Cancer registry

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History of Cancer registration:

- The first efforts to estimate the number of new and existing cases of cancer in a given population were made at the turn of the XIX and XX century in various European countries.
- In Germany, an attempt was made in 1900 to register all cancer patients who were under medical treatment.
- The same approach was adopted between 1902 and 1908 in Denmark, Hungary,Iceland, the Netherlands, portugal, Spain and Sweden.
- The first population – based cancer registry was set up in Hamburg(Germany) in 1929

History of cancer registration:

Country (region)	Year of establishment	Notification
Germany(Hamburg)	1929	Voluntary
USA(New York state) USA (Connecticut	1940 1941	Compulsory Compulsory(since 1971)
Denmark Canada (Saskatchewan)	1942 1944	Compulsory(since 1987) Compulsory
England and Wales(SW Re gion) England and Wales (Liverpool)	 1945 1948	 Voluntary Voluntary
New Zealand Canada (Manitoba)	1948 1950	Compulsory Voluntary
Slovenia Canada(Alberta) USA(EL paso) Hungary (Szabolcs,Miskolc,vas)	1950 1951 1951 1951	Compulsory Compulsory Compulsory Compulsory
Norway Former USSR Former GDR Finland Iceland	1952 1953 195319531954	Compulsory Compulsory Compulsory Compulsory (since1961) Voluntary

International Agency for Research on Cancer
Lyon , France

Cancer registration process:

- Cancer registration may be defined as the process of continuing, systematic collection of data on the occurrence and characteristics of reportable neoplasms.
- The overall aim of the cancer registration process is to assess and control the impact of cancer on the community (population).

Cancer registration process:

- The cancer registration is an essential part of any rational programme of cancer control.
- The data from cancer registries can be used in a wide variety of areas of cancer control, such as:
  - etiological research
  - primary prevention
  - secondary prevention
  - health care planning
  - evaluation of patients care

- The *cancer registry* is the office or institution which attempts to collect, store, analyse and interpret data on persons with cancer.
- There are two basic types of cancer registries:
  - population-based cancer registry
  - hospital-based cancer registry
- The *population-based cancer registry* records all new new cases in a defined population (most frequently a geographical area)
- The *hospital-based cancer registry* records all cases in a given hospital, usually without knowledge of the background population (the emphasis is on clinical care and hospital administration).

TYPES OF REGISTRIES

- Hospital-based Registry
- Population-based Registry
- Special Cancer Registries

Objectives of the registry:

- Collecting and classifying information on cancer cases in order to produce statistics on the occurrence of cancer in a defined population.
- Linkage of incidence data sets with external data sets (e.g. mortality data sets) to improve completeness and quality of incidence data
- Evaluation of quality of data provided by particular registries (completeness of data, % of MV, % of DCO/DCN)
- Analysis of the data collected.

Planning a population-based cancer registry:

- The purposes of cancer registration must be clearly defined before a registry is established.
- The population-based cancer registry must collect information on every case of cancer identified within a specific population over a given time period.

Planning a population-based cancer registry:

- The registry operates within a defined geographical area, to be able to:
  - distinguish between residents of the area and those who have come from outside;
  - register cases of cancer in residents treated outside the area;
  - have sufficient information on each case to avoid registering the same case twice;
  - have an access to an adequate number of sources within area.

Planning a population-based cancer registry:

- Several condition are necessary to develop a population-based cancer registry:
  - generally available medical care and ready access to medical facilities - so that the great majority of cancer cases will come into contact with the health care system at some point in their illness;
  - system for reporting clinical and pathological data;
  - reliable population data should be available;
  - the cooperation of the medical community is vital to successful functioning of a registry
  - adequate budget must be available (expenses tend to increase in time)

Planning a population-based cancer registry:

Population denominators

- Accurate and regularly published population data must be available;
- Population figures by sex and age-groups are required for the registration area (and for any subdivisions which the registry might wish to examine)
- The cancer registry must use the definitions of population groups, geographical areas, etc. exactly as they are presented in the official vital statistics

Planning a population-based cancer registry:

Size of the population and the number of cases

- No strict rules concerning the optimal size of the population covered by a single cancer registry
- In practice, most cancer registries operate with a source population of between one and five million
- In countries with large populations, autonomous but linked regional registries are usually more effective, e.g. England & Wales or Poland
- For countries in which national coverage is difficult to achieve, it is preferable to set up smaller registries in representative areas, e.g. SEER Program in the USA, or in India.

