EJC Paediatric Oncology 6 (2025) 100420

Contents lists available at ScienceDirect

EJC Paediatric Oncology

journal homepage: www.journals.elsevier.com/ejc-paediatric-oncology

Original research

The path towards a population-based childhood cancer registry in the region of Dakar in Senegal: A feasibility study of the Franco-African Paediatric Oncology Group (GFAOP)

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ARTICLE INFO

Keywords:
Epidemiology
childhood cancers
registry
LMIC
Dakar
Senegal
GFAOP

ABSTRACT

Introduction and Background: The Global Initiative for Childhood Cancer of the World Health Organisation emphasise the importance of registration, especially in low-and middle-income countries, where data are sparse. The Hospital-Based Cancer Registry (HBCR) established in the Paediatric Oncology Unit (POU) at Le Dantec Hospital in Dakar, Senegal, collects data about patients from the whole of Senegal. This study investigates the potential for establishing a Population-Based Childhood Cancer Registry (PBCR) in the region of Dakar in Senegal.

Methodology: In an attempt to cover the entire Dakar region in addition to those included in the HBCR, cases were also sought in other hospitals and departments susceptible to diagnose or treat cancer in children. Completeness was assessed and cancer patterns described.

Results: From 2017–2019, 568 cancers in children under 18 were recorded in the HBCR, including 133 residents of the Dakar region. An additional 283 cases were identified from other sources, 149 of them without information on their place of residence. Discrepancies in cancer type distribution were observed between the data sources. The overall incidence rate estimate was 33 per million person-years.

Discussion: The additional cases found outside the HBCR, the observed variability of cancer types, and the low incidence rates highlight the need for a PBCR to standardize the registration process and improve completeness of ascertainment. Given the few identified data sources, a PBCR in the Dakar region would provide accurate information about childhood cancer burden in the covered population. However, political and financial support is necessary to sustain the registry.

Abbreviations: ALL, Acute Lymphoblastic Leukaemia; AFCRN, African Cancer Registry Network; BL, Burkitt lymphoma; CNS, Central Nervous System.; CRA, Clinical Research Assistant; GFAOP, Group Franco African d'Oncologie Paediatric; GICC, Global Initiative for Childhood Cancer; GICR, Global Initiative for Cancer Registry Development; HBCR, Hospital Based Cancer Registry; HL, Hodgkin Lymphoma; HIC, High-Income Countries; IACR, International Association of Cancer Registries; IARC, International Agency for Research on Cancer; ICCC-3, International Classification of Childhood Cancer-3rd Edition; ICD-O-3, International Classification of Diseases for Oncology-3rd Edition; LMICs, Low- and Middle- Income Countries; MRI, Magnetic Resonance Imaging; NCD, Non-Communicable Disease; PBCR, population based cancer registry; POU, Paediatric Oncology Unit; RB, Retinoblastoma; SSA, Sub-Saharan Africa; TG, Toronto Childhood Cancer Stage Guidelines; TNM, Cancer staging classification Tumour, Nodes, Metastases.; WHO, World Health Organisation; WT, Wilms' tumour.

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https://doi.org/10.1016/j.ejcped.2025.100420
Received 26 June 2025; Received in revised form 22 September 2025; Accepted 25 September 2025
Available online 30 September 2025

1. Background

The World Health Organisation (WHO) Global Initiative [1] for Childhood Cancer describes hospital-based cancer registry (HBCR) development as crucial, for population based cancer registries (PBCR) [1]. In 2024, the African Cancer Registry Network (AFCRN) comprised 30 population-based cancer registries, in 22 countries in the sub-Saharan region, six in French-speaking countries [2]. Overall, childhood cancer incidence in Africa is derived from data of 14 population-based cancer registries (complying with quality and comparability criteria), which combined, cover only 5 % of the total population of Africa [3,4].

In 2016, the French African Paediatric Oncology Group (GFAOP) launched a centralized hospital-based cancer registry, collecting data from the different Paediatric Oncology Units (POU). Aiming to enhance understanding of patient volume, facilitate patient management, evaluate the impact of projects and support the development of cancer plans [5]. This registry uses the International Classification of Childhood Cancers, third edition (ICCC-3) [6], and staging according to the Tier 1 of the Toronto childhood cancer stage guidelines (TG) [7].

