European Network of Cancer Registries

European Commission

CANCER REGISTRY DATA COLLECTION AND COMPARABILITY: Introduction

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Ispra May 3-5 2017

Course aims

At the end of the course, participants should be able to:

- Identify and assess the quality of their local sources of cancer data;
- be familiar commonly used cancer coding systems and some of the difficulties in applying these;
- Be familiar with European and world guidelines on registration and their application;
- Use a range of techniques to examine and improve the quality of registered data;
- Be aware of the specific requirements for haematological and childhood cancer registration;
- Pass on the skills learned to other registry staff;
- Prepare routine data sets for different users.

Course structure

- The course will be a mixture of didactic and interactive exercises.
- Participants will be assigned to one of a number of small groups for the didactic exercises.
- The group will discuss the topic or do the exercises assigned.
- They will then return with conclusions and comments to a plenary session, followed by general discussion and conclusions.

Day 1

9.30-9.45 Introduction.

9.45-10.00 The basic principles of cancer registration

10.00-10.45 Interactive exercise--data sources

10.45-11.10 Introduction to coding systems

11.30-12.30 Interactive exercise 2. Coding exercises in topography and morphology

12.30-13.00 Introduction to ENCR and IACR recommendations

13.00-14.00 Break

14.00-14.30 Interactive exercise: coding exercises on incidence date and multiple primarie

14.30-15.00 Coding stage: sources of data; coding systems

15.00-15.30 Interactive exercise 4. coding exercises on TNM staging. **LVE/OV**

15.30-15.45 Break

15.45-16.15 Introduction to coding treatments – sources, coding systems

16.15-17.00 Interactive exercise 5. coding exercises on treatments. **LV**

17.00-17.30 Wrap-up and comments from participants.

Day 2

9.30-10.00 Introduction to childhood cancer registration

10.00-10.30 Collecting long-term follow-up data.

10.30-11.00 ICCC update:

11:00-11:15 Break

11.15-11.45 Interactive exercise 6.Coding exercises in childhood cancer

11.45-12.15 Routine quality control in practice

12.15-12.45 ENCR/JRC quality check software: its use in practice

12.45-13.45: Break

13.45-14.15. Interactive exercise 7. Interpreting and using the ENCR/JRC quality check outputs.

14.15-14.45. Staff training –registry manuals/ standard operating procedures.

14.45-15.00: Break

15.00-15.30: Interactive exercise 8. staff training and training materials

15.30: 16.00 Outputs – preparing data for external users, registry reports.

16.00-17.00 General discussion, comments and suggestions from participants.

Quality assurance: an overview

Context

- Staff and training
- Know your health system
- Cooperation from health providers

Processes

- Multiple sources
- Routine checks
- Use the data: analysis and research

Continuous quality improvement

Quality in registration

Registration should be:

- Continuous
- Complete
- Consistent
- Relevant

Discontinuity—Hamburg registry

Requirements for continuity

- Structures
- Funding
- Cooperation
  - Official
  - Medical

Quality in registration

Registration must be:

- Continuous
- **Complete**
- Consistent

What does “complete” mean?

- All eligible cases should be registered
- All relevant data should be registered on each case

What is to be registered?

Cancers

- Invasive (malignant) cancers
  - Non-melanoma skin cancer
- Benign intracranial and intraspinal cancers
- Carcinoma in situ
- Cancer of uncertain behaviour

Patients

- Residents of the area
  - Population denominator
- Those treated in the area?

