of Medical Science, Chennai.	2	0	2
12	VS Hospitals, Chennai.	2	2	4
13	Kauvery Hospital, Chennai.	2	0	2

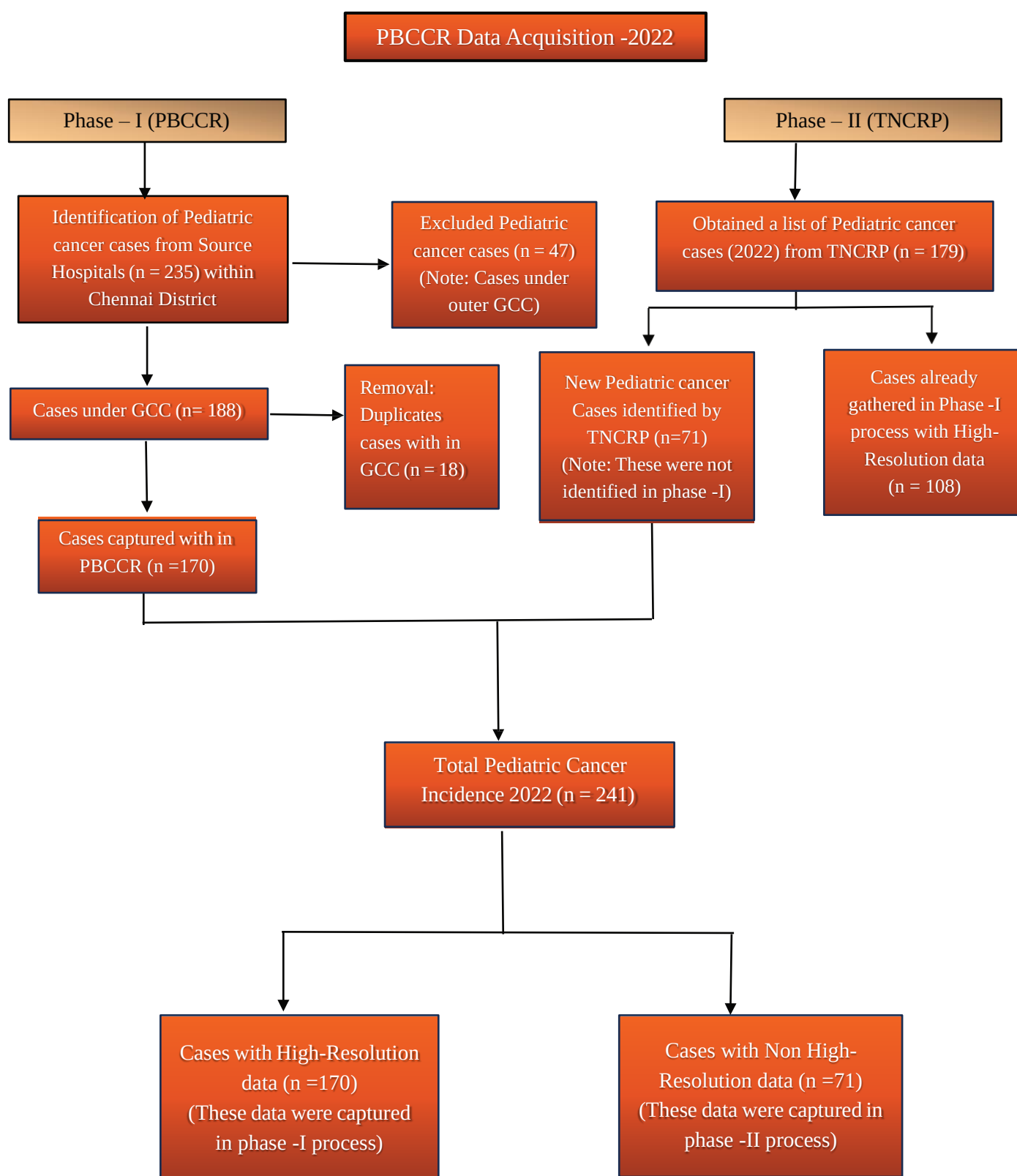
14	Kumaran Hospital (Madras Cancer Care Foundation), Chennai.	2	0	2
15	Sankara Nethralaya Eye Hospital, Chennai.	1	0	1
16	Tamil Nadu Government Multi Super Speciality Hospital, Chennai	0	1	1
17	*Government Stanley Medical College, Chennai.	0	5	5
18	*Dr Rai Memorial Hospital, Chennai.	0	1	1
19	*ESI Hospital, Chennai.	0	2	2
20	*Saveetha Medical College Hospital & Research Institute, Chennai.	0	1	1
21	*MGM Hospital, Chennai.	0	2	2
22	*Vasanth Memorial Hospital, Chennai.	0	1	1
23	*Vijaya Hospital, Chennai.	0	1	1
24	*National Institute of Siddha (Central) – Tambaram	0	2	2
	Total	170	71	241

*: awaiting the signing of a Memorandum of Understanding (MOU)

Abbreviation: PBCCR – Population-Based Childhood Cancer Registry, TNCRP – Tamil Nadu Cancer Registry Project.

Reason for not Collecting High-Resolution Data

Among the 241 incident cases in Chennai in 2022, high-resolution data could only be collected in 170 cases (70.5%). High-resolution data could not be collected in 71 patients (29.5%); 56 (23.5 %) cases from PBCCR sources due to a lack of case records for high-resolution data; 15 (6.2 %) cases from hospitals who have not yet signed an MOU with the Chennai PBCCR. It is expected that PBCCR coverage for the registration of incident cases will improve in the coming year.

Figure10.1: Flow Chart Giving the Process of Population-Based Childhood Cancer Registry

Cancer Cases Registered by Hospital Source of Registration and Sex in PBCCR (Table 10.2)

A total of 241 new Pediatric cancers were diagnosed in 2022, including 140 boys and 101 girls, reflecting a male preponderance (1:1:39). A majority of cases for PBCCR were registered from Institute for Child Health and Hospital for Children (43.1%), followed by Cancer Institute (WIA), Adyar, Chennai (10.4%), and Kanchi Kamakoti Childs Trust Hospital, Chennai (8.29%).

Table 10.2: Cancer Case Information by the First Source of Cancer Registration

S.No	Registration Hospitals	Boys	%	Girls	%	Total	%
1	Institute of Child Health and Hospital For Children, Chennai	62	44.6	42	41.1	104	43.1
2	Cancer Institute (WIA), Adyar, Chennai	16	11.5	9	8.8	25	10.4
3	Kanchi Kamakoti Childs Trust Hospital, Chennai	10	7.2	10	9.8	20	8.2
4	Apollo Cancer Centers, Chennai	8	5.7	11	10.8	19	7.8
5	Rajiv Gandhi Government General Hospital, Chennai	7	5.0	5	4.9	12	4.9
6	Sri Ramachandra Medical College and Research Institute	7	5.0	4	3.9	11	4.5
7	Dr Rela Institute and Medical Centre, Chennai	7	5.0	3	2.9	10	4.1
8	Government Royapettah Hospital, Chennai	3	2.2	3	2.9	6	2.4
9	Gleneagles Health City, Chennai	3	2.2	0	0	3	1.2
10	Dr Mehta's Hospital, Chennai	3	2.2	1	0.9	4	1.6
11	VS Hospitals, Chennai	2	1.4	2	1.9	4	1.6
12	MGM Hospital, Chennai	2	1.4	0	0	2	0.8
13	Government Stanley Medical College, Chennai	1	0.7	3	2.9	5	2.0
14	ESI Hospital, Chennai	1	0.7	1	0.9	2	0.82
15	Kauvery Hospital, Chennai	1	0.7	1	0.9	2	0.82
16	Kumaran Hospital (Madras Cancer Care Foundation), Chennai	1	0.7	1	0.9	2	0.8
17	National Institute of Siddha (Central), Tambaram	1	0.7	1	0.9	2	0.8
18	SRM Institute of Medical Science, Chennai	1	0.7	1	0.9	2	0.8
19	Sankara Nethralaya Eye Hospital, Chennai	1	0.7	0	0	1	0.4
20	Saveetha Medical College Hospital & Research Institute, Chennai	1	0.7	0	0	1	0.4
21	Vijaya Hospital, Chennai	1	0.7	0	0	1	0.4
22	Dr Rai Memorial Hospital, Chennai	0	0	1	0.9	1	0.4
23	Tamil Nadu Government Multi Super Speciality Hospital, Chennai	0	0	1	0.9	1	0.4
24	Vasanth Memorial Hospital, Chennai	0	0	1	0.9	1	0.4
	Total	139	100	102	100	241	100

11. CANCER INCIDENCE

Incidence Statistics, Chennai 2022

The cancer incidence statistics for all cancers together by sex registered in the PBCCR for the year 2022 are given in Table. 11.1

Table 11.1: Incidence Statistics of Cases Registered in PBCCR 2022

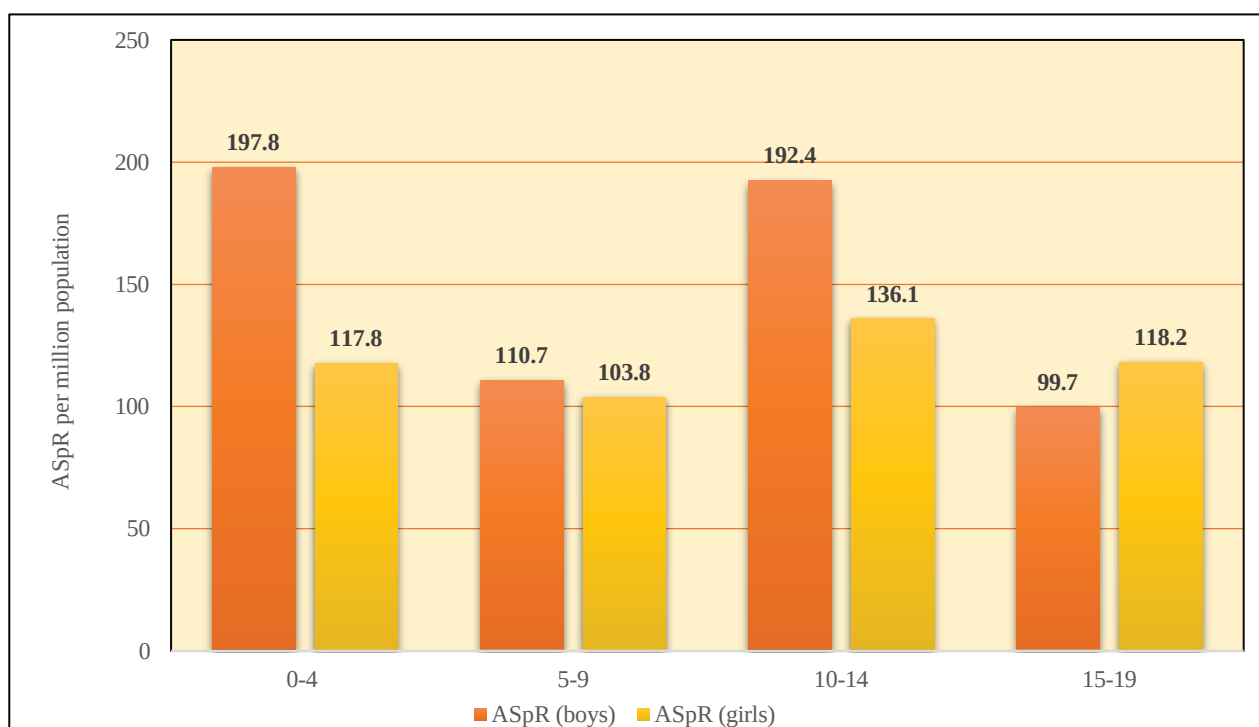
Incidence of Statistics	New Cases	Percentage %	CIR	CR %	ASR
Boys	139	57.67	152.1	0.299	152.7
Girls	102	42.33	119.0	0.236	118.5
Total	241	100	136.1	0.267	136.3

(ASR – Age-standardised rate, CIR- Crude incidence rate, CR - Cumulative Risk) per million population

The Age Standardized rate (ASR) for boys was 152.1 and 119 for girls per million.

The cumulative risk of getting cancer in 0-19 years of age was one in 334 boys and one in 424 girls in Chennai.

Figure 11.1: Age-Specific Incidence by Sex in Pediatric Age Group- All Cancer



The age-specific rate (ASpR) was the highest at 0-4 years of age among boys, while it was the highest at 10-14 years of age among girls.

Figure 11.2: Number of Incident Cancer Cases Distributed by 15 Zones in Greater Chennai.

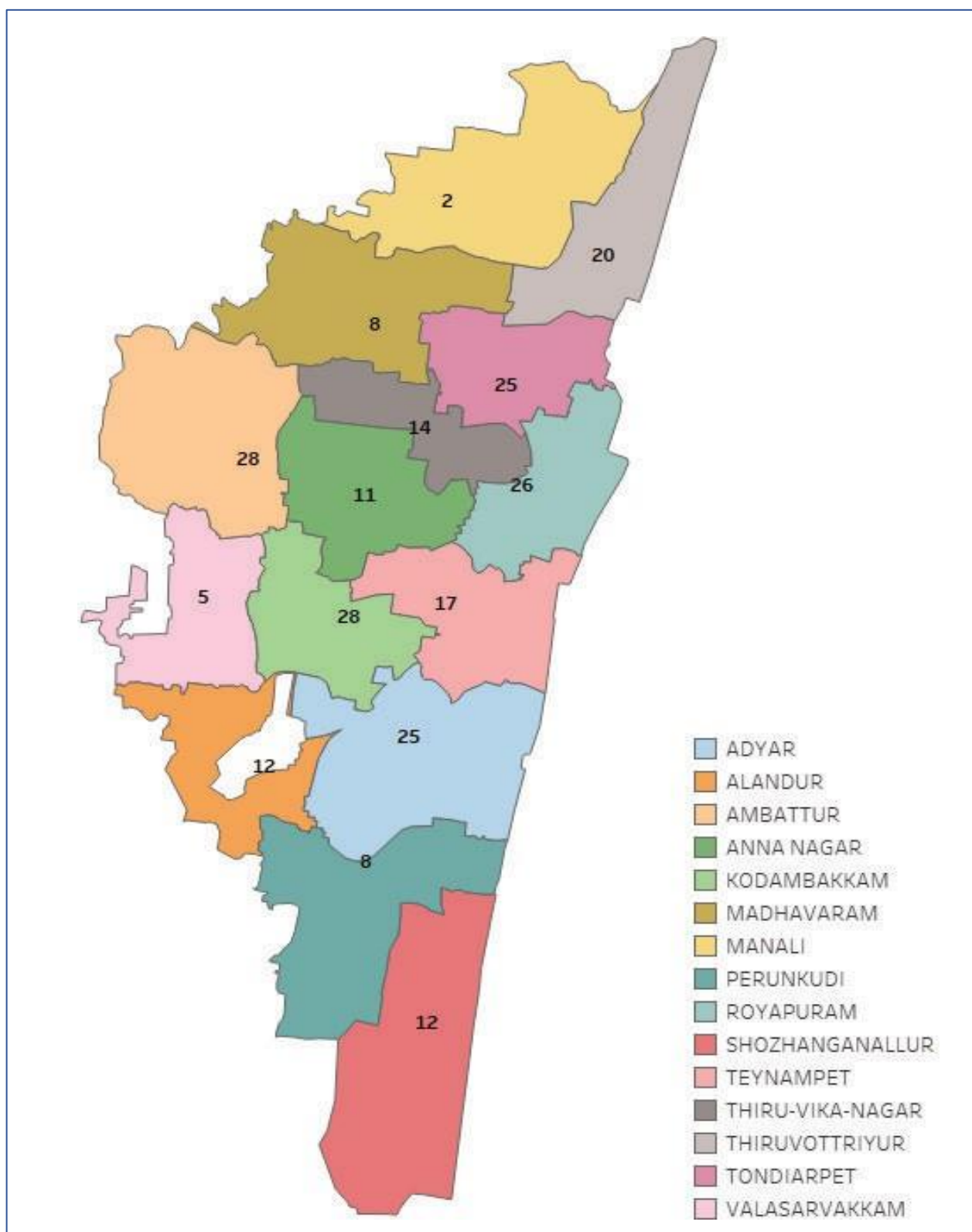


Figure 11.3: Crude Incidence Rate Distribution by Greater Chennai Zone-Wise

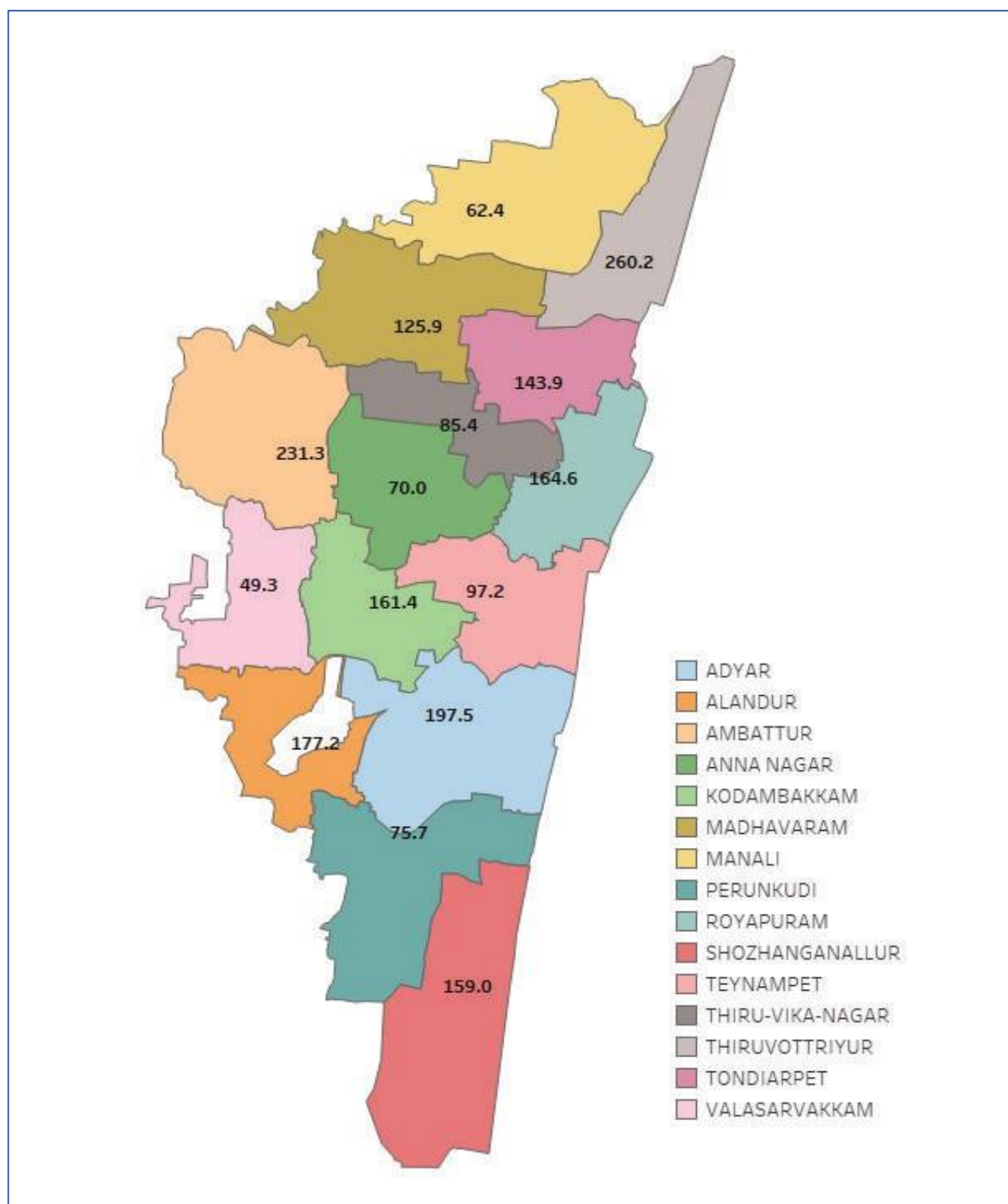
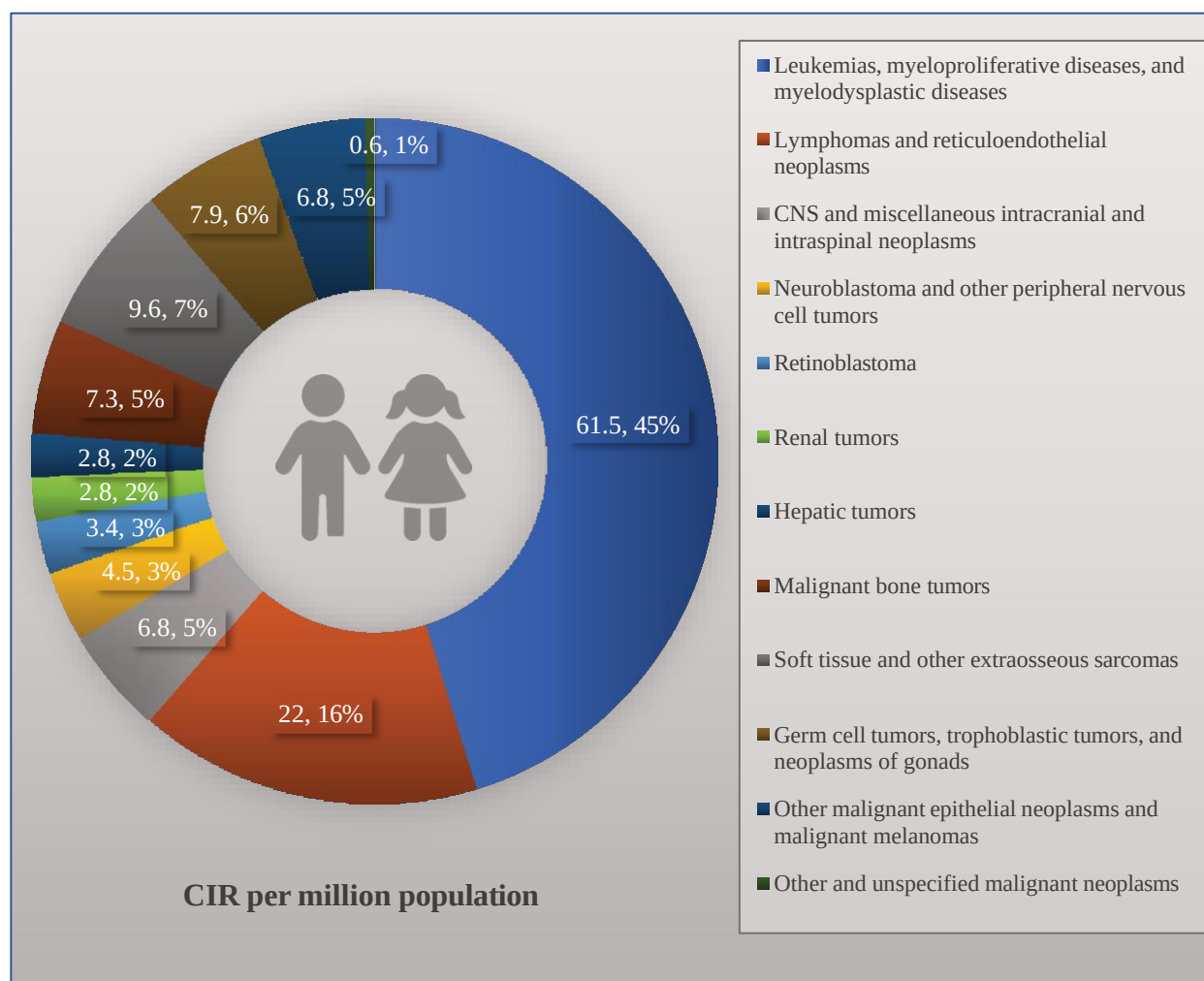
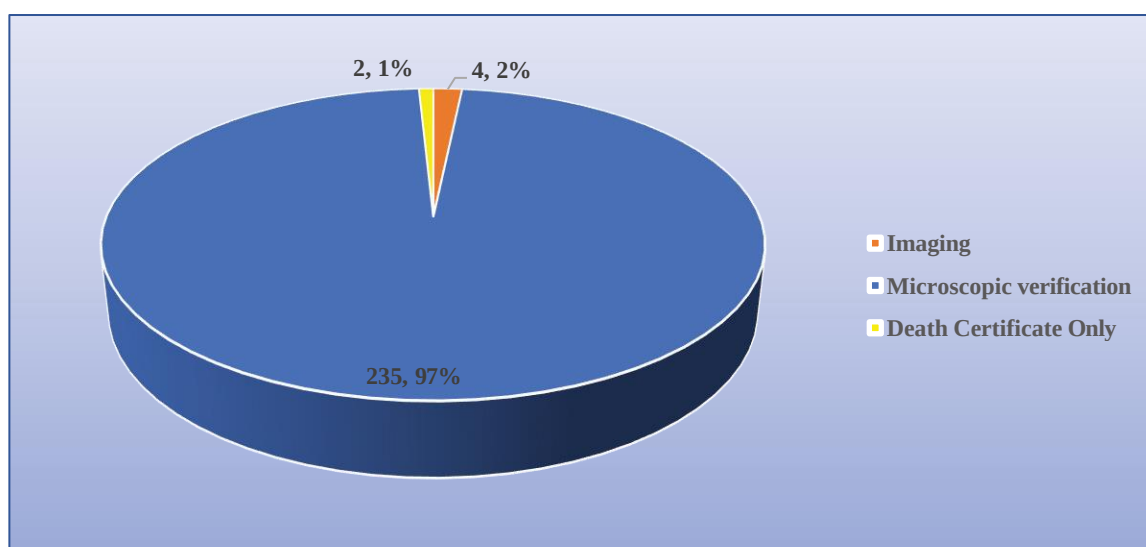


Figure 11.4: ICCC 3-Classified Cancer with a Crude Incidence Rate (CIR) in Both Sexes

All Leukemias together were the most commonest, followed by lymphomas, soft tissue sarcomas, malignant bone, and CNS tumors.

