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Health in focus



PANORAMA OF PEDIATRIC ONCOLOGY

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EDITORIAL

This year, the Desiderata Institute publishes the first panorama of Pediatric Oncology in Brazil, providing regional and state-level information on the profile of childhood cancer, access to treatment and surveillance information in Brazil. By bringing together the information of a country with continental dimensions like ours in one document, we have the opportunity to reflect on the state of affairs and shed light on where we need to act to reduce regional inequalities and achieve more cures. This panorama was produced with the technical assistance of experts from the Cancer Foundation, the National Cancer Institute and the Global Initiative of the World Health Organization for Childhood Cancer in Latin America and the Caribbean. We could also count with the collaboration of specialists in the field, who provide reflections on the current scenario and future prospects of childhood cancer in Brazil.

The analysis was performed using the most recent data available in mortality information systems, population data, health facilities, hospital-based and population-based cancer registries. The information analyzed was published up to 2019, so it does not reflect the impact of the Covid 19 pandemic, which will only be measured in future editions.

In the Brazilian territory, there are thirty active Population-Based Cancer Registries (RCBP) and three in the implementation phase. The systematized data in these centers support the planning and evaluation of cancer prevention and control programs, and the quality of the information collected is fundamental.

In terms of classification by cancer type, an accurate diagnosis of cases is still a challenge in the country, with 8.1% of the diagnosis are classified as unspecified neoplasms in the RCBP. In the United States, this figure is less than 1%.

Regarding histopathological diagnosis, an important positive indicator of the degree of certainty of a tumor, the national scenario is better: the diagnosis was confirmed microscopically in 88.9% of the cases on the Hospital Cancer Registry (RHC), with the highest percentage in the Northern Region (91.4%) and the lowest in the Midwest (81.5%). Among the states, the lowest percentage was observed in Goiás (36.7%) and the highest (100%) in Amapá and Roraima.

It is also worth highlighting the high rate of treatment of adolescents in unlicensed hospitals: 43% of the patients between 15 and 19 years of age were treated in non licensed hospitals for pediatric oncology, which is contrary to national and international guidelines that require treatment in specialized centers for this audience.

Cancer mortality follows the same pattern, with the highest specific rate in adolescents (51.1/million), followed by children aged 0 to 4 years (46.9/million). The rates are close in the 5 to 9 and 10 to 14 age groups: 37.9 and 37.1 per million, respectively.

Another fact worth noting is mortality by race/color. Brazil has the highest rates for indigenous children and adolescents:

67.7 per million. Additionally, the overall childhood and adolescent cancer mortality rate for the period studied is 43.4 per million. The access to cancer care is another important aspect of the treatment for children and adolescents. In the North and Midwest regions, we observed the greatest shift of users seeking help to states outside their region of residence. These regions also have the lowest number of qualified services and physicians trained in pediatric oncology. São Paulo is the state that receives the most children and adolescents from other states for cancer treatment: 70.4%.

At the national level, the completeness of most (75%) of the variables required to complete the Hospital Cancer Records was considered excellent. We did not have access to data for analysis for the variable considering the extent of neoplastic disease (staging), identified by 28b¹.

The Desiderata Institute believes that the access to high-quality information is essential for the development of strategies to improve the chances of cure for Brazilian children and adolescents. To this end, we have committed to develop and publish biennial data on childhood cancers in this Pediatric Oncology Overview in the hope that this will be a tool to guide the formulation of equitable public policies that seek better outcomes and better chances of cure for all Brazilian children and adolescents.

Enjoy reading!

¹ The classification 28b is used for staging systems other than TNM and for cases less than or equal to 18 years of age.

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CHILDHOOD CANCER IN BRAZIL

POPULATION OF CHILDREN AND ADOLESCENTS (0 - 19 YEARS OLD) AND ESTIMATE OF ANNUAL INCIDENCE OF CANCER IN THE REGIONS.

Brazil, 2020

Sources: IBGE, 2021; INCA, 2019.

