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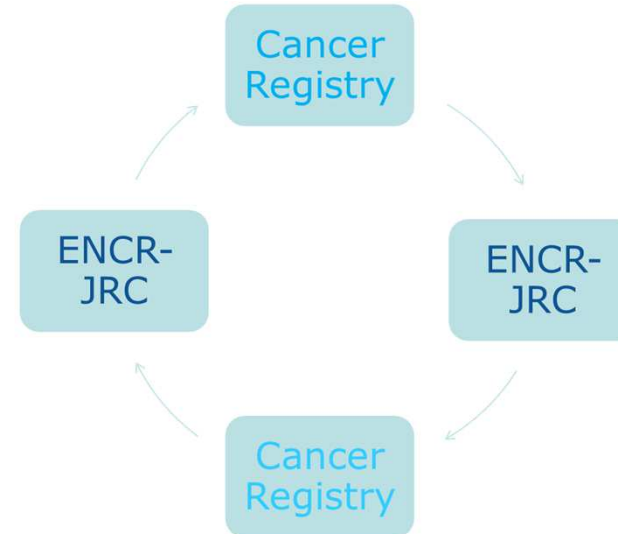
The feedback to Cancer Registries on the quality assessment of data submitted to the ENCR-JRC project

**ENCR-JRC Training on
Quality of Cancer Registry Data
Baveno (Italy) 5 October 2016**

<https://ec.europa.eu/jrc>

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*The ENCR has among its objectives:
to improve the quality, comparability
and availability of cancer incidence
data*





The feed-back document

Centred on the ENCR-JRC 2015 data call.

Aimed at improving in a transparent way the awareness of CR on data quality.

Part of the bidirectional collaboration between ENCR-JRC and CRs

Based on the huge amount of knowledge available but also with room for improvement



Sources of information

- Information on **general information/choices of the CR**, not related to the data but which affect any (many/some) case
- Information from **original data as a whole**
- Information from **original data as single records**
- **Computed** information from original data

The feed-back document

1. History of submission
2. General information
3. Outputs of Quality Check Software
4. A series of tables and figures
5. A summary interpretation

1. History of submission

DATA FLOW

REGISTRY

Registry name:

Registry code:

SUBMISSION

Submission author

Date of creation

Data closure

Specific Data Restrictions:

Encode Patient ID:

Files submitted:

Incidence

Mortality

Population

Lifetables

FLOW OF DATA

File format check (incidence, mortality, population, life tables)

Major problems

Resubmission



2. General information (Questionnaire)

E.g.

- *original classification/s used for coding*
- *rules followed for date of incidence*

...

- *inclusion of non melanoma skin cancers*
- *inclusion of in situ tumours*
- *inclusion of borderline tumours*
- *inclusion of benign tumours*

...

...

- *mortality source*
- *population source*

COMPARABILITY



3. Quality Check Software

OUTPUTS (Incidence, Mortality, Population)

Format

Duplicates

Internal consistency

Inter-variables consistency

Multiple primaries

VALIDITY (ENCR-JRC 2014 report!)





4. A series of tables and figures

***NEW** information **computed** from the original data*

Based on the available knowledge:

- Bray F, Parkin DM. Eur J Cancer 2009;45(5): 747-55.
- Parkin DM, Bray F. Eur J Cancer 2009;45(5): 756-64.
- Bray F, Kohler B, Ferlay J. Data comparability and quality. In CI5-X.
- ...

VALIDITY

COMPLETENESS



4. A series of tables and figures: incidence (1)

- SELECTION OF MALIGNANT CANCER
- DEFINITION OF CANCER SITES (ICD-10) AS COMBINATION OF ICD-O-3 TOPOGRAPHY AND MORPHOLOGY
- SPLIT OF CHECKS ACCORDING TO YEARS OF INCIDENCE
 - A) UNTIL 2007
 - A1) NOT INCLUDED IN CI5 (to be checked)
 - A2) INCLUDED IN CI5 (numerical comparison between published and submitted data by sex, and 5-year period of incidence)

4. A series of tables and figures: incidence (2)

Cancer Cases, All-but C44, 2003-2007

CR	Sex	CI5-X	Nordcan	Diff.	%diff
DK	M	75150	75830	680	0.9
	W	73071	74468	1397	1.9
FI	M	64910	66230	1320	2.0
	W	58583	60976	2393	4.1
SE	M	121297	122597	1300	1.1
	W	105901	107169	1268	1.2
NO	M	62620	63568	948	1.5
	W	55200	57026	1826	3.3