Figure 11.5: Most Valid Basis of Diagnosis, All Cancer Together

12. LEADING SITES OF CHILDHOOD CANCER

The major leading cancers (according to the age-standardized rate of per million population) are Leukemia (61.9), Lymphoma & Related (21.7), Soft Tissue Sarcomas (9.7), Germ cell tumors (7.6), Malignant Bone tumor (7.1) and CNS & Neoplasms(7.0)

Figure 12.1: Leading Site of Cancer of Both Sexes Based on ASR

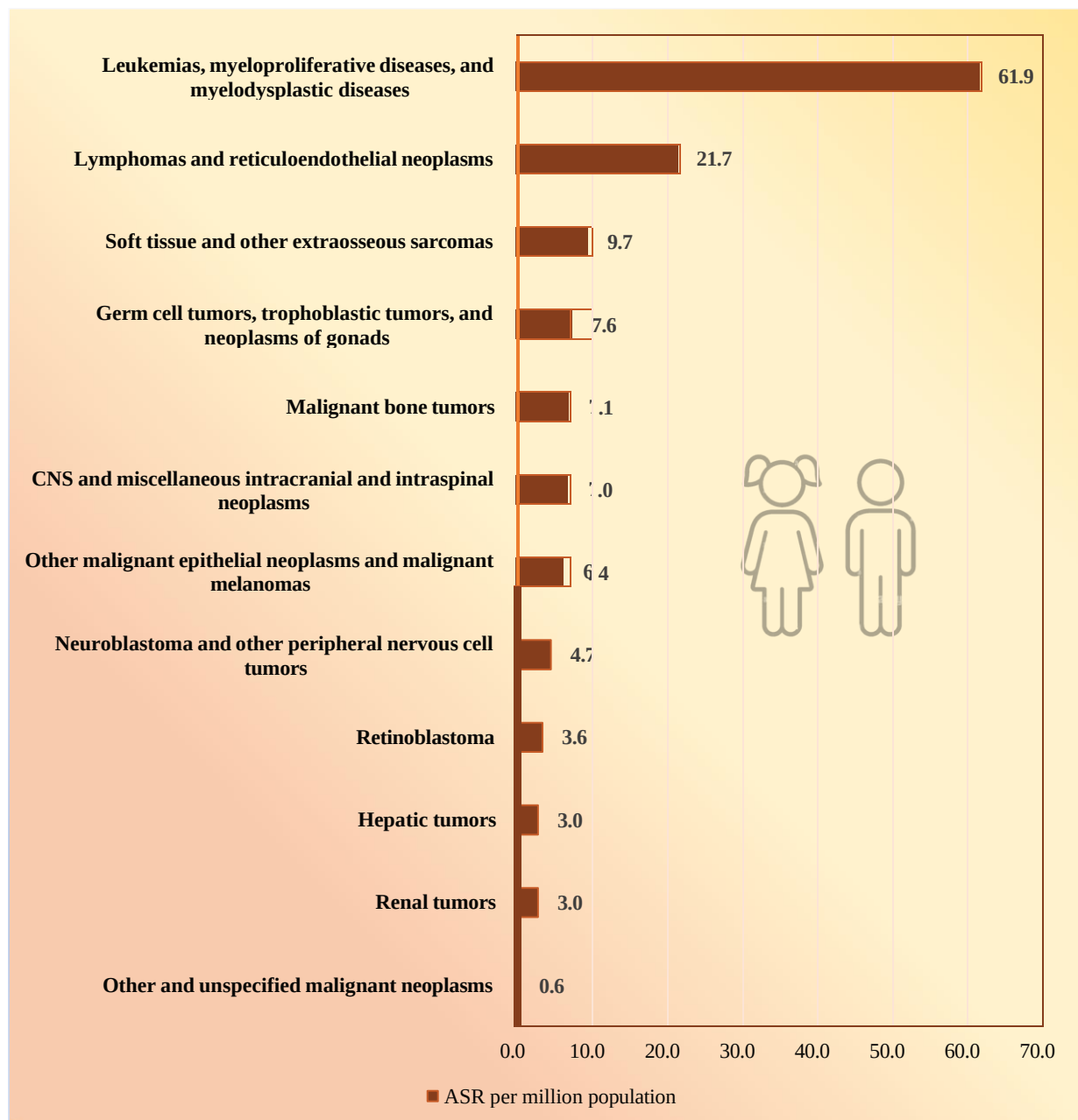
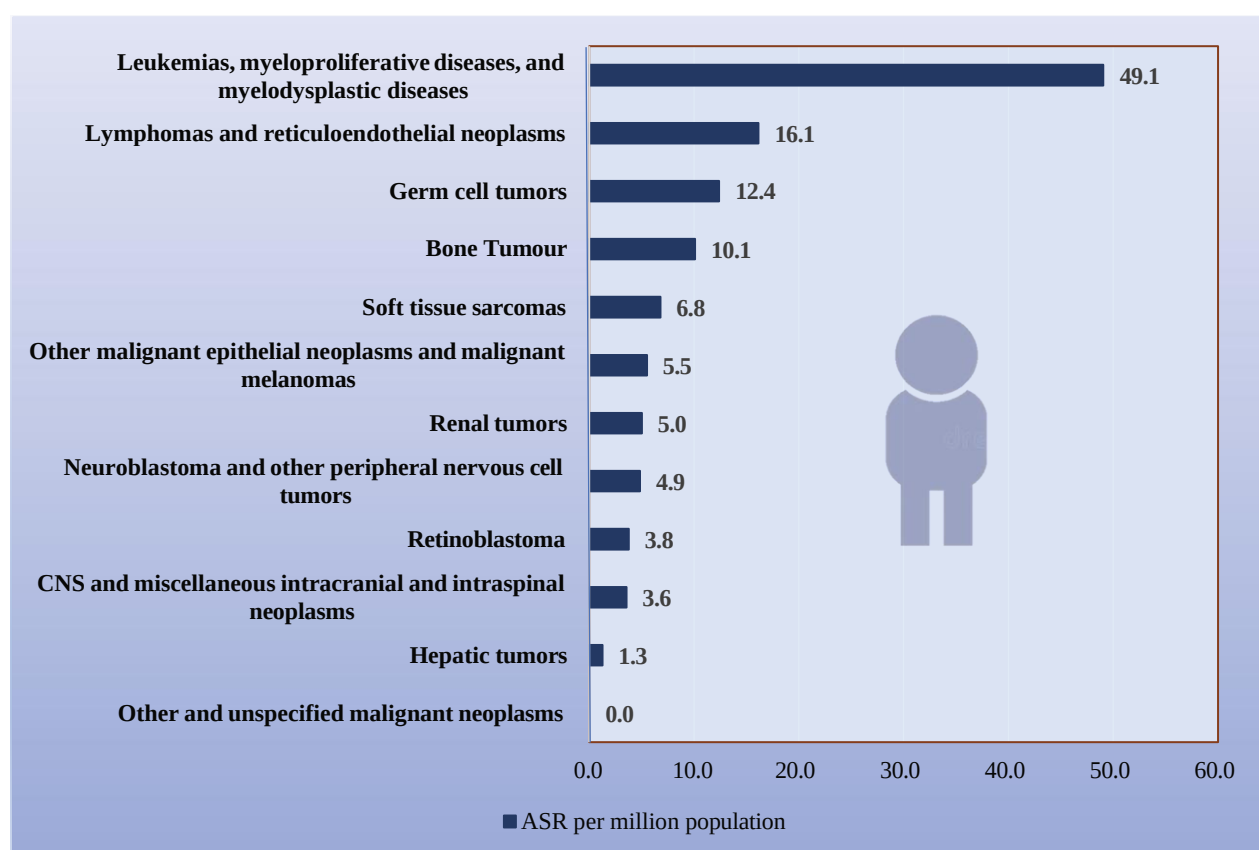
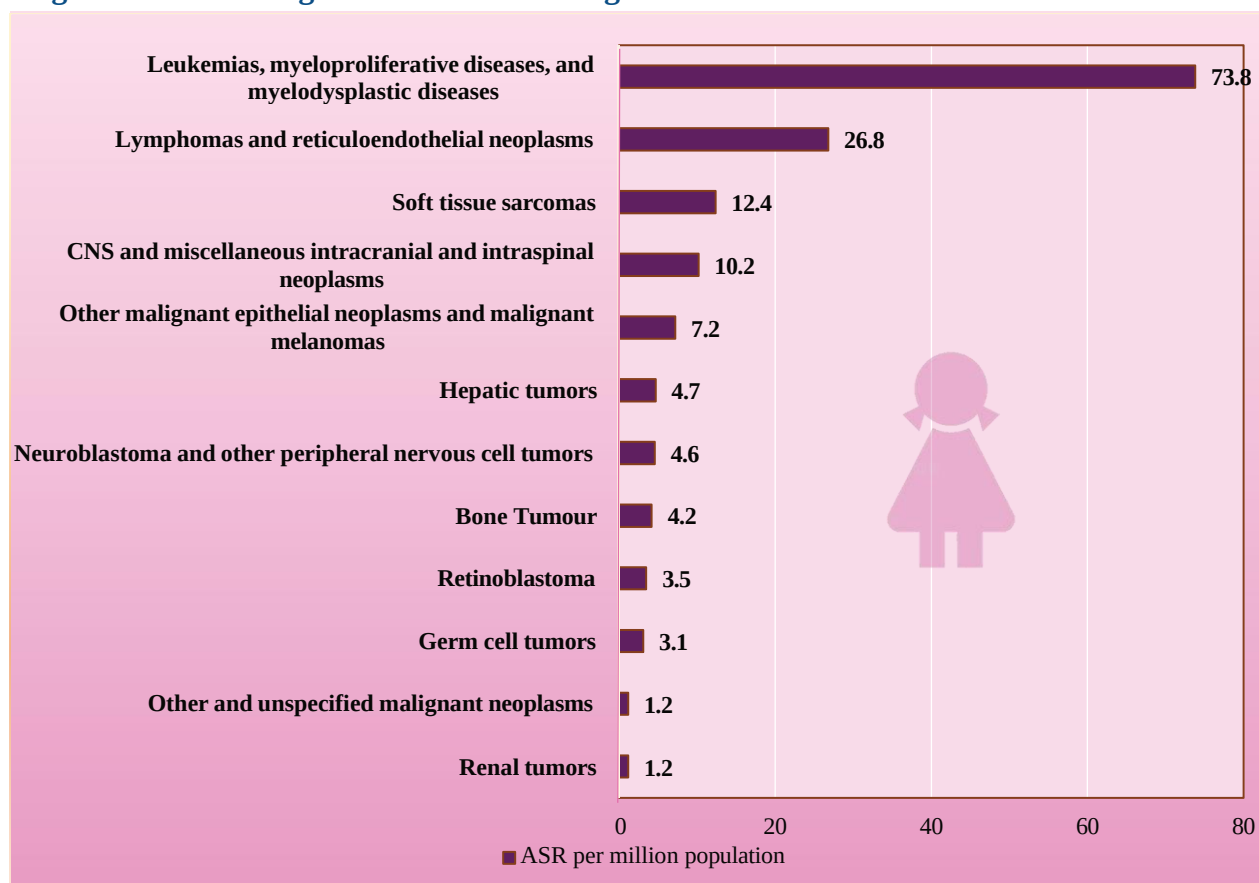


Figure 12.2: Leading Site of Cancer Among Boys Based on ASR**Figure 12.3: Leading Site of Cancer Among Girls Based on ASR**

13. CHENNAI PBCCR HIGH-RESOLUTION DATA

In total, 241 cancer incidences were registered in the PBCCR in 2022. Among those, 170 cases were collected from the 17 collaborating hospitals, and 71 cases were collected from other sources (TNCRP) to ensure the completeness of the data. Hence, the High-Resolution Data was abstracted from 170 cases. The report of high-resolution data is presented in the following chapters.

Figure 13.1: Distribution of Cases by Source Wise

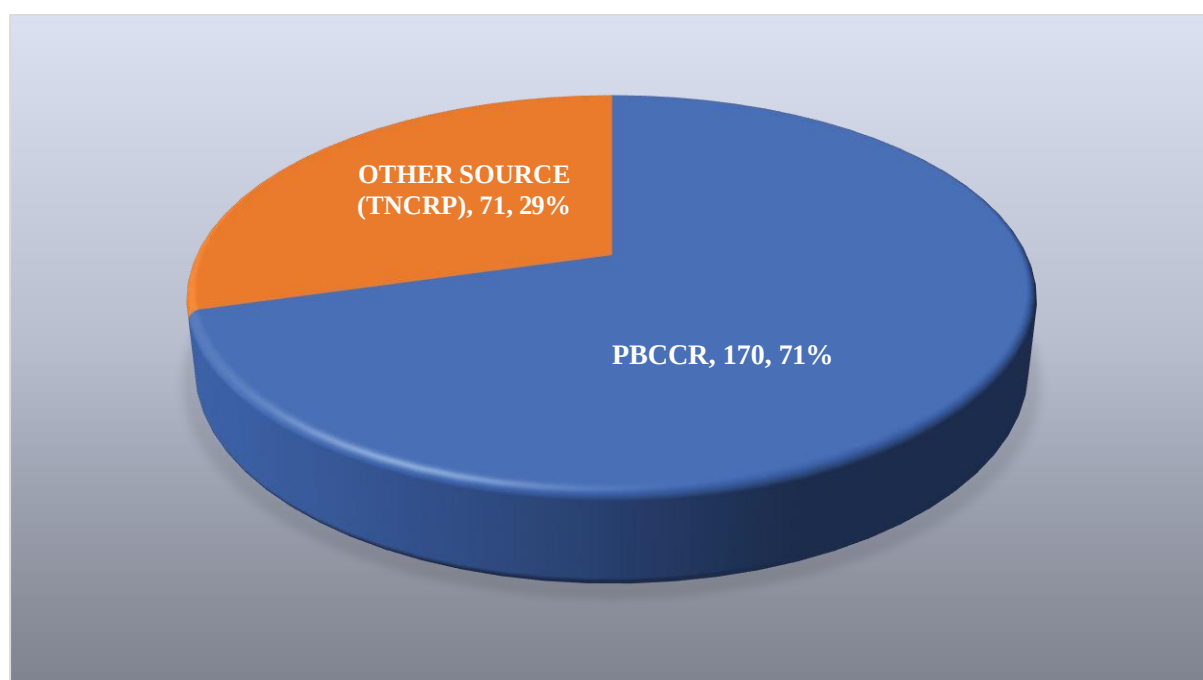


Table 13.1: Frequency and Percentage in the High-Resolution Data by Sex

S. No	Gender	Frequency (n = 170)	Percentage %
1	Boys	94	55%
2	Girls	76	45 %
Total		170	100

14. SOCIO-DEMOGRAPHICS AND METHOD OF DIAGNOSIS

The number of cancer incidences by registration hospitals and treated hospitals is presented in the following figure 18. The parent's/Caregiver's education qualifications and Methods of Diagnosis are listed in Table 14.1 and Table 14.2

Table 14.1: Parent/ Caregiver Education Qualification

S.NO	Parent/Primary Caregiver Highest Education	Frequency (n = 170)	Percentage %
1	1-8 years (grade school)	69	40.58
2	9-12 years (high school/O-level), but did not graduate	19	11.17
3	College Graduate	21	12.35
4	Completed high school/GED/A-levels	17	10
5	Post-graduate level	12	7.05
6	Training after high school, other than college (vocation)	10	5.88
7	Unknown	20	11.76
8	None	2	1.17
	Total	170	100

Table 14.2: Frequency Distribution of Most Valid Basis of Diagnosis

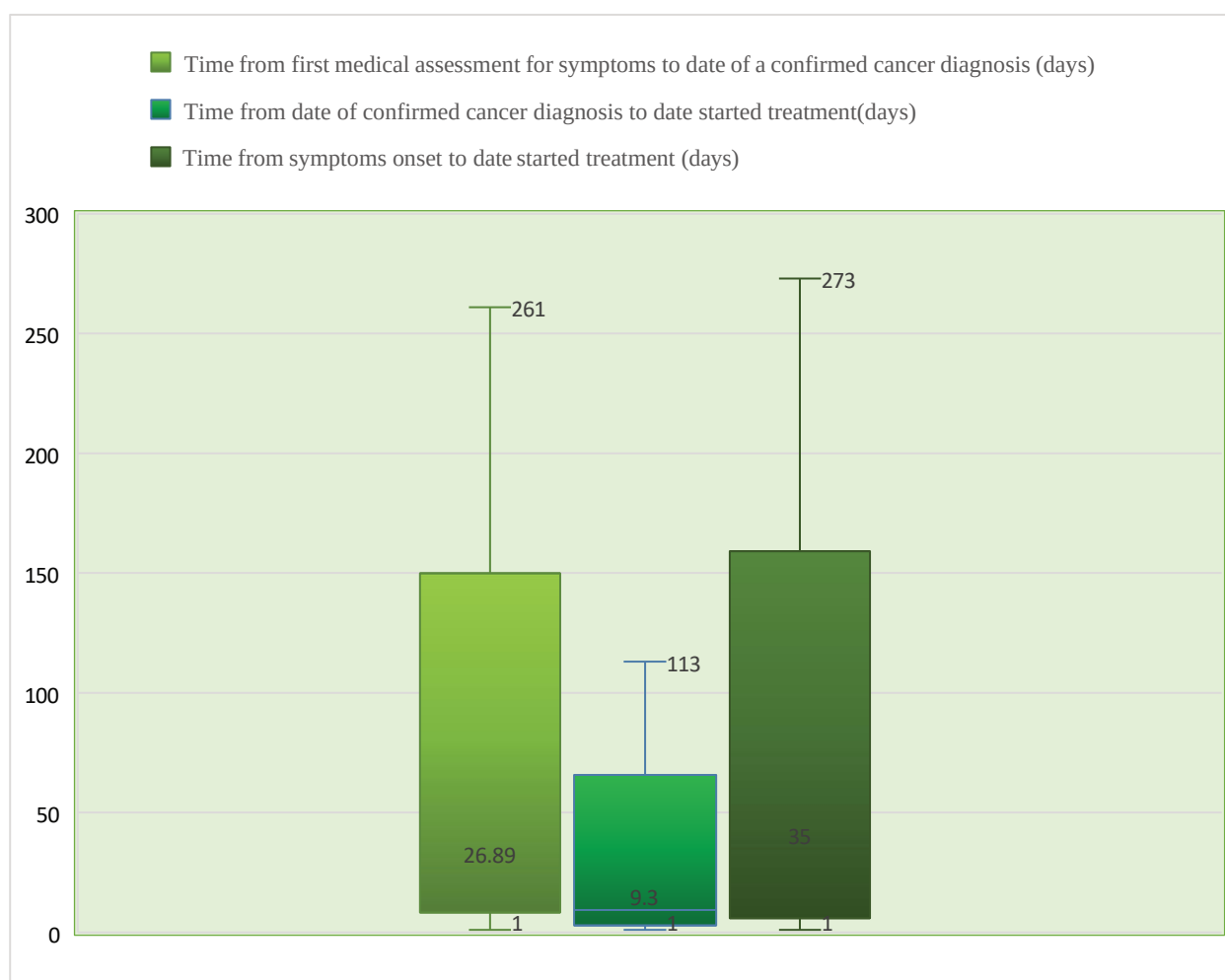
Most valid basis of Diagnosis	Frequency (n = 170)	Percentage %
Imaging	4	2.4
Microscopic verification	166	97.6
Total	170	100

15. DIAGNOSTIC AND THERAPEUTIC PATHWAYS TIMELINES

Table 15.1: Diagnostic and Therapeutic Pathway Timelines

Time Interval	N (n = 170)	Mean	Minimum	Median	Maximum
Time from first medical assessment for symptoms to date of a confirmed cancer diagnosis (days)	170	26.89	1	12.5	261
Time from date of confirmed cancer diagnosis to date started treatment(days)	146	9.3	1	2	113
Time from symptoms onset to date started treatment (days)	147	35	1	21	273

Figure 15.1: Diagnostic and Therapeutic Pathway Timelines



16. NUMBER OF INCIDENT CASES BY ICCC3 AMONG DIFFERENT AGE GROUPS

Table 16.1: Cancer Incidence by ICCC3 Extended Classification Code Among Different Age Groups

ICCC3 Extended Classification Code		Age Group				Total
		00-04	05-09	10-14	15-19	
Ia	Leukemias, myeloproliferative diseases, and myelodysplastic diseases	20	13	21	9	63
Ib		2	3	2	3	10
Ic		0	2	1	2	5
IIa	Lymphomas and reticuloendothelial neoplasm	0	2	6	6	14
IIb		4	0	0	2	6
IIc		0	0	2	0	2
IId		1	3	1	0	5
IIIb	CNS and miscellaneous intracranial and intraspinal neoplasms	3	0	0	0	3
IIIc		1	0	1	0	2
IIId		1	0	0	0	1
IVa	Neuroblastoma and other peripheral nervous cell tumor	4	1	0	0	5
V	Retinoblastoma	5	0	0	0	5
VIa	Renal tumor	3	1	0	0	4
VIIa	Hepatic tumors	4	0	0	0	4
VIIIa	Malignant bone tumors	0	1	6	0	7
VIIIc		0	2	2	1	5
IXa	Soft tissue and other extraosseous sarcomas	4	0	0	0	4
IXb		1	0	0	0	1
IXd		1	1	2	2	6
Xa	Germ cell tumors, trophoblastic tumors, and neoplasms of gonads	0	1	0	1	2
Xb		0	0	0	1	1
Xc		0	1	4	2	7
XIa	Other malignant epithelial neoplasms and malignant melanomas	1	0	0	0	1
XIb		0	0	0	1	1
XIc		0	0	1	1	2
XIf		0	0	1	2	3
XIIa	Other and unspecified malignant neoplasms	1	0	0	0	1
Total		56	31	50	33	170

17. CLASS OF CASES BY REGISTRATION HOSPITAL

Table 17.1: Class of Case Registration.

