

# Case Finding



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National Population Based Cancer  
Registry Program

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# Case Finding



## ☞ Aim:

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

## ☞ Case definition

## ☞ Data sources

## ☞ Case finding process



# Case Finding



- ☞ Every new case of cancer arising In the area covered by the registry
- ☞ During the defined registration period
- ☞ In the defined groups of population
- ☞ On the list of reportable cases



# Reportable cases



- ❧ All malignant diagnosed in the morphology section of ICD-O-3
- ❧ In-situ and benign tumors as decided by registry
  - ❧ In situ carcinoma of cervix
  - ❧ Benign and uncertain malignancies in CNS
  - ❧ Others

# Collectable case information



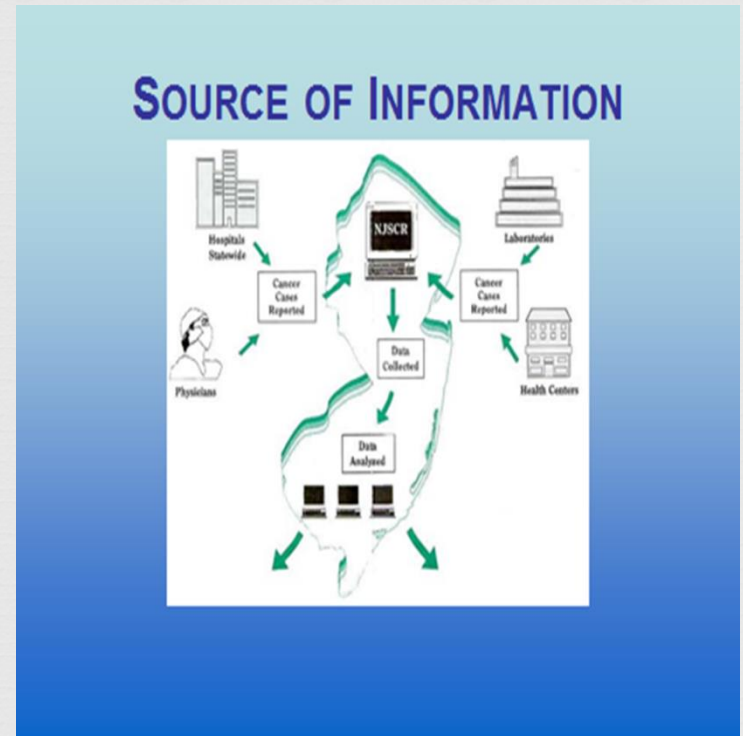
- ❧ Depends to variables
- ❧ Variables to collect
  - ❧ Mandatory
    - ❧ No need to run a cancer registry in their absence
    - ❧ Must be present for all observations
  - ❧ Optional/ Additional data
    - ❧ Improve the value of the output from the registry
  - ❧ Wish list
    - ❧ A list to be reviewed periodically
    - ❧ Only start collecting if all necessary resources are secured for complete collection

# MDS in Our Program



اقلام هویتی	☞
کد ملی (اجباری)	☞
نام، نام خانوادگی، نام پدر (اجباری)	☞
جنسیت (اجباری)	☞
تاریخ تولد (اجباری)	☞
محل تولد در استان/شهرستان (اجباری)	☞
محل سکونت در استان/شهرستان (اجباری)	☞
تلفن تماس بیمار	☞
اقلام ارائه دهنده خدمت (مربوط به متخصص و دستیار آسیب شناسی	☞
نام نام خانوادگی و شماره نظام پزشکی متخصص آسیب شناسی	☞
نام و نام خانوادگی و شماره نظام پزشکی دستیار/همکار متخصص آسیب شناسی	☞
اقلام مربوط به نمونه	☞
تاریخ پذیرش نمونه (اجباری)	☞
اقلام تشخیص آسیب شناسی	☞
گروه بیماری بر اساس طبقه بندی ICD 10	☞
کد مورفولوژی مطابق با سیستم کدینگ ICD-O-3 (Morphology) (اجباری)	☞
کد توپوگرافی مطابق با سیستم کدینگ ICD-O-3 (Topography) (اجباری)	☞
تاریخ گزارش آسیب شناسی (اجباری)	☞

