

## Work plan: 10 work packages

- WP1 Exchange of knowledge about national programmes
- WP2 Ethical conduct of research
- WP3 Tools for improving the quality, coverage and use of cancer registration data in Europe
- **WP4 The development, harmonization, analysis and exchange of European cancer registry data**
- WP5 Interface of cancer registries with cancer screening programmes
- WP6 Interface of cancer registries with clinical care
- WP7 Interface of cancer registries with biobanks
- WP8 Dissemination of findings and training
- WP9 European cancer control summit
- WP10 Coordination of EUROCOURSE activities

## Work package 4: tasks and deliverables

### **Tasks**

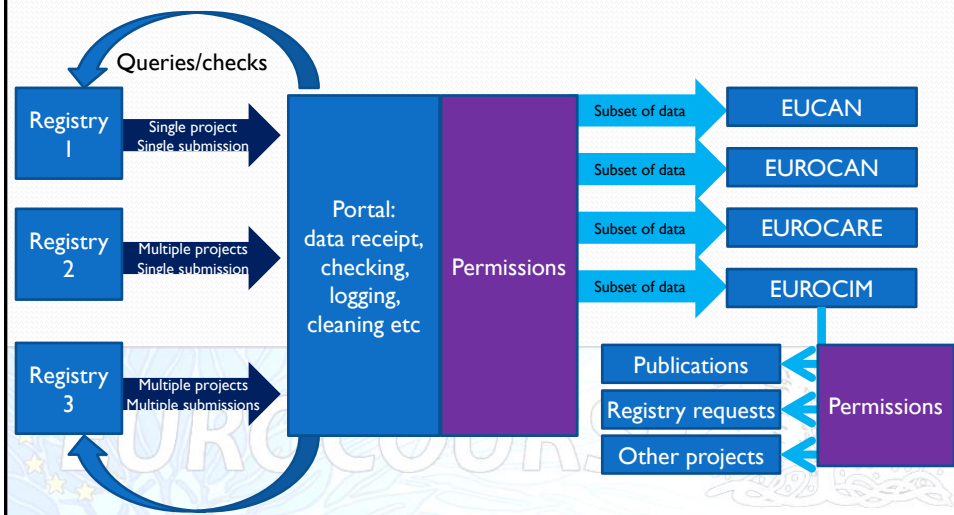
- 4.1: Harmonization of data submission and standardised European Cancer Database
- 4.2: Development of the analytical capacity for quality statistics in Europe
- 4.3: Exchange of data between registries

## Work package 4

- Call for data
- Data collection
- Data processing
- Website—European Cancer Observatory
- Descriptive analysis
- Research and publication of results
- Further development of data and analysis



## Data collection: Registries portal



International Agency for Research on Cancer

 World Health Organization

EUROCOURSE




[Log in](#) [Main menu](#) [Registry contact](#) [File upload](#) [Feedback](#) [Questionnaires](#) [Links](#) [Elections](#) [ENCR](#)

You are here: [Log in](#) > [Main menu](#) Connected: [National Cancer Registry Ireland](#) | [Log Out](#)


Welcome! This is the CIN portal at IARC.

 [Update Registry Contact](#)

Edit the contact details and other information concerning your registry.

 [Perform File Upload](#)

Upload new files, delete those uploaded by mistake and see file upload history.

 [View Your Feedback](#)

View and download files prepared for your registry by CIN staff at IARC.

 [Take Questionnaires](#)

Take a new questionnaire or check the status of completion of those started or submitted.

 [View Links](#)

View links to related projects or websites and download important documentation.

 [Vote In Elections](#)

The IARC elections are now open. **Vote before 16<sup>th</sup> June 2012!**

 [ENCR page](#)

ENCR related info and news. Accessible only to the ENCR members.

IARC, 150 Cours Albert Thomas, 69372 Lyon CEDEX 08, France - Tel: +33 (0)4 72 73 84 85 - Fax: +33 (0)4 72 73 85 75  
© IARC 2010 - All Rights Reserved - Email: [enccr@iarc.fr](mailto:enccr@iarc.fr)

International Agency for Research on Cancer

 World Health Organization

EUROCOURSE





## European Cancer Observatory

European Cancer Observatory (ECO) is a project developed at the International Agency for Research on Cancer (IARC) in partnership with the European Network of Cancer Registries (ENCR) in the framework of the EUROCOURSE project supported by the European Commission. The ECO platform provides a comprehensive system of information on cancer burden in Europe across three websites: [EUCAN national estimates](#), [EUREG registry data](#) and [EUROCOM downloadable data](#).