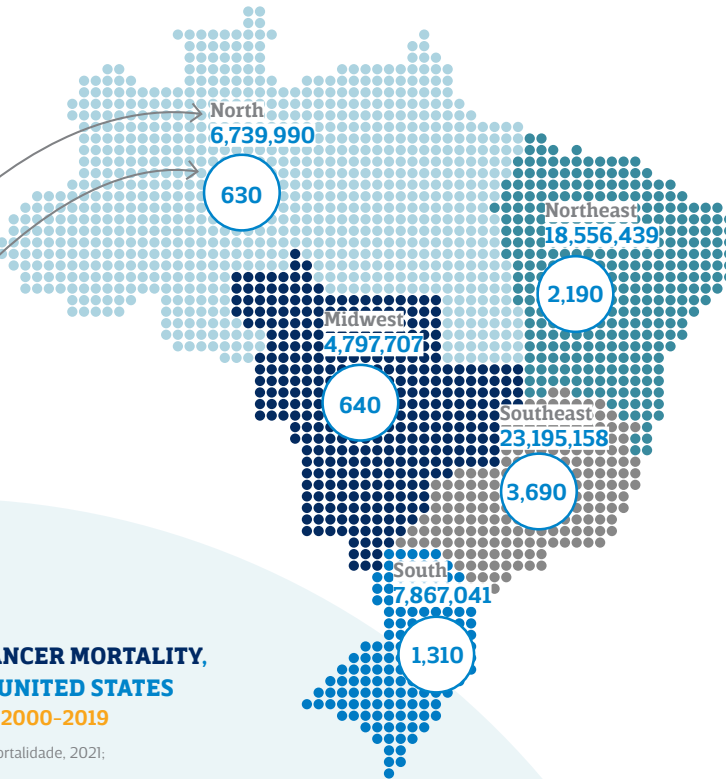
Estimation of new cases

BRAZIL: 8.460

Gross rate: 138.44/million

Population of children and adolescents

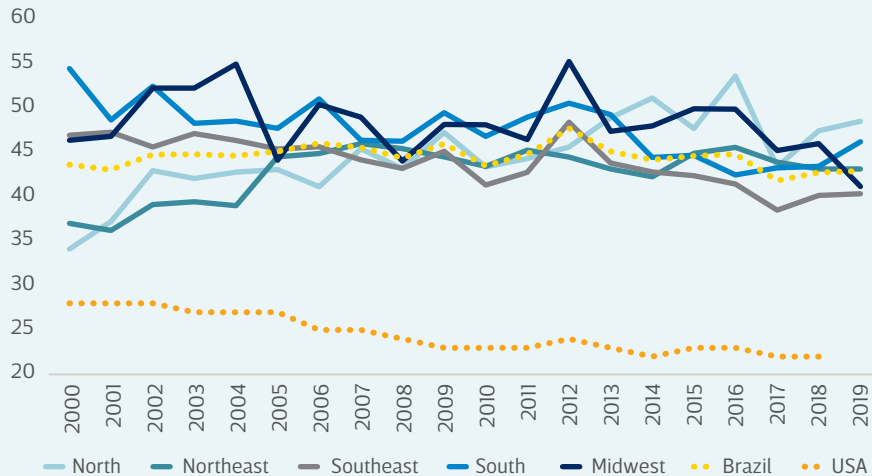
New cases



TIME SERIES OF CHILDHOOD CANCER MORTALITY, BY REGION IN BRAZIL AND THE UNITED STATES

per million children and adolescents 2000-2019

Sources: IBGE, 2021; Sistema de Informações sobre Mortalidade, 2021; SEER, National Cancer Institute, 2021.



CHILD AND YOUTH CARE December 2020.

NUMBER OF SERVICES QUALIFIED IN PEDIATRIC ONCOLOGY



BRAZIL: 75

Note: Hematology services are not included.

RATIO OF PEDIATRIC ONCOLOGISTS PER MILLION CHILDREN AND ADOLESCENTS



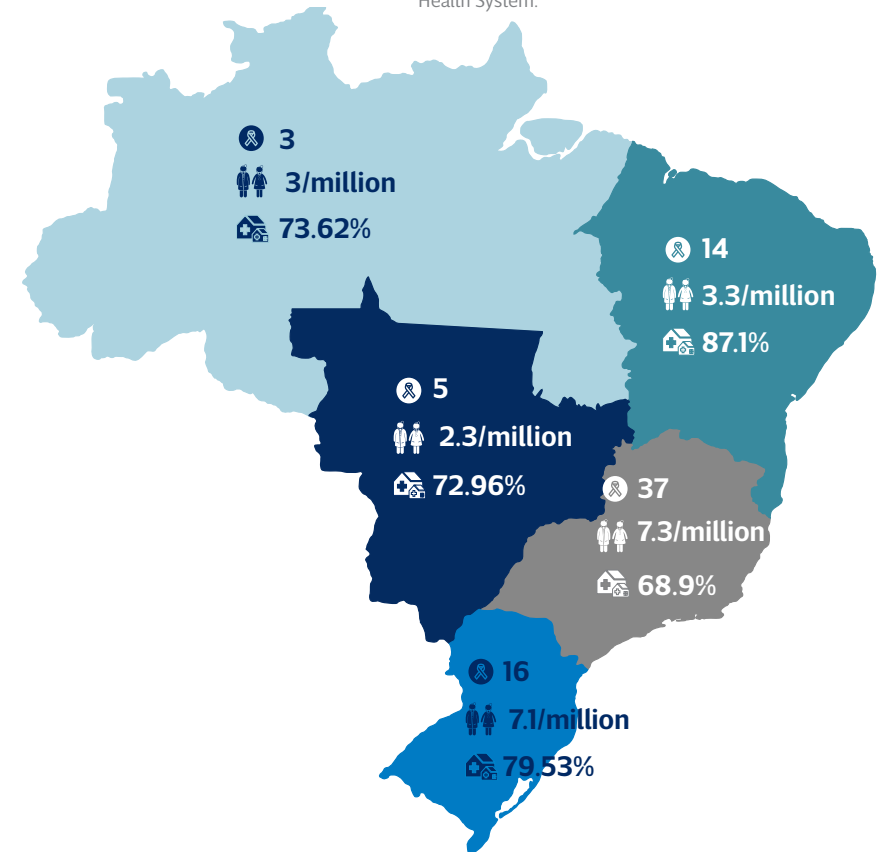
BRAZIL: 5.2/million

89.9% of the total number of pediatric oncologists work at the Public Health System.