Class of Case	Frequency (n = 170)	Percentage %
New case to center with diagnosis and chemotherapy treatment elsewhere	10	5.9
New case to center with diagnosis but without treatment	14	8.2
New case to center without diagnosis and without treatment	144	84.7
New relapse or refractory / disease case to center	2	1.2
Total	170	100.0

Figure 17.1: Class of Cases in the Registration Hospital

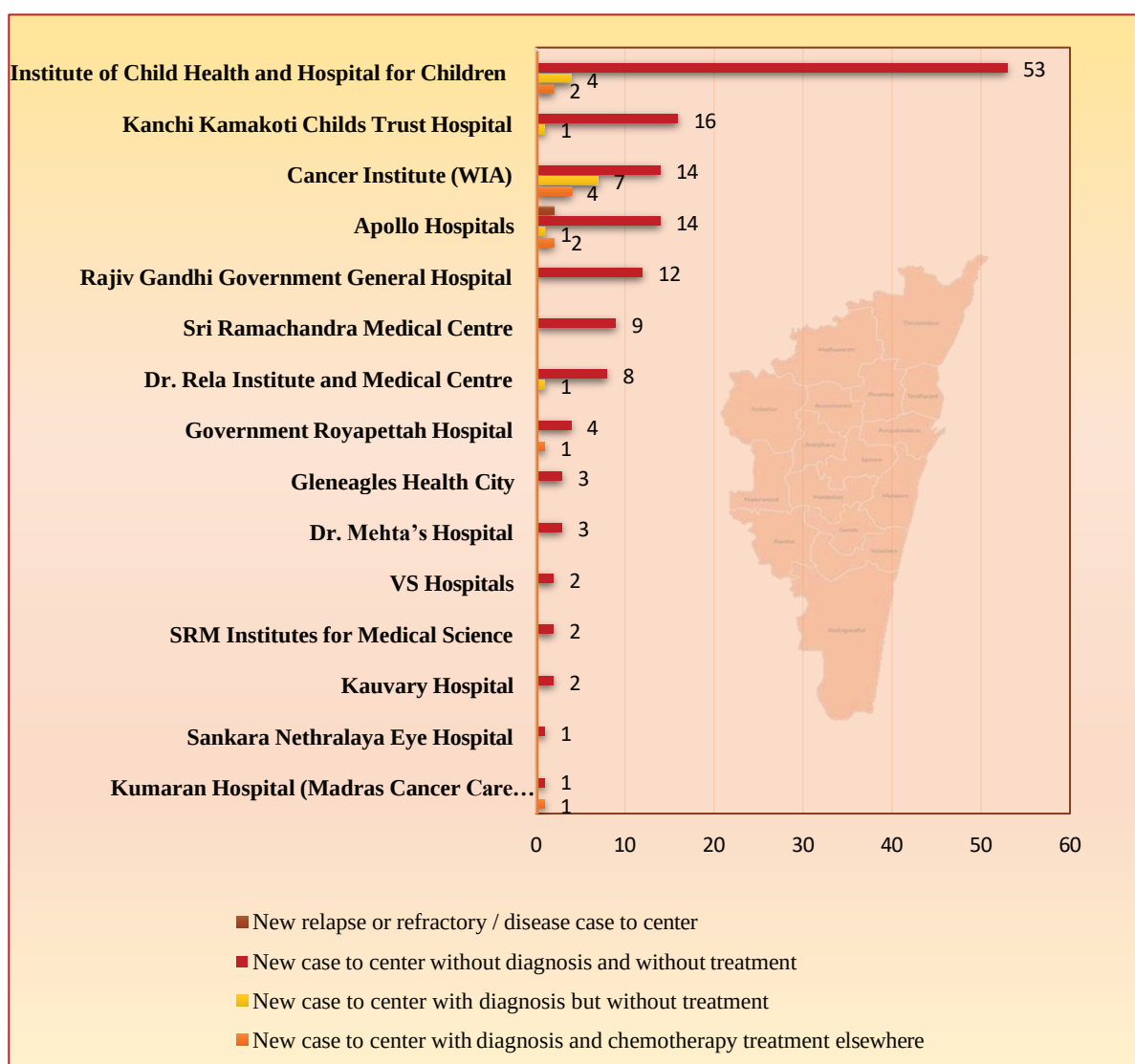
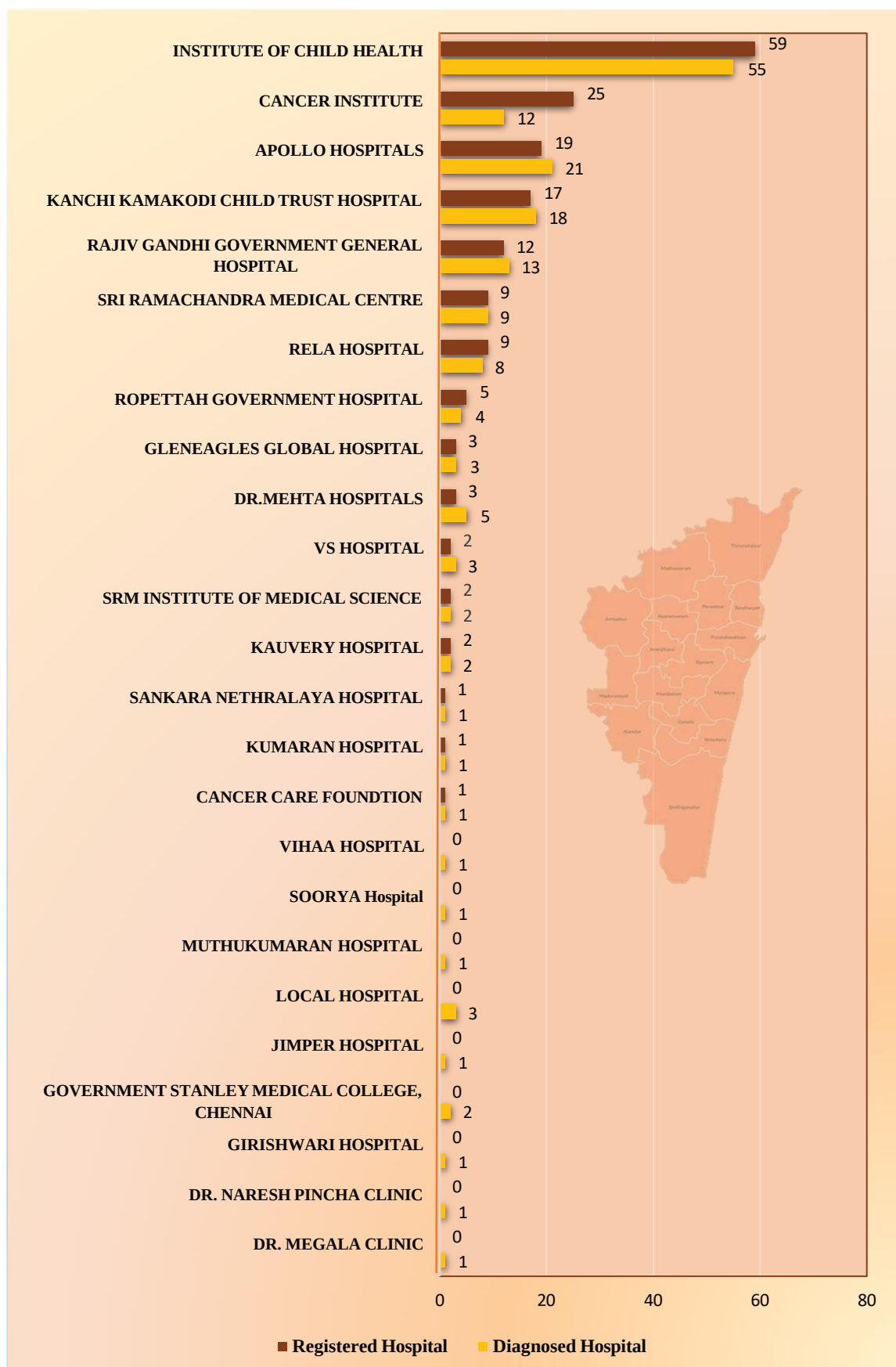


Figure 17.2: Initially Diagnosed Hospital (Source Hospital) and Treated Hospital (Registered Hospital)



18. STAGING - CLASSIFICATION OF CHILDHOOD CANCER

Out of 170 cases in high-resolution data, 63 were diagnosed with Acute Lymphoblastic Leukemia (ALL), and immunophenotyping was obtained for all 63 cases (100%).

Figure 18.1: Diseases Specific Acute Lymphoblastic Leukemia - Immunopheno Typing

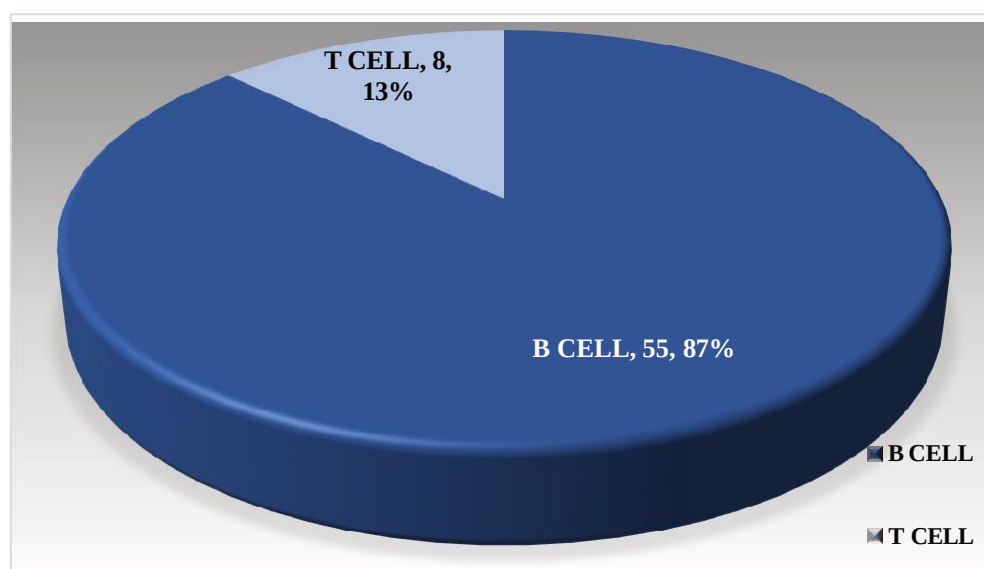
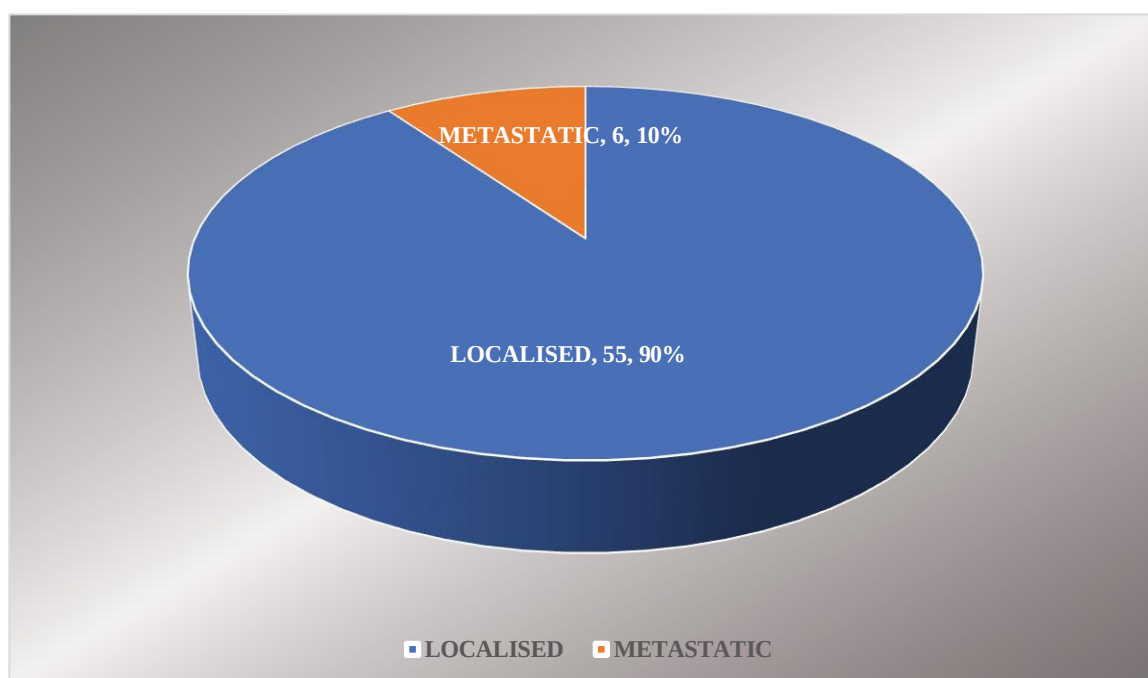


Table 18.1: ALL Leukemia Cases with CNS Involvement

CNS Involvement	Stage	Frequency (n = 73)	Percentage %
No	CNS 1 (No Involvement)	72	98.11
Yes	CNS 2	1	1.3
Total		73	100

Abbreviations: ALL – Acute Lymphoblastic Leukemia, CNS – Central Nervous System

Figure 18.2: Toronto Tier 1: (Solid Tumor)**Table 18.2: Toronto Tier 1 – (Lymphomas and Other Solid Tumors)**

Toronto Tier 1	Frequency (n = 72)	Percentage %
Advanced	1	1.39
Intraocular	4	5.56
Limited	5	6.94
Localized	51	70.83
Localized/M0	3	4.71
Locoregional	1	1.39
Metastatic	6	8.33
Regional	1	1.39
Total	72	100.0

Distribution of ICCC3 Extended Classification Code and Toronto Tier 1 Staging is given in Annexure 1

Table 18.3: Toronto Tier 2/ Staging – (Specific Lymphomas and Other Solid Tumors)

Toronto Tier 2/ Staging	Frequency (n = 81)	Percentage %
L1	3	3.7
L2	1	1.2
M	1	1.2
M+	3	3.7
M0	2	2.4
Stage 0	3	3.7
Stage I	41	50.6
Stage II	14	17.2
Stage III	5	6.1
Stage IV	8	9.8
Total	81	100.0

Distribution of ICCC3 Extended Classification Code and Toronto Tier 1 Staging is given in Annexure 2

19. TREATMENT- TYPES OF TREATMENTS

Table 19.1: Treatment with Curative Intent at the Registration Hospital

Curative Treatment	Frequency (n =170)	Percentage %
Yes	138	81.2
No	32	18.8
Total	170	100.0

Figure 19.1: Reason Curative Treatment Not Given

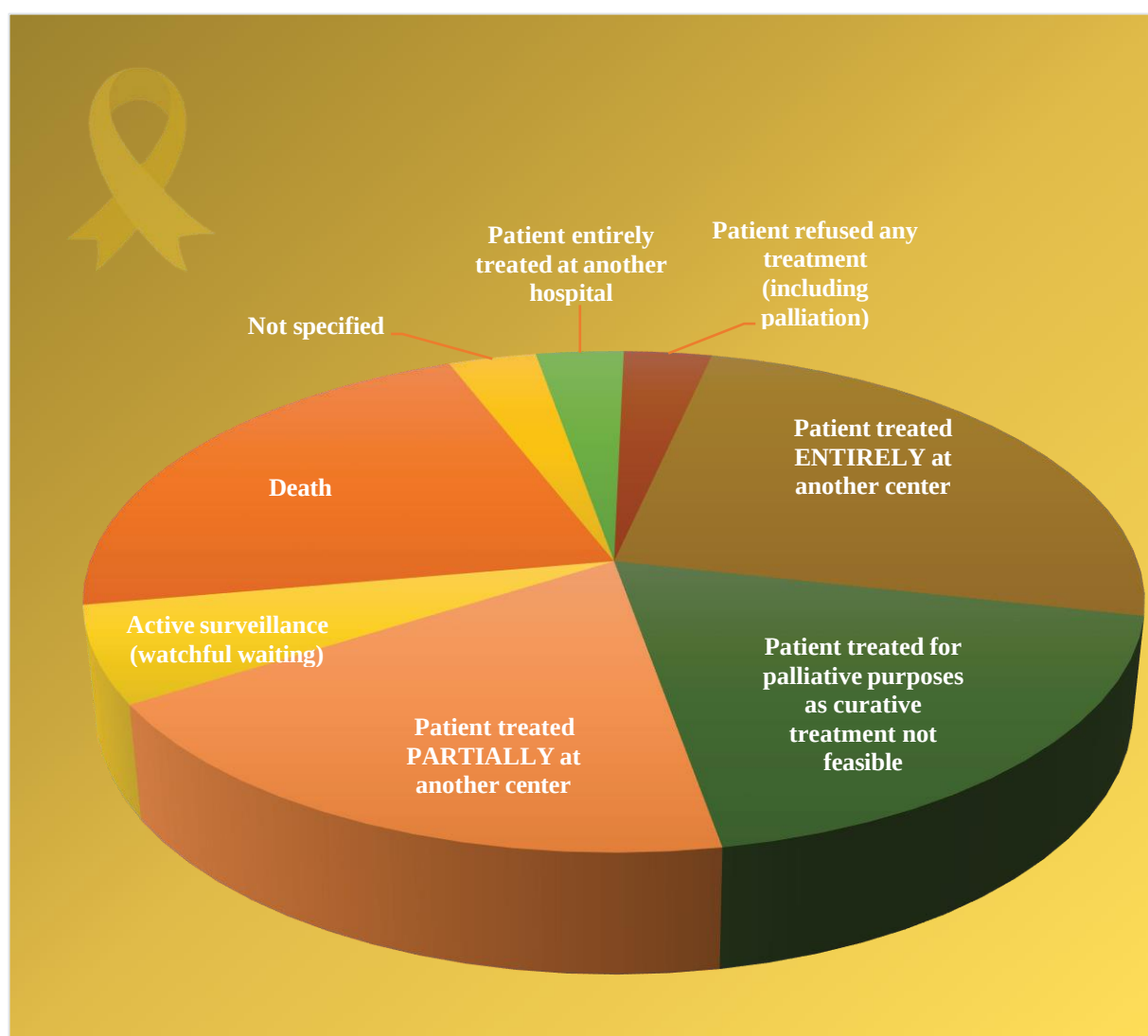


Table 19.2: Patient Treated with Chemotherapy with Therapeutic Protocol

Therapeutic Protocol	Frequency (n = 170)	Percentage %
Treated on Therapeutic Protocol	144	84.7
Not Treated on Therapeutic Protocol	9	5.3
Unknown Treatment Details	13	7.6
Not on Chemotherapy	4	2.4
Total	170	100.0

Table 19.3: Type of Treatment With ICC3 Classification of Cancer and Frequency

Iccc3 Extended Classification	Total Incidence (n=170)	Chemotherapy (n = 170)	%	Radiation (n = 170)	%	Surgery (n = 170)	%	Bone Marrow Transplant (n = 170)	%
Ia	63	61	35.88	0	0	0	0	1	0.59
Ib	10	7	4.12	0	0	0	0	0	0
Ic	5	5	2.94	0	0	0	0	0	0
IIa	14	14	8.24	0	0	0	0	0	0
IIb	6	4	2.35	0	0	0	0	0	0
IIc	2	2	1.18	0	0	0	0	0	0
IId	5	3	1.76	0	0	0	0	0	0
IIIb	3	3	1.76	0	0	2	1.18	0	0
IIIc	2	2	1.18	0	0	0	0	0	0
IIId	1	0	0	0	0	0	0	0	0
IVa	5	5	2.94	0	0	4	2.35	0	0
V	5	5	2.94	4	2.35	0	0	0	0
VIa	4	3	1.76	2	1.18	3	1.76	0	0
VIIa	4	2	1.18	0	0	3	1.76	0	0
VIIIa	7	2	1.18	1	0.59	4	2.35	0	0
VIIIc	5	5	2.94	0	0	4	2.35	0	0
IXa	4	4	2.35	0	0	2	1.18	0	0
IXb	1	1	0.59	0	0	1	0.59	0	0
IXd	6	3	1.76	1	0.59	1	0.59	0	0
Xa	2	2	1.18	0	0	2	1.18	0	0
Xb	1	1	0.59	0	0	0	0	0	0
Xc	7	5	2.94	1	0.59	1	0.59	0	0
XIa	1	0	0	0	0	1	0.59	0	0
XIb	1	1	0.59	0	0	1	0.59	0	0
XIc	2	2	1.18	2	1.18	0	0	0	0
XIf	3	2	1.18	2	1.18	2	1.18	0	0
XIIa	1	1	0.59	0	0	0	0	0	0
Total (n = 170)	170	145	85.29	13	7.65	27	15.88	1	0.59

20. 1st FOLLOW UP STATUS

Table 20.1: First-Year Follow-Up Treatment Details

Treatment Details	Frequency (n =170)	Percentage %
Curative	69	40.5
Palliative	1	0.5
No Treatment	58	34.7
Unknown	42	24.7
Total	170	100.0

Figure 20.1: 1st Year Follow-Up, No Treatment Details at Registration Hospital

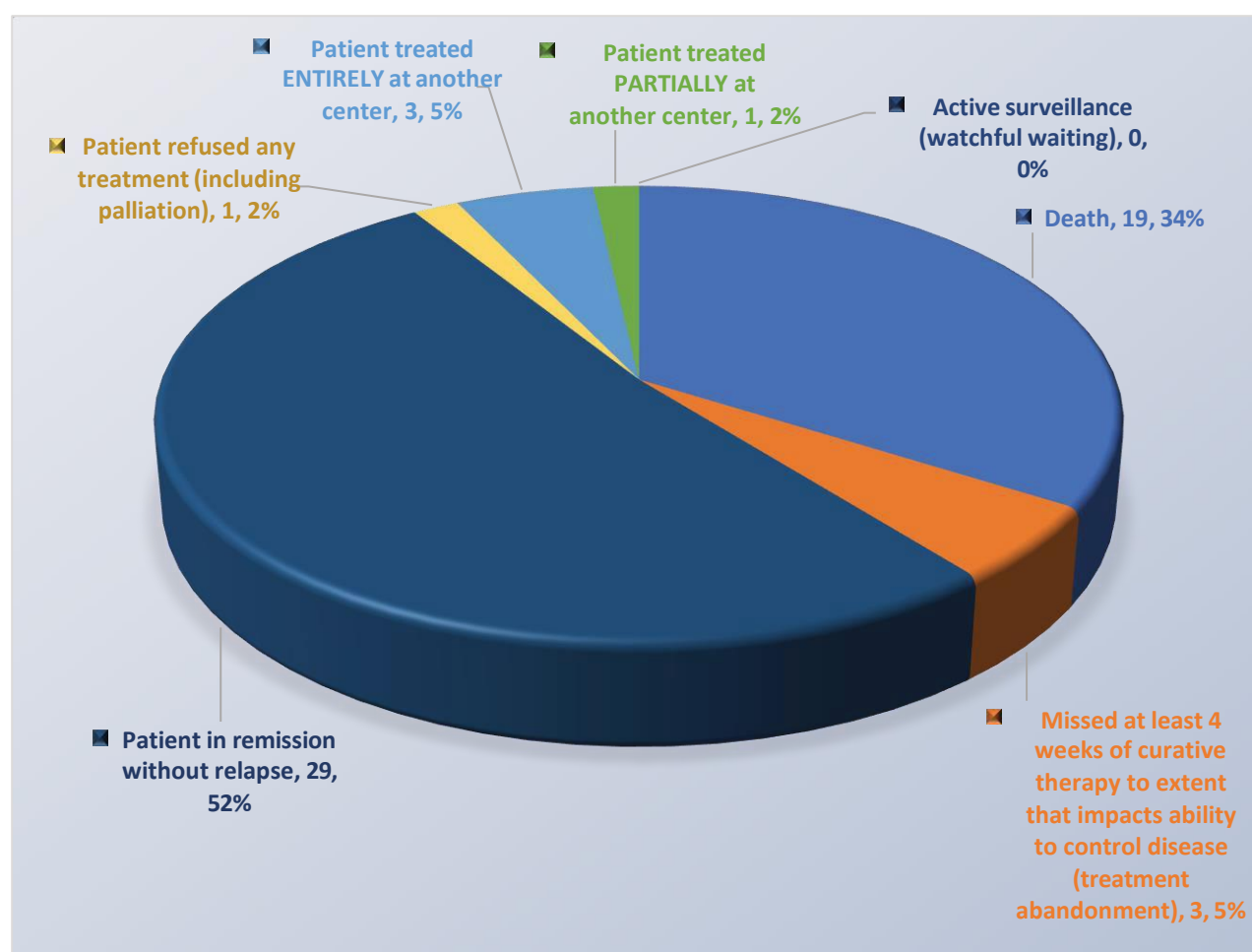


Table 20.2: 1st Year Follow-Up Treatment Types

Iccc3 Extended Classification	Total Incidence (n = 170)	Chemo therapy (n =170)	%	Radia tion (n =170)	%	Surgery (n =170)	%	Bone Marrow Transplant (n =170)	%
Ia	63	32	18.82	0	0	0	0	1	0.59
Ib	10	4	2.35	0	0	0	0	1	0.59
Ic	5	5	2.94	0	0	0	0	1	0.59
IIa	14	4	2.35	0	0	0	0	0	0
IIb	6	2	1.18	0	0	0	0	0	0
IIc	2	1	0.59	0	0	0	0	0	0
IId	5	3	1.76	0	0	0	0	0	0
IIIb	3	2	1.18	0	0	0	0	0	0
IIIc	2	1	0.59	0	0	0	0	0	0
IIId	1	0	0	0	0	0	0	0	0
IVa	5	2	1.18	0	0	1	0.59	0	0
V	5	0	0	2	1.18	0	0	0	0
VIa	4	2	1.18	0	0	0	0	0	0
VIIa	4	0	0	0	0	0	0	0	0
VIIIa	7	2	1.18	0	0	0	0	0	0
VIIIc	5	0	0	0	0	0	0	0	0
IXa	4	0	0	0	0	1	0.59	0	0
IXb	1	0	0	0	0	0	0	0	0
IXd	6	3	1.76	1	0.59	1	0.59	0	0
Xa	2	0	0	0	0	0	0	0	0
Xb	1	0	0	0	0	0	0	0	0
Xc	7	0	0	0	0	1	0.59	0	0
XIa	1	0	0	0	0	0	0	0	0
XIb	1	0	0	0	0	0	0	0	0
XIc	2	1	0.59	0	0	0	0	0	0
XIf	3	1	0.59	0	0	0	0	0	0
XIIa	1	0	0	0	0	0	0	0	0
Total	170	65	38.24	1	0.59	4	2.35	3	1.76

21. 2nd FOLLOW UP STATUS

Table 21.1: 2nd Year Follow-Up Treatment Details

Treatment Details	Frequency (n = 170)	Percentage %
Curative	41	24.1
Death at 1 st Follow-Up	23	13.5
No Treatment	59	34.7
Palliative	1	0.6
Unknown	46	27
Total	170	100.0

Figure 21.1: 2nd Year Follow-Up Reason for Not Taken Treatment.