In 2020, Senegal signed a tripartite agreement with the International Atomic Energy Agency (IAEA), the World Health Organization (WHO), and Senegal (Ministry for health) to support the development of strategic plans for cancer control (personal communication from Dr Anne, Head of the Division of Control of Non-Contagious Diseases, Ministry of health in Senegal). Thus propelling oncology into the forefront of non-communicable diseases (NCD) in the country.

Senegal has 14 administrative regions, subdivided into 46 departments. The Dakar region encompasses 4 departments covering 586 km^2 (see Fig. 1). The country has 76 health districts to serve its population. At the time of the study, (2019) the population of 17 million included almost 40 % of children < 15 years of age. The Dakar region, housing the Capital City of Dakar was 3732,282, representing 23 % of the country's total population with an annual population growth of 2.7 %.

The Paediatric Oncology Unit (POU) at the Dantec Hospital in Dakar is a founder member of the GFAOP [8–11], and reference center for paediatric oncology in Senegal, registering approximately 190 cases annually.

This study investigates establishing a population-based childhood cancer registry for the Dakar region, leveraging the existing data from the HBCR in the Dantec POU and other institutions potentially seeing children with cancer in the region. We also investigated the extent to which the POU reference center registers the incidents of childhood cancers under 18 years in the region.

2. Method

The geographical region of Dakar includes 4 departments, Dakar, Guediawaye, Pikine and Rufisque. (Fig. 1: Map of the region of Dakar). Local paediatric oncologists, pathologists and public health specialists, were consulted to identify services where children might be referred for diagnosis.

2.1. Patients

Children less than 18 years old diagnosed with a first malignant neoplasm between January 1, 2017, and December 31, 2019, and living in the Dakar region were eligible. Children with a history of a malignant neoplasm diagnosis prior to January 1, 2017, were excluded. A confirmed diagnosis, requiring cytology, histology or imaging, was a prerequisite for inclusion while children with a diagnosis only based on clinical examination were excluded.

Eight departments in seven hospitals were identified as potential sources of cases (Table 1): the Hospital Aristide the Dantec (Le Dantec) housing the POU and the hematology department. The Centre Hospitalier National Universitaire de Fann (FANN), the Hôpital Général de Grand Yoff (HOGIP) (renamed Hospital General Idrissa Pouye), the Hôpital Principal in the department of Dakar, the Centre Hospitalier National Dalal Jamm (DALAL JAMM), the Diamniadio Hôpital pour Enfant (DIAMNIADIO), and the University Cheikh Anta Diop (UCAD). Consent was requested from all heads of services for data use. In the POU

Fig. 1. Map of Dakar Region, illustrating its four departments including the six hospitals and the University of Dakar where research was carried out. A smaller inset map of Senegal provides geographical context, situating Dakar within the country.

Table 1
Description of the 7 different hospitals identified in the Dakar region with their different facilities for diagnostic capacity.

Hospital in Dakar region	Short Name	Description	Clinical departments				Diagnostic departments		
			Paediatric Oncology	Paediatricdepartment	Neurosurgery	Radiotherapy	Anatomopathology (Pathologists/technicians)	Haematology . department	Radiology
Centre hospitalier Aristide le Dantec	LE DANTEC	University hospital including the GFAOP POU (National Paediatric Oncology reference centre) diagnostic service for all childhood haematological cancers in Senegal since 2017	Yes[a]	Yes	No	Adult + child[c]	Yes 2 P,3 T[b]	Yes	Yes
Centre Hospitalier National Universitaire de Fann Albert ROYER (pediatric Hospital in the CHU)	FANN	University hospital	No	Yes	Yes	No	Yes 3 P,2 T	No	Yes
Hôpital de Grand Yoff	HOGIP	General Hospital	No	Yes	No	No	Yes 2 P,4 T	No	Yes
Hôpital Principal de Dakar	HPD	Military General hospital	No	Yes	Yes	No	Yes 4 P,3 T	No	Yes
Hôpital Dalal Jamm[b]	DALAL JAMM[b]	Paediatric Hospital 0–15-year-olds Specializing in digestive tract disorders and child nutrition	No	Yes	No	Adult + child[c]	Yes 1 P,2 T	Yes	Yes
Hôpital d'enfants de Diamniadio[b]	DIAMNIADIO[b]	Paediatric Hospital 0–15-year-olds	No	Yes	No	Yes	No	No	Yes
Université Cheikh Anta Diop	UCAD	Reference Centre for the Diagnosis of Childhood Cancers (CRDCE)	No	No	No	No	Yes 0 P,3 T	No	No