Planning a population-based cancer registry:

Physical location of the registry

The physical location of the cancer registry is often intimately linked to the administrative dependency of the registry.

There are several possible locations, such as:

- universities
- oncological (and/or university) hospitals
- health statistics offices
- pathology institutes

Cancer registries should be as autonomous as possible (to facilitate cooperation with other health agencies).

Planning a population-based cancer registry:

Personnel

The level and the quantity of staff depend to a great extent on:

- the size of the population covered
- the number of new cases diagnosed annually
- choice of information to be collected
- the methods used for case finding
- recording, coding, and data management practices used

In general, it was found in CI5 survey, that one staff member is necessary for each 1000 or so new cases occurring annually in the population covered by the registry.

Planning a population-based cancer registry:

Personnel (cont.)

The staff of the registry consists of persons with professional and technical training and experience.

The technical staff comprise the record clerks and statistical clerks.

Training of the registry personnel at all levels is an important aspect of the cancer registry's operation.

Formal, continued training courses recommended

Change is a constant

Retain registry staff

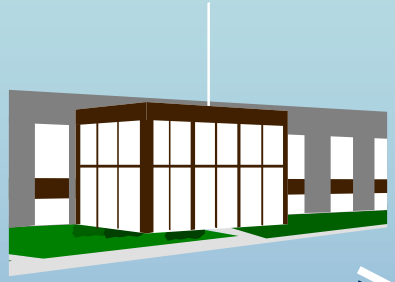
Cancer registration methodology

Data collection

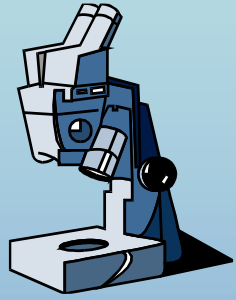
Usually, the main sources of information of a population-based cancer registry are:

- information from treatment facilities, such as cancer centers and major hospitals (sometimes private clinics, hospices, homes for the elderly, and general practitioners)
- information from diagnostic services, especially pathology departments, but also haematological, biochemical and immunological laboratories, X-ray and ultrasound departments, other imaging centers
- death certificates from the death registration system (if available)

SOURCE OF INFORMATION



CLINICS



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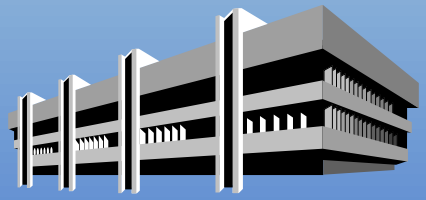
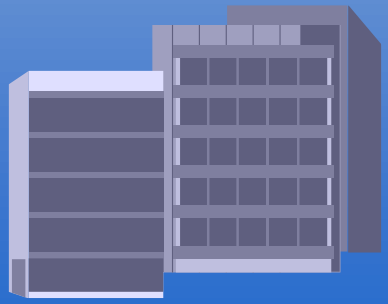


