

CANCER REGISTRATION : **PRINCIPLES AND METHODS**

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DEFINITIONS

- **CANCER REGISTRATION** :

The process of continuing systematic collection of data on the occurrence, characteristics, and outcome of reportable neoplasms with the purpose of helping to assess and control the impact of malignant disease in the community.

- **CANCER REGISTRY**

The office or institution which is responsible for the collection storage, analysis and interpretation of data on persons with cancer.

PURPOSES AND USES OF CANCER REGISTRATION

1- Epidemiological research

- Descriptive Epidemiology
Describes patterns of disease
- Analytic Epidemiology
Study of the causes of disease

2 - Health care planning and monitoring

- Patient care
- Survival
- Screening
- Prevention

TYPES OF CANCER

REGISTRIES

- **DEPARTMENTAL (PATHOLOGY, RADIOLOGY, ENT, Ob/G, ONCOLOGY, ETC)**
- HOSPITAL BASED CANCER REGISTRY
- Records all cases of cancer treated in a given hospital
- The population from which the cases come is not defined
- Collects information from one or more laboratories on histologically diagnosed cancers
- The population from which the tumour tissue has come is not defined
- The information has high diagnostic quality but is difficult to generalize
- If the population is unknown only the PERCENTAGE FREQUENCY can be calculated

POPULATION CANCER REGISTRY

There are 2 sets of data collected:

- The tumour and the pop at risk

The tumour:

- Topography – the site or location of the tumour in the body
- Morphology – the microscopic appearance of the tumour (ICD-O-10)
- Behaviour – benign, in situ, malignant or uncertain

Population at risk:

- Must be defined (town, area, country)
- All non-residents to be excluded
- From Census data / estimates
- All cases in a defined population are registered
- True (unbiased) profile of cancer in the community
 - incidence, stage distribution, survival, etc.
 - calculation of incidence rates (because population at risk is quantified)

- Collects information on all new cases of cancer in a defined population
- The population covered is usually that of a geographic area
- the main interest is for epidemiology and public health

WHY POPULATION BASED REGISTRATION ?

- If the population from which the cases come (« population at risk ») is known
- The incidence rate can be calculated (gives a true picture of the difference in risk between populations or groups)

CASE-FINDING

- To find every new case of cancer diagnosed in the geographical area covered by the registry.

METHODS OF DATA

COLLECTION:

- **ACTIVE** collection at source by registry staff (visit, abstract, copy)
- **PASSIVE** notification by health-care workers from copies of discharge forms ,abstracts, reports etc
- **MIXED**
- **AUTOMATED** - use of data already stored in other information systems « down the wire »

REPORTABLE CASES

- Every new case of cancer from area covered by the registry
- Diagnosed and /or treated on or after the registry's reference date
- On the reportable list

SOURCES OF INFORMATION

- Hospitals
- Clinics
- Laboratories
- Vital statistics
- Death certificates

MAIN SOURCES OF DATA

- Highly developed medical infrastructure
- Cancer centres
- Hospitals (medical records)
- Death certificates.

HOSPITAL DATA SOURCES

- pathology laboratory
- haematology unit
- Radiology
- ultrasound
- nuclear medicine
- computerized tomography
- magnetic resonance imaging
- medical records
- hospital cancer registry
- hospital departments (gynaecology, ent, paediatrics,)
- Pathology, Radiotherapy , Oncology treat practically only cancer cases and generally have good records

PATHOLOGY DEPARTMENTS

- CASES DIAGNOSED :
- By biopsy
- By cytology
- (at autopsy)
- Quality of information
- Diagnostic data are very good
- Identifying information often poor

AUTOPSY

- Good source of information when available high level of diagnostic accuracy

Note

- The proportion of :
 - all deaths
 - all cancer deaths autopsied in a country / region may influence incidence
- Cancers discovered incidentally at autopsy should be marked to assess impact.

SCREENING PROGRAMMES

- cervix
- breast
- prostate
- large bowel
- occupational groups at risk

Note

- take care to differentiate pre-invasive from invasive diagnoses
- screening of asymptomatic people = possible detection of cancers which may never become apparent clinically.

PRIVATE CLINICS AND HOSPITALS

- important to obtain cooperation but often, difficult (confidentiality)
- useful when clinicians are also on staff of local hospitals
- problem of diagnosed patients who go abroad for treatment.