Achieving complete ascertainment

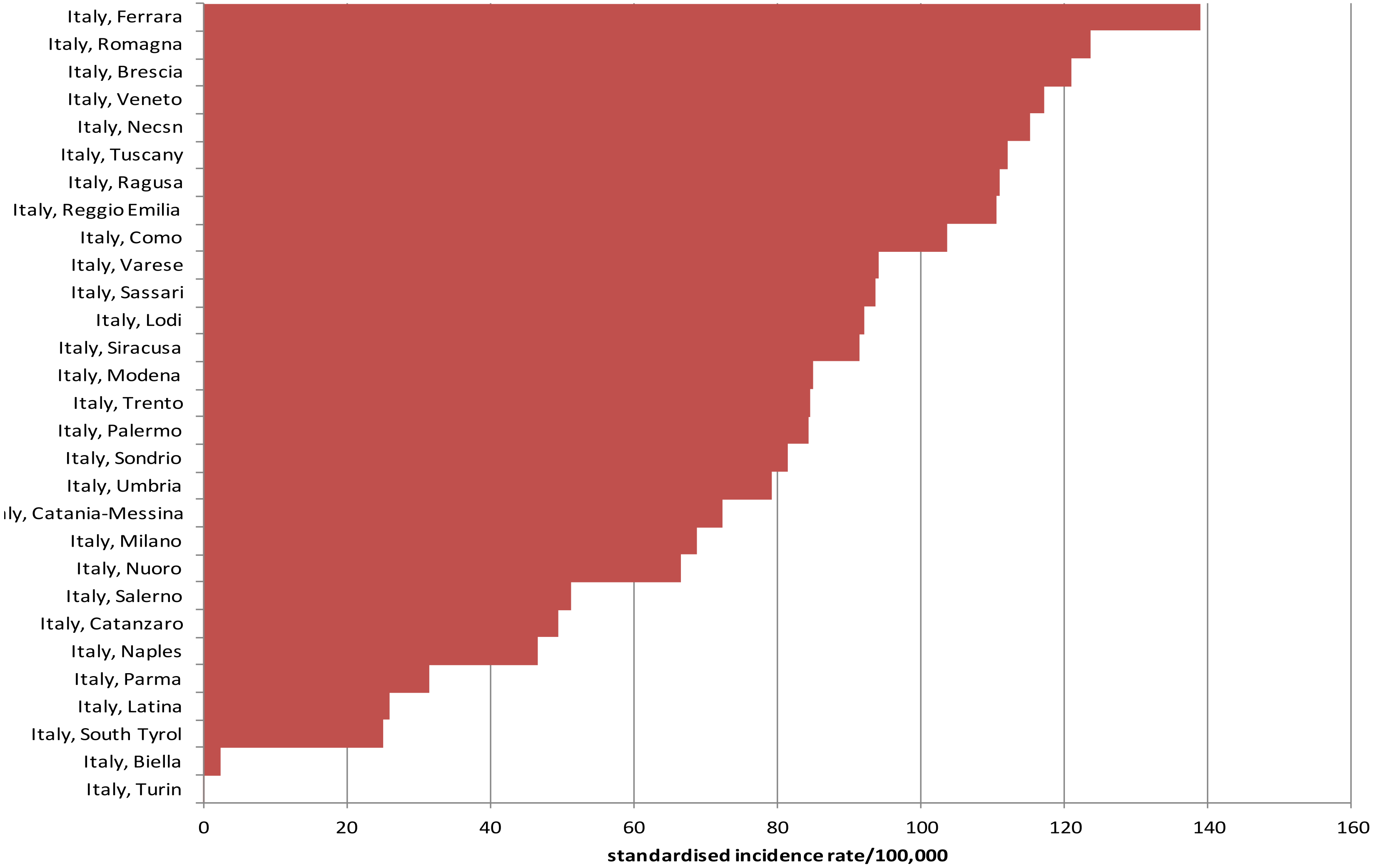
- Multiple sources
- Know your health system and sources
- Good communication with data sources
- Regular checks and follow up on case detection
- Effective linkage

