

PANORAMA OF PEDIATRIC ONCOLOGY

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INTRODUCTION

Instituto Desiderata has monitored the pediatric oncology scenario in Rio de Janeiro for five years in order to consolidate information and highlight the challenges to be faced in the specialization of diagnosis, access, and treatment for childhood cancer. Built in collaboration with professionals from the Fundação do Câncer and the Instituto Nacional do Câncer (INCA), the Panorama of Pediatric Oncology of Rio de Janeiro is launched annually on November 23rd in order to commemorate the National Childhood Cancer Awareness Day.

Divided into four sections, it also contains a panel of expert opinions, with texts that help understand the advances and challenges for childhood cancer treatment. We highlight below the following main advances and challenges observed:

Classification of cancer type:

▮ 89.2% of the diagnoses of the Hospital-Based Cancer Registry (HBCR) have histopathological confirmation, an important positive indicator for the degree of certainty in the diagnosis of a tumor.

▲ In the Population-Based Cancer Registries (PBCR), 8.1% of the diagnoses in Brazil, and 10.3% in the Southeast were classified as *unspecified* neoplasms, a category that suggests uncertainty about the type of diagnosed cancer. In countries such as the United States, this number is less than 1%, and in other regions of Brazil, such as the South, the total is less than 3%. This challenge can also be observed in the HBCR, in which

39.7% of the cases are reported as having no information about the staging of the disease (variable 28b), making it impossible to evaluate the extent of its severity.

Treatment in specialized hospitals:

▮ Five of the seven hospitals that have specialized healthcare services for childhood cancer offer Palliative Care; four of the seven have a hospital classroom, and two of the seven present pedagogical care, allowing the patients to study during their hospitalization; six of the seven hospitals have a chemotherapy room that is set up exclusively for children and adolescents, following the orientation of Ordinance nº 140/2014.

▲ 9.6% of patients under the age of 1, 6.6% of children and adolescents between 1 and 14 years of age, and 14% of adolescents between 15 and 19 years of age were treated in hospitals without qualification in pediatric oncology.

Access to treatment:

▮ Five of the seven hospitals with qualification in pediatric oncology offered outpatient vacancies to the State Regulation System in 2017. Four of the seven offered vacancies in hematology. Two of the three that treat solid tumors offered vacancies in oncology.

▲ There is not an exact number of vacancies to be offered on a monthly basis by the specialized hospitals. The reduced number of vacancies has a direct impact on the regulation of

supply and demand. In addition, it contributes to maintaining the invisibility of access problems for children and adolescents with cancer. This situation is clear when we see that children and adolescents with a cancer diagnosis performed at unspecialized units wait more than those diagnosed at specialized hospitals, reflecting the inequality of access to diagnosis and initiation of cancer treatment.

Finally, it is worth highlighting that currently:

▮ Six of the seven hospitals specialized in treating cancer in children and adolescents have implemented the Hospital-Based Cancer Registry, and many of the mandatory variables of the HBCR presented a completeness considered excellent (<5% not filled out).

▲ The impact of deaths by childhood cancer on the Years of Potential Life Lost by Brazilians is high: although childhood cancer accounts for 2.8% of all neoplasms in Brazil and 2% in the Southeast, we observed that childhood cancer deaths accounted for 12% of the total Years of Potential Life Lost due to cancer for the entire Brazilian population.

Data registration, as well as the analysis, monitoring, and production of quality information are some of the key factors for improving childhood cancer treatment. We hope that this material contributes to monitoring the disease, and to assisting the managers' decision-making.

Enjoy your read!

Editorial team: Evelyn K. Santos; Fábila Andrez; Laurence Pires; Roberta Costa Marques.

Collaborators: Ana Mello, Alcides Carneiro, Alfredo Scaf, Beatriz Busch, Beatriz de Camargo, Carlos Ornelas, Marcell Santos, Monique Silvino, Rejane Reis, Renata Barros, Sima Ferman.

Instituto Desiderata

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▮ **Advance** ▲ **Challenge**

METHODOLOGY

In the section **CHILDHOOD CANCER IN THE STATE OF RIO DE JANEIRO**, the calculation for the estimate of cancer incidence considered the median incidence rate by age in the Southeast region (INCA, 2016), and the population estimate for the state in 2017 (DATASUS, 2018). For the calculation of the child and adolescent population, the cases were divided between the health regions by following the percentage distribution in the age range of 0 to 19 years in the 2010 Census.