HOSPITAL

VITAL STATISTICS
DEATH CERTIFICATES



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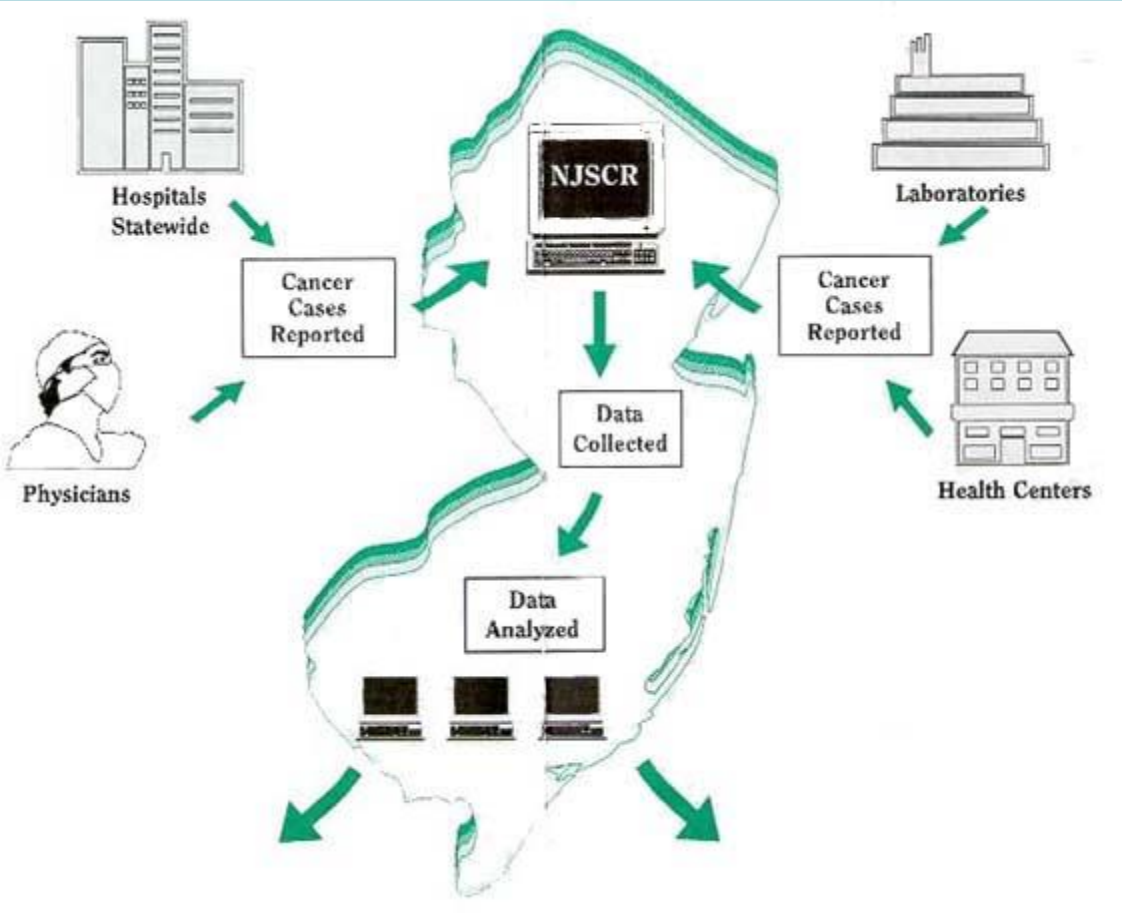


Cancer registration methodology

Data collection

The information is collected by:

- active collection
- passive reporting

Active collection involves registry personnel actually visiting the different sources and abstracting the data on special forms

Passive reporting involves health-care workers completing the notification forms developed and distributed by the registry (or sending copies of discharge abstracts to the registry)

Mixture of the two above is often used in many registries.

Cancer registration methodology

Data collection - basic data items to be collected:

- The patient
  - Registration number - assigned by the registry
  - Name
  - Sex
  - Date of birth (or age) - estimate if not known
  - Address - usual residence
  - Ethnic group - if relevant (optional)
- The tumour
  - Incidence date
  - Most valid basis of diagnosis
  - Topography (site) - coded using ICD-O or ICD-10
  - Morphology (histology)- coded using ICD-O
  - Behaviour - coded using ICD-O
  - Source of information

Cancer registration methodology

Source of information:

- type of source
  - physician
  - laboratory
  - hospital
  - death certificate
  - other
- actual source
  - name of physician
  - laboratory
  - hospital, etc.
- dates
  - dates of relevant appointments
  - hospital admission
  - diagnostic procedures

Cancer registration methodology

Source of information:

Other data items may also be included - however it increases the complexity and cost of the registration process, and should be done only if justified by local needs and if necessary resources are available.

The most relevant additional items are:

- clinical extent of disease before treatment (stage at presentation)
- follow-up data

Cancer registration methodology

Data collection - additional data items to be collected:

- The patient
  - personal identification number (e.g. national identity number or social security number)
  - place of birth
  - marital status
  - age at incidence date
  - nationality
  - religion
  - occupation and industry
  - year of immigration
  - country of birth of father and/or mother

Cancer registration methodology

Data collection - additional data items to be collected:

- The tumour and its investigations
  - certainty of diagnosis
  - method of first detection
  - clinical extent of disease before treatment
  - surgical-cum-pathological extent of disease before treatment
  - TNM system
  - site(s) of distant metastases
  - multiple primaries
  - laterality
- Treatment
  - initial treatment
- Follow up
  - date of last contact
  - status at last contact (alive, dead, emigrated, unknown)
  - date of death
  - cause of death
  - place of death

Cancer registration methodology

Registration form

The data from the various sources are usually abstracted by using a standard registration form developed according to the needs of the registry.

