What information does a Cancer Registry need to collect

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What Data Are We Attempting To Collect?

What would you like to collect?

Variables of interest

- Demographic
  - Name
  - Date of birth/Age
  - Gender
  - Address
  - Religion, Ethnicity
  - Education
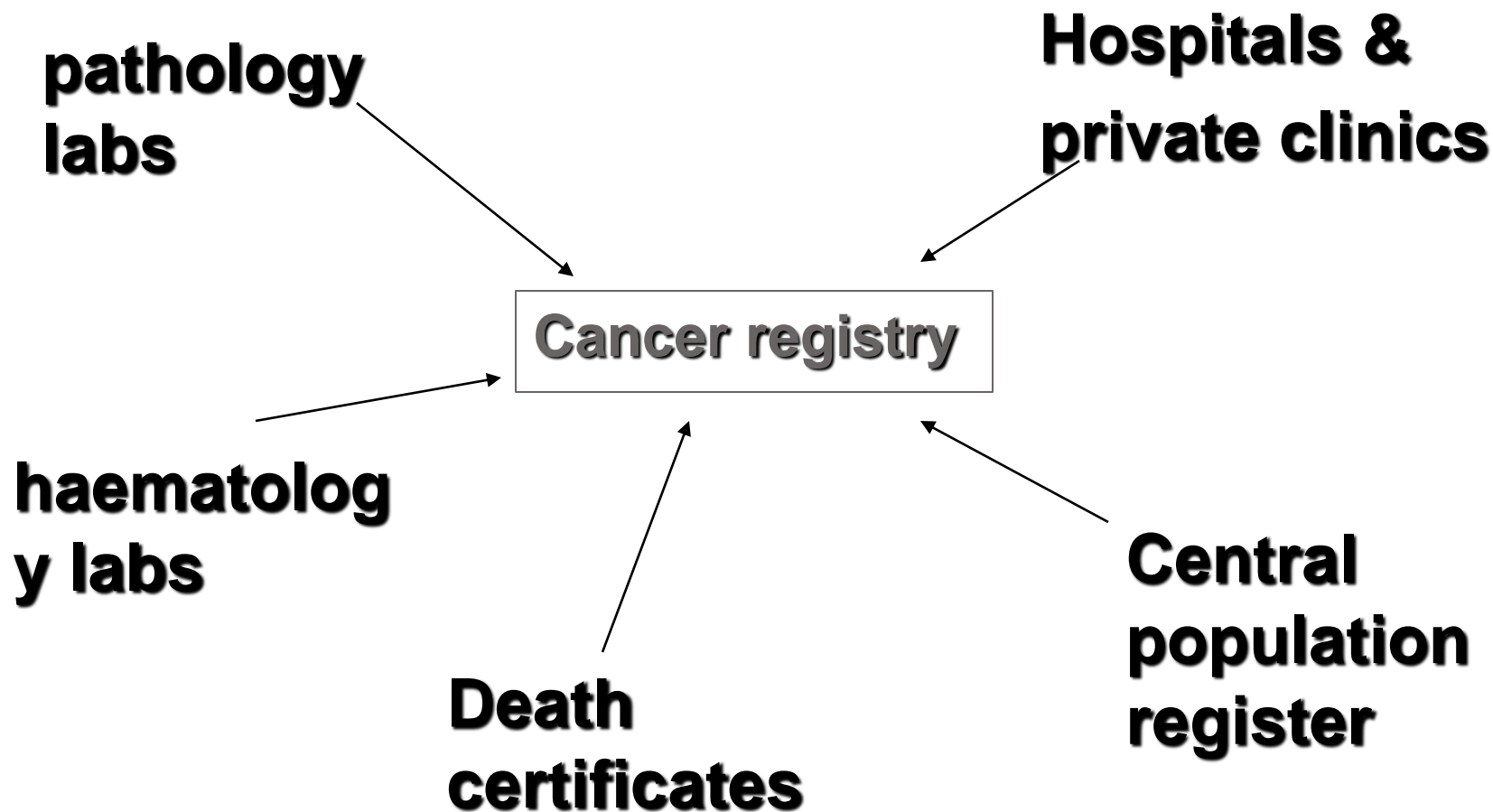 - Duration of stay
  - Marital status
  - Mother tongue

- Epidemiological data
- Tobacco use
- Dietary habit
- Obesity

Variables of interest

Clinical data

- Source of information
- Incidence date
- Topography, histology, laterality
- Primary or secondary disease
- Method of diagnosis
- Clinical extent of disease at diagnosis
- Stage
- Initial treatment
- Details of treatment
- Follow up information

Sources of information

pathology labs

Hospitals & private clinics

Cancer registry

haematology labs

Death certificates

Central population register

Sources of data: Usually multiple

- Cancer outpatient, medical record and other departments of major hospitals – government or private
- Consultants/clinics/nursing homes
- Pathology/haematology/biochemical laboratories
- Radiology and other diagnostic services/ laboratories
- General practitioners, if feasible
- Screening programs, if any
- Hospices
- Vital statistics division-Death certificates

How much details we should collect?

The detail of information depends on the needs of the cancer registry and is balanced out by what is available in hospitals, clinics, death registers, etc. and the available resources.

What Data Are We Attempting To Collect?

What data one should collect?

Type of Registry
Method of data collection
Main objective

CANCER REGISTRATION

Definition

The process of continuing, systematic collection of data on the occurrence and characteristics of reportable neoplasms

Scope: Record <u>all new</u> cases in a defined population, in a defined time period.

