Cancer Registration

Noncommunicable Diseases and Health Promotion

Outlines

- Definition of registry: registration
- Types of cancer registries
- Essential variables required
- Quality indices: Quality control
- Software: CanReg5
- Use of Cancer Registry and cancer control

Cancer Registration & Registry

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 (prevent) 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.

Types of Cancer Registry

1. Population-based cancer registry (PBCR)

2. Hospital-based cancer registry (HBCR)

3. Pathology registry

Population-based Cancer Registry

- All new 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)
- The main interest is for epidemiology and public health

Hospital-based Cancer Registry

- Records all cases of cancer treated in a given hospital
- The population from which the cases come is not defined
- The main interest is clinical care hospital administration

Pathology Tumor Registry

- Collects information from one or more laboratories on histological 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

Planning a population-based cancer registry

- Advisory committee
- Population denominators
- Legal aspect and confidentiality
- Size of population and number of cases
- Physical location of the registry
- Finance
- Personnel/Staffing
  - Numbers; Qualifications; Training
- Equipment and office space

Problems of cancer registration in developing countries

- Lack of basic health services
  - Facilities for diagnosis and treatment of cancer cases may be particularly scanty
- Lack of stability of the population
- Identity of individuals
- Lack of trained personnel
- Lack of follow-up
- Non-availability of census data
- Lack of data-processing facilities
- Confidentiality

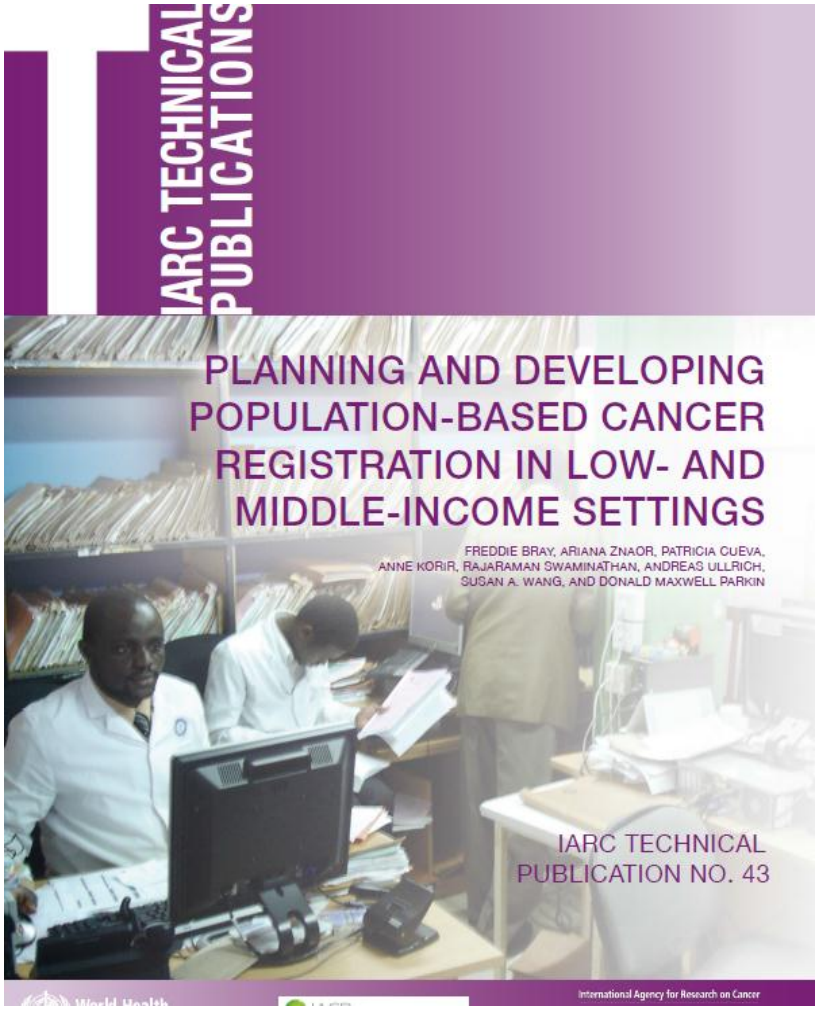


Table of contents

Contributors v
Acknowledgements vi
Foreword vii
Preface viii
Executive summary ix
Abbreviations x

Chapter 1 1
Introduction

Chapter 2 3
The role and status of population-based cancer registration

Chapter 3 9
Planning and developing a population-based cancer registry

Chapter 4 15
Sources of information for the population-based cancer registry

Chapter 5 21
Quality control at the population-based cancer registry

Chapter 6 27
Making the population-based cancer registry heard – reporting the results

