The Narratives and The Maps
Algeria, Sétif

Registration area

The Sétif Cancer registry covers the population of 10 dairates, which include a total of 60 communes. The population at the last census (1998) was 1,299,117, representing 4.33% of the overall Algerian population making it the second-largest population centre after Algiers. The population growth rate for this area in 2001 was 1.8%. About 48% of the population live in rural areas, and 99% are Sunni Muslims. The wilaya (province) of Sétif covers an area of 6,504 km², corresponding to 0.27% of the country. The wilaya of Sétif is the capital of the highlands, having an altitude of 1,300 m and a semi-arid continental climate. It represents 4.7% of the national population at a density of 213 inhabitants per km².

Cancer care facilities

General health care in the region is provided predominantly by the CHU (University Hospital Centre) and 6 other hospitals, 16 health centres and 55 primary care centres. These are supplemented by private practitioners and hospitals for a total of 2115 beds, or 1 bed per 690 inhabitants. The total number of health workers is 5772: 215 public specialists, 198 private specialists, 387 public generalists, 278 private generalists, 2944 public nurses and 50 private nurses. The CHU, located in Sétif, provides cancer surgery and chemotherapy services. Radiotherapy is provided by the cancer centres of Constantine (120 km distant) and Algiers (300 km distant), and as a result many patients are treated in Algiers and Constantine. All breast cancers are treated at the breast health centre in Algiers. A large new Cancer Centre is now being implemented in Sétif, and is expected to provide care for all cancer patients from the area of about 5 million inhabitants in 2008.

Registry structure and methods

The registry, founded in 1989, is located in the epidemiology and preventive Medicine service of the Hospital Mère Enfant of the CHU in Sétif under the auspices of the Ministry of Health and Ministry of Research and Education. The registry is staffed by two epidemiology assistants, one pathology assistant, one technician in epidemiology, and 3 postgraduate students in epidemiology. The Sétif Cancer Registry uses active case finding from 16 sources of data consisting of University Hospital Centres, cancer hospitals, public health hospitals, pathology laboratories, private hospitals and offices, insurance offices, other cancer registries in Algeria and death registration offices. The death registration system is incomplete; the certificates of death are examined and a record completed for each certificate mentioning cancer or malignant tumour. Collection is primarily active. For each patient we collect data from four or five different sources, which permits the information to be completed and checked before coding. For each cancer case a limited number of variables (18) have been put into a sample record. The variables include the sources of information. For the tumour, only four variables are collected, including the date of diagnosis, the site, and the morphology. The data are coded according to ICD-O. Impossible or improbable combinations (site, sex, age and morphology) are identified by computer. Duplicate registrations have been reduced to a minimum thanks to a careful control of name, sex, date of birth and diagnosis. The registry staff visit these sources once a month.

Interpreting the results

Arrangements have been made with the hospitals outside the registration area to notify the registry of any area-resident cancer cases that they may diagnose and treat. These outside hospitals are visited regularly to collect records, but some small underestimation due to cancer cases treated outside the area is possible.

Uses of the data

The registry has prepared a report of cancer incidence from 1986 to 2005, with 20 years of registration highlighting trends and changes. A study of survival of registered cancer cases of breast, colon, rectum, large bowel, and prostate during 1990–1994 has been carried out within the CONCORD Survival study.

Source of population

The populations of 1999−2000−2001−2002 are estimated on the basis of the 1998 National Census.

Multiple primary rules used IACR rules (2000)

Notes on the data

The Editors recommend that some care be taken in the interpretation of these data; see Chapter 5 (Categorisation).
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The registry has prepared a report of cancer incidence from 1986 to 2005, with 20 years of registration highlighting trends and changes. A study of survival of registered cancer cases of breast, colon, rectum, large bowel, and prostate during 1990–1994 has been carried out within the CONCORD Survival study.

Source of population

Multiple primary rules used
IACR rules (2000)

Notes on the data
The Editors recommend that some care be taken in the interpretation of these data; see Chapter 5 (Categorisation).
### Egypt, Gharbiah

**Registration area**
The Gharbiah Population-based Cancer Registry (GPCR) covers the population of eight districts (Tanta, Elmahalla Elkobra, Kafr Elzayat, Zefta, Kotour, Elsanta, Basyou & Samannoud) within the state of Gharbiah, in the west and central Delta region in lower Egypt. The population at the most recent census (1996) was 3.406 million (5.7% of the total population of Egypt). About 40% of the population lives in urban areas. The majority are Moslems and the remainder are Christians.