What Are We Trying To Measure?

- Cancer Incidence: the total number of NEW cancer cases diagnosed during a calendar YEAR among RESIDENTS of a defined geographic area

What Do We Need To Know In Order To Accomplish Our Goal?

- Identification of person

- Definition of residence

- Definition of a case

- Identification of cancer site

- Definition of date of diagnosis

Personal identifier

Name (full)

Father's /spouse name

Gender

Date of birth/age

Unique id (if available)

Need to collect personal identification

✓ To identify duplicate notification of same person with same cancer from different sources.

✓ To identify second cancer occurring in same individual.

Definition of residence

Address (as complete as possible)

How long staying on this address (Duration of stay)

Need to collect information on residence

To know whether person belongs to defined geographical area

If come to defined geographical area only for diagnosis/treatment then label it as Non Resident case.

If not regular resident of defined geographical area (say less than year) then label it as Non Resident case

Most valid basis of Diagnosis

Microscopic
    Cytology or hematology
    Histology of primary
    Histology of metastasis
    Autopsy
    Unknown

Non-microscopic
    Clinical only (signs & symptoms of the disease)
    Clinical investigations, including X-ray, Ultrasound, etc.
    Exploratory surgery
    Biochemical or immunological test

Death certificate only

Definition of case

Generally , all malignant neoplasm are included.

Generally, Carcinoma in-situ are not included.

Definition of New Case

Date of first diagnosis.

Date of microscopic confirmation.

Date of admission in hospital.

Date of clinical suspicion of malignant tumor

Information about tumor

- Anatomic (topographic) site

- Histological (morphologic) type

- Behavior

- Grade

- Tumor sequence

Other information

- Type of treatment

- Clinical extent of tumor

- Last contact date

- Date of death (if any)

- Cause of death

Treatment data

- Treatment given within six month at reporting institution
- Surgery
- Radiation
- Chemotherapy
- Hormone therapy

To ascertain level of development of treatment services

Clinical extent of disease

- Localized

- Regional involvement

- Distant Metastasis

Cause of Death

- Even if the diagnosis is not very accurate identifying information and date of death are (important for survival.

Other considerations

- Laterality

- Multiple primary
  - Only one tumor recognized in a pair of organs, unless histology is different.
  - Each new tumor is registered in a registry, so multiple primaries need to be captured.
  - Need to rule out extension, recurrence & metastases.

Reporting of cancer Cases for PBCR
Minimum Required information for morbidity cases

Information	Must	Optional
I. Patient Identity		
1.Name (in full)	√	
2.Father's or Husband's name	√	
3.Age/Sex	√	
4.Father/Spouse Name	√	
5.Postal Code/Locality	√	
6.Address	√	
7. Native place address /Address of relative		√
8. Place of Birth		√
9. Education		√
10. Marital status		√
11 Unique id (if any)	√	

Reporting of cancer Cases for PBCR
Minimum Required information for morbidity cases

Information	Must	Optional
I. Disease related		
1.Most valid basis of diagnosis	√	
2. Date of first diagnosis	√	
3. Clinical extent of disease		√
4. Primary Site of Tumor (ICDO-3)	√	
5. Histology type (ICDO-3)	√	
6.Behavior	√	
7. Tumor grade		√
8. Clinical stage		√

Reporting for cancer cases For morbidity cases Minimum required information for morbidity cases

Information	Must	Optional
iii. Treatment Related 1. Present treatment , if any 2. Previos treatment , if any	√	
IV. Outcome/Follow up 1. Last contact date 2. Date of death (if any) 3. Cause of death	√	
Source of information 1. Source name/ID 2. Hospital record number	√	

Death registration system

- Based on place of death generally

- Death from a defined population in a defined geographical area considered for registry purpose

- Quality and completion are major limiting factors in many places

- Cancer mortality is an important measure of cancer control

Reporting of cancer deaths for PBCR: Minimum required information

Information	Must	Optional
I. Sources of registration & deceased's identity		
1. Sources of registration – VSD/ Other	√	
2. Name (in full)	√	
3. Age/ Sex	√	
4. Father/Spouse name	√	
5. Postal code/ locality of residence		√

- The objective to collect accurate and complete deceased's identity information. Usual source of data is vital statistics division (VSD).

- The Primary reason is :

  To Link every death from VSD/ other with every cancer cases from different sources of possible matching.

Reporting of cancer deaths for PBCR: Minimum required information

Information	Must	Optional
II. Death particulars		
Date of death	√	
Cause of death –ICD10	√	
Place of death	√	
Autopsy	√	

Variables for HBCR

- Stage of disease

- Details of treatment

- Details of Follow up

- Information on lifestyle factors

Variables for Special Registry
eg.: Registries near nuclear power plants

- Occupation

- Nature of job

- Duration of employment

- Information on lifestyle variables

Basic information for cancer registry (PBCR)

- Personal identification
- Name
- Age/Date of birth
- Gender
- Address
- Ethnic group
- Incidence date
- Topography (primary)
- Morphology (histology)
- Behavior
- Clinical extent of disease at diagnosis
- Source of information
- Most valid basis of diagnosis

Basic information for cancer registry

- Treatment given within six month at reporting hospital

- Date of death

- Cause of death

- Place of death

- Autopsy done

- Tumor sequence