GULU CANCER REGISTRY

Improving the health status of the people of Northern Uganda through cancer notification to create interventional programs aimed at mitigating cancer burden in the region for economic development.

STANDARD OPERATING PROCEDURES

Case Finding, Data Abstraction, Consolidation, Coding and Entry

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<tr>
<td><strong>UNAIDS</strong></td>
<td>United Nations programs on AIDS</td>
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<tr>
<td><strong>UBOS</strong></td>
<td>Uganda Bureau of Statistics</td>
</tr>
<tr>
<td><strong>GCR</strong></td>
<td>Gulu Cancer Registry</td>
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<tr>
<td><strong>ICD-O</strong></td>
<td>International Classification of Diseases for Oncology</td>
</tr>
<tr>
<td><strong>EUA</strong></td>
<td>Examination under Anaesthesia</td>
</tr>
<tr>
<td><strong>FNAB</strong></td>
<td>Fine Needle Aspiration Biopsy</td>
</tr>
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<td><strong>UN</strong></td>
<td>United Nations</td>
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<tr>
<td><strong>GOPD</strong></td>
<td>Gynaecology Out Patient Department</td>
</tr>
<tr>
<td><strong>SOPD</strong></td>
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</tr>
<tr>
<td><strong>AFCRN</strong></td>
<td>African Cancer Registry Network</td>
</tr>
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<td><strong>EACRN</strong></td>
<td>East African Cancer Registry Network</td>
</tr>
<tr>
<td><strong>CT</strong></td>
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</tr>
<tr>
<td><strong>MRI</strong></td>
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<tr>
<td><strong>KCR</strong></td>
<td>Kampala Cancer Registry</td>
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1.0 Introduction
Gulu cancer registry (GCR) is a population based cancer registry that became operational in June 2014. It is located at St. Mary’s Hospital Lacor, about 7 Km west of Gulu town in Northern part of Uganda. It serves the districts of Gulu, Nwoya and Amuru with a total population of 629,300 people \([M= 310,900 \ F= 318,400]\) (UBOS, 2012 population projection). The registry collects cancer data from the health facilities and medical centres within the three districts. It uses CanReg 5 system version 5.00.32build1469 for data entry, cleaning and analysis.

1.1 Mission
The mission of Gulu Cancer Registry is to keep accurate and up to date information on the occurrences of common malignancies in the districts of Gulu, Amuru and Nwoya. This enables quality studies on cancers through research activities and planning cancer control programs aimed at mitigating cancer disease burdens in the community.

1.2 Vision
To improve the health status of the people of Northern Uganda through cancer notification in order to create interventional programs aimed at mitigating cancer burden in the region for economic development.

1.3 Core Values
- Data collection accuracy.
- Information Completeness.
- Quality Data.
- Pro-activeness.
- Work Collaboration.
- Confidentiality of information.
2.0 Background

The registry catchment area has been the center of 20 years civil war which displaced over 90% of the people into the internally displaced camps (UN, 2004). The displaced persons were surviving on food handouts by the World Food Program and living in extreme poverty with poor living conditions and poor access to health services. Despite current normalization of the security situation, the post conflict impact on the health of the people is visible. Redundancy at the internally displaced camps resulted into change of lifestyle. Cancer is now the second leading proportional mortality in Lacor (Accorsi et al., 2005). Poor health seeking behaviour, Poverty and illiteracy are some of the risk factors which increase the burden of cancers Northern Uganda. The region has the highest prevalence of HIV/AIDS standing at 9.2% compared to 7.2% national average (UNAIDS, 2012). This trend is consistent with the study by Fabiani et al. (2005) where they found that HIV-1 prevalence in this rural district of Northern Uganda is high, probably reflecting the effect of the last 18 years of civil strife. There is association between HIV and malignancies such as invasive cervical cancer, Kaposi’s sarcoma, Breast cancer. Cervical cancer, Kaposi’s sarcoma, Hepatocellular carcinoma, Burkitts’ lymphoma incidence in Uganda per 100,000 population stands at about 30%, 10%, 8% respectively (Parkin et al. 2009). However little is known about all the other cancers and their impact on the community of Northern Uganda. Given the above background, operationalizing Gulu Cancer Registry ensures continuous and systematic cancer data collection and analysis to guide policy on cancer in the region. Consequently, cancer prevention and control programs aimed at reducing the cancer burden can be instituted for better health of the community members of Gulu, Amuru and Nwoya Districts and beyond.
3.0 Catchment Population and Geographical Area

Gulu Cancer Registry operates in the districts of Amuru, Gulu and Nwoya with a total population of 629,300 inhabitants. It covers an area 567,800 Km in total and on average the three districts has a population density of 80 people per square kilometers (UBOS, 2009).

Figure 1: Map of Uganda showing the location of Amuru, Nwoya and Gulu Districts
Figure 2: Map of Gulu, Amuru and Nwoya Districts indicating the sub counties and the parishes
4.0 Cancer Data Collection and Entry

4.1 Case Finding

The case finding strategy of GCR involves identifying individuals living with or deceased from cancers. The data sources includes the following health facilities; Lacor Hospital, Gulu Independent Hospital, Gulu Regional Referral Hospital, Gulu Military Hospital, Anaka Hospital. Out Patients Clinics such as TASO Gulu and other private clinics/medical centres are data sources for the registry. Other sources of data also include the media; National and Local Television news or programs on Non-communicable diseases like cancer. The print media (Newspapers) and local radio announcements on cancer illness and deaths also forms part of the data source. Community gathering reports namely Local leaders meetings and announcements, funeral rites announcement at burials sites and places of worship about cancer being cause of death also forms the source of data for the registry.
Hospital/Clinic Sites for source of cancer data

1. Medical procedures reports; Endoscopy, Colposcopy, Colonoscopy, EUA, FNAB records.
   OPD attendance records; General Attendance Register, Special Clinics (SOPD, GOPD) registers.
2. In patient records; Clinical Charts, Admission and Discharge books.
3. Electronic and hard copies medical records Archives.
4. Imaging Diagnostic records; X-Ray, Ultrasound, CT scan, MRI records.
5. Radiotherapy referral records.
6. Autopsy reports.
7. Histology reports
8. Treatment logs; In-patient Medication sheets, chemotherapy logs in the pharmacy.
9. Laboratory findings; Hematology reports.
10. Death Certificates.