PRIMARY HEALTH CARE COVERAGE



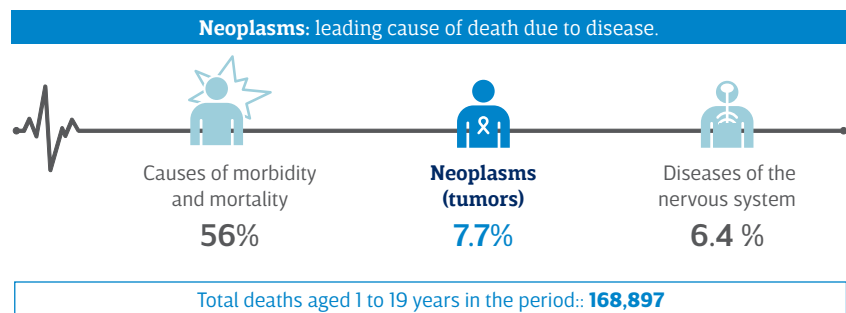
BRAZIL: 76.08%



Source: Administrative Rule no. 1399 of 12/17/2019; IBGE, 2021; National Registry of Health Facilities; Primary Health Care Secretariat/ MoH. (Jun 2021).

THREE MAIN CAUSES OF MORTALITY AMONG CHILDREN AND ADOLESCENTS IN BRAZIL (1-19 years old), 2015-2019

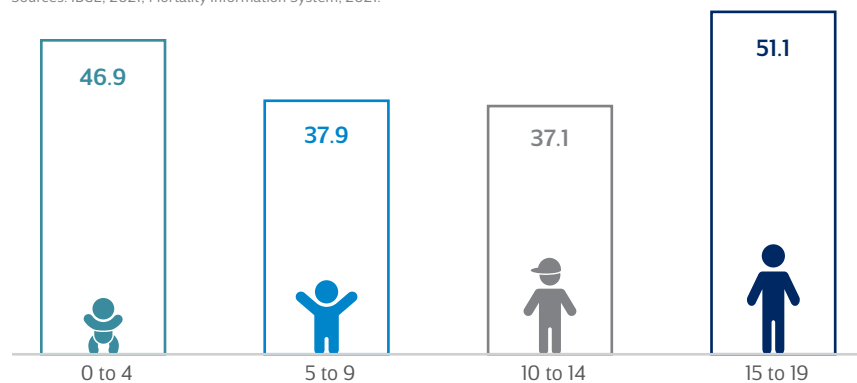
Source: Mortality Information System, 2021.



MORTALITY DUE TO CHILDHOOD CANCER IN BRAZIL per million children and adolescents 2000-2019.

ACCORDING TO AGE GROUP

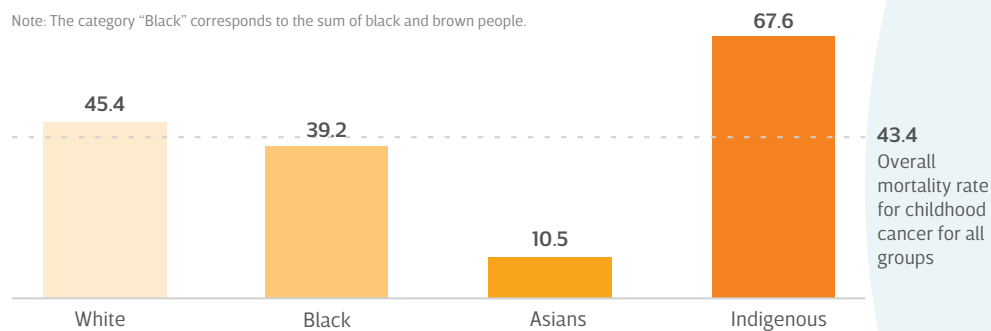
Sources: IBGE, 2021; Mortality Information System, 2021.