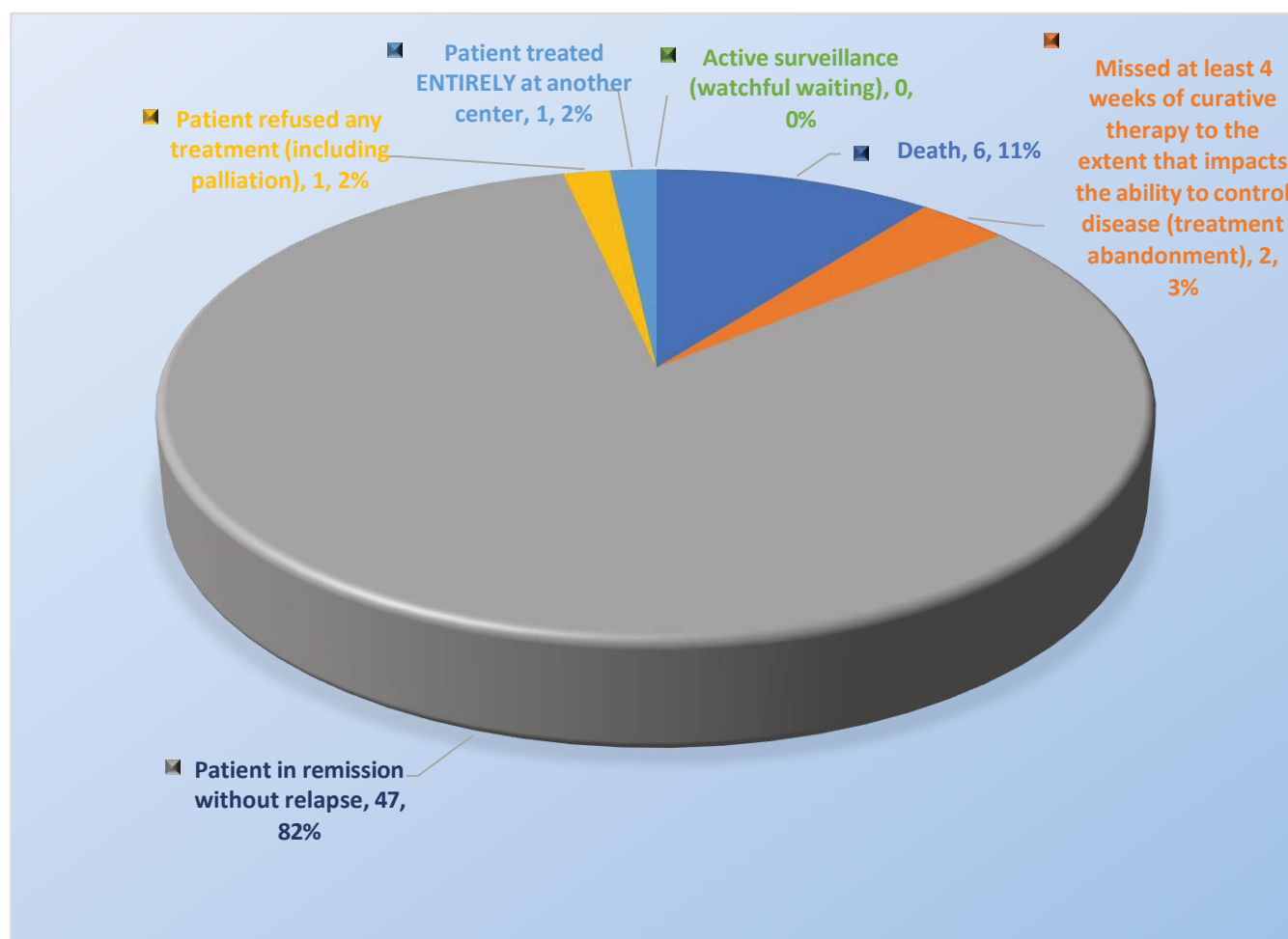


Table 21.2: 2nd Year Follow Up Type of Treatment

ICCC3 Extended Classification	Total Incidence (n = 170)	Chemotherapy (n =170)	%	Radiation (n =170)	%
Ia	63	28	16.47	0	0
Ib	10	0	0	0	0
Ic	5	5	2.94	0	0
IIa	14	3	1.76	0	0
IIb	6	2	1.18	0	0
IIc	2	2	1.18	0	0
IId	5	1	0.59	0	0
IIIb	3	1	0.59	0	0
IIIc	2	0	0	0	0
IIId	1	0	0	0	0
IVa	5	0	0	1	0.59
V	5	0	0	0	0
VIa	4	1	0.59	1	0.59
VIIa	4	1	0.59	0	0
VIIIa	7	0	0	0	0
VIIIc	5	1	0.59	0	0
IXa	4	0	0	0	0
IXb	1	0	0	0	0
IXd	6	0	0	0	0
Xa	2	0	0	0	0
Xb	1	1	0.59	0	0
Xc	7	0	0	0	0
XIa	1	0	0	0	0
XIb	1	0	0	0	0
XIc	2	0	0	0	0
XIf	3	0	0	0	0
XIIa	1	0	0	0	0
Total	170	46	27.06	2	1.18

22. REMISSION AND RELAPSE STATUS

Table 22.1: Final Remission and Relapse Status After 2nd Year Follow-Up

Status	Frequency (n =170)	Percentage %
No Remission	45	26.5
Relapse	6	3.5
Remission	93	54.7
Unknown	26	15.3
Total	170	100

Table 22.2: Comparison of ICC3 Extended Classification Code with Relapse / Remission Status

Iccc3 Extended Classification	Total Incidence (n = 170)	No Remission	Relapse	Remission	Unknown	Total
Ia	63	12	3	40	8	63
Ib	10	5	0	5	0	10
Ic	5	4	0	1	0	5
IIa	14	0	0	14	0	14
IIb	6	0	1	4	1	6
IIc	2	0	0	2	0	2
IId	5	3	1	1	0	5
IIIb	3	1	0	2	0	3
IIIc	2	1	0	1	0	2
IIId	1	1	0	0	0	1
IVa	5	3	0	2	0	5
IXa	5	1	0	3	0	4
IXb	4	0	0	1	0	1
IXd	4	2	0	3	1	6
V	7	0	0	4	1	5
VIa	5	1	1	1	1	4
VIIa	4	2	0	2	0	4
VIIIa	1	5	0	2	0	7
VIIIc	6	2	0	2	1	5
Xa	2	1	0	1	0	2
Xb	1	0	0	1	0	1
Xc	7	2	0	3	2	7
XIa	1	0	0	1	0	1
XIb	1	0	0	1	0	1
XIc	2	0	0	2	0	2
XIf	3	1	0	2	0	3
XIIa	1	0	0	1	0	1
Total	170	47	6	102	15	170

23. VITAL STATUS AFTER 2 YEARS FOLLOW-UP

Table 23.1: Vital Status After 2nd Year Follow-Up for Total Incidence

Vital Status	Frequency (n = 241)	Percentage %
Alive	143	59.3
Death	40	16.5
Unknown	58	24
Total	241	100

Table 23.2: Vital Status After 2nd Year Follow-Up for High-Resolution Data

Vital Status	Frequency (n = 170)	Percentage %
Alive	120	70.6
Death	38	22.3
Unknown	12	7.1
Total	170	100

Table 23.3: Comparison of Relapse / Remission Status With Vital Status for High-Resolution Data

Disease Status	Alive	Death	Unknown	Total
No Remission	15	32	0	47
Relapse	5	1	0	6
Remission	97	5	0	102
Unknown	3	0	12	15
Total	120	38	12	170

24. COMPARISON WITH OTHER COUNTRIES / REGISTRIES

The Chennai PBCCR will be compared with the other international registries in low- and middle-income countries in 2022. The National Cancer Registry released a report on cancer incidence and mortality among Indian registries in 2012-2016. The Chennai PBCCR(2022) is compared with other Asian registries in low-middle-income countries.

Figure 24.1: Comparison of PBCCR With Asian LMIC Registries in all Cancer Among 0-19 Age ⁴

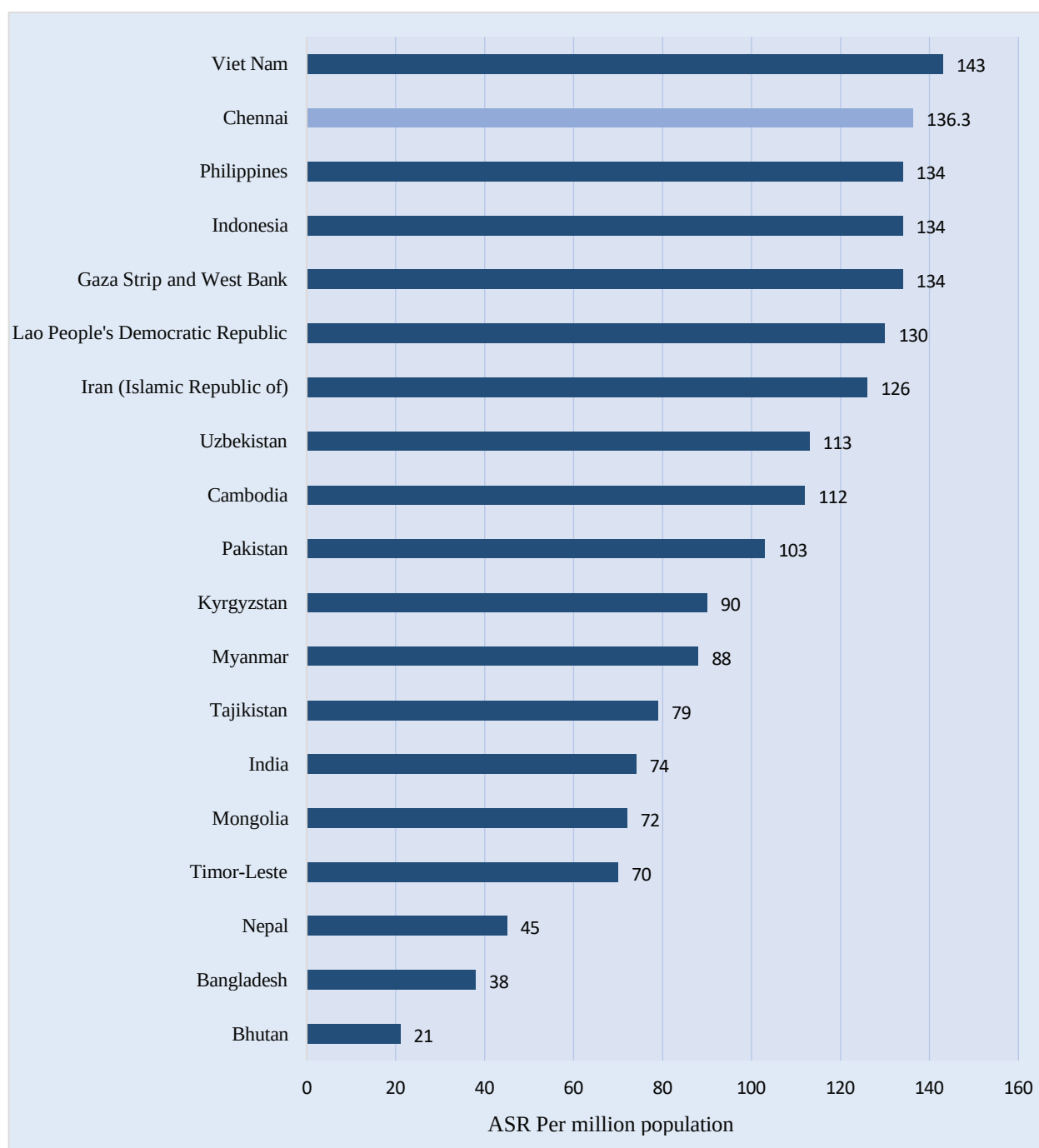


Figure 24.2: Comparison of PBCCR With Asian LMIC Registries in all Cancer Among 0-19 Age – Boys and Girls ⁴

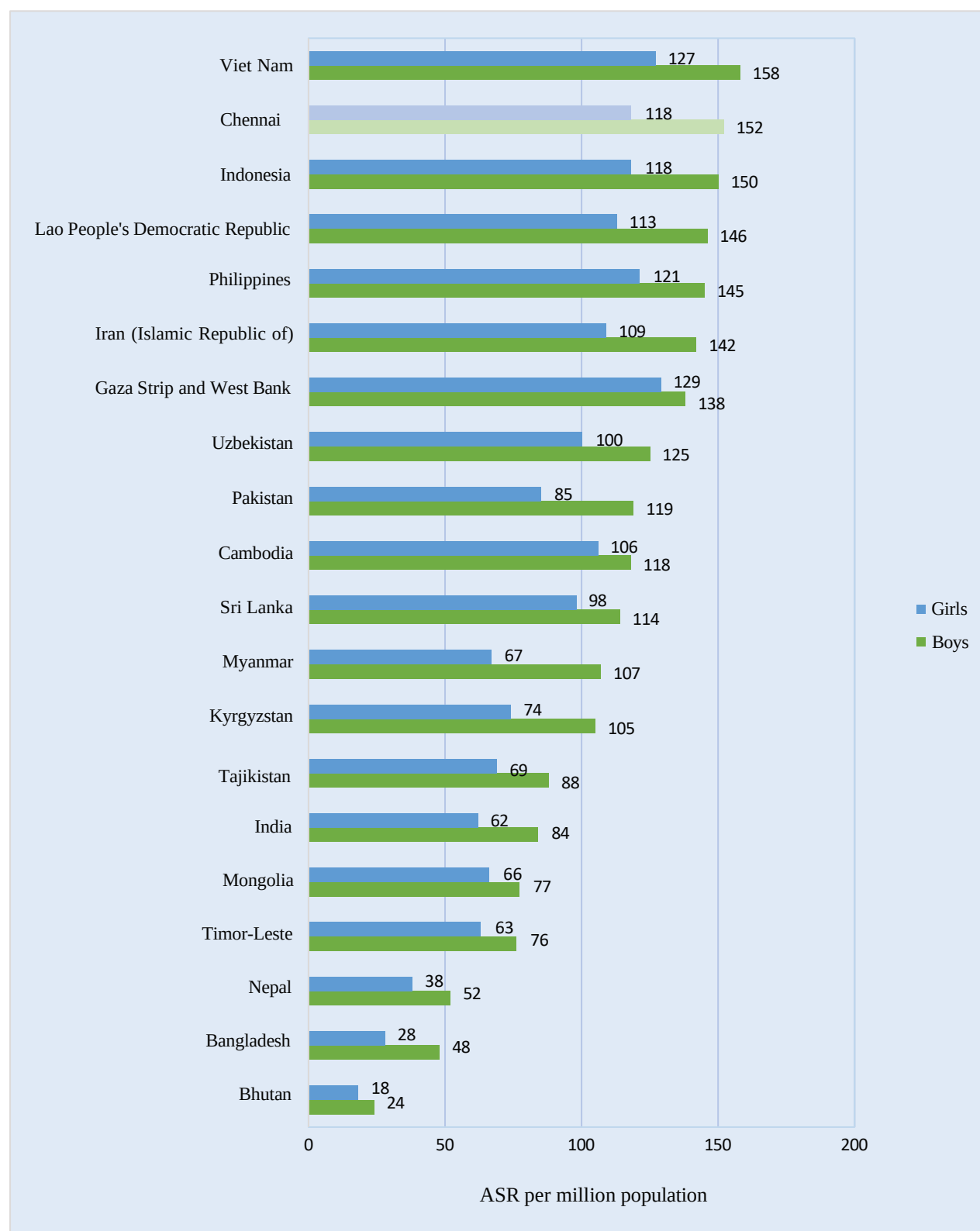


Figure 24.3: Comparison of PBCCR With International LMIC Registries in all Cancer Among 0-19 Age⁴

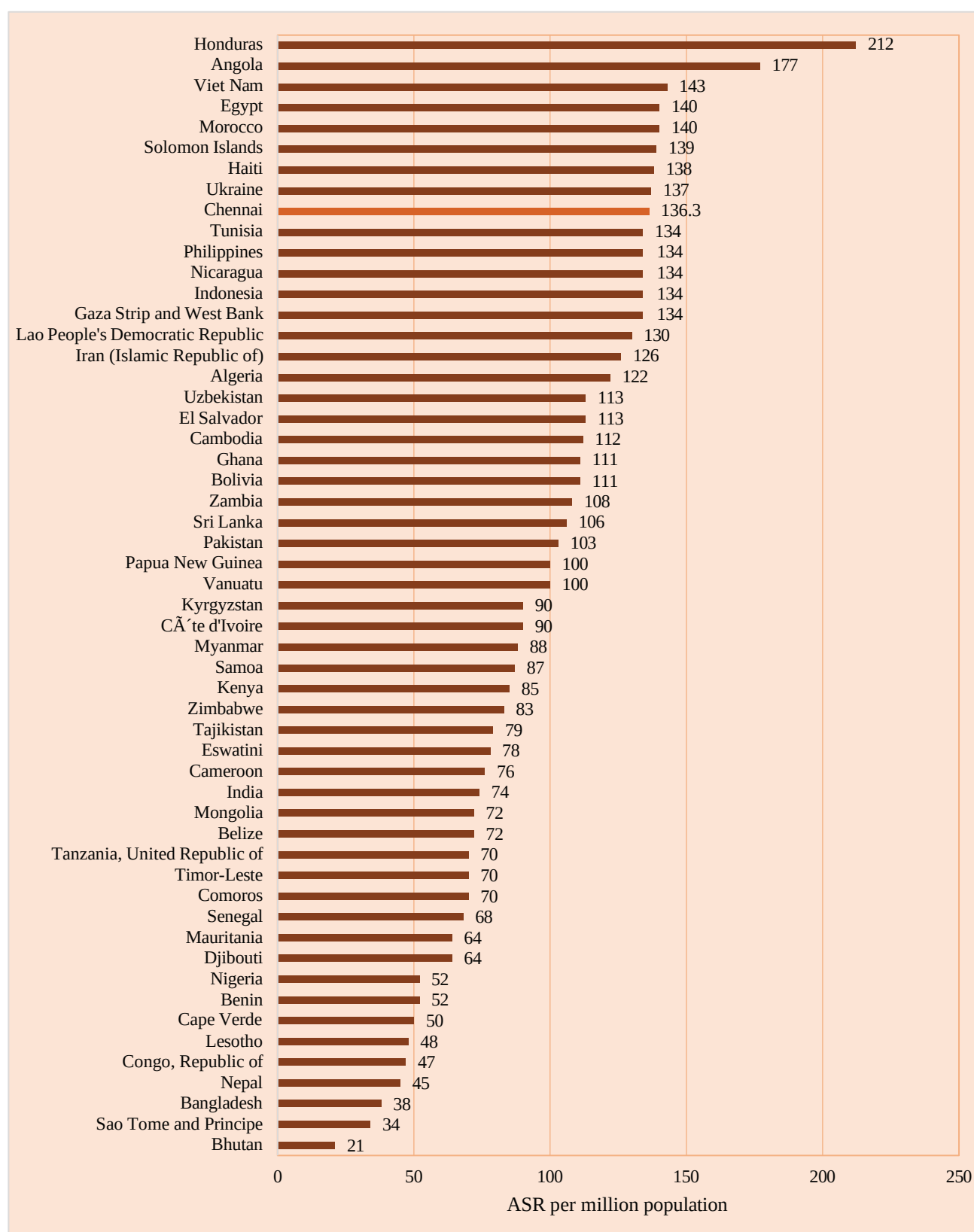


Figure 24.4: Comparison of PBCCR With International LMIC Registries in all Cancer Among 0-19 Age – Boys and Girls ⁴

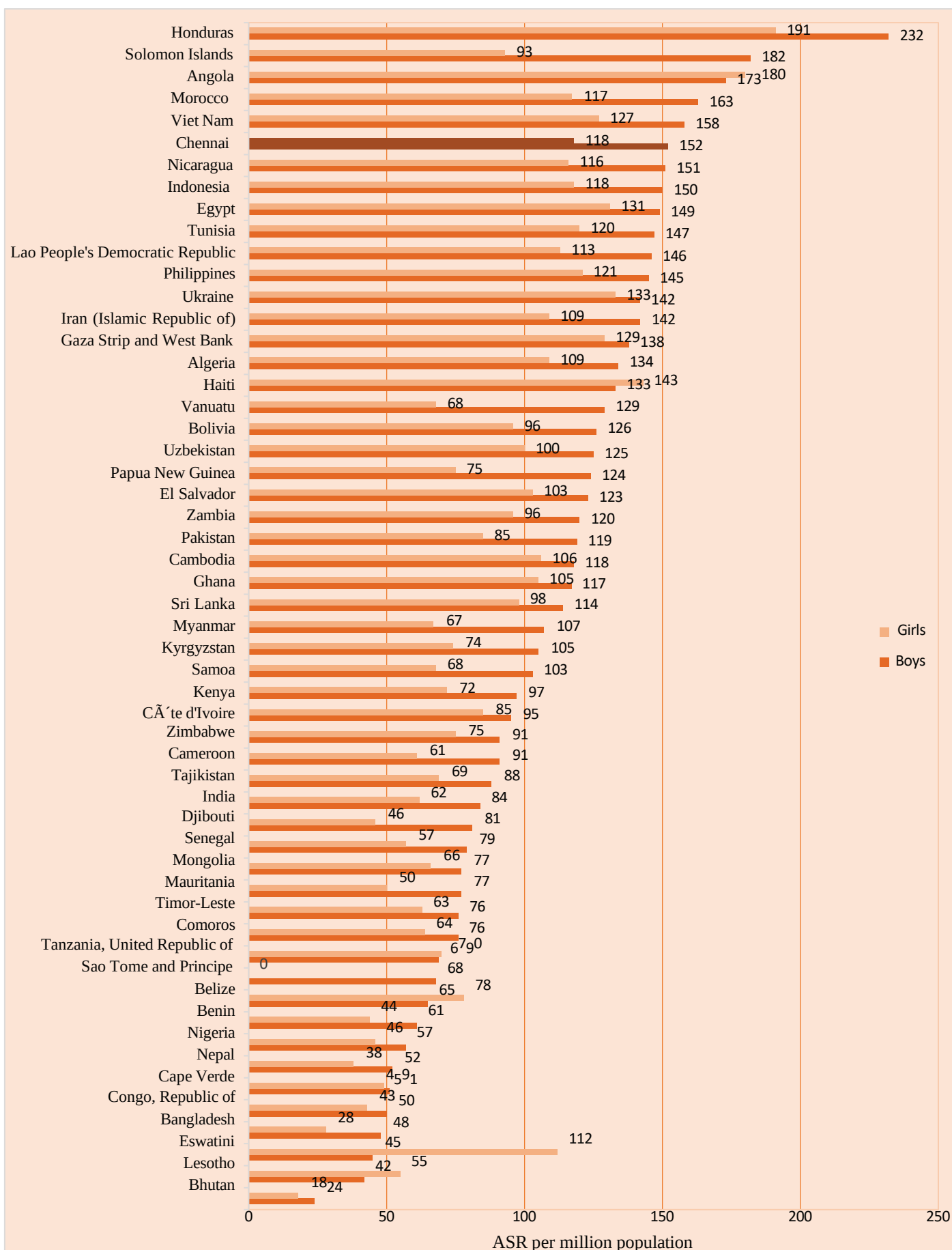


Figure 24.5: Comparison of PBCCR With Indian Registries in all Cancer Among 0-19 Age – Both Sexes ⁵