The proportion of childhood cancer types recorded in the Brazilian Population-Based Cancer Registries was organized according to the International Classification of Childhood Cancer - CICI-3 (STELIAROVA-FOUCHER et al, 2005) based on available information in the Population-Based Cancer Registry (RCBPop, 2018).

Information on deaths by childhood cancer was extracted from the Information System on Mortality (DATASUS, 2018), and the International Agency for Research on Cancer's (IARC, 2016) official report on childhood cancer. The incidence rates considered are those from the technical area of the IARC (STELIAROVA, 2017) and the INCA (2016) for each age group, considering the median Brazilian incidence, the median of the adjusted incidence rate for the age range of 0-14 years in the Southeast region, and the median of the specific incidence rate for 15-19 years in the Southeast region.

The information in the **PUBLIC PEDIATRIC CARE** section was obtained from the databases of the National Registry of Health Establishments (DATA-SUS, 2018), the Department of Basic Care (DAB, 2018), and information

provided by the Regulation Superintendency of the Health Department of the State of Rio de Janeiro.

In the section about **INFRASTRUCTURE FOR DIAGNOSIS AND TREATMENT**, the following sources were used: Ordinance nº 140 of 02/27/2014 and its alterations; CNES (DATASUS, 2018), the HBCR Integrator database (SisRHC, 2018); information from the Instituto Municipal Helena Antipoff, and the Working Group for Humanization from the Pediatric Oncology Forum 2017; in addition to consultations made directly to the hospitals in order to update information that, up until the material's final edition, had not been made available by the responsible public entities.

Information for the **MONITORING OF INFORMATION** section was obtained in the HBCR Integrator (SIS-RHC, 2018) in April 2018, considering undiagnosed and untreated analytic cases with the first consultation in the period from 2009 to 2015 in the state of Rio de Janeiro, and the classification according to CICI-3 (STELIAROVA-FOUCHER et al, 2005). The Division of Situation Surveillance and Analysis - Conprev/ INCA provided information about the implementation of the Hospital-Based Cancer Registry (HBCR), and the sending of the databases by the authorized hospitals. In the evaluation of data completion, the following grades were considered: excellent (less than 5%), good (5 to 10%), regular (10 to 20%), bad (20 to 50%), and very bad (50% or more), according to criteria proposed by Romero and Cunha (2006).

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PANEL OF OPINIONS

THE IMPORTANCE OF PRIMARY CARE IN THE CHILDHOOD CANCER TREATMENT NETWORK

The changes in large urban areas lead to a new scenario in childhood mortality, with a decrease in infectious diseases and an increase in deaths by external causes and chronic diseases.

Neoplasms occupy the second place as the cause of death in children and adolescents, but if external causes are excluded, cancer is the leading cause of death in this group.

Since 2007, Rio de Janeiro participates in a network with several public and non-governmental institutions committed to the early diagnosis of childhood cancer and its timely treatment.

In the city of Rio de Janeiro, the subject has been discussed with Primary Care professionals, and the following actions were carried out: the professional training and organization of the primary care network, monitoring the referrals for diagnostic research, and the active search for shortcomings.

The early detection of childhood cancer is a challenge in the public network organization, and remains on the agenda of the administration's commitments.

Beatriz Busch – Health Secretary of the City of Rio de Janeiro

CHILDHOOD CANCER IN THE STATE OF RIO DE JANEIRO

In a recent evaluation of deaths by cancer in children (0-14 years of age) in Brazil, we observed that in the state of Rio de Janeiro only 28% of children living outside the capital passed away in their cities. The rest passed away in the capital. In the Southeast region as a whole, this proportion is 57.8%.

In other states of the Southeast, children are mostly dying in their place of residence, unlike the state of Rio de Janeiro. Therefore, the implication is that in this state the children are being treated in the capital and monitored there until their moment of death.

We do not know if the deaths occurred during the curative treatment or during the progression of the refractory disease, but we noticed that there should be greater contact with the medical care from their place of residence, allowing the death to occur close to loved ones.

It is well known and discussed that the "ideal death" should be in one's own environment. Today, with the increased possibility of cure, high technologies, and new drugs, the deaths have occurred more frequently in the hospital. However, for children considered out of therapeutic possibility, the ideal continues to be maintaining as much time as possible at home and under palliative care.

Beatriz de Camargo – Researcher, Research Center, INCA

THE IMPORTANCE OF THE HOSPITAL-BASED CANCER REGISTRY'S (HBCR) DATA FOR THE DISSEMINATION OF INFORMATION AND RESEARCH

The HBCR is one of the technical operational components that support the identification and prioritization of continuous actions for monitoring cancer and facing problems in public healthcare.