ACCORDING TO RACE/COLOR

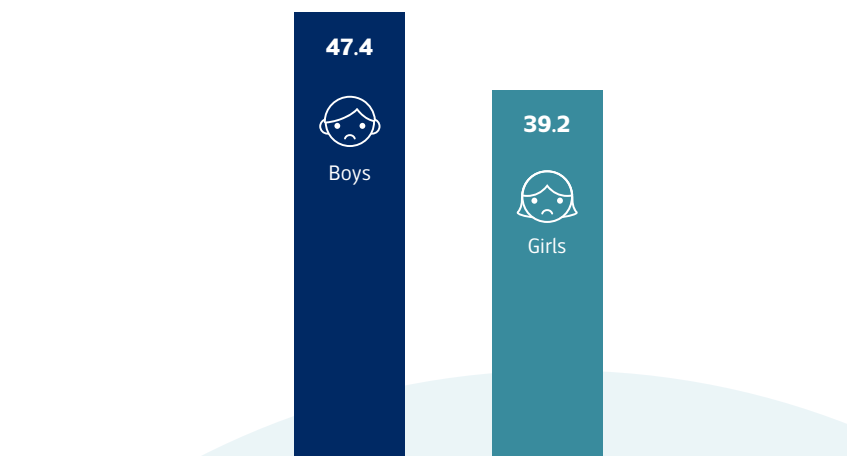
Sources: IBGE Census, 2010; Mortality Information System, 2021.

Note: The category "Black" corresponds to the sum of black and brown people.



CHILDHOOD CANCER MORTALITY AMONG BOYS AND GIRLS, per million children and adolescents 2000-2019.

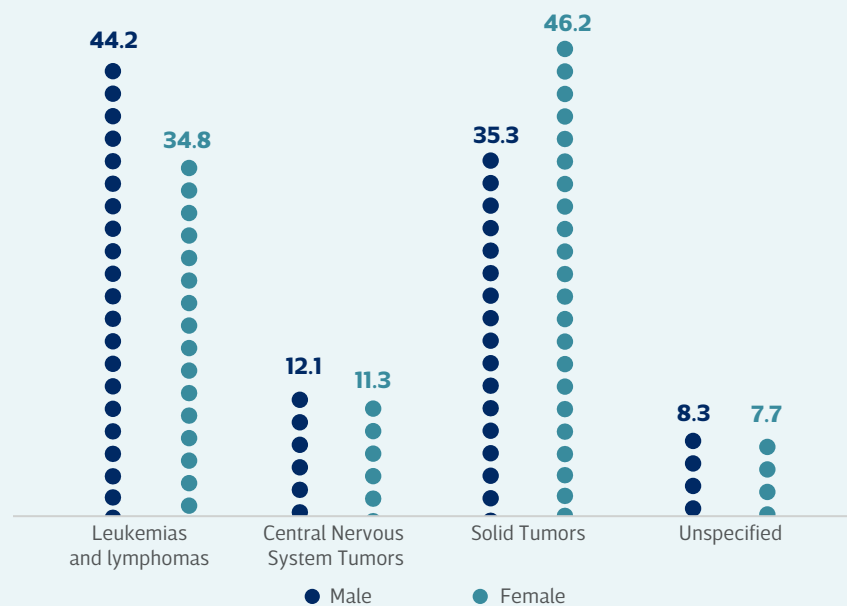
Sources: IBGE, 2021; Mortality Information System, 2021.



Note: All mortality rates were age-standardized, adopting the World Standard population, modified by Doll et al. (1966)

MAIN TYPES OF CHILDHOOD CANCER REGISTERED, in Population-Based Cancer Registry 2008-2016 (%)

Source: Population-Based Cancer Registry, MS/INCA/Division of Surveillance and Situation Analysis, 2021

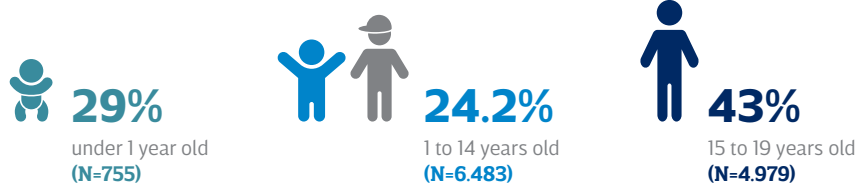


ACCESS TO TREATMENT

CASES ASSISTED IN HOSPITALS NOT QUALIFIED IN PEDIATRIC ONCOLOGY, ACCORDING TO AGE GROUP

Brazil, 2010 - 2017 (N=41,017)