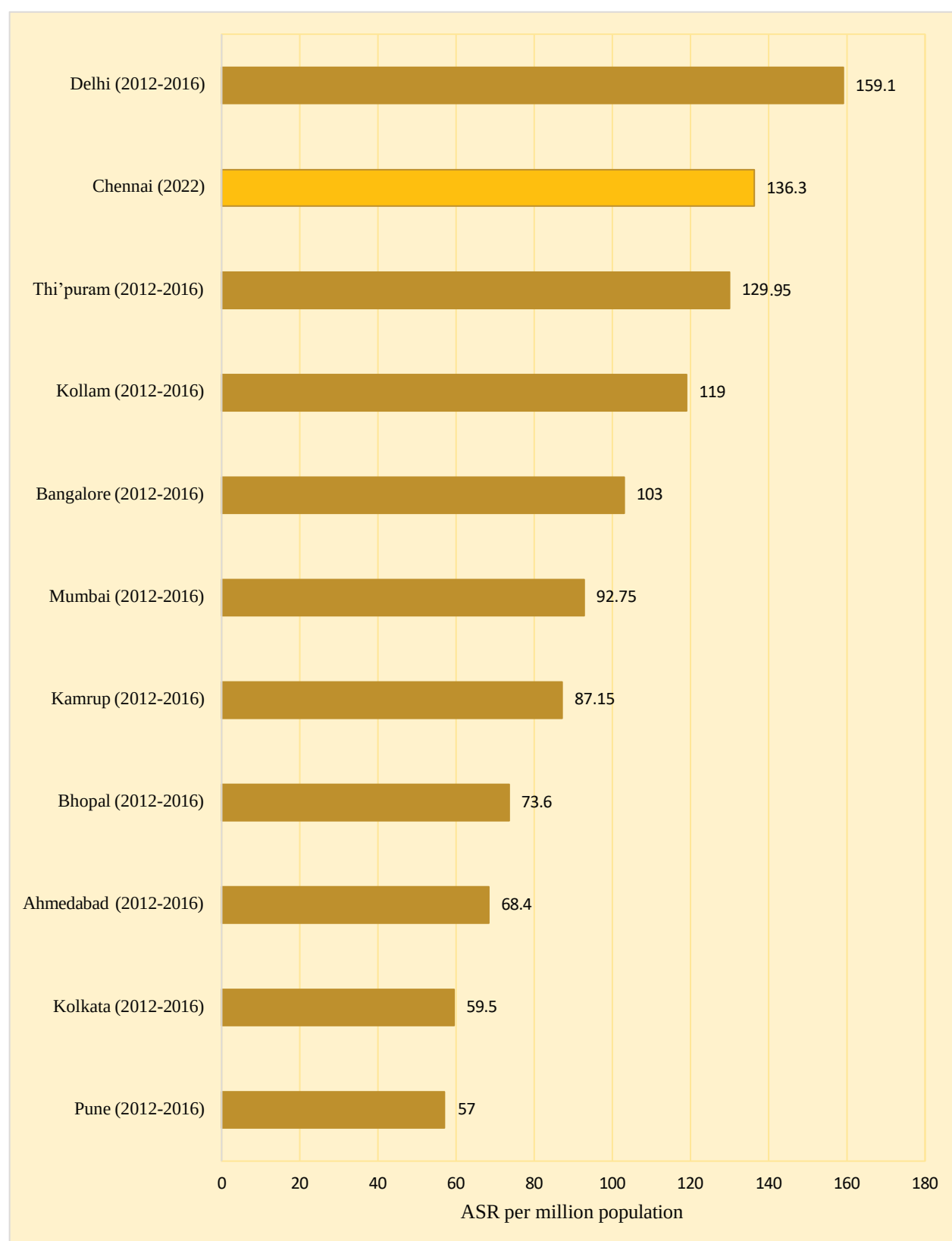


Figure 24.6: Comparison of PBCCR With Indian Registries in all Cancer Among 0-19 Age – Boys⁵

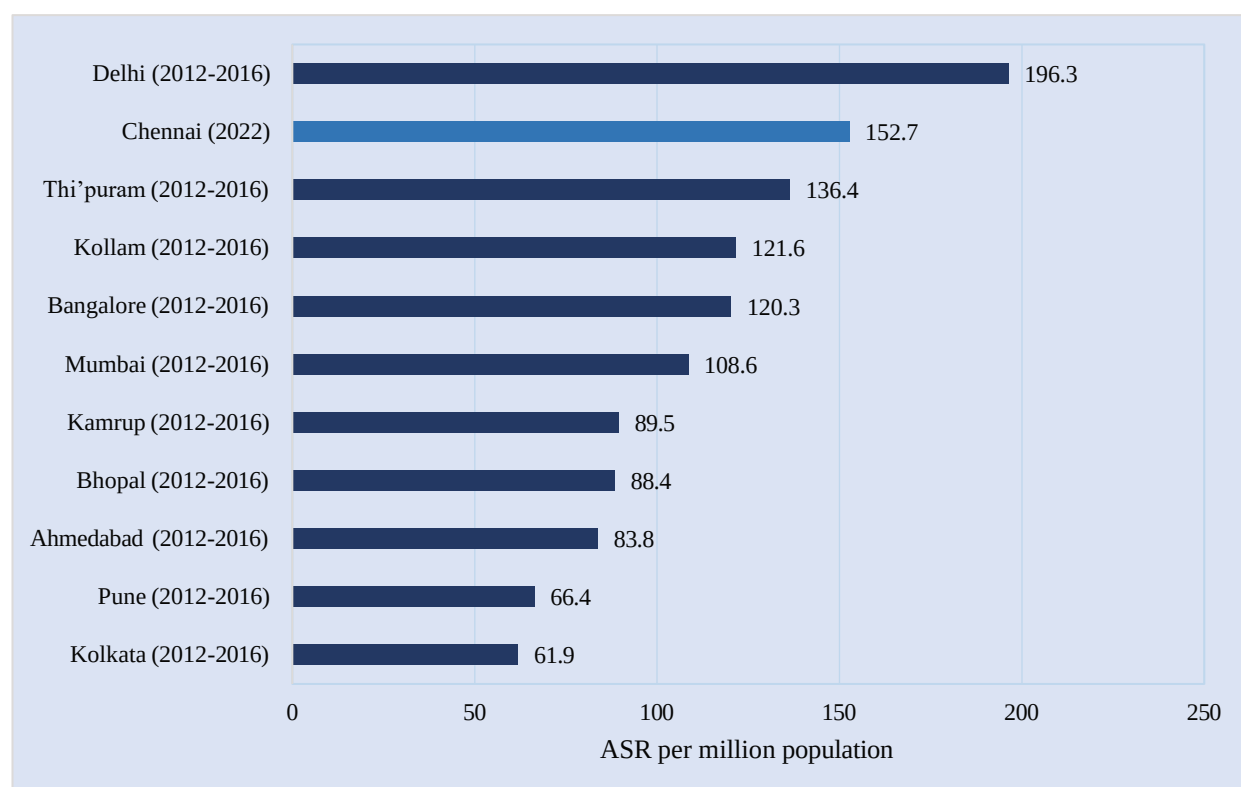
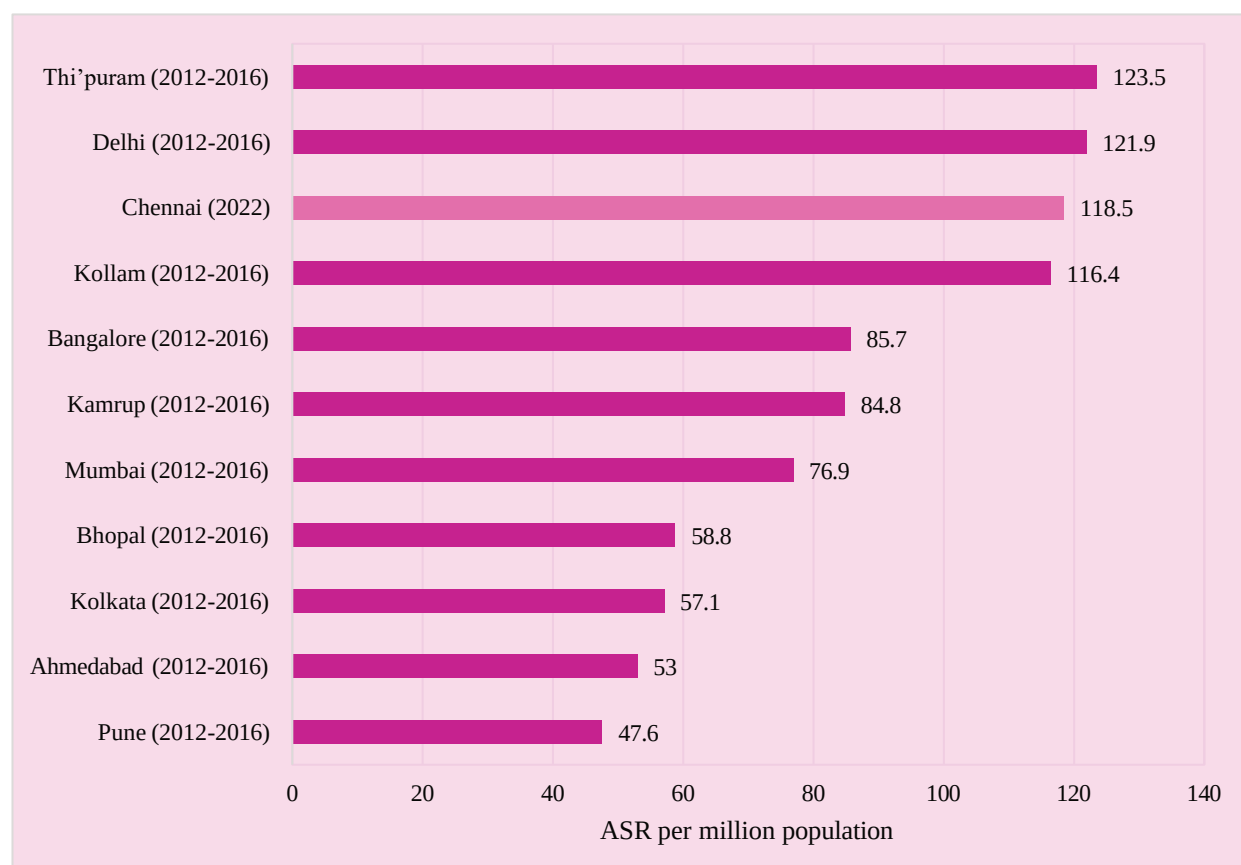


Figure 24.7: Comparison of PBCCR With Indian Registries in all Cancer Among 0-19 Age – Girls⁵



25. STATISTICAL TERMS AND METHODS USED IN CALCULATIONS

Statistical Terms used for calculation⁶

Cancer Incidence- Cancer Incidence refers to the number of new cancer cases diagnosed in a particular year within a defined population.

Rates- For pediatric cancer, rates are always expressed per million.

Crude Incidence Rate (CIR): The CIR is obtained by dividing the total cancer cases by the corresponding estimated mid-year population and multiplying by 10,00,000.

$$\text{CIR} = \frac{\text{New cases of cancer in a particular year}}{\text{Estimated mid-year population of the same year}} \times 10,00,000$$

Age-specific rate (ASpR)- refers to the rate obtained by dividing the total cases by the corresponding estimated population in the particular age group and multiplying by 10,00,000.

$$\text{ASpR} = \frac{\text{New cases of cancer in a particular year in the given age group}}{\text{Estimated mid-year population of the same year for the given age group}} \times 10,00,000$$

Age-Adjusted Rate(or) Age-Standardized Rate- refers to the rate obtained by multiplying age-specific rates by the total number of the standard world population in the given particular age group and divided by 10,00,000. In this report, the age groups of 0-4, 5-9, 10-14, and 15-19 were considered to calculate the age-standardized rate. The standard world population of the pediatric age group of 0-19 is 40,000, and the same is applied in calculations.

$$\text{ASR} = \frac{\sum (\text{ASpR}) \times (\text{Number of person in the standard world population in the particular age group})}{10,00,000}$$

Cumulative Risk- refers to the probability that the person will develop a particular cancer during a certain age group in the absence of any other cause of death. Cumulative Rate – is an approximation of the cumulative risk. It is obtained by adding the annual age-specific incidence rates for each five-year age interval multiplied by five times 100/10,00,000

$$\text{CuR} = 5 \times \sum (\text{ASpR}) \times 100$$

$$10,00,000$$

$$\text{Cumulative Risk} = 100 \times [1 - \exp(-\text{cumulative rate}/100)]$$

26. Assessment of Barriers and Enablers for Implementing a Population-Based Childhood Cancer Registry in Chennai, India.

Link for the paper: <https://doi.org/10.1002/pbc.31500>

Abstract

Background

Despite most childhood cancer cases being diagnosed in low and middle-income countries, there is a significant deficit of population-based childhood cancer registries (PBCCRs) in these regions. To address this critical gap, we established India's first dedicated PBCCR in Chennai on 4th October 2022, covering ages 0-19 years. This study aims to identify the barriers and enablers to implementing the Chennai PBCCR.

Procedure

Between April 2023 and March 2024, a sequential explanatory mixed-method study was conducted across 10 of the 16 centers in Chennai that agreed to implement the PBCCR. A total of 25 professionals agreed to participate in the quantitative phase utilizing a structured questionnaire. For the qualitative phase, in-depth interviews were conducted with 23 participants, including 16 from the quantitative phase, two stakeholders, and five caregivers. The interview guide was constructed, and the transcripts were analyzed using the Consolidated Framework for Implementation Research.

Results

Themes from the qualitative analysis revealed technological constraints, poor record-keeping, insufficient details captured in case records, and inadequate human resources as impediments. At the same time, factors such as knowledge, belief in sharing high-resolution data, the requirement and advantages of implementing a childhood cancer registry, professional self-efficacy, work infrastructure, and collaborative networks emerged as facilitators to the successful implementation of PBCCR.

Conclusion

Our experience and the findings of this study have the potential to serve as a model for successfully implementing and operating PBCCRs not only in India but also in other countries. This could significantly improve the understanding and management of childhood cancer, offering hope to countless children and their families.

Introduction

An essential component of improving the survival of children with cancer in low and middle-income countries (LMICs) and achieving the targets set by the World Health Organization (WHO) within the Global Initiative for Childhood Cancer (GICC) is to measure the incidence and outcome of children with cancer.^{1,2} This objective can only be attained using data generated by a population-based cancer registry. Given the distinct nature and epidemiology of cancer in childhood, setting up a dedicated population-based childhood cancer registry (PBCCR) may be an effective approach to collecting

quality data on the childhood population.^{1,2} The intended goal of a PBCCR is to record data on all newly diagnosed cancer cases in a geographical region with a defined resident population from multiple and heterogeneous sources, including hospitals, community, and government vital statistics records, and provide information on cancer incidence and patterns in the population being served.^{3,4} To date, there is a lack of reliable data to perform an in-depth analysis of variation in childhood cancer incidence and survival in India and many other LMICs due to multiple reasons (Figure 1).^{5–11}

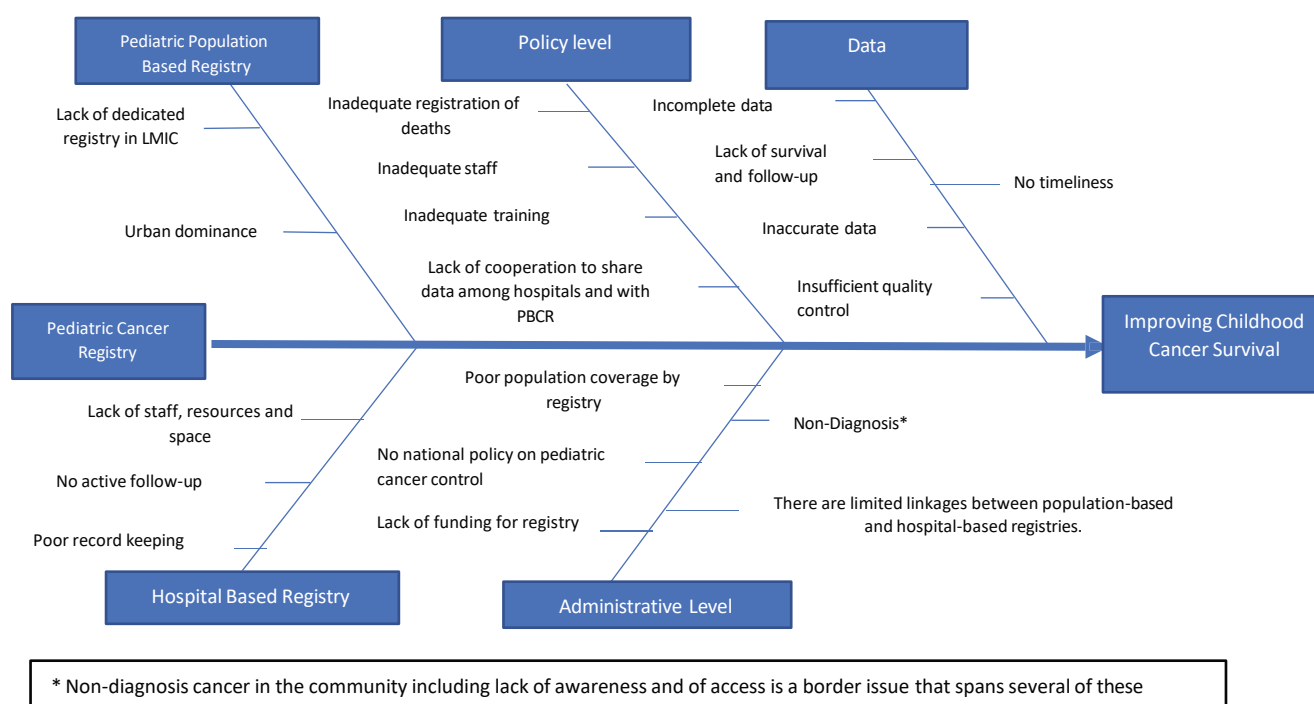


FIGURE 26.1 | Challenges facing childhood cancer registries in low-and middle-income countries (LMICs)

A general population-based cancer registry, which records information on cancer at any age, infrequently focuses on the extent and quality of data required to study childhood cancer, such as reporting statistics on typical cancer types or recording stages. Therefore, understanding childhood cancer epidemiology based on reporting by general registries is often inadequate. Notwithstanding, childhood cancers have a high potential for cure if identified early and afforded access to quality anti-neoplastic therapy.^{1,12} Therefore, adequate reporting may help to improve the cancer outcome in childhood populations.

In India, health is a state subject, with each state responsible for its health policies, including cancer registration. Although the Indian Council of Medical Research (ICMR) and the Tamil Nadu state government mandate cancer registration and data sharing, this regulation is not strictly followed due to a lack of enforcement.

Chennai (formerly Madras) is the capital city of Tamil Nadu state in Southern India. To address the need for a specific focus on childhood cancer in Chennai, we established the first dedicated PBCCR in India on 4th October 2022. This was supported by the Chennai population-based general cancer registry, known as the Madras Metropolitan Tumor Registry (MMTR), which has recorded cancer data on patients diagnosed at any age in the Chennai Metropolitan Region since 1981.¹³

The Chennai PBCCR was established to collect high-resolution data on all pediatric cancer cases in patients aged 0-19 years, including benign brain tumors, for residents of Chennai who have lived there for at least one year. Unlike the MMTR, the Chennai PBCCR captures additional details such as Toronto staging, treatment specifics, socioeconomic background, treatment compliance, and referral sources. Data from the Chennai PBCCR will be published as annual reports and shared with participating centers, the National Cancer Registry Program of India, and the International Agency for Research on Cancer to support informed policy development to improve childhood cancer outcomes.

In this study, we identify the barriers and describes the drivers of implementing the Chennai PBCCR while offering insights into successful strategies for enhancing the collection and analysis of childhood cancer data.

Methods

Study design:

The present study adopted a sequential explanatory mixed-method design. It was conducted between April 2023 and March 2024 with a cross-sectional quantitative component followed by an in-depth qualitative component. The Cancer Institute Ethics Committee approved the study. Informed consent was obtained from all participants.

Study setting:

The MMTR covers an area of 170 Kilometer square (KM²) and has an estimated population of 1.24 million individuals aged 0-19 years within a total population of 4.8 million. The Chennai PBCCR has an active data collection. system team whereby the PBCCR team (project manager, research associate, and data managers) visits the collaborating hospitals regularly to collect data. The Chennai PBCCR is supervised by the MMTR head and the PBCCR principal investigator. The Chennai PBCCR team assists the participating hospitals in establishing dedicated hospital-based childhood cancer registries covering patients aged 0 to 19 years.

Participants recruitment, sampling, and Data collection process: The flowchart below outlines the process of participant recruitment and data collection process (Figure 26.2)

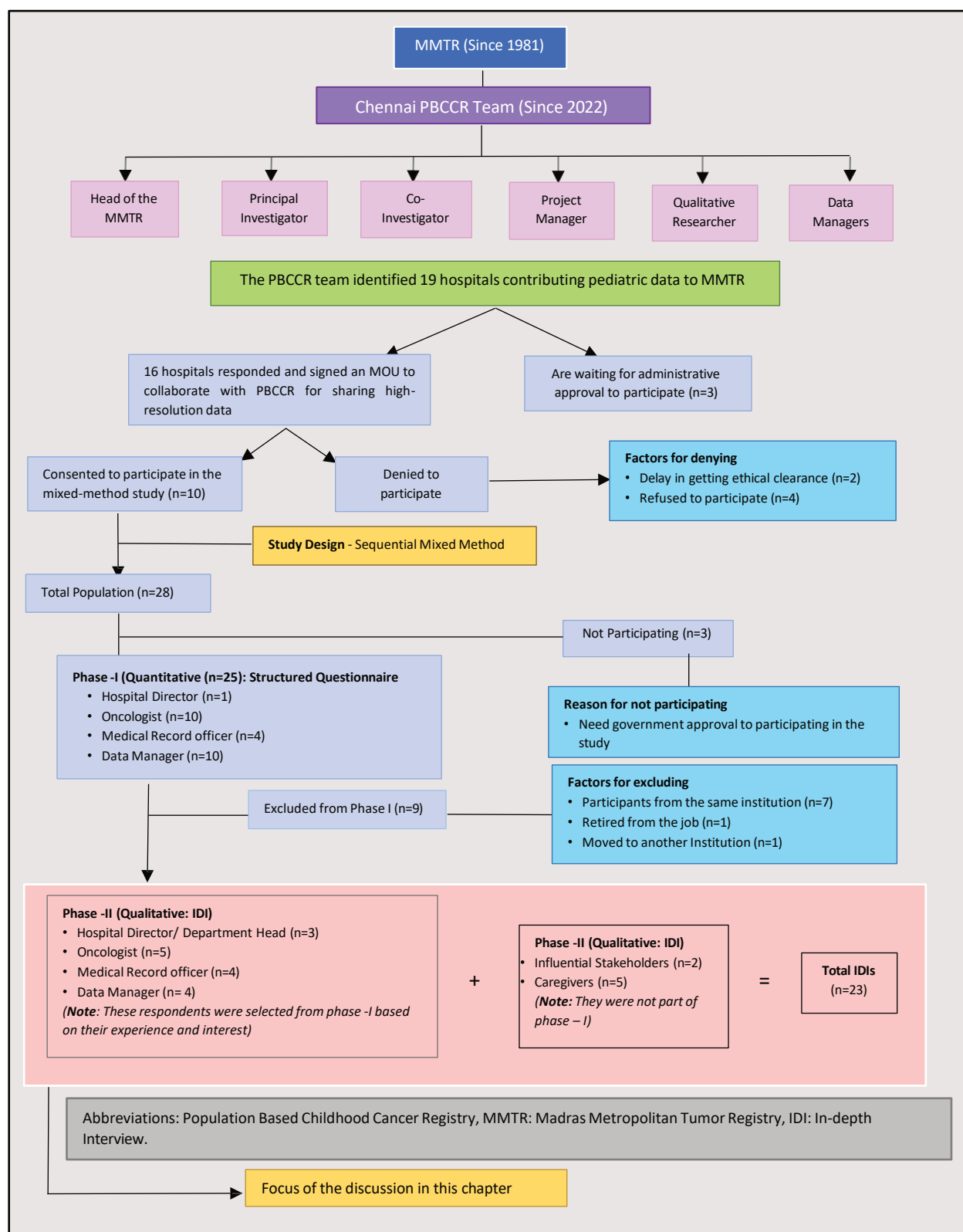


FIGURE 26.2 | The Chennai Population - Based Childhood Cancer Registry (PBCCR) organizational structure and the study workflow.

