5. Summary

The situational analysis was conducted using a cross-sectional survey design. The participants included 137 tertiary level hospitals, 92 secondary level hospitals, 16 State Nodal Officers/NPCDCS officers, and nine civil society organizations/non-governmental organizations (CSOs/NGOs) in 26 states and four union territories (UT). The key study findings are as follows:

(a) Availability of childhood cancer care services

- Childhood cancer care services were provided at over one-third (39.1%) of the Secondary level hospitals, which was higher for private (56.5%) than public (32.8%) hospitals.
- A dedicated paediatric oncology department was available in less than half of the public and private tertiary hospitals.
- In secondary-level public hospitals, treatment for childhood cancers was mainly provided through the pediatric medicine departments.
- There was a shortage of hospice care services at tertiary hospitals and medical social services at secondary hospitals
- Over three quarters (76.6%) of the public tertiary hospitals adopted a multidisciplinary team approach for childhood cancer treatment, compared to 35% of the private hospitals.
- The most frequently employed mechanism for following up with childhood cancer patients (in between hospital visits) was through telephonic follow-up.

(b) Referral linkages

- Over two-thirds of government tertiary hospitals had referral linkages with lower-tier non-childhood cancer-treating facilities, versus 45.7% of private hospitals
- Written mode of referring patients was the most frequently employed patient referral mechanism
- Less than a tenth of the government tertiary hospitals and a little over one-third of the private hospitals had formal agreements for a referral.
- 74.4% of public and 60% of private secondary level hospitals had referral linkages with tertiary cancer treating hospitals.
- Referral linkages with primary health facilities were present for 60.9% of the public and 52.1% of private secondary-level health facilities.

(c) Availability of diagnostic services

- Over 90% of the tertiary hospitals had facilities for histopathology; however, a lower proportion of public tertiary hospitals had facilities for immunohistochemistry, flowcytometric immunophenotyping, cytogenetics, and tumour markers and fluorescence in situ hybridization (FISH).
- Availability of bone and PET scans was lower, especially in public tertiary hospitals.
- Among secondary level hospitals, a higher proportion of private hospitals reported the availability of laboratory and radiologic investigations.

(d) Availability of cancer treatment procedures

- Less than a quarter (20.8%) of the public tertiary hospitals had facilities for Haemopoietic Stem Cell Transplantation (HSCT) compared to half of the private tertiary hospitals (54.3%)
- The proportion of public sector hospitals that provided bone marrow biopsy, drug infusion chemotherapy, intrathecal chemotherapy, immunotherapy and brachytherapy was less than two-thirds of the hospitals
- The proportion of hospitals providing focal therapy was deficient, public (20.8%) and private (31.4%).
- The majority of the hospitals had treatment protocols for the management of chemotherapy, febrile neutropenia and central venous access devices.

(e) Availability of human resources

- At public tertiary hospitals, less than half of the hospitals had a pediatric oncologist (48%), pediatric oncosurgeon (14.2%), pediatric intensivist (38.9%), and medical oncologist (46.7%), and palliative care physician (37.6%).
- About a quarter of the public tertiary hospitals not having regular oncology specialists made arrangements for specialized consultations
- Nurses trained in pediatric cancer and palliative care were available in less than 50% of the public and private tertiary hospitals.
- Dieticians were available in 52.4% of the secondary hospitals, while 42.9% of these hospitals had a social worker.

(f) Physical infrastructure, availability of medications and financing of treatment

- A separate neutropenic room, brachytherapy treatment planning room, biosafety units for chemotherapeutic drugs, separate chemotherapy mixing room and daycare beds were available in less than half of the public sector tertiary hospitals
- A higher proportion of private hospitals had the relevant physical infrastructure relevant for managing childhood cancer care services
- Less than 50% of the public tertiary hospitals had stocks of all four classes of cancer-treating drugs. The availability of targeted therapies was the lowest.
- The proportion of private and NGO tertiary hospitals having available stocks of cancer-treating drugs was higher than public sector hospitals
- Private pharmacies constituted the major source of procuring drugs in case of non-availability.
- Less than 40% of the public sector tertiary hospitals provided all classes of cancer-treating drugs.
- Drugs including Cyclophosphamide, Methotrexate, Mercaptopurine and Vincristine were available in less than a third of the public tertiary level hospitals.
- The most commonly adopted financing mechanism comprised the Ayushman Bharat Scheme at public tertiary and secondary level public hospitals and ESI/State specific schemes at private tertiary hospitals.

(g) Training programmes, research, record maintenance and IEC activities

- The proportion of hospitals offering degree and training programmes in pediatric oncology for medics and paramedics was less than 10%
- A higher proportion of private facilities provided such kinds of training programmes
- Over half of the tertiary level hospitals had IEC (information, education and communication) material -pamphlets/posters on childhood cancer in waiting areas and organized public talks/seminars by experts.
- The health care providers in less than one-third of the public and private secondary hospitals had received training for early diagnosis of childhood cancer
- None of the tertiary level hospitals conducted retinoblastoma screenings in siblings of retinoblastoma patients. At the same time, this was done in less than a quarter of the public and private secondary level hospitals.
- A lower proportion of public tertiary level hospitals maintained electronic health records than private and NGO/charitable hospitals.
- About one-fourth of the tertiary hospitals had active pediatric oncology clinical research programs at hospital or pediatric oncology unit/ward

(h) Challenges faced in the diagnosis and treatment of childhood cancers

- Public tertiary and secondary level hospitals faced challenges with a shortage of human resources, lack of beds, shortage of equipment and lack of physical space for extending facilities
- Treatment denial and treatment abandonment were the commonest challenges faced in the treatment of childhood cancers
- According to the state nodal officers and civil society organizations, The main challenges in the diagnosis of childhood cancers include gender bias in seeking care, lack of insurance, lack of awareness among parents and caregivers regarding early signs and symptoms, lack of expertise among grass-root level workers in diagnosis and poor accessibility to diagnostic centres due to geographical conditions.
- The main barriers in the treatment of childhood cancers were treatment abandonment, treatment refusal, financial barriers and gender barriers in seeking care, care-seeking from traditional healers, lack of palliative care facilities, sub-optimal treatment at peripheral health centres, poor accessibility, shortage of health workforce and cancer treatment facilities and lack of referral pathways.

(i) Impact of COVID 19 on the delivery of childhood cancer care services

- Childhood cancer care services had been impacted in the majority of the tertiary and secondary hospitals
- The most frequently encountered impact was decreased new diagnoses and increased treatment abandonment rates.