# Case sources



# Main sources of information



## Highly developed medical infrastructure

- Cancer centers
- Hospitals(medical records)
- Death certificates



# Main sources of information



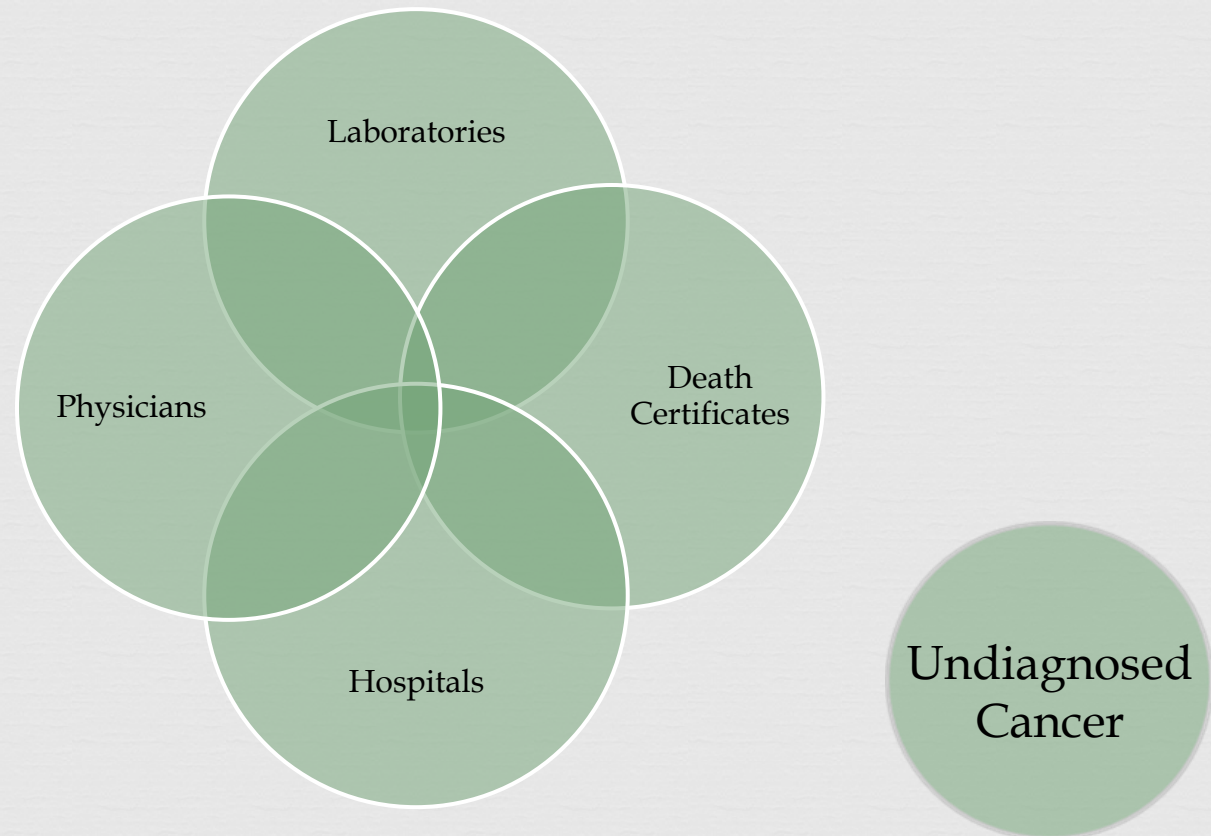
- ❧ Less developed infrastructure
  - ❧ Departments of pathology
  - ❧ Departments of radiotherapy/ oncology
  - ❧ Other hospital departments(Medical records)
  - ❧ Other laboratory services
  - ❧ Outpatients clinics
  - ❧ Private clinics and diagnostic laboratories
  - ❧ Death certificates?