The information on cancer cases should be collected and classified

Although data should be collected (and reported) according to local needs and interests, an effort should be made to ensure that comparisons with data from other national and international cancer registries will be possible.

مرکز تحقیقات سرطان انستیتو کانسر - طرح ثبت سرطان

1.نام:..... 2.نام خانوادگی:..... شماره بایگانی: (در داخل کادر بالا چیزی ننویسید)

مشخصات فردی بیمار

3.جنسیت: ☐مونث ☐مذکر ☐نامشخص شماره بایگانی: (در داخل کادر بالا چیزی ننویسید)

4.نام پدر:..... 5.ش شناسنامه:..... 6.کد ملی:.....

7.تاریخ تولد:..... 8.کشور تولد: ..... 9.استان تولد:..... 10.شهرتولد:.....

11.وضعیت تاهل: ☐ازدواج کرده ☐هرگز ازدواج نکرده ☐نامشخص 12.تحصیلات:.....

13.دین: ☐مسلمان ☐مسیحی ☐زرتشتی ☐کلیمی ☐نامشخص ☐سایر.....

14.آدرس محل سکونت در زمان تشخیص: کشور:..... استان:..... شهر:.....

.....15.کدپستی:.....16 تلفن:.....

اطلاعات پزشکی

17.شماره پرونده:..... 18.شماره بیمه:..... 19.نوع بیمه:.....

20.مرکز تشخیصی:..... 21.مرکز درمانی:..... 22.سن ابتلا:.....

23.تشخیص:.....

.....

24.کد ICD-O-M :..... 25.کد ICD-O-C :..... 26.تاریخ اولین تشخیص:..... 27. تاریخ فوت:.....

28.روش تشخیص قطعی: ☐سیتولوژی ☐باتولوژی ☐هماتولوژی ☐رادیولوژی ☐گواهی فوت ☐تشخیص بالینی/جراحی ☐نامشخص

29. منبع کسب اطلاعات بالا: ☐پرونده بالینی ☐ گزارش آسیب شناسی ☐گواهی فوت ☐ سایر:.....

نام تکمیل کننده..... تاریخ تکمیل:.....

این قسمت توسط مرکز تحقیقات سرطان تکمیل میگردد (تکمیلی)

30.شماره سریال:..... 31.تاریخ بایگانی: ..... 32.شماره ثبت: ..... 33.تاریخ ثبت:.....

34.نام:..... 35.نام خانوادگی:..... 36.جنسیت: ☐خانم ☐آقا ☐نامشخص

37.نام پدر:..... 38.ش شناسنامه:..... 39.کد ملی:.....

40.تاریخ تولد:..... 41.کشور تولد: ..... 42.استان تولد:..... 43.شهرتولد:.....

44.وضعیت تاهل: ☐ازدواج کرده ☐هرگز ازدواج نکرده ☐نامشخص

45.دین: ☐مسلمان ☐مسیحی ☐زرتشتی ☐کلیمی ☐ نامشخص ☐سایر:.....

46.آدرس محل سکونت در زمان تشخیص: کشور:..... استان:..... شهر:.....

.....47.کدپستی:..... 48.تلفن:.....

49.سن ابتلا:..... 50.تاریخ تشخیص:..... 51.تحصیلات:..... 52.شغل:.....

53.آدرس فعلی : کشور:..... استان:..... شهر:.....54.کدپستی:.....

..... 55.تلفن:.....

56.وضعیت بیمار: ☐ زنده ☐فوت شده ، تاریخ فوت:...../...../.....

توضیحات:.....

نام تکمیل کننده..... تاریخ تکمیل:.....

(قسمت ذیل توسط کاربر رایانه با مداد مشکی تکمیل میگردد)

کد کاربر:..... کد ورود اطلاعات:..... کد خطای ورود اطلاعات: 1..... 2..... 3.....

