



**NATIONAL CANCER REGISTRY**

**Division of the National Health Laboratory Service**



**health**

Department:  
Health  
**REPUBLIC OF SOUTH AFRICA**

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# CHILDHOOD CANCER REGISTRY 2019 ANNUAL REPORT

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# Table of Contents

<b>Acknowledgements .....</b>	<b>v</b>
<b>List of Figures .....</b>	<b>vi</b>
<b>List of Tables .....</b>	<b>vi</b>
<b>Acronyms and Abbreviations .....</b>	<b>vii</b>
<b>EXECUTIVE SUMMARY .....</b>	<b>viii</b>
<b>INTRODUCTION.....</b>	<b>1</b>
Background.....	2
<b>METHODS .....</b>	<b>3</b>
Data sources .....	3
Confidentiality .....	5
Statistical Methods.....	5
<b>RESULTS.....</b>	<b>6</b>
Cancer Incidence by type .....	6
Cancer Incidence by sex .....	7
Cancer Incidence by age-groups .....	12
<b>DISCUSSION .....</b>	<b>14</b>
Other Childhood Cancers Registry activities ( 01 April 2022- 31 March 2023).....	16
<b>REFERENCES .....</b>	<b>18</b>
Appendix 1: Cancer Notification Form.....	19
Appendix 2: Sites cancer notification forms received from (paediatric cases), 2019 .....	20
Appendix 3: International Classification of Childhood Cancer, 3 <sup>rd</sup> edition .....	20

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## List of Figures

Figure 1: Population pyramid of South Africa (2019). Age groups 0 - 14 years highlighted in red.....	2
Figure 2: Distribution of major public health facilities with paediatric oncology units in South Africa, 2022. ....	3
Figure 3: Data sources and data flow to create a comprehensive national dataset of childhood cancers in South Africa, 2019.....	5
Figure 4: Number of childhood cancer cases per main group as classified by the ICCC-3, South Africa, 2019. ....	13
Figure 5: Distribution of childhood cancers by cancer type and sex, South Africa, 2019 .....	13
Figure 6: IARC-GICR collaborating centre inauguration held at NICD campus, Johannesburg, South Africa (November 2022). Left to right: Natasha Abraham (NCR), Dr Kibachio Mwangi (WHO), Sandhya Singh (DoH), Dr Kamy Chetty (NHLS), Dr Mazvita Muchengeti (NCR), Dr Magdalena Paczkowski (Vital Strategies), Sizeka Mashele (NCR), Prof Adrian Puren (NICD), Dr Freddie Bray (IARC). ....	16
Figure 7: The NCR staff supporting CHOC Flip-flop day, February 2023.....	17

## List of Tables

Table 1: Most commonly diagnosed childhood cancers by sex, South Africa, 2019.....	7
Table 2: Cancer incidence for children 0 - 14years old by main cancer groups as defined by the 12 main groups per the ICCC-3, South Africa (2019).....	8
Table 3: Cancer incidence for children 0 - 14years old by sub-groups as defined by the ICCC-3, South Africa (2019) .....	9
Table 4: Most commonly diagnosed childhood cancers by age group, South Africa, 2019. ....	12

## Acronyms and Abbreviations

ASR	: Age-Standardised Incidence Rate
CHOC	: Childhood Cancer Foundation South African
CNS	: Central Nervous System
NDoH	: National Department of Health, South Africa
EPBCR	: Ekurhuleni Population-Based Cancer Registry
GICC	: Global Initiative for Childhood Cancer
GICR	: Global Initiative for Cancer Registry
IACR	: International Association of Cancer Registries
IARC	: International Agency for Research on Cancer
ICCC-3	: International Classification of Childhood Cancer, Third Edition
ICDO-3	: International Classification of Diseases for Oncology, Third Edition
NICD	: National Institute for Communicable Diseases
NCR	: National Cancer Registry, South Africa
PBCR	: Population-Based Cancer Registries
POPI Act	: Protection of Personal Information Act, South Africa
SA	: South Africa
SSA	: sub-Saharan Africa
STATSSA	: Statistics, South Africa
WHO	: World Health Organization
WSP	: World Standard Population

## **EXECUTIVE SUMMARY**

There is a need for accurate childhood cancer estimates globally, but this is particularly difficult and scarce in sub-Saharan Africa. Only 20% of children with cancer in low- and middle-income countries survive, while 80% of children diagnosed with cancer in high-income countries survive. The World Health Organization (WHO) has made childhood cancer a global priority to reduce these disparities and to improve cancer outcomes for children. Cancer surveillance is the responsibility of the National Cancer Registry (NCR) in South Africa (SA). In 2011, the South African National Department of Health enacted Regulation No. 380 of the National Health Act (Act 61 of 2003), which formally established the NCR as its delegated agency for the collection of cancer surveillance information and made cancer a reportable disease. This is the second childhood cancers report using the International Classification of Childhood Cancers Third Edition (ICCC-3) by the NCR. A total of 961 cancers were diagnosed in children aged 0 - 14 years old in South Africa in 2019. This equated to an overall age-standardized rate of 57.7 cases per million (95% CI: 46.8-70.8). We found the most common cancer group diagnosed to be leukaemias and the second most common cancers were lymphomas. Approximately 40% of the cases (n=376) were diagnosed in children aged 0 - 4 years old. Our results are comparable to results from within the African region and global trends. Annual reports of childhood cancers are the first step towards improving reporting of childhood cancers and raising awareness of the incidence of childhood cancers. Efforts are ongoing to receive data from all possible data sources.



## INTRODUCTION

The National Cancer Registry (NCR) is responsible for cancer surveillance in South Africa (SA). This includes the systemic collection, storage, analysis, interpretation and reporting of cancer cases [1]. The NCR achieves cancer surveillance through its pathology-based cancer registry, its sentinel population-based cancer registries located in the Gauteng and Kwa-Zulu Natal provinces and the childhood cancer registry.

For the NCR to accurately report cancer incidence, the South African Department of Health enacted Regulation No 380 of the National Health Act (Act 61 of 2003), which formally appointed the National Cancer Registry (NCR) as its delegated agency for the collection of cancer surveillance information [2]. This regulation made cancer a reportable disease with every healthcare worker obliged to report confirmed cancers to the NCR [2,3].

There is a need for accurate childhood cancer estimates globally, but this is particularly difficult and scarce in sub-Saharan Africa (SSA) [4,5]. One of the reasons is that childhood cancers are rare compared to adult cancers [6]. Diagnosis of childhood cancers is also challenging as it may mimic communicable diseases common in SSA, with the additional challenges of inadequate diagnostic abilities in resource-poor settings. Survival rates of childhood cancers in low- and middle-income countries are far lower, approximately 20%, compared to high-income countries where the survival rate is approximately 80%. This was recently highlighted in the Global Initiative for Childhood Cancer (GICC) of the World Health Organization (WHO); which was launched to improve cancer outcomes for children with cancer and to attain a survival rate of 60% by 2030 [7].

Cancers affecting children have been identified as a national priority in South Africa and work is underway on drafting a “Childhood Cancer Strategic Framework” [8]. This is the second standalone report on childhood cancers using the International Classification of Childhood Cancers Third Edition (ICCC-3) [9]. The report is a much-needed to guide both clinicians and policymakers to improve childhood cancer awareness, screening, diagnosis, treatment and outcomes. For this report, childhood cancers are defined as malignant tumours diagnosed in children aged 0 - 14 years old.

## Background

In 2019, South Africa reported a population of approximately 58,78 million, with children aged 0-14 years old comprising  $\approx 28,8\%$  of the population [10]. The distribution of males and females aged 0-14 years old is comparable (Figure 1).