# Other sources of information

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- ❧ Neurological clinics
- ❧ Dermatologists
- ❧ Endocrinologists
- ❧ Pediatrics services
- ❧ Hospices(home for terminally ill)
- ❧ Long stay hospitals/homes for elderly
- ❧ Insurance companies

# Population -based CR



National Population Based Cancer Registry

# Multiple source reporting



# Multiple source reporting



- ❧ Improve completeness of registration
  - ❧ The more sources per case the fewer cases will be missed and quality of information is improved because it is more complicated
  - ❧ Number of notifications/sources per case is a data quality/completeness indicator
- ❧ Requires precise identification of individuals
  - ❧ Record linkage to avoid duplicates
  - ❧ Identifiable information must be available to the registry

# Methods of data collection



- ❧ Active: registry searched for information collection at source by registry staff(visit, abstract, copy)
- ❧ Passive: registry receives information
  - ❧ Notification
  - ❧ Copies of discharges abstracts
  - ❧ Reports
- ❧ Mixed

# Passive methods of data collection



- ❧ Require agreement, usually imposed by a **Law**, between the data providers and the cancer registry
- ❧ Compulsory notification of every cancer case
- ❧ Adherence to a law
- ❧ Need for records validation

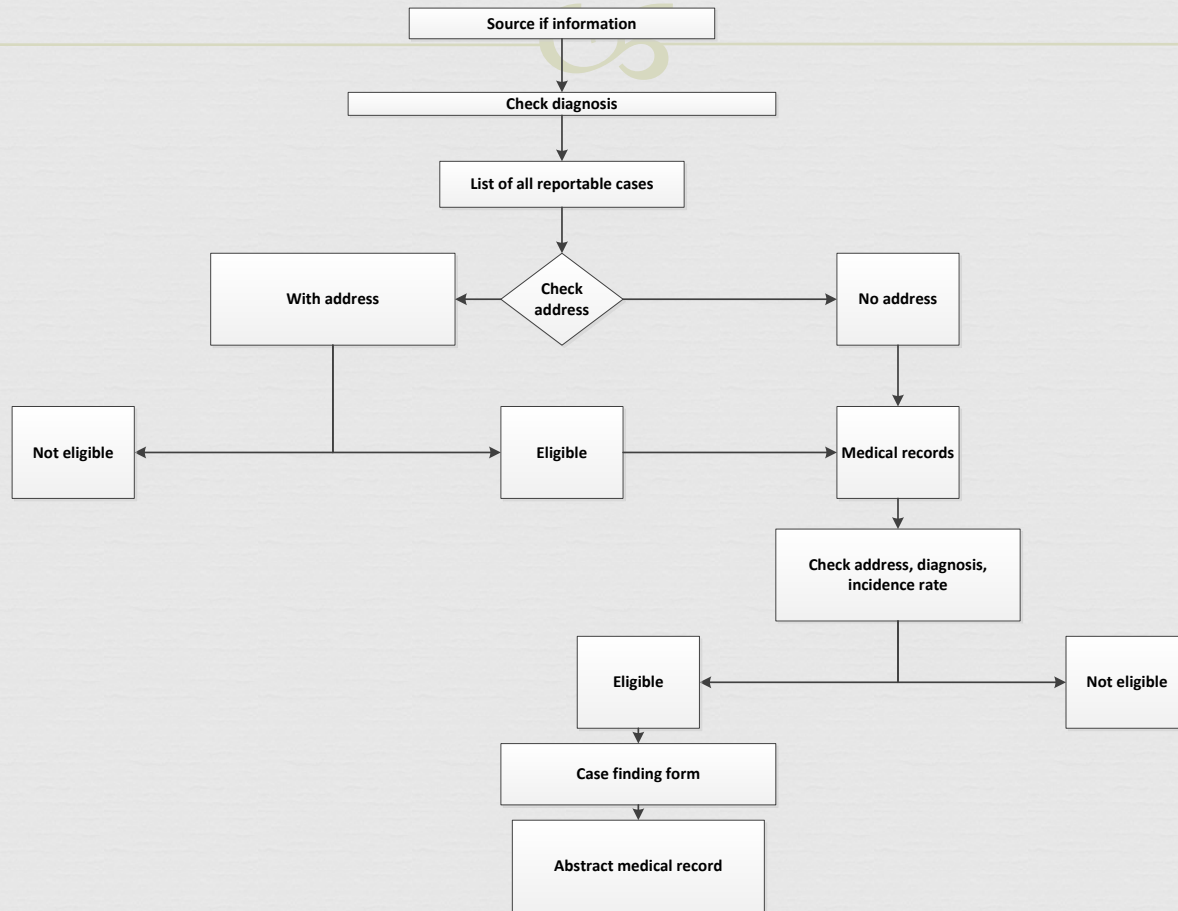
# Active methods of data collection



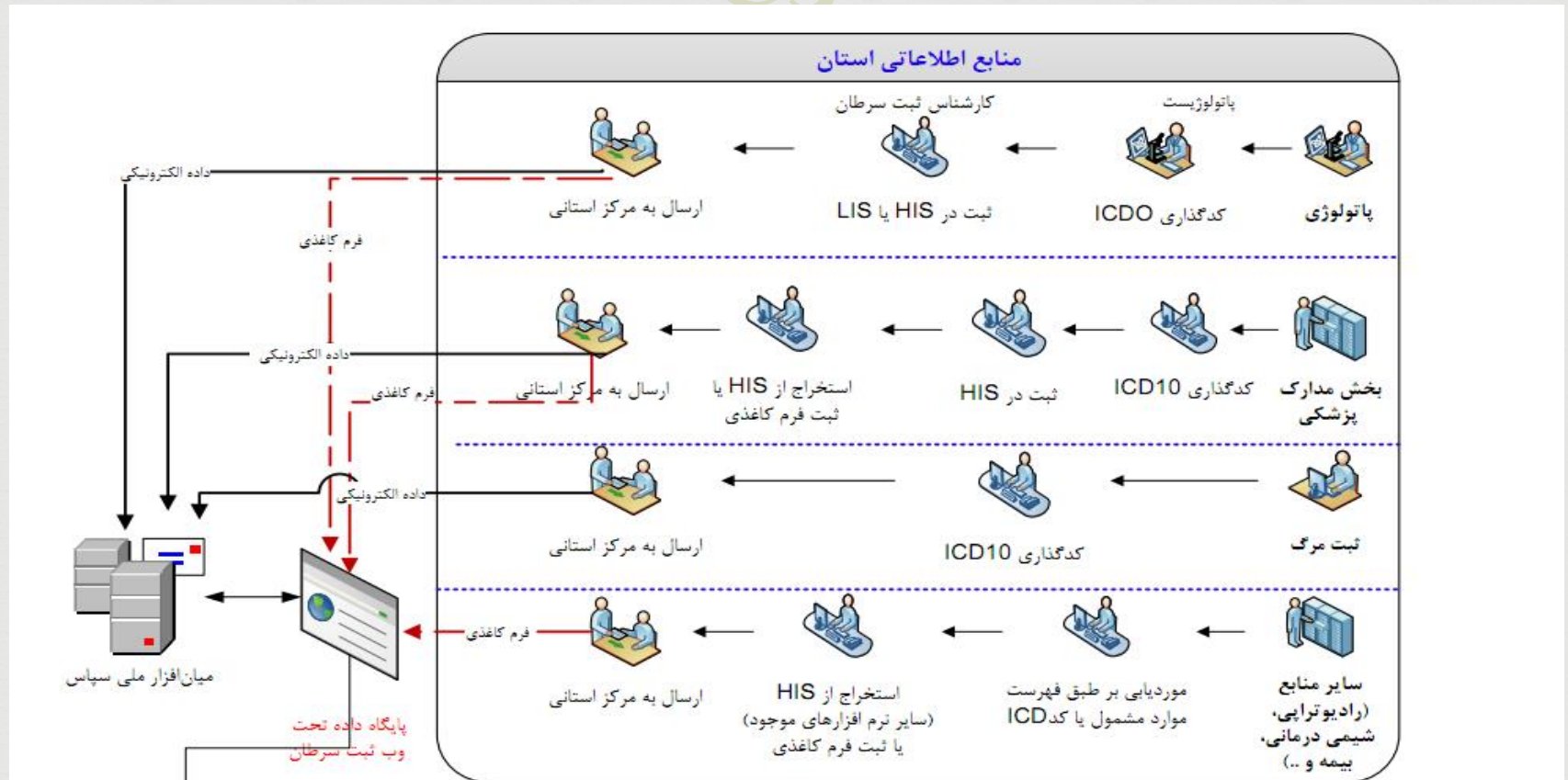
- ❧ A list of all data sources in the registration area
  - ❧ Addresses
  - ❧ Contact persons
  - ❧ Frequency of visits
  - ❧ Other details
- ❧ Case finding form(s)
  - ❧ Adopted to different sources of information
- ❧ Flow chart for case finding
  - ❧ Including all different sources of information or
  - ❧ Charts adapted to different sources of information



