Cancer registries and breast cancer quality of care in Europe

Harry Comber, Alexander Katalinic, Nadya Dimitrova
European Network of Cancer Registries
Breast cancer incidence and mortality in Europe – estimates for 2012

~ 460 000 new breast cancer cases a year
Incidence: 92.8 per 100 000

~ 130 000 breast cancer deaths
Mortality: 23.1 per 100 000

http://eco.iarc.fr/EUCAN
Cancer registration in Europe

- **Definition**: A cancer registry (CR) is an information system designed for the collection, storage, management, and analysis of data on persons with cancer, usually covering a whole country or a region (population-based) or hospitals (clinical CR).

- **History**:
  - 1926: First cancer registry in Hamburg
  - 1942: Danish Cancer Registry
  - 1950-1960: Start of Europe-wide implementation of cancer registration
  - Today: about **150 - 200 CR** in Europe
European Network of Cancer Registries –
**ENCR – www.encr.eu**

- The ENCR was established (1990) within the framework of the Europe Against Cancer Programme of the European Commission.

- Objectives:
  - To promote collaboration between cancer registries.
  - To define data collection standards.
  - To provide training for cancer registry personnel.
  - To disseminate information (incidence, mortality and survival) from cancer in the European Union and Europe.

The ENCR is governed by the Steering Committee.

The ENCR is hosted by the European Commission's Joint Research Centre.

The ENCR is affiliated to the International Association of Cancer Registries (IACR).
European Network of Cancer Registries

about 160 cancer registries in Europe
ENCR membership survey 2014

ENCR membership

Population-based cancer registries

1. They operate in **Europe**.

2. They completed the ENCR questionnaire 'Overview of the registration practices' launched on May 2010 and on May 2014.

159 members (37 countries and 66% of population)
(incl. specialized CRs)

21 countries (1 registry) ........Spain (16), France (20) and Italy (37)

**In the EU**: 20 national and 82 regional CRs, covering 72% of the population
ENCR and JRC collaboration towards a harmonised cancer information system in Europe

- Starting **December 2012** – JRC hosting ENCR Steering Committee meetings at Ispra (Italy)
- **August 2013** – Official transfer of ENCR Secretariat to JRC
- **August 2013** – Launch of the new ENCR website, Newsflash and Cancer Factsheets
- **September-October 2013** – Organisation and funding of cancer registry training course (ENCR, JRC, IARC)
- **November 2014** – ENCR Scientific meeting and general assembly at Ispra (Italy)
- **November 2015** - ENCR-JRC Workshop “Defining the roadmap towards revision of ENCR coding standards and training plan for cancer registries”
ENCR and JRC collaboration towards a harmonised cancer information system in Europe

- Laying the foundations for a framework for interoperability of all European cancer registries

A proposal on cancer data quality checks: one common procedure for European cancer registries

Carmen Martos, Emanuele Crocetti (Coordinator), Otto Visser, Brian Rous and the Cancer Data Quality Checks Working Group

### Variables example: Patient

#### Table 1. Quality checks for the variables and their formats.

<table>
<thead>
<tr>
<th>Variable description</th>
<th>Format</th>
<th>Mandatory</th>
<th>Missing/unknown values</th>
<th>Allowed values</th>
</tr>
</thead>
</table>
| (Check flag)         | F1     | Yes             | Not allowed                     | Allowed values: 0, 1  
0 → Not checked  
1 → Checked |
| The ENCR-JRC QC list |        |                 |                                 |                                                                                 |
| Patient identification number | A20   | Yes (according to registry coding) | Not allowed | Not allowed to have duplicate combination of the two variables:  
Patient identification number +Tumour sequence number in the same dataset |
| Tumour sequence number | F2     | Yes (according to registry coding) | 99                 |                                                                                 |
| Day of birth         | A2 DD  | Y               | 99                              | Range of allowed values:  
from 01 to 31 and 99 |
| Month of birth       | A2 MM  | Y               | 99                              | Range of allowed values:  
from 01 to 12 and 99  
**Warning for value = 99** |
| Year of birth        | F4 YYYY| Y               | 9999                            | Range of allowed values:  
>1842 and ≤ the current year  
**Warning for value = 9999** |

F: Numeric variable  
A: Alphanumeric variable  
Y=yes  
N=not
### Variables example: Diagnosis