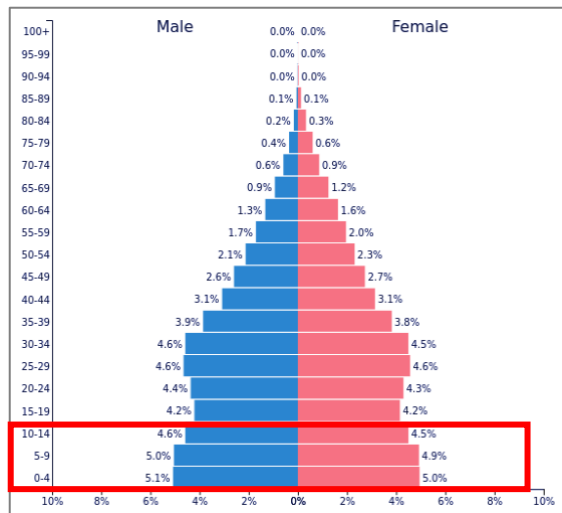


Figure 1: Population pyramid of South Africa (2019). Age groups 0 - 14 years highlighted in red.

In South Africa, there are currently 13 paediatric oncology units housed within the public sector health facilities in the country. Figure 2 shows the distribution of paediatric oncology units within the public health sector of South Africa.

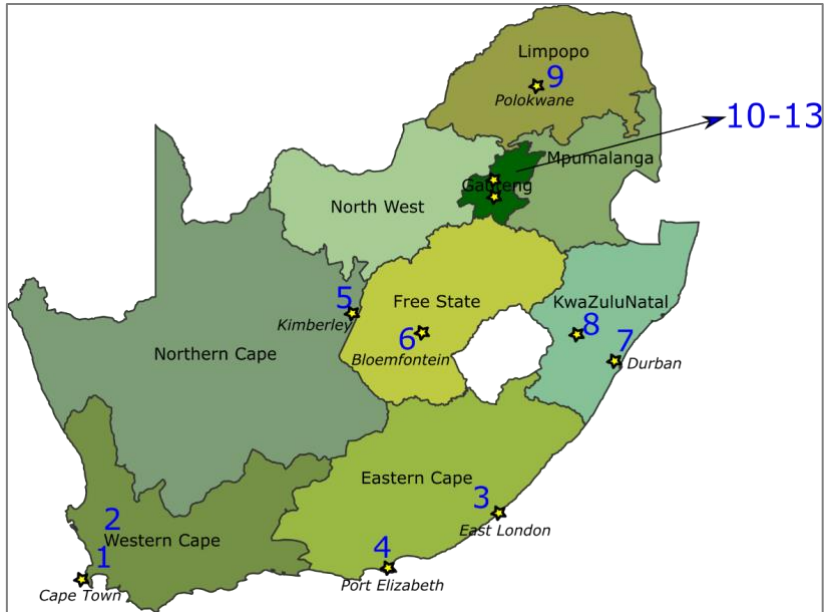


Figure 2: Distribution of major public health facilities with paediatric oncology units in South Africa, 2022.

The sites are (1) Red Cross War Memorial Children’s Hospital (2) Tygerberg Hospital (3) Frere Hospital (4) Port Elizabeth Provincial Hospital (5) Robert Mangaliso Sobukwe Hospital (6) Universitas Academic Hospital (7) Inkosi Albert Luthuli Central Hospital (8) Greys Hospital (9) Pietersburg Hospital (10) Charlotte Maxeke Johannesburg Academic Hospital (11) Chris Hani Baragwanath Academic Hospital (12) Steve Biko Academic Hospital (13) Dr George Mukhari Academic Hospital

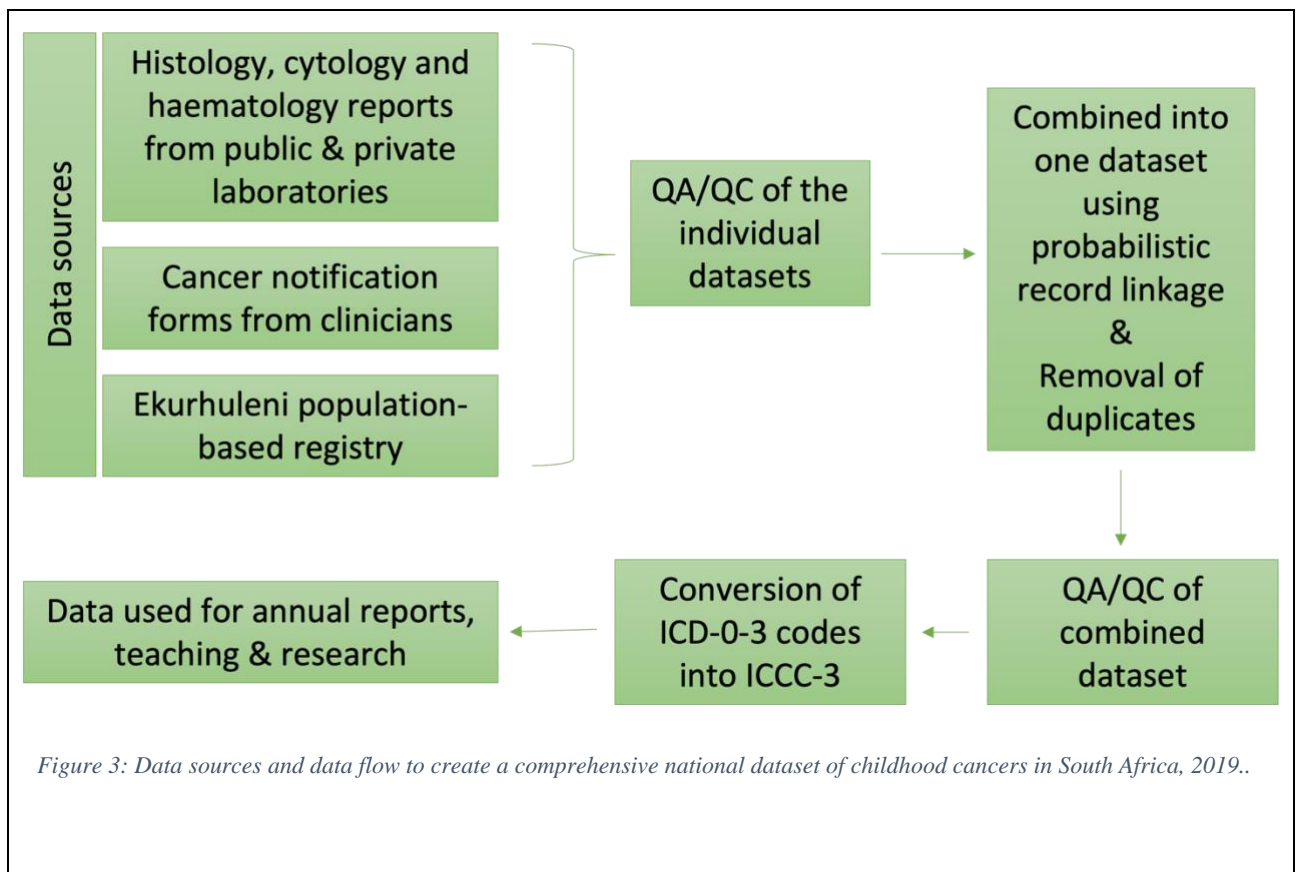
## METHODS

### Data sources

The NCR currently includes all reported pathology-diagnosed cases of childhood cancers (0 - 14 years) within the annual pathology-based cancer incidence report using the International Classification of Diseases for Oncology Third Edition (ICD-0-3) classification system. However, this is an under-estimation of incidence as it only captures cancers diagnosed pathologically (histology, cytology, bone marrow aspirate or trephine). The pathology-based cancer registry includes data from both private and public laboratories. The Ekurhuleni Population-Based Cancer Registry (EPBCR) also reports on all childhood cancer cases identified through both active and passive case finding as detailed in the EPBCR reports (11).