Tools and Data Collection Method:

The quantitative phase utilized Google Forms to gather data on participants and institutional characteristics, data management, and readiness for collaborating with PBCCR. For the qualitative phase, a semi-structured interview schedule was developed using Consolidated Framework for Implementation Research (CFIR)¹⁴⁻¹⁶, which focused on the involvement, insights, experience, and process of implementing PBCCR among professionals. For caregivers, the focusing on their perspectives on the cancer registry. The interview schedule was translated into Tamil and refined by the study team for accuracy, clarity, and understanding. Interviews were conducted in Tamil and English based on the participants' convenience, either face-to-face or virtually through the ZOOM videotelephony platform by the researcher. On average, the interviews lasted between 20-30 minutes. All interviews were audio recorded, professionally transcribed, and then translated into English for those conducted in Tamil and de-identified for analysis.

Qualitative Data Analysis:

The transcripts were read and reviewed to gain an in-depth understanding of the subject before coding. A codebook was constructed using a priori codes from CFIR 2009 and the updated CFIR (2022) to enhance accessibility. All transcripts were coded using MAXQDA software (VERBI Software, 2021), using a top-down coding method with the constructed CFIR codebook. The interviews with caregivers were also coded inductively. Any coding discrepancies were resolved through discussion among the study team. The codes/themes were related to the original data to ensure the results accurately reflected the data. Thematic content analysis was used to identify the barriers and enablers for implementing PBCCR, utilizing the CFIR domains in a comparative table format.

Results

Nineteen centers providing care to pediatric cancer patients and contributing pediatric data to the MMTR were invited to participate in the Chennai PBCCR project, and representatives of 16 centers agreed. Ten of these 16 centers consented to participate in this study investigating barriers and drivers of implementing the PBCCR (Figure 26.2).

Qualitative Phase

In the qualitative phase, 23 in-depth interviews were conducted (5 oncologists, three directors or department heads, 4 MRD staff, 4 data managers, two influential stakeholders, and five caregivers). Five themes were identified and categorized during interviews with professionals and stakeholders using CFIR constructs. An additional theme emerged during interviews with caregivers. A concise overview of the enabler and barrier to implementing PBCCR is presented in Table 1. The emerging themes are depicted in a thematic diagram (Figure 26.3).

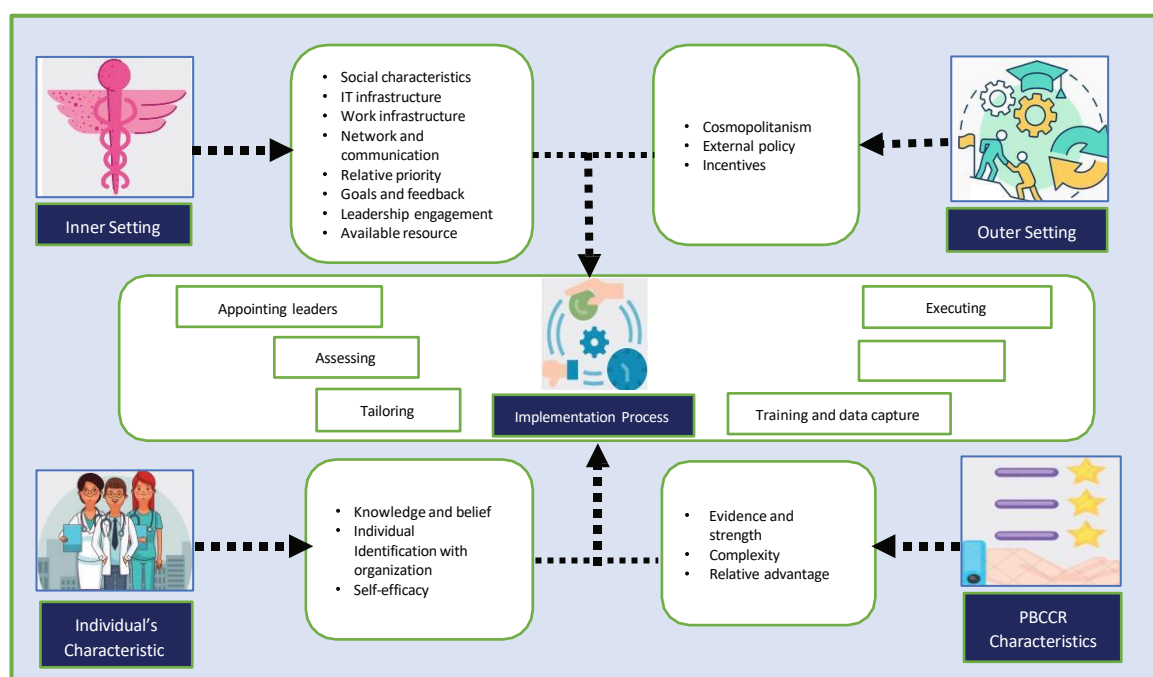


FIGURE 26.3 | Themes identified using the consolidated Framework for Implementation Research (CFIR)

Themes and sub-themes

Six main themes and their corresponding subthemes emerged from the interviews:

1. Characteristics of PBCCR:

Subthemes include the strength and quality of evidence, relative advantage, and complexity.

2. Outer Setting:

This theme encompasses subthemes such as cosmopolitanism, external policies, and incentives.

3. Inner Setting:

Subthemes within this category include structural characteristics, network and communication dynamics, relative priority, leadership engagement, and available resources.

4. Individual Characteristics:

This theme includes subthemes like knowledge and belief systems, self-efficacy, and individual identification with the institution.

5. Implementation Process:

This theme pertains to implementing the cancer registry and its associated procedures.

6. Interviews with primary caregivers:

This theme includes the child's cancer diagnosis, treatment procedures, perspectives on the cancer registry, willingness to share high-resolution data, and factors influencing sharing.

Table 26.1: Summary of enablers and barriers in implementing Chennai Population-Based Childhood Cancer Registry (PBCCR).

Themes	Barrier	Enabler
PBCCR/HBCCR Characteristics	• Missed cases due to undiagnosed pediatric cancer patients. • Limited resources for diagnosis and treatment of pediatric cancer patients. • Absences of pediatric oncologist in some centers.	• Provides valuable data for improving outcome in childhood cancer. • Assist in the development of policies
Outer setting	• Registry reports not shared with Providers. • Irregular periodic meeting between the PBCCRs core team and hospital administration.	• Effective communication between the PBCCRs core team and hospital. • Funds from other cancer registries support the development of technology and human resources.
Inner setting	• Insufficient equipment, such as computer and office space. • Lack of dedicated software for data collection. • Lack of human resources to operate HBCCRs and PBCCRs • No financial incentives for data collection.	• Dedicated HBCCRs. • Regular meeting among registry staff. • Strong leadership support for registry operations. • Availability of electronic medical records. • Utilizing NGO volunteer to address staffing shortage.
Characteristics of Individuals	• Concerns over data privacy and potential misuse. • Inadequate training in cancer registration and data collection.	• Training of registry staff and oncologist in pediatric cancer registration through courses and workshops. • Individual's belief in the importance of cancer registration within the PBCCR for enhancing treatment plans.
Implementation Process	• Delays in hospital administrative approvals for data sharing with PBCCR. • Multiple registries collecting overlapping data, leading to duplication of effort. • Unclear guidelines on data sharing with PBCCR. • Poorly stored or missing case records. • Incomplete information in case records. • High staff turnover due to low salaries and limited career growth. • Insufficient or no funding to establish HBCCRs and PBCCRs. • Lack of perceived benefit for centers contributing data to PBCCR.	• State law mandating compulsory cancer registries. • Previous experience contributing data to registries • Demonstrating the impact of PBCCR data to policymakers and stakeholders through reports and publications.

Abbreviations. HBCCR: Hospital-Based Childhood Cancer Registry; NGO: Non-Government Organization.

Caregiver's views on sharing child's medical information.

All caregivers of children with cancer were unfamiliar with the term "cancer registry," while some parents expressed a desire to learn more about it. A few refused the registration concept due to misconceptions and lack of awareness, viewing the registry as something worse than the disease. Upon understanding the cancer registry, parents were generally willing to share their child's medical information for various reasons.

Caregivers felt it would be helpful to have the cancer registry to maintain treatment and follow-up details, especially since they do not have their child's treatment records readily available and the belief that sharing data could improve treatment outcomes for others. However, some parents remained hesitant to share due to concerns about their children's privacy and the stigma associated with cancer.

Conclusion:

The establishment of the Population-Based Childhood Cancer Registry (PBCCR) in Chennai represents a significant step toward improving childhood cancer data collection in low- and middle-income countries (LMICs). This study identifies key barriers, such as limited resources, infrastructural challenges, and delays in obtaining ethical clearances, alongside enablers like strong leadership, effective coordination, and external funding. Addressing systemic gaps through enhanced training, resource allocation, and improved communication is crucial. Caregivers' willingness to share data underscores the potential for public engagement in advancing Pediatric cancer care.

Our experience, along with the findings of this study, has the potential to serve as a model for successfully implementing and operating PBCCRs, not only in India but also in other countries. By improving the understanding and management of childhood cancer, this initiative could offer hope to countless children and their families.

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ANNEXURE

ANNEXURE 1: Distribution of ICC3 Extended Classification Code and Toronto Tier 1 Staging

ICCC3 Extended Classification	Toronto Tier 1								Total
	Advanced	Intraocular	Limited	Localized	Localized/M0	Locoregional	Metastatic	Regional	
Ia	0	0	0	0	0	0	0	0	0
Ib	0	0	0	0	0	0	0	0	0
Ic	0	0	0	0	0	0	0	0	0
IIa	0	0	0	0	0	0	0	0	0
IIb	1	0	4	0	0	0	0	0	5
IIc	0	0	2	0	0	0	0	0	2
IId	0	0	0	0	0	0	0	0	0
IIIb	0	0	0	3	0	0	0	0	3
IIIc	0	0	0	0	2	0	0	0	2
IIId	0	0	0	0	1	0	0	0	1
IVa	0	0	0	3	0	1	1	0	5
V	0	4	0	1	0	0	0	0	5
VIa	0	0	0	3	0	0	1	0	4
VIIa	0	0	0	3	0	0	1	0	4
VIIIa	0	0	0	6	0	0	1	0	7
VIIIc	0	0	0	5	0	0	0	0	5
IXa	0	0	0	4	0	0	0	0	4
IXb	0	0	0	1	0	0	0	0	1
IXd	0	0	0	5	0	0	1	0	6
Xa	0	0	0	2	0	0	0	0	2
Xb	0	0	0	1	0	0	0	0	1
Xc	0	0	0	5	0	0	1	1	7
XIa	0	0	0	1	0	0	0	0	1
XIb	0	0	0	1	0	0	0	0	1
XIc	0	0	0	2	0	0	0	0	2
XIf	0	0	0	3	0	0	0	0	3
XIIa	0	0	0	1	0	0	0	0	1
Total	1	4	6	50	3	1	6	1	

ANNEXURE 2: Distribution of ICC3 Extended Classification Code and Toronto Tier 2 Staging

ICCC3 Extended Classification	Toronto Tier 2										
	L1	L2	M	M+	M0	Stage 0	Stage I	Stage II	Stage III	Stage IV	Total
Ia	0	0	0	0	0	0	0	0	0	0	0
Ib	0	0	0	0	0	0	0	0	0	0	0
Ic	0	0	0	0	0	0	0	0	0	0	0
IIa	0	0	0	0	0	0	4	8	0	2	14
IIb	0	0	0	0	0	0	4	0	0	1	5
IIc	0	0	0	0	0	0	1	0	1	0	2
IId	0	0	0	0	0	0	0	0	0	0	0
IIIb	0	0	0	1	1	0	1	0	0	0	3
IIIc	0	0	0	1	1	0	0	0	0	0	2
IIId	0	0	0	1	0	0	0	0	0	0	1
IVa	3	1	1	0	0	0	0	0	0	0	5
V	0	0	0	0	0	2	3	0	0	0	5
VIa	0	0	0	0	0	0	2	0	1	1	4
VIIa	0	0	0	0	0	0	1	2	0	1	4
VIIIa	0	0	0	0	0	0	4	1	1	1	7
VIIIc	0	0	0	0	0	0	3	0	2	0	5
IXa	0	0	0	0	0	0	2	2	0	0	4
IXb	0	0	0	0	0	0	1	0	0	0	1
IXd	0	0	0	0	0	0	5	0	0	1	6
Xa	0	0	0	0	0	0	1	1	0	0	2
Xb	0	0	0	0	0	0	1	0	0	0	1
Xc	0	0	0	0	0	1	4	0	0	1	7
XIa	0	0	0	0	0	0	1	0	0	0	1
XIb	0	0	0	0	0	0	1	0	0	0	1
XIc	0	0	0	0	0	0	1	0	0	0	2
XIf	0	0	0	0	0	0	0	0	0	0	3
XIIa	0	0	0	0	0	0	0	0	0	0	1
Total	3	1	1	3	2	3	41	14	5	8	81

ANNEXURE 3: No of Cases, Percentage, Age Specific Rate (ASPR), Crude Incidence Rate (CIR), Age Standardised Rate (ASR), Cumulative Risk (0 – 19; C.R %) per million population: year 2022 – Boys

ICCC HEAD	ICCC 3	ICCC3 DESCRIPTION	TOTAL NUMBER OF CASES				TOTAL	AGE SPECIFIC RATES (0-19)					RATES AGE : 0 - 19		
			0-4'	5-9'	10-14'	15-19'		%	0-4'	5-9'	10-14'	15-19'	C.I R	A.S. R	CR%
I.		Leukemias, myeloproliferative diseases, and myelodysplastic diseases	24	13	23	7	67	48.2	93.1	60.0	105.3	31.7	73.3	73.8	0.145
I.	Ia	Lymphoid leukemias	23	13	21	4	61	43.9	89.2	60.0	96.2	18.1	66.8	67.5	0.132
I.	Ib	Acute myeloid leukemias	1	0	1	3	5	3.6	3.9	0.0	4.6	13.6	5.5	5.3	0.011
I.	Ic	Chronic myeloproliferative diseases	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
I.	Id	Myelodysplastic syndrome and other myeloproliferative diseases	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
I.	Ie	Unspecified and other specified leukemias	0	0	1	0	1	0.7	0.0	0.0	4.6	0.0	1.1	1.0	0.002
II.		Lymphomas and reticuloendothelial neoplasms	5	4	9	7	25	18.0	19.4	18.5	41.2	31.7	27.4	26.8	0.055
II.	IIa	Hodgkin lymphomas	2	1	7	6	16	11.5	7.8	4.6	32.1	27.2	17.5	16.8	0.036
II.	IIb	Non-Hodgkin lymphomas	2	0	0	1	3	2.2	7.8	0.0	0.0	4.5	3.3	3.3	0.006
II.	IIc	Burkitt lymphoma	0	0	1	0	1	0.7	0.0	0.0	4.6	0.0	1.1	1.0	0.002
II.	IId	Miscellaneous lymphoreticular neoplasms	1	3	1	0	5	3.6	3.9	13.8	4.6	0.0	5.5	5.7	0.011
II.	IIe	Unspecified lymphomas	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
III.		CNS and miscellaneous intracranial and intraspinal neoplasms	5	2	1	1	9	6.5	19.4	9.2	4.6	4.5	9.9	10.2	0.018
III.	IIIa	Ependymomas and choroid plexus tumor	0	1	0	0	1	0.7	0.0	4.6	0.0	0.0	1.1	1.2	0.002
III.	IIIb	Astrocytomas	3	0	0	1	4	2.9	11.6	0.0	0.0	4.5	4.4	4.5	0.008
III.	IIIc	Intracranial and intraspinal embryonal tumors	1	0	1	0	2	1.4	3.9	0.0	4.6	0.0	2.2	2.2	0.004
III.	IIId	Other gliomas	1	1	0	0	2	1.4	3.9	4.6	0.0	0.0	2.2	2.3	0.004
III.	IIIe	Other specified intracranial and intraspinal neoplasms	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
III.	IIIf	Unspecified intracranial and intraspinal neoplasms	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
IV.		Neuroblastoma and other peripheral nervous cell tumors	2	2	0	0	4	2.9	7.8	9.2	0.0	0.0	4.4	4.6	0.008
IV.	IVa	Neuroblastoma and ganglioneuroblastoma	2	2	0	0	4	2.9	7.8	9.2	0.0	0.0	4.4	4.6	0.008
IV.	IVb	Other peripheral nervous cell tumors	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
V.	V	Retinoblastoma	3	0	0	0	3	2.2	11.6	0.0	0.0	0.0	3.3	3.5	0.006
VI.		Renal tumors	1	0	0	0	1	0.7	3.9	0.0	0.0	0.0	1.1	1.2	0.002
VI.	VIa	Neuroblastoma and other peripheral nervous cell tumors	1	0	0	0	1	0.7	3.9	0.0	0.0	0.0	1.1	1.2	0.002
VI.	VIb	Renal carcinomas	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
VI.	VIc	Unspecified malignant renal tumors	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
VII.		Hepatic tumors	4	0	0	0	4	2.9	15.5	0.0	0.0	0.0	4.4	4.7	0.008
VII.	VIIa	Hepatoblastoma	4	0	0	0	4	2.9	15.5	0.0	0.0	0.0	4.4	4.7	0.008
VII.	VIIb	Hepatic carcinomas	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
VII.	VIIc	Unspecified malignant hepatic tumors	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
VIII.		Malignant bone tumors	0	1	3	0	4	2.9	0.0	4.6	13.7	0.0	4.4	4.2	0.009
VIII.	VIIIa	Osteosarcomas	0	1	3	0	4	2.9	0.0	4.6	13.7	0.0	4.4	4.2	0.009
VIII.	VIIIb	Chondrosarcomas	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
VIII.	VIIIc	Ewing tumor and related sarcomas of bone	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
VIII.	IIId	Other specified malignant bone tumors	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
VIII.	IIIe	Unspecified malignant bone tumors	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
IX.		Soft tissue and other extraosseous sarcomas	6	2	1	2	11	7.9	23.3	9.2	4.6	9.1	12.0	12.4	0.023
IX.	IXa	Rhabdomyosarcomas	5	1	0	0	6	4.3	19.4	4.6	0.0	0.0	6.6	7.0	0.012

IX.	IXb	Fibrosarcomas, peripheral nerve sheath tumors, and other fibrous neoplasms	0	0	0	1	1	0.7	0.0	0.0	0.0	4.5	1.1	1.0	0.002
IX.	IXc	Kaposi sarcoma	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
IX.	IXd	Other specified soft tissue sarcomas	1	1	1	1	4	2.9	3.9	4.6	4.6	4.5	4.4	4.4	0.009
IX.	IXe	Unspecified soft tissue sarcomas	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
X.		Germ cell tumors, trophoblastic tumors, and neoplasms of gonads	0	0	1	2	3	2.2	0.0	0.0	4.6	9.1	3.3	3.1	0.007
X.	Xa	Intracranial and intraspinal germ cell tumors	0	0	0	1	1	0.7	0.0	0.0	0.0	4.5	1.1	1.0	0.002
X.	Xb	Malignant extracranial and extragonadal germ cell tumors	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
X.	Xc	Malignant gonadal germ cell tumors	0	0	1	1	2	1.4	0.0	0.0	4.6	4.5	2.2	2.1	0.005
X.	Xd	Gonadal carcinomas	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
X.	Xe	Other and unspecified malignant gonadal tumors	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
XL		Other malignant epithelial neoplasms and malignant melanomas	0	0	4	3	7	5.0	0.0	0.0	18.3	13.6	7.7	7.2	0.016
XL	XIa	Adrenocortical carcinomas	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
XL	XIb	Thyroid carcinomas	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
XL	XIc	Nasopharyngeal carcinomas	0	0	2	1	3	2.2	0.0	0.0	9.2	4.5	3.3	3.1	0.007
XL	XId	Malignant melanomas	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
XL	XIe	Skin carcinomas	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
XL	XIf	Other and unspecified carcinomas	0	0	2	2	4	2.9	0.0	0.0	9.2	9.1	4.4	4.1	0.009
XII.		Other and unspecified malignant neoplasms	1	0	0	0	1	0.7	3.9	0.0	0.0	0.0	1.1	1.2	0.002
XII.	XIIa	Other specified malignant tumors	1	0	0	0	1	0.7	3.9	0.0	0.0	0.0	1.1	1.2	0.002
XII.	XIIb	Other unspecified malignant tumors	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
		TOTAL	51	24	42	22	139	100	197.8	110.7	192.4	99.7	152.1	152.7	0.299

ANNEXURE 3: No of Cases, Percentage, Age Specific Rate (ASPR), Crude Incidence Rate (CIR), Age Standardised Rate (ASR), Cumulative Risk (0 – 19; C.R %) per million population: year 2022 – Girls

ICCC HEAD	ICCC3	ICCC3 DESCRIPTION	TOTAL NUMBER OF CASES				TOTAL	%	AGE SPECIFIC RATES (0-19)				RATES AGE : 0 - 19		
			0-4'	5-9'	10-14'	15-19			0-4'	5-9'	10-14'	15-19	C.I.R	A.S.R	CR%
I.		Leukemias, myeloproliferative diseases, and myelodysplastic diseases	9	13	12	8	42	41.2	37.9	64.2	58.3	37.8	49.0	49.1	0.100
I.	Ia	Lymphoid leukemias	7	5	9	5	26	25.5	29.5	24.7	43.7	23.6	30.3	30.2	0.061
I.	Ib	Acute myeloid leukemias	2	5	2	1	10	9.8	8.4	24.7	9.7	4.7	11.7	12.0	0.024
I.	Ic	Chronic myeloproliferative diseases	0	3	1	2	6	5.9	0.0	14.8	4.9	9.5	7.0	6.9	0.015
I.	Id	Myelodysplastic syndrome and other myeloproliferative diseases	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
I.	Ie	Unspecified and other specified leukemias	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
II.		Lymphomas and reticuloendothelial neoplasms	4	2	4	4	14	13.7	16.8	9.9	19.4	18.9	16.3	16.1	0.032
II.	IIa	Hodgkin lymphomas	0	1	2	2	5	4.9	0.0	4.9	9.7	9.5	5.8	5.5	0.012
II.	IIb	Non-Hodgkin lymphomas	2	0	0	2	4	3.9	8.4	0.0	0.0	9.5	4.7	4.7	0.009
II.	IIc	Burkitt lymphoma	0	0	1	0	1	1.0	0.0	0.0	4.9	0.0	1.2	1.1	0.002
II.	IId	Miscellaneous lymphoreticular neoplasms	2	1	1	0	4	3.9	8.4	4.9	4.9	0.0	4.7	4.9	0.009
II.	IIE	Unspecified lymphomas	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
III.		CNS and miscellaneous intracranial and intraspinal neoplasms	1	1	0	1	3	2.9	4.2	4.9	0.0	4.7	3.5	3.6	0.006
III.	IIIa	Ependymomas and choroid plexus tumor	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
III.	IIIb	Astrocytomas	1	0	0	1	2	2.0	4.2	0.0	0.0	4.7	2.3	2.3	0.004
III.	IIIc	Intracranial and intraspinal embryonal tumors	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
III.	IIId	Other gliomas	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
III.	IIIe	Other specified intracranial and intraspinal neoplasms	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
III.	IIIf	Unspecified intracranial and intraspinal neoplasms	0	1	0	0	1	1.0	0.0	4.9	0.0	0.0	1.2	1.2	0.002
IV.		Neuroblastoma and other peripheral nervous cell tumors	3	0	0	1	4	3.9	12.6	0.0	0.0	4.7	4.7	4.9	0.009
IV.	IVa	Neuroblastoma and ganglioneuroblastoma	3	0	0	1	4	3.9	12.6	0.0	0.0	4.7	4.7	4.9	0.009
IV.	IVb	Other peripheral nervous cell tumors	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
V.	V	Retinoblastoma	3	0	0	0	3	2.9	12.6	0.0	0.0	0.0	3.5	3.8	0.006
VI.		Renal tumors	3	1	0	0	4	3.9	12.6	4.9	0.0	0.0	4.7	5.0	0.009
VI.	VIa	Neuroblastoma and other peripheral nervous cell tumors	3	1	0	0	4	3.9	12.6	4.9	0.0	0.0	4.7	5.0	0.009
VI.	VIb	Renal carcinomas	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
VI.	VIc	Unspecified malignant renal tumors	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
VII.		Hepatic tumors	1	0	0	0	1	1.0	4.2	0.0	0.0	0.0	1.2	1.3	0.002
VII.	VIIa	Hepatoblastoma	1	0	0	0	1	1.0	4.2	0.0	0.0	0.0	1.2	1.3	0.002
VII.	VIIb	Hepatic carcinomas	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
VII.	VIIc	Unspecified malignant hepatic tumors	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
VIII.		Malignant bone tumors	0	2	6	1	9	8.8	0.0	9.9	29.2	4.7	10.5	10.1	0.022
VIII.	VIIIa	Osteosarcomas	0	0	4	0	4	3.9	0.0	0.0	19.4	0.0	4.7	4.4	0.010
VIII.	VIIIb	Chondrosarcomas	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
VIII.	VIIIc	Ewing tumor and related sarcomas of bone	0	2	2	1	5	4.9	0.0	9.9	9.7	4.7	5.8	5.7	0.012
VIII.	IIId	Other specified malignant bone tumors	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
VIII.	IIIe	Unspecified malignant bone tumors	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
IX.		Soft tissue and other extraosseous sarcomas	2	0	1	3	6	5.9	8.4	0.0	4.9	14.2	7.0	6.8	0.013
IX.	IXa	Rhabdomyosarcomas	1	0	0	0	1	1.0	4.2	0.0	0.0	0.0	1.2	1.3	0.002
IX.	IXb	Fibrosarcomas, peripheral nerve sheath tumors, and other fibrous neoplasms	1	0	0	1	2	2.0	4.2	0.0	0.0	4.7	2.3	2.3	0.004

