

ASSESSMENT OF THE CURRENT DATA SOURCES IN THE REGION OF DAKAR IN SENEGAL IN VIEW OF INSTITUTING POPULATION-BASED CHILDHOOD CANCER REGISTRATION: A FEASIBILITY ANALYSIS. FROM THE FRANCO-AFRICAN PAEDIATRIC ONCOLOGY GROUP (GFAOP).



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BACKGROUND

The Franco African Pediatric Oncology Group (GFAOP) established a Hospital Based Cancer registry (HBCR) in 2016. In 2019 the WHO announced the Global Scaling-up of HBCR. In 2020, Senegal signed a tripartite agreement with the International Atomic Energy Agency (IAEA), the World Health Organization (WHO), and the International Agency for Research on Cancer (IARC) to support the development of strategic plans for cancer control. Placing oncology in the forefront of non-communicable diseases (NCD). This facilitated the consideration of Dakar for this work.

Because of the temptation to presume that all cases get registered in the one service with capacity to diagnose and treat in a given region: a structured research project with academic backing was considered to establish concrete baselines and future pathways for the development of a childhood cancer register to support a cancer plan in Senegal.

Here we describe the method and findings of this project, for the development of a childhood cancer registry for the region of Dakar in Senegal.

AIMS

- Identify key public health services susceptible to support this work, motivated in the development of a childhood cancer register.
- Determine geographic limits of the region covered
- Help local teams strengthen the hospital registry.
- Confirm the completeness of the existing data.
- Identify the services where pediatric cancer cases might be sent in the Dakar Region.
- Describe the characteristics of the population found.

METHOD

Authorization was sought from the GFAOP. Identification and contact with key teams in Dakar including: Université Cheikh-Anta-Diop, Dakar (UCAD), government department of non communicable diseases, pediatric, oncology, Anatomopathology, hematological and imagery services. Permission to visit and carry out this research in the different units and the university UCAD was obtained.

The geographical boundaries of the region were established. The time period was 01 Jan. 2017 to 31 of Dec. 2019. Data from the existing pediatric Oncology Unite (POU) "Le Dantec" was extracted from the GFAOP data base and missing data, follow up and queries were completed.

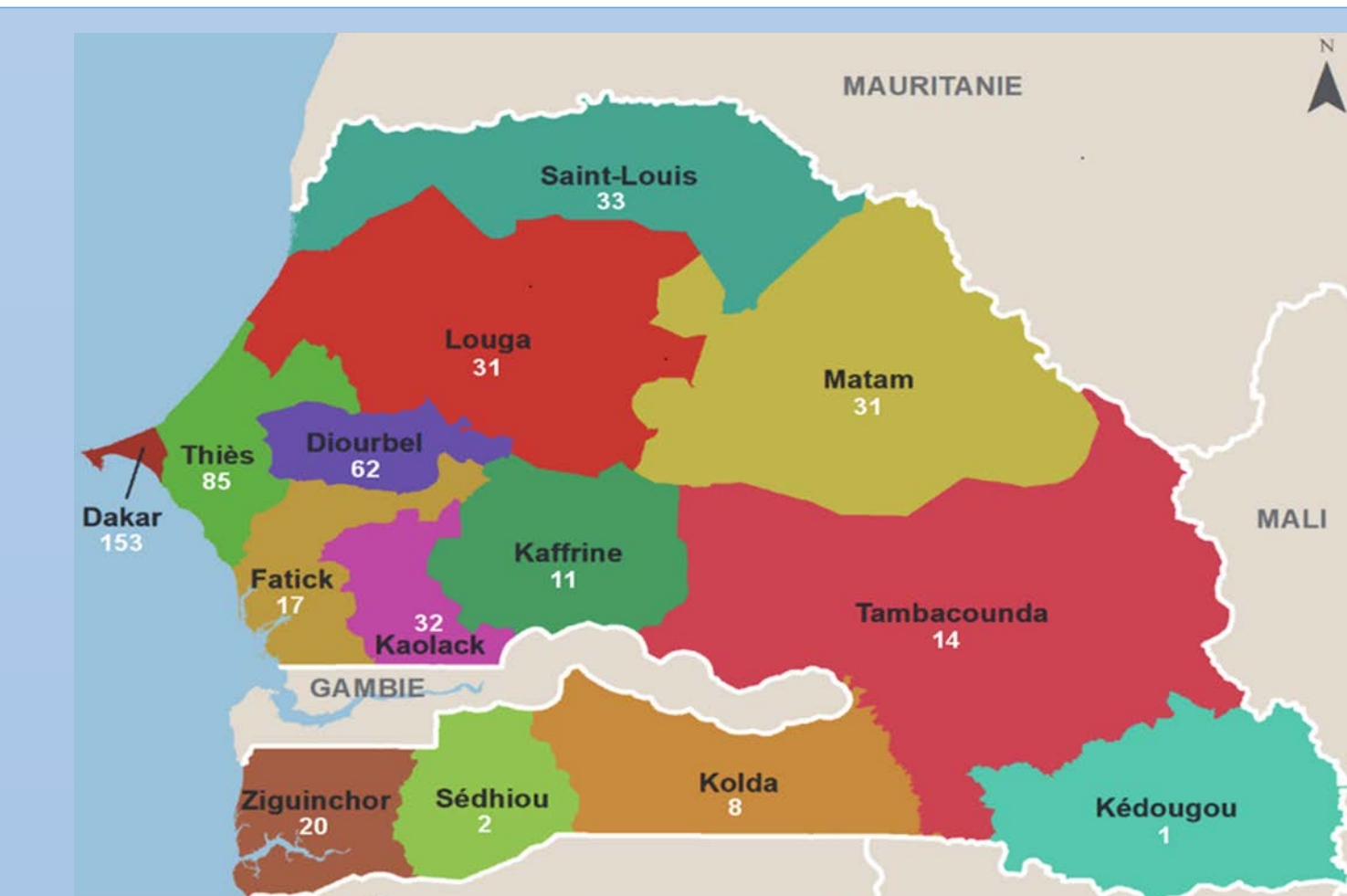
Eight services in six hospitals including the university were targeted. Registries in services were examined to identify children <18 years with a suspicion or diagnosis of a cancer. Theses cases were compared to the existing data using 4 identification variables: first name, family name, date of birth or age, sex and diagnosis.