[EUCAN national estimates](#)

EUCAN presents national estimates of cancer incidence, mortality and prevalence for 26 major cancer types in 40 European countries for 2000 in a series of factbooks. All estimates were derived by a standard methodology, which may produce results different from national estimates developed by national bodies. EUCAN provides the links to these national data sources

[EUREG registry data](#)

[EUROCOM downloadable data](#)

EUROCOURSE



ENCR

EUROPEAN NETWORK OF CANCER REGISTRIES

 European Commission

Research & Innovation

IARC, 150 Cours Albert Thomas, 69372 Lyon CEDEX 08, France - Tel: +33 (0)4 72 73 84 85 - Fax: +33 (0)4 72 73 85 75  
© IARC 2011 - All Rights Reserved - Images Credits: Eurostat, public domain

International Agency for Research on Cancer  
World Health Organization

**EUROCOURSE**

## European Cancer Observatory

European Cancer Observatory (ECO) is a project developed at the International Agency for Research on Cancer (IARC) in partnership with the European Network of Cancer Registries (ENCR) in the framework of the EUROCOURSE project supported by the European Commission. The ECO platform provides a comprehensive system of information on cancer burden in Europe across three websites: [EUCAN national estimates](#), [EUREG registry data](#) and [EUROCM downloadable data](#).

<a href="#">EUCAN national estimates</a>	<a href="#">EUREG registry data</a>	<a href="#">EUROCM downloadable data</a>
	<p>EUREG is an online tool exploring geographical patterns and temporal trends of incidence, mortality and survival observed in European population-based cancer registries. Tables and charts for 35 major cancer entities in around 100 registration areas by sex, age and time period may be created and exported.</p>	

**EUROCOURSE** **ENCR** **European Network of Cancer Registries** **European Commission Research & Innovation**

IARC, 150 Cours Albert Thomas, 69072 Lyon CEDEX 08, France - Tel: +33 (0)4 72 73 84 85 - Fax: +33 (0)4 72 73 85 75  
© IARC 2011 - All Rights Reserved - Image Credits - Email: [eco@iarc.fr](mailto:eco@iarc.fr)

