

## 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

There was a predominance of women and patients under 50 years of age, mostly residing in the Lukunga district, with cancer diagnosed at an invasive stage (stage II) among the patients whose records were analyzed. The MCAR hypothesis was verified ( $p = 0.767$ ). A significant difference was observed between the five evaluated recording domains ( $\chi^2 = 135$ ;  $p < 0.001$ ). Furthermore, the overall completeness score decreases significantly according to age ( $\beta = -0.174$ ;  $p = 0.016$ ); bilateral organ involvement ( $\beta = -7.349$ ;  $p = 0.029$ ); year of detection 2024 vs 2025 ( $\beta = -10.732$ ;  $p < 0.001$ ); non-invasive nature of the disease ( $\beta = -5.893$ ;  $p = 0.047$ ); family history of cancer ( $\beta = -4.491$ ;  $p = 0.028$ ); of residence in the Funa district vs. Lukunga ( $\beta = -4.547$ ;  $p = 0.017$ ) and of initial traditional treatment/prayer ( $\beta = -5.822$ ;  $p = 0.025$ ). However, this score increases with the time elapsed before consultation ( $\beta = 0.476$ ;  $p < 0.001$ ) and then with origin from the Tshangu district ( $\beta = 9.236$ ;  $p = 0.009$ ).

#### 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

**Submitted:** March 23, 2026    **Accepted:** July 1, 2026    **Published:** August 1, 2026

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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.

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

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.

### 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.

Fourth, the identification of the determinants of completeness was based on a multiple linear regression model. The adjusted  $\beta$  coefficients, accompanied by their 95% confidence intervals, were presented.

However, the chosen regression model was systematically evaluated using the coefficient of determination, the Durbin

-Watson test for autocorrelation, the Shapiro-Wilk test for residual normality, and the Cook and Mahalanobis distances for outliers and influential values. Collinearity was also verified based on VIF and tolerance, the values of which were all close to 1.

### 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

#### Patient identification and location

Table 1 shows that the majority of patients whose records were analyzed were under 50 years old (43.2%), female (71.6%), had a higher education level (28.4%), were married (44.4%), and lived in the Lukunga district (32.1%).

Of the quality of the data, the level of education (66.7%), marital status (42.0), and province of origin (96.3%) were the main elements of patient identification and location with the most missing data.

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

| Variable                 | Data entered |      | Missing data |      |
|--------------------------|--------------|------|--------------|------|
|                          | Effective    | %    | Effective    | %    |
| ID (patient name)        | 81           | 100  | 0            | 0.0  |
| Age (in completed years) |              |      |              |      |
| < 50                     | 35           | 43.2 | 3            | 3.7  |
| 50-64                    | 26           | 32.1 |              |      |
| ≥ 65                     | 17           | 21.0 |              |      |
| Sex                      |              |      |              |      |
| Female                   | 58           | 71.6 | 0            | 0.0  |
| Male                     | 23           | 28.4 |              |      |
| Level of education       |              |      |              |      |
| Secondary                | 4            | 4.9  | 54           | 66.7 |
| Superior                 | 23           | 28.4 |              |      |
| Marital status           |              |      |              |      |
| Bachelor                 | 4            | 4.9  | 34           | 42.0 |
| Divorce                  | 1            | 1.2  |              |      |
| Bride)                   | 36           | 44.4 |              |      |
| Widower/ widow           | 6            | 7.4  |              |      |
| Province of origin       |              |      |              |      |
| Kinshasa                 | 3            | 3.7  | 78           | 96.3 |
| Address/District         |              |      |              |      |
| Funa                     | 21           | 25.9 | 5            | 6.2  |
| Lukunga                  | 26           | 32.1 |              |      |
| Mount Amba               | 21           | 25.9 |              |      |
| Tshangu                  | 8            | 9.9  |              |      |

### Medical history, behavior, and comorbidities

Table 2 shows that many of the patients whose records were used had no family history of cancer (48.1%) or obesity (75.3%), had never received hormone therapy (38.3%), had a normal body weight (21.0%), reported never having smoked (53.1%) or consumed alcohol (28.4%), with a negative serological status for HIV/AIDS (11.1%), Hepatitis B or C (12.3%) and then HPV (12.3%).

