

Analysis of missing data and completeness modeling of cancer clinical records: The case of the Ngaliema Clinic in Kinshasa, Democratic Republic of Congo

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Summary

Introduction

The present study aims to examine the completeness and model the exhaustiveness of clinical records of cancer patients followed at the Ngaliema Clinic in Kinshasa.

Materials and methods

A retrospective study analyzed the records of 81 patients with cancer followed at the Ngaliema clinic between 2023 and 2025. Using JASP 0.95.4.0 software, descriptive and inferential analyses based on the Little, Friedman, Durbin -Conover test and a multiple linear regression model were performed at the usual threshold of 0.05.

Results

Analysis of the SNIS data revealed significant heterogeneity in cancer reporting across Kinshasa's health zones, with the highest completeness observed in Limete and Mont-Ngafula I, while several zones remained below 40%. Over the period 2021–2025, the trend in reported cases showed no significant temporal pattern ($p > 0.05$), and unspecified cancers accounted for more than three-quarters (¾) of the records. These limitations of the aggregated data system prompted a refocusing of the analysis on individual patient data, using medical records from the Ngaliema Clinic. The mean record completeness score was $61.7\% \pm 6.4\%$, with a completely random missing data mechanism (Little's MCAR test: $\chi^2 = 1.830$; $df = 4$; $p = 0.767$). The multilevel Bayesian analysis revealed that combined therapeutic use increased the mean completeness score (+4.69 points; 95% CI: 0.77–8.61), while each month of delayed consultation improved it by 0.20 points. Inter-municipality heterogeneity persisted ($\sigma = 2.15$), justifying the multilevel approach.

Conclusion

The completeness of cancer records at the Ngaliema Clinic depends markedly on clinical severity, patient age, and therapeutic pathway.

Recommendation

Implement a standardized oncology form, strengthen digital skills, support digitization and develop a sustainable provincial cancer registry.

Keywords: Cancer; Medical records; Missing data; Ngaliema Clinic; Kinshasa, Democratic Republic of Congo

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Introduction

Cancer is increasingly becoming a central public health issue worldwide. Estimates for 2022 projected approximately 20 million new diagnoses and 9.7 million deaths, with a particularly pronounced increase in low- and middle-income countries. The development, implementation, and evaluation of prevention, diagnosis,

treatment, and surveillance policies therefore require robust and reliable data.

However, cancer registries, along with hospital clinical records, constitute the main sources of information on patients, tumor characteristics, and treatment modalities (Parkin, 2006). Their scientific utility remains, however, closely contingent on the quality of the data collected (Bray

et al., 2014) . Insufficient completeness can impair the estimation of the burden of disease, reduce comparability between populations, and undermine data-informed decision-making (Jena et al., 2023) .

Furthermore, missing values represent a major methodological threat to the validity of epidemiological analyses. They degrade the accuracy of estimates and can introduce biases since their occurrence depends on patient characteristics or treatment. Their explicit handling is therefore essential to guarantee the robustness of results derived from clinical databases (Cro et al., 2020; Jakobsen et al., 2017) .

From this, the methodological literature classically distinguishes three mechanisms of missing data: completely random (MCAR), random conditional on observed information (MAR), and non-random (MNAR). Identifying the predominant mechanism guides the choice of analytical approaches and conditions the validity of statistical inferences (Bhaskaran & Smeeth, 2014) . This approach constitutes an essential step in any rigorous evaluation of the quality of health data.

Across sub-Saharan Africa, oncology information systems remain hampered by structural constraints that degrade the reliability and completeness of data (Ayubi et al., 2024) . Numerous analyses have highlighted coverage gaps, marked heterogeneity in completeness levels, and organizational obstacles that compromise the production of robust indicators necessary for epidemiological surveillance and the planning of cancer control interventions (Bray et al., 2022).