Regulation 380 made cancer a reportable disease with every healthcare worker obliged to report confirmed cancers to the NCR. The NCR has set up a dedicated email for direct reporting of paediatric cancers from healthcare workers (12). These cancer notifications sent by clinicians, from both private and public sectors, are a valuable data source as it allows cases to be identified that may have been diagnosed without a pathology report, or cases diagnosed outside of the population-based registry demarcation.

For this report, data from the pathology-based cancer registry, the EPBCR and cancer notifications sent by clinicians from various sites throughout the country (Appendix 2) were used. The data from the three sources were combined to create one comprehensive national dataset (Figure 3). Duplicate cases were removed. All new cancer cases diagnosed from 01 January 2019 to 31 December 2019 were included. Furthermore, these cases were checked against the previous year's dataset to ensure reporting of only new cases within the year. Cases that were not South African residents were excluded i.e. specimens sent to laboratories from other countries or patients with home address based in other countries. Using the ICD-0-3, the cancers have been classified into 12 main groups and 48 sub-groups according to the third edition of the International Classification of Childhood Cancer (ICCC-3) [9]. The 12 main groups are I. Leukaemias, myeloproliferative diseases, and myelodysplastic diseases (*Leukaemias*) II. Lymphomas and reticuloendothelial neoplasms (*Lymphomas*), III. CNS and miscellaneous intracranial and intraspinal neoplasms (*malignant CNS tumours*), IV. Neuroblastoma and other peripheral nervous cell tumours (*Sympathetic nervous system tumours*), V. Retinoblastomas (*Retinoblastomas*), VI. Renal tumours (*Renal tumours*), VII. Hepatic tumours (*Hepatic tumours*), VIII. Malignant bone tumours (*Malignant bone tumours*), IX. Soft tissue and other extraosseous sarcomas (*Soft tissue sarcomas*), X. Germ cell tumours, trophoblastic tumours, and neoplasms of gonads (*Germ cell tumours*), XI. Other malignant epithelial neoplasms and malignant melanomas (*Malignant epithelial neoplasms*), and XII. Other and unspecified malignant neoplasms (*Other and unspecified malignant tumours*).



### Confidentiality

The NCR adheres to the NHLS, the IARC/IACR guidelines and the POPI Act to ensure the preservation of confidentiality [11]. Cancer statistics are released in an aggregated format in annual reports published on the NCR website.

### Statistical Methods

The results are presented as:

- the number of new cancer cases,
- the percentage of all new cancer cases,
- Age-Specific Incidence rates (ASIR) per million
- Age-Standardised Incidence Rate (ASR) per million

The results are further stratified by:

- sex (Male and Female),

- by ICCC-3 groups and sub-groups (Appendix 3)
- age groups (4-year interval e.g. 0 - 4 years, 5 - 9, 10 - 14)

For Age standardization, the Segi-World Standard Population (WSP) is used as per international cancer registration norms. STATSSA mid-year population data for South Africa is used as a denominator.

The Calculation methods are as follows:

$$\text{Crude} = \frac{\text{Number of new cases}}{\text{Mid-year population}} \times 1,000,000$$

$$\text{WSP weighting} = \frac{\text{WSP (for each age group)}}{\text{Total WSP for all age groups}}$$

$$\text{ASR} = \text{Crude} \times \text{WSP weighting}$$

## RESULTS

A total of 961 cancers were diagnosed in children aged 0 - 14years old in South Africa in 2019. This equated to an overall age-standardized rate of 57.7 cases per million (95%CI: 46.8-70.8) (Table 2).

Of the 961 cases, 285 cases (29.7%) were found both in the NCR registries and in cancer notifications sent by clinicians. There were 372 cases (38.7%) identified from the NCR pathology-based registry and/or the EPBCR. Of the remaining cases 304 (31.6%) were reported by clinicians only.

Incidence rates were comparable in boys compared to girls (incidence sex ratio was 1.11 boys:1 girl (Table 2).

### Cancer Incidence by type

The most common cancer diagnosed in children was leukaemia, which accounted for 20% of all cancers diagnosed in children aged 0 - 14yrs with an ASR of 11.61 per million children (95%CI 10.03-13.37) (Table 2). Of the leukaemias, lymphoid leukaemias were the most commonly diagnosed (Table 3) with an ASR of 8.02 per million (95%CI: 6.71-9.50) with the highest incidence being found in the 5 - 9 years and 0 - 4 years age groups with an age-specific incidence rate of 8.21 and 8.11 cases per million respectively.

Lymphomas were the second most common cancer group diagnosed in children, with the highest number of cases (n=74) occurring in the 10 - 14 years age group with an age-specific incidence rate 13.5 per million (Table 2). Non-Hodgkin lymphomas (except Burkitt lymphoma) and Hodgkin lymphomas were the most common type of lymphomas diagnosed (Table 2). Only 18 cases of malignant bone tumours were diagnosed making it the least commonly diagnosed cancer in children in 2019. However, of the 18, 61.1% (n=11) were diagnosed in children aged 0 - 4 years old.

### Cancer Incidence by sex

Of the 961 cancers diagnosed, 52.7% (n=506) were diagnosed in boys and 47.1% (n=453) were diagnosed in girls (Figure 5). There were two cases (0.21%) reported with unknown sex.

Lymphoid leukaemias, nephroblastoma, retinoblastoma and non-Hodgkin lymphomas were the most common cancers among boys and girls. Hodgkin lymphoma is one of the top five commonly diagnosed cancer in boys, but not in girls (Table 1).

Table 1: Most commonly diagnosed childhood cancers by sex, South Africa, 2019

<b>Boys</b>	<b>n</b>	<b>(%)</b>
(Ia) Lymphoid leukaemias	71	14.0
(VIa) Nephroblastoma and other nonepithelial renal tumours	56	11.0
(IIb) Non-Hodgkin lymphomas (except Burkitt lymphoma)	44	8.7
(IIa) Hodgkin lymphomas	35	6.9
(V) Retinoblastoma	31	6.1
<b>Girls</b>	<b>n</b>	<b>(%)</b>
(Ia) Lymphoid leukaemias	63	13.9
(VIa) Nephroblastoma and other nonepithelial renal tumours	60	13.2
(IXd) Other specified soft tissue sarcomas	31	6.8
(V) Retinoblastoma	27	6.0
(IIb) Non-Hodgkin lymphomas (except Burkitt lymphoma)	23	5.0

Table 2: Cancer incidence for children 0 - 14years old by main cancer groups as defined by the 12 main groups per theICCC-3, South Africa (2019)