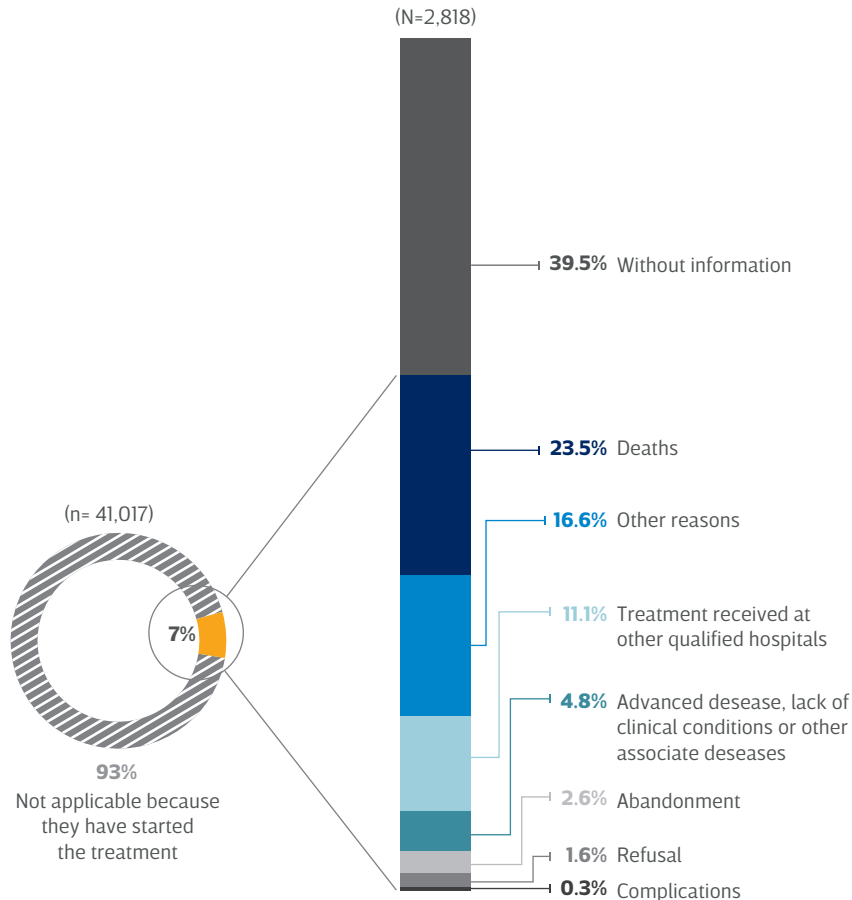
Source: Integrador RHC, 2021, analytical cases.



MAIN REASONS FOR NOT STARTING TREATMENT

in Brasil, 2010-2017.

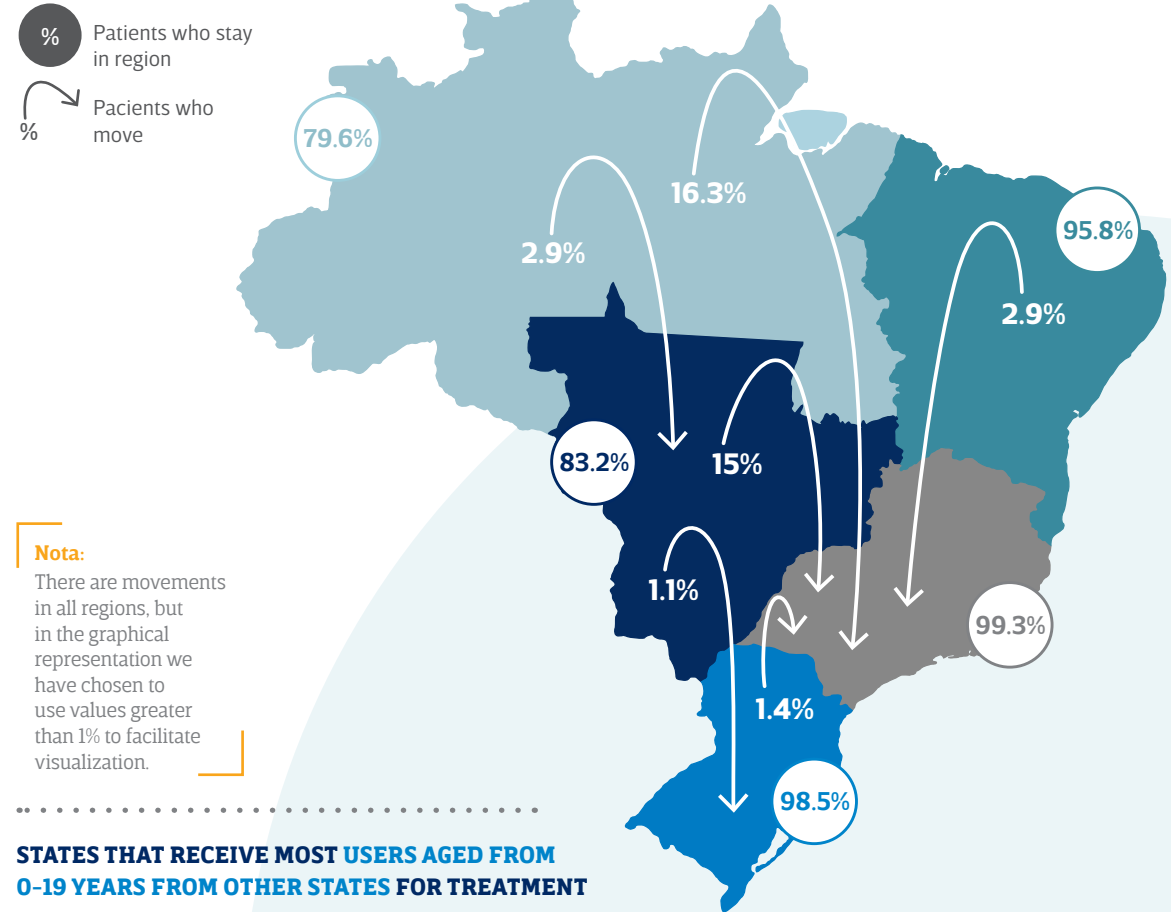
Source: Integrador RHC, 2021, analytic cases with no previous treatment.