The quality of cancer patient care in hospitals that have implemented the HBCR is better. By collecting information about the patient, tumor diagnosis, treatment, and follow-up, it is possible to alter or improve the processes involved in each step, therefore optimizing the care provided to the individual. The analyses presented in this Panorama were based on the information provided by the HBCR. It is interesting to mention that 10% of children under the age of one are interested in mentioning that specialized in pediatric oncology. When we analyze adolescents, this number rises to 14%.

In order for this information to be available, and for the research analyzing hospital performance to be developed, it is necessary for health institutions and their managers to maintain and update the HBCR. Responses to the demands and needs of the managers, the civil community, and the scientific community will be more effective when the whole process is organized and standardized.

Rejane de Souza Rei – Epidemiological biologist, Fundação do Câncer.

THE INCIDENCE OF CHILDHOOD CANCER AS A STRATEGIC OPPORTUNITY FOR PLANNING

Accurate information about incidence can only be obtained from the specialized collecting developed by the Population-Based Cancer Registries (PBCR). This information is essential for understanding the impact of cancer, as well as monitoring population-level patterns, generating hypotheses for causal studies, assessing the effect of disease control actions on the population, supporting decision-making, and defining priorities in cancer prevention and care. The PBCR represents the "gold standard" for providing information on cancer incidence. Knowing the profile of childhood cancer then becomes strategic to manage decision-making and establish guidelines.

In this Panorama, estimates are available for the state and the capital, as well as their distribution throughout the Health Regions, which will be essential for better planning and an improved allocation of resources and efforts. The incidence rate observed is similar to the regional profile, and the main types of cancer in the region are hematological tumors (leukemias and lymphomas) and those of the central nervous system.

This profile is the same as that observed in the national and global scenario. The high incidence of non-specific tumors stands out, both in the national and regional scenarios, with a much higher occurrence than that observed in developed countries. This situation reinforces the need to have a support network for diagnostic confirmation and accuracy.

Marceli O. Santos – Instituto Nacional de Câncer José Alencar / Coordination of Prevention and Monitoring.

CHILDHOOD CANCER IN THE STATE OF RIO DE JANEIRO

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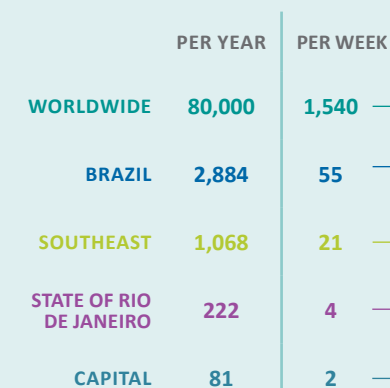
CHILD AND ADOLESCENT POPULATION (AGES 0 TO 19 YEARS) AND ESTIMATE OF ANNUAL CANCER INCIDENCE BY HEALTH REGION in the state of Rio de Janeiro

Sources: IBGE, 2010; DATASUS, 2018; INCA, 2016



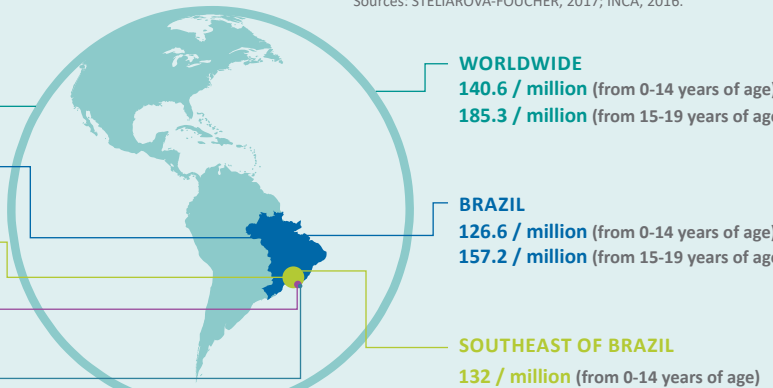
DEATHS BY CHILDHOOD CANCER

Sources: SIM, 2009-2015 (Brazil); IARC, 2016 (worldwide).