<table>
<thead>
<tr>
<th>Variable description</th>
<th>Format</th>
<th>Mandatory</th>
<th>Missing/unknown values</th>
<th>Allowed values</th>
</tr>
</thead>
<tbody>
<tr>
<td>Basis of diagnosis (BoD) ENCR recommendations</td>
<td>F1</td>
<td>Y</td>
<td>9</td>
<td>Allowed values: 0, 1, 2, 4, 5, 6, 7, 9</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0 → Death certificate only (DCO)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1 → Clinical</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2 → Clinical investigation</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>4 → Specific tumour markers</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>5 → Cytology</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>6 → Histology of a metastasis</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>7 → Histology of a primary tumour</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>9 → Unknown</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td><strong>Warning for value = 9</strong></td>
</tr>
<tr>
<td>ICD-0-3 topography (topography of the metastasis is not admitted)</td>
<td>A4</td>
<td>Y</td>
<td>Not allowed</td>
<td>Valid code in ICD-0-3.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td><strong>Warning for undefined topography when BoD is 5 or 7</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>C809; C76 (C760, C761, C762, C763, C764, C765, C767 and C768); C14 (C140, C148); C26 (C260, C268, C269); C39 (C390, C398, C399); C559; C579; C639; C689; C729; C759</td>
</tr>
</tbody>
</table>

F: Numeric variable  A: Alphanumeric variable  Y=yes  N=not

* If complete date of birth and/or date of incidence are missing or unknown.
### Variables example: Stage

<table>
<thead>
<tr>
<th>Topography</th>
<th>TNM edition</th>
<th>T</th>
<th>N</th>
<th>M</th>
<th>Stage grouping</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast C50</td>
<td>6</td>
<td>TX, Tis, T1, T1mic, T1a, T1b, T1c, T2, T3, T4, T4a, T4b, T4c, T4d</td>
<td>NX, NO, N1, N2, N2a, N2b, N3, N3a, N3b, N3c Pathological N: pNX, pNO, pN1, pN1mi, pN1a, pN1b, pN1c, pN2, pN2a, pN2b, pN3, pN3a, pN3b, pN3c</td>
<td>MX, MO, M1</td>
<td>0, I, IIA, IIB, IIIA, IIIB, IIIC, IV</td>
</tr>
<tr>
<td></td>
<td>7</td>
<td>TX, Tis, T1, T1mi, T1a, T1b, T1c, T2, T3, T4, T4a, T4b, T4c, T4d</td>
<td>NX, NO, N1, N2, N2a, N2b, N3, N3a, N3b, N3c Pathological N: pNX, pNO, pN1, pN1mi, pN1a, pN1b, pN1c, pN2, pN2a, pN2b, pN3, pN3a, pN3b, pN3c</td>
<td>M0, M1</td>
<td>0, IA, IB, IIA, IIB, IIIA, IIIB, IIIC, IV</td>
</tr>
</tbody>
</table>
## Variables example: Treatment

<table>
<thead>
<tr>
<th>Variable description</th>
<th>Format</th>
<th>Mandatory</th>
<th>Missing/unknown values</th>
<th>Allowed values</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surgery</td>
<td>F1</td>
<td>N</td>
<td>9</td>
<td>Allowed values: 1, 2, 9</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1 → Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2 → No</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>9 → Unknown</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>F1</td>
<td>N</td>
<td>9</td>
<td>Allowed values: 1, 2, 9</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1 → Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2 → No</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>9 → Unknown</td>
</tr>
<tr>
<td>Systemic therapy, other than chemotherapy</td>
<td>F1</td>
<td>N</td>
<td>9</td>
<td>Allowed values: 1, 2, 9</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1 → Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2 → No</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>9 → Unknown</td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>F1</td>
<td>N</td>
<td>9</td>
<td>Allowed values: 1, 2, 9</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1 → Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2 → No</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>9 → Unknown</td>
</tr>
<tr>
<td>Hormone therapy</td>
<td>F1</td>
<td>N</td>
<td>9</td>
<td>Allowed values: 1, 2, 9</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1 → Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2 → No</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>9 → Unknown</td>
</tr>
<tr>
<td>Bone marrow transplantation</td>
<td>F1</td>
<td>N</td>
<td>9</td>
<td>Allowed values: 1, 2, 9</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1 → Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2 → No</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>9 → Unknown</td>
</tr>
</tbody>
</table>
Compulsory variables

- Patient identification number
- Tumour sequence number
- Date of Birth (day, month, year)
- Sex
- Date of Incidence (day, month, year)
- Age at diagnosis in years
- Basis of diagnosis
- Topography (ICD-O-3)
- Morphology (ICD-O-3)
- Behaviour

- Incidental finding of cancer at the autopsy
- Grade (ICD-O-3)
- Vital status at last contact
- Date of the last known vital status (day, month, year)
- Age at the last known vital status in years
- Duration of the survival in days
Non-compulsory variables

- Date of registration
- Laterality (bilateral and separated organs)
- Official underlying cause of death
- ICD ed. used for coding cause of death

Extent of disease
- Pathological TNM stage
- Clinical TNM stage
- TNM stage grouping
- TNM edition
- Condensed TNM
- Dukes' stage
- FIGO stage
- Summary extent of disease