**Cancer care facilities**
General health care in the region is provided predominantly by the Gharbiah Health Services Department (Ministry of Health and Population), through the district hospitals and a network of primary health centres. These are supplemented by Tanta University Hospitals, insurance hospitals and clinics, private practitioners and private hospitals. The Tanta Cancer Center (TCC) is located in Tanta, the principal town and capital of Gharbiah, and provides cancer surgery and chemotherapy services. Gharbiah Cancer Society (GCS), NGO, and the radiotherapy department at Tanta University Hospital provide radiotherapy services. In the registry area, patients at the primary and secondary care facilities suspected to have cancer are generally referred to TCC or to one of the two hospitals with comprehensive cancer services within a 60-km radius (Mansoura Urology Center & Mansoura Gastroenterology Center) or to the National Liver Institute, Menoufeya University (40 km distant), or occasionally to National Cancer Institute, Cairo University (100 km distant).

**Registry structure and methods**
The registry is located within TCC, and is sponsored by MECC, the US National Cancer Institute in Bethesda, USA, and the Ministry of Health and Population, Cairo, Egypt. A principal investigator, executive director, two co-investigators and field supervisors, two data managers, four part-time registrars and four full-time secretaries staff the registry.

The Gharbiah Population-based Cancer Registry (GPCR) uses active case finding from 57 sources of data consisting of cancer hospitals, general hospitals, university hospitals, insurance hospitals, private hospitals and clinics, specialized hospitals and centres, pathology and haematology labs and the district death registration offices.

The death registration system is adequate; the cause of death from cancer is often mentioned. The registry staff visit these sources, where they scrutinise the records kept in medical records departments and the registers of individual departments concerned with diagnosis and treatment of cancers in order to identify and abstract information on cases of cancer, diagnosed by all methods, among residents of the registry region.

Although cancer is a notifiable disease by administrative order (without a specific law), few registration forms are received from private practitioners. Arrangements have been made with the hospitals outside the registration area to be visited every 1–3 months according to workload in order to abstract resident cancer cases which are diagnosed and treated in them.

**Interpreting the results**
It is not possible to estimate how many cancer cases remain undiagnosed, but underdiagnosis probably occurs for elderly subjects in rural areas. TCC has a full range of diagnostic facilities, so that it is unlikely that cases referred will be missed. There is a breast cancer early detection program in Tanta Cancer Centre. PSA testing is not common in this population.

Bladder cancer, which is the most common cancer in Egypt, is related to Schistosomiasis, which is currently being eradicated. Smoking is becoming the most important risk factor for bladder cancer. Liver cancer incidence is high compared to almost all countries in the world except some in Asia and Africa; this could be attributed to high prevalence of the hepatitis virus, mainly HCV. Aflatoxin contamination might be another risk factor. High incidence of NHL is another characteristic feature in Egypt, but no specific culprit risk factor for this has been identified.

**Use of the data**
The registry prepares an annual report of cancer incidence, highlighting trends and changes. Some specific studies of survival of registered cancer cases (breast and liver cancer) have been carried out.

**Source of population**
The estimate of the population–at–risk is based on the 1996 census, making allowance for births and deaths, but it was not possible to estimate migration into and out of the registration area.

**Multiple primary rules used**
Tunisia, Central Region

Registration area

Tunisia, an Arab-Islamic North African country, is usually divided into three regions: the northern, the central and the southern region. The Central Region registry includes six provinces: Sousse, Monastir, Mahdia, Kairouan, Kasserine and Sidi Bouzid.

Sousse province, with an area of 2669 km² and the capital of the central region, had a 2000 population of 495 000, 18.3% of the overall population of the central region (2 697 200). The population is relatively young, with 48.1% being under 20 years of age, and 8% being over 60 years.

The main economic sectors of the region are agriculture, industry (textile) and tourism.

Registry structure and methods

The registry of the central region, staffed by four full-time physicians, is located in the Department of Pathology of the University Hospital of Sousse.

The search for new cases is proactive, which means that the registry does not wait to be informed, but actively looks for information from certain specific sources. Primary sources include the Departments of Pathology of the public and private medical centres (five, three of which are in Sousse). The other primary sources are the Departments of Radiotherapy (in Sousse), Oncology (in Sousse) and Haematology, in addition to the other 24 departments of the University Hospital of Sousse.