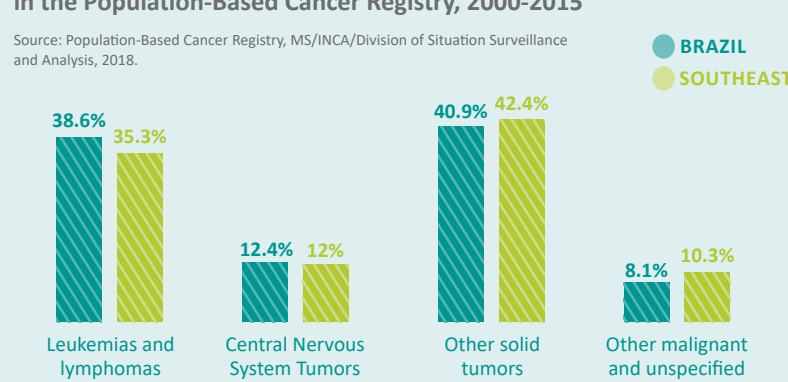
PROJECTION OF ANNUAL INCIDENCE OF CHILDHOOD CANCER

Sources: STELIAROVA-FOUCHER, 2017; INCA, 2016.



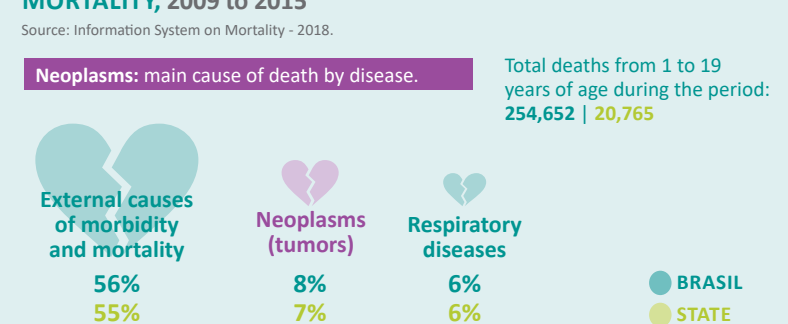
MAIN TYPES OF CHILDHOOD CANCER REGISTERED in the Population-Based Cancer Registry, 2000-2015

Source: Population-Based Cancer Registry, MS/INCA/Division of Situation Surveillance and Analysis, 2018.

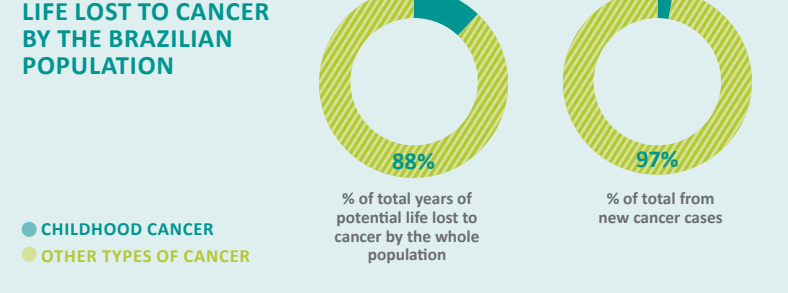


THREE MAIN CAUSES OF CHILD AND ADOLESCENT MORTALITY, 2009 to 2015

Source: Information System on Mortality - 2018.