[a] Two full time equivalents of paediatric oncologist and one part time;
[b] Not visited because of time restraints; P: Pathologists, T: Technicians.
[c] Children accepted, however the service is not specialised in the care of children.

parents are systematically informed of the data collection.

Prior to data collection in Dakar, we reviewed the national mortality filing system. While the civil registration system, managed by the town hall, records the date and place of death, it does not include the cause of death except in cases of suicide. This limitation made the POU database the only reliable source for mortality data; however, this information was not collected for the purpose of this research.

2.2. Data collection

Patient identifiers included names, sex and age. Age was systematically noted, whereas date of birth was only documented at the Dantec and Hospital Principal. The absence of date of birth data is a well-known limitation in many low-and middle-income countries (LMICs), where the date of birth is not required for completing patient files nor for biological sample identification. Consequently, data for this variable is often poor or nonexistent limiting linkage. Residence was defined as the place where the child lived not the residence used during hospitalization: information that was only available from the GFAOP POU.

Diagnostic date was defined as the date of examination confirmation. When not available, the date of the beginning of treatment was used. This date was only available for cases in the POU. The cancer types were directly classified into the main diagnostic groups of the ICCC-3 [6], ICD-O coding was not available [12].

Data from the pathology and hematology departments included: sample numbers, referring hospital, arrival/examination dates, and name of the referring doctor. Diagnoses were manually entered. Electronic reports were verified in the different departments to validate the data found and to gather supplementary information such as residence, age, referring hospital or any other relevant details to improve matching.

To match cases found (Table 1), and eliminate duplicates, we compared names, sex, age, and dates, arrival/analysis/diagnosis. Both clinical and confirmed diagnosis and treatment protocol types allocated to the patient were also used to confirm identity. Allowing the identification of children diagnosed elsewhere and subsequently transferred or not to the POU. The "Hospital Général de Grand Yoff" (HOGIP) was the only pathology service with a retrospective Excel database which was consulted to research cases not identified in the pathology departments hand written registry. We excluded 12 cases of metastatic cancer whose site of primary cancer and date of diagnosis remained unknown after investigation. They were crosschecked with the cases known as previously diagnosed in the POU.

2.3. Statistical methods

We described patient characteristics and diagnostic types. Incidence rates (per/million/year) were calculated as the total number of new cancer cases diagnosed from 2017 to 2019 and resident in the region of Dakar divided by the population at risk in the corresponding period, sex and age (age groups 0–4, 5–9, 10–14, and 15-17 years). The age-standardised incidence rates were calculated to enable comparison between different age groups, using the Segi (1960) world population as the reference standard. The method involved weighting age-specific incidence rates by their corresponding proportions in the reference population. For the 0–14 year age group, rates for age classes 0–4, 5–9, and 10–14 were weighted by the proportions 12,000/31,000, 10,000/31,000, and 9000/31,000, respectively. For the 0–17 year age group, rates were weighted by the proportions 12,000/36,500, 10,000/36,500, 9000/36,500, and 5400/36,500. The 15–17 age group was assigned a weight of 5400, which is three-fifths of the standard weight for the 15–19 year age group (9000) [13,14]. The 2017 – 2019 population was based on the 2013 Census, provided by the National Institute of Statistics and Demography (ANSD) of Senegal; this data categorises the population by region, by calendar year, by sex and by year of age [13].