In addition to the histologically confirmed cases, more and more cases have been discovered in recent years without microscopic confirmation and are related to the gall bladder, the pancreas, the prostate, the lungs and the ovaries.

Interpreting the results

The registry counts all of the new declared cases of cancer in the entire central region of Tunisia. Nevertheless, apart from the province of Sousse where the completeness reaches 97%, a lack of completeness is observed in the other 5 provinces. We suggest therefore studying the epidemiological particularities of that province and not of the whole region. Moreover, we have encountered other practical difficulties related to the systematic declaration of cancerous diseases, changes in patient names, and the lack of information on the evolution of patients (treated outside the hospitals of Sousse or lost).

These difficulties are also due to the lack of precision in issued death certificates, which can be a source of information on the evolution of the diseases.

We have two national screening programs concerning cervix and breast cancer. PSA testing is done only in university institutions; to date there is no large screening program for prostate cancer.

Use of the data

The registry develops an annual report on the incidence of cancer in order to define the epidemiological profile of the region and compare it with those of the north and south regions of Tunisia and those of other countries. Certain special studies of five-year survival of cervical cancer, breast cancer and lung cancer have been performed.

Our registry is involved in some epidemiological research, especially in cancer genetics. Our registry is used as a base for planning and providing some health services, for example providing instruments for new cancer diagnosis and treatment (radiation, new-generation CT scans, and mammographs).

Source of population


Multiple primary rules used


Notes on the data

The Editors recommend that some care be taken in the interpretation of these data; see Chapter 5 (Categorisation).
Uganda, Kyadondo County

Registration area
The Kampala Cancer Registry collects data on the population of Kyadondo County, which includes the city of Kampala (the capital of Uganda), with its peri-urban areas and an area extending 30km to the north. This population, which is mainly urban (80%), is composed of the Ganda ethnic group (50%) and other ethnic groups (30%). There are also immigrants from neighbouring countries, particularly from Kenya and Rwanda. Europeans, Asians and other nationalities make up 1% of the population.

The major activities of the residents of the capital include administration, trade, professional and para-professional activities, personal services, and plant and machine operation. There are no major industries in the county; subsistence farming is carried out on the outskirts of the capital.

Fifty percent of the population are Catholic, 30% Anglican, 15% Muslim and 5% other.

Staple foods consumed by the population of Kyadondo County include matoke (steamed green banana), posho (maize bread), beans and groundnuts. About 50% of the city dwellers receive chlorine-treated piped water from the freshwater Lake Victoria.

Cancer care facilities
Kyadondo County is served by a 900-bed national referral hospital, Mulago Hospital, which is well equipped with modern diagnostic facilities. Mulago, which is also a teaching hospital for Makerere University Faculty of Medicine, is well supplied with consultants and teaching staff in all disciplines of medicine. An oncology unit involved in chemotherapy for various types of cancer and a radiotherapy unit are attached. The county has three other missionary hospitals with 100 beds each. The Uganda Hospice provides services for the care of terminal cases of cancer in addition to other terminal diseases. Two private histopathology laboratories provide additional histological data to the registry.

Registry structure and methods
The Kampala Cancer Registry is situated in the Department of Pathology, Faculty of Medicine, Makerere University. Personnel include a pathologist director, a cancer registrar and an assistant cancer registrar. All are employees of Makerere University.

However, in various hospitals and units the registry has recruited personnel to assist in coordinating collection of data. Submission of data to the registry is voluntary, as cancer is not a notifiable disease, and registration is almost entirely active. Doctors report a few cases to the registry directly. For hospitals, hospices and histopathology laboratories, the registrars visit at least once a month and consult the hospital records, which include admissions and discharge registers, clinical notes and pathology reports. For each case both demographic and cancer diagnostic data are sought. Certification of death is only carried out for legal reasons, and is very incomplete, so death certificates are not used as a source of information.

The registry is computerised, and data management is carried out using the IARC/IACR CanReg software, which includes checks for consistency and validity and permits a search for potential duplicate registrations.

Patient confidentiality is ensured by using only registration numbers during analysis of data. The registry is off-limits for unauthorised persons.