COMPLETENESS



4. A series of tables and figures: incidence (3)

B) MOST RECENT PERIOD (2008-2013)

- # of cases per year overall and by sex (including also both sexes)
- proportion of cases for each year, assuming 100% the last available year of incidence
- # of cases for major cancer groups (and proportion on the total of cancers) per year, and sex (including also both sexes)
- Age-adjusted (European) rates for major cancer groups (and proportion on the total of cancers) per year, and sex (including also both sexes)

COMPLETENESS



4. A series of tables and figures: incidence (4)

Major cancer groups:

C00-C14 Malignant neoplasms of lip, oral cavity and pharynx

C15-C26 Malignant neoplasms of digestive organs

C30-C39 Malignant neoplasms of respiratory and intrathoracic organs

C40-C41 Malignant neoplasms of bone and articular cartilage

C43-C44 Melanoma and other malignant neoplasms of skin

C45-C49 Malignant neoplasms of mesothelium and soft tissue

C50-C50 Malignant neoplasm of breast

C51-C58 Malignant neoplasms of female genital organs

C60-C63 Malignant neoplasms of male genital organs

C64-C68 Malignant neoplasms of urinary tract

C69-C72 Malignant neoplasms of eye, brain and other parts of central nervous system

C73-C75 Malignant neoplasms of thyroid and other endocrine glands

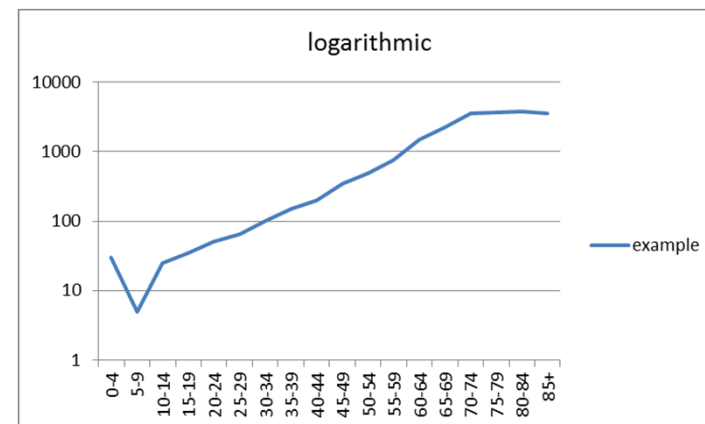
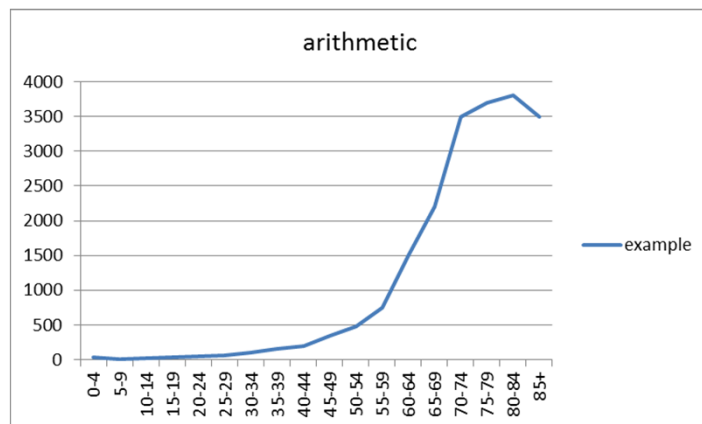
C81-C96 Malignant neoplasms, stated or presumed to be primary, of lymphoid, haematopoietic and related tissue

C76-C80 Malignant neoplasms of ill-defined, secondary and unspecified sites

C00-C96 but C44 All sites but skin

4. A series of tables and figures: incidence (5)

Figures with 5-year age-specific incidence rates for the 15 most frequent cancer sites (by number men+women), by sex, on linear and logarithmic scale **COMPLETENESS**