Table 2
Distribution by ICCC-3 group [6] of the 133 and 149 unmatched cases of childhood cancer diagnosed before the age of 18 years found in the Dakar region during 2017–2019.

ICCC-3	Diagnostic group	POU HBCR		Other sources									
				Haemato		Pathology department						Total	
				Dantec		Fann		Grand Yoff		UCAD			
		N	%	N	%	N	%	N	%	N	%	N	%
I. Leukaemia		**43**	**32,3**	**43**	**71,7**	**0**	**0,0**	**0**	**0,0**	**0**	**0,0**	**43**	**28,9**
	I.a ALL	31	23,3	24	40,0	0	0,0	0	0,0	0	0,0	24	16,1
	I.b AML	11	8,3	17	28,3	0	0,0	0	0,0	0	0,0	17	11,4
	I.c CML	1	0,8	2	3,3	0	0,0	0	0,0	0	0,0	2	1,3
II. Lymphoma		**13**	**9,8**	**15**	**25,0**	**4**	**12,1**	**8**	**16,3**	**0**	**0,0**	**27**	**18,1**
	II.a Hodgkin lymphoma	7	5,3	14	23,3	4	12,1	4	8,2	0	0,0	22	14,8
	II.c Burkitt lymphoma	5	3,8	1	1,7	0	0,0	4	8,2	0	0,0	5	3,4
	II.e Malignant lymphoma NOS	1	0,8	0	0,0	0	0,0	0	0,0	0	0,0	0	0,0
III. CNS tumour		**1**	**0,8**	**0**	**0**	**14**	**42,4**	**2**	**4,1**	**1**	**14,3**	**17**	**11,4**
	III.a Epandymoma	0	0,0	0	0,0	5	15,2	0	0,0	0	0,0	5	3,4
	III.b. Astrocytoma	0	0,0	0	0,0	1	3,0	1	2,0	1	14,3	3	2,0
	III.c. Medulloblastoma	0	0,0	0	0,0	3	9,1	0	0,0	0	0,0	3	2,0
	III.d. Glioma	0	0,0	0	0,0	5	15,2	0	0,0	0	0,0	5	3,4
	III.f CNS NOS	1	0,8	0	0,0	0	0,0	1	2,0	0	0,0	1	0,7
IV. Neuroblastoma and other peripheral nervous cell tumors		7	5,3	**1**	**1,7**	**0**	**0,0**	**2**	**4,1**	0	**0,0**	**3**	**2,0**
V. Retinoblastoma		5	**3,8**	**0**	**0,0**	0	**0,0**	**6**	**12,2**	**1**	**14,3**	**7**	**4,7**
VI. Renal tumor		**29**	**21,8**	**0**	**0,0**	**1**	**3,0**	**2**	**4,1**	**0**	**0,0**	**3**	**2,0**
VII. Hepatic tumor		5	**3,8**	**0**	**0,0**	**0**	**0,0**	**1**	**2,0**	**0**	**0,0**	**1**	**0,7**
VIII. Malignant bone tumors		**10**	7,5	**0**	**0,0**	**0**	**0,0**	**7**	**14,3**	**1**	**14,3**	**8**	**5,4**
IX. Soft tissue and other extraosseous sarcomas		7	**5,3**	**1**	**1,7**	**2**	**6,1**	**5**	**10,2**	**0**	**0,0**	**8**	**5,4**
X. Germ cell tumors, trophoblastic tumors, and neoplasms of gonads		5	**3,8**	**0**	**0,0**	**0**	**0,0**	**4**	**8,2**	**1**	**14,3**	**5**	**3,4**
XI. Other malignant epithelial neoplasms and malignant melanomas		**8**	**6,0**	**0**	**0,0**	**9**	**27,3**	**9**	**18,4**	**3**	**42,9**	**21**	**14,1**
XII. Other and unspecified malignant neoplasms		**0**	**0,0**	**0**	**0,0**	**3**	**9,1**	**3**	**6,1**	**0**	**0,0**	**6**	**4,0**
TOTAL		**133**	**100,0**	**60**	**100,0**	**33**	**100,0**	**49**	**100,0**	**7**	**100,0**	**149**	**100,0**

Haemato: haematological laboratory; Pathology: pathological laboratory.