Cancer Group	Number of cases				Ratio (M/F)	%	Rates per Million Age-Specific Rates			Crude	ASR	LCL	UCL
	Age 0-4	Age 5-9	Age 10-14	All ages			ASIR 0-4	ASIR 5-9	ASIR 10-14				
I. Leukaemias, myeloproliferative diseases, and myelodysplastic diseases	65	69	62	196	1.2	20.4	11.46	12.05	11.33	11.62	11.61	10.03	13.37
II. Lymphomas and reticuloendothelial neoplasms	24	58	74	156	1.9	16.2	4.23	10.13	13.52	9.25	8.83	7.50	10.34
III. CNS and miscellaneous intracranial and intraspinal neoplasms	54	54	41	149	1.1	15.5	9.52	9.43	7.49	8.83	8.90	7.52	10.46
IV. Neuroblastoma and other peripheral nervous cell tumours	23	15	1	39	0.8	4.1	4.05	2.62	0.18	2.31	2.47	1.75	3.37
V. Retinoblastoma	48	9	1	58	1.1	6.0	8.46	1.57	0.18	3.44	3.83	2.91	4.95
VI. Renal tumours	76	35	6	117	0.9	12.2	13.39	6.11	1.10	6.94	7.48	6.18	8.96
VII. Hepatic tumours	20	4	3	27	1.1	2.8	3.52	0.70	0.55	1.60	1.75	1.15	2.54
VIII. Malignant bone tumours	3	4	11	18	1.0	1.9	0.53	0.70	2.01	1.07	1.01	0.60	1.61
IX. Soft tissue and other extraosseous sarcomas	37	32	48	117	1.1	12.2	6.52	5.59	8.77	6.94	6.87	5.68	8.25
X. Germ cell tumours, trophoblastic tumours, and neoplasms of gonads	24	9	10	43	0.5	4.5	4.23	1.57	1.83	2.55	2.68	1.93	3.60
XI. Other malignant epithelial neoplasms and malignant melanomas	1	12	26	39	1.2	4.1	0.18	2.10	4.75	2.31	2.12	1.51	2.91
XII. Other and unspecified malignant neoplasms	1	0	1	2	1.0	0.2	0.18	0.00	0.18	0.12	0.12	0.01	0.44
<b>Total</b>	<b>376</b>	<b>301</b>	<b>284</b>	<b>961</b>	<b>1.1</b>	<b>100</b>	<b>66.3</b>	<b>52.6</b>	<b>51.9</b>	<b>57.0</b>	<b>57.7</b>	<b>46.8</b>	<b>70.8</b>

Ratio (M/F): male-to-female ratio

ASIR: Age-specific incidence rates per million

Crude: crude rates expressed per million aged 0-14 years

ASR: age-standardized incidence rate per million (World Standard population)

LCL: Lower 95% confidence intervals for the ASR

UCL: Upper 95% confidence intervals for the ASR



Table 3: Cancer incidence for children 0 - 14years old by sub-groups as defined by the ICC3, South Africa (2019)

Cancer type	Number of cases				Ratio (M/F)	%	Rates per Million Age-Specific Rates				Crude	ASR	LCL	UCL
	Age 0-4	Age 5-9	Age 10-14	All			Age 0-4	Age 5-9	Age 10-14					
<b>I. Leukaemias, myeloproliferative diseases, and myelodysplastic diseases</b>														
(Ia) Lymphoid leukaemias	46	47	42	135	1.1	14.0	8.11	8.21	7.68	8.00	8.02	6.71	9.50	
(Ib) Acute myeloid leukaemias	15	18	14	47	1.5	4.9	2.64	3.14	2.56	2.79	2.78	2.04	3.70	
(Ic) Chronic myeloproliferative diseases	0	0	1	1	-	0.1	0.00	0.00	0.18	0.06	0.05	0.00	0.31	
(Id) Myelodysplastic syndrome and other myeloproliferative diseases	0	0	1	1	-	0.1	0.00	0.00	0.18	0.06	0.05	0.00	0.31	
(Ie) Unspecified and other specified leukaemias	4	4	4	12	0.7	1.2	0.70	0.70	0.73	0.71	0.71	0.37	1.24	
<b>II. Lymphomas and reticuloendothelial neoplasms</b>														
(IIa) Hodgkin lymphomas	3	21	28	52	2.1	5.4	0.53	3.67	5.12	3.08	2.87	2.14	3.78	
(IIb) Non-Hodgkin lymphomas (except Burkitt lymphoma)	12	20	35	67	1.9	7.0	2.11	3.49	6.40	3.97	3.80	2.94	4.84	
(IIc) Burkitt lymphoma	5	16	8	29	1.2	3.0	0.88	2.80	1.46	1.72	1.67	1.11	2.40	
(IId) Miscellaneous lymphoreticular neoplasms	1	1	2	4	3.0	0.4	0.18	0.17	0.37	0.24	0.23	0.06	0.60	
(IIe) Unspecified lymphomas	3	0	1	4	-	0.4	0.53	0.00	0.18	0.24	0.26	0.07	0.65	
<b>III. CNS and miscellaneous intracranial and intraspinal neoplasms</b>														
(IIIa) Ependymomas and choroid plexus tumour	14	8	5	27	2.4	2.8	2.47	1.40	0.91	1.60	1.67	1.10	2.43	
(IIIb) Astrocytomas	13	13	11	37	0.9	3.9	2.29	2.27	2.01	2.19	2.20	1.55	3.04	
(IIIc) Intracranial and intraspinal embryonal tumours	11	9	11	31	1.2	3.2	1.94	1.57	2.01	1.84	1.84	1.25	2.62	
(IIId) Other gliomas	6	14	4	24	0.7	2.5	1.06	2.45	0.73	1.42	1.41	0.90	2.10	
(IIIe) Other specified intracranial and intraspinal neoplasms	9	9	9	27	0.8	2.8	1.59	1.57	1.64	1.60	1.60	1.05	2.33	
(IIIff) Unspecified intracranial and intraspinal neoplasms	1	1	1	3	2.0	0.3	0.18	0.17	0.18	0.18	0.18	0.04	0.52	

Cancer type	Number of cases				Ratio (M/F)	%	Rates per Million Age-Specific Rates				Crude	ASR	LCL	UCL
	Age 0-4	Age 5-9	Age 10-14	All			Age 0-4	Age 5-9	Age 10-14					
<b>V. Retinoblastoma</b>														
(V) Retinoblastoma	48	9	1	58	1.1	6.0	8.46	1.57	0.18	3.44	3.83	2.91	4.95	
<b>VI. Renal tumours</b>														
(VIa) Nephroblastoma and other nonepithelial renal tumours	75	35	6	116	0.9	12.1	13.2	2	6.11	1.10	6.88	7.41	6.12	8.89
(VIb) Renal carcinomas	0	0	0	0	-	0.0	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.22
(VIc) Unspecified malignant renal tumours	1	0	0	1	-	0.1	0.18	0.00	0.00	0.06	0.07	0.00	0.36	
<b>VII. Hepatic tumours</b>														
(VIIa) Hepatoblastoma	20	3	0	23	1.1	2.4	3.52	0.52	0.00	1.36	1.53	0.97	2.29	
(VIIb) Hepatic carcinomas	0	1	3	4	1.0	0.4	0.00	0.17	0.55	0.24	0.22	0.06	0.56	
(VIIc) Unspecified malignant hepatic tumours	0	0	0	0	-	0.0	0.00	0.00	0.00	0.00	0.00	0.00	0.22	
<b>VIII. Malignant bone tumours</b>														
(VIIIa) Osteosarcomas	1	2	9	12	1.0	1.2	0.18	0.35	1.64	0.71	0.66	0.34	1.16	
(VIIIb) Chondrosarcomas	0	1	0	1	-	0.1	0.00	0.17	0.00	0.06	0.06	0.00	0.32	
(VIIIc) Ewing tumour and related sarcomas of bone	1	0	0	1	-	0.1	0.18	0.00	0.00	0.06	0.07	0.00	0.36	
(VIId) Other specified malignant bone tumours	0	1	2	3	-	0.3	0.00	0.17	0.37	0.18	0.16	0.03	0.49	
(VIIIE) Unspecified malignant bone tumours	1	0	0	1	-	0.1	0.18	0.00	0.00	0.06	0.07	0.00	0.36	
<b>IX. Soft tissue and other extrasosseous sarcomas</b>														
(IXa) Rhabdomyosarcomas	22	12	9	43	1.1	4.5	3.88	2.10	1.64	2.55	2.65	1.92	3.58	
(IXb) Fibrosarcomas, peripheral nerve sheath tumours, and other fibrous neoplasms	4	2	0	6	5.0	0.6	0.70	0.35	0.00	0.36	0.39	0.14	0.83	
(IXc) Kaposi sarcoma	1	2	6	9	2.0	0.9	0.18	0.35	1.10	0.53	0.50	0.23	0.96	
(IXd) Other specified soft tissue sarcomas	9	14	31	54	0.7	5.6	1.59	2.45	5.67	3.20	3.05	2.29	3.98	
(IXe) Unspecified soft tissue sarcomas	1	2	2	5	1.5	0.5	0.18	0.35	0.37	0.30	0.29	0.09	0.68	