International Agency for Research on Cancer  
World Health Organization

**EUROCOURSE**

## European Cancer Observatory

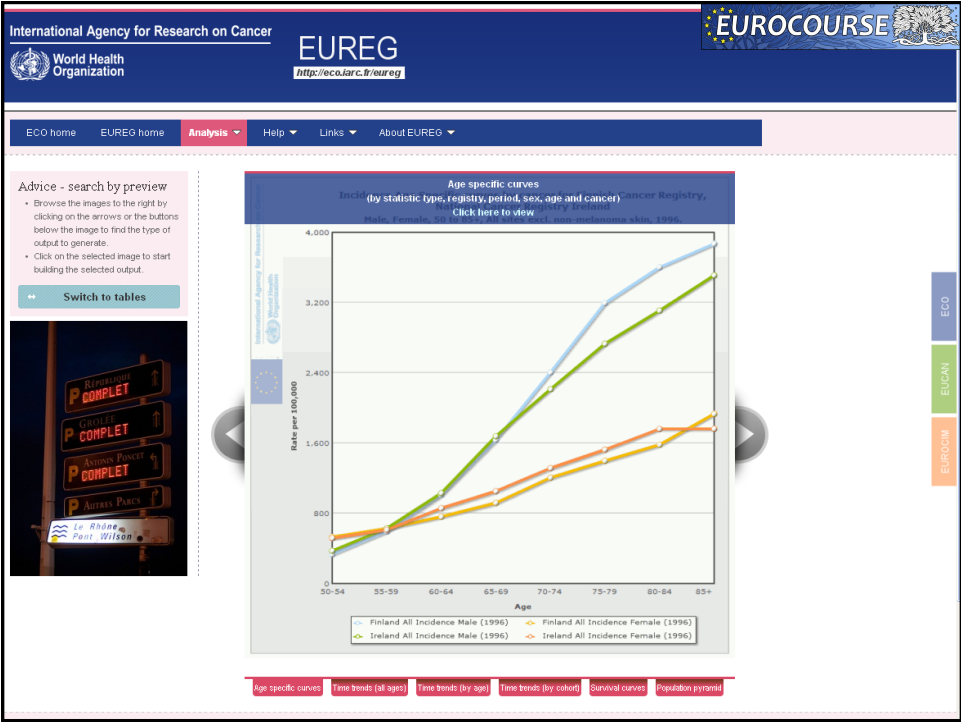
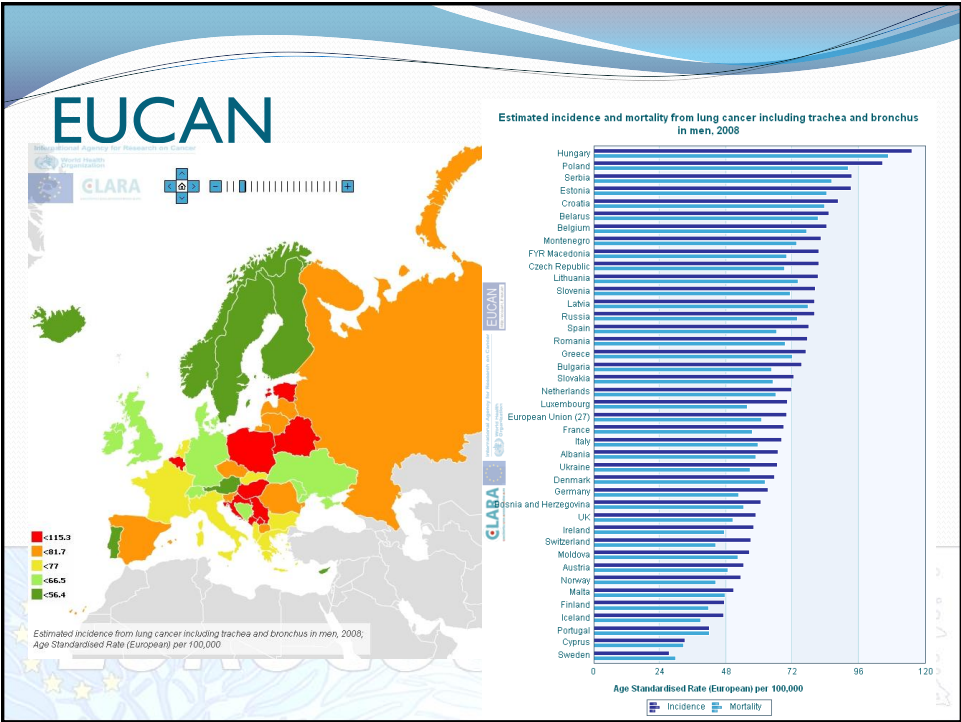
European Cancer Observatory (ECO) is a project developed at the International Agency for Research on Cancer (IARC) in partnership with the European Network of Cancer Registries (ENCR) in the framework of the EUROCOURSE project supported by the European Commission. The ECO platform provides a comprehensive system of information on cancer burden in Europe across three websites: [EUCAN national estimates](#), [EUREG registry data](#) and [EUROCM downloadable data](#).