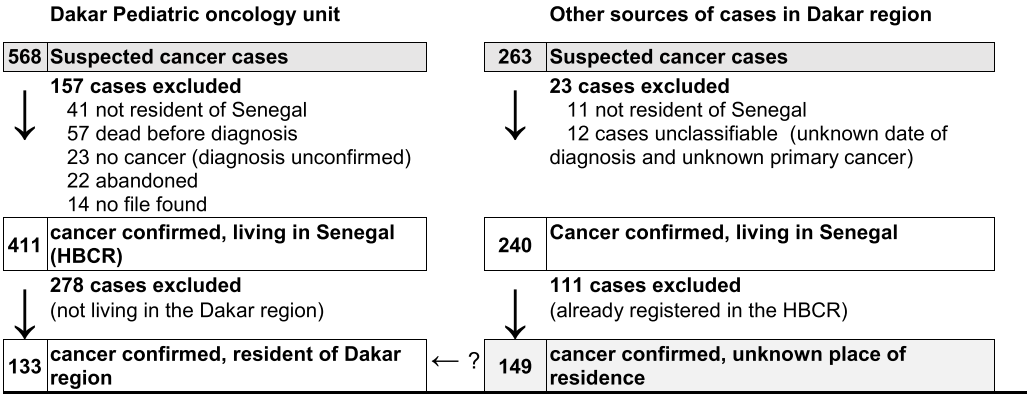

Fig. 2. Flow chart of the fallout of suspected cases identified from 2017 to 2019 in Le Dantec POU and the hematology department, UCAD HOGIP, FANN, and the Hôpital Principal in the Dakar region.

Table 3
Minimum incidence rate (IR) of childhood cancer in the Dakar region in 2017–2019, based on the data collected in the POU.

Age (years)	Dakar Region 2017–2019, age < 18 years				
	Person-years		Resident cancer cases		Incidence rate per million
	N	%	N	%	
0–4	1 570 859	36,2	56	42,1	35,6
5–9	1 161 293	26,7	43	32,3	37,0
10–14	1 038 676	23,9	29	21,8	27,9
15–17	573 362	13,2	5	3,8	8,7
0–14	3 770 828	86,8	128	96,2	33,9
0–17	4 344 190	100,0	133	100,0	30,6

3. Results

From 2017–2019, the POU registered N = 568 children. Of these, 157 (28 %) were excluded because a diagnosis could not be established, primarily due to precipitous death or abandonment. From the remainig group, 133 cases respected the criteria for inclusion. Table 2 presents the distribution by ICCC-3 [6] group for these 133 cases, Fig. 2 shows the reasons for fallout for suspected cases found in the POU and cases found in the different departments visited.

During the study period, 263 cases were identified from other hand written registries in 6 of the departments visited shown on Fig. 2. Of these, 111 were matched with POU cases and 23 were excluded, (12 metastatic). Leaving 149 unmatched cases lacking residence confirmation. (See Fig. 2 for description).

Comparing cancer cases from the two groups, (149 unmatched and 133 POU cases) reveals some key differences. Among the 149 cases, the most common cancer was leukaemia (28.9 %) followed by lymphoma (18.1 %) and (14.1 %) carcinomas. This contrasts with the POU cases where leukaemia was also the most common cancer (32.3 %) the second most frequent was renal tumours (21.8 %) followed by lymphoma (9.8 %) Table 2)

Of the 149 unmatched cases, all the leukaemia cases (n = 43) were diagnosed in the haematology department of Le Dantec. Despite the POU being located in the same hospital they were not referred there. Efforts were made to identify the residence of these patients but because of resources, this was unsuccessful. One leukemia case, found at the military 'Hospital Principal' was managed at the POU and is included with the 31 ALL cases from the POU. Burkitt lymphoma cases were present in similar proportions in both groups: 3.8 % in the POU and 3.4 % in the other sources. A striking difference emerges for the CNS tumors, representing 0.8 % of cases in the POU and 11.4 % in the unmatched group. Of the 18 CNS cases, 14 were found at the Fann Hospital, which houses both a Paediatric hospital (Albert Royer) and a neurosurgery department. Five children, with intracranial hypertension were referred from the Paediatric department to the neurosurgical department in the Principal Hospital, no imaging or histology is known to confirm their diagnosis.