Regarding data recording, a significant proportion of missing information was found concerning diet, HIV status, Hepatitis B/C, HPV infection, BMI, and prior hormone therapy, which were undocumented for more than half of the patients. Similarly, more than a third of the records lacked information regarding family history of cancer, smoking, and alcohol use.

**Table 2: Proportion of missing data related to history, behavior, and comorbidities**

| Variables                    | Data entered<br>Effective | %    | Missing data<br>Effective | %    |
|------------------------------|---------------------------|------|---------------------------|------|
| Family history of cancer     |                           |      |                           |      |
| No                           | 39                        | 48.1 | 28                        | 34.6 |
| Yes                          | 14                        | 17.3 |                           |      |
| Cases of obesity in families |                           |      |                           |      |
| No                           | 61                        | 75.3 | 18                        | 22.2 |
| Yes                          | 2                         | 2.5  |                           |      |
| Previous hormone therapy     |                           |      |                           |      |
| No                           | 31                        | 38.3 | 42                        | 51.9 |
| Yes                          | 8                         | 9.9  |                           |      |
| BMI (in kg/m <sup>2</sup> )  |                           |      |                           |      |
| < 18.5                       | 3                         | 3.7  | 45                        | 55.6 |
| 18.5 – 24.9                  | 17                        | 21.0 |                           |      |
| 25.0 – 29.9                  | 7                         | 8.6  |                           |      |
| ≥ 30.0                       | 9                         | 11.1 |                           |      |
| Smoking                      |                           |      |                           |      |
| Active smoker                | 1                         | 1.2  | 36                        | 44.4 |
| Former smoker                | 1                         | 1.2  |                           |      |
| Never                        | 43                        | 53.1 |                           |      |
| Alcohol consumption          |                           |      |                           |      |
| None                         | 23                        | 28.4 | 40                        | 49.4 |
| Casual                       | 17                        | 21.0 |                           |      |
| Regular                      | 1                         | 1.2  |                           |      |
| Diet                         |                           |      |                           |      |
| Rich in salt/smoky           | 1                         | 1.2  | 80                        | 98.8 |
| HIV/AIDS Status              |                           |      |                           |      |
| Negative                     | 9                         | 11.1 | 71                        | 87.7 |
| Positive                     | 1                         | 1.2  |                           |      |
| Hepatitis (B or C)           |                           |      |                           |      |
| Negative                     | 10                        | 12.3 | 71                        | 87.7 |
| HPV infection (cervix)       |                           |      |                           |      |
| Negative                     | 10                        | 12.3 | 71                        | 87.7 |

### Disease characteristics (tumor variables)

The results in Table 3 describe the characteristics of cancer among the patients whose records were analyzed. They show that the majority were diagnosed in 2025 (46.9%), based on clinical findings combined with radiography (51.9%). Isolated breast cancer accounted for 34.6% of all diagnoses. Unilateral and single-organ involvement were

predominant (82.7%). Carcinoma was the most common type of cancer, both in terms of morphology (80.2%) and histological type (58.0%). Finally, many of the diagnosed cancers were invasive (66.7%) and stage II (30.9%). Regarding the quality of documentation, the evolutionary stage at the time of diagnosis shows the highest proportion of missing data (59.3%), followed by the degree of impairment (28.3%).