Purposes and uses of cancer registration

Epidemiological research

- descriptive studies
- cohort studies
- case-control studies
- intervention studies
- ecological studies
- cross-sectional studies

Cancer control

- patient care
- survival
- screening and early detection
- prevention (primary and secondary)

Quality Control

Quality control

- Comparability
- Completeness
- Validity or accuracy
- Timeliness

Comparability

- standardization of practices concerning classification and coding of new cases, and consistency in basic definitions of incidence, such as rules for the recording and reporting of multiple primary cancers occurring in the same individual

Quality control

- **Comparability**
  - **definition of incidence date**
  - **multiple primaries**
  - **incidental diagnosis**
  - **autopsy diagnosis**
  - **classification and coding**
  - **death certificates**

Quality control

- **Comparability**

  - **definition of <u>incidence date</u>**

1. Date of first histological or cytological confirmation
   a) date when the specimen was taken (biopsy or operation)
   b) date of receipt by the pathologist
   c) date of the pathology report.
2. Date of admission to the hospital because of this malignancy.
3. Date of first consultation at the outpatient clinic (only).
4. Date of diagnosis, other than 1, 2 or 3.
5. Date of death, if no information than that the patient has died because of a malignancy.
6. Date of death, if the malignancy is discovered at autopsy.

Quality control

- **Comparability**
  - **definition of incidence date**

- The incidence date should not be later than the date of the start of the treatment, or decision not to treat, or date of death.

- Discover your potentials for trace back.
- Change incidence date if new information.

Quality control

- **Comparability**
  - **definition of <u>incidence</u>**

Be aware:

1. Recurrence or extension of existing cancer and new primaries.
2. Incidental detection of cancer in asymptomatic patients.
3. Detection of cancer in autopsy.

Quality control

- **Comparability**
  - **– multiple primaries**

The recognition of the existence of two or more primary cancers does not depend on time.

A primary cancer originates in a primary site or tissue
and is not an extension, a recurrence nor a metastasis.

Only one tumour shall be recognized in an organ or pair of organs or tissue.

Quality control

- **Comparability**
  - **incidental diagnosis**
    - **screening (Cervix, breast, prostate)**
    - **increased incidence (temporarily?)**
    - **decreased mean age**
    - **increased survival time**
    - **method of detection?**

Quality control

- **Comparability**
  - **autopsy diagnosis**
    - **subset of incidental cancers**
    - **latent, subclinical disease, competing causes of death**
    - **basis of diagnosis, method of detection?**

Quality control

- **Comparability**
  - **classification and coding**
    - **ICD-O-3**
    - **skin, bladder, nervous system**
    - **leukemias, lymphomas**
    - **benign/malignant, CIN, in situ, borderline**
    - **childhood cancers**

Quality control

- **Comparability**
  - **mortality data**
    - **national statistics**
    - **corrected mortality data in cancer registry**
  - **death certificates**
    - **access (cancer only or all)**
    - **underlying cause (official statistics)**
    - **any mention of cancer (DCO, DCN)**
    - **date (end of follow-up)**

Completeness

- the extent to which all of the incident cancers occurring in the population are included in the registry database completeness is a very important attribute – only with maximum completeness in case-finding procedures will incidence rates and survival proportions be close to their true values.

Quality control

- **Completeness**
  - **under-diagnosis**
  - **under-registration**
  - **selection biases**
  - **duplicates**
  - **constant monitoring**

Quality control

- **Completeness**
  - **number of sources/notifications per case**
  - **death certificate method**
  - **histological verification (HV%)**
  - **independent case ascertainment**
  - **re-screening of cases**
  - **capture/recapture methods**
  - **mortality/incidence ratio**
  - **stability of rates over time: between populations, by age group, in children**

Quality control

- **Completeness**
  - **types of sources available**
  - **number of sources per case**
  - **number of notifications per case**
  - **number of cases per hospital (other source)**
  - **record the numbers by case**

Quality control

- **Completeness**
  - **number of sources/notifications per case**
    - **doctors, hospitals, outpatient clinics**
    - **pathology labs, hematologists**
    - **autopsy reports**
    - **suspicion, diagnostics, treatment**
    - **surgery, radiotherapy, chemotherapy**
    - **oncologist, gynecological oncologists…**
    - **death certificates**
    - **other registries, insurance, social security**