Cancer type	Number of cases				Ratio (M/F)	%	Rates per Million Age-Specific Rates			Crude	ASR	LCL	UCL
	Age 0-4	Age 5-9	Age 10-14	All			Age 0-4	Age 5-9	Age 10-14				
<b>X. Germ cell tumours, trophoblastic tumours, and neoplasms of gonads</b>													
(Xa) Intracranial and intraspinal germ cell tumours	8	4	1	13	1.2	1.4	1.41	0.70	0.18	0.77	0.82	0.44	1.41
(Xb) Malignant extracranial and extragonadal germ cell tumours	5	1	2	8	0.3	0.8	0.88	0.17	0.37	0.47	0.50	0.22	0.99
(Xc) Malignant gonadal germ cell tumours	11	4	7	22	0.3	2.3	1.94	0.70	1.28	1.30	1.35	0.84	2.04
(Xd) Gonadal carcinomas	0	0	0	0	-	0.0	0.00	0.00	0.00	0.00	0.00	0.00	0.22
(Xe) Other and unspecified malignant gonadal tumours	0	0	0	0	-	0.0	0.00	0.00	0.00	0.00	0.00	0.00	0.22
<b>XI. Other malignant epithelial neoplasms and malignant melanomas</b>													
(XIa) Adrenocortical carcinomas	0	2	0	2		0.2	0.00	0.35	0.00	0.12	0.11	0.01	0.41
(XIb) Thyroid carcinomas	0	1	3	4	0.3	0.4	0.00	0.17	0.55	0.24	0.22	0.06	0.56
(XIc) Nasopharyngeal carcinomas	0	1	7	8	7.0	0.8	0.00	0.17	1.28	0.47	0.43	0.18	0.85
(XIc) Malignant melanomas	1	1	0	2	1.0	0.2	0.18	0.17	0.00	0.12	0.12	0.01	0.44
(XIe) Skin carcinomas	0	2	7	9	0.5	0.9	0.00	0.35	1.28	0.53	0.48	0.22	0.93
(XIe) Other and unspecified carcinomas	0	5	9	14	1.8	1.5	0.00	0.87	1.64	0.83	0.76	0.42	1.28
<b>XII. Other and unspecified malignant neoplasms</b>													
(XIIa) Other specified malignant tumours	1	0	0	1	-	0.1	0.18	0.00	0.00	0.06	0.07	0.00	0.36
(XIIb) Other unspecified malignant tumours	0	0	1	1	-	0.1	0.00	0.00	0.18	0.06	0.05	0.00	0.31
<b>Total</b>	<b>376</b>	<b>301</b>	<b>284</b>	<b>961</b>		<b>100</b>	<b>66.3</b>	<b>52.6</b>	<b>51.9</b>	<b>57.0</b>	<b>57.7</b>	<b>40.5</b>	<b>84.3</b>

Ratio (M/F): male-to-female ratio

ASIR: Age-specific incidence rates per million

Crude: crude rates expressed per million aged 0-14 years

ASR: age-standardized incidence rate per million (World Standard population)

LCL: Lower 95% confidence intervals for the ASR

UCL: Upper 95% confidence intervals for the ASR

### Cancer Incidence by age-groups

A majority of all childhood cancers were diagnosed in children aged 0 - 4 years (n=376, 49.1%) (Table 2). The annual incidence of the most common cancers by age group is shown in Table 4. Although found in varying percentages (12.8%-15.6%), lymphoid leukaemias were found across all three age groups.

Table 4: Most commonly diagnosed childhood cancers by age group, South Africa, 2019.

Cancer Type	No. of cases	(%)
<b>0 - 4 years</b>		
(VIa) Nephroblastoma and other nonepithelial renal tumours	75	19.95
(V) Retinoblastoma	48	12.77
(Ia) Lymphoid leukaemias	46	12.23
(IVa) Neuroblastoma and ganglioneuroblastoma	23	6.12
(IXa) Rhabdomyosarcomas	22	5.85
<b>5 - 9 years</b>		
(Ia) Lymphoid leukaemias	47	15.61
(VIa) Nephroblastoma and other nonepithelial renal tumours	35	11.63
(IIa) Hodgkin lymphomas	21	6.98
(IIb) Non-Hodgkin lymphomas (except Burkitt lymphoma)	20	6.64
(Ib) Acute myeloid leukaemias	18	5.98
<b>10 - 14 years</b>		
(Ia) Lymphoid leukaemias	42	14.79
(IIb) Non-Hodgkin lymphomas (except Burkitt lymphoma)	35	12.32
(IXd) Other specified soft tissue sarcomas	31	10.92
(IIa) Hodgkin lymphomas	28	9.86
(VIIIa) Osteosarcomas	32	12.74
(Ib) Acute myeloid leukaemias	14	4.93

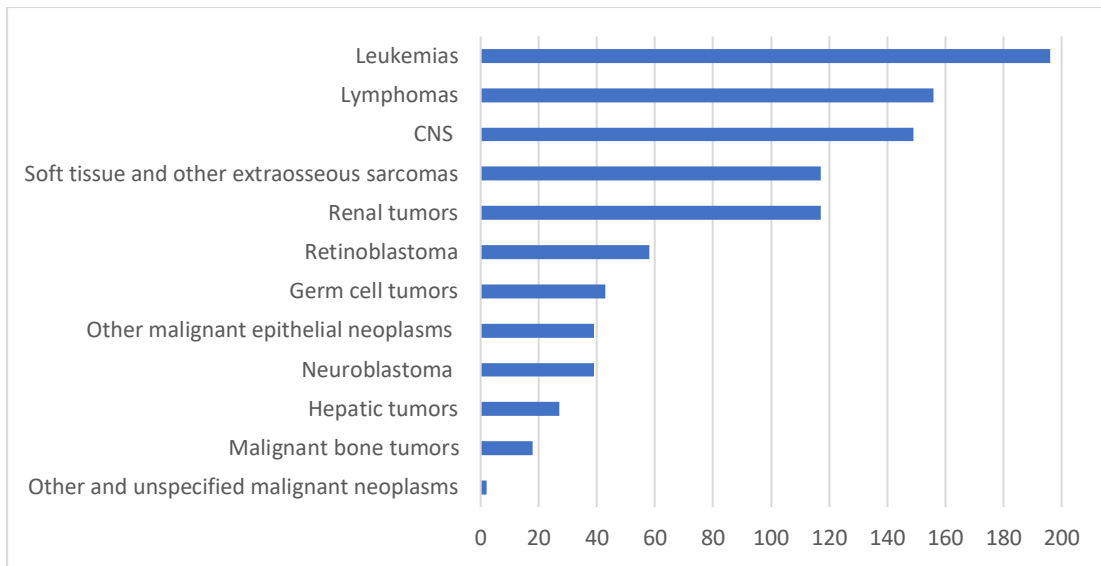


Figure 4: Number of childhood cancer cases per main group as classified by the ICCC-3, South Africa, 2019.