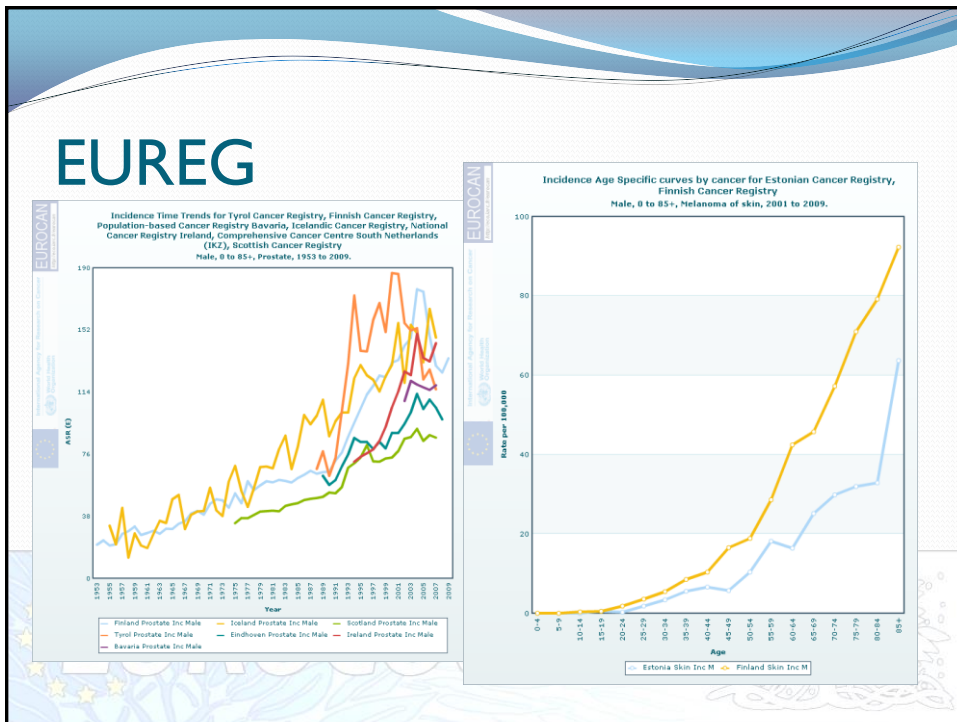
<a href="#">EUCAN national estimates</a>	<a href="#">EUREG registry data</a>	<a href="#">EUROCM downloadable data</a>
		<p>The EUROCM website allows the user to download aggregated data or request set of individual records following an on-line definition of the dataset of interest. Release of the data is subject to conditions or permissions.</p>

**EUROCOURSE** **ENCR** **European Network of Cancer Registries** **European Commission Research & Innovation**

IARC, 150 Cours Albert Thomas, 69072 Lyon CEDEX 08, France - Tel: +33 (0)4 72 73 84 85 - Fax: +33 (0)4 72 73 85 75  
© IARC 2011 - All Rights Reserved - Image Credits - Email: [eco@iarc.fr](mailto:eco@iarc.fr)







# EUROCIM

- Proposed data access (to be agreed by registries)
  - **public access data:** aggregated by registry, sex, 5-year age group, year of incidence and cancer entity.
  - **research data set:** de-identified, individual records, either full or with selected variables only. Each cancer registry will be required to give explicit permission to allow download of their individual records for each individual project.

# EUROCOURSE

## Advantages of portal

- Population-based data
- Common data submission for all projects
- Clear diagnostic criteria
- International coding and classification standards
- European structure
- Data inventory
- Rapid dissemination and reporting

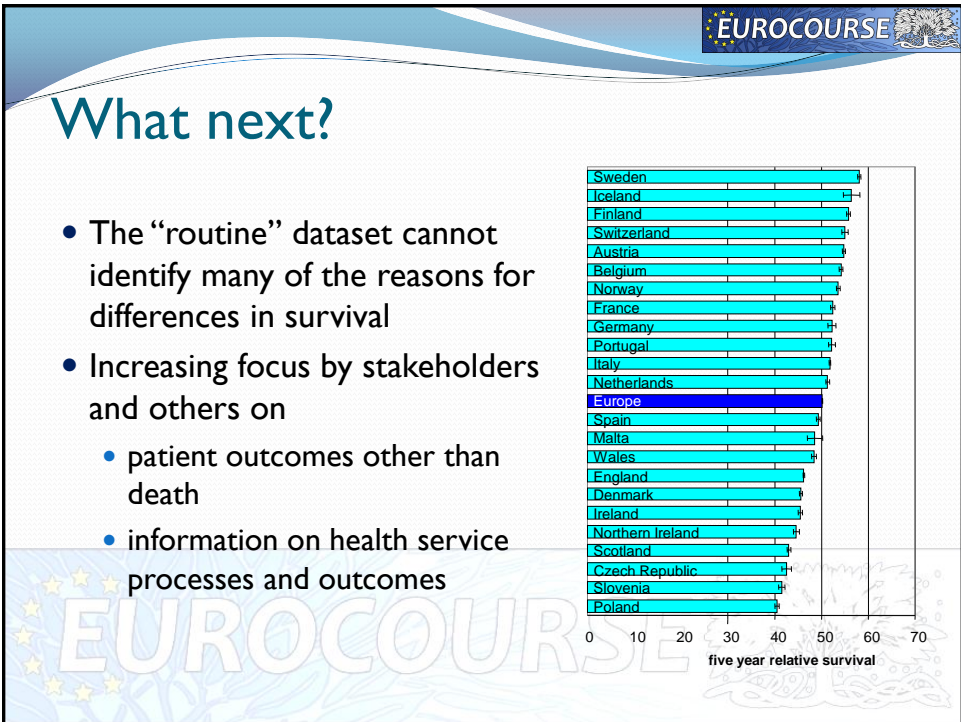


## The future of the Observatory

- European cancer database
- Updated annually
- Routine statistics and analysis available on-line
- Dataset downloads
- Expanded dataset