3.1. Estimate of minimal incidence rates

Estimates of incidence rates based on the 133 cases identified in the region in the HBCR over the period 2017–2019 were low, 33.9/million/year for the age 0–14 age group and 30.6/million/year for the 0–17 group (Table 3). World age standardized incident rates (WSR) were even lower (30.4 and 27.2 per million and year, respectively) [15]. Under the hypothesis that all the 149 unmatched cases were residents of the Dakar Region, crude incidence rate would be 65 cases per million and year for the 0–17 age group. The incidence range for the region of Dakar is between 30.6 and 62.9 for the 0–14 age group.

4. Discussion

A preliminary assessment establish an inventory of potential data sources and key stakeholders for a population-based childhood cancer registry in the region. This inventory revealed that children were seen in other departments outside the POU.

We showed that the number of childhood cancers recorded in the POU are similar to the cumulative number of children seen in other institutions in the region. We identified variations in cancer type distribution between the two groups, suggesting potential issues with referral pathways, and selective referral systems.

Key needs identified were: data source inventory, standardized patient identifiers, patient file access, active process of registration and ongoing CRA training on registry processes and quality control [16].

The exclusion of 28 % of the 586 POU cases not confirmed, primarily due to death or abandonment, underscores the barriers caused by late arrival and abandonment to effective registration of childhood cancers [17,18]. Addressing early diagnosis and abandonment, should improve information on burden, which in turn, fosters awareness, and enhances registration. The GFAOP is currently addressing the subject of abandon, a multifaceted issue where families cease to bring their child to confirm diagnosis or to start or continue treatment. Reason for this often include financial hardship, lack of access to transportation, and a poor understanding of the necessity of long-term care. The GFAOP hopes to conduct exploratory analysis to generate hypotheses regarding factors potentially associated with abandonment, ultimately leading to recommendations to reduce abandonments.

Residence data was only available for POU-identified cases (see Table 1), requiring access to patient files for other sources. Due to time constraints, residence data for the 149 cases was incomplete. However, this first step in their identification could encourage further funding for

local researchers to follow up. Ultimatly providing data for a strategic cancer plan for Senegal.

Defining the target population and essential data sources during planning is crucial for ensuring data quality. Given the low numbers of childhood cancer cases, even one missed case can significantly influence incidence rates. A PBCR that covers ≥ 50 % of the target population and using standardised coding can be consider a high quality registry in LMIC, as indicated in the IARC Technical publication N° 43 "Planning and developing population-based cancer registration in low-and middle-income settings" [16].

This present study indicates that data concerning personal identification, residency, and dates registered in pathology and haematology services require improvement, to facilitate cross-matching [15,19,20]. Although the neoplasms are grouped into the ICCC-3 diagnostic groups based on their ICD-O coding [12,21], retrospective ICD-O coding was impossible for the registered patients. Therefore introducing ICD-O-3 is crucial for PBCR statistics.

Table 4
Recommendation for the development of a Population Based Childhood Cancer registry in the region of Dakar.

Recommandation		
Governance and Leadership	**Steering Committee Member**	Paediatric oncologists, parent groups, government, paediatric civil society, leadership, Office space: location-hosting, equipment.
	Registry Director:	Epidemiology training and interest in Public health, Responsable for funding.
	AFCRN Local Hub	Linking with the International Agency for Research on Cancer (IARC), AFCRN to help provide guidance, legal aspects, confidentiality, and support
Sustainability and Funding:	**International Grants and Foundations:**	Initial funding source Advocacy for childhood cancer (raise awareness)
	Government Support	Necessary for long-term sustainability
	Local stakeholder involvement:	Importance for project success
Data Management and Quality:	**Mandatory Registration** [32]	Consideration of South African model, explore partnerships with pharmaceutical companies for funding Data sharing with paediatric research groups
	Medical Research Environment:	Research assistants, data validation, quality assessment, analysis
	Training:	Conducted by quality assurance specialists
	Case Finding Audits:	International agencies IARC, local Hub, or peer registries. Mentorship Programs/ Connect with new registries /with established registries, develop audit system
	Expert Involvement:	Ongoing reflection on process and output improvement, written reports
Training and Capacity Building:	**AFCRN Standard Training**	Available for cancer registries
	IARC and St Jude Course	Specific for childhood cancer registration Mentorship programs with other
	Ongoing Distance Training and Support [33]	Provided by AFCRN