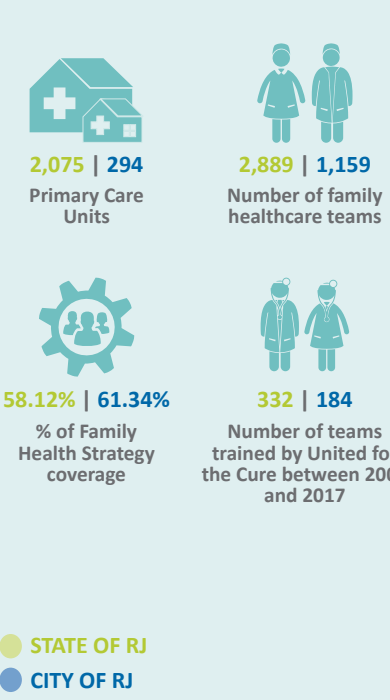
YEARS OF POTENTIAL LIFE LOST TO CANCER BY THE BRAZILIAN POPULATION



PUBLIC PEDIATRIC CARE

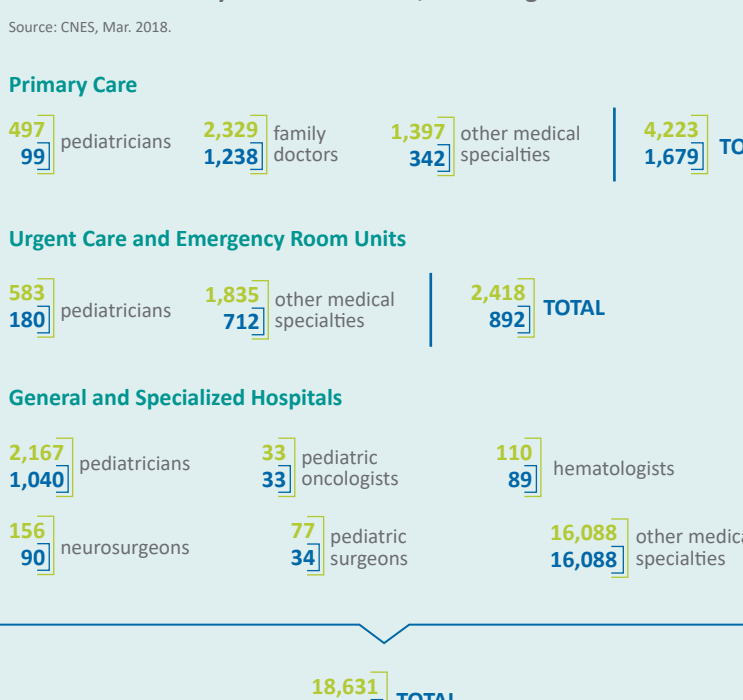
PRIMARY CARE

Sources: CNES, Mar. 2018; MS/SAS/DAB, Mar. 2018.



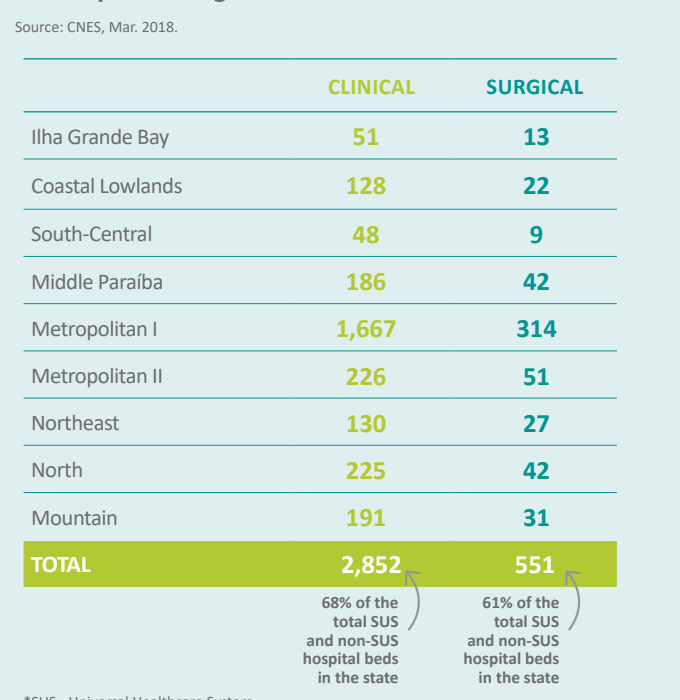
DISTRIBUTION OF DOCTORS IN THE PUBLIC HEALTH NETWORK of the state and city of Rio de Janeiro, according to level of care

Source: CNES, Mar. 2018.



CLINICAL AND SURGICAL PEDIATRIC BEDS IN THE SUS* by health region

Source: CNES, Mar. 2018.



INFRASTRUCTURE FOR DIAGNOSIS AND TREATMENT

CHILDHOOD CANCER CASES REGISTERED IN HOSPITALS BY TYPE OF QUALIFICATION*, 2009 to 2015 (n=1,708)

Sources: SISRHC, 2018, analytic cases.

Qualification	Available Period	Annual Average of Cases	% of Total Cases
CACON with service in pediatric oncology	INCA - HC I (RJ)	2009-2013	211 (61.6%)
UNACON exclusive for hematology	HEMORIO (RJ)	2009-2014	42 (14.6%)
UNACON with services in radiotherapy, hematology, and pediatric oncology	Hospital Federal dos Servidores do Estado (RJ)	2012-2014	22 (3.9%)
UNACON exclusive for pediatric oncology	Instituto de Puericultura e Pediatria Martagão Gesteira / UFRJ (RJ)	2011-2014	14 (4.2%)
UNACON with services in radiotherapy and pediatric oncology	Hospital São José do Avai (Itaperuna)	2009-2011/2013-2015	3 (1.1%)
UNACON with service in pediatric oncology	Hospital Federal da Lagoa (RJ)	-	-
UNACON exclusive for pediatric oncology	Hospital Estadual da Criança (RJ)	-	-
UNACON	INCA - HC II (RJ)	2010-2014	17 (5.1%)
CACON	Hospital Universitário Clementino Fraga Filho - UFRJ (RJ)	2009-2013	8 (2.2%)
UNACON	Soc. Port. de Ben. De Campos (Campos dos Goytacazes)	2009-2014	6 (2.4%)
UNACON with radiotherapy service	Mário Kroeff (RJ)	2009-2011	7 (1.3%)
UNACON with services in radiotherapy and hematology	Hospital Universitário Antonio Pedro - UFF (RJ)	2009-2013	3 (0.9%)
UNACON with service in hematology	Hospital Geral de Bonsucesso (RJ)	2012	7 (0.4%)
UNACON	Hospital Santa Isabel (Cabo Frio)	2012-2015	3 (0.6%)
UNACON	Hospital Escola Álvaro Alvim (Campos dos Goytacazes)	2011-2012/2014-2015	3 (0.6%)
UNACON	Hospital São José (Terresópolis)	2012	1 (0.1%)
UNACON	Hospital Alcides Carneiro - Centro de Terapia Oncológica (Petrópolis)	2011-2013	1 (0.2%)
UNACON with service in radiotherapy	INCA - HC III	2009/2011-2012/2015-2016	2 (0.6%)
UNACON	Hospital Universitário Gaffrée e Guinle (RJ)	2015	3 (0.2%)