Consequences of incompleteness

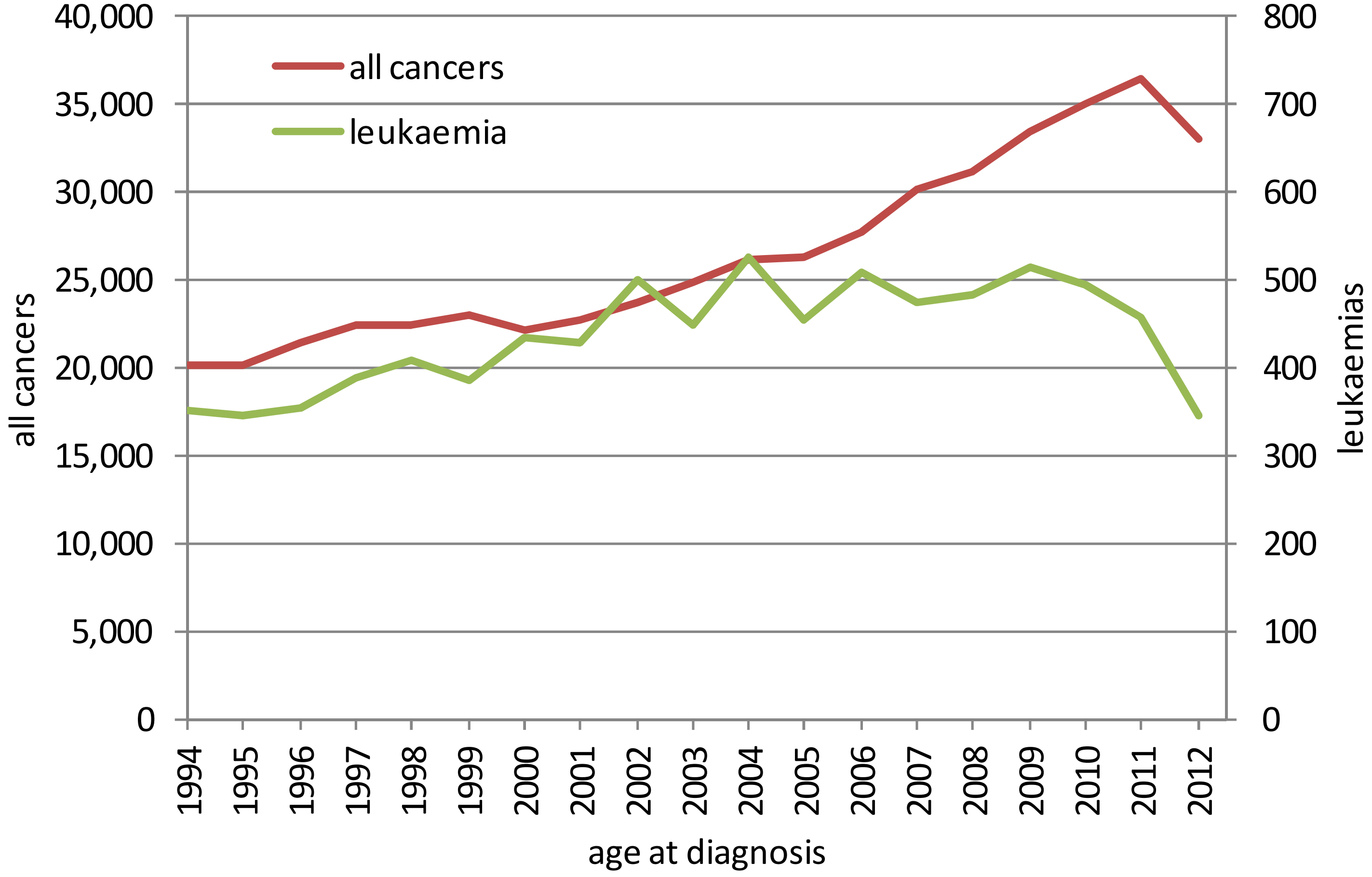
Inaccuracy in:

- Comparisons
- Trends
- Projections
- Survival

Non-melanoma skin cancer incidence Italy, 2005



Timeliness and completeness



Completeness of variables

Variable collected include

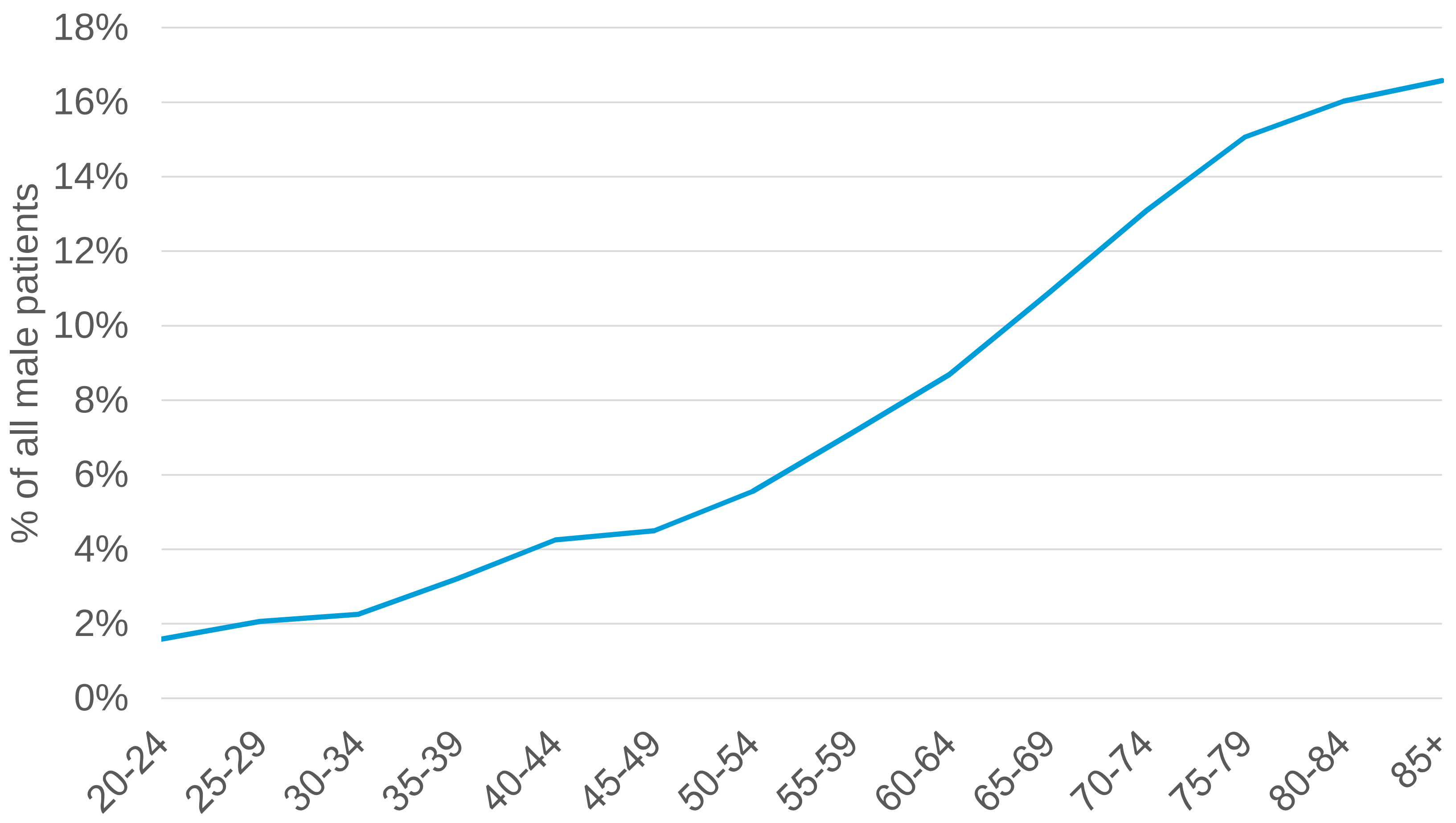
- Patient
- cancer
- method of diagnosis
- treatment
- follow-up

Completeness of data (UK, 2013)

	Target	**UK**	**England**	**ECRIC**	**NWCIS**	**NYCRIS**	**OCIU**	**SWCIS**	**Thames**	**Trent**	**WMCIU**	**Scot**	**WCISU**	**NICR**
Patient's name	*100.0*	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Patient's address	*99.9*	99.9	100.0	100.0	100.0	100.0	100.0	100.0	99.9	100.0	100.0	100.0	100.0	99.5
Sex	*100.0*	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Ethnicity	*51.8*	50.0	59.4	77.9	28.5	89.1	74.1	77.0	18.5	26.5	83.2	46.9	28.2	0.0
Date of death (where dead)	*100.0*	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Postcode	*100.0*	99.9	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	99.9	100.0	100.0	99.5
Date of birth	*100.0*	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Unique health identifier	*99.0*	99.8	99.9	100.0	99.9	100.0	99.9	99.9	99.6	100.0	99.9	100.0	99.9	98.7
Anniversary (diagnosis) date	*100.0*	99.9	99.9	99.6	100.0	100.0	100.0	100.0	99.4	100.0	99.96	100.0	100.0	100.0
Site of primary growth	*96.7*	96.9	96.9	97.0	97.1	96.8	97.1	97.6	96.7	96.7	96.7	97.1	96.4	97.2
Type of growth	*87.0*	88.0	88.7	91.0	87.5	86.3	87.9	91.6	89.4	85.5	90.6	87.6	83.0	87.9
Behaviour of growth	*99.7*	99.8	99.7	100.0	100.0	99.2	100.0	100.0	99.9	100.0	98.8	100.0	100.0	100.0
Basis of diagnosis	*98.7*	98.6	99.3	99.7	100.0	100.0	100.0	100.0	99.8	95.4	99.5	99.6	93.6	96.5