See also the IARC Technical Publication NO 43: (Planning and developing population-based cancer registration in low and middle income settings [16, 32]).

Estimates of the minimal annual incidence of 33.9 cases per million for children <15 are low compared to sub-Saharan figures of 56.3 for children <15 (a quarter less than French rates) [22], likely reflecting both under-diagnosis and under registration [4,6]. Incidence is particularly low in the 15–17-age group. Teenagers may be referred to other institutions; especially adult services treating cancers, not identify as data sources for childhood cancers, but should be identified in the future. If the 149 unmatched cases detected in departments are considered as resident of the Dakar region then by taking them into account the incidence rate is closer to those reported for SSA [3,4].

The low proportion (3.7 %) of BL in the POU is consistent with historically low numbers in the POU compared to other Sub Saharan (SS) units documented by the GFAOP [5,7,23]. However, these differences may reflect different referral practices across the GFAOP network and potential disparities in underlying populations. Consequently, caution is necessary when interpreting these figures. Among the 149 additional cases, we identified only 3.3 % cases of BL. Thus, our study shows that BL cases were not diagnosed and treated in the other paediatric departments or institutions in the Dakar region. The POU's specialization in hematological neoplasms, its application of GFAOP protocol and chemotherapy availability likely result in most BL cases being referred there.

In most parts of Senegal, the prevalence of malaria, the purported risk factor of BL, is low compared to other sub-Saharan countries located in tropical regions [24-26]. The Burkitt belt identified by David Burkitt in 1962 extends to the point of Dakar [25,27]. The public health action for the elimination of malaria carried out in the country from 2015 may also have helped reduce the frequency of BL.

It is possible that more CNS cases were diagnosed in specialized neurosurgical services, not visited, especially those in the "Hospital Principal". We suspect that the absence of CNS tumors in the HBCR can be attributed to selective referral. Referral systems likely prioritize sending patients with cancers for which the POU has protocols, this is not the case for CNS tumors, and so brain tumors are possibly directed elsewhere [5,28,29]. The Hospital Fann's recent MRI acquisition, resulting in 7 CNS tumors of the 24 cancers diagnosed in 2020, compared to 14 CNS cases diagnosed over the 3-year period of the study, illustrating the impact of MRI on CNS tumor diagnoses. Only a complete PBCR could provide a clear indication of the incidence rate of childhood cancers.

During the study period, the POU in the Dantec had 34 beds for 7.5 million children < 18. In 2022, this number was reduced to 13 because of the demolition of the Dantec hospital, presently under reconstruction. This abrupt demolition, with no transition or archiving, complicates data retrieval. Rehoused in the National Hospital Centre Dalal Jamm (Fig. 1), the reduced bed capacity diverts patients, potentially increasing the development of the private sector, a trend observed elsewhere in Africa [19,29]. The private sector offers access to costly diagnostic techniques such as MRI, PET, CT scans and specialised haematological and pathological techniques [29,30]. However, it may have a negative impact on registration because adherence to data from private clinics is often lower. In the strategic cancer plan for Senegal, it is noted that "the private sector is not sufficiently involved in the development, implementation and evaluation of health policies and programmes" [31]. While the declaration claims the use of the private sector by all income levels, it does not mention the extent of their impact, alliance in the strategic plan, should include joint programs to ensure complete childhood cancer registration and follow-up [31].

Numbers of pathologists in Senegal are rising (15 pathologists at the time of the study, and 50 students specialising in Pathology in 2022). Government and FoundationS aid has significantly supported visited laboratories, including university haematology and pathology departments.