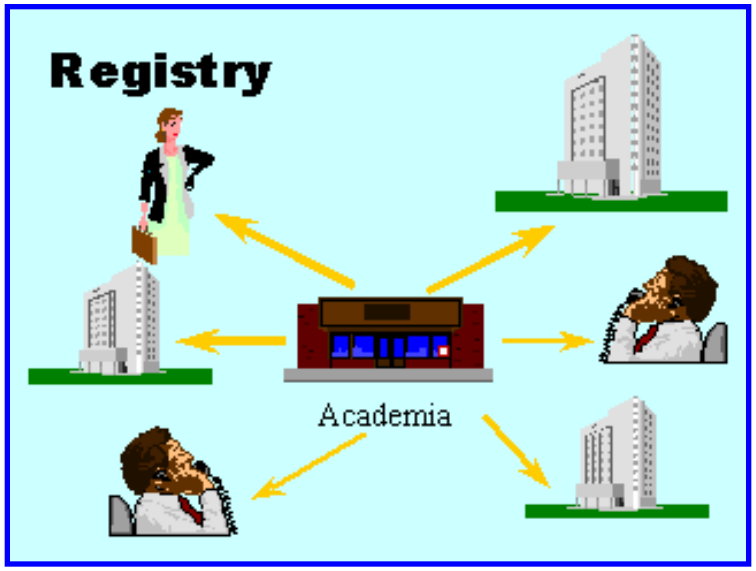
References 31

Annex 1 32
CanReg5

Annex 2 33
Selected data quality indicators by country or region

Data Sources

- 1. Med Records Dept
- 2. Outpatient clinic
- 3. Pathology lab
- 4. Hematology lab
- 5. Radiol Oncology
- 6. Diagnostic Rad
- 7. Health Insurance
- 8. Screening
- 9. Death certificates
- 10. Autopsy
- 11. Others



Basic information required and variable definitions

Item no.	Item	Item no.	Item
The person		**The tumour**	
Personal identification		16	Incidence date
3	Name	17	Most valid basis of diagnosis
4	Sex		
5	Date of birth or age	20	Topography (site)
Demographic		21	Morphology (histology)
6	Address	22	Behavior
11	Ethnic group	35	Source of information

HOSPITAL CANCER REGISTRY
Additional variables

- Contact details
- Admission + Discharge dates
- Hospital referred from , to
- Physicians (treating, following)
- Diagnostic procedures
- Extent of disease
- Treatment details (first, subsequent)
- Outcome (recurrence)
- Follow - up

Quality Control in Cancer Registry

- **The registry data – reliable and of good quality**
- **Should be complete, consistent and accurate**
- **Quality of data can be assessed**

  *** a formal ongoing programme & ad hoc survey**

Quality of information

1. **Completeness of cover**

   every cancer cases, no duplicates

2. **Completeness of detail**

   essential items: diagnosis, sex,

   non-essential items: "not recoded" "not applicable", and " not known"

3. **Accuracy of detail**

   errors of detail: abstraction, transcription, coding…

4. **Accuracy of reporting**

5. **Accuracy of interpretation**

   to properly interpret the information, it is essential to have an understanding of the data sources and how the data are collected and processed

Completeness

- **The extent to which all of the incident cancers occurring in the population are included in the registry database**

- **Coverage**

Assessment of Completeness

- **The population-based registry aims to record all cancer cases occurring within its defined geographical area**
- **Constantly monitored, rather than occasionally measured**

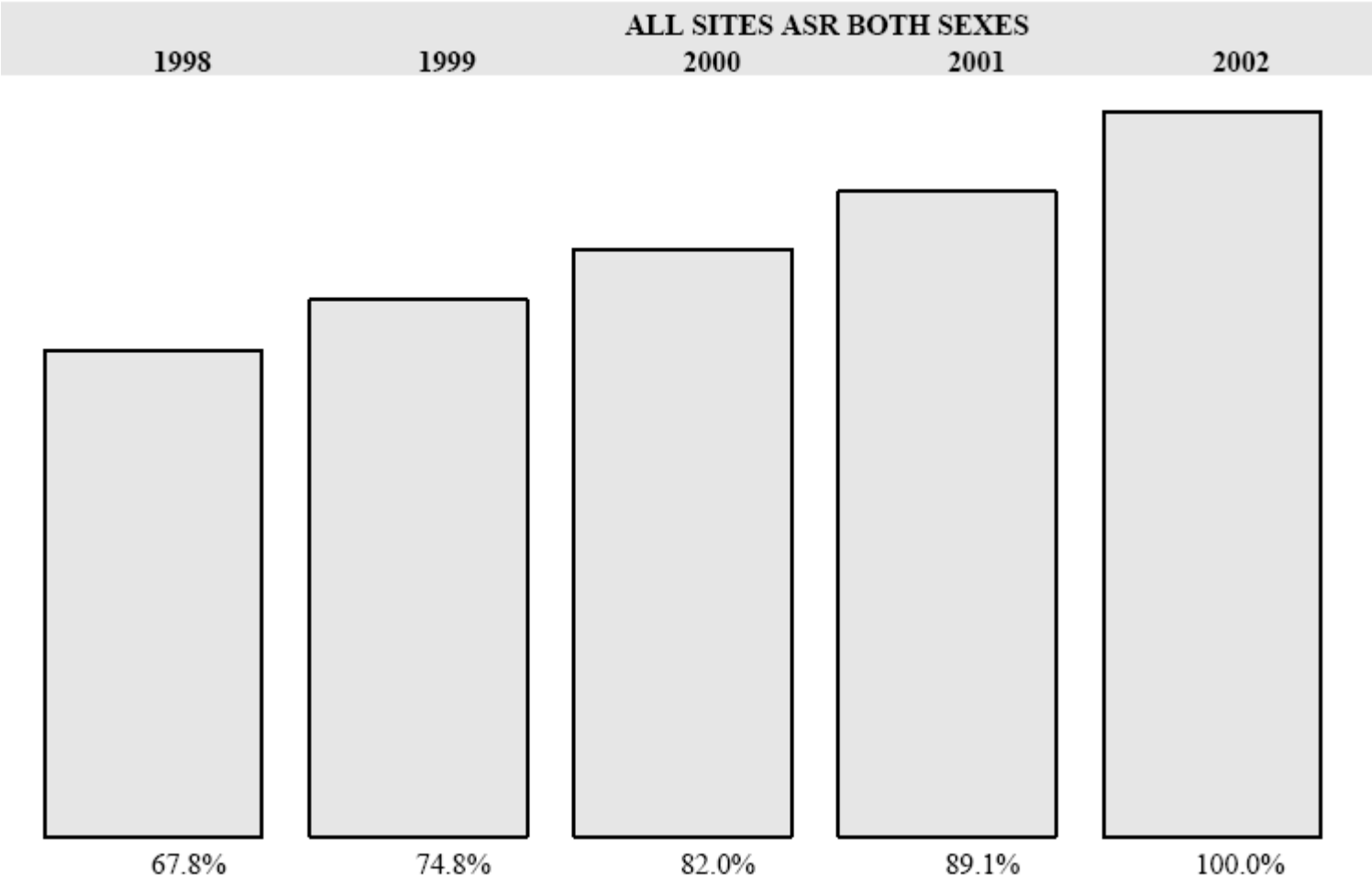
(a) by monitoring the proportions of death certificates (DCN versus DCO)