MOVEMENT OF USERS AGED 0-19 YEARS OLD, BY REGION FROM THEIR HOUSES TO THE TREATMENT LOCATION

Brazil, 2010 - 2017 (N=41,017).

Source: Integrador RHC, 2021, analytical cases.



STATES THAT RECEIVE MOST USERS AGED FROM 0-19 YEARS FROM OTHER STATES FOR TREATMENT

Brazil, 2010 - 2017

STATE	N	%
SÃO PAULO	1,236	70.4
DISTRITO FEDERAL	211	12.0
PARANÁ	67	3.8
ESPÍRITO SANTO	55	3.1

INFORMATION MONITORING

POPULATION-BASED CANCER REGISTRY DISTRIBUTION IN BRAZIL

Source: Population-Based Cancer Registry, MS/INCA/Division of Surveillance and Situational Analysis, 2021.

Active RCBP: **30**

RCBP under implementation: **3**



² DRS - Regional Health Department

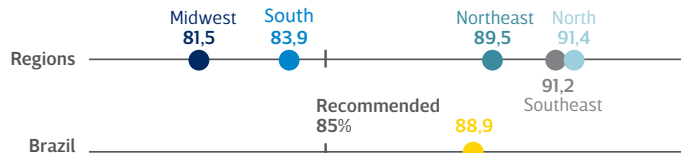
³ SMS - Municipal Health Secretariat

PERCENTAGE OF HISTOPATHOLOGICAL DIAGNOSIS,

Brazil, 2010 - 2017 (N=41.017).

Source: IntegradorRHC, 2021, analytic cases.

The percentage of Histopathological Diagnosis is the microscopic review of histological, cytological, and hematological examinations. It is a positive indicator of validity and registry information.



Analytical cases: those in which the therapeutic plan, treatment and follow-up are performed by the health care unit responsible for patient assistance. (INCA, 2016).

CASES OF CHILDHOOD CANCER REGISTERED IN HOSPITALS

Brazil, 2010-2018.

Source: Integrador RHC, 2021, analytical cases.



The decrease in cases registered in 2017 and 2018 does not mean the reduction of childhood cancer. The information reflects the data consolidation process in IntegradorRHC.

INCOMPLETENESS OF MANDATORY VARIABLES SELECTED IN BRAZIL

Brazil, 2010 - 2017 (N=41.017).

Source: Integrador RHC, 2021, analytical cases.

INFORMATION RATED AS EXCELLENT⁴

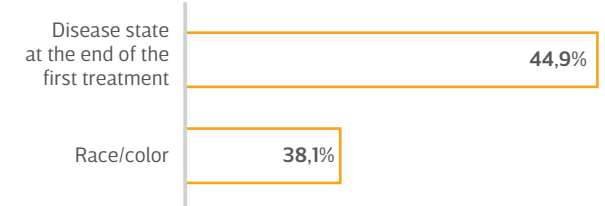
<5% no information considering all variables

- Gender
- Primary tumor location
- Histological type
- First treatment received at the hospital
- Most important diagnostic basis
- Date of treatment initiation
- Diagnosis date
- Previous diagnosis and treatment
- Main reason for not having started treatment

Note: We did not get the data on Staging (Variable 28b) for incompleteness analysis.

INFORMATION RATED AS POOR (20 TO 50%)

% "no information"



⁴ Romero e Cunha et al, 2006.

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OPINION PANEL

THE IMPORTANCE OF THE NETWORK IN ACCESSING CARE

Sima Ferman- Head of the Pediatric Oncology Service at the Nacional Cancer Institute- INCA

Today, a large number of children and adolescents with cancer can be cured if diagnosed and treated early in specialized centers. The progress in cancer treatment is most evident in high-income countries, where the 5-year survival rate is 80%, while it can still be improved in low- and middle-income countries. Many factors account for these differences and present challenges to overcome: difficult access to diagnosis and treatment, advanced disease at diagnosis, financial difficulties, and treatment dropout.

Childhood cancer is the leading cause of death in children aged 1-19 years in Brazil and is a public health problem in our country. Since it is a chronic disease, treatment involves several phases: prevention, early diagnosis, referral for treatment, palliative care, and follow-up of patients in long-term control. The cure is not the only goal of treatment and we must also pay attention to the quality of life of cancer patients. However, health care systems in different parts of the world are still more focused on acute diseases, which is not efficient for chronic diseases like cancer.