**Table 3: Proportion of missing data related to disease characteristics**

| Variables                | Data entered<br>Effective | %    | Missing data<br>Effective | %    |
|--------------------------|---------------------------|------|---------------------------|------|
| Date of diagnosis/Period |                           |      |                           |      |
| 2023                     | 8                         | 9.9  | 0                         | 0.0  |
| 2024                     | 35                        | 43.2 |                           |      |
| 2025                     | 38                        | 46.9 |                           |      |
| Diagnostic basis         |                           |      |                           |      |
| Clinical/X-ray           | 42                        | 51.9 | 2                         | 2.5  |
| Cyto -histology          | 37                        | 45.7 |                           |      |
| Topography               |                           |      |                           |      |
| Other organs             | 38                        | 46.9 | 0                         | 0.0  |
| Prostate                 | 2                         | 2.5  |                           |      |
| Breast                   | 28                        | 34.6 |                           |      |
| Gynecological sphere     | 13                        | 16.0 |                           |      |
| Laterality               |                           |      |                           |      |
| Bilateral                | 3                         | 3.7  | 11                        | 13.6 |
| Unilateral/single organ  | 67                        | 82.7 |                           |      |
| Morphology               |                           |      |                           |      |
| Carcinoma                | 65                        | 80.2 | 7                         | 8.6  |
| Leukemia                 | 1                         | 1.2  |                           |      |
| Sarcomas                 | 8                         | 9.9  |                           |      |
| Degree of impact         |                           |      |                           |      |
| Invasive                 | 54                        | 66.7 | 23                        | 28.4 |
| In situ                  | 4                         | 4.9  |                           |      |
| Evolutionary stage       |                           |      |                           |      |
| Stage I                  | 3                         | 3.7  | 48                        | 59.3 |
| Stage II                 | 25                        | 30.9 |                           |      |
| Stage III                | 5                         | 6.2  |                           |      |
| histological type        |                           |      |                           |      |
| Other types              | 14                        | 17.3 | 20                        | 24.7 |
| Carcinoma                | 47                        | 58.0 |                           |      |

### Treatment and follow-up

Regarding patient management, Table 4 shows that more than half of the cancers were diagnosed more than three months after the onset of symptoms (55.6%), and the initial treatment was non-medical (54.3%). In the hospital, the predominant treatment regimen was chemotherapy alone

(27.2%) or combined with radiotherapy (24.7%). More than half of these patients were lost to follow-up.

Regarding the quality of information, the monitoring method and the treatment regimen were very poorly documented, with 46.9% and 98.8% of data missing, respectively.

**Table 4: Proportion of missing data related to Treatment and follow-up**

| Variables                          | Data entered<br>Effective | %    | Missing data<br>Effective | %    |
|------------------------------------|---------------------------|------|---------------------------|------|
| Consultation timeframe (in months) |                           |      |                           |      |
| ≤ 1                                | 11                        | 13.6 | 1                         | 1.2  |
| 2 - 3                              | 24                        | 29.6 |                           |      |
| ≥ 4 months                         | 45                        | 55.6 |                           |      |
| Initial therapeutic approach       |                           |      |                           |      |
| Others                             | 44                        | 54.3 | 12                        | 14.8 |
| Modern medicine                    | 25                        | 30.9 |                           |      |
| Treatment plan                     |                           |      |                           |      |
| Chemotherapy alone                 | 22                        | 27.2 | 38                        | 46.9 |
| Chemotherapy & Surgery             | 1                         | 1.2  |                           |      |
| Chemotherapy & UV                  | 20                        | 24.7 |                           |      |
| Patient's Outcome                  |                           |      |                           |      |
| Continue treatment                 | 9                         | 11.1 | 1                         | 1.2  |
| Deceased                           | 29                        | 35.8 |                           |      |
| Lost sight of                      | 42                        | 51.9 |                           |      |
| Monitoring method used             |                           |      |                           |      |
| Phone                              | 1                         | 1.2  | 80                        | 98.8 |

#### Missing value analysis

The results of the Little test (MCAR) presented in Table 5 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 presented in point 3.4.