In the Democratic Republic of Congo, available knowledge on the quality of oncological information remains fragmented. Data originate primarily from a few specialized centers, and the determinants of incomplete clinical records have received virtually no rigorous scientific investigation. This deficiency hinders the development of information systems capable of effectively and sustainably supporting cancer surveillance.

This study examines the completeness and models the exhaustiveness of clinical records of cancer patients followed at the Ngaliema Clinic in Kinshasa. It aims to estimate the completeness of the main recording domains, to characterize the mechanisms of missing data, and to identify the determinants of the documentary quality of the records.

Methodology

Study setting

This study was conducted at the Ngaliema Clinic, a referral and tertiary level hospital in the Gombe health zone, one of 35 health zones in the Kinshasa Provincial Health Division, in the Democratic Republic of Congo, and the main zone where there has been consistency in the number of cancer cases reported over the last decade after an analysis of SNIS data at the DPS level.

This structure also provides diagnostic and therapeutic care for multiple neoplastic entities and has structured medical

archives facilitating the retrospective exploitation of clinical data.

Study design

This is a retrospective observational study covering the period from 2023 to 2025.

Population and sampling

The population of interest consisted of all patients for whom cancer had been formally diagnosed and for whom a clinical file was kept in the archives of the Ngaliema Clinic. Only files containing, at a minimum, the information essential for patient identification and validation of the oncological diagnosis were included. Any illegible file or one that did not allow for a definitive diagnosis was excluded from the analysis. The primary statistical unit corresponded to each clinical file, and thus, 81 files were ultimately analyzed.

Data collection technique and source

Document analysis technique (document review) of the records provided by the oncology department of the Ngaliema Clinic was relied on. The data were recorded from the records into the KoboCollect application, which served as our data collection tool. This had the advantage of reducing the bias of multiple transcriptions that could occur if the information were initially recorded on printed paper for subsequent encoding.

Variables of interest

The analyzed information was divided into five levels of registration according to the terminology used in most cancer registries (Parkin , 2006; Bray et al., 2014; WHO, 2019; Jensen et al., 1991) . These levels are, for example:

- (i) Patient identification: the name coded here, sex, age at diagnosis, level of education, occupation, and marital status.
- (ii) Geographic location: province, municipality, district, avenue, number.
- (iii) History, risk factors/behavior, and comorbidities: family history of cancer, obesity, smoking, alcoholism, diet, HIV status, Hepatitis B or C, HPV.
- (iv) Tumor and diagnostic information: date of diagnosis, topography, laterality, morphology, evolutionary stage, TNM stage (AJCC - 8th edition), Biomarker status (Site-Specific variables) and histological type.
- (v) Therapeutic management and follow-up: consultation time, initial therapeutic recourse, therapeutic regimen in hospital, patient outcome, method of monitoring vital status. Each of these variables was coded "1" if information was marked in the patient's file, and "0" if it was not recorded.

Creation of completeness indicators

Completeness was assessed using a multi-level approach, successively considering variables, recording domains, and individual records. For each record, an overall completeness index was derived, corresponding to the proportion of variables actually completed divided by the total number of expected variables, then weighted as a percentage.

$$\text{Complétude (\%)} = \frac{\text{Number of variables entered}}{\text{Total number of variables expected}} \times 100$$

After its application, five intermediate scores corresponding to the five levels or domains of registration were obtained, and then the overall score was also created.

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Data processing and analysis

The data were processed using the modern version of Excel integrated with Microsoft 365 and JASP 0.95.4.0. The results were presented in figures and tables after descriptive and inferential analyses.

Initially, a descriptive characterization of the incompleteness was carried out in order to estimate, for each variable and for each of the recording fields, the proportions of missing values.

In a second step, Little's test was used to verify the hypothesis of completely random missing data (MCAR). In accordance with the usual non-rejection criteria, a p-value strictly greater than 0.05 was considered compatible with the MCAR hypothesis and the entire inferential part.

Thirdly, the distributions of completeness scores were compared between recording domains using the Friedman test, and then by post hoc comparisons according to the Durbin-Conover method.