11. Mortuary records

12. Patients’ Medical form 5 (MF5) information.

4.2 Data Abstraction
This process involves recording information from the patient’s and or deceased medical records into the cancer notification form (see appendix 8). The abstraction is on patients’ bio-data, tumour, treatment, source of information and follow up. Only patients with malignant tumour (Behaviour 3, ICD-O-3) except for neurological tumours and residing within the catchment area (Gulu, Amuru and Nwoya Districts) are considered for data abstraction.

4.3 Case Consolidation
This process involves updating and reconciling information on each tumour, patient bio-data, treatment and follow up. Periodically, follow back is conducted by pursuing leads from secondary sources. Both active and passive follow up is conducted to determined patients status for update.

4.4 Data entry, cleaning and analysis
Gulu Cancer Registry uses CanReg5 system to enter, clean and analyzed data on cancer cases. The database is installed and run from an internet server for purpose of data back in the cloud server. The accounts is accessible by namely; Supervisor, Registrars and Analyst all of whom have different level of rights to accessing the features and
functionality of the CanReg5 system (See Figure 4). The data cleaning process is run periodically using the inbuilt tool to weed out duplicate entry and missing information.

*Figure 4: CanReg5 System Used by Gulu Cancer Registry*

### 4.4.0 Coding

Gulu Cancer Registry assigns codes to each variable in the cancer notification form. The variables are; patient bio-data, tumour, source, treatment and patient’s status. Coding tumours follow ICD-O-3 rules for morphology and topography of the tumour(s) in question. Other local codes used especially for addresses and data source facilities are as discussed and approved by Gulu Cancer Registry and or other registry networks nationally and globally.

**Cancer Data Quality Control**

*To ensure good quality of data collected, the following criteria for cancer data exclusion/inclusion shall be adhered to by Gulu Cancer Registry:*

- Only cancer patients (alive or dead) residing in Amuru, Nwoya and Gulu Districts for the last 12 months qualifies for entry into the registry.

- Population of the catchment area is that used by Uganda Bureau of Statistics (UBOS, 2012 projection) awaiting update with the national census due for August 2014.
- The population data set of the catchment area is distributed into 5 years groups by sex as 0-4, 5-9, 10-14......75+.

- Only patients living with or deceased from malignant tumour are entered into the cancer registry. Clinically diagnosed malignancies are considered for entry into the cancer registry. Patients with benign lesions, tumours with uncertain behaviour, in situ, metastatic with unknown primary are excluded. However, all neurological tumours; benign or malignant are entered into the cancer registry.

- Periodic re-review of sample of case finding reports, re-abstraction is done. Active updates by the registry staff, data quality audit by external registry expert (KCR, AFRCN, and EACRN) is also conducted.

- Missing records from one source but available in another with pursuable leads are included in the registry data after update.

- Duplicate entry is checked manually and electronically using CanReg5 tools (MP Search) for data cleaning.

- Missing data with leads to primary data source not pursuable are omitted from entry into the cancer registry.

- Data available from multiple sources but not the same is entered into the registry only after reconciliation. If lead is not pursuable, data is deleted from Gulu Cancer Registry.

- Clinicians are encouraged to biopsy all tumours suspected to be malignant for histological examination to be performed. This increase the MV% of Gulu Cancer Registry.

- Death Certificates are updated with substantive information about the patient’s malignancy medical records to reduce on the DCO%.
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<td>LYMPH NODES</td>
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Morphology Codes

