



In reply, please refer to: DE/92/29-4  
Prière de rappeler la référence: DEP/cd

*By e-mail attachment*

***Last update 12/9/2008***

### EUROCIM 2008 Call for Data

Dear ENCR member:

On behalf of the Steering Committee I would like to invite you to contribute data to the EUROCIM database, Europe's main repository of cancer data. Our goal is to build the database by December 31<sup>st</sup>, 2008, with all submitted data going through various quality control edit checks before compilation. The EUROCIM database will be the collective property of the cancer registries, and the ENCR Secretariat at IARC, in Lyon, will provide the technical support required for building it.

Your data will be used for the update of EUROCIM, if they comply with the minimum requirements in the project protocols (posted on [http://www.encr.com.fr/encr\\_studyproposals.htm](http://www.encr.com.fr/encr_studyproposals.htm)). All cancer registries will be informed before processing takes place, and will have the opportunity to restrict the use of their data if they choose to do so.

The EUROCIM database can be used for other purposes **only** upon your permission, as agreed explicitly in each case by each contributing cancer registry. Additionally, all users of EUROCIM will sign an agreement to comply with the Vancouver rules for authorship (Uniform requirements for manuscripts submitted to biomedical journals. International Committee of Medical Journal Editors. Ann Intern Med 1997; 126:36-47). The ENCR Steering Committee will manage such requests.

To expedite and streamline the data collection and quality control process, we are kindly requesting that **all registries prior to data submission:**

- Convert their data to ICD-O-3,
- Perform data corrections where required (DEPeditis /check module),
- Remove duplicate records (IARC Tools / multiple primary module) and
- Deliver the data in the fixed record layout proposed below.

**Please note that registries that have their own software to perform the above-mentioned tasks, are welcome to use it. Alternatively, the following software is available:**

The old and new DEPeditis programs (versions 1 and 2) can be used to assist with the unduplication of the records at the patient level (unduplicate module). They can also help you convert your data to ICD-O-3 (conversions module) and perform edit checks (checks module). The DEPeditis, version 1, can be downloaded from the ENCR website ([http://www.encr.com.fr/encr\\_downloads.htm](http://www.encr.com.fr/encr_downloads.htm)). The new DEPeditis, version 2, will become available by the end of July 2008. Please note that this program was designed to accommodate the edits of the new data items requested and provide assistance with the multiple primaries. It

was created in a short period of time and although we have put a lot of effort in evaluating this new version, it is still a beta version and needs fine-tuning. Please report all problems you identify with it to [encr@iarc.fr](mailto:encr@iarc.fr) (cc: [votil@iarc.fr](mailto:votil@iarc.fr)). We need your assistance to improve and eventually perfect this program to accommodate the ENCR registries' needs. We will be posting an updated version of the DEPeditis (version2) on the website as we correct the problems identified.

The IARCTools program can also be used to convert the data to ICD-O-3, perform some (not all!) edit checks, identify multiple primaries and remove duplicate records (<http://www.iacr.com.fr/software-menu.htm> ). Please note that the DEPeditis include additional checks for the additional items requested such as TNM stage, follow up data etc.

We appreciate your contribution. Your participation in the EUROCCIM call for data promotes cancer surveillance and research in Europe, and at the same time it demonstrates your registry's active involvement and contribution in the cancer control efforts.

If you have questions, comments or wish to discuss your submission, do not hesitate to contact me at +33 (0)4 72-73-84-35 or via email: [votil@iarc.fr](mailto:votil@iarc.fr).

Sincerely,

Lydia Voti, DSc MS MS  
Descriptive Epidemiology Production Group  
150 Cours Albert-Thomas  
69372 Lyon – France

Tel: + 33 (0)4 72 73 84 35  
Fax:+ 33 (0)4 72 73 86 96

### **Inclusion criteria**

Cancer registries are invited to submit all primary tumours recorded since the beginning of the registry's collection date and through 2007, or through the most complete year of the registry. We welcome submission of all available complete years, regardless of whether these were already submitted. Cancers of ANY behaviour should be submitted (including behaviors 6 and 9). Skin cancers: Only melanomas are collected for this call. Basal cell and squamous cell carcinomas are excluded.

**Multiple primaries:** We request that you submit **all** recorded tumours. Please include multiple primaries, but REMOVE duplicate records (for the same tumour). Example:

Patient no	Tumour no	Hospital	Diagnosis date	Site	Morph	Duplicate Yes/No	Submit to EUROCIM
123	1	2345	3/11/1998	C53.0	8140	No	Yes
123	1	2444	5/12/1998	C53.0	8140	Yes	No
123	2	1234	3/6/2001	C50.2	8010	No	Yes

**Deadline:** September 30, 2008

### **Format of the data submission:**

Please use the record layout below (page 5). If you do not collect or do not submit some of the data items requested, fill the corresponding fields with the appropriate missing values and indicate it in the 'Record layout form' provided below. Please fill and send the last 2 columns of the Record Layout form', along with you data submission.