CANCER REGISTRATION:

Special problems in some countries

- Lack of basic health services
- Lack of stability of population
- Identity of individuals
- Lack of trained personnel
- Lack of follow-up
- Non-availability of census data
- Non-availability or poor quality of death certificates

BASIC INFORMATION :

- **compulsory and optional variables**

THE PERSON

- Name (according to local usage)
- Sex
- Date of birth or age (estimate if not known)
- Address (usual residence)
- Ethnic group (where appropriate)
- Profession
- Marital status

- Address (place of usual residence)
- Place of birth
- Marital status
- Nationality
- Religion
- *Occupation & industry
- Year of immigration
- Country of birth of father/mother

THE TUMOUR

- Incidence date
- Most valid basis of diagnosis
- Method of detection
- Site of primary*
- Histology
- Behaviour
- Extent of disease/stage
- Site(s) of metastases
- Multiple primaries
- Laterality

BEHAVIOUR

- Benign
- Uncertain
- Insitu
- Malignant
- Metastatic

STAGING

- The extent of disease defined in terms of an established set of rules
- **CLINICAL STAGING**
- - **TNM**
- TNM (pTNM, cTNM, PTNM, rTNM)
- STAGE: May be up to 40 combinations of
 - T (0-4)
 - N (0-3)
 - M (0-1)
- They are condensed into stage groups 0-1V

- **AJCC**
- **Site-specific staging**
- (Dukes, FIGO...) schemes

- **PURPOSES**
- **CLINICAL :**
- Planning treatment
- Providing prognosis
- Evaluate results of treatment

EPIDEMIOLOGY/PUBLIC HEALTH:

- Evaluate cancer screening/early detection
- Evaluate outcome of cancer control

EXTENT OF DISEASE CODING

- The extent of involvement of the tumour as determined using all diagnostic & therapeutic evidence available at the end of the first course of therapy, or within four months of the date of diagnosis, whichever is earlier

- EXTENT OF DISEASE CODES
 - End results groups :
 - In situ
 - Localized
 - Regional
 - Distant
- Disease outcome: Dead or Alive

MORTALITY RATES AS A MEASURE OF

CANCER OCCURRENCE

- 1. Poor survival (lung, oesophagus, stomach, liver)
 $M=I$
- 2. Fair survival (breast, cervix, colon) $M<I$
- 3. Good survival (skin) No value
- 4. Variable survival rates between places/persons
or due to rapid changes (Hodgkin's) little value
- 5. For developing countries, frequently not
available or poor in quality

GOOD QUALITY MORTALITY STATISTICS

- Requirements :
 - High level of medical coverage
 - Good diagnostic data (problem for older people)
 - Standardized completion of certificate
 - Accurate and consistent coding

FREQUENCIES

- **Percentage frequency or relative frequency**
- the proportion that each type of cancer constitutes of a total series
- the total series adds up to 100%
- if the registry does not have information on the population-at-risk this measure is used to describe cancer in the registry.

OTHER MEASURES OF **OCCURENCE**

- prevalence = proportion of existing cases (old and new) in a population at a given point in time
- incidence = number of new cases that develop in a population of individuals at risk during a specified time interval.

INCIDENCE RATE

- (crude incidence)

Number of new cases in a specified time period

$$\frac{\text{Number of new cases in a specified time period}}{\text{Population at risk}} \times 100\,000$$

Population at risk = no of persons exposed to risk

CRUDE INCIDENCE RATES

- Summary measure and easily interpreted
- Crude rates are difficult to interpret as they are not adjusted for factors such as age, gender and ethnic distribution, with cancer being mainly a disease of elderly, crude rates are expected to be low in a population that has a large proportion of children, such as Cameroon.

AGE-SPECIFIC RATES

- Concern age-groups (e.g . 0-4, 5-9, 10-14..... 75+
OR 1-14, 15-24, 25-34....75+)
- For each age group the rate is calculated by dividing the number of cases in the age-group by the corresponding population.

COMPARISON OF DATA

- Between populations
- Over time

AGE-STANDARDIZED RATE (ASR)

- A summary measure of a rate that a population would have if it had a standard age structure.
- Standardization is necessary when comparing populations that differ in age-structure because age has a very strong influence on cancer incidence.
- **ASR**
- The ASR is calculated using a standard population.
- The population usually used is the ‘world’ standard population :
- 0-44 74 000
- 45-64 19 000
- 65+ 7 000
- All ages 100 000

INCIDENCE RATE

- Can be calculated for population based cancer registry, when all cases in a defined population are recorded :
- Number of new disease cases per population at risk
 - High incidence implies high disease occurrence
 - Low incidence implies low disease occurrence
- Measured over a given time interval

EPIDEMIOLOGY

- « the study of the distribution and determinants of health-related states or events in specified populations,
- and, the application of this study to control of health problems ».