000  C00.0  External upper lip
001  C00.1  External lower lip
002  C00.2  External lip, NOS
003  C00.3  Mucosa of upper lip
004  C00.4  Mucosa of lower lip
005  C00.5  Mucosa of lip, NOS
006  C00.6  Commissure of lip
008  C00.8  Overl. lesion of lip
009  C00.9  Lip, NOS
019  C01.9  Base of tongue, NOS
020  C02.0  Dorsal surface of tongue, NOS
021  C02.1  Border of tongue
022  C02.2  Ventral surface of tongue, NOS
023  C02.3  Anterior 2/3 of tongue, NOS
024  C02.4  Lingual tonsil
028  C02.8  Overl. lesion of tongue
029  C02.9  Tongue, NOS
030  C03.0  Upper gum
031  C03.1  Lower gum
039  C03.9  Gum, NOS
040  C04.0  Anterior floor of mouth
041  C04.1  Lateral floor of mouth
048  C04.8  Overl. lesion of floor of mouth
049  C04.9  Floor of mouth, NOS
050  C05.0  Hard palate
051  C05.1  Soft palate, NOS
052  C05.2  Uvula
058  C05.8  Overl. lesion of palate
059  C05.9  Palate, NOS
060  C06.0  Cheek mucosa
061  C06.1  Vestibule of mouth
062  C06.2  Retromolar area
068  C06.8  Overl. lesion of other/unspec. parts of mouth
069  C06.9  Mouth, NOS
079  C07.9  Parotid gland
080  C08.0  Submandibular gland
081  C08.1  Sublingual gland
088  C08.8  Overl. lesion of major salivary gland
089  C08.9  Major salivary gland, NOS
090  C09.0  Tonsillar fossa
091  C09.1  Tonsillar pillar
098  C09.8  Overl. lesion of tonsil
099  C09.9  Tonsil, NOS
100  C10.0  Vallecula
101  C10.1  Anterior surface of epiglottis
102  C10.2  Lateral wall of oropharynx
103  C10.3  Posterior wall of oropharynx
104  C10.4  Branchial cleft
108  C10.8  Overl. lesion of oropharynx
109  C10.9  Oropharynx, NOS
110  C11.0  Superior wall of nasopharynx
111  C11.1  Posterior wall of nasopharynx
112  C11.2  Lateral wall of nasopharynx
113  C11.3  Anterior wall of nasopharynx
118  C11.8  Overl. lesion of nasopharynx
119  C11.9  Nasopharynx, NOS
129  C12.9  Pyriform sinus
130  C13.0  Postcricoid region
131  C13.1  Aryepiglottic fold
132  C13.2  Posterior wall of hypopharynx
138  C13.8  Overl. lesion of hypopharynx
139  C13.9  Hypopharynx, NOS
140  C14.0  Pharynx, NOS
141  C14.1  Laryngopharynx
142  C14.2  Waldeyer's ring, NOS
148  C14.8  Overl. lesion of lip, oral cavity, pharynx
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<td>C25.3</td>
<td>Pancreatic duct</td>
</tr>
<tr>
<td>C25.4</td>
<td>Islets of Langerhans</td>
</tr>
<tr>
<td>C25.7</td>
<td>Other specified parts of pancreas</td>
</tr>
<tr>
<td>C25.8</td>
<td>Overl. lesion of pancreas</td>
</tr>
<tr>
<td>C25.9</td>
<td>Pancreas, NOS</td>
</tr>
<tr>
<td>C26.0</td>
<td>Intestinal tract, NOS</td>
</tr>
<tr>
<td>C26.8</td>
<td>Overl. lesion of digestive system</td>
</tr>
<tr>
<td>C26.9</td>
<td>Gastrointestinal tract, NOS</td>
</tr>
<tr>
<td>C30.0</td>
<td>Nasal cavity</td>
</tr>
<tr>
<td>C30.1</td>
<td>Middle ear</td>
</tr>
<tr>
<td>C30.9</td>
<td>Trachea</td>
</tr>
<tr>
<td>C31.0</td>
<td>Maxillary sinus</td>
</tr>
<tr>
<td>C31.1</td>
<td>Ethmoid sinus</td>
</tr>
<tr>
<td>C31.2</td>
<td>Frontal sinus</td>
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<tr>
<td>C31.3</td>
<td>Sphenoid sinus</td>
</tr>
<tr>
<td>C31.8</td>
<td>Overl. lesion of accessory sinuses</td>
</tr>
<tr>
<td>C31.9</td>
<td>Accessory sinus, NOS</td>
</tr>
<tr>
<td>C32.0</td>
<td>Glottis</td>
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<td>C32.1</td>
<td>Supraglottis</td>
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<td>Subglottis</td>
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<tr>
<td>C32.3</td>
<td>Laryngeal cartilage</td>
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<tr>
<td>C32.8</td>
<td>Overl. lesion of larynx</td>
</tr>
<tr>
<td>C32.9</td>
<td>Larynx, NOS</td>
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<tr>
<td>C33.9</td>
<td>Trachea</td>
</tr>
<tr>
<td>C34.0</td>
<td>Main bronchus</td>
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<tr>
<td>C34.1</td>
<td>Upper lobe, lung</td>
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<tr>
<td>C34.2</td>
<td>Middle lobe, lung</td>
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<tr>
<td>C34.3</td>
<td>Lower lobe, lung</td>
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<tr>
<td>Code</td>
<td>Description</td>
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<tr>
<td>348</td>
<td>C34.8 Overl. lesion of lung</td>
</tr>
<tr>
<td>349</td>
<td>C34.9 Lung, NOS</td>
</tr>
<tr>
<td>379</td>
<td>C37.9 Thymus</td>
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<tr>
<td>380</td>
<td>C38.0 Heart</td>
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<tr>
<td>381</td>
<td>C38.1 Anterior mediastinum</td>
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<tr>
<td>382</td>
<td>C38.2 Posterior mediastinum</td>
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<tr>
<td>383</td>
<td>C38.3 Mediastinum, NOS</td>
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<td>384</td>
<td>C38.4 Pleura, NOS</td>
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<tr>
<td>388</td>
<td>C38.8 Overl. lesion of heart, mediastinum, pleura</td>
</tr>
<tr>
<td>390</td>
<td>C39.0 Upper respiratory tract</td>
</tr>
<tr>
<td>398</td>
<td>C39.8 Overl. lesion of respiratory system</td>
</tr>
<tr>
<td>399</td>
<td>C39.9 Ill-defined sites within respiratory system</td>
</tr>
<tr>
<td>400</td>
<td>C40.0 Long bones of upper limb, scapula</td>
</tr>
<tr>
<td>401</td>
<td>C40.1 Short bones of upper limb</td>
</tr>
<tr>
<td>402</td>
<td>C40.2 Long bones of lower limb</td>
</tr>
<tr>
<td>403</td>
<td>C40.3 Short bones of lower limb</td>
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<tr>
<td>408</td>
<td>C40.8 Overl. lesion of bones of limb</td>
</tr>
<tr>
<td>409</td>
<td>C40.9 Bone of limb, NOS</td>
</tr>
<tr>
<td>410</td>
<td>C41.0 Bones of skull and face</td>
</tr>
<tr>
<td>411</td>
<td>C41.1 Mandible</td>
</tr>
<tr>
<td>412</td>
<td>C41.2 Vertebral column</td>
</tr>
<tr>
<td>413</td>
<td>C41.3 Rib, Sternum, Clavicle</td>
</tr>
<tr>
<td>414</td>
<td>C41.4 Pelvic bones, Sacrum, Coccyx</td>
</tr>
<tr>
<td>418</td>
<td>C41.8 Overl. lesion of bones</td>
</tr>
<tr>
<td>419</td>
<td>C41.9 Bone, NOS</td>
</tr>
<tr>
<td>420</td>
<td>C42.0 Blood</td>
</tr>
<tr>
<td>421</td>
<td>C42.1 Bone marrow</td>
</tr>
<tr>
<td>422</td>
<td>C42.2 Spleen</td>
</tr>
<tr>
<td>423</td>
<td>C42.3 Reticuloendothelial system, NOS</td>
</tr>
<tr>
<td>424</td>
<td>C42.4 Hematopoietic system, NOS</td>
</tr>
<tr>
<td>440</td>
<td>C44.0 Skin of lip, NOS</td>
</tr>
<tr>
<td>441</td>
<td>C44.1 Eyelid</td>
</tr>
<tr>
<td>442</td>
<td>C44.2 External ear</td>
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</table>
498 C49.8 Overl. lesion of soft tissues
499 C49.9 Other soft tissues
500 C50.0 Nipple
501 C50.1 Central portion of breast
502 C50.2 Upper-inner quadrant of breast
503 C50.3 Lower-inner quadrant of breast
504 C50.4 Upper-outer quadrant of breast
505 C50.5 Lower-outer quadrant of breast
506 C50.6 Axillary tail of breast
508 C50.8 Overl. lesion of breast
509 C50.9 Breast, NOS
510 C51.0 Labium majors
511 C51.1 Labium minor
512 C51.2 Clitoris
518 C51.8 Overl. lesion of vulva
519 C51.9 Vulva, NOS
529 C52.9 Vagina, NOS
530 C53.0 Endocervix
531 C53.1 Exocervix
538 C53.8 Overl. lesion of cervix uteri
539 C53.9 Cervix uteri
540 C54.0 Isthmus uteri
541 C54.1 Endometrium
542 C54.2 Myometrium
543 C54.3 Fundus uteri
548 C54.8 Overl. lesion of corpus uteri
549 C54.9 Corpus uteri
559 C55.9 Uterus, NOS
569 C56.9 Ovary
570 C57.0 Fallopian tube
571 C57.1 Broad ligament
572 C57.2 Round ligament
573 C57.3 Parametrium
574 C57.4 Uterine adnexa
577 C57.7 Other parts of female genital organs
578 C57.8 Overl. lesion of female genital organs
579 C57.9 Female genital tract, NOS
589 C58.9 Placenta
600 C60.0 Prepuce
601 C60.1 Glans penis
602 C60.2 Body of penis
608 C60.8 Overl. lesion of penis
609 C60.9 Penis, NOS
619 C61.9 Prostate gland
620 C62.0 Undescended testis
621 C62.1 Descended testis
629 C62.9 Testis, NOS
630 C63.0 Epididymis
631 C63.1 Spermatic cord
632 C63.2 Scrotum, NOS
637 C63.7 Other parts of male genital organs
638 C63.8 Overl. lesion of male genital organs
639 C63.9 Male genital organs, NOS
649 C64.9 Kidney, NOS
659 C65.9 Renal pelvis
669 C66.9 Ureter
670 C67.0 Trigone of urinary bladder
671 C67.1 Dome of urinary bladder
672 C67.2 Lateral wall of urinary bladder
673 C67.3 Anterior wall of urinary bladder
674 C67.4 Posterior wall of urinary bladder
675 C67.5 Bladder neck
676 C67.6 Ureteric orifice
677 C67.7 Urachus
678 C67.8 Overl. lesion of bladder
679 C67.9 Urinary bladder, NOS
680 C68.0 Urethra
681 C68.1 Paraurethral gland
688 C68.8 Overl. lesion of urinary organs
Morphology Codes