Finally, a multilevel analysis was performed, taking into account inter-group/inter-district variability (random effects) and ensuring accurate estimation of standard errors and 95% Bayesian credibility intervals (95% CCI). Three models were compared before selecting the last one, which had the lowest LOO-CI (587.0). This indicates superior predictive power compared to the null model and the sociodemographic model, whose difference in predictive density (Δ ELPD = -7.7) confirmed that the simultaneous integration of consultation time, care pathway (therapeutic recourse), and clinical characteristics significantly improves the model fit.

Ethical considerations

The overall protocol for this study was submitted to the ethics committee of ISTM/Kinshasa and received authorization No.

0036/CBE/ISTM/KIN/RDC/PMBBL/2025 on February 12, 2026. Additionally, the data underwent an anonymization protocol and were then processed according to standardized operating procedures to preserve confidentiality, maintain source integrity, and ensure the reproducibility of the analyses. The analytical basis was established without any alteration of the original clinical information.

Results

Sample description

The data in Table 1 show the percentage of missing data in a subset of 81 oncology records. The results reflect the level of omission of information necessary for patient identification, risk profiling, medical conditions, and follow-up.

Geographic parameters are not well documented. The province of origin is missing in 96.3% of cases, and specific addresses (municipality, district, avenue) have omission rates exceeding 90%, thus making territorial traceability impossible.

The section on medical history and risk behaviors received the lowest possible score. Dietary habits were missing in 98.8% of cases, as were HIV status, hepatitis, and HPV infection, which were also missing in 87.7%. Gaps were also present in the disease characteristics. A total of 59.3% of observations did not include the stage of disease progression.

Other significant gaps in documentation exist in terms of degree of involvement (28.4%) and histological type (24.7%). In contrast, age (3.7% missing), topography (0.0%), consultation delay (1.2%), and patient outcome (1.2%) had a very low percentage of omissions, suggesting that these parameters, even with almost complete data collection, do not constitute total completeness.

Table 1: Proportion of missing data related to patient identification and geographic location

Variables	Number of employees (n = 81)	Percentage
Identification		
Age (in year (over)	3	3.7
Sex	0	0.0
Level study	54	66.7
Marital status	34	42.0
Location geographical		
Province of origin	78	96.3
Municipality	5	6.2
Neighborhood	5	6.2
Avenue	7	8.6
Number	18	22.2
History and risky behavior		
history of cancer	28	34.6
Case obesity in family	18	22.2
Hormone therapy previous	42	51.9
BMI (in kg/m ²)	45	55.6
Smoking	36	44.4
Consumption alcohol	40	49.4
Diet	80	98.8
HIV/AIDS Status	71	87.7
Hepatitis (B or C)	71	87.7
HPV infection (cervix)	71	87.7
Characteristics of the disease		
Diagnostic basis	2	2.5
Topography	0	0.0
Laterality	11	13.6
Morphology	7	8.6
Degree of harm	23	28.4
Stadium evolving	48	59.3
histological type	20	24.7
Treatment and follow-up		
Consultation timeframe (in months)	1	1.2
Appeal initial therapy	12	14.8
Plan therapeutic	38	46.9
Patient's Outcome	1	1.2

Missing value analysis

The results of the Little test (MCAR) presented in Table 2 indicate that the missing data mechanism is completely

random ($\chi^2 = 1.830$; $p = 0.767$). This gives mathematical validity to the final analysis based on complete records in the event of the completeness modeling.

Table 2 : Analysis of missing data

continuous variables	Data entered	Missing data	MCAR/ χ^2	ddl	p-value
Consultation period	80	1 (1,2)	1,830	4	0.767
Age at diagnosis	78	3 (3.7)			
BMI	36	45 (55.6)			

Comparative analysis of the completeness score of cancer patients' medical records

Figure 1 presents the results of the comparison of the fill/completeness scores of individual information of cancer

patients (Friedman Test) and shows a significant difference between the five record domains studied ($p < 0.001$).