(b) Monitor incidence of each site annually

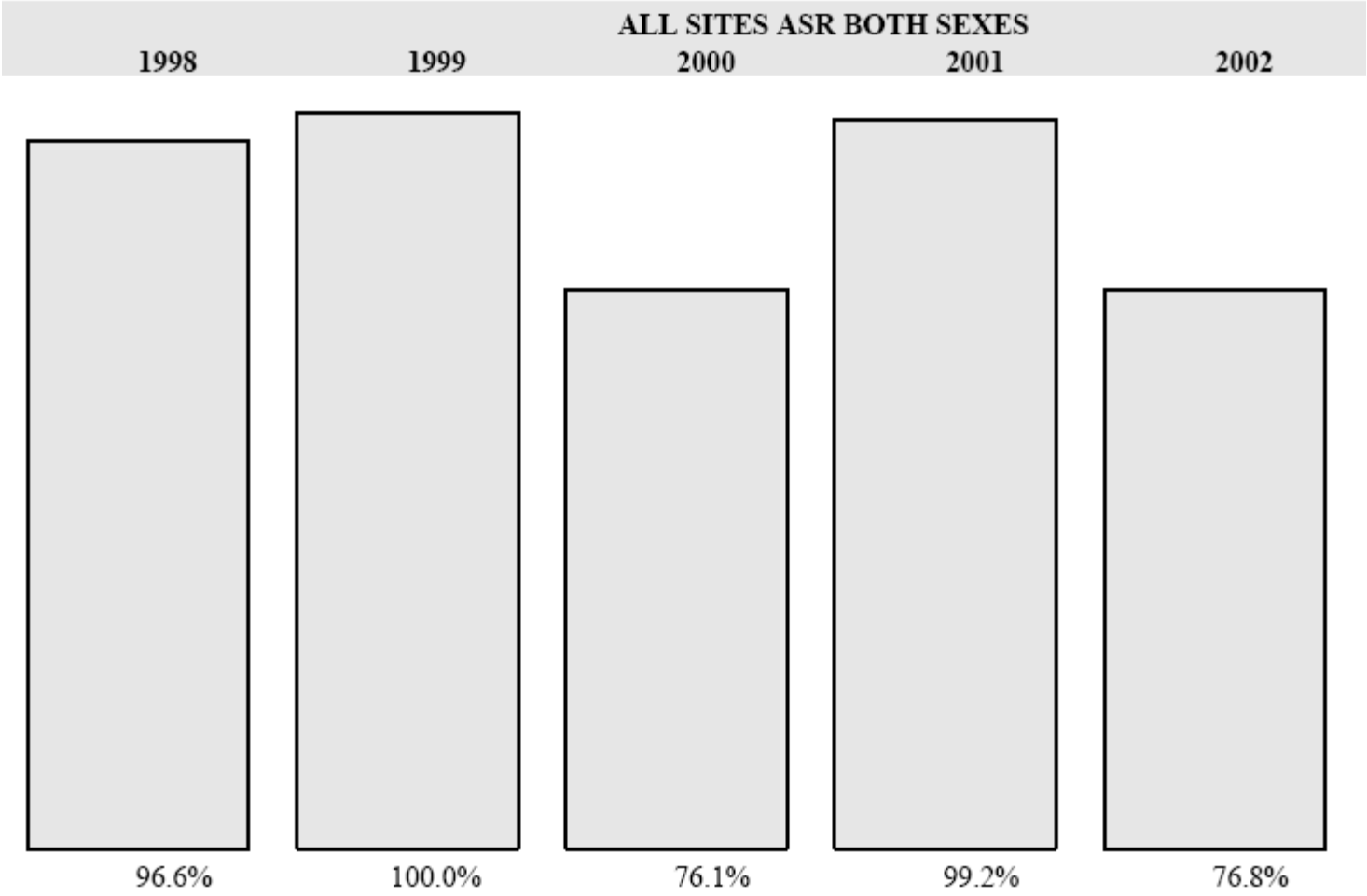
(c) Monitor the difference in incidence rats for the subdivision in incidence rates