**Table 5: Analysis of missing data**

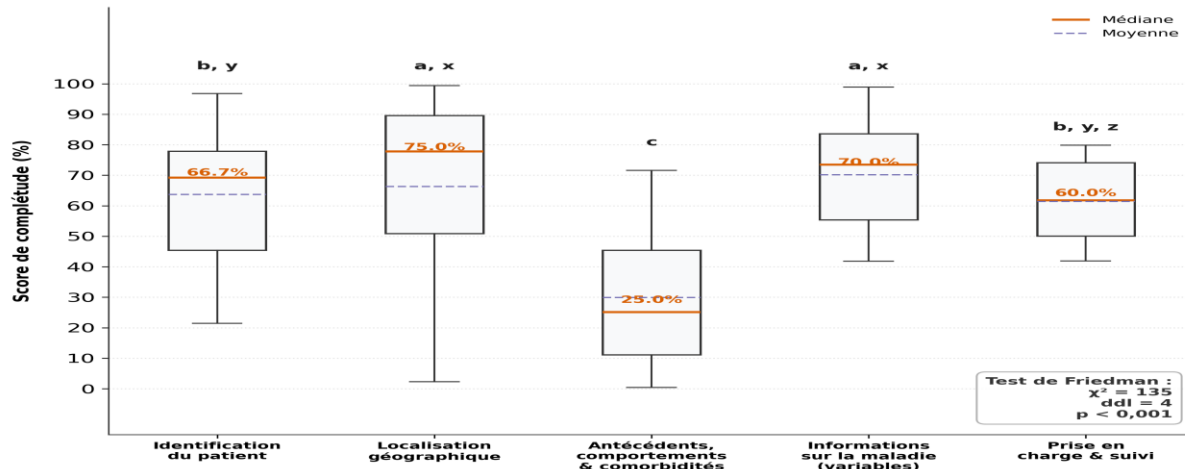
| continuous variables | Data entered | Missing data | MCAR/ $\chi^2$ | ddl | p-value |
|----------------------|--------------|--------------|----------------|-----|---------|
| Consultation period  | 80           | 1 (1,2)      | 1,830          | 4   | 0.767   |
| Age at diagnosis     | 78           | 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 in Table 6 indicate that the overall completeness score of the assessed medical records decreases significantly according to age at cancer diagnosis ( $\beta = -0.174$ ;  $p = 0.016$ ); bilateral organ involvement ( $\beta = -7.349$ ;  $p = 0.029$ ); year of

detection 2024 vs 2025 ( $\beta = -10.732$ ;  $p < 0.001$ ); non-invasive nature of the disease ( $\beta = -5.893$ ;  $p = 0.047$ ); family history of cancer ( $\beta = -4.491$ ;  $p = 0.028$ ); of residence in the Funa district versus Lukunga ( $\beta = -4.547$ ;  $p = 0.017$ ) and of initial traditional treatment/prayer ( $\beta = -5.822$ ;  $p = 0.025$ ). However, this score increases with the time elapsed before consultation ( $\beta = 0.476$ ;  $p < 0.001$ ) and then with residence in the Tshangu district compared to Lukunga ( $\beta = 9.236$ ;  $p = 0.009$ ).

**Table 6: Modeling of the overall file completeness score**

| Predictor                       | Estimate ( $\beta$ ) | 95% confidence |          | p-value  |
|---------------------------------|----------------------|----------------|----------|----------|
|                                 |                      | Terminal inf   | Superior |          |
| Originally ordered <sup>a</sup> | 64.439               | 56,573         | 72.3046  | <.001*** |
| Age at diagnosis (in years)     | -0.174               | -0.311         | -0.0368  | 0.016*   |
| Consultation period             | 0.476                | 0.320          | 0.6323   | <.001*** |
| Laterality:                     |                      |                |          |          |
| Bilateral vs Unilateral         | -7,349               | -13,830        | -0.8678  | 0.029*   |
| Year:                           |                      |                |          |          |
| 2023 vs 2025                    | -3.737               | -8,784         | 1.3110   | 0.136    |
| 2024 vs 2025                    | -10.732              | -14,581        | -6.8825  | <.001*** |
| Degree of impact:               |                      |                |          |          |
| In situ vs Invasive             | -5.893               | -11,686        | -0.0994  | 0.047*   |
| Family history of cancer:       |                      |                |          |          |
| Yes vs No                       | -4.491               | -8.424         | -0.5594  | 0.028*   |
| Municipality of residence:      |                      |                |          |          |
| Mount Amba vs Lukunga           | 0.784                | -3.073         | 4.6398   | 0.672    |
| Tshangu – Lukunga               | 9.236                | 2.685          | 15.7867  | 0.009**  |
| Funa vs Lukunga                 | -4.573               | -8.223         | -0.9223  | 0.017*   |
| Initial therapeutic approach:   |                      |                |          |          |
| Traditional/prayer vs Modern    | -5.822               | -10.796        | -0.8486  | 0.025*   |
| Integrated PEC vs Modern        | -0.536               | -4.479         | 3.4065   | 0.777    |