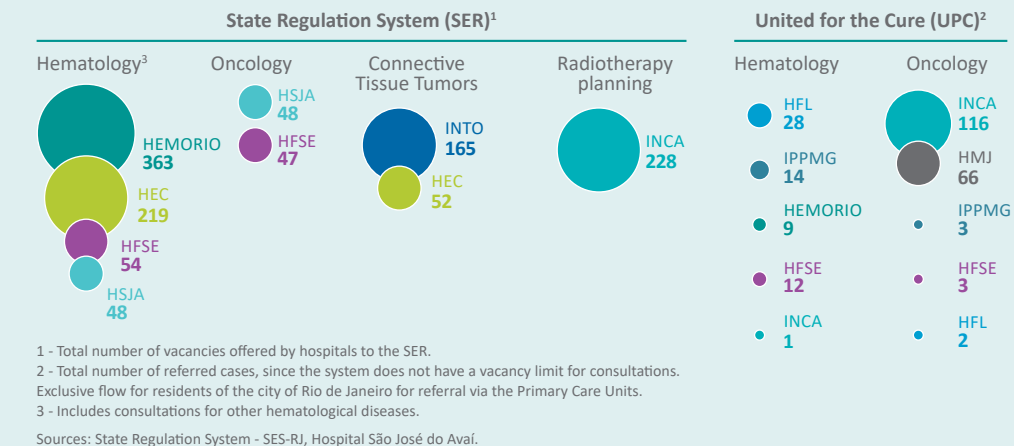
*CACON - High Complexity Oncology Assistance Center Unit :: treats at least the most prevalent cancer types
 *UNACON - High Complexity Oncology Assistance Units :: treats the most prevalent cancers

Ordinance SAS/MS nº 140 of 02/27/2014, and its alterations define the criteria and parameters for the organization, planning, monitoring, control, and evaluation of the healthcare establishments qualified in specialized oncological attention, and define the structural, operational, and human resource conditions for the qualification of these establishments in the Universal Healthcare System (SUS).

Other criteria for specialization are the System of Cancer Information (Siscan) and the Hospital-Based Cancer Registry (HBCR), being implemented and functioning within the structure of the hospital or hospital complex.

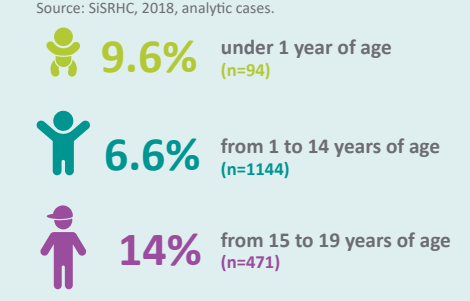
Observations: The Instituto do Cérebro Paulo Niemeyer is the first center in the country focused on the treatment of neurosurgical diseases, and is essential for the treatment of pediatric tumors in the Central Nervous System (including six exclusive beds). Rio Imagem is the center for image diagnosis in the state of Rio de Janeiro and possesses two magnetic resonance imaging devices, two tomographs, and nine ultrasound devices.