IX.	IXc	Kaposi sarcoma	0	0	0	1	1	1.0	0.0	0.0	0.0	4.7	1.2	1.1	0.002
IX.	IXd	Other specified soft tissue sarcomas	0	0	1	1	2	2.0	0.0	0.0	4.9	4.7	2.3	2.2	0.005
IX.	IXe	Unspecified soft tissue sarcomas	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
X.		Germ cell tumors, trophoblastic tumors, and neoplasms of gonads	1	2	5	3	11	10.8	4.2	9.9	24.3	14.2	12.8	12.4	0.026
X.	Xa	Intracranial and intraspinal germ cell tumors	1	1	0	0	2	2.0	4.2	4.9	0.0	0.0	2.3	2.5	0.005
X.	Xb	Malignant extracranial and extragonadal germ cell tumors	0	0	0	1	1	1.0	0.0	0.0	0.0	4.7	1.2	1.1	0.002
X.	Xc	Malignant gonadal germ cell tumors	0	1	5	1	7	6.9	0.0	4.9	24.3	4.7	8.2	7.8	0.017
X.	Xd	Gonadal carcinomas	0	0	0	1	1	1.0	0.0	0.0	0.0	4.7	1.2	1.1	0.002
X.	Xe	Other and unspecified malignant gonadal tumors	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
XI.		Other malignant epithelial neoplasms and malignant melanomas	1	0	0	4	5	4.9	4.2	0.0	0.0	18.9	5.8	5.5	0.011
XI.	XIa	Adrenocortical carcinomas	1	0	0	0	1	1.0	4.2	0.0	0.0	0.0	1.2	1.3	0.002
XI.	XIb	Thyroid carcinomas	0	0	0	1	1	1.0	0.0	0.0	0.0	4.7	1.2	1.1	0.002
XI.	XIc	Nasopharyngeal carcinomas	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
XI.	XId	Malignant melanomas	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
XI.	XIe	Skin carcinomas	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
XI.	XIf	Other and unspecified carcinomas	0	0	0	3	3	2.9	0.0	0.0	0.0	14.2	3.5	3.2	0.007
XII.		Other and unspecified malignant neoplasms	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
XII.	XIIa	Other specified malignant tumors	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
XII.	XIIb	Other unspecified malignant tumors	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
		TOTAL	28	21	28	25	102	99.9	117.8	103.8	136.1	118.2	119.0	118.5	0.236

ANNEXURE 5: No of Cases, Percentage, Age Specific Rate (ASPR), Crude Incidence Rate (CIR), Age Standardised Rate (ASR), Cumulative Risk (0 – 19; C.R %) per million population: year 2022 – Both sexes

ICCC HEAD	ICCC3	ICCC3 DESCRIPTION	TOTAL NUMBER OF CASES				TOTAL	%	AGE SPECIFIC RATES (0-19)				RATES AGE : 0 - 19		
			0-4'	5-9'	10-14'	15-19			0-4'	5-9'	10-14'	15-19	C.I.R	A.S.R	CR%
I.		Leukemias, myeloproliferative diseases, and myelodysplastic diseases	33	26	35	15	109	45.2	66.6	62.0	82.5	34.7	61.5	61.9	0.122
I.	Ia	Lymphoid leukemias	30	18	30	9	87	36.1	60.5	42.9	70.7	20.8	49.1	49.5	0.097
I.	Ib	Acute myeloid leukemias	3	5	3	4	15	6.2	6.1	11.9	7.1	9.3	8.5	8.5	0.017
I.	Ic	Chronic myeloproliferative diseases	0	3	1	2	6	2.5	0.0	7.2	2.4	4.6	3.4	3.4	0.007
I.	Id	Myelodysplastic syndrome and other myeloproliferative diseases	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
I.	Ie	Unspecified and other specified leukemias	0	0	1	0	1	0.4	0.0	0.0	2.4	0.0	0.6	0.5	0.001
II.		Lymphomas and reticuloendothelial neoplasms	9	6	13	11	39	16.2	18.2	14.3	30.7	25.4	22.0	21.7	0.044
II.	IIa	Hodgkin lymphomas	2	2	9	8	21	8.7	4.0	4.8	21.2	18.5	11.9	11.3	0.024
II.	IIb	Non-Hodgkin lymphomas	4	0	0	3	7	2.9	8.1	0.0	0.0	6.9	4.0	4.0	0.008
II.	IIc	Burkitt lymphoma	0	0	2	0	2	0.8	0.0	0.0	4.7	0.0	1.1	1.1	0.002
II.	IId	Miscellaneous lymphoreticular neoplasms	3	4	2	0	9	3.7	6.1	9.5	4.7	0.0	5.1	5.3	0.010
II.	IIe	Unspecified lymphomas	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
III.		CNS and miscellaneous intracranial and intraspinal neoplasms	6	3	1	2	12	5.0	12.1	7.2	2.4	4.6	6.8	7.0	0.012
III.	IIIa	Ependymomas and choroid plexus tumor	0	1	0	0	1	0.4	0.0	2.4	0.0	0.0	0.6	0.6	0.001
III.	IIIb	Astrocytomas	4	0	0	2	6	2.5	8.1	0.0	0.0	4.6	3.4	3.5	0.006
III.	IIIc	Intracranial and intraspinal embryonal tumors	1	0	1	0	2	0.8	2.0	0.0	2.4	0.0	1.1	1.1	0.002
III.	IIId	Other gliomas	1	1	0	0	2	0.8	2.0	2.4	0.0	0.0	1.1	1.2	0.002
III.	IIIe	Other specified intracranial and intraspinal neoplasms	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
III.	IIIf	Unspecified intracranial and intraspinal neoplasms	0	1	0	0	1	0.4	0.0	2.4	0.0	0.0	0.6	0.6	0.001
IV.		Neuroblastoma and other peripheral nervous cell tumors	5	2	0	1	8	3.3	10.1	4.8	0.0	2.3	4.5	4.7	0.009
IV.	IVa	Neuroblastoma and ganglioneuroblastoma	5	2	0	1	8	3.3	10.1	4.8	0.0	2.3	4.5	4.7	0.009
IV.	IVb	Other peripheral nervous cell tumors	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
V.	V	Retinoblastoma	6	0	0	0	6	2.5	12.1	0.0	0.0	0.0	3.4	3.6	0.006
VI.		Renal tumors	4	1	0	0	5	2.1	8.1	2.4	0.0	0.0	2.8	3.0	0.005
VI.	VIa	Neuroblastoma and other peripheral nervous cell tumors	4	1	0	0	5	2.1	8.1	2.4	0.0	0.0	2.8	3.0	0.005
VI.	VIb	Renal carcinomas	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
VI.	VIc	Unspecified malignant renal tumors	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
VII.		Hepatic tumors	5	0	0	0	5	2.1	10.1	0.0	0.0	0.0	2.8	3.0	0.005
VII.	VIIa	Hepatoblastoma	5	0	0	0	5	2.1	10.1	0.0	0.0	0.0	2.8	3.0	0.005
VII.	VIIb	Hepatic carcinomas	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
VII.	VIIc	Unspecified malignant hepatic tumors	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
VIII.		Malignant bone tumors	0	3	9	1	13	5.4	0.0	7.2	21.2	2.3	7.3	7.1	0.015
VIII.	VIIIa	Osteosarcomas	0	1	7	0	8	3.3	0.0	2.4	16.5	0.0	4.5	4.3	0.009
VIII.	VIIIb	Chondrosarcomas	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
VIII.	VIIIc	Ewing tumor and related sarcomas of bone	0	2	2	1	5	2.1	0.0	4.8	4.7	2.3	2.8	2.8	0.006
VIII.	IIId	Other specified malignant bone tumors	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
VIII.	IIIe	Unspecified malignant bone tumors	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
IX.		Soft tissue and other extraosseous sarcomas	8	2	2	5	17	7.1	16.1	4.8	4.7	11.6	9.6	9.7	0.018
IX.	IXa	Rhabdomyosarcomas	6	1	0	0	7	2.9	12.1	2.4	0.0	0.0	4.0	4.2	0.007

IX.	IXb	Fibrosarcomas, peripheral nerve sheath tumors, and other fibrous neoplasms	1	0	0	2	3	1.2	2.0	0.0	0.0	4.6	1.7	1.6	0.003
IX.	IXc	Kaposi sarcoma	0	0	0	1	1	0.4	0.0	0.0	0.0	2.3	0.6	0.5	0.001
IX.	IXd	Other specified soft tissue sarcomas	1	1	2	2	6	2.5	2.0	2.4	4.7	4.6	3.4	3.3	0.007
IX.	IXe	Unspecified soft tissue sarcomas	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
X.		Germ cell tumors, trophoblastic tumors, and neoplasms of gonads	1	2	6	5	14	5.8	2.0	4.8	14.1	11.6	7.9	7.6	0.016
X.	Xa	Intracranial and intraspinal germ cell tumors	1	1	0	1	3	1.2	2.0	2.4	0.0	2.3	1.7	1.7	0.003
X.	Xb	Malignant extracranial and extragonadal germ cell tumors	0	0	0	1	1	0.4	0.0	0.0	0.0	2.3	0.6	0.5	0.001
X.	Xc	Malignant gonadal germ cell tumors	0	1	6	2	9	3.7	0.0	2.4	14.1	4.6	5.1	4.8	0.011
X.	Xd	Gonadal carcinomas	0	0	0	1	1	0.4	0.0	0.0	0.0	2.3	0.6	0.5	0.001
X.	Xe	Other and unspecified malignant gonadal tumors	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
XI.		Other malignant epithelial neoplasms and malignant melanomas	1	0	4	7	12	5.0	2.0	0.0	9.4	16.2	6.8	6.4	0.014
XI.	XIa	Adrenocortical carcinomas	1	0	0	0	1	0.4	2.0	0.0	0.0	0.0	0.6	0.6	0.001
XI.	XIb	Thyroid carcinomas	0	0	0	1	1	0.4	0.0	0.0	0.0	2.3	0.6	0.5	0.001
XI.	XIc	Nasopharyngeal carcinomas	0	0	2	1	3	1.2	0.0	0.0	4.7	2.3	1.7	1.6	0.004
XI.	XId	Malignant melanomas	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
XI.	XIe	Skin carcinomas	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
XI.	XIf	Other and unspecified carcinomas	0	0	2	5	7	2.9	0.0	0.0	4.7	11.6	4.0	3.7	0.008
XII.		Other and unspecified malignant neoplasms	1	0	0	0	1	0.4	2.0	0.0	0.0	0.0	0.6	0.6	0.001
XII.	XIIa	Other specified malignant tumors	1	0	0	0	1	0.4	2.0	0.0	0.0	0.0	0.6	0.6	0.001
XII.	XIIb	Other unspecified malignant tumors	0	0	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.000
		TOTAL	79	45	70	47	241	100.1	159.4	107.4	165.1	108.7	136.1	136.3	0.267

ANNEXURE 6: In-Depth Interviews with Collaborating Hospitals of PBCCR



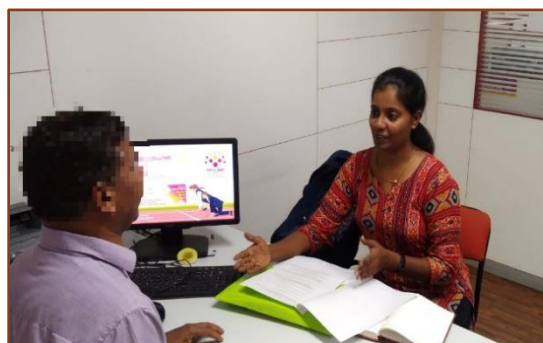
An IDI with Head Department of oncology in Government sector



An IDI with Data Manager in private Hospital



An IDI with an oncologist at a Non-Government Organization Hospital



An IDI with Medical Record Officer at a private Hospital.



An IDI with an oncologist in private Hospital



An IDI with a caregiver of a Pediatric cancer patient

APPENDIX

APPENDIX 1: Population-Based Childhood Cancer Registry Case Record Form

ESTABLISHING THE FIRST DEDICATED POPULATION-BASED CHILDHOOD CANCER REGISTRY (PBCCR) AND A NETWORK OF HOSPITAL-BASED CHILDHOOD CANCER REGISTRIES (HBCCRs) IN INDIA

DATA COLLECTION FORM		
Patient Number:.....		
A. Essential Information (NOTE: this form may be completed on admission to reporting hospital)		
SJCARES ID:[auto-generated] First Name: Last Name:		
Date of birth:/...../..... Gender: ☐ Male ☐ Female ☐ Other		
Are you attempting to report a second cancer in a patient who was previously registered? ☐ Yes ☐ No NOTE: If yes, these cases will now be linked in the Registry and a new SJCARES ID will be assigned for the second cancer. Do you confirm this is accurate? ☐ Yes ☐ No		
B. Demographics (NOTE: this form may be completed on admission to reporting hospital)		
National ID: Medical record number:		
Usual residence address: Address line 1: Address line 2:.....		
City: State/Province: Country:.....		
Race: (specify) or ☐ unknown ☐ Declined to respond ☐ notapplicable		
Ethnic group: (specify) or ☐ Unknown ☐ Declined to respond ☐ Not applicable		
Parent/Primary Caregiver name:		
Parent/Primary Caregiver Highest Education:		
☐ None	☐ 1-8 years (grade school)	☐ 9-12 years (high school/O-level), but did not graduate
☐ Completed high school/GED/A-levels	☐ Trainings after high school, other than college (vocational/community college)	☐ College graduate
☐ Post-graduate level	☐ Unknown	
Parent/Contact information: Best phone number: Best e-mail for contact:		
C. Diagnosis (NOTE: this form may be completed +3 months post admission)		
Date of initial onset of cancer-related symptoms:/...../.....		
Date of First Medical Assessment for cancer associated symptoms:/...../.....		
Does the patient have a confirmed cancer diagnosis? ☐ Yes ☐ No (NOTE: If "No", data collection for this patient ends here)		
Date of diagnosis:/...../.....		

Best method of diagnosis: (select the highest in the hierarchy if multiple diagnosis Methods were used.
(Lowest: Clinical exam, highest: Autopsy/Death certificate)

☐ Clinical examination
☐ Lab exams (including tumor markers)
☐ Imaging
☐ Exploratory surgery (without specimen/biopsy)
☐ Microscopic verification
☐ Autopsy/Death certificate

ICD-O-3 Topography/site:

ICD-O-3 Morphology: Type and Behavior code:

NOTE: ICCC3 Extended classification code-(automatically generated in the system based on ICD-O-3)

Laterality of primary site:

- ☐ Not paired to a site ☐ Right: origin of primary ☐ Left: origin of primary
☐ Only one side involved, right or left origin unspecified ☐ Bilateral involvement at time of diagnosis
☐ Paired SITE, midline tumor ☐ Paired SITE, but no information concerning laterality

HIV status: ☐ HIV positive ☐ HIV negative ☐ HIV status not addressed or unknown if assessed

Referral source:

If Reporting hospital:	If Outside Hospital/Clinic
	Select referral source: <u>Select <i>only one</i></u> ☐ Pathology/Diagnostic lab ☐ Radiation Therapy Dept/Center ☐ General Surgery ☐ Neuro-Surgery ☐ Orthopedics ☐ Diagnostic Imaging/Radiology ☐ Family physician/pediatrician ☐ Other (specify).....
Select the class of case:	Select the class of case:
☐ New case to center without diagnosis and without treatment ☐ New case to center with diagnosis but without treatment ☐ New case to center with diagnosis and non-chemotherapy treatment ☐ New case to center with diagnosis and chemotherapy treatment elsewhere ☐ New relapse or refractory/disease case to center	☐ New case to center without diagnosis and without treatment ☐ New case to center with diagnosis but without treatment ☐ New case to center with diagnosis and non-chemotherapy treatment ☐ New case to center with diagnosis and chemotherapy treatment elsewhere ☐ New relapse or refractory/disease case to center

If Yes to "Outside Hospital/Clinic" → provide the details on the Place of Diagnosis:

Name of Outside Hospital Clinic:.....

Country: City: State/Province:.....

Address line1: Address line 2:.....

D. Staging

(NOTE: this form may be completed +3 months post admission)

Diagnosis:

Diagnosis: Lymphoid leukemia (Ia)a

Is there central nervous system involvement?

☐ No ☐ Yes ☐ Unknown☐ CNS1 ☐ CNS2 ☐ CNS3 ☐ UnknownWhat is the patient's peripheral white blood cell count (as measured by patient's peripheral blood sample) at diagnosis? _____ (μL) ☐ Not reported**Diagnosis: Acute myeloid leukemia (Ib)**

Is there central nervous system involvement?

☐ No ☐ Yes ☐ Unknown**Diagnosis: Hodgkin lymphoma (IIa)***Ann Arbor*

Stage

☐ Stage I ☐ Stage II ☐ Stage III ☐ Stage IV ☐ Unknown

Designation

☐ A ☐ B ☐ E ☐ S ☐ Unknown**Diagnosis: Non-Hodgkin Lymphoma (IIb), Burkitt (IIc), Lymphoreticular (IIId)**Localized ☐ Advanced ☐ Unknown*St Jude Murphy*☐ Stage I ☐ Stage II ☐ Stage III ☐ Stage IV**Diagnosis: Ependymoma (IIIa), CNS embryonal (IIIc)**☐ Localized ☐ Metastatic ☐ Unknown☐ M0 ☐ M1 ☐ M2 ☐ M3 ☐ Unknown**Diagnosis: Astrocytoma (IIIb), Other gliomas (IIId), Other specified (IIIe), and Unspecified (III f) CNS neoplasms**☐ Localized ☐ Metastatic ☐ Unknown☐ M0 ☐ M+ ☐ Unknown**Diagnosis: Neuroblastoma (IVa and IVb)**☐ Localized ☐ Locoregional ☐ Metastatic ☐ MS Disease ☐ Unknown*International Neuroblastoma Risk Group Staging System*☐ L1 ☐ L2 ☐ M ☐ MS ☐ Unknown

Diagnosis: Retinoblastoma (V)
☐ Intraocular ☐ Orbital/Regional Lymph Nodes ☐ Extraorbital ☐ Unknown
International Retinoblastoma Staging System
☐ Stage 0 ☐ Stage I ☐ Stage II ☐ Stage III ☐ Stage IV ☐ Unknown
International Classification for Intraocular Retinoblastoma
☐ Group A ☐ Group B ☐ Group C ☐ Group D ☐ Group E ☐ Unknown
Diagnosis: Nephroblastoma (VIa)
☐ Localized ☐ Metastatic ☐ Unknown
*Children's Oncology Group/National**Wilms Tumor Study Group*
☐ Stage 0 ☐ Stage I ☐ Stage II ☐ Stage III ☐ Stage IV ☐ Unknown
International Society of Pediatric Oncology
☐ Stage y-I ☐ Stage y-II ☐ Stage y-III ☐ Stage y-IV ☐ Unknown
Diagnosis: Renal carcinomas (VIb)
☐ Localized ☐ Metastatic ☐ Unknown
Diagnosis: Hepatoblastoma (VIIa)
☐ Localized ☐ Metastatic ☐ Unknown
PRETEXT
☐ Stage 0 ☐ Stage I ☐ Stage II ☐ Stage III ☐ Stage IV ☐ Unknown
Diagnosis: Hepatic carcinomas (VIIb)
☐ Localized ☐ Metastatic ☐ Unknown
Diagnosis: Osteosarcoma (VIIIa), Ewing, pPNET, & related (VIIIc) bone tumors
☐ Localized ☐ Metastatic ☐ Unknown
TNM

☐ Stage I	☐ Stage Ia	☐ Stage Ib
☐ Stage II	☐ Stage IIa	☐ Stage IIb
☐ Stage III		
☐ Stage IV	☐ Stage Iva	☐ Stage IVb
☐ Unknown		

Diagnosis: Chondrosarcoma (VIIIb), Other specified (VIIId), and Unspecified (VIIIe) bone tumors
☐ Localized ☐ Metastatic ☐ Unknown
Diagnosis: Soft tissue sarcomas (IXa-IXe)
☐ Localized ☐ Metastatic ☐ Unknown
TNM

☐ Stage I	☐ Stage Ia	☐ Stage Ib
☐ Stage II	☐ Stage IIa	☐ Stage IIb
☐ Stage III		
☐ Stage IV	☐ Unknown	

Diagnosis: CNS germ cell (Xa), Other extragonadal (Xb), and Unspecified gonadal (Xe) germ cell tumors
☐ Localized ☐ Metastatic ☐ Unknown
TNM-testicular
☐ Stage I ☐ Stage II ☐ Stage III ☐ Unknown
Diagnosis: Gonadal germ cell (Xc) and Gonadal carcinoma (Xd)
☐ Localized ☐ Metastatic ☐ Unknown
FIGO-ovarian
☐ Stage I ☐ Stage II ☐ Stage III ☐ Stage IV ☐ Unknown
Diagnosis: Carcinomas and Melanomas
☐ Localized ☐ Metastatic ☐ Unknown

NOTE: The data fields in the Staging form may appear different than shown on this form. The Staging fields are automatically generated by the system based on the Topography and Morphology data provided on the diagnosis form.

E. Treatment

(NOTE: this form may be completed +6 months post admission)

Date of Referral to Treatment institution:/...../.....

Date curative treatment started:/...../.....