### **Where to submit the data:**

- Please send via email all files containing population and life-tables to [encr@iarc.fr](mailto:encr@iarc.fr)
- Zipped, password protected files containing CANCER RECORDS can be submitted via email as well to [encr@iarc.fr](mailto:encr@iarc.fr), if they don't exceed 10MB. Please send the password in a separate file!

If the ZIPPED file is larger than 10MB, you can send it on a CD-ROM or FTP it.

**Mailing address:** ENCR Secretariat, EUROCIM study  
Descriptive Epidemiology Production Group  
IARC  
150 Cours Albert-Thomas  
69372 Lyon – France

### **FTP instructions:**

- ↪ Go to <https://pftp.iarc.fr> and login:
- ↪ Login: eurocim2008-ro.
- ↪ Password : dedomena1

Go to the 'upload' directory and you will be prompted to upload your file. You can not see the contents of the directory but as soon as you hit the upload button a message will in your screen stating 'A new file has been added': yourfilename – size XXX MB'.

Home > Online File Sharing Service

## EUROCIMFTP Online File Sharing Area

[Site Contact](#) - [Exit](#)

A new file has been added: tmasdoa.sql - size : 8 kb

Back to : [EUROCIMFTP](#)      Current directory : EUROCIMFTP\upload

Subdirectory	Size	File	Size
<input style="width: 90%;" type="text"/> <input style="width: 10%; border: none;" type="button" value="Choose..."/>		<input style="width: 100%;" type="button" value="Upload the File"/>	

Please name your files according to the following scheme:

**For cancer records:**

'C\_country\_registryregionaname.zip'  
 Example 'C\_Italy\_Palermo.zip'

**For population files:**

'P\_country\_registryregionaname.xls'  
 Example: 'P\_Greece\_Crete.zip'

**For life tables:**

'L\_country\_registryregionaname.xls'

**All Population and Lifetable files should be sent by email to [encr@iarc.fr](mailto:encr@iarc.fr). Cancer records can be sent by email if their size does not exceed 10MB, otherwise FTP them as described above. Independently of file size, please make an effort to submit the cancer records through the secure FTP site which was set up for this call.**

Note: The distribution principles and the content of the **old** dataset are described in the EUROCIM-2 protocol which was developed by the ENCR steering committee and posted on [http://www.encr.com.fr/encr\\_studyproposals.htm](http://www.encr.com.fr/encr_studyproposals.htm)

### Record Layout – Check list

Please submit an **ASCII, PIPE-DELIMITED** file with the following variables, in the order specified and fill the last 2 columns of the table.

(F=Numeric, A=Alphanumeric)

Var #	Variable Name	Format	Comment	Missing values/ Unknown	Collected? (Y/N)	Submitted? (Y/N)
1	Patient enumeration - <b>unique</b> number <sup>1</sup>	A10.0		Not allowed	Yes	Yes
2	Tumor sequence number A sequential numbering of all multiple primary tumors diagnosed over the lifetime of a person, indicating their chronological order. Code 00 if only 1 primary and 01, 02 etc. for multiple tumors. (ENCR standards)	F2.0		99	Yes	Yes
3	Incidence date (ENCR standards) <sup>2</sup>	F8.0	DDMMYYYY	99999999	Yes	Yes
4	Birth date	F6.0	MMYYYY	999999	Yes	Yes
5	Age at diagnosis in <b>years</b> (truncated-completed year at diagnosis)	F3.0		999	Yes	Yes
6	Sex 1=Male, 2=Female	F1.0		9	Yes	Yes
7	ICDO-3 Topography <sup>3</sup>	A4	example:C531	Not allowed	Yes	Yes
8	ICDO-3 Morphology <sup>3</sup>	F4.0		Not allowed	Yes	Yes
9	ICD-O-3 Behaviour <sup>3</sup>	F1.0		9	Yes	Yes
10	Basis of diagnosis (ENCR standards)	F1.0		9	Yes	Yes
11	Grade (ICDO-3) <sup>3</sup>	F1.0		9	Yes	Yes

Var #	Variable Name	Format	Comment	Missing values/ Unknown	Collected? (Y/N)	Submitted? (Y/N)
12	Laterality (SEER standard) 0 = Not a paired site 1 = Right: origin of primary 2 = Left: origin of primary 3 = Unilateral NOS. For in-situ cases, if the laterality is unknown or midline, use code '3'. 4 = Bilateral involvement, lateral origin unknown, stated to be a single primary. 9 = Paired site, but lateral origin unknown; midline tumor	F1.0	Never use code 4 for bilateral primaries for which separate abstracts are prepared or for bilateral primaries where the side is known and the tumor has spread to the other side (contralateral site).	9  (If your registry was not collecting laterality up to a certain year, please use 0 if the tumor was diagnosed in a non-paired organ and 9 if it was diagnosed in a paired organ)	Yes	Yes
13	Vital status at last contact 1 = Alive, 2 = Dead	F1.0		9	Yes	Yes
14	Date of last contact with patient Code as date of death, if the patient is known to be dead OR as date of last follow-up -passive or active-, if the patient is known to be alive	F8.0	DDMMYYYY	99999999	Yes	Yes
15	Date of Death	F8.0	DDMMYYYY Blank if alive	99999999	Yes	Yes
16	Cause of Death (Blank if patient alive at last contact 8888 if death certificate not available)	A4	ICD-10 Left justified blank filled	9999	Yes	Yes
17	Number of <b>days</b> from incidence date to last contact (blank if patient alive)	F5.0		99999	Yes	Yes
18	Extent of disease: <u>condensed</u> TNM (ENCR standard) 1 = Localized, 2 = Advanced	F1.0	Code 8 if hematopoetic, blank if in situ	9	Yes	Yes