Quality control

- **Completeness**
  - **number of sources/notifications per case**
    - **duplicates**
    - **trace-back**
    - **confusing information**

Quality control

- **Completeness**
  - **death certificate method**
    - **finds missed cases <u>if</u>**
      - **death certificates available**
      - **cancer is lethal**
      - **patient dies of the cancer**
      - **certificate correct**
      - **death in the area of registration**

Quality control

- **Completeness**
  - **death certificate method**
    - **all certificates allow follow-up**
    - **all cancer diagnoses allow trace-back**
    - **cancer as the underlying cause only**
    - **aim at low DCN% and low DCO%**

Quality control

- **% DCN as indicator of completeness**

a = registered dead

b = registered alive

c = unregistered dead (DCN)

d = unregistered alive

$$\frac{d}{a + b + c + d}$$

then d = bc/a

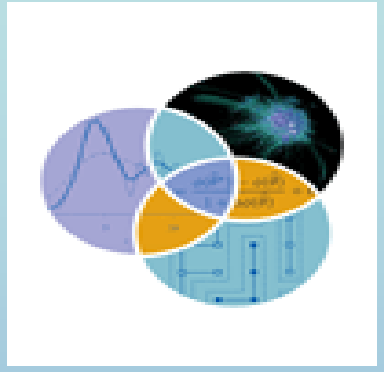
Quality control

- **Completeness**
  - **death certificate method**
    - **proportions of DCN cases**
    - **vary by site**
    - **increase with age**
    - **vary by method of detection (HV% vs. radiology)**
    - **decrease with maturing registry practices**
    - **decrease with increasing resources**

Quality control

- **Completeness**
  - **histological verification (HV%)**
    - **set local standard**
  - **independent case ascertainment**
    - **research data bases (biased?)**
    - **autopsy series**
    - **hospital discharge registries**
    - **(cancer survey)**
  - **re-screening of cases**
    - **active and passive registration**
    - **case- finding study**

Quality control



- **Completeness**
  - **capture/recapture methods**
    - **<u>independent</u> data sources**
    - **unique identifiers**
    - **estimates proportions of missing cases**

Quality control

- **Completeness**
  - **capture/recapture methods** **?**

		Source A: present	Source A: absent
Source B	present	a	b
Source B	absent	c	d

if independent sources ad/bc = 1

maximum likelihood estimate d(MLE) = bc/a

Quality control

- **Completeness**
  - **capture/recapture methods**

		Hospital	
		present	absent
Path + DC	present	1020	230
	absent	99	?

d(MLE) = 230x99/1020 = 22

incompleteness 22 / (1349+22) = 1.6%

Quality control

- **Completeness**
  - **capture/recapture methods**
    - **can be used as a standard method to compare registries (if similar sources)**

Quality control

- **Completeness**
  - **mortality/incidence ratio (M:I)**
    - **number of deaths and incident cases in the same time period**
    - **NOT identical patients, but**
    - **identical diagnoses**
    - **M:I = (1 - overall survival probability)**
    - **if incidence and survival steady**

Quality control

- **Completeness**
  - **mortality/incidence ratio (M:I)**
    - **M:I > 1 or**
    - **M:I > (1 - survival probability)**
      - **under-registration**
      - **small registries, rare cancers**
      - **declining incidence rates**
      - **inaccurate causes of death**

Quality control

- **Completeness**
  - **stability of rates**
    - **over time**
    - **between populations**
    - **by age group**
    - **in children**

Quality control

- **Validity**
  - **proportion of cases in a registry with a given characteristic**
    - **diagnostic criteria**
    - **reabstracting and recoding**
    - **internal consistency**
    - **% of registered cases with missing information for indicator variable**

Quality control

- **Validity**
  - **diagnostic criteria**
    - **basis of diagnosis**

- **Histology of a primary tumour (including autopsy)**
- **Histology of a metastasis (including autopsy)**
- **Cytology**
- **Specific tumour markers**
- **Clinical investigation (all dg techniques without a tissue dg)**
- **Clinical (before death)**
- **Death Certificate Only**
- **Unknown**