DESCRIPTIVE EPIDEMIOLOGY

« Exposure » variables

• Person	Place	Time
• Age	Of residence	Date of diagnosis
• Sex	Of treatment	Date of birth
• Religion		
• Marital status		
• Occupation		
• Education		
• Parity		
• Birthplace		

EXPOSURE : Place of residence

- Descriptive study :
- Disease rates by place of residence,
- Analogy is a cohort study, comparing rates of disease according to exposure (residence)
- Exposure of study subjects :
- From routine source (census, survey, register)
- Outcome for study subjects :
- From routine source (cancer registry, death certification)
- Person-years of observation :
- Estimated from census or survey data (not individual follow-up)

EXPOSURE : Place of residence

- Interpretation
- Living in a particular place has many co-variates
- At the broadest level :
 - genetic differences (ethnic groups, ect)
 - environmental exposures
- external environment (air, water, soil)
- lifestyle (diet, tobacco, reproduction ...)

MIGRANT STUDIES

- Are useful in giving an idea about relative importance

USES OF CANCER REGISTRY

- Planning & evaluation of cancer control programmes
- Defining the Burden of cancer
- Past trends
- Future projections

CANCER INCIDENCE

- « Burden » of cancer as number of new cases
- Priority for which cancer to control (prevention, treatment)
- Estimating the resources required, based on numbers of new cases (by age, stage, etc)

2-screening & early detection

- outcomes (incidence or mortality)
- time trend studies (in relation to inputs)
- linkage with screening programme records
- (distinguish screened/unscreened individuals)
- intermediate endpoints
 - incidence of interval cancers
 - size and stage of screen-detected cases
 - incidence of advanced cancers
- 3-treatment : study of survival
- 4-cancer care

CANCER CONTROL

- Prevention
- Early detection
- Treatment
- Rehabilitation / palliation

EVALUATION OF SCREENING

- What is the objective of the screening procedure ?
- To detect pre-invasive disease
- Cervix cancer, (oral and colon cancer)
- To detect early invasive cancer
- Breast cancer, colon cancer, prostate cancer, etc

EVALUATION OF SCREENING

Observational studies

- 1 population – level studies
 - Geographical comparisons
 - Time trends
- 2 studies of individuals
 - Cohort (follow-up) studies
 - Case-control studies

- **II INTERVENTION STUDIES**
 - Randomized controlled trials
- **EVALUATION OF SCREENING**
 - Effectiveness
 - Does the programme achieve its objective ?
 - Efficiency
 - Costs in relation to outcome

Patterns of clinical care

- place of treatment
- percentage on treatment protocols
- delay (diagnosis-treatment)

Making the data public

Cancer Incidence in Five Continents Vol. VIII

- Constrains comparable incidence data for the period 1993-1997
- 214 populations (cancer registries and sub-populations within them) in 57 countries around 250 diagnostic units : cancer sites and histological subtypes

- Presenting the data
- Annual report
- Journal article
- Internet
- Newspapers, radio, television
- International Association of Cancer Registries
(<http://www.iacr.com.fr/>)

- **QUALITY CONTROL IN THE CANCER REGISTRY**
- **COMPLETENESS**
- The extent to which all of the incident cancers occurring in a target population are included in the registry database

THE CANCER REGISTRY

- It is the function of the registry to record, as fully and as accurately as may be possible, both a clinical description of the extent of the disease and also information which will identify the patient, the tumour, the hospital and the clinicians involved with the case.

MEDICAL CONFIDENTIALITY

- The treating physician who provides information to a cancer registry about a patient with cancer has the right to expect that the registry observes strict rules of confidentiality.
- The registry must maintain same standards of confidentiality as the doctor in his/her relationship with the patient.

POPULATION-BASED CANCER REGISTRY (PCR) YAOUNDE : MID-YEAR REPORT (JUNE)1995.

- The Yaounde population-based registry was established in September 1994 at the anti-cancer centre in the central hospital Yaounde with the financial support of the International Agency for Research on Cancer (IARC). The registry started data collection regularly from January 1,1995.

- The registry's activities are limited to the Yaounde city. The projected population of Yaounde, as on April 1987 census is 1078892 (males : 561,622 females 517270. The sex ratio is 921 females per 1000 males. Yaounde city is situated at latitude 3°50' N and longitude 11°30' F in the Republic of Cameroon at the west central part of the sub-continent. It is at sea level at an altitude of 750 m. With an average annual temperature of 23.5° the cold seasons falling in the months of November to February and the hot between April and June. The area of registration is 254 square kilometers.

- The registry had identified 35 principal institutions for data collection on cancer patients. During the months January to June 1995, 80.64% cases were registered from the central hospital Yaounde ; the remaining cases came from other sources. The percentage of cases registered for which histological confirmation was available was 90.32% for males and 83.87% for females 0% of male cases and 0% of female cases were registered on the basis of information from « death certificate only » cancer deaths in period appear to be under registered and efforts have been made to improve upon the death notification with the help of the Yaounde Municipal council and other health authorities.