8000  Neoplasm, malignant
8001  Tumor cells, malignant
8002  Malignant tumor, small cell type
8003  Malignant tumor, giant cell type
8004  Malignant tumor, spindle cell type
8005  Malignant tumor, clear cell type
8010  Carcinoma, NOS
8011  Epithelioma, malignant
8012  Large cell carcinoma, NOS
8013  Large cell neuroendocrine carcinoma
8014  Large cell carcinoma with rhabdoid phenotype
8015  Glassy cell carcinoma
8020  Carcinoma, undifferentiated, NOS
8021  Carcinoma, anaplastic, NOS
8022  Pleomorphic carcinoma
8030  Giant cell and spindle cell carcinoma
8031  Giant cell carcinoma
8032  Spindle cell carcinoma, NOS
8033  Pseudosarcomatous carcinoma
8034  Polygonal cell carcinoma
8035  Carcinoma with osteoclast-like giant cells
8041  Small cell carcinoma, NOS
8042  Oat cell carcinoma
8043  Small cell carcinoma, fusiform cell
8044  Small cell carcinoma, intermediate cell
8045  Combined small cell carcinoma
8046  Non-small cell carcinoma
8050  Papillary carcinoma, NOS
8051  Verrucous carcinoma, NOS
8052  Papillary squamous cell carcinoma
8070  Squamous cell carcinoma, NOS
8071  Squamous cell carcinoma, keratinizing, NOS
8072  Squamous cell carcinoma, large cell, nonkeratinizing, NOS
8073  Squamous cell carcinoma, small cell, nonkeratinizing
8074  Squamous cell carcinoma, spindle cell
8075  Squamous cell carcinoma, adenoid
8076  Squamous cell carcinoma, microinvasive
8078  Squamous cell carcinoma with horn formation
8082  Lymphoepithelial carcinoma
8083  Basaloid squamous cell carcinoma
8084  Squamous cell carcinoma, clear cell type
8090  Basal cell carcinoma, NOS
8091  Multifocal superficial basal cell carcinoma
8092  Infiltrating basal cell carcinoma, NOS
8093  Basal cell carcinoma, fibroepithelial
8094  Basosquamous carcinoma
8095  Metatypical carcinoma
8097  Basal cell carcinoma, nodular
8098  Adenoid basal carcinoma
8102  Trichilemmocarcinoma
8110  Pilomatrix carcinoma
8120  Transitional cell carcinoma, NOS
8121  Schneiderian carcinoma
8122  Transitional cell carcinoma, spindle cell
8123  Basaloid carcinoma
8124  Cloacogenic carcinoma
8130  Papillary transitional cell carcinoma
8131  Transitional cell carcinoma, micropapillary
8140  Adenocarcinoma, NOS
8141  Scirrhous adenocarcinoma
8142  Linitis plastica
8143  Superficial spreading adenocarcinoma
8144  Adenocarcinoma, intestinal type
8145  Carcinoma, diffuse type
8147  Basal cell adenocarcinoma
8150  Islet cell carcinoma
8151  Insulinoma, malignant
8152  Glucagonoma, malignant
8153  Gastrinoma, malignant
8154  Mixed islet cell and exocrine adenocarcinoma
8155  Vipoma, malignant
8156  Somatostatinoma, malignant
Enteroglucagonoma, malignant
Cholangiocarcinoma
Bile duct cystadenocarcinoma
Klatskin tumor
Hepatocellular carcinoma, NOS
Hepatocellular carcinoma, fibrolamellar
Hepatocellular carcinoma, scirrhous
Hepatocellular carcinoma, spindle cell variant
Hepatocellular carcinoma, clear cell type
Hepatocellular carcinoma, pleomorphic type
Combined hepatocellular carcinoma and cholangiocarcinoma
Trabecular adenocarcinoma
Adenoid cystic carcinoma
Cribriform carcinoma, NOS
Adenocarcinoma in adenomatous polyp
Tubular adenocarcinoma
Parietal cell carcinoma
Adenocarcinoma of anal glands
Adenocarcinoma in adenomatous polyposis coli
Adenocarcinoma in multiple adenomatous polyps
Solid carcinoma, NOS
Carcinoma simplex
Carcinoid tumor, NOS
Enterochromaffin cell carcinoid
Enterochromaffin-like cell tumor, malignant
Goblet cell carcinoid
Composite carcinoid
Adenocarcinoid tumor
Neuroendocrine carcinoma, NOS
Merkel cell carcinoma
A typical carcinoid tumor
Bronchiolo-alveolar adenocarcinoma, NOS
Alveolar adenocarcinoma
Bronchiolo-alveolar carcinoma, non-mucinous
Bronchiolo-alveolar carcinoma, mucinous
Bronchiolo-alveolar carcinoma, mixed mucinous / non-mucinous
Adenocarcinoma with mixed subtypes
Papillary adenocarcinoma, NOS
Adenocarcinoma in villous adenoma
Villous adenocarcinoma
Adenocarcinoma in tubulovillous adenoma
Chromophobe carcinoma
Pituitary carcinoma, NOS
Acidophil carcinoma
Mixed acidophil-basophil carcinoma
Oxyphilic adenocarcinoma
Basophil carcinoma
Clear cell adenocarcinoma, NOS
Renal cell carcinoma, NOS
Clear cell adenocarcinofibroma
Lipid-rich carcinoma
Glycogen-rich carcinoma
Cyst-associated renal cell carcinoma
Renal cell carcinoma, chromophobe type
Renal cell carcinoma, sarcomatoid
Collecting duct carcinoma
Granular cell carcinoma
Water-clear cell adenocarcinoma
Mixed cell adenocarcinoma
Follicular adenocarcinoma, NOS
Follicular adenocarcinoma, well differentiated
Follicular adenocarcinoma, trabecular
Fetal adenocarcinoma
Follicular carcinoma, minimally invasive
Insular carcinoma
Papillary carcinoma, follicular variant
Papillary microcarcinoma
Papillary carcinoma, oxyphilic cell
8343 Papillary carcinoma, encapsulated
8344 Papillary carcinoma, columnar cell
8345 Medullary carcinoma with amyloid stroma
