

# The ENCR, its role and future perspectives

UKACR NCIN meeting  
London June 2011

Stefano Rosso, ENCR Chairman  
Piedmont Cancer Registry – CPO Turin, Italy



- Membership:
  - Belonging to Europe in geographical sense
  - Being a Population-Based Cancer Registry
  - Filling & updating the ENCR questionnaire (next implementation)

**Steering Committee:** S. Rosso  
(chairman, Italy), A. Gavin (UK), S.  
Siesling (The Netherlands), A Katalinic  
(Germany), JM. Lutz (Switzerland), R.  
Sankila (ANCR), E. Crocetti (GRELL),  
DM. Parkin (IACR), F. Bray (IARC), E.  
Steliarova (secretariat, IARC).

The European Network of Cancer Registries was established in 1989 within the framework of the **‘Europe Against Cancer’** programme of the **European Commission** and has the following objectives:

- to improve the **quality**, comparability and availability of cancer incidence data,
- to create a basis for **monitoring** cancer incidence and mortality in Europe,
- to provide **regular information** on the burden of cancer in Europe,
- to promote the **use** of cancer registries in cancer control, health-care planning and research.

# Recommendation for cancer registration

TITLE	Year First Publication & Revisions	Availability	Notes
Incidence date	1995, 1997	Download avail	
Basis of Diagnosis	1999	Download avail	
Multiple primaries	1995, 2000, 2004	Download avail	
Bladder tumours	1995	Download avail	
Tumours of the Brain and Central Nervous System	1998	Download avail	
Leukaemias and Lymphomas	2000	See note	Included in the ICD-O-3 <sup>rd</sup> rev.
Non-Melanoma Skin Cancers	2000	Download avail	
Method of Detection in Relation to Screening	2001	Download avail	
Confidentiality in Cancer registration	2002	Download avail	
Condensed TNM for Coding the Extent of Disease	2002	Download avail	
Standards and Guidelines for Cancer Registration in Europe	2003	Out of Print (no downloadable pdf avail)	This document includes some, but not all, of the documents previously published
Standard dataset	2005	Download avail	Differences from previous doc and subsequent 2010 Eurocim-2 Data Call
ENCR 2010 Data call	2010	Download avail	<i>De facto</i> it partially updates recommendation on minimum data set & multiple primaries