**EUROCOURSE**

# The “routine” European dataset

1. Patient identification number*	14. Incidental finding of cancer at the autopsy	31. Extent of disease
2. Tumour sequence number*	15. Grade (ICDO-3)	
	16. Laterality of paired organ	
3. Total number of tumours		32. Tumour size in mm
4. Date of birth*	17. Vital status at last contact	33. Examined nodes
		34. Metastatic nodes
5. Sex at birth*	18. Date of end of follow-up	35. C factor
6. Date of incidence*	19. Age at end of follow-up	36. Surgery
7. Date of registration	20. Duration of survival	37. Systemic therapy
8. Age in years*	21. Cause of Death	38. Radiotherapy
9. ICDO-3 Topography*	22. ICD edition	39. Hormone therapy
10. ICDO-3 Morphology*		40. Curative intent: surgery with curative intent
11. ICD-O-3 Behaviour*	23. TNM stage, primary site	41. Curative intent: chemotherapy, including adjuvant
12. Basis of diagnosis*	24. TNM stage, lymph nodes	42. Curative intent: radiotherapy
	25. TNM stage, metastases	43. Curative intent: other therapy
13. Detection of non-symptomatic cancer in an organised population-based screening programme	26. TNM stage grouping	44. Symptomatic treatment
	27. TNM reference	45. IARC flag
	28. Condensed TNM, T	
	29. Condensed TNM, N	
	30. Condensed TNM, M	

# Quality measures

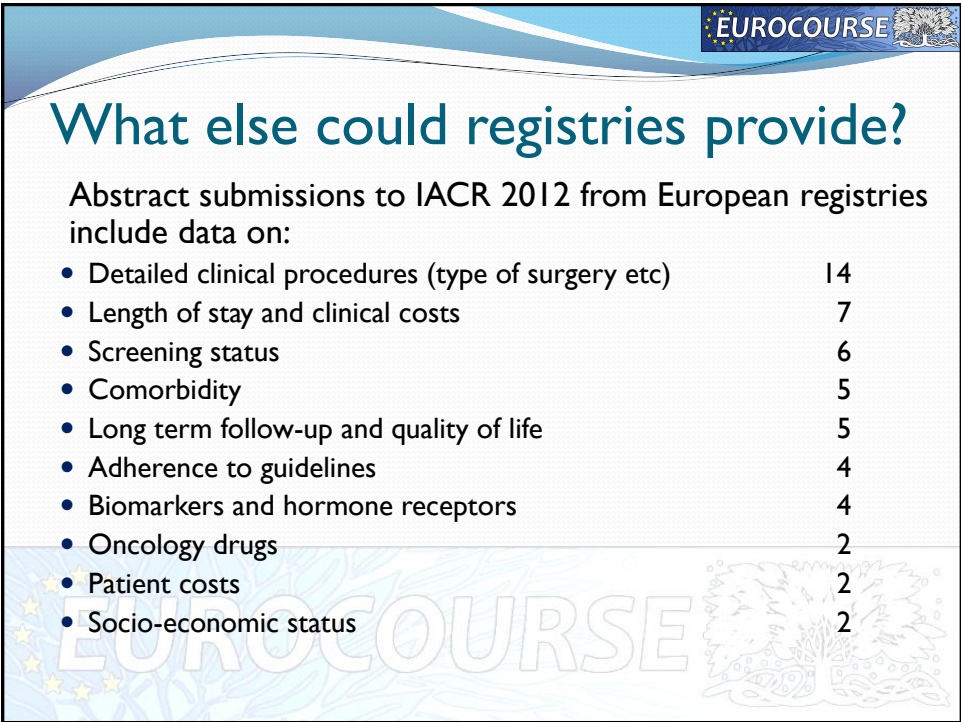
- Structure: quality of cancer services
  - Service utilisation
  - Screening
  - Access and delays
  - Costs and effectiveness
- Process: quality of care
  - Adherence to guidelines
  - Complications and side-effects of treatment
  - Equity
- Outcomes: quality of life
  - Patient-reported outcomes
  - Disease-free interval
  - Survival



