Cancer registration

Basic concept and use of cancer registries data

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The concept of "cancer registration"

- Cancer registration = the continuous and systematic process of data collection regarding the occurrence and characteristics of reportable neoplasms

- **General scope** – to evaluate and control the impact of cancer in a community (population)
  - ✓ What is the cancer burden in the country and how is it likely to evolve?
  - ✓ How successful are the implemented cancer control policies?

- Two **cancer surveillance** mechanisms are available and complementary:
  - ✓ For mortality: vital statistics on deaths (by cause)
  - ✓ For morbidity: disease (cancer) registries

Population-based cancer registration

- Population-based cancer registration is a well established concept. The first cancer registries were established over 90 years ago and today there are more than 700 cancer registries worldwide. In developing countries, their progress is notably slower as they face the very same obstacles as other health services – that is a lack of financial resources and expertise

The history of cancer recording

The first efforts of estimating the number of new and existing cancers in a given population, have been initiated at the beginning of the XXth century, in different European countries

- Germany-1900 – attempt to record all cancer patients under treatment
- 1902-1908 – the same type of attempt in Denmark, Netherlands, Portugal, Spain and Sweden
- The first population-based cancer registry was established in Hamburg (Germany) in 1929
- The first National Cancer Registry – Denmark - 1943

Kræft-Kartoteket viser Vej for Sygdommens Behandling

Stigning i Tilfældene, fordi Folk bliver ældre nu end tidligere?

Dr. med. Joh. Clemmesen, der er Kræftkartotekets daglige Leder.

Hver 6. Time dør en Københavner af Kræft

Oplysninger om alle Kræftpatienter

Sygdommens Udbredelse indenfor Erhvervene

Kræften og Alderen

Brystkræften overordentlig hyppig

Johannes Clemmesen, 1908-2010

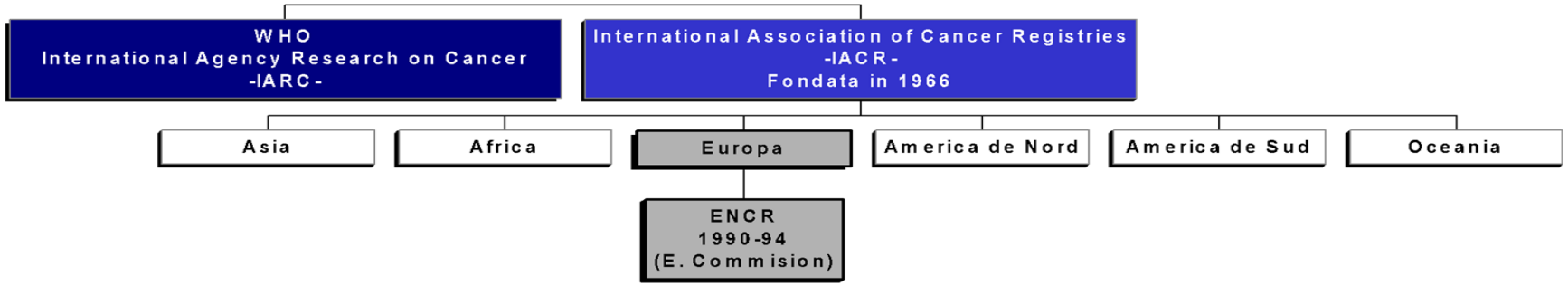
Founder of the Danish Cancer Registry

1942

- Is cancer increasing due to ageing of the population?
- Every 6 hour a citizen of Copenhagen die from cancer. In 1980 this will be 1 every hour unless a cure is found.
- Reports from hospitals is the backbone.
- Accurate death certificates of outmost importance.
- GP's have difficulties in assessing the diagnose.
- Breast cancer is very frequent.
- Stomach cancer predominates in rural areas.
- The cancer pattern is different among workers and academics.
- Ageing due better social and personal hygiene bring people into cancer ages – cancer incidence increases.
- Why do some get more than 1 cancer?
- Is there a link between cancer of the ovary and breast?
- Could it be due to hormonal factors?