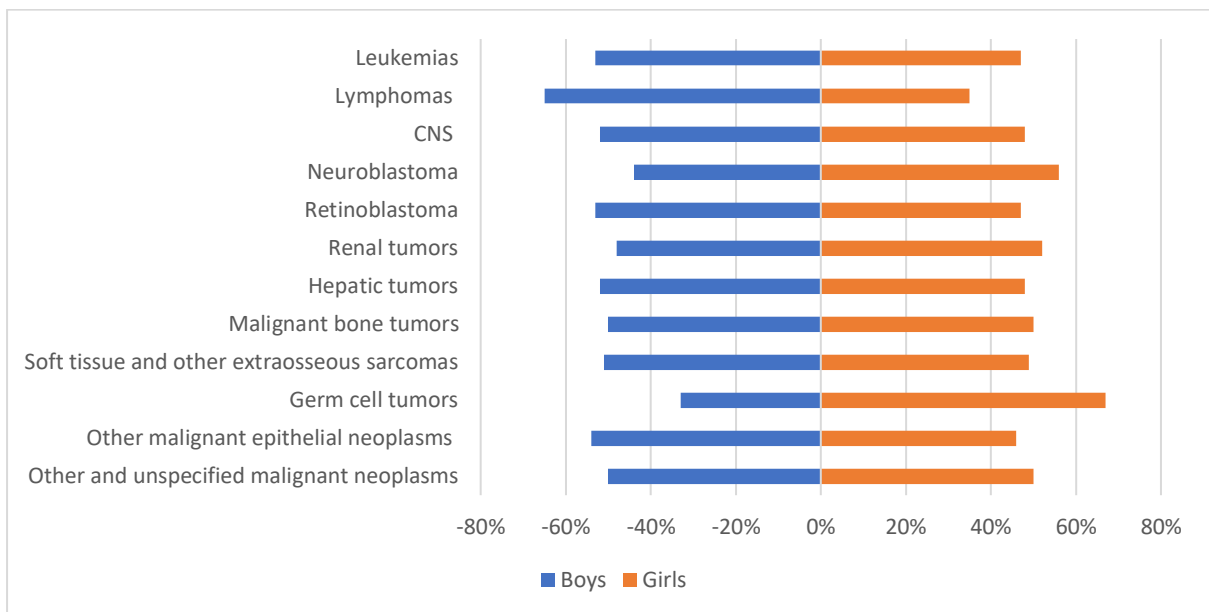


Figure 5: Distribution of childhood cancers by cancer type and sex, South Africa, 2019

## DISCUSSION

This is the second report on childhood cancer incidence by the National Cancer Registry of South Africa. A total of 961 cancers cases were recorded in children aged 0 - 14 years old. The overall ASR of 57.7 per million. Although, the total number of cases was lower compared to 2018 (n=975), some variation is expected from year-to-year due to improved quality-control and data collection. Nonetheless, the overall ASR of 57.7 per million is higher than the previously reported ASR of 45.7 per million children using NCR data from the period 2000-2006 [12] and 45.2 per million from the period 1987-2007 by the South African Children's Tumour Registry (SACTR) [13]. The higher incidence rate is likely a result of improved completeness by linking the various data sources. As there is a lack of unique identifiers in the SA healthcare system, the NCR links data sources using probabilistic record linkage to achieve a more complete estimate of childhood cancers.

Similar to the 2018 report, we found the most common cancer group diagnosed to be leukaemias (20.4%), followed by lymphomas (16.2%). This is in line with previous reports on childhood cancers in South Africa [14,15]. There is higher number of CNS tumours reported in 2019 (n=149; 15.5%), compared to 2018(n=136; 13.9%). This is likely due to additional submission of notification forms from two major tertiary academic hospitals in South Africa that are considered the paediatric oncology treatment centres in their respective regions. As pathology diagnosis is unlikely with CNS tumours, the notification forms submitted by clinicians are an important data source for CNS tumours. Despite the increase in numbers, the number of CNS tumours may still be under-diagnosed and/or under-reported as it is not in line with global trends of being the second most commonly diagnosed childhood cancer [5,15].

Soft tissue sarcomas (12.2%) and renal tumours (12.2%) were the fourth most common cancer. However, compared to 2018, rhabdomyosarcomas were not the most prominent sub-group for soft tissue sarcomas, but were other specified soft tissue sarcomas, making up 46% of all

rhabdomyosarcomas in 2019. Renal tumours, predominantly nephroblastomas, were most prevalent in the 0 - 4 years old age group comparable to global trends [16]

Most childhood cancer cases were diagnosed in children aged 0 - 4years old (n = 376; 39%). The age-specific incidence rates were the highest in children aged 0 - 4 years (66.3 per million) group similar to global patterns[16]. The lowest rates were in the 10 - 14 years old (51.9 per million). Globally the most common cancer in children aged 0 – 4 years is leukaemia, however rates in sub-Saharan Africa (SSA) have always been lower than the global rates [16]. The trend in South Africa is similar to SSA, where leukaemias were the most frequently diagnosed cancer in the 0 - 4 years age group but at lower rates compared to global rates.

In 2019, the number of malignant bone tumours diagnosed was lower in 2018. Although the overall numbers were low, the age group 10 - 14years old (n= 9; 75%) had the most cases of osteosarcomas in line with global trends.

The ratio of boys diagnosed with cancers compared to girls is 1.1:1. Similar to reported global trends, we saw a higher incidence of germ and gonadal tumours in girls compared to boys [16].

The 2019 dataset indicates that the NCR pathology registry is missing at least 32% of all childhood cancers. Of the missed cancers, 65.5% were haematological malignancies (leukaemias and lymphomas) and brain tumours. Although two major tertiary, academic hospitals with paediatric oncology units have been added as data sources in 2019, there is still room for improvement to build a more comprehensive national dataset to provide accurate incidence rates childhood cancers in South Africa. Annual reports of childhood cancers by the NCR are a key step towards improving reporting of childhood cancers and raising awareness of the incidence of childhood cancers. Efforts are ongoing to improve reporting by including information on staging and survival. These are currently limited by poor access to clinical information for staging and poor reporting of vital status.

## **Other Childhood Cancers Registry activities ( 01 April 2022- 31 March 2023)**

The NCR was inaugurated as one of three IARC-GICR Collaborating Centres for SSA by the International Agency for Research in Cancer (IARC) Global Initiative for Cancer Registry development (GICR) in November 2022. As a collaborating centre, NCR will expand the support offered by African Cancer Registry Network (AFCRN) to cancer registries within the continent with a special focus on record linkage training for cervical cancer elimination and childhood cancer registration. This initiative is currently funded by Vital Strategies, an implementation partner of Bloomberg Philanthropies. Our main activities will include reviewing the situation of the target countries; training courses to provide training on cancer registration for childhood cancers and childhood cancer staging. Ms Natasha Abraham has been trained as a master trainer on childhood cancers for the region by IARC. In March 2023, she recently held a training on childhood cancer registration in Tanzania as part of collaborating centre activities.



*Figure 6: IARC-GICR collaborating centre inauguration held at NICD campus, Johannesburg, South Africa (November 2022). Left to right: Natasha Abraham (NCR), Dr Kibachio Mwangi (WHO), Sandhya Singh (DoH), Dr Kamy Chetty (NHLS), Dr Mazvita Muchengeti (NCR), Dr Magdalena Paczkowski (Vital Strategies), Sizeka Mashele (NCR), Prof Adrian Puren (NICD), Dr Freddie Bray (IARC).*

The NCR concluded the Childhood Cancer Surveillance in Southern Africa (CCSSA) project funded by the African-Oxford Research Development grant. The project looked at enhancing existing capacity in the population-based cancer registries (PBCRs) in Eswatini, Mozambique, South Africa, Zambia and Zimbabwe by collecting and analysing data on the occurrence and outcome of childhood cancers. Cancer registrars in the five countries received specific training on childhood cancer registration and



staging. The main outcome was enhanced completeness and quality of the database and improved information on stage at diagnosis. The NCR has also applied for additional grants to further childhood cancer surveillance work within the continent and to supplement collaborating centre activities.