<p>International Agency for Research on Cancer World Health Organization</p> <p>Log in Main menu Registry contact File upload Feedback Questionnaires Links Elections</p> <p>You are here: Log in &gt; Main menu &gt; Questionnaires available Connected: Registro Tumori Piemonte Città di Torino   Log Out</p> <h3>Questionnaires available</h3> <ul style="list-style-type: none"> <li>A list of currently available questionnaires can be seen below.</li> <li>Please click on the questionnaire that you wish to take part in.</li> <li>Depending on the questionnaire, you will have an option to complete it in online, download it or upload it.</li> </ul> <table> <tr> <th>ID</th><th>Project</th><th>Title</th><th>Launch date</th><th>Start date</th><th>Finish date</th><th>Status</th><th>Access count</th></tr> <tr> <td>1005</td><td>EUROCOURSE</td><td>Access to registry data</td><td>11/09/2011 12:18:03</td><td>31/09/2011 16:16:41</td><td>31/09/2011 16:32:26</td><td>COMPLETED</td><td>1</td></tr> <tr> <td>1008</td><td>EUROCOURSE</td><td>Timeliness &amp; Completeness Questionnaire</td><td>27/01/2011 15:50:14</td><td></td><td></td><td>NOT STARTED</td><td>0</td></tr> <tr> <td>1000</td><td>ENCR</td><td>Overview of cancer registration practices</td><td>04/05/2010 10:13:46</td><td>21/05/2010 12:12:48</td><td>21/05/2010 12:40:24</td><td>COMPLETED</td><td>7</td></tr> <tr> <td>1001</td><td>ACCIS and IICC-3</td><td>ACCIS and IICC-3 Survey</td><td></td><td></td><td></td><td>NOT STARTED</td><td>0</td></tr> </table> <p>Here is a world map of the registries that have submitted the ENCR survey so far</p>								ID	Project	Title	Launch date	Start date	Finish date	Status	Access count	1005	EUROCOURSE	Access to registry data	11/09/2011 12:18:03	31/09/2011 16:16:41	31/09/2011 16:32:26	COMPLETED	1	1008	EUROCOURSE	Timeliness & Completeness Questionnaire	27/01/2011 15:50:14			NOT STARTED	0	1000	ENCR	Overview of cancer registration practices	04/05/2010 10:13:46	21/05/2010 12:12:48	21/05/2010 12:40:24	COMPLETED	7	1001	ACCIS and IICC-3	ACCIS and IICC-3 Survey				NOT STARTED	0
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International Agency for Research on Cancer  
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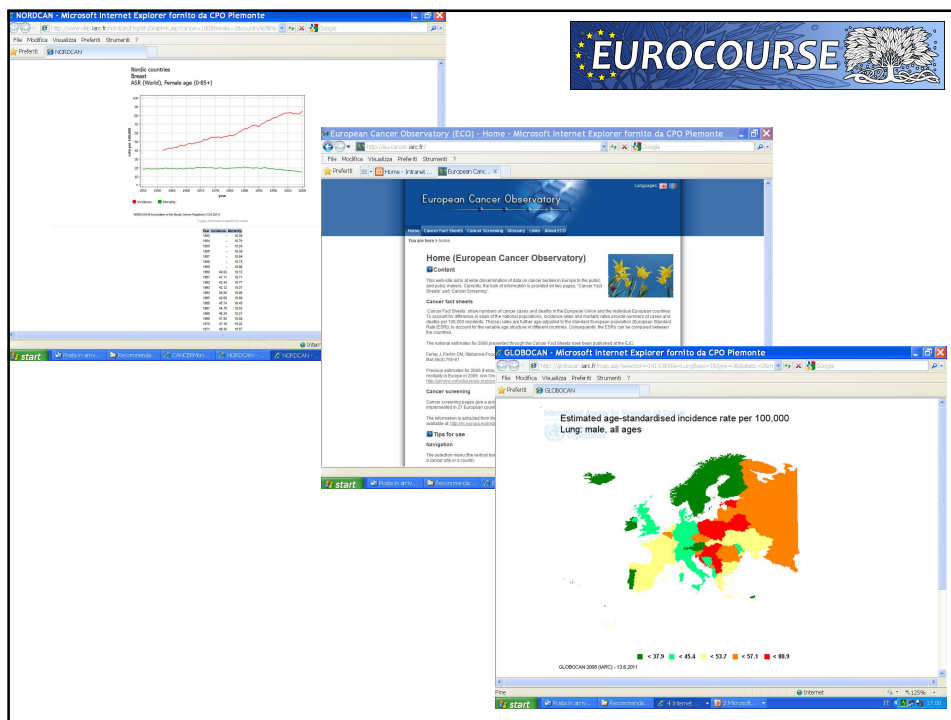
Connected: Regione Piemonte CNIS di Torino | Log Out

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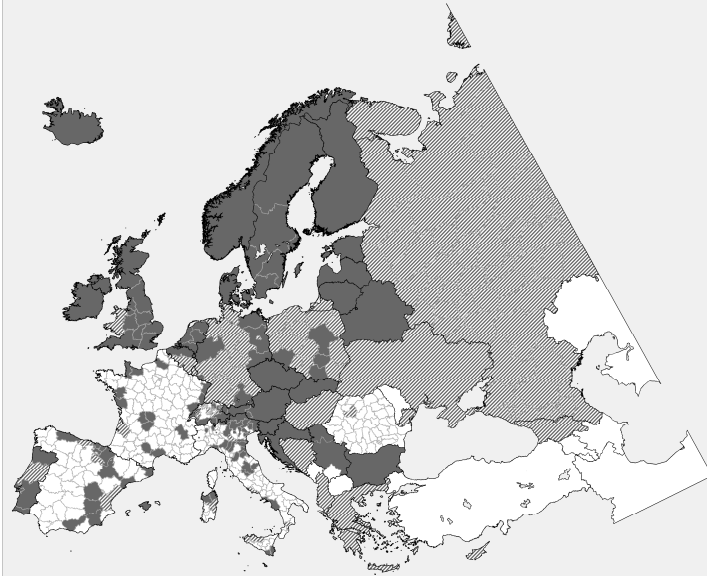
• Here are the files that have been transferred from your registry to the ENCR portal at IARC.  
• Click on a field header to sort by it.  
• If there are many files, use the pages at the bottom of the table to navigate.  
• Click here to view field definitions.