8346 Mixed medullary-follicular carcinoma
8347 Mixed medullary-papillary carcinoma
8350 Nonencapsulated sclerosing carcinoma
8370 Adrenal cortical carcinoma
8380 Endometrioid adenocarcinoma, NOS
8381 Endometrioid adenofibroma, malignant
8382 Endometrioid adenocarcinoma, secretory variant
8384 Endometrioid adenocarcinoma, ciliated cell variant
8390 Skin appendage carcinoma
8400 Sweat gland adenocarcinoma
8401 Apocrine adenocarcinoma
8402 Nodular hidradenoma, malignant
8403 Malignant eccrine spiradenoma
8407 Sclerosing sweat duct carcinoma
8408 Eccrine papillary adenocarcinoma
8409 Eccrine poroma, malignant
8410 Sebaceous adenocarcinoma
8413 Eccrine adenocarcinoma
8420 Ceruminous adenocarcinoma
8430 Mucoepidermoid carcinoma
8440 Cystadenocarcinoma, NOS
8441 Serous cystadenocarcinoma, NOS
8450 Papillary cystadenocarcinoma, NOS
8452 Solid pseudopapillary carcinoma
8453 Intraductal papillary-mucinous carcinoma, invasive
8460 Papillary serous cystadenocarcinoma
8461 Serous surface papillary carcinoma
8470 Mucinous cystadenocarcinoma, NOS
8471 Papillary mucinous cystadenocarcinoma
8480 Mucinous adenocarcinoma
8481 Mucin-producing adenocarcinoma
8482 Mucinous adenocarcinoma, endocervical type
8490 Signet ring cell carcinoma
8500 Infiltrating duct carcinoma, NOS
8501 Comedocarcinoma, NOS
8502 Secretory carcinoma of breast
8503 Intraductal papillary adenocarcinoma with invasion
8504 Intracystic carcinoma, NOS
8508 Cystic hypersecretory carcinoma
8510 Medullary carcinoma, NOS
8512 Medullary carcinoma with lymphoid stroma
8513 Atypical medullary carcinoma
8514 Duct carcinoma, desmoplastic type
8520 Lobular carcinoma, NOS
8521 Infiltrating ductular carcinoma
8522 Infiltrating duct and lobular carcinoma
8523 Infiltrating duct mixed with other types of carcinoma
8524 Infiltrating lobular mixed with other types of carcinoma
8525 Polymorphous low grade adenocarcinoma
8530 Inflammatory carcinoma
8540 Paget disease, mammary
8541 Paget disease and infiltrating duct carcinoma of breast
8542 Paget disease, extramammary (except Paget disease of bone)
8543 Paget disease and intraductal carcinoma of breast
8550 Acinar cell carcinoma
8551 Acinar cell cystadenocarcinoma
8560 Adenosquamous carcinoma
8562 Epithelial-myoepithelial carcinoma
8570 Adenocarcinoma with squamous metaplasia
8571 Adenocarcinoma with cartilaginous and osseous metaplasia
8572 Adenocarcinoma with spindle cell metaplasia
8573  Adenocarcinoma with apocrine metaplasia
8574  Adenocarcinoma with neuroendocrine differentiation
8575  Metaplastic carcinoma, NOS
8576  Hepatoid adenocarcinoma
8580  Thymoma, malignant, NOS
8581  Thymoma, type A, malignant
8582  Thymoma, type AB, malignant
8583  Thymoma, type B1, malignant
8584  Thymoma, type B2, malignant
8585  Thymoma, type B3, malignant
8586  Thymic carcinoma, NOS
8588  Spindle epithelial tumor with thymus-like element
8589  Carcinoma showing thymus-like element
8600  Thecoma, malignant
8620  Granulosa cell tumor, malignant
8630  Androblastoma, malignant
8631  Sertoli-Leydig cell tumor, poorly differentiated
8634  Sertoli-Leydig cell, poorly diffn, with heterologous elements
8640  Sertoli cell carcinoma
8650  Leydig cell tumor, malignant
8670  Steroid cell tumor, malignant
8680  Paraganglioma, malignant
8693  Extra-adrenal paraganglioma, malignant
8700  Pheochromocytoma, malignant
8710  Glomangiosarcoma
8711  Glomus tumor, malignant
8720  Malignant melanoma, NOS (except juvenile melanoma)
8721  Nodular melanoma
8722  Balloon cell melanoma
8723  Malignant melanoma, regressing
8728  Meningeal melanomatosis
8730  Amelanotic melanoma
8740  Malignant melanoma in junctional nevus
8741  Malignant melanoma in precancerous melanosis
8742  Lentigo maligna melanoma
8743  Superficial spreading melanoma
8744  Acral lentiginous melanoma, malignant
8745  Desmoplastic melanoma, malignant
8746  Mucosal lentiginous melanoma
8761  Malignant melanoma in giant pigmented nevus
8770  Mixed epithelioid and spindle cell melanoma
8771  Epithelioid cell melanoma
8772  Spindle cell melanoma, NOS
8773  Spindle cell melanoma, type A
8774  Spindle cell melanoma, type B
8780  Blue nevus, malignant
8800  Sarcoma, NOS
8801  Spindle cell sarcoma
8802  Giant cell sarcoma (except of bone)
8803  Small cell sarcoma
8804  Epithelioid sarcoma
8805  Undifferentiated sarcoma
8806  Desmoplastic small round cell tumor
8810  Fibrosarcoma, NOS
8811  Fibromyxosarcoma
8812  Periosteal fibrosarcoma
8813  Fascial fibrosarcoma
8814  Infantile fibrosarcoma
8815  Solitary fibrous tumor, malignant
8830  Malignant fibrous histiocytoma
8832  Dermatofibrosarcoma, NOS
8833  Pigmented dermatofibrosarcoma protuberans
8840  Myxosarcoma
8850  Liposarcoma, NOS
8851  Liposarcoma, well differentiated
8852  Myxoid liposarcoma
8853  Round cell liposarcoma
8854  Pleomorphic liposarcoma
8855  Mixed liposarcoma
8857  Fibroblastic liposarcoma
24