Country (Region)	Year of establishment	Type of notification
Germany (Hamburg)	1929	voluntary
USA (State of New York)	1940	mandatory
Denmark	1942	mandatory (since 1987)
Canada (Saskatchewan)	1944	mandatory
New Zealand	1948	mandatory
Slovenia	1950	mandatory
Canada (Alberta)	1951	mandatory
USA (El Paso)	1951	mandatory
Norway	1952	mandatory
Former URSS	1953	mandatory
Former RDG	1953	mandatory
Finland	1953	mandatory (since 1961)
Iceland	1954	voluntary
….Romania	**1981**	**mandatory**

Relevant international forums



1950 – **WHO** – Sub-committee on cancer registration

1950s – **ANCR** – Association of Nordic Cancer Registries - https://www.ancr.nu

1965 – **IARC** - International Agency for Cancer Research - **https://www.iarc.who.int/**

1966 – **IACR** - International Association of Cancer Registries - **http://www.iacr.com.fr/**

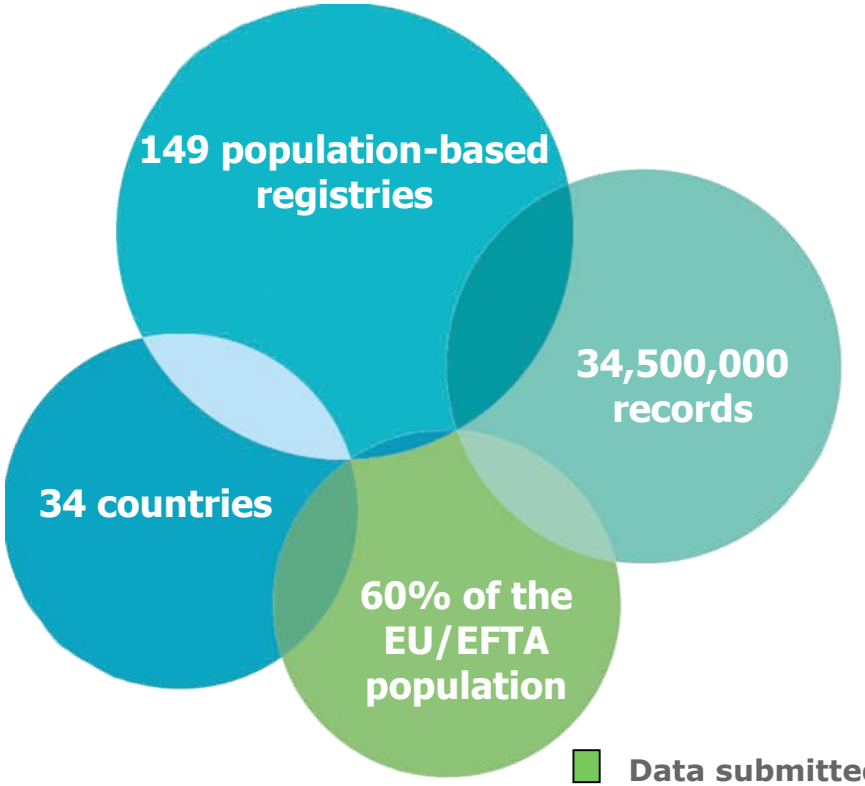
1976 – **GRELL** - Group for Cancer Epidemiology and Registration in Latin Language Countries - https://www.grell-network.org/