Furthermore, comparative pairwise analyses (Durbin - Conover) revealed seven notable disparities. The level/domain "Medical History/Behaviors/Comorbidities

(c)" had a lower completeness score compared to the other categories (a,x; b,y; b,y,z) examined ($p < 0.001$). Moreover, the "Geographic Location" dimension showed significantly higher completeness compared to "Patient Identification" (p

< 0.001) and "Management and Follow-up" ($p = 0.037$). Finally, "Patient Identification" was recorded less frequently than "Disease Information" ($p < 0.001$).

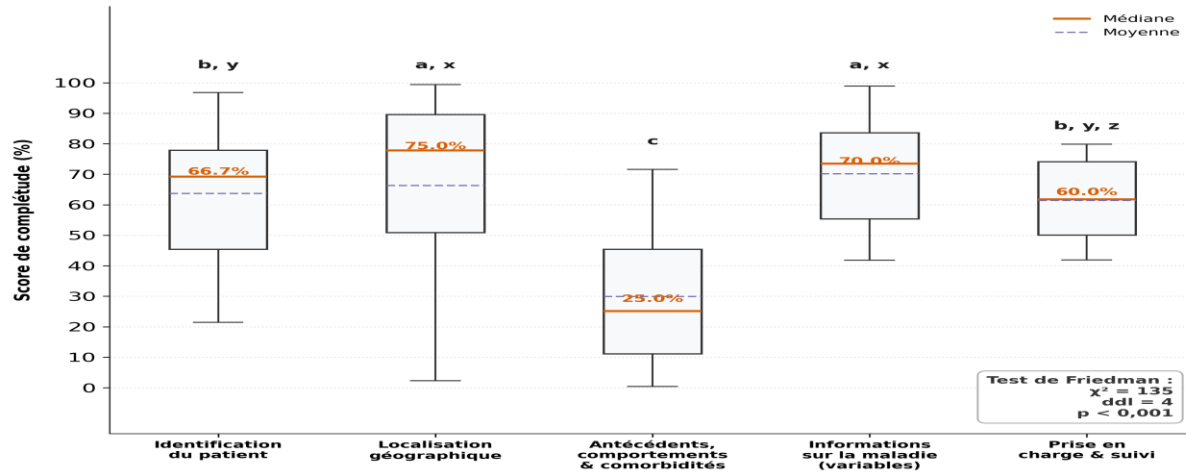


Figure 1: Comparative analysis of medical record completeness scores

Modeling the overall file completeness score

Identification of predictors of medical record completeness

The results of the final model in Table 3 indicate that initial combined or traditional/prayer-based treatment is associated with a 4.69-point higher completeness score (95% ICD: [+0.77; +8.61]) compared to exclusive modern medical treatment. The posterior probability of a positive effect is 99.0%.

Regarding the time to consultation, each additional month of consultation delay is associated with an average increase in the completeness score of 0.20 points (95% ICD: [0.00; 0.41], $P(\beta > 0) = 97.5\%$). Cases seen late often have more documented clinical records due to complications.

Regarding the district/place of residence; Compared to Lukunga (reference), the districts of Mont Amba ($\beta = +3.48$, $P = 91.5\%$) and Tshangu ($\beta = +4.17$, $P = 88.5\%$) showed higher mean completeness scores.

Regarding family history and degree of involvement, cases with a family history of cancer had a score 2.57 points higher (95% ICD: [-2.81; 7.94], $P = 82.8\%$), and in situ forms had a score 2.55 points higher than invasive forms.