The NCR participated in national stakeholder meetings with the South African Department of Health, South African Children’s Cancer Study group and St. Jude Global to discuss the harmonization of national data. The NCR also supports local childhood cancer research projects and has worked on two projects with clinicians on retinoblastoma and germ cell tumours. Abstracts from these have been submitted to international conferences. The NCR was invited to chair and present at the London Global Cancer Week to showcase our experiences with creating e-learning materials on childhood cancer registration. Ms Natasha Abraham was also invited to chair the “Pandemic’s Impact on Registry Operations” at the 2022 International Association of Cancer Registries (IACR).

NCR supported the Childhood Cancer Foundation (CHOC) South African, one of our key stakeholders, local fundraising campaign “Flip-Flop day” by organizing staff participation at the National Institute for Communicable Diseases (NICD) Sandringham campus to raise awareness around childhood cancers.




*Figure 7: The NCR staff supporting CHOC Flip-flop day, February 2023*

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# Appendix 1: Cancer Notification Form

	<p><b>health</b> Department of Health REPUBLIC OF SOUTH AFRICA</p>	<p>Republic of South Africa Department of Health</p> <p><b>CANCER REGISTRATION FORM</b></p>	<p>To be completed in duplicate in <b>BLOCK LETTERS</b>. Please mark with <input checked="" type="checkbox"/> the CORRECT box, where required. Original to be submitted to the National Cancer Register and copy to be retained: To be submitted to the National Cancer Register via: e-mail: cancer.registry@nhls.ac.za fax: 011 489 9132 / 011 489 9152 Post: P.O. Box 1038, Johannesburg, 2000.</p>
<b>A. PARTICULARS OF INDIVIDUAL</b>			
<p>1. Name of facility <input type="text"/></p> <p>USE PATIENT STICKER <i>if available</i></p> <p>2. Surname <input type="text"/></p> <p>3. Full names <input type="text"/></p> <p>4. Date of birth <input type="text"/></p> <p>5. Folder number <input type="text"/></p> <p>6. Sex <input type="checkbox"/> Male <input type="checkbox"/> Female</p> <p>7. ID number/Passport number <input type="text"/></p> <p>8. Race group <input type="checkbox"/> African <input type="checkbox"/> Coloured <input type="checkbox"/> White <input type="checkbox"/> Indian <input type="checkbox"/> Other _____</p> <p>9. Area of residence</p> <p>9.1 City/town/village <input type="text"/></p> <p>9.2 Postal code <input type="text"/> 9.3 How long at this address? <input type="text"/> years</p> <p>Please record place of birth if not the same as current address</p> <p>9.4 City/town/village <input type="text"/></p> <p>9.5 Postal code <input type="text"/></p>			
<b>B. RISK FACTOR PROFILE</b>			
<p>10. Usual occupation of patient <input type="text"/> (If retired, give type of work done for most of working life)</p> <p>11. Type of industry/business <input type="text"/> (e.g. Mining, farming etc)</p> <p>12. Did the patient ever smoke tobacco? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown</p> <p>13. Did the patient ever consume alcohol regularly? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown (that is, more than once a week)</p> <p>14. HIV status <input type="checkbox"/> Negative <input type="checkbox"/> Positive <input type="checkbox"/> Unknown</p>			
<b>C. CLINICAL AND LABORATORY DETAILS</b>			
<p>15. Date of diagnosis <input type="text"/></p> <p>16. Cancer diagnosis and Histology <input type="text"/> 17. ICD-10 <input type="text"/> • <input type="text"/></p> <p><i>Please give all information available on the site, laterality, histology and behaviour of the tumour</i></p> <hr/> <p>18. Grade <input type="checkbox"/> Well differentiated <input type="checkbox"/> Moderately differentiated <input type="checkbox"/> Poorly differentiated <input type="checkbox"/> Unknown/Not applicable</p> <p>19. Stage <input type="checkbox"/> Primary/localised <input type="checkbox"/> Metastatic <input type="checkbox"/> Unknown/Not applicable</p> <p>20. Invasiveness <input type="checkbox"/> In-situ <input type="checkbox"/> Invasive</p> <p>21. Basis of diagnosis <input type="checkbox"/> Clinical <input type="checkbox"/> Clinical with investigation <input type="checkbox"/> Cytology/histopathology <input type="checkbox"/> Molecular <input type="checkbox"/> Death Certificate</p> <p>22. Prescribed treatment <input type="checkbox"/> Surgery <input type="checkbox"/> Radiation <input type="checkbox"/> Chemotherapy <input type="checkbox"/> Other <input type="checkbox"/> Palliation <input type="checkbox"/> Alternative <input type="checkbox"/> None</p>			
<p><b>INFORMANT PARTICULARS</b></p> <p>Name (Print) _____</p> <p>MP/NC Number <input type="text"/></p> <p>Signature _____ Date _____</p>	<p><b>OFFICE CODING</b></p> <p><input type="text"/> • <input type="text"/></p> <p>M - <input type="text"/> / <input type="text"/> / <input type="text"/></p>		

## Appendix 2: Sites cancer notification forms received from (paediatric cases), 2019

- Chris Hani Baragwanath Academic Hospital
- Charlotte Maxeke Johannesburg Academic Hospital
- Ethekewini Hospital and Heart Complex
- Frere Hospital
- Greys Hospital
- Inkosi Albert Luthuli Central Hospital
- Netcare Clinton Hospital
- P.E. Provincial Hospital (Paediatric Oncology)
- Robert Mangaliso Sobukwe Hospital
- Steve Biko Academic Hospital
- Tygerberg Hospital
- Universitas Hospital
- Wits Donald Gordon Medical Centre
- Red Cross War Memorial Children's Hospital
- Stanger Hospital

## Appendix 3: International Classification of Childhood Cancer, 3<sup>rd</sup> edition

Site Group	ICD-O-3 Histology (Type)	ICD-O-2/3 Site
<b>I Leukaemias, myeloproliferative diseases, and myelodysplastic diseases</b>		
(a) Lymphoid leukaemias	9820, 9823, 9826, 9827, 9831-9837, 9940, 9948	C000-C809
(b) Acute myeloid leukaemias	9840, 9861, 9866, 9867, 9870-9874, 9891, 9895-9897, 9910, 9920, 9931	C000-C809
(c) Chronic myeloproliferative diseases	9863, 9875, 9876, 9950, 9960-9964	C000-C809
(d) Myelodysplastic syndrome and other myeloproliferative diseases	9945, 9946, 9975, 9980, 9982-9987, 9989	C000-C809
(e) Unspecified and other specified leukaemias	9800, 9801, 9805, 9860, 9930	C000-C809
<b>II Lymphomas and reticuloendothelial neoplasms</b>		
(a) Hodgkin lymphomas	9650-9655, 9659, 9661-9665, 9667	C000-C809
(b) Non-Hodgkin lymphomas (except Burkitt lymphoma)	9591, 9670, 9671, 9673, 9675, 9678-9680, 9684, 9689-9691, 9695, 9698-9702, 9705, 9708, 9709, 9714, 9716-9719, 9727-9729, 9731-9734, 9760-9762, 9764-9769, 9970	C000-C809
(c) Burkitt lymphoma	9687	C000-C809
(d) Miscellaneous lymphoreticular neoplasms	9740-9742, 9750, 9754-9758	C000-C809