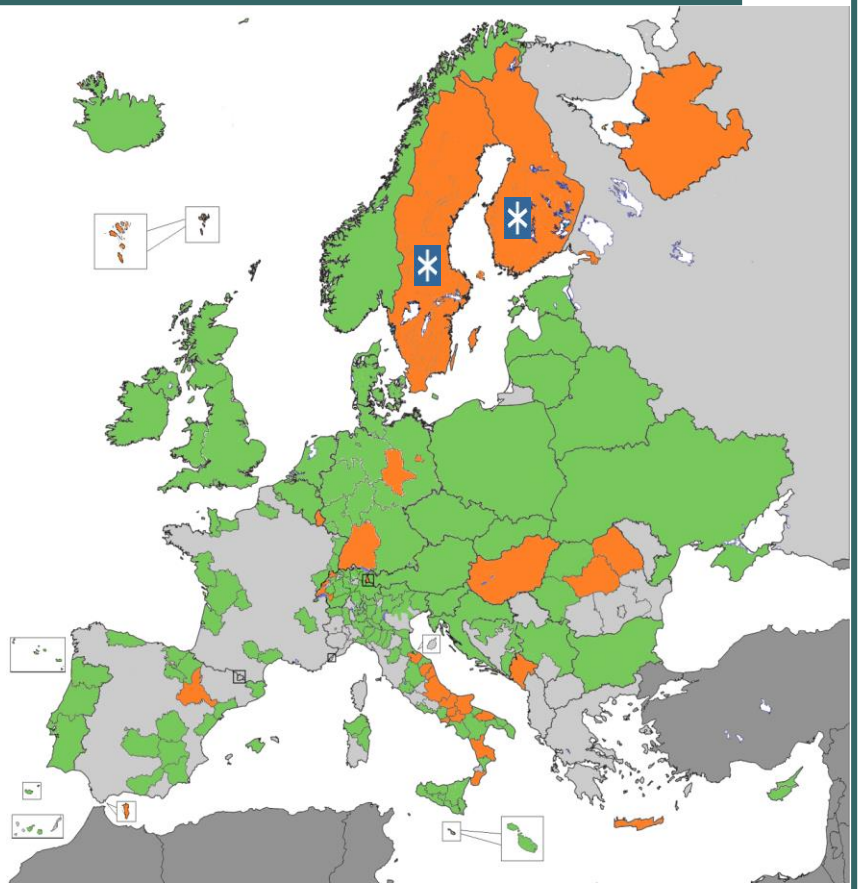
1989 – **ENCR** - European Network of Cancer Registries - **https://www.encr.eu/**

The European Network and its structure

- Active since 1990
- Established within the framework of the "*Europe Against Cancer* " *programme of the* ***European Commission*** on the initiative of IARC, ANCR, IACR and GRELL
- Governed by a **Steering Committee** (currently 11 people) with 3-years term
- **Secretariat** hosted at the EC **Joint Research Centre** (JRC) since 2012 (previously at IARC)
- The JRC also support the ENCR in its activities aimed at harmonisation and improvement of cancer registration in Europe

Active members / Participation in latest call for data (2015)





Types of cancer registries

- Population-based registries
- Hospital-based and pathology-based registries
- Special (site specific, age specific, eg. Childhood cancer registries, etc)

Population-based cancer registry

- In order to plan and evaluate health services, we need to know what is happening at a population level – a population of a whole country or province or even a substantial sector.
- A National Cancer Registry is often thought as an ideal tool but may not always be feasible due to the scale or cost of implementation. Most of the requirements for planning and monitoring can be achieved through registration of a well described from the national population, such as a specific **region**. The subset sample can then be extrapolated to the national level.

Hospital-based and pathology-based registry

- Clinical registries and pathology-based registries serve another purpose, that is, to guide clinical management in the institution where they are located
- Clinical registries collect individual cancer patient reports by physicians in a given hospital. Pathology based registries record cancer cases diagnosed in pathology laboratories.

Special Registries - Childhood cancer registry

Childhood cancers are ascertained by:

- general population based cancer registries,
- population-based cancer registries dedicated to collecting data on paediatric cases exclusively.