# What else could registries provide?

Abstract submissions to IACR 2012 from European registries include data on:

- |  |    |
|--|----|
| • Detailed clinical procedures (type of surgery etc) | 14 |
| • Length of stay and clinical costs                  | 7  |
| • Screening status                                   | 6  |
| • Comorbidity  | 5  |
| • Long term follow-up and quality of life            | 5  |
| • Adherence to guidelines                            | 4  |
| • Biomarkers and hormone receptors                   | 4  |
| • Oncology drugs                                     | 2  |
| • Patient costs                                      | 2  |
| • Socio-economic status                              | 2  |



## Expanding the dataset: some issues

- Less control of quality by registries
- Varying levels of completeness
- National or local, rather than international, coding and classification standards
- Additional work for registries in matching, de-duplicating outside data sources
- Additional work in data management and quality assurance for central repository
- Data protection and other local issues
- Self-protection
- Collecting routine data is already difficult enough—resources!



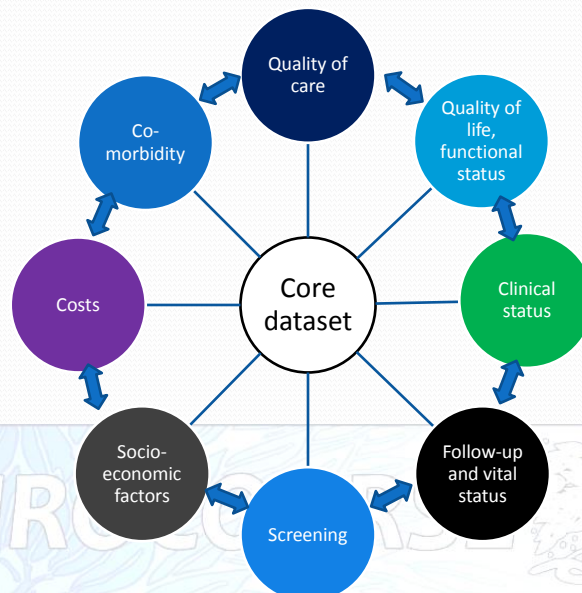
## One-speed or multi-speed Europe?



## Possible next steps

- Agreement on data sharing and release
  - Bring together collaborators
  - Agree data sharing and publication plan for additional data
  - Essential to have “payback” to registries for the additional work
- Develop standards for additional items
  - Define domains in which standards could be developed
  - ENCR to coordinate work on these
  - Develop standards for a wide range of data items

## Domains for standard development

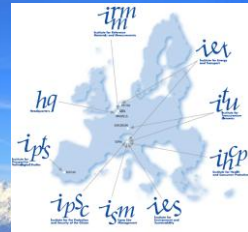


## European cancer information system (EPAAC proposals)

- Individual data from population based cancer registries
- Individual data from clinical registers
- WHO-IARC-Eurostat mortality data (for all causes and cancer)
- Population counts
- Socio-economic data aggregated at national and cancer registry level
- Risk factors aggregated at national and cancer registry level (tobacco, alcohol, diet)
- Area specific data on health care system resources (hospitals, RT machines, doctors)

## Proposal from EU Joint Research Centre, Ispra, Italy

- Host and develop portal for all European cancer registry data
- Host and develop European Cancer Observatory
- Data checking, cleaning, storage
- Administrative support of ENCR
- Work with registries on
  - Development of standards
  - Training
  - Publication





Thank you—if you would like to hear more...

Cork September 2012

- IACR Conference 17-19<sup>th</sup>
- ENCR Conference 19-20<sup>th</sup>
- CONCORD meeting 20-21<sup>st</sup>

[www.iacr2012.org](http://www.iacr2012.org)

IACR 2012

Registration methods  
Data quality  
Burden of disease  
Cancer risk factors and geography  
Evaluation of clinical care  
Survivorship and survival  
Linkages to other data  
Cancer control  
Workshops:  
•Geographical methods  
•ICDO3 and TNM coding;  
•time trends and projections

17-19 September 2012  
Cork, Ireland  
34th International Association of Cancer Registries Conference