Quality control

- **Validity**
  - **histological verification (HV%)**
    - **or microscopical (incl. biopsy/cytology)**
    - **primary vs. metastatic vs. infectious**
    - **HV% of <u>all</u> registered cases (include DCOs)**
    - **HV% varies by site, available technology, age, stage, sex (all sites combined)**

Quality control

- **Validity**
  - **DCO ‘death certificate only’**
    - **measure of completeness and of validity**
    - **DCO incidence date = date of death**
    - **If no access to DCs, no DCOs**

Quality control

- **Validity**
  - **DCN ‘death certificate notification’**
    - **improve validity of data**
    - **allocate correct date of diagnosis**

Quality control

- **Validity**
  - **reabstracting and recoding**
    - **identify problems in interpretating source material**
    - **standardise abstracting and coding**
    - **determine need for additional training**
    - **correct (systematical) errors**
    - **correct existing rules**

Quality control

- **Validity**
  - **internal consistency**
    - **‘edit checks’ during or after coding**
    - **incorrect codes**
    - **incorrect combinations**
    - **incorrect order of events, age vs. dates**
    - **missing information**

    - **reject**
    - **flag for check**
    - **warn for rarity**

Timeliness

- Access to recent data is perceived as a priority by users, but, since registries are constantly updating their database as reports are received, and some notifications arrive long after the case was diagnosed, statistics for the recent periods will be incomplete, and will need future updates. There is, therefore, some conflict between the requirement for timely data, and other aspects of data quality, particularly completeness.

Timeliness

- Definition: rapidity at which a registry can collect, process and report sufficiently reliable and complete cancer data
  - –Benefit
    - health providers
    - Researchers
    - Reputation of the registry
- Tradeoff:
  - –Timeliness or completeness and accuracy?

Timeliness

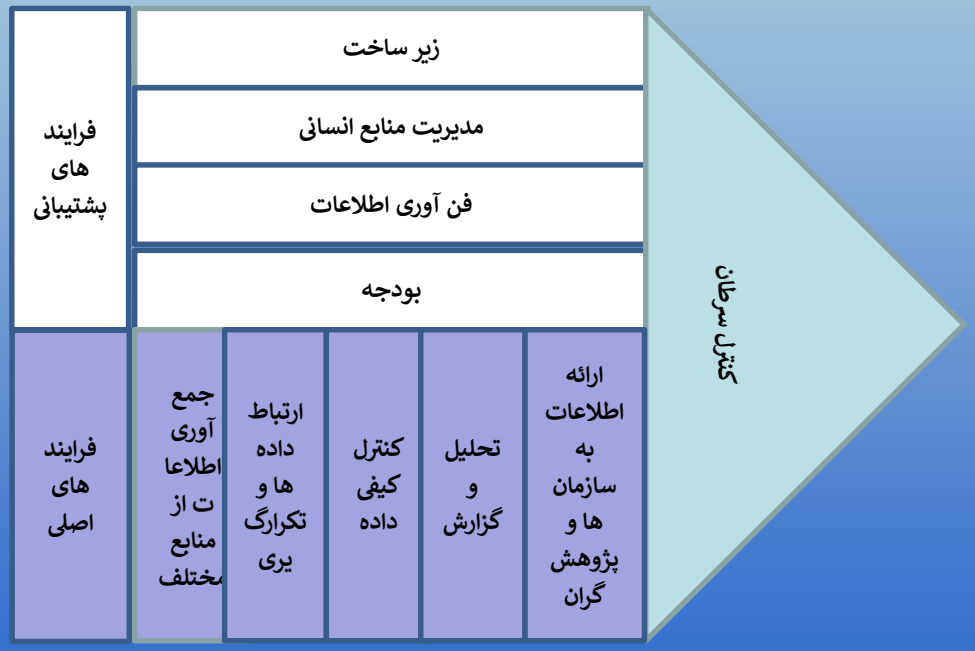
- Factors influencing timeliness
  - Efficient procedures
  - Dedicated and well-trained staff
  - Real time reporting
  - Electronic data capture
- International guidelines for timeliness
  - 6 months-24 months (CDC, SEER, …)

Cancer Registry Definition

- ?

- A Cancer Registration system includes systematic collection, storage, analysis, interpretation and reporting of cancer-related data

فرایند های ثبت سرطان



QUESTIONS????

ARE THERE ANY