Treatment
- Surgery
- Chemotherapy
- Systemic therapy, other than chemotherapy
- Radiotherapy
- Hormone therapy
- Bone marrow transplantation
Availability of breast cancer data for Europe

Long-term trends in incidence and mortality by country (eco.iarc.fr)
Availability of breast cancer data for Europe

EUROCARE-5 database - https://w3.iss.it/site/EU5Results/forms/S...
Availability of breast cancer data for Europe

Cancer survival in Europe 1999–2007 by country and age: results of EUROCARE-5—a population-based study

Robertina De Angeli MSc 2 3, Milena Sant MD 4, Prof Michel P Coleman BM BCh 4, Silvia Francischi PhD 2, Paolo Balli MSc 2, Daniela Pierannunzi PhD 2, Annalisa Trama MD 5, Otto Visser MD 5, Prof Hermann Brenner MD 5, Eva Ardanaz MD 5, Prof Magdalena Bielska-Lasota MD 4, Gerda Engholm MSc 1, Alice Henneke MD 1, Sabine Siesling PhD 2, Franco Berrino MD 5, Riccardo Capocaccia MSc 4, the EUROCARE-5 Working Group


ScienceDirect

Survival of women with cancers of breast and genital organs in Europe 1999–2007: Results of the EUROCARE-5 study

Milena Sant a,*, Maria Dolores Chirleaq Lopez b,*, Roberto Agresti d, Maria José Sánchez Pérez e, c, Bernd Holleczek f, Magdalena Bielska-Lasota g, Nadya Dimitrova h, Kaire Innos i, Alexander Katalinic j, Hilde Langseth k, Nerea Larrañaga l, c, Silvia Rossi m, Sabine Siesling n, o, Pamela Minicozzi a, The EUROCARE-5 Working Group
New data calls

- **ENC R/JRC** – incidence and mortality – rates, trends and prognosis
- **EUROCARE-6** – survival and prevalence
- Deadline for data collection: 01.11.2015, but **still ongoing**
- Diagnoses up to 2013, patients followed-up until the end of 2014
Stage, treatment, adherence to clinical guidelines, screening

- Breast cancer studies, using data from population-based registries: more than 100 in PubMed
- Some examples:
  - Kiderlen M et al. Treatment strategies and survival of older breast cancer patients - an international comparison between the Netherlands and Ireland. PLoS One. 2015
  - de Glas NA et al. Survival of older patients with metastasised breast cancer lags behind despite evolving treatment strategies--a population-based study. Eur J Cancer. 2015
  - Anttila A et al. Towards better implementation of cancer screening in Europe through improved monitoring and evaluation and greater engagement of cancer registries. Eur J Cancer. 2015
Cost of cancer registration in Europe

Original Article

Economic Evaluation of Cancer Registration in Europe

R. Zanetti\(^a\); L. Sacchetto\(^a\); M. Calvia\(^a\); A. Bordoni\(^b\); T. Hakulinen\(^c\); A. Znaor\(^d\), H. Møller\(^e\), S. Siesling\(^f\); H. Comber\(^g\); A. Katalinic\(^h\); S. Rosso\(^i\); Eurocourse WP3 Working Group\(^l\)

Figure 4. Cost of Cancer Registration in Europe Per Inhabitant Covered in 2010 (Expressed in Euro PPS EU27) According to Year of Establishment of the Registry

Figure 3. Cost of Cancer Registration in Europe Per Inhabitant According to GDP Per Capita in 2010 (PPS EU 27)
There are registries (as in the Netherlands, UK, Germany) that collect \textit{comprehensive clinical data} and these registries are able to provide quality indicators for breast cancer care.

Probably, such registries are not a solution for all countries, for different reasons.
**Limitations** for breast cancer quality of care assessment by CRs

- Cancer registration in Europe remains **heterogeneous** for:
  - historical
  - economic and
  - legal reasons

- The **scope** of data captured by registries is very **variable**:
  - Some registries don’t have an **access to death certificates** (inaccurate survival calculation);
  - Many, but not all, capture **stage and treatment at diagnosis**;
  - Some can provide **more detail** – type of surgery, molecular markers, co-morbidity and follow-up data;
  - A few – collect data on **quality of life**;
  - Linkage of **screening data** to CRs is not being done in some countries
Conclusion

- ENCR, with JRC, is working on improving the **standardisation and coverage** of cancer registration in Europe.
- Cancer registries **could be used** for detailed quality assurance in principal, but this is only possible in few regions of Europe.
- If quality assurance is wanted, **the CR should be used**. New specialized registries for QA should not be built up.
- There is **considerable potential** for quality assurance and research through:
  - More widespread sharing of the more extensive data collected by cancer registries, clinical programmes and screening programmes
  - More detailed analysis of the data already collected.
Thank you!

Painting by Yanko Yanev, Bulgaria