Completeness of registration was evaluated at 90% for the period 1994–1996 (Wabinga et al, Cancer Causes & Control 2001; 12:147-52)

Interpreting the results
Since its inception in 1951, the county covered by the registry has not changed its boundaries. However the population is becoming increasingly urbanised as the city expands. Immigration is also increasing as part of the worldwide trend of rural to urban migration. Another factor that may influence incidence rates is the improvement in availability of diagnostic services, particularly in the national referral hospital.

Screening programmes for cancer are not organised, but with the health-oriented population of the county, many patients seek screening services. PSA testing, mammography and Pap smears are done on an individual basis.

Uganda was one of the first countries to be severely affected by the HIV/AIDS epidemic, and has profoundly influenced the pattern of cancer in Kyadondo County (Wabinga et al, Int J Cancer. 1993; 54:26-36). However, as a result of vigorous national campaigns, prevalence of HIV infection is now falling—according to UNAIDS, prevalence in pregnant women in Kampala fell from 18.5% in 1995 to 13.8% in 1998 and 8.3% in 2002. This, together with the slowly increasing availability of anti-retroviral therapy, will result in changes in the incidence of AIDS-related cancers.

Use of the data
The registry provides the longest continuous time series of cancer incidence in Africa. This makes the data of special value for analytical studies and intervention studies. The registry has also published the first population-based estimates of cancer survival in sub-Saharan Africa.

Source of population
The population at risk is based on the results of the 1992 and 2002 census data, with intercensal years estimated from the observed rate of growth within 5 year age groups.

Multiple primary rules used
Notes on the data
The Editors recommend that some care be taken in the interpretation of these data; see Chapter 5 (Categorisation).
This registry has the lowest histological verification rate in the monograph.
Zimbabwe, Harare

Registration area
Harare is located in north-eastern Zimbabwe and is the capital city. The population of the city according to the 2002 national census was 1.9 million. The national population was 11.6 million.

Cancer care facilities
The current difficult economic situation currently in Zimbabwe is negatively affecting healthcare delivery, particularly in the public sector. In spite of this, the system in Harare, based on a network of primary health care facilities provided by the municipality, government-funded referral facilities and a private sector that caters mainly to middle- and higher-income groups, continues to perform reasonably.

Registry structure and methods
The Zimbabwe National Cancer Registry (NCR) was established in 1985 in Harare as a result of an agreement between IARC and the Zimbabwean Ministry of Health. The target population of the registry is that of Harare city, and adequate population coverage was achieved in 1990. Although the registry records all cancer patients identified from its diverse sources irrespective of residence, the present data for 1998–2002 are confined to the Harare city population.

The activities of the registry are overseen by a constituted advisory committee, and the day-to-day administration is the responsibility of the registrar under the guidance of the medical director. The registry has four full-time staff comprising the registrar, secretary and two data collection clerks. It is strategically located at Parirenyatwa Hospital, a large government referral centre and also the location of the University of Zimbabwe College of Health Sciences. The registry is supported by the Ministry of Health and Child Welfare, the IARC and other organisations.

Case-finding is mainly active, with the registry staff visiting institutions within the healthcare delivery system which are involved in the management of cancer patients.

- Histology reports from the public and private sectors, medical records of the radiotherapy department, death certificates of patients dying of cancer in greater Harare, and records of specific clinical research studies.
- Hospital inpatients are interviewed to verify the accuracy of reported age, residential status and other demographic data.
- Information recorded on each case includes sex, date of birth or age, residence, racial group, basis of diagnosis, tumour site and histology. Residence status is defined as the patient’s place of residence during the previous six months.
- All notifications coming into the registry are thoroughly vetted to ensure that only Incident cases are verified by the treating doctors to confirm the diagnosis, and completed forms are coded. The data are stored electronically using the IARC/IACR CanReg system. Patient name lists are generated periodically to physically eliminate duplicates.
- When several lesions of the same histological type occur in a patient, only the first lesion is recorded. Subsequent lesions are ignored. For example, the incidence of non-melanoma skin cancer is very high in the white community of Zimbabwe, and many patients develop several lesions of the same histological type during their lifetime. However, if basal cell carcinoma and squamous cell carcinoma of the skin occur in the same patient affecting the same or different sites, they are recorded separately.

Use of the data
Data from the registry are extensively utilised by both indigenous and foreign researchers, lecturers, students, conference participants, health educators, and the Ministry of Health and Child Welfare for management planning and cancer control programmes.

Source of population
Claimed to derive from the 2002 census, but the data do not correspond to the period 1998–2002.

Multiple primary rules used

Notes on the data
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