Dedifferentiated liposarcoma
Leiomyosarcoma, NOS
Epithelioid leiomyosarcoma
Angiomyosarcoma
Myosarcoma
Myxoid leiomyosarcoma
Rhabdomyosarcoma, NOS
Pleomorphic rhabdomyosarcoma, adult type
Mixed type rhabdomyosarcoma
Embryonal rhabdomyosarcoma, NOS
Spindle cell rhabdomyosarcoma
Alveolar rhabdomyosarcoma
Rhabdomyosarcoma with ganglionic differentiation
Endometrial stromal sarcoma, NOS
Endometrial stromal sarcoma, low grade
Adenosarcoma
Carcinofibroma
Stromal sarcoma, NOS
Gastrointestinal stromal sarcoma
Mixed tumor, malignant, NOS
Carcinoma in pleomorphic adenoma
Mullerian mixed tumor
Mesodermal mixed tumor
Malignant cystic nephroma
Nephroblastoma, NOS
Malignant rhabdoid tumor
Clear cell sarcoma of kidney
Hepatoblastoma
Pancreatoblastoma
Pulmonary blastoma
Pleuropulmonary blastoma
Carcinosarcoma, NOS
Carcinosarcoma, embryonal
Malignant myoepithelioma
Mesenchymoma, malignant
Embryonal sarcoma
Brenner tumor, malignant
Serous adenocarcinofibroma
Mucinous adenocarcinofibroma
Phyllodes tumor, malignant
Synovial sarcoma, NOS
Synovial sarcoma, spindle cell
Synovial sarcoma, epithelioid cell
Synovial sarcoma, biphasic
Clear cell sarcoma, NOS (except of kidney)
Mesothelioma, malignant
Fibrous mesothelioma, malignant
Epithelioid mesothelioma, malignant
Mesothelioma, biphasic, malignant
Dysgerminoma
Seminoma, NOS
Seminoma, anaplastic
Spermatocytic seminoma
Germinoma
Germ cell tumor, nonseminomatous
Embryonal carcinoma, NOS
Yolk sac tumor
Polyembryoma
Teratoma, malignant, NOS
Teratocarcinoma
Malignant teratoma, undifferentiated
Malignant teratoma, intermediate
Teratoma with malignant transformation
Mixed germ cell tumor
Struma ovari, malignant
Choriocarcinoma, NOS
Choriocarcinoma combined with other germ cell elements
Malignant teratoma, trophoblastic
Trophoblastic tumor, epithelioid
Mesonephroma, malignant
Hemangiosarcoma
Kupffer cell sarcoma
Hemangiioendothelioma, malignant
Epithelioid hemangiioendothelioma, malignant
Kaposi sarcoma
Hemangiopericytoma, malignant
Lymphangiosarcoma
9180  Osteosarcoma, NOS
9181  Chondroblastic osteosarcoma
9182  Fibroblastic osteosarcoma
9183  Telangiectatic osteosarcoma
9184  Osteosarcoma in Paget disease of bone
9185  Small cell osteosarcoma
9186  Central osteosarcoma
9187  Intraosseous well differentiated osteosarcoma
9192  Parosteal osteosarcoma
9193  Periosteal osteosarcoma
9194  High grade surface osteosarcoma
9195  Intracortical osteosarcoma
9220  Chondrosarcoma, NOS
9221  Juxtacortical chondrosarcoma
9230  Chondroblastoma, malignant
9240  Mesenchymal chondrosarcoma
9242  Clear cell chondrosarcoma
9243  Dedifferentiated chondrosarcoma
9250  Giant cell tumor of bone, malignant
9251  Malignant giant cell tumor of soft parts
9252  Malignant tenosynovial giant cell tumor
9260  Ewing sarcoma
9261  Adamantinoma of long bones
9270  Odontogenic tumor, malignant
9290  Ameloblastic odontosarcoma
9310  Ameloblastoma, malignant
9330  Ameloblastic fibrosarcoma
9342  Odontogenic carcinosarcoma
9362  Pineoblastoma
9364  Peripheral neuroectodermal tumor
9365  Askin tumor
9370  Chordoma, NOS
9371  Chondroid chordoma
9372  Dedifferentiated chordoma
9380  Glioma, malignant
9381  Gliomatosis cerebri
9382  Mixed glioma
9390  Choroid plexus carcinoma
9391  Ependymoma, NOS
9392  Ependymoma, anaplastic
9393  Papillary ependymoma
9400  Astrocytoma, NOS
9401  Astrocytoma, anaplastic
9410  Protoplasmic astrocytoma
9411  Gemistocytic astrocytoma
9420  Fibrillary astrocytoma
9423  Polar spongioblastoma
9424  Pleomorphic xanthoastrocytoma
9430  Astroblastoma
9440  Glioblastoma, NOS
9441  Giant cell glioblastoma
9442  Gliosarcoma
9450  Oligodendroglioma, NOS
9451  Oligodendroglioma, anaplastic
9460  Oligodendroblastoma
9470  Medulloblastoma, NOS
9471  Desmoplastic nodular medulloblastoma
9472  Medullomyoblastoma
9473  Primitive neuroectodermal tumor, NOS
9474  Large cell medulloblastoma
9480  Cerebellar sarcoma, NOS
9490  Ganglioneuroblastoma
9500  Neuroblastoma, NOS
9501  Medullopithelioma, NOS
9502  Teratoid medullopithelioma
9503  Neuroepithelioma, NOS
9504  Spongioneuroblastoma
9505  Ganglioglioma, anaplastic
9508  Atypical teratoid/rhabdoid tumor
9510  Retinoblastoma, NOS
9511  Retinoblastoma, differentiated
9512  Retinoblastoma, undifferentiated
9513  Retinoblastoma, diffuse
9520  Olfactory neurogenic tumor
9521  Olfactory neurocytoma
9522  Olfactory neuroblastoma
9523  Olfactory neuroepithelioma
9530  Meningioma, malignant
9538  Papillary meningioma
9539  Meningeal sarcomatosis
9540  Malignant peripheral nerve sheath tumor
9560  Neurilemoma, malignant
9561  Malig. peripheral nerve sheath tumor, rhabdomyoblastic difftn.
9571  Perineurioma, malignant