# Case finding flow chart



# Case finding in our program



# Case Finding form



- ☞ Hospital:
- ☞ Source of information:
- ☞ Date:
- ☞ Prepared by:

Hospital case no	Family name	Other name	Age	Sex	Address	Date dg	Diagnosis

# Sources of information



## ❧ Considerations

- ❧ Cost
- ❧ Accessibility
- ❧ Quality (validity / completeness)

## ❧ Strategy

- ❧ Sources which yield most cases
- ❧ Frequency of visit required

# Data source in a general hospital



- ❧ Pathology laboratories
- ❧ Hematology laboratory
- ❧ Radiotherapy unit
- ❧ Radiology
- ❧ Ultrasound
- ❧ Nuclear medicine
- ❧ Computerized tomography
- ❧ Magnetic resonance imaging
- ❧ Hospital departments
  - ❧ Gynecology, ENT, Pediatrics, etc.
- ❧ Medical record
- ❧ Hospital registry

# Pathology departments



- ❧ Cases diagnosed
  - ❧ By biopsy
  - ❧ By cytology
- ❧ Quality of information
  - ❧ Diagnostic data are very good
  - ❧ Identifying information is often poor

# Hematology



- ❧ Leukemia and lymphomas( the hematopoietic malignancies)
- ❧ NB: often separate from the pathology laboratory dealing with solid tumors
- ❧ Prepare special list of terms
- ❧ Obtain copies of hematology reports

# Radiotherapy / oncology departments

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☞ Treat practically only cancer cases

☞ Generally have good records



# Laboratories



- ❧ Set up method to identify reports needed by the cancer registry
- ❧ Try to obtain copies of the reports
- ❧ If coding is done in the laboratory, use the codes to identify “reportable” diagnosis
- ❧ If morphology is not coded, have a list of terms to identify cancer diagnosis

# Out-patient clinics



- ❧ Who visits an outpatient clinic with cancer and is not hospitalized?
  - ❧ The elderly
  - ❧ Advanced/ untreatable cancers
  - ❧ Increasing number of cancer patients treated as outpatients (there should be further diagnostic information from, for example laboratories)
- ❧ new patients identified by consulting logbooks and appointment listings
- ❧ **Identifying information** on out-patients might be incomplete

# Out-patient clinics



- ❧ General
- ❧ Specialized clinics
  - ❧ Medical oncology
  - ❧ Gynecology
  - ❧ Hematology
  - ❧ Urology
  - ❧ Ophthalmology
  - ❧ ENT
  - ❧ Breast
  - ❧ Dermatology
  - ❧ Endoscopy

# Private clinics and hospitals



- ❧ Important to obtain cooperation but often difficult(**confidentiality**)
- ❧ Useful when clinicians are also on staff of local hospitals

# Medical records



- ❧ Accessibility:
  - ❧ Electronic
  - ❧ Centralized
    - ❧ Hospital (cancer) registry
    - ❧ Disease index
    - ❧ Logbook of admissions/ discharges
  - ❧ By department
  - ❧ With the patient
- ❧ Hospital case numbering
  - ❧ Serial(new for each diagnosis)
  - ❧ Unit(same for all admissions of one patient)