Recommendations, (Table 4).

Financing PBCR for children in countries with many other health

priorities is a challenge. In a survey of 18 active PBCR in SS Africa, only 48 % of registries received funding from government, and 23 % were supported by research funding [30]. In 2015, the operational costs of a cancer registry in SSA setting have been quantified comprehensively as roughly 7-8€ (8–9$) per case, excluding the cost of data analysis and research activities which represent 47 % of the total expenditure [32]. If we considered the findings of this study of 560 cases over a 3-year period as the number of new cases for the region. We could consider that per year there are approximately 200 new cases. Using the AFCAN costing for running a register (7–8€ or 8–9$) the estimated cost is 3200€/3510$ or 2096,606 which includes analysis and follow up representing about 50 % of the cost. International grants might initiate registry setup, but the Senegalese government and local stakeholders are necessary for sustainability [32].

Mandatory registration could be considered as is enforced in South Africa [32].

Using ChildGICR Masterclass courses on registration of childhood cancer developed by IARC offering ongoing distance training and support for cancer registries in LMIC, aiming to increase data production [33].

Registration of childhood cancers requires specific standards, such as ICCC [6,34] and ICD-O. Using standard registration procedures developed by the International Agency for Research on Cancer [16,20] and supported by registry associations such as International Association of Cancer Registries (IACR) and African Cancer Registries Network (AFCRN) https://afcrn.org/[15,23].

Limiting variables optimizes collection, quality control, and cost-effectiveness [35]. Having excessive variables is costly leading to missing data and poor quality data especially in LMIC settings. Requirements on the population coverage and quality of data collected on childhood cancer are increased due to the low number of cases, whereby each error causes a large relative difference [15,20,36].

5. Conclusion

This study investigates establishing a PBCR in the Dakar region. We propose initial steps that could lead to its foundation. Despite existing expertise, gaps were documented with possible selective referral systems. Dakar's dense population offers high coverage potential, presenting a compelling opportunity for such a project, but requires funding, skilled staff, and international standards. A robust registry, with sustained political support, will enhance cancer control.

CRediT authorship contribution statement

Laila Hessissen: Resources. **Jacqueline Clavel:** Writing – review & editing, Validation, Supervision, Methodology, Conceptualization. **Chérif Dial:** Validation, Supervision, Data curation. **Eva Steliarova-Foucher:** Writing – review & editing, Supervision, Methodology, Conceptualization. **Brenda Mallon:** Writing – review & editing, Writing – original draft, Validation, Project administration, Methodology, Formal analysis, Conceptualization. **Marie Jo Diémé Ahouidi:** Resources, Methodology, Data curation. **Fatou Binetou Akonde:** Data curation. **Malick Anne:** Writing – review & editing, Resources. **Ndella Diouf:** Data curation. **Francis Diedhiou:** Formal analysis. **Awa Toure:** Data curation. **Aïssatou Ndiaye:** Resources, Data curation. **Adama Faye:** Methodology.

Acknowledgments of research support for the study

GFAOP grant by the "My Child Matters" programs, funded by the Foundation Sanofi Espoir and FoundationS, Logistic support by Gustave Roussy.

While this project benefited from financial assistances from the GFAOP and the FoundationS the authors maintained complete independence in the development of the methodology, analysis and preparation of this article.

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This work uses data from registered observational study under the number: NCT03803735 in clinicalTrials.gov.

For the moment, data from this study are not available from the authors because of ethical restrictions.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgments

Deep gratitude to all involved, for their contribution to this project. Especially heads of services who opened their doors so that this research could be carried out. A special thank you to the staff members of the POU, especially Madame Fatou DIENG the clinical research assistant who was always available to answer questions or clarify points.

Thank you also goes to the GFAOP, particularly Prof Pierre Bey and Dr Catherine Patte providing essential support and expertise. To the FoundationS, for its continuing support, crucial for the success of this project. Gustave Roussy in Paris also requires a special thank you for its backing of the GFAOP from the outset and in particular for its logistic support for this work.

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