(d) Sample patient attendance at a specialized clinic

Example: Incidence rates by year



Example: Incidence rates by year



Comparability

- The system used for classification and coding of neoplasms;
- The definition of incidence, i.e. what is defined as a case, and what is the definition of the incidence date;
- The distinction between a primary cancer (new case) and an extension, recurrence or metastasis of an existing one (multiple primary);
- The recoding of most valid diagnostic method of cancer

International standards for classification and coding of neoplasm

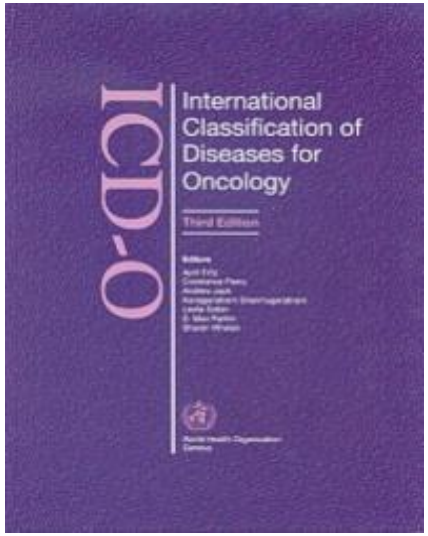
ICD-O-3 (2000, WHO)

Topography: location of the tumour in the body (T code: C16)

Morphology: microscopic appearance and cellular origin of the tumor of diagnosis of cancers(M code: 8000)

Behavior: whether the tumour is malignant, benign, in situ or uncertain (/3)

Grade: the extent of defferentiation of tumour



Date of diagnosis: Incidence date

Standards and Guidelines For Cancer Registration in Europe, IARC, 2003

Standards recommended for the definitions of incidence

1. Date of first histological or cytological confirmation
2. Date of admission to the hospital
3. Date of first evaluation (outpatient clinic)
4. Date of diagnosis other than 1,2,3
5. Date of death, if no information is available
6. Date of death – at autopsy

Multiple primaries

International rules for multiple primary cancers ICD-O-3rd ed 2004. IARC Internal Report No. 2004 /02

Cancer registries use different rules for defining multiple primaries when registering cancer cases. The rules here are for **reporting** data on cancer incidence and survival, so that cancer risk **outcome are comparable between different populations.**

IARC/IACR Multiple Primary Rules

(2000)

Groups of topography for a single site

Tcode	Description
C01	Base of tongue
C02	Other and unspecified parts of tongue
C05	Palate
C06	Other and unspecified parts of mouth
C07	Parotid gland
C08	Other and unspecified major salivary glands
C09	Tonsil
C10	Oropharynx
C12	Hypopharynx
C13	Hypopharynx
C19	Rectosigmoid junction
C20	Rectum
C23	Gallbladder
C24	Other & unspecified parts of biliary tract
C30	Nasal cavity & middle ear
C31	Accessory sinus
C33	Trachea
C34	Bronchus & lung
C37	Thymus
C38.0-3	Heart and mediastinum
C38.8	Overlapping lesion of heart, mediastinum and pleura
C40	Bones, joints & articular cartilage of limbs
C41	Bones, joints & articular cartilage of other sites
C51	Vulva
C52	Vagina
C57.7	Other specified female genital
C57.8-9	Overlapping lesion and female genital tract, NOS
C60	Penis
C63	Other & unspecified male genital organs
C64	Kidney
C65	Renal pelvis
C66	Ureter
C68	Other & unspecified urinary organs
C74	Adrenal gland
C75	Other endocrine glands & related structures

(2004)

Groups of topography for a single site

Tcode	Description	*
C01	Base of tongue	
C02	Other and unspecified parts of tongue	**C02.9**
C00	**Lip**	
C03	**Gum**	
C04	**Floor of mouth**	
C05	Palate	
C06	Other and unspecified parts of mouth	**C06.9**
C09	Tonsil	
C10	Oropharynx	
C12	**Pyriform sinus**	
C13	**Hypopharynx**	
C14	**Other and ill-defined sites in lip, oral cavity and pharynx**	**C14.0**
C19	Rectosigmoid junction	
C20	Rectum	**C20.9**
C23	Gallbladder	
C24	Other & unspecified parts of biliary tract	**C24.9**
C33	Trachea	
C34	Bronchus & lung	**C34.9**
C40	Bones, joints&articular cartilage of limbs	
C41	Bones, joints & articular cartilage of other sites	**C41.9**
C65	Renal pelvis	
C66	Ureter	
C67	**Bladder**	
C68	Other & unspecified urinary organs	**C68.9**