OUTPATIENT CONSULTATIONS FOR THE INVESTIGATION OF CHILDHOOD CANCER, in 2017



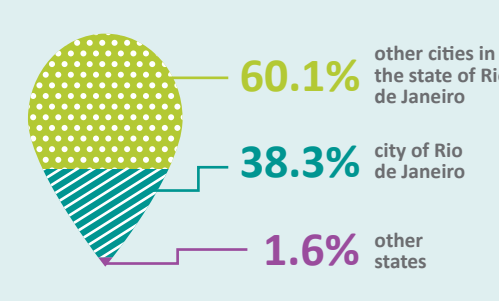
CASES RECEIVED IN HOSPITALS NOT SPECIALIZED IN CHILDHOOD CANCER, according to age group, 2009 to 2015 (n=1,708)

Source: SISRHC, 2018, analytic cases.



CASES RECEIVED IN THE STATE OF RIO DE JANEIRO, according to place of residence, 2009 to 2015 (n=1,708)

Source: SISRHC, 2018, analytic cases.



HUMANIZED CARE IN PEDIATRIC ONCOLOGY

Sources: GT de Humanização FOP 2017; Instituto Municipal Helena Antipoff, 2018; Hospital São José do Avai (Itaperuna), 2018, Hospital Estadual da Criança, 2018.

Hospital	Palliative Care	Hospital classroom ¹	Humanized and exclusive chemotherapy room for children and adolescents ²
INCA - HC I (RJ)	Yes	Yes	Yes
HEMORIO (RJ)	Yes	Yes	Yes
Hospital dos Servidores (RJ)	Yes	Yes	Yes
IPPMG/UFRJ (RJ)	Yes	Yes	Yes
Hospital São José do Avai (Itaperuna)	Yes	Yes	Yes
Hospital Federal da Lagoa (RJ)	Yes	Yes	Yes
Hospital Estadual da Criança (RJ) ³	Yes	Yes	Yes

¹ Hospital classroom: Hospitalized children and adolescents have the right to enjoy some form of recreation, health education programs, and supervision of the school curriculum during their hospital stay (RESOLUTION nº 41/1995 CONANDA).

² Humanized and exclusive chemotherapy rooms for children and adolescents: "The room for applying chemotherapy in children and adolescents should be different from the room for applying chemotherapy in adults" (Ordinance 140, 02/27/2014). The Carioca Aquarium (AC) is a humanized chemotherapy room with a seabed theme, implemented by Instituto Desiderata since 2007 in public hospitals that are part of United for the Cure.

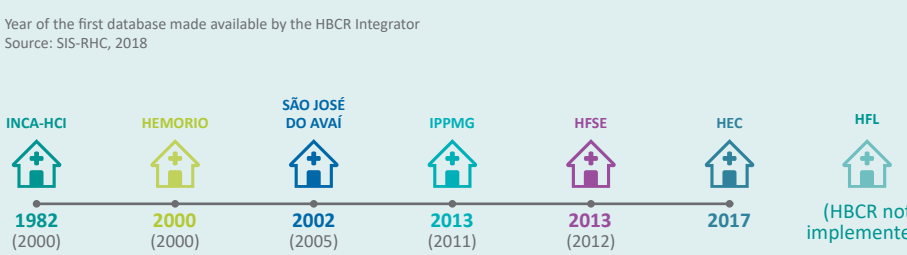
The humanization of the chemotherapy and tomography room with the Intergalactic Theme (TI) at the Hospital Estadual da Criança was performed by the State Department of Health. Tomography equipment was decorated as a Yellow Submarine by Instituto Desiderata in 2012 at the Hospital Municipal Jesus. INCA transformed its whole pediatric oncology sector in 2017.

³ The Hospital Estadual da Criança was authorized as UNACON in 2017.

MONITORING OF INFORMATION

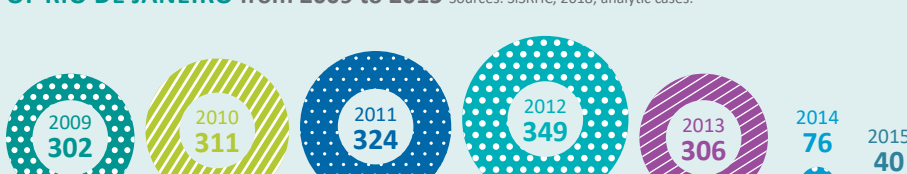
HISTORY OF IMPLEMENTATION OF HOSPITAL-BASED CANCER REGISTRIES IN SPECIALIZED PEDIATRIC ONCOLOGY HOSPITALS

Year of the first database made available by the HBCR Integrator
 Source: SIS-RHC, 2018