For age, laterality, and year, the effect of age ($\beta = -0.03$) and bilateral laterality ($\beta = -2.53$) did not show strong, statistically significant variations a posteriori. From the multilevel structure, the inter-commune variance ($\sigma_{\text{district}} = 2.15$) confirms the presence of spatial heterogeneity between the health districts of Kinshasa, validating the multilevel approach

Table 3 : Post-hoc estimates of the multilevel Bayesian linear model (Continuous completeness score)

Variables / Modalities	Average Effect (β)	Standard deviation (SD)	ICD 95%	$P(\beta > 0)$
Constant (Intercept)	56.35	3.90	[48.58 ; 64.12]	> 99.9%
Age at diagnosis (in years)	-0.03	0.06	[-0.16 ; 0.09]	29.7%
Consultation timeframe (months)	+0.20	0.10	[0.00 ; 0.41]	97.5%
Laterality: Unilateral	Ref.	-	-	-
Laterality: Bilateral	-2.53	5.27	[-13.04 ; 7.98]	31.7%
Year: 2025	Ref.	-	-	-
Year: 2023 vs 2025	-2.14	3.51	[-9.14 ; 4.86]	27.2%

Year: 2024 vs 2025	-1.01	2.14	[-5.28 ; 3.26]	32.0%
Degree of involvement: Invasive	Ref.	-	-	-
Degree of involvement: In situ vs. Invasive	+2.55	4.72	[-6.86 ; 11.97]	70.5%
Family history: No	Ref.	-	-	-
Family history: Yes vs No	+2.57	2.70	[-2.81 ; 7.94]	82.8%
Municipality: Lukunga	Ref.	-	-	-
Municipality: Mont Amba vs Lukunga	+3.48	2.50	[-1.52 ; 8.48]	91.5%
Municipality: Funa vs Lukunga	+2.05	2.49	[-2.92 ; 7.02]	79.4%
Commune: Tshangu vs Lukunga	+4.17	3.44	[-2.70 ; 11.04]	88.5%
Initial recourse: Modern	Ref.	-	-	-
Initial recourse: Traditional/Prayer/Comb. vs Mod.	+4.69	1.96	[+0.77 ; +8.61]	99.0%
σ_{district} (Inter-municipal Variance)	2.15	0.82	[0.95; 4.10]	-
σ_{residual} (Residual Variance)	7.85	0.62	[6.72; 9.18]	-

Discussion

This section discusses the key findings of the present study, focusing on (i) the mechanisms of missing data and the validity of the analyses, (ii) the variability of completeness scores by domain, and (iii) the systemic and clinical determinants of the overall completeness score. The section concludes with the implications of the study, followed by its strengths and limitations.

Mechanisms of missing data and validity of analyses

Little's test, demonstrating a completely random missing data mechanism, statistically justifies the exclusion of incomplete records from the final modeling of the completeness score. This methodological requirement eliminates selection bias and strengthens the legitimacy of decision-making analyses.

These results are promising and differ from those reported by other authors who found that incomplete medical records in oncology are most often not random, resulting from recurrent clinical negligence or structural losses of follow-up related to the cost of examinations (Habib Ullah) . Riaz et al., 2025; Gachau et al., 2020) .

According to international recommendations, rigorous statistical validation and transparent management of missing clinical data are essential to harmonize survival indicators, a major methodological challenge supported by recommendations for breast cancer registries (Dahm et al.,

2023; "Correcting bias due to missing stage data in the non-parametric estimation of stage-specific net survival for colorectal cancer using multiple imputation," 2017) , particularly the Global Stage multicenter study. Distributi o n de 2023 (Jama , 2023) .

That being said, in the following paragraphs, we proceed to analyze the variability of the completeness scores of medical records of patients with cancer according to the different levels or areas of information recording.

Variability of completeness scores by data recording field

The highly significant difference observed between the five recording fields ($p < 0.001$) indicates inconsistent completeness of records for the same patient. The subscore related to history, behavior, and comorbidities (HIV, HPV, BMI) is the least detailed. This could be explained by the fact that, in practice, clinical urgency takes precedence over systematic behavioral questioning.