Both approaches are **relevant to childhood cancer surveillance**. The general cancer registries should ensure that these rare cancers are given due attention, while the paediatric registries should strive for as accurate and complete data as possible

Population-based Cancer Registry

Main recorded information

https://www.encr.eu/recommendations-and-working-groups

Data collection

- What are the data we are collecting and about whom?
  - List of reportable diagnoses
  - List of reportable events
  - List of collected variables
- Where do we obtain this data from?
  - Data source
- How do we obtain this data?
  - Data collection method

List of reportable tumors

- **In situ** cancers (behavior code "2") or malign / invasive (behavior code "3") according the International Classification of Diseases for Oncology, third edition (ICD-O-3.2);
- All intracranial and intraspinal tumors regardless of their behavior benign / uncertain / malign (0/1/3) with topography codes ICD-O-3.2 C70-C72 and C75.1–C75.3. Are exempt from reporting benign vascular lesions of the meninges (hemangiomas) and cystic lesions;
- **Borderline** conditions (behavior code "1"), regardless of topography.

List of reportable episodes

- Establishing a reportable diagnosis for a new cancer case or the first evidence for monitoring and/or treatment;
- Any revision of the diagnosis of a reportable condition to another reportable diagnosis category;
- Invalidating the diagnosis of an already reported tumor;
- Relapse
- Death with or by cancer

ENCR Standard the Minimum Dataset

- **Essential data**– minimum dataset, collected by all cancer registries, regardless of their scope, method of data collection and available sources

Scope of standardization

- Data in European Cancer Registries to be compared among themselves and with other registries in the world.
- Establishing joint measures for data quality control → ensuring data quality in registries

How must the data of a cancer registry be?

- Adequate
- Relevant
- Not excessive
- Correct
- Exact
- Complete
- Actual

Essential Variables

Recommended by ENCR

- **Personal data**
  - ID number
  - Names
  - Gender
  - Date of Birth (at least age at incidence date)
  - Address
  - Ethnic group
  - Vital state & date
  - Date of death
  - Last follow-up date
- **Tumor data**
  - Incidence date
  - Topography (primary tumor site)
  - Laterality (pair organs)
  - Morphology (primary tumor histology)
  - Behavior
  - Basis of diagnosis
  - Stage (TNM, Toronto stage)
  - Initial therapy (started within 4 months after diagnosis)
  - Data source

Optional variables

ENCR recommended

Personal data

- Occupation
- Workplace
- Marital status
- Smoking status at diagnosis
- Cause of death
- Place of death

Follow-up data

- Quality of life
- Rehabilitation
- Palliation

Tumour data

- Diagnosis method – detection method in relation to screening
- Therapy data – type of intervention
- Differentiation degree – according to the ICD-O-3 manual
- Recurrence- dd/mm/yyyy
- Metastasis – site of metastasis and the date of diagnosis (dd/mm/yyyy) or at least – local, regional or long distance (dd/mm/yyyy)
- TNM complete, FIGO, etc. – if the registry has access to information on TNM or other stage classification, these must be recorded

Optional variables

- Increase costs and the complexity of processes
- Key questions:
  - "Why do we want to know this?"
  - "Can we afford the data collection?"
  - "Will the information be of good quality?"

Cancer registration: Variables

Minimal information:

- patient identification
  - Names
  - PIN/Unique registration number
  - Place of residence (at least region/county→population of origin)
  - Sex
  - Date of birth or age at incidence date

Cancer registration: Variables

Minimal information:

- tumour characteristics
  - incidence date
  - basis of diagnosis
  - topography, i.e. primary site
  - morphology, I.e. histology
  - behaviour
  - multiple primaries
  - source of information

Incidence date

Order of declining priority:

1. Date of first histological or cytological confirmation of this malignancy (with the exception of histology or cytology at autopsy) in the following order:

a) date when the specimen was taken (biopsy)

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. When evaluated at an outpatient clinic only: date of first consultation at the outpatient clinic because of this malignancy.