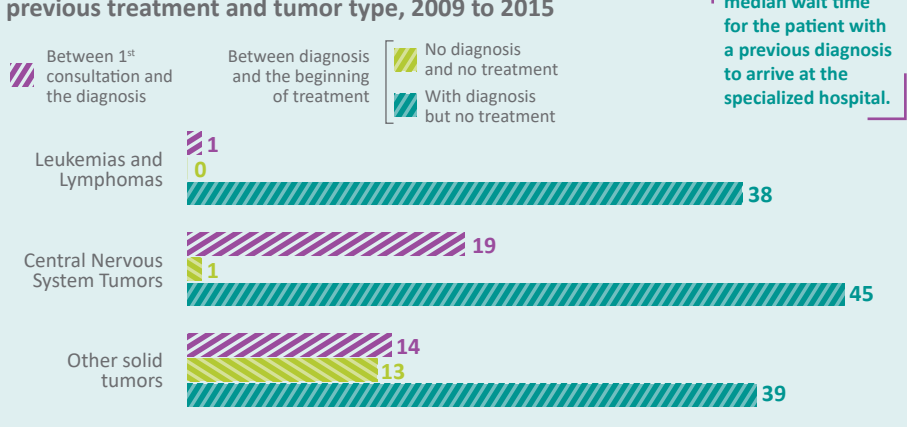


CHILDHOOD CANCER CASES REGISTERED IN HOSPITALS IN THE STATE OF RIO DE JANEIRO from 2009 to 2015

Sources: SISRHC, 2018, analytic cases.



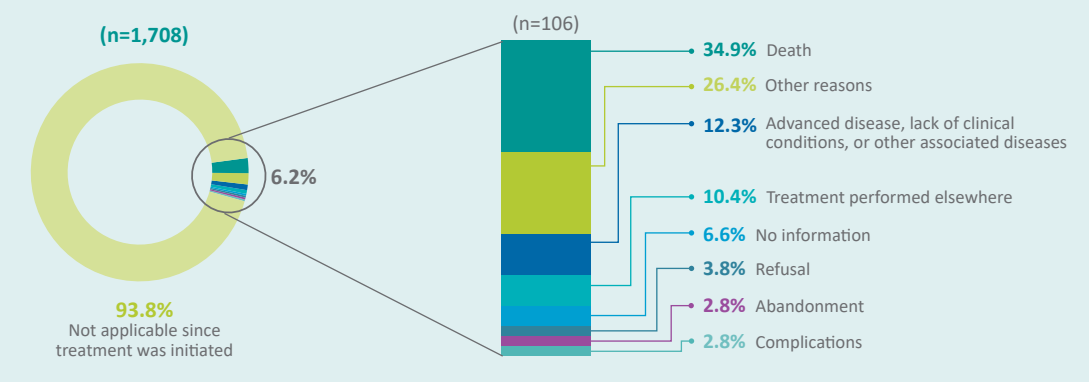
MEDIAN WAIT TIME IN DAYS, according to previous treatment and tumor type, 2009 to 2015



Source: SISRHC, 2018, analytic cases.

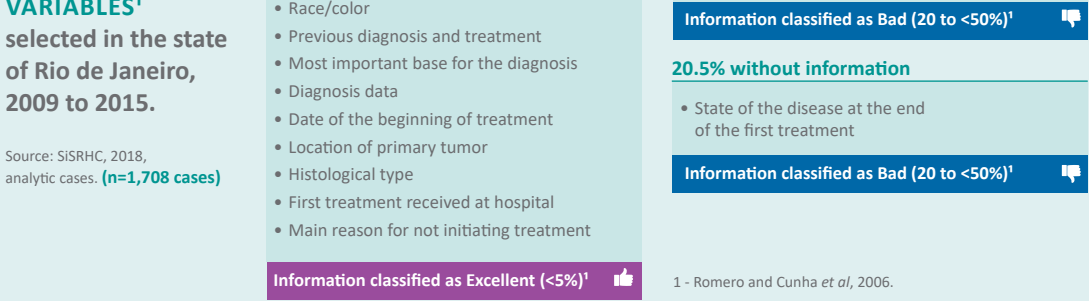
MAIN REASONS FOR NOT INITIATING TREATMENT in the state of Rio de Janeiro, 2009 to 2015

Source: SISRHC, 2018, considered analytic cases.



INCOMPLETENESS OF MANDATORY VARIABLES¹ selected in the state of Rio de Janeiro, 2009 to 2015.

Source: SISRHC, 2018, analytic cases (n=1,708 cases)



PERCENTAGE OF HISTOPATHOLOGICAL DIAGNOSIS IN THE STATE OF RIO DE JANEIRO, 2009 to 2015

Sources: SISRHC, 2018, analytic cases; INCA, Manual for Hospital-Based Cancer Registries, 2008.