9580  Granular cell tumor, malignant
9581  Alveolar soft part sarcoma
9590  Malignant lymphoma, NOS
9591  Malignant lymphoma, non-Hodgkin, NOS
9596  Composite Hodgkin and non-Hodgkin lymphoma
9650  Hodgkin lymphoma, NOS
9651  Hodgkin lymphoma, lymphocyte-rich
9652  Hodgkin lymphoma, mixed cellularity, NOS
9653  Hodgkin lymphoma, lymphocyte depletion, NOS
9654  Hodgkin lymphoma, lymphocyte depletion, diffuse fibrosis
9655  Hodgkin lymphoma, lymphocyte depletion, reticular
9659  Hodgkin lymphoma, nodular lymphocyte predominance
9661  Hodgkin granuloma
9662  Hodgkin sarcoma
9663  Hodgkin lymphoma, nodular sclerosis, NOS
9664  Hodgkin lymphoma, nodular sclerosis, cellular phase
9665  Hodgkin lymphoma, nodular sclerosis, grade 1
9667  Hodgkin lymphoma, nodular sclerosis, grade 2
9670  Malignant lymphoma, small B lymphocytic, NOS
9671  Malignant lymphoma, lymphoplasmacytic
9673  Mantle cell lymphoma
9675  Malignant lymphoma, mixed small and large cell, diffuse
9678  Primary effusion lymphoma
9679  Mediastinal large B-cell lymphoma
9680  Malignant lymphoma, large B-cell, diffuse, NOS
9684  Malignant lymphoma, large B-cell, diffuse, immunoblastic, NOS
9687  Burkitt lymphoma, NOS
9689  Splenic marginal zone B-cell lymphoma
9690  Follicular lymphoma, NOS
9691  Follicular lymphoma, grade 2
9695  Follicular lymphoma, grade 1
9698  Follicular lymphoma, grade 3
9699  Marginal zone B-cell lymphoma, NOS
9700  Mycosis fungoides
9701  Sezary syndrome
9702  Mature T-cell lymphoma, NOS
9705  Angioimmunoblastic T-cell lymphoma
9708  Subcutaneous panniculitis-like T-cell lymphoma
9709  Cutaneous T-cell lymphoma, NOS
9714  Anaplastic large cell lymphoma, T cell and Null cell type
9716  Hepatosplenic (gamma-delta) cell lymphoma
9717  Intestinal T-cell lymphoma
9718  Primary cutaneous CD30+ T-cell lymphoproliferative disorder
9719  NK/T-cell lymphoma, nasal and nasal-type
9727  Precursor cell lymphoblastic lymphoma, NOS
9728  Precursor B-cell lymphoblastic lymphoma
9729  Precursor T-cell lymphoblastic lymphoma
9731  Plasmacytoma, NOS
9732  Multiple myeloma
9733  Plasma cell leukemia
9734  Plasmacytoma, extramedullary (not occurring in bone)
9740  Mast cell sarcoma
9741  Malignant mastocytosis
9742  Mast cell leukemia
9750  Malignant histiocytosis
9754  Langerhans cell histiocytosis, disseminated
9755  Histiocytic sarcoma
9756  Langerhans cell sarcoma
9757  Interdigitating dendritic cell sarcoma
9758  Follicular dendritic cell sarcoma
9760  Immunoproliferative disease, NOS
9761  Waldenstrom macroglobulinemia
9762  Heavy chain disease, NOS
9764  Immunoproliferative small intestinal disease
9766  Acute myeloid leukemia, NOS
9800  Leukemia, NOS
9801  Acute leukemia, NOS
9805  Acute biphenotypic leukemia
9820  Lymphoid leukemia, NOS
9823  B-cell chronic lymphocytic leukemia/small lymphocytic lymphoma
9826  Burkitt cell leukemia
9827  Adult T-cell leukemia/lymphoma (HTLV-1 positive)
9832  Prolymphocytic leukemia, NOS
9833  Prolymphocytic leukemia, B-cell type
9834  Prolymphocytic leukemia, T-cell type
9835  Precursor cell lymphoblastic leukemia, NOS
9836  Precursor B-cell lymphoblastic leukemia
9837  Precursor T-cell lymphoblastic leukemia
9840  Acute myeloid leukemia, M6 type
9860  Myeloid leukemia, NOS
9861  Acute myeloid leukemia, NOS
9863  Chronic myeloid leukemia, NOS
9866  Acute promyelocytic leukemia, t(15;17)(q22;q11-12)
9867  Acute myelomonocytic leukemia
9870  Acute basophilic leukemia
9871  Acute myeloid leukemia with abnormal marrow eosinophils
9872  Acute myeloid leukemia, minimal differentiation
9873  Acute myeloid leukemia without maturation
9874  Acute myeloid leukemia with maturation
9875  Chronic myelogenous leukemia, BCR/ABL positive
9876  Atypical chronic myeloid leukemia, BCR/ABL negative
9891  Acute monocytic leukemia
9895  Acute myeloid leukemia with multilineage dysplasia
9896  Acute myeloid leukemia, t(8;21)(q22;q22)
9897  Acute myeloid leukemia, 11q23 abnormalities
9910  Acute megakaryoblastic leukemia
9920  Therapy-related acute myeloid leukemia, NOS
9930  Myeloid sarcoma
9931  Acute panmyelosis with myelofibrosis
9940  Hairy cell leukemia
9945  Chronic myelomonocytic leukemia, NOS
9946  Juvenile myelomonocytic leukemia
9948  Aggressive NK-cell leukemia
9950  Polycythemia vera
9960  Chronic myeloproliferative disease, NOS
9961  Myelosclerosis with myeloid metaplasia
9962  Essential thrombocythemia
9963  Chronic neutrophilic leukemia
9964  Hypereosinophilic syndrome
9980  Refractory anemia
9982  Refractory anemia with sideroblasts
9983  Refractory anemia with excess blasts
9984  Refractory anemia with excess blasts in transformation
Refractory cytopenia with multilineage dysplasia