Var #	Variable Name	Format	Comment	Missing values/ Unknown	Collected? (Y/N)	Submitted? (Y/N)
19	TNM stage Path T AJCC/UICC standard – 6 <sup>th</sup> edition	A2	Upper case, alphanumeric, left justified, blank filled	TX  88=Not applicable	Yes	Yes
20	TNM stage Path N AJCC/UICC standard – 6 <sup>th</sup> edition	A2	Upper case, alphanumeric, left justified, blank filled	NX  88=Not applicable	Yes	Yes
21	TNM stage Path or Clin M AJCC/UICC standard – 6 <sup>th</sup> edition	A2	Upper case, alphanumeric, left justified, blank filled	MX  88=Not applicable	Yes	Yes
22	Grouped stage 0 = In situ 1 = Localized only 2 = Regional 3= Distant site(s)/distant node(s) involved 9 = Unknown if extension or metastasis	F1.0	Use code 9 for : unstaged, unknown, unspecified, or death certificate only case	9	Yes	Yes
23	IARC flag – indicator of successful pass through ICD-O-3 conversion and edits (1=Yes, 2=Yes, after verification, 0=No)	F1.0	Recode to 1 if warnings were checked and cleared.	9 (if not run)	Yes	Yes

<sup>1</sup> **This variable is meant to permit the grouping of records pertaining to the same patient. DO NOT use an identification of a person in real life.**

<sup>2</sup> All elements of the date fields should be 9-filled separately when missing. For example, if the day is missing/unknown/not collected but the month and the year are known, please code as 99MMYYYY.

<sup>3</sup> Registries which do not use the 3<sup>rd</sup> revision of the ICD-O have to convert their data before submission using the DEPedit software, downloadable from the ENCR web site (<http://www.encl.com.fr/download.htm>).

**The ENCR recommendations' can be found on the ENCR web site [www.encl.com.fr](http://www.encl.com.fr), under the 'downloads' tab.**

**UICC standards:** Please visit the site: <http://www.uicc.org/>

TNM classification of malignant tumors:

[http://www.uicc.org/index.php?option=com\\_content&task=view&id=14275&Itemid=197](http://www.uicc.org/index.php?option=com_content&task=view&id=14275&Itemid=197)

An online version of TNM can be found at :

<http://www3.interscience.wiley.com/cgi-bin/mrwhome/104554799/HOME>

**ENCR standards:** Please visit the site: <http://www.encl.com.fr/> select the 'downloads' tab and go to the end of the page to: Recommendations.

**IACR standards:** Please visit the site: <http://www.iacr.com.fr/> select the 'standards' tab

**SEER standards:** Please visit the site: <http://seer.cancer.gov/tools/codingmanuals/>. Use ONLY for laterality definition for this call for data. Please note that the SEER multiple primary rules are DIFFERENT from the IACR/ENCR rules.

**Population at risk: Denominators**

The population data corresponding to your area of registration should be submitted by sex and individual years of age or, if not available, 5-years age groups and for each calendar year of incidence. Qualify each population data set by source (e.g. census, local vital statistics office, estimate, etc.).

Each line of the population file should include population figures for the combination of calendar year, sex and age. Ideally, the codes for these variables should be the same as for the cancer cases. Please provide the source of the table (registry, Census Bureau etc)

1. Calendar year
2. Sex
3. Age or age-group (please provide the 18 standard 5-year age groups, if available)

The file should be sorted from left to right. Example:

Year	Sex	Age group	Population
1991	1	1 (0-4 yrs)	13000
1991	1	2 (5-9 yrs)	13500
.....	.....	.....	
1991	1	18 (85+ yrs)	20374
1991	1	19 (unknown age)	50
1991	2	1 (0-4 yrs)	
.....	.....	.....	

**Population life tables for relative survival analysis**

Ideally population life tables by sex and individual year of age should be submitted for each calendar year of incidence. However, estimates so detailed are rarely available. Please submit life tables to the closest level of detail available. The accompanying documentation should specify:

- a) The layout and format of the file
- b) The key for any specific codes used for variables
- c) The source reference

All **cancer record files** should be zipped, password protected (password to be communicated to the secretariat separately), if sent via email.

**Population or lifetable files** should be send in the form of EXCEL spreadsheets.

Data (zipped files) and accompanying documents can be submitted by e-mail to [encr@iarc.fr](mailto:encr@iarc.fr) However, we can only receive files of **maximum 10Mb in size by e-mail**. If you submit files of larger size use the FTP instructions above or send them by airmail on CD-ROM to:

ENCR Secretariat, EUROCIM study  
Descriptive Epidemiology Production Group  
IARC  
150 Cours Albert-Thomas  
69372 Lyon – France