# Medical records



- ❧ Multiple sources should be used, because likely none of them provides all necessary information
- ❧ Disease index: name, age, sex, hospital information, diagnosis(ICD)
- ❧ Clinical diagnoses(no pathology or other examinations)
- ❧ Patients diagnosed histologically elsewhere and for whom there is no record in the pathology department

# Problems with medical records

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- ❧ Accessibility
  - ❧ Case notes and reports may be collected/ retained by clinicians involved in treatment or research
  - ❧ One clinician may refuse to cooperate
- ❧ Quality(accuracy + completeness)
- ❧ Missing records
- ❧ Careful archiving of records of deceased patients
- ❧ Duplication of records
  - ❧ Long term treatment of protocols/frequent follow-up
- ❧ Representativeness
  - ❧ Slow progression tumors(late final diagnosis, no treatment)
  - ❧ Special condition e.g. diabetes
  - ❧ Specialized clinics e.g. laryngectomy
  - ❧ Transplant patients(retained by units)
  - ❧ Terminal care patients
- ❧ Working condition for the registry staff

# General practitioner



- ☞ Often the first person to see the cancer patient- but usually has little information on the cancer
- ☞ May be a primer source for patients with advanced cancer(therapy useless, painful diagnostic examination not undertaken)
- ☞ May be a good source of information for elderly patients



# Screening programs



- ❧ Cervix
- ❧ Breast
- ❧ Prostate
- ❧ Colon
- ❧ Occupational groups at risk
- ❧ Precautions
  - ❧ Take care to differentiate pre-invasive from invasive diagnoses
  - ❧ Screening of asymptomatic people=false positives: possible detection of cancers which may never be confirmed

# Health insurance



- ❧ National(social security)
- ❧ For specific groups
- ❧ Voluntary
- ❧ Advantage
  - ❧ Identification information very accurate
- ❧ Disadvantages:
  - ❧ Insured vs. ill person
  - ❧ **Medical information** often inaccurate and incomplete
  - ❧ Accessibility and confidentiality

# Death certificates



- ☞ All death certificates with mention of cancer should be collected (not just those with underlying cause of death)
- ☞ Best to see original (or copies of original) of death certificates
- ☞ Even if the diagnosis is not very accurate, **identifying information** and **date of death** are important

# Registry manual checklist

(relevance to case-finding)



- ❧ Definition of the reportable cases
- ❧ List, definition and coding of all variables
- ❧ List and details of all data sources
- ❧ Notification form
- ❧ Case finding form(may be source-specific)
- ❧ Procedures
  - ❧ Data flow
  - ❧ Frequency of contacts
  - ❧ Decision trees

# Obstacle to case finding



- ❧ Security situation
- ❧ Transportation
- ❧ Unstable population
- ❧ Identify of individuals
- ❧ Non-availability of population registry
- ❧ Non-availability of poor quality of death certificates
- ❧ Lack of basic health services
- ❧ Treatment migration
- ❧ Lack of trained personnel

# Evaluation of case finding methods



- ❧ initial and periodic evaluation
  - ❧ True cost of each method of collection
  - ❧ Quality of data provided
  - ❧ Uses which can be made of the data
    - ❧ Short term
    - ❧ Long term(+20 years)
      - ❧ Storing the original copies of medical reports
- ❧ Constraints on future research if
  - ❧ Data items are not collected at all
  - ❧ Data items are collected in an abbreviated form
- ❧ Burden of providing data for the contributing services

# Case finding completeness



☞ Case finding completeness = completeness of registration

# Tips to achieve completeness



- ❧ Involve representatives of the major data sources in the registry governance structure
- ❧ Seek win-win arrangements
  - ❧ Propose a return of the electronic-lists of patients
  - ❧ Justification for a law on compulsory notification
- ❧ Feedback
  - ❧ Data providers
  - ❧ Policy makers
  - ❧ Public
- ❧ Diligent work of the registry personnel



# References



- ❧ Case finding and notifications, Eva Steliarova-Foucher, IARC Summer school 2011



Thank you!