Myelodysplastic syndrome with 5q-syndrome

Therapy-related myelodysplastic syndrome, NOS

Myelodysplastic syndrome, NOS
### Appendix 2: ICD-O-3 Coding for behaviour

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### Appendix 3: Coding for Gulu Cancer Registry Catchment Area

<table>
<thead>
<tr>
<th>Gulu District</th>
<th>Counties/Sub-Counties</th>
<th>Codes</th>
<th>Parishes</th>
<th>Codes</th>
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<tr>
<td>Aswa, Paicho</td>
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<tr>
<td>Aswa, Palaro</td>
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<td>Aswa, Patiko</td>
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**Omoro County Code = 110**

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<td>Counties/Sub-Counties</td>
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<td>Parishes</td>
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### Appendix 4a: Other codes used

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<td>Rubaga Hospital</td>
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**Appendix 4b: Codes used for units in the health facilities as cancer data sources**

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**Appendix 5: Coding for ethnic groups**

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Appendix 6: Table showing the population of Gulu, Amuru and Nwoya Districts

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<th>GULU Male</th>
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<td>75+:</td>
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<td>4,004</td>
<td>532</td>
<td>548</td>
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</table>

| TOTAL     | 88,000     | 90,800       | 196,300   | 200,200     | 26,600     | 27,400        | 318,400   |

## 1. PATIENT

| I.D. Number: | .......................................................... |
| Given Name (First name(s)): | ............................................................................................................................ | 
| Surname (Family Name): | ........................................................................................................................ |
| Date of birth | ................................................. Age: | ................................................................ | Sex: | (1=Male, 2=Female, 9=NK) |
| Usual residence address: (Village, Parish, County & District): | ............................................................................................................................. | 
| Patient/NOK Telephone No: | ............................................................................................................................. | 
| LC1 leader Name/Telephone Number: | ............................................................................................................................. | 
| Ethnic group: | ............................................................................................................................. | 

## 2. TUMOUR

| Date of incidence: | ................................................. (dd/mm/yyyy) |
| Basis of diagnosis: | ............................................................................................................................. | 
| Primary site of tumour: | ............................................................................................................................. | 
| Morphology: | ............................................................................................................................. | 
| Stage: | ............................................................................................................................. | 

## 3. TREATMENT

| Surgery | ............................................................................................................................. | 
| Radiotherapy | ............................................................................................................................. | 
| Chemo/Hormonal | ............................................................................................................................. | 
| Other (Specify): | ............................................................................................................................. | 

## 4. SOURCE OF INFORMATION

| Institution/Ward: | ............................................................................................................................. | 
| Case number: | ............................................................................................................................. | 
| Laboratory: | ............................................................................................................................. | 
| Lab number: | ............................................................................................................................. | 

## 5. FOLLOW UP

| Date of last contact (dd/mm/yyyy): | ............................................................................................................................. | 
| Status at last contact (1= alive, 2 = dead, 9 = NK): | ............................................................................................................................. | 
| Cause of death (1 = this cancer, 2 = other cause, 9 = NK): | ............................................................................................................................. | 
| Form filed by: | ............................................................................................................................. | 
| Data entered by: | ............................................................................................................................. |
Reference Lists