*** If diagnosed at different times, code first diagnosis. If diagnosed at the same time use codes given below.**

Most valid basis of diagnosis of cancer

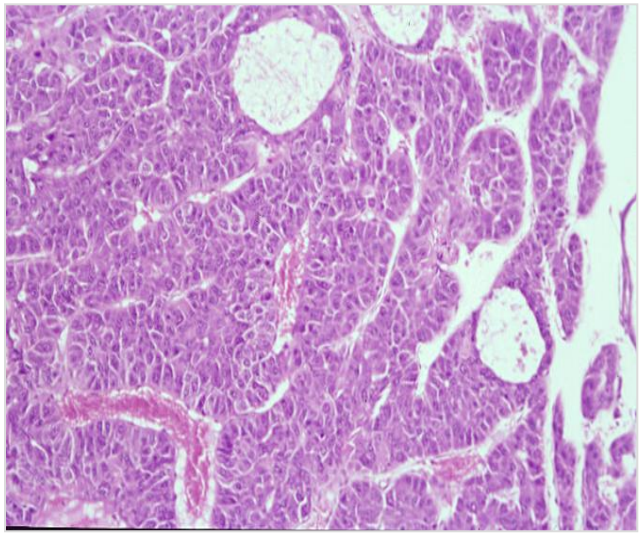
- ***Non-microscopic***

1. **Clinical only**
2. **Clinical investigation (including X-ray, ultrasound, etc)**
3. **Exploratory surgery/autopsy**
4. **Specific tumor markers (biochemical and/ or immunological tests)**

Most valid basis of diagnosis of cancer

- ***Microscopic***

5. **Cytology or haematology**
6. **Histology of metastasis**
7. **Histology of primary**
8. **Autopsy with concurrent or previous histology**



Hepatocellular carcinoma

9. ***Unknown***

0. ***Death Certificate Only (DCO)***

Validity (Accuracy)

- **The proportion of cases in the registry with a given characteristics which truly have that attribute**

- **Accuracy of source documents**
- **Skill in abstracting, coding, recoding**

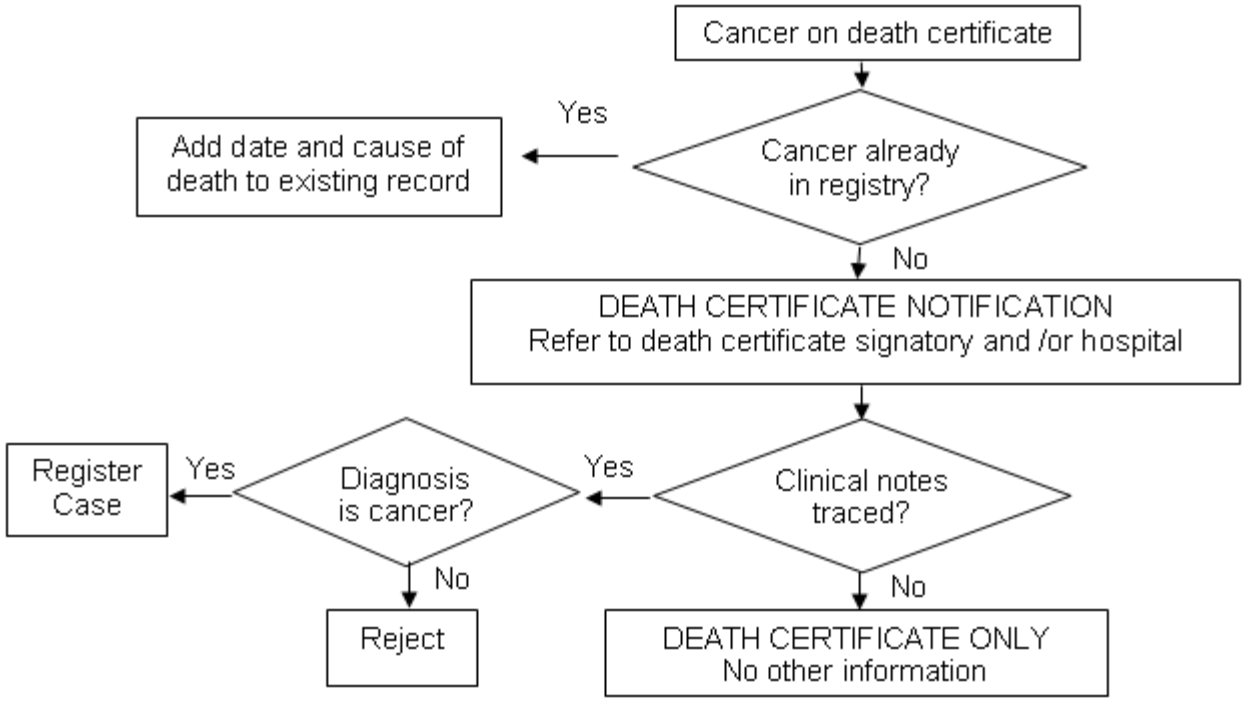
Validity (accuracy)

1. Re-abstracting and recoding
2. Histological verification

   the index of validity: the percentage of cases morphologically verified

3. Death Certificate Only (DCO)
4. Missing information
5. Internal consistency:

   IARC, IACR CHECK program



Death Certificate Only (DCO) means those cancers for which no other information than a death certificate mentioning cancer could be obtained. This must not be confused with the cases first notified by a death certificate (death certificate notification - DCN).

Office for "Death Certificates" in terms of storage (record keeping)?