Treatment with curative intent given ENTIRELY at your site? ☐ Yes ☐ No ☐ Unknown

If "YES", to curative treatment given:

NOTE: if answer is "No" or "Unknown" for question about *curative intent* leave this table blank

Date curative treatment started:/...../.....	Is the patient being treated on a therapeutic protocol? ☐ Yes ☐ No If "Yes", Protocol ID:.....
<i>Treatments administered since diagnosis:</i>	
Did the patient receive chemotherapy? ☐ Yes ☐ No If "Yes", select all Chemotherapies administered, ☐ Carboplatin ☐ Cisplatin ☐ Cyclophosphamide ☐ Daunorubicin ☐ Dinutuximab (Anti-GD2 Ab) ☐ Doxorubicin ☐ G-CSF (or Filgrastim) ☐ Topotecan ☐ Tretinoin (ATRA) ☐ Allopurinol ☐ Asparaginase ☐ Bleomycin ☐ Cytarabine ☐ Dacarbazine ☐ Dactinomycin ☐ Etoposid ☐ Ifosfamide ☐ Imatinib (or other TKI) ☐ Leucovorine ☐ Mercaptopurine ☐ Mesna ☐ Methotrexate ☐ Paxlitaxel ☐ Steroids ☐ Thioguanine ☐ Vinblastine ☐ Vincristine ☐ Other:	
Did the patient receive radiation? ☐ Yes ☐ No If "Yes", select all the external beam radiation treatments administered, ☐ Head ☐ Neck ☐ Chest ☐ Abdomen ☐ Pelvis ☐ Extremity ☐ Spine ☐ Other	
Has the patient had cancer tumor directed surgery? ☐ Yes ☐ No If "Yes", select all the surgery treatments administered, ☐ Gross-total resection plus removal of adjacent structures ☐ Gross-total resection but limited to a single topographical location ☐ Sub-total resection	
Has the patient had a hematopoietic stem cell transplant? ☐ Yes ☐ No If "Yes", select all the treatments administered, ☐ Autologous stem cells ☐ Matched related stem cells ☐ Matched unrelated stem cells ☐ Unmatched related stem cells	

If "NO" to curative treatment given:

NOTE: if answer is "YES" for question about *curative intent* leave this table blank

<i>Reasons treatment not given (select only one)</i>	
☐ Curative treatment planned	☐ Patient treated PARTIALLY at another Center
☐ Active surveillance (watchful waiting)	☐ Patient treated for palliative purposes as curative treatment feasible
☐ Definitive control or cure of disease not a feasible goal	☐ Death
☐ Failed to start treatment to accomplish cure or definitive control	☐ Not Specified
☐ Patient treated ENTIRELY at another center	☐ Patient Refused any treatment (including palliation)

<i>If treated ENTIRELY at another site:</i>	<i>If treated PARTIALLY at another site:</i>
Center name:	Center name:
Country:	Country:
Address line 1:	Address line 1:
Address line 2:	Address line 2:
City: State/Province:	City: State/Province:

<i>If palliative treatment given: Type of palliative therapies delivered?</i>
NOTE: Questions below will only appear when selecting "Patient treated for palliative purposes as curative treatment feasible"
☐ Palliative anti-cancer therapies given (without curative intent) ☐ Symptom management only (watchful waiting) ☐ Unknown type of palliative treatment given
Types of palliative treatments administered: Did the patient receive chemotherapy? ☐ Yes ☐ No (Specify type of chemotherapies) Did the patient receive radiation? ☐ Yes ☐ No (Specify location of radiation) Did the patient had cancer tumor directed surgery? ☐ Yes ☐ No (Specify type of resection) Has the patient had any pain/symptom management specific treatment? ☐ Yes ☐ No If "Yes" to pain/symptom management specify treatments: ☐ Opiates ☐ Psychiatric medications (i.e. antipsychotics, antidepressants, etc.) ☐ Traditional medicines ☐ Homeopathic/alternative therapies (acupuncture, massage therapy) ☐ Psychological interventions

<i>Retinoblastoma specific Treatment options. Select all that apply</i>	
NOTE: Only applies if confirmed cancer diagnosis is Retinoblastoma	
☐ Laser	☐ Brachytherapy
☐ Cryotherapy	☐ Intra-arterial
☐ Intraocular/Local Chemotherapy	

F. Follow Up

NOTE: This form must be completed 1 year post admission and yearly thereafter for a period of 5 years unless there is a reported patient death, lost of follow up or patient gets transferred to another treatment institution.

Has the patient achieved remission (no evidence of disease) since diagnosis? ☐ Yes ☐ No

NOTE: Answer the table below **ONLY** if "Yes" to the previous question

If "Yes" to remission:

1. Date of remission:/...../.....
2. Has the patient had a relapse/recurrence since remission? ☐ Yes ☐ No

If "Yes" to relapse:

1. Date of relapse:/...../.....
2. Has the patient achieved remission since relapse/recurrence? ☐ Yes ☐ No

If "Yes" to achieved remission since relapse:

1. Date of remission since relapse:/...../.....
2. Has the patient had a relapse/recurrence since remission? ☐ Yes ☐ No

If "Yes" to relapse since remission:

1. Date of relapse since remission:/...../.....

Has the patient received cancer-directed treatment ENTIRELY AT YOUR SITE since the last data entry? ☐ Yes ☐ No ☐ Unknown

If "Yes" to cancer-directed treatment ENTIRELY at site:

NOTE: if answer is "No" or "Unknown" for question about *cancer-directed treatment*, leave this table blank

Curative treatment given? ☐ Yes ☐ No	Palliative treatment given? ☐ Yes ☐ No
If "Yes"	If "Yes", specify treatment given
Did the patient receive chemotherapy? ☐ Yes ☐ No If "Yes", select all Chemotherapies administered, ☐ Carboplatin ☐ Cisplatin ☐ Cyclophosphamide ☐ Daunorubicin ☐ Dinutuximab (Anti-GD2 Ab) ☐ Doxorubicin ☐ G-CSF (or Filgrastim) ☐ Topotecan ☐ Tretinoin (ATRA) ☐ Allopurinol ☐ Asparaginase ☐ Bleomycin ☐ Cytarabine ☐ Dacarbazine ☐ Dactinomycin ☐ Etoposide ☐ Ifosfamide ☐ Imatinib (or other TKI) ☐ Leucovorine ☐ Mercaptopurine ☐ Mesna ☐ Methotrexate ☐ Paxlitaxel ☐ Steroids ☐ Thioguanine ☐ Vinblastine ☐ Vincristine ☐ Other:	Type of palliative therapies delivered: ☐ Palliative anti-cancer therapies given (without curative intent) ☐ Symptom management only (watchful waiting) ☐ Unknown type of palliative treatment given

Did the patient receive radiation? ☐Yes ☐No If "Yes", select all the external beam radiation treatments administered, ☐ Head ☐ Neck ☐ Chest ☐ Abdomen ☐ Pelvis ☐ Extremity ☐ Spine ☐ Other	Types of palliative treatments administered: Did the patient receive chemotherapy? ☐Yes ☐No List all chemotherapies: Did the patient receive radiation? ☐Yes ☐No Specify location of radiation: Did the patient had cancer tumor directed surgery? ☐Yes ☐No Specify type of resection: Has the patient had any pain/symptom management specific treatment? ☐Yes ☐No
Has the patient had cancer tumor directed surgery? ☐Yes ☐No If "Yes", select all the surgery treatments administered, ☐ Gross-total resection plus removal of adjacent structures ☐ Gross-total resection but limited to a single topographical location ☐ Sub-total resection	If "Yes" to pain/symptom management specify treatments: ☐ Opiates ☐ Psychiatric medications (i.e. antipsychotics, antidepressants, etc.) ☐ Traditional medicines ☐ Homeopathic/alternative therapies (acupuncture, massage therapy) ☐ Psychological interventions
Has the patient had a hematopoietic stem cell transplant? ☐Yes ☐No If "Yes", select all the treatments administered, ☐ Autologous stem cells ☐ Matched related stem cells ☐ Matched unrelated stem cells ☐ Unmatched related stem cells	

If “NO” to cancer-directed treatment ENTIRELY at site:

NOTE: if answer is “YES” for question about cancer-directed treatment, leave this table blank

Curative treatment not given at follow up, reason:	
☐ Treatment planned	☐ Active surveillance (watchful waiting)
☐ Definitive control or cure of disease not a feasible goal	☐ Missed at least 4 weeks of curative therapy to extent that might impact ability to control disease (treatment abandonment)
☐ Patient treated ENTIRELY at another center	☐ Patient treated PARTIALLY at another center
☐ Patient treated for palliative purposes as curative treatment not feasible	☐ Death
☐ Patient in remission without relapse	☐ Patient refused any treatment (including palliation)
☐ Not specified	

<i>If treated ENTIRELY at another site:</i>	<i>If treated PARTIALLY at another site:</i>
Center name:	Center name:
Country:	Country:
Address line 1:	Address line 1:
Address line 2:	Address line 2:
City: State/Province:	City: State/Province:

If palliative treatment given: Type of palliative therapies delivered?

NOTE: Questions below will only appear when selecting “Patient treated for palliative purposes as curative treatment feasible”

☐ Palliative anti-cancer therapies given (without curative intent)

☐ Symptom management only (watchful waiting)

☐ Unknown type of palliative treatment given

Types of palliative treatments administered:

Did the patient receive chemotherapy? ☐ Yes ☐ No (Specify type of chemotherapies)

Did the patient receive radiation? ☐ Yes ☐ No (Specify location of radiation)

Did the patient had cancer tumor directed surgery? ☐ Yes ☐ No (Specify type of resection)

Has the patient had any pain/symptom management specific treatment?

☐ Yes ☐ No

If “Yes” to pain/symptom management specify treatments:

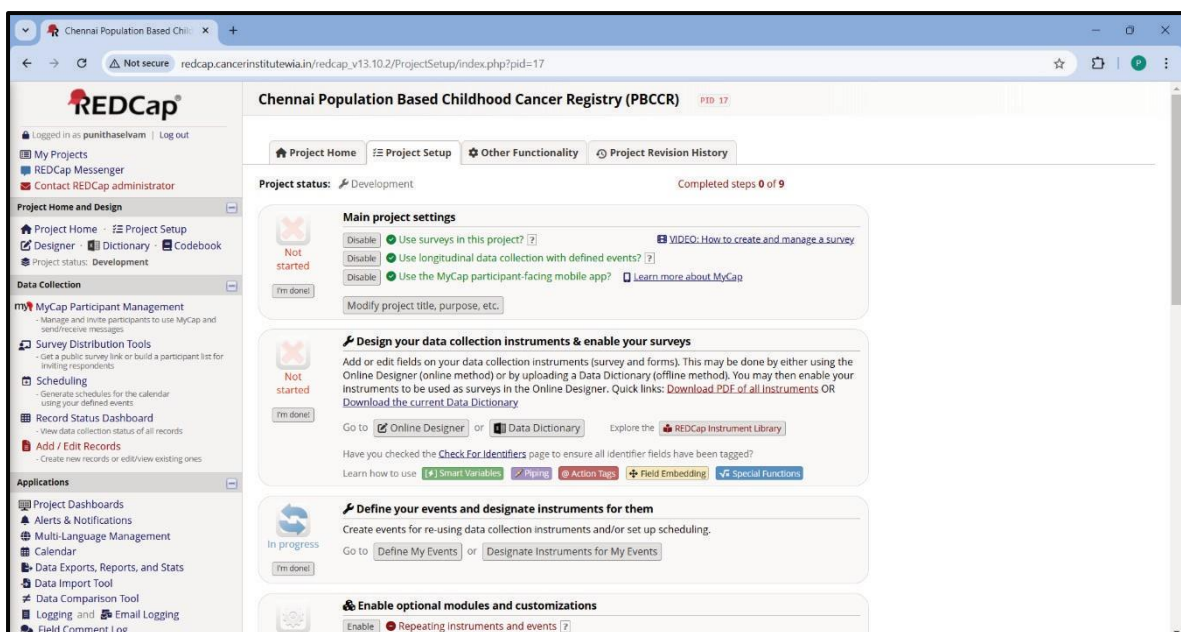
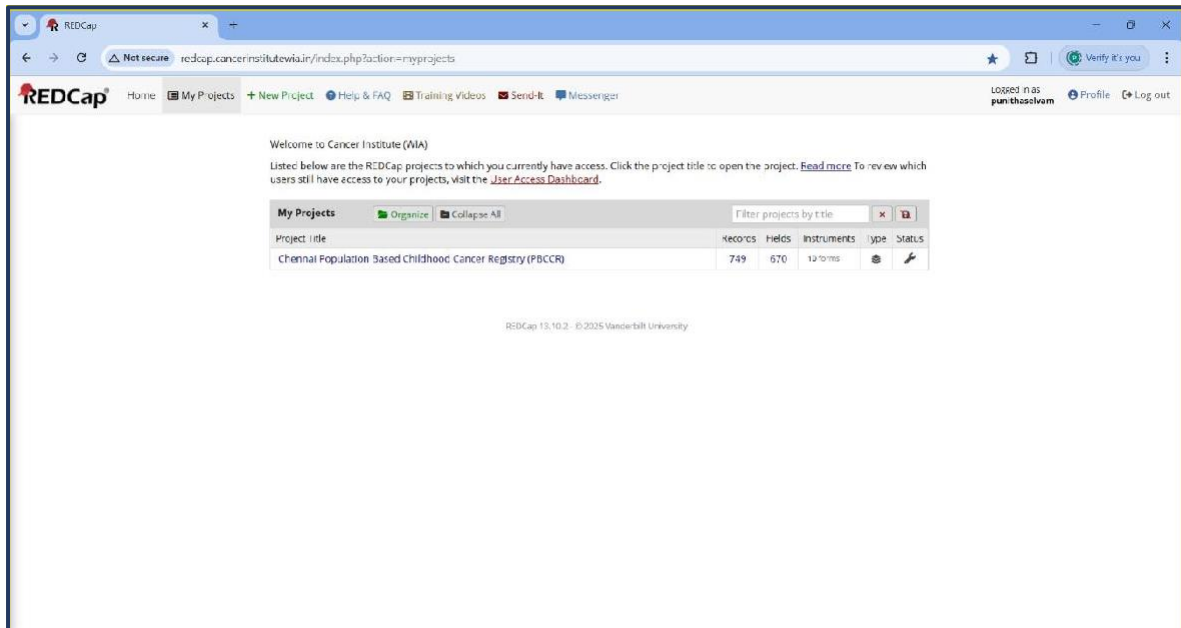
☐ Opiates ☐ Psychiatric medications (i.e. antipsychotics, antidepressants, etc.)

☐ Traditional medicines ☐ Homeopathic/alternative therapies (acupuncture, massage therapy)

☐ Psychological interventions

Vital status:		
Last known vital status? ☐ Alive ☐ Dead ☐ Unknown ☐ Not seen since last follow-up		
If Alive →	Date of last follow-up:/...../.....	
Source/method of contact: ☐ Medical Record ☐ Phone call ☐ E-mail ☐ Fax ☐ Outside clinician ☐ Death certificate ☐ Other:		
If Dead →	Date of death:/...../.....	
Source of vital status: ☐ Medical Record ☐ Phone call ☐ E-mail ☐ Fax ☐ Outside clinician ☐ Death certificate ☐ Other:		
Primary cause of death:		
Secondary cause of death:		
Tertiary cause of death:		
Quaternary cause of death:		
Place of death→	Country:	Location: ☐ Home ☐ Hospital ☐ Hospice ☐ Other ☐ Unknown
Does the patient information need to be updated? ☐ Yes ☐ No		
If "Yes", update the information below:		
Address: Phone: Email:		

Appendix 2: Redcap Software



Chennai Population Based Childhood Cancer Registry (PBCCR) PID 17

Add / Edit Records

You may view an existing record/response by selecting it from the drop-down lists below. To create a new record/response, click the button below.

NOTICE: This project is currently in Development status. Real data should NOT be entered until the project has been moved to Production status.

Total records: 749

Choose an existing PBCCR ID:

Data Search

Choose a field to search: (excludes multiple choice fields)

Search query:

Begin typing to search the project data, then click an item in the list to navigate to that record.

Chennai Population Based Childhood Cancer Registry (PBCCR) PID 17

Record Home Page

Record "750" is a new PBCCR ID. To create the record and begin entering data for it, click any gray status icon below.

The grid below displays the form-by-form progress of data entered for the currently selected record. You may click on the colored status icons to access that form/event. If you wish, you may modify the events below by navigating to the [Define My Events](#) page.

Legend for status icons:

- Incomplete (red circle with exclamation mark)
- Incomplete (no data saved) (gray circle with exclamation mark)
- Unverified (yellow circle with exclamation mark)
- Partial Survey Response (orange circle with exclamation mark)
- Complete (green circle with checkmark)
- Completed Survey Response (green circle with checkmark)

NEW PBCCR ID 750

Data Collection Instrument	Demographics	Diagnosis	Treatment	Year 1 follow up	Year 2 follow up	Year 3 follow up	Year 4 follow up	Year 5 follow up
Essential Information								
Demographics								
Diagnosis								
Stage								
Treatment								
Initial Followup								
Followup 2								
Followup 3								
Followup 4								
Followup 5								

■ = Mandatory; ■ = Recommended; ■ = Optional.

Population Based Cancer Registries

Core Form - Incidence Data

8. PLACE OF RESIDENCE:

Place of Usual Residence (where the person has been residing for the past one year (at least))

Urban Areas (Town / Cities)

House No.

Road / Street Name

Area / Locality

Ward / Corporation / Division

Name of City / Town

Name of District * (In Capitals)

* Not applicable for solely urban PBCRs

Postal Pin Code

Telephone No(s): Off. Res.

Mobile Email ID

9. DURATION OF STAY (at the place of usual residence (in years))

10. OTHER ADDRESSES:

10.1 LOCAL ADDRESS

.....

.....

Name of City/Town/District.....

Pin Code

10.2 SECOND (Office / Caretaker / Family Doctor) ADDRESS

.....

.....

Name of City/Town/District.....

Pin Code 12. AGE (in years)

13. AGE ESTIMATED BY

(1) Patient

(2) Person Accompanying Patient

(3) Social Investigator

(8) Others (specify)

(9) Unknown

14. SEX

(1) Male

(2) Female

(8) Others

Non-urban / Rural Areas

House No. and Ward

Name of Gram Panchayat / Village, etc:

Name of Sub-Unit of District (Taluk / Tehsil / Other):

Name of PHC / Sub Centre

10.3 NATIVE PLACE ADDRESS

.....

.....

Name of City/Town/District.....

Pin Code

11. PLACE OF BIRTH

.....

.....

Name of City/Town/District.....

Pin Code DATE OF BIRTH

dd mm yy

■ = Mandatory; ■ = Recommended; ■ = Optional.

2

II BASIC DEMOGRAPHIC PARAMETERS

15. **MARITAL STATUS**
 (1) Unmarried (2) Married (3) Widowed (4) Divorced
 (5) Separated (8) Others (specify)..... (9) Unknown
16. **MOTHER TONGUE**
 (01) Assamese (02) Bengali (03) Gujarathi (04) Hindi (05) Kannada (06) Kashmiri (07) Malayalam
 (08) Marathi (09) Oriya (10) Punjabi (11) Sanskrit (12) Sindhi (13) Tamil (14) Telugu
 (15) Urdu (16) English (17) Konkani (18) Bhutia (19) Manipuri (20) Mizo (21) Nepali
 (22) Lepcha (23) Rajasthani (88) Others (specify)..... (99) Unknown
17. **RELIGION**
 (1) Hindu (2) Muslim (3) Christian (4) Sikh (5) Jain (6) Neo-Budhist (7) Parsi
 (8) Indigenous Faith / Others (specify)..... (9) Unknown
18. **CULTURAL GROUP / BACKGROUND*** (Refer Procedure Manual for Codes)
 * Only for North East PBCRs.
19. **EDUCATION**
 (0) Not applicable (for children below 5 years) (1) Illiterate (2) Literate (3) Primary
 (4) Middle (5) Secondary (6) Technical-after matric (7) College and above
 (8) Others (specify)..... (9) Unknown

III DIAGNOSTIC DETAILS

20. **DIAGNOSTIC STATUS AT REGISTRATION AT SOURCE OF REGISTRATION / REPORTING INSTITUTION (RI)**
 (0) Not Registered at RI (1) Microscopically Confirmed
 (2) Suspected (Microscopically/Radiologically) (3) Unequivocal Clinical Diagnosis
 (4) Suspected Clinically/To rule out Malignancy (8) Others (specify).....
 (9) Unknown
21. **METHOD OF DIAGNOSIS**
 (1) Clinical Only (2) Microscopic (3) X-Ray / Imaging Techniques (4) DCO (8) Others (9) Unknown
- Microscopic (if 2 above)** **X-Ray / Imaging Techniques (if 3 above)** **Others (if 8 above)**
 (1) Histology of Primary (1) X-Ray (1) Endoscopy
 (2) Histology of Metastasis (2) Isotopes (2) Surgery or Autopsy without Histology
 (3) Autopsy with Histology (3) Angiography (3) Specific Biochemical and / or Immunological Tests
 (4) Bone Marrow (4) Ultrasonogram (8) Others (Specify).....
 (5) Blood Film (8) All Others (Specify).....
 (6) Cytology of Primary
 (7) Cytology of Metastasis
22. **ANATOMICAL SITE OF SPECIMEN / BIOPSY / SMEAR**.....
23. **COMPLETE PATHOLOGICAL DIAGNOSIS: (With Complete Description of Primary Site of Tumour and Morphological Diagnosis)**
- 23.1 **PRIMARY SITE OF TUMOUR - TOPOGRAPHY**.....
- 23.2 **MORPHOLOGY**.....
- 23.3 **PATHOLOGY SLIDE NO.** **DATE**
 dd mm yy
24. **CODING ACCORDING TO ICD-O-3:**
- 24.1 **PRIMARY SITE OF TUMOUR - TOPOGRAPHY** **C**
 (Include sub-site if any)
- 24.2 **PRIMARY HISTOLOGY - MORPHOLOGY** **M**
 If morphology is that of metastasis mention Primary Site above and
- 24.3 **SECONDARY SITE OF TUMOUR** **C**
- 24.4 **MORPHOLOGY OF METASTASIS** **M**
 If the morphology diagnosis is only that of metastatic site, mention the Primary Site as decided by the treating clinician either through discussion or from case record

■ = Mandatory; ■ = Recommended; ■ = Optional.

II BASIC DEMOGRAPHIC PARAMETERS**15. MARITAL STATUS**

- (1) Unmarried (2) Married (3) Widowed (4) Divorced
(5) Separated (8) Others (specify)..... (9) Unknown

☐**16. MOTHER TONGUE**

- (01) Assamese (02) Bengali (03) Gujarathi (04) Hindi (05) Kannada (06) Kashmiri (07) Malayalam
(08) Marathi (09) Oriya (10) Punjabi (11) Sanskrit (12) Sindhi (13) Tamil (14) Telugu
(15) Urdu (16) English (17) Konkani (18) Bhutia (19) Manipuri (20) Mizo (21) Nepali
(22) Lepcha (23) Rajasthani (88) Others (specify)..... (99) Unknown

☐**17. RELIGION**

- (1) Hindu (2) Muslim (3) Christian (4) Sikh (5) Jain (6) Neo-Budhist (7) Parsi
(8) Indigenous Faith / Others (specify)..... (9) Unknown

☐**18. CULTURAL GROUP / BACKGROUND* (Refer Procedure Manual for Codes)**☐

* Only for North East PBCRs.

19. EDUCATION

- (0) Not applicable (for children below 5 years) (1) Illiterate (2) Literate (3) Primary
(4) Middle (5) Secondary (6) Technical-after matric (7) College and above
(8) Others (specify)..... (9) Unknown

☐**III DIAGNOSTIC DETAILS****20. DIAGNOSTIC STATUS AT REGISTRATION AT SOURCE OF REGISTRATION / REPORTING INSTITUTION (RI)**

- (0) Not Registered at RI (1) Microscopically Confirmed
(2) Suspected (Microscopically/Radiologically) (3) Unequivocal Clinical Diagnosis
(4) Suspected Clinically/To rule out Malignancy (8) Others (specify).....
(9) Unknown

☐**21. METHOD OF DIAGNOSIS**

- (1) Clinical Only (2) Microscopic (3) X-Ray / Imaging Techniques (4) DCO (8) Others (9) Unknown

☐**Microscopic (if 2 above)**

- (1) Histology of Primary
(2) Histology of Metastasis
(3) Autopsy with Histology
(4) Bone Marrow
(5) Blood Film
(6) Cytology of Primary
(7) Cytology of Metastasis

X-Ray / Imaging Techniques (if 3 above)

- (1) X-Ray
(2) Isotopes
(3) Angiography
(4) Ultrasonogram
(8) All Others (Specify).....

Others (if 8 above)

- (1) Endoscopy
(2) Surgery or Autopsy without Histology
(3) Specific Biochemical and / or Immunological Tests
(8) Others (Specify).....

☐**22. ANATOMICAL SITE OF SPECIMEN / BIOPSY / SMEAR.....****23. COMPLETE PATHOLOGICAL DIAGNOSIS: (With Complete Description of Primary Site of Tumour and Morphological Diagnosis)****23.1 PRIMARY SITE OF TUMOUR - TOPOGRAPHY.....****23.2 MORPHOLOGY.....****23.3 PATHOLOGY SLIDE No. DATE**

dd mm yy

24. CODING ACCORDING TO ICD-O-3:**24.1 PRIMARY SITE OF TUMOUR - TOPOGRAPHY..... C**

(Include sub-site if any)

24.2 PRIMARY HISTOLOGY - MORPHOLOGY..... M

If morphology is that of metastasis mention Primary Site above and

24.3 SECONDARY SITE OF TUMOUR..... C **24.4 MORPHOLOGY OF METASTASIS..... M**

If the morphology diagnosis is only that of metastatic site, mention the Primary Site as decided by the treating clinician either through discussion or from case record

■ = Mandatory; ■ = Recommended; ■ = Optional.

References

1. District Profile- Chennai District - India. (<https://chennai.nic.in/about-district/district-profile/>)
2. Government of Tamil Nadu – Tamil Nadu Government portal (https://www.tn.gov.in/district_details/535)
3. Statistical Hand Book of Tamil Nadu-2021-22, Area and Population (<https://www.tn.gov.in/deptst/areaandpopulation.pdf>)
4. IARC, Data visualization tools for exploring the global cancer burden in 2022 (<https://gco.iarc.fr/today/en/dataviz/tables?mode=population>)
5. National Cancer Registry Program, 2012-2016
6. National Cancer Registry Program, 1997-1998

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