4. Date of diagnosis, other than 1, 2 or 3.

5. Date of death, if no information is available other than the fact that the patient has died because of a malignancy.

6. Date of death, if the malignancy is discovered at autopsy.

Incidence date

By definition ‘incidence date’ must be given – the most important data

- Whichever date is selected, the date of incidence should not be later than the date of the start of the treatment, or decision not to treat, or date of death.
- The choice of the date of incidence does not determine the coding of the item "basis of diagnosis".
- Do not use date of registration

Cancer registration: Variables

Minimal information:

- tumour characteristics
  - incidence date
  - basis of diagnosis
  - topography, i.e. primary site
  - morphology, I.e. histology
  - behaviour
  - multiple primaries
  - source of information

Basis of diagnosis

- Non-microscopic (codes 1, 2, 4)
- Microscopic (codes 5, 6, 7)
- Unknown (code 9)

Basis of diagnosis

Non-microscopic

1 Clinical Diagnosis made before death, but without the benefit of any of the following (2-7)

2 Clinical investigation To include all diagnostic techniques, including x-ray, endoscopy, imaging, ultrasound, exploratory surgery (e.g. laparotomy) and autopsy, without a tissue diagnosis.

4 Specific tumour markers To include biochemical and/or immunological markers which are specific for a tumour site

Basis of diagnosis

Non-microscopic

4 Specific tumour markers To include biochemical and/or immunological markers which are specific for a tumour site:

- Human Chorionic Gonadotrophin (HCG) in diagnosis of Choriocarcinoma
- Prostate Specific Antigen (PSA) in diagnosis of Prostate carcinoma
- Alphafetoprotein (AFP) in diagnosis of Hepatocellular carcinoma
- Catecholamine degradation products (HVA, VMA) in diagnosis of Neuroblastoma
- Elevated serum immunoglobulins in diagnosis of Myeloma, Waldenström's macroglobulinaemia
- Urinary immunoglobulins in diagnosis of Myeloma (light chain excretion > 1g/24hr)

Basis of diagnosis

Microscopic

5 **Cytology** Examination of cells whether from a primary or secondary site, including fluids aspirated using endoscopes or needles. Also to include the microscopic examination of peripheral blood film and trephine bone marrow aspirates.

6 **Histology of a metastasis** Histological examination of tissue from a metastasis, including autopsy specimens.

7 **Histology of a primary tumour** Histological examination of tissue from the primary tumour, however obtained, including all cutting techniques and bone marrow biopsies. Also to include autopsy specimens of a primary tumour.

Basis of diagnosis

- Combinations of specific morphology codes, and non-microscopic basis of diagnosis codes, which are considered acceptable (incomplete list)

MORPHOLOGY		Most Valid	
Code	Description	Basis	Other criteria
9590	Lymphoma NOS	1 or 2	
9800	Leukaemia NOS	1 or 2	
8720	Melanoma	1 or 2	
9140	Kaposi's sarcoma	1 or 2	HIV positive (exc. Africa)
8960	Nephroblastoma	2	Age 0-8
9100	Choriocarcinoma	4	Female, and age 15-49
9500	Neuroblastoma	2 or 4	Age 0-9
9510	Retinoblastoma	2	Age 0-5
9732	Myeloma	4	Age 40+
8170	Hepatocellular carcinoma	4	
9380	Glioma	2	C71.7 (brain stem)
9530-9539	Meningioma	2	C70 (meninges)

Cancer registration: Variables

Minimal information:

- tumour characteristics
  - incidence date
  - basis of diagnosis
  - topography, i.e. primary site –ICD-O-3.2 (starting 2020 data)
  - morphology, I.e. histology – ICD-O-3.2 (starting 2020 data)
  - behavior
  - multiple primaries
  - source of information

Cancer registration: Variables

Minimal information:

- tumour characteristics
  - incidence date
  - basis of diagnosis
  - topography, i.e. primary site
  - morphology, I.e. histology
  - behavior
  - multiple primaries
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Behaviour

0	Benign
1	Uncertain whether benign or malign, Borderline malignancy
2	Carcinoma *in situ*
3	Malignant

6* Malignant, metastatic site

9* Malignant, unknown primary or metastatic

* Not in use for cancer registries

Cancer registration: Variables

Minimal information:

- tumour characteristics
  - incidence date
  - basis of diagnosis
  - topography, i.e. primary site
  - morphology, I.e. histology
  - behaviour
  - multiple primaries
  - source of information

Multiple primaries

IARC/IACR rules for coding multiple primaries

- For the purpose of **incidence** comparison, the IARC/IACR rules should be used.
- Internally, registries can apply practices which permit more multiple primary tumours to be recorded, but those not conforming to the IARC/IACR definition should be flagged (multiple tumours).
- Each tumour should be recorded separately, but should be linked to enable patient-based records to be constructed.
- Any publication of incidence data by registries should include the definition of multiple tumours in use.