The absence of a structured collection of risk factors, including smoking, alcohol consumption (Jeandria) Nkodia et al., n.d.), and obesity, constitutes a recurring weakness in Central Africa, as indicated by the World Health Organization. Recent studies confirm this observation, showing that workload overload and a shortage of well-trained oncologists lead to lifestyle variables deemed non-immediate being relegated to the background (Habib Ullah) . Riaz et al., 2025) . Conversely, better completeness of the

variable "Geographic location" would decouple administrative constraints inherent in hospital admission. In view of this variability, it is essential to analyze the determinants of the overall completeness score of these patients' records.

Systemic and clinical determinants of the overall completeness score

Residual heterogeneity between health districts is confirmed by a multilevel analysis ($\sigma = 2.15$), also supporting the use of a hierarchical model. This variability indicates that record completeness depends not only on individual patient characteristics but also on contextual factors related to referral pathways and the organization of care. This view is consistent with the recent suggestion to improve the governance of hospital information systems (Gichoya et al., 2025)

Furthermore, initial therapeutic use is the determinant most strongly associated with record completeness. Thus, patients who used both modern medicine and traditional or spiritual treatments obtained a score 4.69 points higher (95% CI = 0.77–8.61) and a posterior probability of 99.0% compared to those who used only modern medicine. This finding may indicate more complex care pathways requiring comprehensive clinical notes (James et al., 2018; Kwame, 2021; Pérez-Jiménez et al., 2026)

Delay in consultation is also positively associated with the completeness score. The score increases by an average of 0.20 points per month before the first consultation (95% CI: 0.00–0.41; $P(\beta > 0) = 97.5\%$). Patients with delayed consultations often present with more complex clinical presentations that include more diagnostic investigations and a progressive accumulation of information in patient records (Jumhour, 2026; Rahman et al., 2019; Tesfaw et al., 2020)

Compared to the Lukunga district, where the Ngaliema clinic is located and where the data were collected, patients residing in the Mont-Amba ($\beta = +3.48$; $P = 91.5\%$) and Tshangu ($\beta = +4.17$; $P = 88.5\%$) districts had higher mean completeness scores. We believe this difference not only reflects better documentation quality in these districts but could also indicate more complex patient profiles or different management approaches prior to admission to the Ngaliema clinic.

A family history of cancer (+2.57 points) and in situ forms (+2.55 points) showed a trend toward greater documentation completeness, although their credibility intervals included zero. Thus, these associations are consistent with a positive influence but require studies with larger samples to confirm robustness (Cockayne et al., 2005).

Finally, the data from our study indicate that age ($\beta = -0.03$) and bilateral laterality ($\beta = -2.53$) are not statistically significant correlates with the completeness score. This non-negligible trend indicates that the quality of clinical records is not influenced by the demographic or anatomical characteristics of patients. On the contrary, it is a direct

response to aspects of both the care pathway and the organizational environment.

In other words, the thoroughness of the records is not dictated by these individual patient characteristics but rather by the complexity of their overall therapeutic journey (delayed consultations, mixing of traditional medicine and modern treatment) and by the coordination of activities required within healthcare institutions (Jumhour, 2026)

Conclusion

The results indicate that the completeness of cancer records at the Ngaliema Clinic is dependent on clinical severity, patient age, and treatment pathway. The MCAR hypothesis is consistent with the observations, thus strengthening the validity of our modeling framework. This work provides the baseline diagnosis necessary for the development of the forthcoming thesis dedicated to the first pilot hospital cancer registry in the DRC in general and in Kinshasa in particular.

Recommendations

In light of the results, it is imperative to implement, upon patient admission, a standardized minimum oncological form to systematically record a comprehensive medical history, including comorbidities, past medical history, and BMI. Hospital administrations in Kinshasa should prioritize ongoing digital skills training for staff and the ergonomic optimization of data collection tools. Such measures will mitigate the impact of workload overload on document quality, particularly during clinical emergencies.