The approach to childhood and adolescent cancer should be developed using the chronic care model, through health network systems. This requires that primary, secondary, and tertiary care networks act in a proactive, integrated, coordinated, and fully communicating manner to ensure continuity of care for these patients. Collaborative care planning will enable the optimization of network resources to include the full cycle of care for childhood cancers. In this way, it will be possible to provide patients with comprehensive multidisciplinary care through health promotion, prevention, curative treatment, rehabilitation, and palliative care.

Studies show that the health network can improve quality of life, treatment outcomes, user satisfaction, and reduce costs. Improving the network structure in our country is important to ensure access to diagnoses, comprehensive treatment, and consistent improvement in outcomes.

THE SITUATION OF CHILDHOOD CANCER IN BRAZIL, THE QUALIFICATION OF DIAGNOSIS AND TREATMENT

Neiçolino Pereira de Carvalho Filho - President of the Brazilian Society of Pediatric Oncology

In Brazil, 12,960 new cases of childhood cancer (0-19 years old) are expected in males (137.87 new cases per million) and 12,450 in females (139.04 per million) for the three-year period 2020-2022, according to José Alencar Gomes da Silva National Cancer Institute (INCA).

Cancer has been the leading cause of death in young people under 19 years old in Brazil since 2005 if deaths from external causes are excluded. It is

therefore a public health problem that must be addressed as a priority by public authorities, medical professionals, multi-professional teams, non-governmental organizations, and civil society.

The importance of early diagnosis and access to specialized treatment centers are fundamental factors in ensuring that children and adolescents have the best chance of recovery.

Diagnostic tools have evolved considerably in recent decades, making the biological classification of virtually all tumor types more precise and refined, which has led to new categories of risk stratification that are essential for adapting treatment.

With regard to treatment, the progress in molecular knowledge of tumors opens a new scenario. Targeted therapies have been developed and the importance of immunotherapy in the fight against cancer has increased. On the other hand, we are confronted with the recurrent or definitive shortage of chemotherapeutic agents, which are essential to fight pediatric tumors, directly affecting treatment strategies.

Technological improvements in diagnosis and treatment are still far from being widely available in many countries, including Brazil.

Currently, initiatives are being developed by different sectors of society, together with medical institutions and health managers, to discuss the issue and develop solutions to the problems of childhood cancer, with the aim of implementing public policies to improve broad and equitable access to diagnosis and treatment.

THE IMPORTANCE OF USING THE HOSPITAL CANCER RECORDS IN THE MANAGEMENT OF PUBLIC POLICIES ON CHILDHOOD CANCER.

Rejane de Souza Reis - Brazilian Association of Cancer Registries

The knowledge of information about a disease is essential for public health management and decision making, as we see from the pandemic COVID-19. To meet demand and allocate effort and resources, the health manager must have the support of the pillars of cancer surveillance: incidence, hospital morbidity, and mortality.

The incidence is determined through the Population-Based Cancer Registries (PBCR), which is the "gold standard" for knowing the population profile of childhood and adolescent cancer and it is used to strategically support decision making and guideline development (REIS, DE CAMARGO, SANTOS, 2018). One of the ways an RCBP obtains its information is directly from the Hospital Cancer Records (RHC).

In relation to the RHC, they are responsible for providing hospital morbidity information (INCA, 2010). In addition to meeting the administrative needs of a hospital, an RHC aims to contribute to a better understanding of the

disease (WHO, 1995; SILVA, 1999).

It is well known that the quality of care for cancer patients improves in hospitals where RHCs are implemented and active (MOHAMMADZADEH ET AL., 2017). In childhood cancer, this brings tremendous benefits because it allows the identification, correction, and improvement of the entire process, from diagnosis to outcome, throughout the treatment period. With the dynamics of the RHC, it is possible to identify bottlenecks in waiting times between care, diagnosis, and treatment, which allows effective action by those responsible at all levels.

Another fact that points to the importance of RHC information is the identification of hospitals that treat these children and adolescents, whether or not they are hospitals qualified to provide pediatric oncology. It is a fact that childhood cancer, due to its small size, must be treated in specialized centers, and not scattered. Unfortunately, today in Brazil we can only perform this type of analysis in public hospitals and in some private hospitals that have volunteered to create an RHC. The ideal would be to know hospital morbidity in both segments in a more reliable and comprehensive way. This requires that health facility managers make efforts to establish, maintain and update RHCs and give them due importance.

Finally, the information is essential for decision-making, planning, and implementation of childhood cancer surveillance and evaluation activities at different levels. The answers related to morbidity will be understandable only if the process is organized and standardized.

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CHILDHOOD CANCER IN BRAZIL

Alfredo Scaff - Medical Consultant- Cancer Foundation

Cancer is a complex disease that, when properly diagnosed, offers tremendous opportunities for successful treatment. In pediatric oncology (we consider the age group from 0 to 19 years), the cure can be up to 80% of cases.

In Brazil, about 8,500 new cases of cancer are diagnosed in children and adolescents every year. This represents about 2-3% of all diagnosed

cancer cases and is the main cause of death due to diseases at this age (although it should be noted that in the country most deaths in children are caused by so-called external causes such as violence, and only after that comes cancer).