(e) Unspecified lymphomas	9590, 9596	C000-C809
<b>III CNS and miscellaneous intracranial and intraspinal neoplasms</b>		
(a) Ependymomas and choroid plexus tumour	9383, 9390-9394	C000-C809
(b) Astrocytomas	9380	C723
	9384, 9400-9411, 9420, 9421-9424, 9440-9442	C000-C809
(c) Intracranial and intraspinal embryonal tumours	9470-9474, 9480, 9508	C000-C809
	9501-9504	C700-C729
(d) Other gliomas	9380	C700-C722, C724-C729, C751, C753
	9381, 9382, 9430, 9444, 9450, 9451, 9460	C000-C809
(e) Other specified intracranial and intraspinal neoplasms	8270-8281, 8300, 9350-9352, 9360-9362, 9412, 9413, 9492, 9493, 9505-9507, 9530-9539, 9582	C000-C809
(f) Unspecified intracranial and intraspinal neoplasms	8000-8005	C700-C729, C751-C753
<b>IV Neuroblastoma and other peripheral nervous cell tumours</b>		
(a) Neuroblastoma and ganglioneuroblastoma	9490, 9500	C000-C809
(b) Other peripheral nervous cell tumours	8680-8683, 8690-8693, 8700, 9520-9523	C000-C809
	9501-9504	C000-C699, C739-C768, C809
<b>V Retinoblastoma</b>	<b>9510-9514</b>	<b>C000-C809</b>
<b>VI Renal tumours</b>		
(a) Nephroblastoma and other nonepithelial renal tumours	8959, 8960, 8964-8967	C000-C809
	8963, 9364	C649
(b) Renal carcinomas	8010-8041, 8050-8075, 8082, 8120-8122, 8130-8141, 8143, 8155, 8190-8201, 8210, 8211, 8221-8231, 8240, 8241, 8244-8246, 8260-8263, 8290, 8310, 8320, 8323, 8401, 8430, 8440, 8480-8490, 8504, 8510, 8550, 8560-8576	C649
	8311, 8312, 8316-8319, 8361	C000-C809
(c) Unspecified malignant renal tumours	8000-8005	C649
<b>VII Hepatic tumours</b>		
(a) Hepatoblastoma	8970	C000-C809

(b) Hepatic carcinomas	8010-8041, 8050-8075, 8082, 8120-8122, 8140, 8141, 8143, 8155, 8190-8201, 8210, 8211, 8230, 8231, 8240, 8241, 8244-8246, 8260-8264, 8310, 8320, 8323, 8401, 8430, 8440, 8480-8490, 8504, 8510, 8550, 8560-8576	C220, C221
	8160-8180	C000-C809
(c) Unspecified malignant hepatic tumours	8000-8005	C220, C221
<b>VIII Malignant bone tumours</b>		
(a) Osteosarcomas	9180-9187, 9191-9195, 9200	C400-C419, C760-C768, C809
(b) Chondrosarcomas	9210, 9220, 9240	C400-C419, C760-C768, C809
	9221, 9230, 9241-9243	C000-C809
(c) Ewing tumour and related sarcomas of bone	9260	C400-C419, C760-C768, C809
	9363-9365	C400-C419
(d) Other specified malignant bone tumours	8810, 8811, 8823, 8830	C400-C419
	8812, 9250, 9261, 9262, 9270-9275, 9280-9282, 9290, 9300-9302, 9310-9312, 9320-9322, 9330, 9340-9342, 9370-9372	C000-C809
(e) Unspecified malignant bone tumours	8000-8005, 8800, 8801, 8803-8805	C400-C419
<b>IX Soft tissue and other extraosseous sarcomas</b>		
(a) Rhabdomyosarcomas	8900-8905, 8910, 8912, 8920, 8991	C000-C809
(b) Fibrosarcomas, peripheral nerve sheath tumours, and other fibrous neoplasms	8810, 8811, 8813-8815, 8821, 8823, 8834-8835	C000-C399, C440-C768, C809
	8820, 8822, 8824-8827, 9150, 9160, 9491, 9540-9571, 9580	C000-C809
(c) Kaposi sarcoma	9140	C000-C809
(d) Other specified soft tissue sarcomas	8587, 8710-8713, 8806, 8831-8833, 8836, 8840-8842, 8850-8858, 8860-8862, 8870, 8880, 8881, 8890-8898, 8921, 8982, 8990, 9040-9044, 9120-9125, 9130-9133, 9135, 9136, 9141, 9142, 9161, 9170-9175, 9231, 9251, 9252, 9373, 9581	C000-C809
	8830	C000-C399, C440-C768, C809
	8963	C000-C639, C659-C699, C739-C768, C809
	9180, 9210, 9220, 9240	C490-C499

	9260	C000-C399, C470-C759
	9364	C000-C399, C470-C639, C659-C699, C739-C768, C809
	9365	C000-C399, C470-C639, C659-C768, C809
(e) Unspecified soft tissue sarcomas	8800-8805	C000-C399, C440-C768, C809
<b>X Germ cell tumours, trophoblastic tumours, and neoplasms of gonads</b>		
(a) Intracranial and intraspinal germ cell tumours	9060-9065, 9070-9072, 9080-9085, 9100, 9101	C700-C729, C751-C753
(b) Malignant extracranial and extragonadal germ cell tumours	9060-9065, 9070-9072, 9080-9085, 9100-9105	C000-C559, C570-C619, C630-C699, C739-C750, C754-C768, C809
(c) Malignant gonadal germ cell tumours	9060-9065, 9070-9073, 9080-9085, 9090, 9091, 9100, 9101	C569, C620-C629
(d) Gonadal carcinomas	8010-8041, 8050-8075, 8082, 8120-8122, 8130-8141, 8143, 8190-8201, 8210, 8211, 8221-8241, 8244-8246, 8260-8263, 8290, 8310, 8313, 8320, 8323, 8380-8384, 8430, 8440, 8480-8490, 8504, 8510, 8550, 8560-8573, 9000, 9014, 9015	C569, C620-C629
	8441-8444, 8450, 8451, 8460-8473	C000-C809
(e) Other and unspecified malignant gonadal tumours	8590-8671	C000-C809
	8000-8005	C569, C620-C629
<b>XI Other malignant epithelial neoplasms and malignant melanomas</b>		
(a) Adrenocortical carcinomas	8370-8375	C000-C809
(b) Thyroid carcinomas	8010-8041, 8050-8075, 8082, 8120-8122, 8130-8141, 8190, 8200, 8201, 8211, 8230, 8231, 8244-8246, 8260-8263, 8290, 8310, 8320, 8323, 8430, 8440, 8480, 8481, 8510, 8560-8573	C739
	8330-8337, 8340-8347, 8350	C000-C809
(c) Nasopharyngeal carcinomas	8010-8041, 8050-8075, 8082, 8083, 8120-8122, 8130-8141, 8190, 8200, 8201, 8211, 8230, 8231, 8244-8246, 8260-8263, 8290, 8310, 8320, 8323, 8430, 8440, 8480, 8481, 8500-8576	C110-C119
(d) Malignant melanomas	8720-8780, 8790	C000-C809

(e) Skin carcinomas	8010-8041, 8050-8075, 8078, 8082, 8090-8110, 8140, 8143, 8147, 8190, 8200, 8240, 8246, 8247, 8260, 8310, 8320, 8323, 8390-8420, 8430, 8480, 8542, 8560, 8570-8573, 8940, 8941	C440-C449
(f) Other and unspecified carcinomas	8010-8084, 8120-8157, 8190-8264, 8290, 8310, 8313-8315, 8320-8325, 8360, 8380-8384, 8430-8440, 8452-8454, 8480-8586, 8588-8589, 8940, 8941, 8983, 9000, 9010-9016, 9020, 9030	C000-C109, C129-C218, C239-C399, C480-C488, C500-C559, C570-C619, C630-C639, C659-C729, C750-C768, C809
<b>XII Other and unspecified malignant neoplasms</b>		
(a) Other specified malignant tumours	8930-8936, 8950, 8951, 8971-8981, 9050-9055, 9110	C000-C809
	9363	C000-C399, C470-C759
(b) Other unspecified malignant tumours	8000-8005	C000-C218, C239-C399, C420-C559, C570-C619, C630-C639, C659-C699, C739-C750, C754-C809
<b>Not Classified by ICCC or in situ</b>		