<sup>a</sup> Represents the overall average

\* Significant difference at the 0.05 level; \*\* Significant difference at the 0.01 level; Significant difference at the 0.001 level.



### Quality of fit and model validation diagnostics

Table 7a describes the goodness of fit and validation diagnostics of the model. The results demonstrate a well-fitted model explaining 83.9% of the variance in the overall score of completeness of medical records of cancer patients

( $R^2 = 0.839$ ); the independence or absence of residual autocorrelation (DW = 1.980;  $p = 0.908$ ) and the normality (Shapiro- Wilk = 0.977;  $p = 0.766$ ) of the residuals, and the absence of outliers (D-Cook = 0.449) and influential values (D- Mahalanobis = 11.40).

**Table 7a: Fit quality and model validation diagnostics**

| Validation parameters                        | Value | p-value |
|----------------------------------------------|-------|---------|
| Overall adjustment                           |       |         |
| Correlation coefficient (R)                  | 0.916 |         |
| Coefficient of determination ( $R^2$ )       | 0.839 |         |
| Residue analysis                             |       |         |
| Durbin -Watson independence test             | 1,980 | 0.908   |
| Wilk normality test                          | 0.977 | 0.766   |
| Detection of outliers and influential values |       |         |
| Maximum Cook Distance                        | 0.449 |         |
| Maximum Mahalanobis distance                 | 11.40 |         |

Furthermore, the results presented in Table 7b indicate the absence of collinearity between the variables. The VIFs range from 1.19 to 1.46, and the tolerances range from 0.69 to 0.84.

**Table 7b: Collinearity Statistics**

| Factors                               | VIF  | Tolerance |
|---------------------------------------|------|-----------|
| Age at diagnosis (in years)           | 1.19 | 0.838     |
| Consultation period                   | 1.42 | 0.704     |
| Laterality                            | 1.28 | 0.782     |
| Year                                  | 1.24 | 0.805     |
| Cancer behavior/degree of involvement | 1.37 | 0.728     |
| Family history of cancer              | 1.46 | 0.687     |
| Municipality of residence             | 1.21 | 0.828     |
| Initial therapeutic approach          | 1.27 | 0.790     |

### Discussion

This section discusses the key findings of the present study, focusing on (i) the sociodemographic and clinical profile of the patients whose records were reviewed, (ii) the mechanisms of missing data and the validity of the analyses, (iii) the variability of completeness scores by domain, and (iv) 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.

#### *Sociodemographic and clinical profile of patients*

The results of this study, indicating a predominance of women and patients under 50 years of age, mostly living in the Lukunga district with cancer diagnosed at an invasive stage (stage II), illustrate the weight of this pathology in the Oncology department of the Ngaliema clinic.

This clinical picture, both young and severe, agrees with the epidemiological results of Dusingize et al (2026) in DRC ( Dusingize et al., 2026) and those of Anyigba et al. (2021) in PMC, which describe the evolution of the incidence as well

as the hormonal and reproductive specificities of patients in sub-Saharan Africa ( Anyigba et al., 2021) .

Internationally, this late and invasive detection contrasts sharply with the situation in high-income countries, where structured screening and awareness campaigns allow for the identification of the disease at localized or in situ stages ( Benitez Fuentes et al., 2024) . This marked disparity, largely due to the absence of systematic mammography programs, is corroborated by Kamalakanta 's meta-analysis. Gahan in 2024, which highlights major gaps in the completeness of imaging and staging data between registries ( Kamalakanta Gahan, 2024).