Problems:

- Two services were not visited
- Information concerning cause of death is not given on death certificates.
- What becomes of children with CNS tumors following surgery?
- Almost all services note the age and not the date of birth.
- Difficult to know the permanent addresses of the children found as only the referring doctor is registered.
- Having access to patient files is necessary to complete missing information.

RESULTS

Fig 1: Shows the regional origin of the **411 identified cases** in the national Paediatric Oncology Unite (POU) in the Dantec Hospital in Dakar. **Only 133 (32%)** are resident of the Dakar region.



During the same period, **283 other cases were detected in 4 of the other 8** selected services. When cross matched 111 cases with cases found in the POU, and 23 others 23 excluded because residing outside the region, and 12 cases were excluded because they were metastatic samples. Overall, **149 cases were unmatched, because** no information on residence was available.

Among the 411 identified cases, leukemia's accounted for 30% of all the childhood cancers observed followed by 13% nephroblastoma; only 6,1% of BL in the Dakar region. Only 2,2% 18 CNS tumors with 1 referred to the POU none of the remaining 17 were seen in the POU.

Fig 1 shows the minimum incidence rate based on the 133 matched cases diagnosed in 2017-2019.

Age group (years)	Population of the Dakar region		Cases residents of the Dakar region (HBCR)		
	N	%	n	%	IR
0-4	1,570,858	36%	56	42%	35,6
5-9	1,161,293	27%	43	32%	37,0
10-14	1,038,676	24%	29	22%	27,9
15-17	567,751	13%	5	4%	8,7
Total <15	3 770 828	87%	128	96%	33,9
Total <18	4 344 190	100%	133	100%	30,6

The estimates of incidence rates **based on the 133 cases** identified for the region of Dakar is extremely low, 33.9 per million and year for the <15 and 30.6 per million and year for <18 World age standardised incident rate (WSR) were even lower (30.4 and 27.2 per million and year, respectively). Even if all the 149 unmatched cases were residents in the Dakar region, the incident rate would still be low with 65 cases per million and year.

CONCLUSION

- **We identified key stakeholders that could support a population-based cancer registry.**
- **We identified additional data sources, as well as the need for collection of additional data items (e.g. place of residence).**
- **Children with CNS tumours are seen in neurosurgery departments and are not referred to the POU.**
- **BL occurrence in Dakar was relatively low, possibly because of low prevalence of malaria**
- **This study shows the importance of involvement of all local stakeholders to collect quality information in collaboration.**
- **The very low incidence confirms that only a quality population-based registration can generate incidence data.**
- **Access to patients' files is required to ensure high quality registration of childhood cancer the Dakar region.**