Timeliness

- Rapid reporting of information on cancer cases is another priority
- There are no international guidelines for timeliness at present, but

-North American agencies have set out specific standards for the relevant registries

- SEER: with 22 month of the end of the diagnosis year

Software for registration: CanReg5

- **Cancer registration data that are collected and coded in a standard way make possible the production of comparable cancer incidence among various countries.**

- **CanReg5 contains modules for:**
  - **Data entry**
  - **Duality control**
  - **Basic analysis of the data**

- **Open source, multi-user & multi-platform**

Responsible Officer: Mr Ervic Morten, CIN, IARC

Purposes and Uses of Cancer Registration

1 Epidemiological Research

Descriptive Epidemiology

Analytic Epidemiology

2 Health Care Planning and Monitoring

Patient Care

Survival

Screening

Prevention

Use of Cancer Registry data

- Analyses of cancer registry data
- Record linkage studies
- Sources of cases for case-control studies
- Source of reference rates

Analysis of cancer registry data

- Geographical variations
- Time trends
- Analyses by sex and ethnic group
- Analysis of other risk factors
    - occupation
    - place of birth
    - civil status
    - religion

Reporting of Findings

- **Evaluation of findings**
  - **Consistency of the number of cases in each calendar year**
  - **Site distribution**
  - **Indices of validity of diagnosis (MV%, DCO%)**
  - **Demographic data: % of unknown age, sex, residence**
  - **Differences compared with similar areas**

Reporting of Findings

Tabular Presentation
Graphical Presentation

http://www-dep.iarc.fr/

International Agency for Research on Cancer

World Health Organization

CANCER*Mondial*

- ABOUT CANCER*Mondial*
- DATABASES
  - *GLOBOCAN*
  - *CI5*
  - *WHO*
  - *ACCIS*
  - *IICC*
  - *ECO*
  - *NORDCAN*
  - *SurvCan*
- RESOURCES
- GLOSSARY
- USEFUL LINKS

ABOUT CANCER*Mondial*

Welcome to **CANCER*Mondial***. This website provides access to various databases containing information on the occurrence of cancer worldwide held and managed by the Section of Cancer Information (CIN) of IARC.

CIN databases:

- *GLOBOCAN* provides access to the most recent *estimates* (for 2012) of the cancer **incidence**, **mortality** and **prevalence** for 28 cancers **worldwide**.
- *CI5* (Cancer Incidence in Five Continents) provides access to detailed information on the **incidence** of cancer *recorded* by **cancer registries** (regional or national) worldwide.
- *WHO* presents long time series of selected cancer **mortality** *recorded* in selected **countries** of the world, together with advanced prediction and trends analysis facilities.

Collaborative projects:

- *ACCIS* (Automated Childhood Cancer Information System) provides access to data on cancer incidence and survival of children *collected* by European **cancer registries**.

http://globocan.iarc.fr/Default.aspx

International Agency for Research on Cancer

World Health Organization

GLOBOCAN 2012: Estimated Cancer Incidence, Mortality and Prevalence Worldwide in 2012

RSS

ABOUT | DATA SOURCES AND METHODS | FACT SHEETS | ONLINE ANALYSIS | HELP

QUICK LINKS

- Population Fact Sheets
- Cancer Fact Sheets
- Simple Maps
- The Global Cancer Atlas
- Predictions
- FAQ

GLOBOCAN 2012

ESTIMATED CANCER INCIDENCE, MORTALITY AND PREVALENCE WORLDWIDE IN 2012

You are here: **Home**

THE GLOBOCAN PROJECT

Welcome to the **GLOBOCAN** project. The aim of the project is to provide contemporary estimates of the incidence of, mortality and prevalence from major types of cancer, at national level, for 184 countries of the world. The GLOBOCAN estimates are presented for **2012**, separately for each sex. 1-, 3- and 5-year prevalence data are available for the adult population only (ages 15 and over). Please note that:

1. These estimates are based on the most recent data available at IARC and on information publically available on the Internet, but more recent figures may be available directly from local sources.
2. Because the sources of data are continuously improving in quality and extent, estimates may not be

GLOBOCAN, CI5, WHO, SurvCan, IICC...

Cancer Mondial

Cancer Incidence in Five Continents Vol. IX

CI5

Data Sources of Cancer Incidence and Mortality for Globocan 2012 (for WPR)

No	POPULATION	Data source	
		Incidence	Mortality
HIGH-INCOME			
1	Australia	A	1
2	Brunei	F	5
3	Japan	B	1
4	Korea, Republic of	A	2
5	New Zealand	A	1
6	Singapore	A	1
LOW- AND MIDDLE-INCOME			
1	Cambodia	G	6
2	China	C	4
3	Lao PDR	G	6
4	Malaysia	C	2
5	Mongolia	D	5
6	Philippines	B	2
7	Viet Nam	E	4
PACIFIC ISLAND COUNTRIES			
1	Fiji	D	3
2	French Polynesia	D	5
3	Guam	D	6
4	New Caledonia	D	5
5	Papua New Guinea	G	6
6	Samoa	D	6
7	Solomon Islands	G	6
8	Vanuatu	D	6

LEGEND:

Availability of incidence data:

A. High quality* national data or high quality regional (coverage greater than 50%).
B. High quality* regional (coverage between 10% and 50%).
C. High quality* regional (coverage lower than 10%).
D. National data (rates).
E. Regional data (rates).
F. Frequency data.
G. No data.

Availability of mortality data:
National statistics are collated and made available by the WHO for countries with vital registration.