ID	Can	Content	Names	Size	Date Sent	Contacts	Send	Status
114	ENCR can 2000	Mortality	ORIS.TURIN_Mortality1980_2007.xls ENCR.EUTATIF_MORT_20002009_2.xls	10.37 MB	26/06/2010 09:45:00	FROM: stefano.rossi@cpo.it TO: msoucy@iarc.fr cc: galleguham@iarc.fr	YES	EURODIM
115	ENCR can 2000	File history (any file)	ORIS.TURIN.Layout_Sap2010.xls ENCR.EUTATIF_2000_2009_2.xls	44 KB	17/06/2010 10:38:45	FROM: stefano.rossi@cpo.it TO: msoucy@iarc.fr cc: galleguham@iarc.fr	YES	EURODIM
116	ENCR can 2000	Life tables	ORIS.TURIN.LifeTables1978_2008.xls ENCR.EUTATIF_2000_2009_2.xls	130.49 KB	17/06/2010 09:27:23	FROM: stefano.rossi@cpo.it TO: msoucy@iarc.fr cc: galleguham@iarc.fr	YES	EURODIM
117	ENCR can 2000	Cancer cases	ORIS.TURIN.Histocodes1980_2008.xls ENCR.EUTATIF_2000_2009_2.xls	5.74 MB	17/06/2010 09:28:04	FROM: stefano.rossi@cpo.it TO: msoucy@iarc.fr cc: galleguham@iarc.fr	YES	EURODIM
118	ENCR can 2000	File history (any file)	ORIS.TURIN.Layout_Sap2010.xls ENCR.EUTATIF_2000_2009_2.xls	44 KB	17/06/2010 10:38:45	FROM: stefano.rossi@cpo.it TO: msoucy@iarc.fr cc: galleguham@iarc.fr	YES	EURODIM
119	ENCR can 2000	Cancer cases	ORIS.TURIN.Histocodes1980_2008.xls ENCR.EUTATIF_2000_2009_2.xls	5.74 MB	17/06/2010 10:38:45	FROM: stefano.rossi@cpo.it TO: msoucy@iarc.fr cc: galleguham@iarc.fr	YES	EURODIM
120	ENCR can 2000	Mortality	ORIS.TURIN_Mortality1980_2008.xls ENCR.EUTATIF_MORT_20002009_2.xls	6.87 MB	22/06/2010 08:59:55	FROM: stefano.rossi@cpo.it TO: msoucy@iarc.fr cc: galleguham@iarc.fr	YES	EURODIM
121	ENCR can 2000	Life tables	ORIS.TURIN.LifeTables1978_2008.xls ENCR.EUTATIF_2000_2009_2.xls	132.71 KB	11/06/2010 10:35:54	FROM: stefano.rossi@cpo.it TO: msoucy@iarc.fr cc: galleguham@iarc.fr	YES	EURODIM
122	ENCR can 2000	Population	ORIS.TURIN_Pop1980_2008.xls ENCR.EUTATIF_2000_2009_2.xls	79.86 KB	11/06/2010 14:57:35	FROM: stefano.rossi@cpo.it TO: msoucy@iarc.fr cc: galleguham@iarc.fr	YES	EURODIM
123	ENCR can 2000	Population	ORIS.TURIN_Pop1980_2008.xls ENCR.EUTATIF_2000_2009_2.xls	79.86 KB	11/06/2010 14:57:35	FROM: stefano.rossi@cpo.it TO: msoucy@iarc.fr cc: galleguham@iarc.fr	YES	EURODIM

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### Coverage of cancer registration in Europe



From: Steliarova E, Parkin DM. **Cancer registration in Europe**. In: Razum, Oliver; Spallek, Jacob; Reeske, Anna; Arnold, Melina (eds). *Migration-sensitive Cancer Registration in Europe. Challenges and Potentials*. Frankfurt: Peter Lang Verlag 2011 (in press)