It is interesting to note that in twenty years of study (from 2000 to 2019), the standardized death rate for the country is virtually unchanged, in 2000 it was 43 deaths per million adolescents and in 2019 it was 42 deaths per million adolescents. In the United States, this rate decreased from 28 to 22 deaths per million adolescents during the same period. This shows that it is possible to improve the performance of the system for diagnosing and treating childhood cancer.

In 2021, the Pediatric Oncology panorama will begin to analyze and publish national data. It is important to continue to advance the cure for children with cancer, and the first thing we need to know is exactly how this is happening. The Panorama is one of the tools for this monitoring.

We could not leave the pandemic of COVID-19 unmentioned. This analysis uses data up to 2019, before the pandemic.

We know that health services were badly affected by the COVID overuse, and we also know that there was a sharp drop in cancer screenings and diagnoses. But what is the impact of this pandemic on childhood cancer?

The conference Pediatric Oncology Forum (FOP 2021), which will take place this year from August 4 to 14, will be a great challenge in addressing these issues and proposing measures to strengthen innovative initiatives, such as the United for Cure (Unidos pela Cura) initiative, which aims to reduce the mortality rate of childhood cancers in Brazil.

METHODOLOGY

In the section, THE CHILDHOOD CANCER IN BRAZIL, the data of the annual estimate of cancer incidence by Federation Unit were taken from the publication "Cancer Incidence in Brazil" (INCA, 2019), starting from the 2020 population estimate of the IBGE projections (2021).

The proportion of childhood and adolescent cancers registered in Brazilian Population-Based Cancer Registries was organized according to the International Classification of Childhood Cancer - ICCI-3 (STELIAROVA-FOUCHER et al, 2005), based on the information extracted in July 2021, available in the 28 participating cancer registries (RCBPop, 2021), as described below, with the respective period of consolidated information.

RCBP participants and consolidation period

ALAGOAS	from 2010 to 2011	GOIÂNIA	from 2008 to 2013
ANGRA DOS REIS	from 2008 to 2016	JAHU	from 2008 to 2016
ARACAJU	from 2008 to 2014	JOAO PESSOA	from 2008 to 2016
BELÉM	from 2008 to 2016	MANAUS	from 2008 to 2013
BELO HORIZONTE	from 2008 to 2016	MATO GROSSO (COUNTRYSIDE)	from 2008 to 2016
CAMPINAS-SMS ⁵	from 2010 to 2016	NATAL	2008
CAMPO GRANDE	from 2008 to 2012	PALMAS	from 2008 to 2013
CUIABA	from 2008 to 2016	POÇOS DE CALDAS	from 2008 to 2014
CURITIBA	from 2008 to 2016	PORTO ALEGRE	from 2008 to 2012
DISTRITO FEDERAL	from 2008 to 2014	RECIFE	from 2008 to 2016
DRS BARRETOS	from 2008 to 2016	RONDONIA	from 2015 to 2016
ESPIRITO SANTO	from 2008 to 2012	RORAIMA	from 2008 to 2010
FLORIANOPOLIS	from 2008 to 2016	SANTOS	from 2008 to 2009
FORTALEZA	from 2008 to 2013	SÃO PAULO	from 2008 to 2015

Source: Population-Based Cancer Registry, MS/INCA/Division of Surveillance and Situation Analysis. Accessed on 07/13/2021.

Mortality rates were calculated based on information on childhood cancer deaths from the Mortality Information System (DATASUS, 2021) and population projections (IBGE, 2021). For rates by race/color, in the absence of stratified population projections for this variable with the assumed age range, population data from the 2010 Demographic Census (IBGE, 2021) were used and multiplied for the years analyzed; except for the analysis of the three major causes of infant and adolescent mortality, all data are for the population aged 0-19 years. Data for the United States are from the National Center website for Health Statistics (NHI, 2021). Mortality rates were age-adjusted by the direct method, using the world standard population as the reference, modified from Doll et al. (1966) (INCA, 2016).

The following data was used in the ACCESS TO TREATMENT section and the PEDIATRIC PUBLIC CARE data: Decree No. 1399 and 17/12/2019; the

National Register of Health Establishments (CNES) (DATASUS, 2021), the IntegradorRHC⁶ database (2021), and information from the Secretariat of Primary Health Care (BRASIL, 2021). Data from the IntegradorRHC (2021) were extracted in June 2021, considering only analytical cases in the age group of interest.

The information in the INFORMATION MONITORING section was extracted from the IntegradorRHC (2021) and Population-Based Cancer Registries (2021). In assessing the completeness of the data, the following levels were considered: excellent (less than 5%), good (5 to 10%), moderate (10 to 20%), poor (20 to 50%), and very poor (50% or more), according to the criterion proposed by Romero and Cunha (2006).

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⁵ Municipal Health Secretariat

⁶ IntegradorRHC is a web system developed by INCA for the consolidation of hospital data from Hospital Cancer Records (RHC) throughout Brazil