The gaps observed in the present study concerning the level of education and marital status at the time of identification would be explained by systemic failures as presented in the various studies in Sub-Saharan Africa, recalling that the fragility of administrative infrastructures and the shortage of committed staff strongly limit the completeness of hospital oncology databases ( Ngwa et al., 2022; WHO, 2023) .

The presence of unrecorded data in the patient records mentioned above can hinder advanced statistical analyses if



it is not accidental. Therefore, the MCAR hypothesis is verified before addressing disparities in data completeness by domain or recording level.

### Mechanisms of missing data and validity of analyses

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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

The decrease in the overall completeness score in elderly patients, those with bilateral involvement, or those using traditional therapies illustrates the direct effect of clinical and cultural barriers on traceability. Faced with invasive bilateral pathology, medical teams would accelerate the initiation of treatment at the expense of exhaustive data entry, a phenomenon of document exhaustion reported at the regional level by Ngwa et al . ( 2022) and then Gbenonsi et al . ( 2024 ) .

Furthermore, the massive initial recourse to alternative medicines in the sample (54.3%) disrupts the temporal continuity of the care pathway. This therapeutic nomadism, both spiritual and traditional, results in late institutional records, lacking pre-diagnostic history, a problem recently analyzed and published, where the authors show that the use of herbal remedies and certain spiritual beliefs induce major diagnostic delays and the absence of initial clinical data ( Asiimwe et al., 2023; Henke et al., 2022) .

The paradoxical increase in score with longer consultation delays could be explained by the gradual, often delayed, consolidation of assessments carried out outside the institution. To mitigate these temporal effects and smooth inter-annual variations (2024 vs. 2025), Gichoya et al . (2025), in Lancet Digital Health, recommend the adoption of suitable computerized hospital registries to establish a sustainable, robust governance of oncological data ( Gichoya et al., 2025) .

### 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.

### **Acknowledgments**

The authors thank all the administrative staff of the Ngaliema Clinic in general and those of the oncology department in particular, for making the medical records available to them for analysis.

### **Abbreviations**

|                      |                                               |
|----------------------|-----------------------------------------------|
| <b>BCZS</b>          | : Central Health Zone Office                  |
| <b>CSR</b>           | : Referral Health Center                      |
| <b>EMR</b>           | : Electronic Medical Record                   |
| <b>DPS</b>           | : Provincial Health Division                  |
| <b>FOSA</b>          | : Health Training                             |
| <b>GLOBOCAN</b>      | : Global Cancer Observatory                   |
| <b>HGR</b>           | : General Referral Hospital                   |
| <b>IARC</b>          | : International Agency for Research on Cancer |
| <b>IC:</b>           | : Confidence Interval                         |
| <b>ISTM</b>          | : Higher Institute of Medical Techniques      |
| <b>MAR</b>           | : Missing At Random                           |
| <b>MCAR</b>          | : Missing Completely At Random                |
| <b>MNAR</b>          | : Missing Not At Random                       |
| <b>WHO</b>           | : World Health Organization                   |
| <b>NGO</b>           | : Non-Governmental Organization               |
| <b>p-value</b>       | : probability value                           |
| <b>R<sup>2</sup></b> | : determination coefficient                   |
| <b>RC</b>            | : Cancer registry                             |
| <b>DRC</b>           | : Democratic Republic of Congo                |
| <b>RPCR</b>          | : Kinshasa piloted cancer register            |
| <b>SNIS</b>          | : National Health Information System          |
| <b>WHO</b>           | : World Health Organization                   |
| <b>ZS</b>            | : Health Zone                                 |
| <b>β</b>             | : regression coefficient                      |
| <b>χ<sup>2</sup></b> | : chi-square statistic                        |

### **Conflicts of interest**

The authors state that they have no competing interests.

### **Funding statement**

This study did not receive any specific funding from any organization or third party.

### **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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