Furthermore, the Ministry of Health would benefit from integrating spiritual leaders and traditional healers into early referral networks to document symptom history and reduce waiting times for consultations. In addition, the government should provide financial support for the transition to electronic health records. Robust digital governance is essential to ensure the sustainability of the future pilot cancer registry in the face of changing times.

Strengths and limitations of the study

The main strength of this work lies in the robustness of its statistical validation. The application of Little's test confirms that the pattern of missing data stems from a completely random mechanism. This characteristic establishes, for the final regression modeling, conditions of mathematical validity that are rarely met. Furthermore, the integration of observations within the operational context of Kinshasa, by visiting a tertiary-level healthcare facility, provides a unique empirical diagnostic reference for the region.

The major limitation stems from the retrospective and monocentric nature of the data collection, which restricts the external scope of the results to the provincial and national levels. Furthermore, the exclusion of incomplete records mechanically reduced the statistical power of the sample. Finally, the single data collection could increase the risk of transcription errors and the possibility of comparison with other transcriptions.

Implications of the study

Immediate clinical and managerial implications

Clinically, the completeness and accuracy of patient records are closely linked to tumor aggressiveness and the clinical workload of medical teams. Therefore, it is essential to emphasize the systematic inclusion of family history and major comorbidities (HIV, HPV, body mass index) by clinicians—dimensions that are too often omitted today, even though they are crucial for tailoring treatment plans and risk stratification.

Implications for public health policies

The high proportion of people resorting to traditional or spiritual practices (54.3%) is a warning sign for the health authorities in Kinshasa. It is imperative to design, without delay, community awareness campaigns that involve religious authorities and traditional practitioners in a structured way. The aim is to formalize early referral pathways to modern facilities, reduce waiting times for care, and simultaneously document patients' pre-hospital medical histories in a standardized manner, while also maintaining the interdisciplinary approach that remains essential for chronically ill patients.

Doctoral perspectives: towards a pilot registry in Kinshasa

This thesis establishes an essential baseline for a doctoral program. The completely random missing data hypothesis (MCAR) confirms the statistical viability of exploiting current hospital series. This work provides a detailed map of the variables and admission pathways that require a strict quality assurance system during subsequent collections.

The central objective of the thesis will be the design and implementation of the first pilot hospital cancer registry in Kinshasa. The predictive models already developed highlight high-risk profiles (elderly subjects, bilateral involvement, residents of Funa) for which active case finding (active case-finding) will be essential.

This register will constitute the first structuring step of a digital governance of oncology in the Democratic Republic of Congo.

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Abbreviations

BCZS	: Central Health Zone Office
CSR	: Referral Health Center
EMR	: Electronic Medical Record
DPS	: Provincial Health Division
FOSA	: Health Training

GLOBOCAN	: Global Cancer Observatory
HGR	: General Referral Hospital
IARC	: International Agency for Research on Cancer
IC:	: Confidence Interval
ISTM	: Higher Institute of Medical Techniques
MAR	: Missing At Random
MCAR	: Missing Completely At Random
MNAR	: Missing Not At Random
WHO	: World Health Organization
NGO	: Non-Governmental Organization
p-value	: probability value
R²	: determination coefficient
RC	: Cancer registry
DRC	: Democratic Republic of Congo
RPCK	: Kinshasa piloted cancer register
SNIS	: National Health Information System
WHO	: World Health Organization
ZS	: Health Zone
β	: regression coefficient
χ²	: chi-square statistic

Conflicts of interest

The authors state that they have no competing interests.

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Author contributions

AMP designed the study, conducted the formal analyses, and drafted the initial manuscript. KBH and OOJP participated in data collection and contributed to manuscript writing. KKC participated in data collection and analysis. LMJ proposes the methods to be used. IIF and TKF were responsible for supervision and substantial revision of the study manuscript. All authors critically reviewed and approved the final manuscript and accepted full responsibility for the integrity of the work.

Data availability

Data is available upon request.

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