1. High quality* complete vital registration.
2. Medium quality* complete vital registration.
3. Low quality* complete vital registration.
4. Incomplete or sample vital registration.
5. Other sources (cancer registries, verbal autopsy surveys etc.).
6. No data.

Quality Indicators for Cancer Incidence

For example: in Cancer Incidence in 5 Continents

- **Morphologically Verified %**
- **DCO (Death Certificate only)%**
- **MI (Mortality/Incidence ratio)%**
- **% of other and unspecified site**
- **Unknown age-registered case (both sexes)**

INDICES OF DATA QUALITY

1. Tables showing the percentage of cases microscopically verified (MV%), the percentage of cases registered from a death certificate only (DCO%), and the ratio (expressed as a percentage) of the number of deaths from a particular cancer to the number of cases registered during the same period (MI%), by sex, for the following cancer sites or groups:

Key to conventions and symbols used in the tables:

For MV% and DCO%

99 = 99% or more

Blank = DCO not included for this site

0 = cases registered but not microscopically verified/reported on the basis of a death certificate only

- = no cases registered, although data for this site were submitted.

For MI%

Blank = MI not included for this site

0 = cases registered but no deaths

- = no cases and no deaths, although data on both cases and deaths collected for this site.

The * refers to note concerning the data quality which are available on the population page of the registry summary tables.

Percentage of other and unspecified site (O&U) and unknown age (Unk), all sites

	Male		Female	
	O&U	Unk	O&U	Unk
Japan, Aichi Prefecture	1.1	0.0	1.9	0.0
Japan, Fukui Prefecture	0.6	–	1.0	–
Japan, Hiroshima	0.7	–	1.0	0.0
Japan, Miyagi Prefecture	1.1	–	1.7	–
Japan, Nagasaki Prefecture	0.6	–	1.3	–
Japan, Niigata Prefecture	1.1	–	1.9	–
*Japan, Osaka Prefecture	1.2	–	1.8	–
Japan, Saga Prefecture	0.9	–	1.6	–
Republic of Korea	1.3	–	1.3	0.0
Republic of Korea, Busan	1.2	–	1.3	–
Republic of Korea, Daegu	1.4	–	1.3	–
Republic of Korea, Daejeon	1.0	–	1.1	–
Republic of Korea, Gwangju	1.6	–	1.5	–
Republic of Korea, Incheon	1.3	–	1.2	–
Republic of Korea, Jejudo	1.1	–	1.7	–
Republic of Korea, Seoul	1.0	–	1.1	0.0
Republic of Korea, Ulsan	1.1	–	1.0	–
*Philippines, Manila	4.7	0.8	4.0	1.0
*Philippines, Rizal	4.8	0.4	3.5	0.4
Qatar: Qatari	3.1	–	0.8	–
*Saudi Arabia, Riyadh: Saudi	3.7	0.0	3.8	0.0
Singapore	2.3	–	2.0	–
Singapore: Chinese	2.2	–	2.0	–
Singapore: Indian	3.2	–	2.2	–
Singapore: Malay	3.1	–	1.7	–

2. Table of the percentage of other and unspecified site (O&U) and unknown age (Unk), both sexes combined.

All sites (C00-96)

Key to conventions and symbols used in the table:

- (dash) = no cases of unknown age registered.
0.0 = the percentage is greater than 0 but less than 0.05.

Age-standardized (world) incidence rates (per 100,000) of microscopically verified cases by histological type

Cervix uteri (C53)