Cancer registration: Variables

Minimal information:

- tumour characteristics
  - incidence date
  - basis of diagnosis
  - topography, i.e. primary site
  - morphology, I.e. histology
  - behaviour
  - multiple primaries
  - source of information

Source of information

- Hospitals (state and private), elderly care units, family doctors
  - **Hospital-based Cancer Registries**
- Diagnosis services: pathology laboratories, hematology laboratories, biochemistry and immunology laboratories, radiodiagnostic and radiotherapy services
- Death registry – death certificates
- Screening programs

Medical forms with relevant information for abstracting

- Observation chart
- Consultation chart
- Discharge note
- Medical letter
- Chemotherapy form
- Radiology result
- Progress chart
- Cytologic form
- Pathology result
- Endoscopy result
- Laboratory result
- Death certificate
- Autopsy result

Methods for data collection

- Active
- Passive

  Many registries use a mixt method

- Automated

Active method- definition

- It involves the RC personnel, which monitor data sources and abstract information on special forms, or obtain copies of necessary documents

Active method - Requirements

- The RC personnel should be familiarized with the administrative practices and procedures from patient admit up to patient release, as well as with the existing data collection system

- Field operators familiarized with the phases of diagnosis for malign tumor, the contents of medical forms and medical terminology

Passive method (self-report)

- Based on the personnel of the data sources to fill in the notification forms and sending them into the RC
- Can be legally regulated
- Modalities:
  - Special notification forms which include the standard dataset
  - Copies of the medical documentation
    - Ex: Radiotherapy chart, discharge note, medical letter …

Automated registration

- It is the process by which information is received, validated, compared, related and used to update the existing database at the CR level. Automatic registration does NOT mean that there are no "manual" steps. However, for a process to be considered "automated", each stage of the registration process must be able to operate without any "manual" intervention. This capability is solved by a predefined set of algorithms or rules. Automatic cancer registration requires the availability of multiple electronic data sources.

Choosing the method of data collection

- Legal regulations
- Costs
- Data quality
- How CR data will be used:
  - Short-term (registration completed)
  - Long-term
- Constraints for future research:
  - Variables are not collected
  - Variables are incomplete
- Data sources issues in providing cancer information

Quality assurance premises

- Correct enumeration of all incident cancers cases in a given population
- Correct and reproducible coding and classification systems
- Follow-up up to migration from the aria covered, or death

Challenges of cancer registration in Europe

- **Coverage**
- **Variety** of organisation, funding, health systems and infrastructures
- **Data availability**, **harmonisation** of data processing and reporting
- **Timeliness** in data provision (typically 3-4 years lag)
- **Multilingualism**
- Long-term **sustainability**
- Lack of a formal data-collection **mandate** at EU level
- **Confidentiality** and sensitive data
- … **reluctance** to share the data!

…invisible

Efforts of collecting, recording and analyzing data on incidence and survival

adequate, correct and comparative

…visible

Hundreds of projects and studies:

- ✓ EUROCARE, EUROCHIP, EUROCOURSE
- ✓ ACCIS, BENCHISTA – paediatric cancers
- ✓ CIV, ECIS, GLOBOCAN
- ✓ Monitoring and evaluating screening programs
- ✓ Publications on incidence and survival data

Where there are no data (or no independent registry), patients should fear their lives!!!

Prof. Dr. Jan Willem Coebergh – FP7 Project Director – EUROCOURSE (2009-2012)


Thank You!
I wish I could welcome
you all, in Cluj-Napoca!