4. A series of tables and figures: incidence (6)

Tables of quality indexes, for detailed cancer sites, by sex

C00, C01-02, C03-06, C07-08, C09, C10, C11, C12-13, C14, C15, C16, C17, C18, C19-20, C21, C22, C23-24, C25, C30-31, C32, C33-34, C37-38, C40-41, C43, C44, C45, C46, C47+C49, C50, C51, C52, C53, C54, C55, C56, C57, C58, C61,C62, C60+C63, C64, C65, C66, C67, C68, C69, C70-72, C73, C74-C75, C81, C82-85+C96, C88, C90, C91, C92-94, C95, O&U (C39,C76,C80), C00-96, C00-96BUTC44

Site	#	Age unknown	0-4	5-9	...	85+	Crude rate	Proportional incidence	%MV	M/F	ASR (E)	APC
COO - Lip												
C01-02 – Tongue												
...												
All sites but C44												



4. A series of tables and figures: incidence (6)

- Number of observed cases
- Number of cases with unknown age (**VALIDITY**)
- Average 5-year age-specific rates (from 0-4 to 85+)
- Crude rate
- % of site specific numbers on all sites but C44
- % of microscopically verified (**VALIDITY, COMPLETENESS**)
- Male/Female ratio
- ASR (on the European standard population)
- Average percentage annual change (APC) in comparison with the previous period (e.g. 2003-2007). (**internal comparison COMPLETENESS**)



4. A series of tables and figures: incidence (7)

Tables of more quality indexes for selected and aggregated cancer sites

C00-14, C15,C16,C18-21, C22, C25, C32, C33-34, C43, C61, C62, C64-66, C67, C70-72, C73, C81-88+C90, C91-95, C76-80, C00-96BUTC44 FOR MEN; C00-14, C15,C16,C18-21, C22, C25, C32, C33-34, C43, C50, C53, C54-55, C56, C64-66, C67, C70-72, C73, C81-88+C90, C91-95, C76-80, C00-96BUTC44 FOR WOMEN

Number of cases, ASR and (standard error), O/E, MV%, DCO(%) (Validity), M/I (Completeness).

All the measures (out of number of cases) have to be compared with corresponding values from registries in the **same region** (external comparison).



Definition of Regions (to be discussed and tested)

- *Northern Europe* (Denmark, Iceland, Sweden, Finland, Sweden, Estonia, Latvia, Lithuania)
- *Great Britain & Ireland* (England, Wales, Scotland, Northern Ireland, Ireland)
- *Western Europe* (Belgium, Luxembourg, the Netherlands, Austria)
- *Germany* (German CRs)
- *Switzerland* (Swiss CRs)
- *Italy* (Italian CRs)
- *Spain* (Spanish CRs)
- *France* (French CRs)
- *Portugal* (Portuguese CRs)
- *Eastern Europe* (Poland, Czech Republic, Slovakia, Hungary, Romania, Bulgaria, Ukraine, Belarus, Russia..)
- *Southern Europe* (for Slovenia, Croatia, Serbia, Bosnia, Malta, Greece, Cyprus..)



4. A series of tables and figures: incidence (8)

Childhood cancers

lowest and highest deciles of sex specific incidence rates for paediatric age groups (0-4, 5-9 and 10-14 years) to be shown besides the general ones.

Warning:

Information coded (translated) according to the International classification for childhood cancer (ICCC-3) could be produced. ICCC includes, for some sites, also non-invasive tumours.

Some hints from ACCIS



4. A series of tables and figures: population

- Format
- # (and proportion) of residents overall per calendar year
- # (and proportion) of residents, by sex and 5-year age groups, per calendar year (*in case of population changes*)



4. A series of tables and figures: mortality

- Format
- # (and proportion) of deaths by sex per calendar year
- # (and proportion) of deaths by sex and 5-year age groups, per calendar year (*in case of population changes*)
- # of deaths for major cancer groups (and proportion on the total of cancers) per year, and sex (including also both sexes) (*in case of population changes*)



5. Summary interpretation

Suggestions from ENCR-JRC to CR on possible points to be assessed/improved, based on data checks.



....POSSIBLE IMPROVEMENTS!

- **New variables**: e.g. availability of non-compulsory variables (stage), or MV% without unspecified codes, % of MP during a common period of time, etc.
- **New methods**: e.g. coherence of the distribution of the first significant digit of the rates with the theoretical Benford's one.



Thanks!