	Carcinoma				Sarcoma	Other	Unspec.	Number of cases	
	Squamous	Adeno	Other	Unspec.				MV	Total
Asia									
Bahrain: Bahraini	4.1	*1.0*	*0.2*	*0.3*	-	-	-	**44**	44
China, Beijing City	3.3	0.6	0.1	0.1	*0.0*	*0.0*	*0.0*	**1114**	1217
*China, Cixian County	5.2	*0.4*	-	-	-	-	-	**77**	86
China, Haining County	2.6	0.8	*0.0*	1.1	–	–	–	**102**	104
*China, Harbin City, Nangang District	1.3	*0.2*	-	*0.1*	-	-	5.2	**234**	277
China, Hong Kong	6.0	1.2	0.4	0.3	*0.0*	*0.0*	*0.0*	**2063**	2080
China, Jiashan County	–	–	–	–	–	–	2.6	**40**	40
China, Jiaxing City	–	–	–	–	–	–	3.9	**42**	48
China, Macao	6.6	1.5	*0.3*	*0.1*	-	-	-	**141**	148
China, Qidong County	1.7	0.6	–	1.9	*0.0*	-	-	**176**	194
*China, Shanghai City	2.5	0.7	0.1	*0.0*	*0.0*	*0.0*	0.4	**907**	1038
*China, Wuhan City	–	–	–	–	–	–	6.4	**970**	983
*China, Yangcheng County	64.0	4.0	–	–	–	–	3.1	**743**	749
*China, Yanting County	6.4	1.1	*0.1*	-	*0.1*	-	-	**126**	128
*China, Zhongshan City	6.3	1.2	*0.2*	-	-	-	*0.2*	**243**	245
Japan, Aichi Prefecture	4.8	1.5	0.3	*0.1*	*0.0*	*0.0*	*0.1*	**339**	346
Japan, Fukui Prefecture	5.7	1.2	*0.3*	*0.1*	-	*0.0*	*0.2*	**236**	264
Japan, Hiroshima	7.3	1.6	0.8	*0.1*	-	*0.1*	-	**426**	440
Japan, Miyagi Prefecture	4.7	1.2	0.2	*0.1*	-	*0.0*	-	**518**	603
Japan, Nagasaki Prefecture	7.5	1.6	*0.1*	0.6	*0.0*	*0.0*	-	**572**	590
Japan, Niigata Prefecture	6.3	1.5	0.4	*0.1*	*0.0*	*0.0*	-	**709**	748
*Japan, Osaka Prefecture	4.7	1.3	0.2	0.1	*0.0*	*0.0*	0.4	**2337**	2509
Japan, Saga Prefecture	6.6	1.4	0.3	*0.1*	-	-	0.3	**293**	317
Republic of Korea	9.8	1.5	0.5	0.1	0.0	0.0	0.1	**19375**	20234
Republic of Korea, Busan	10.4	1.5	0.5	*0.1*	*0.0*	*0.0*	*0.1*	**1606**	1704
Republic of Korea, Daegu	10.2	1.6	0.3	0.1	–	*0.0*	*0.0*	**1016**	1037
Republic of Korea, Daejeon	11.3	1.7	0.5	*0.2*	*0.0*	*0.0*	*0.1*	**611**	638
Republic of Korea, Gwangju	8.9	1.7	0.3	1.1	*0.0*	*0.0*	*0.0*	**516**	526
Republic of Korea, Incheon	11.3	1.4	0.5	*0.1*	*0.0*	*0.1*	*0.1*	**1083**	1119
Republic of Korea, Jejudo	10.9	2.7	0.8	–	–	–	–	**206**	217
Republic of Korea, Seoul	9.4	1.4	0.5	0.1	*0.0*	0.0	0.1	**3882**	4023
Republic of Korea, Ulsan	8.2	1.3	0.5	*0.2*	*0.1*	*0.0*	*0.1*	**327**	343

Age-standardized (world) incidence rates (per 100,000) of microscopically verified cases by histological type

Liver (C22) - Male (contd)

	Carcinoma				Hepato-	Sarcoma		Other	Unspec.	Number of cases	
	Hepato	Cholangio	Other	Unspec.	blastoma	Haemangio	Other			MV	Total
Japan, Aichi Prefecture	3.3	1.2	*0.1*	*0.1*	-	-	-	-	*0.0*	**284**	1181
Japan, Fukui Prefecture	2.5	1.1	0.3	*0.1*	-	*0.0*	-	-	*0.0*	**179**	912
Japan, Hiroshima	11.8	1.6	0.5	0.8	-	-	-	*0.0*	-	**769**	1842
Japan, Miyagi Prefecture	4.0	0.7	0.1	*0.0*	*0.1*	*0.0*	*0.0*	-	-	**566**	1900
Japan, Nagasaki Prefecture	7.3	1.2	0.2	*0.1*	*0.2*	-	*0.0*	-	-	**681**	1976
Japan, Niigata Prefecture	2.9	0.5	0.2	-	*0.1*	*0.0*	-	-	*0.0*	**486**	1769
*Japan, Osaka Prefecture	4.3	0.9	0.2	0.0	*0.1*	*0.0*	*0.0*	*0.0*	*0.0*	**2468**	11922
Japan, Saga Prefecture	9.6	0.9	0.2	*0.0*	*0.1*	*0.0*	-	-	*0.1*	**458**	1484
Republic of Korea	7.0	2.6	0.7	0.1	0.1	0.0	0.0	0.0	0.2	**14564**	55652
Republic of Korea, Busan	6.1	2.5	0.8	0.1	*0.1*	*0.0*	*0.0*	*0.0*	*0.1*	**1077**	5176
Republic of Korea, Daegu	8.0	2.7	0.7	0.2	*0.1*	-	*0.0*	*0.0*	*0.1*	**804**	2830
Republic of Korea, Daejeon	7.1	2.4	1.2	*0.2*	*0.1*	*0.0*	*0.1*	*0.1*	*0.1*	**406**	1230
Republic of Korea, Gwangju	5.0	1.9	*0.3*	*0.1*	*0.1*	*0.1*	-	-	*0.0*	**252**	1547
Republic of Korea, Incheon	6.1	1.8	0.4	*0.0*	*0.1*	*0.1*	*0.1*	*0.0*	*0.0*	**583**	2251
Republic of Korea, Jejudo	10.3	2.2	1.0	*0.2*	*0.2*	-	-	-	*0.1*	**178**	633
Republic of Korea, Seoul	6.5	2.3	0.6	0.1	*0.1*	*0.0*	*0.0*	*0.0*	0.1	**2703**	10083
Republic of Korea, Ulsan	7.0	2.9	0.7	*0.1*	*0.2*	*0.0*	*0.0*	-	*0.1*	**285**	1007

Cancer Statistics

refining

Information

Patients/Family
Policy makers
/Researchers

Calculation
Estimation

Central CR

Regional CR

Site-spec CR

Insurance info

NSO etc

Collaboration

Supports

Technically

Financially

WHO/IARC:IACR

Supports

Legislation (Act)

Budget (Finance)

Administration

Roles

Ministry of Health

Ministry of Administration

Ministry of Law

Thank you very much for your attention

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