Bias in completeness of variables:

occupation; farmers as % of all patients



Essentials of registration

Registration must be:

- Continuous
- Complete
- **Consistent**
- Relevant

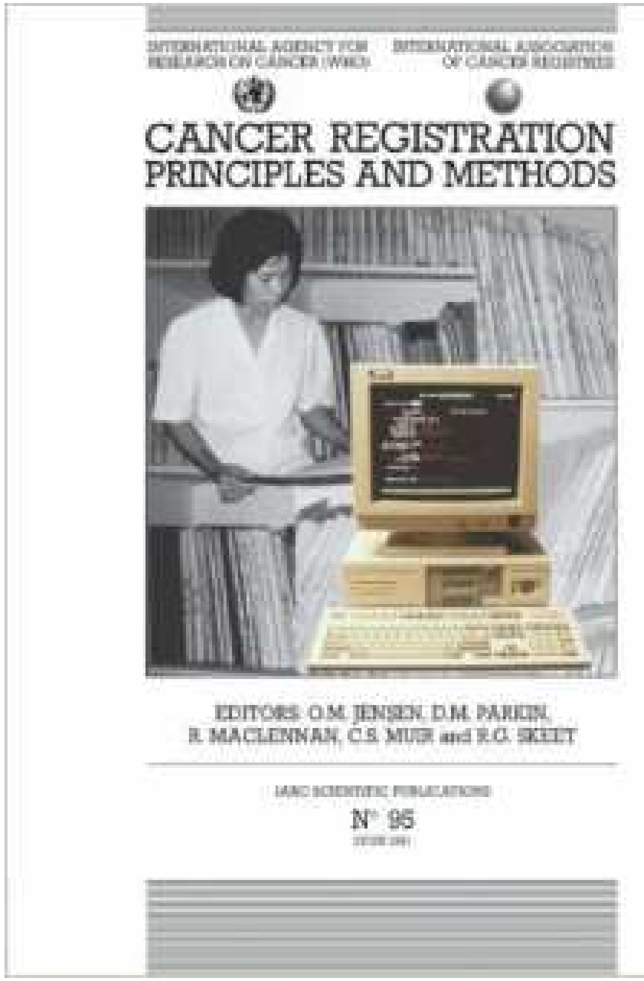
Consistency

- Internal
  - Between different hospital sites
  - Between years
  - Between cancers
- External
  - With other registries
  - With other local/regional/national data

Achieving consistency

- Clear guidelines
  - International recommendations
  - Local policies
- Quality assurance
- Staff training
  - Local
  - International

International guidelines



INTERNATIONAL AGENCY FOR RESEARCH ON CANCER (WHO)

INTERNATIONAL ASSOCIATION OF CANCER REGISTRIES

CANCER REGISTRATION PRINCIPLES AND METHODS

EDITORS: O.M. JENSEN, D.M. PARKIN, R. MACLENNAN, C.S. MUIR and R.G. SKEET

IARC SCIENTIFIC PUBLICATIONS

N° 95

w.encr.eu/index.php/news/186-encr-jrc-workshop-standards-training-2

European Network of Cancer Registries

Last news

- ENCR-JRC Workshop on standards and trainings
- GRELL Ascension Meeting 2016
- AIRTUM Meeting 2016
- IARC Conference 2016
- 10th European Breast Cancer Conference (EBCC-10)
- NAACCR 2016 Annual Conference "Gateway to Cancer Discoveries"

Vacancies

- Vacancy at Zürich and Zug Cancer Registry

Search

ENCR-JRC Workshop on standards and trainings

Published on Monday, 18 January 2016 17:16

This Workshop took place on 24 November 2014, at JRC, Ispra. Participants included ENCR SC members, representatives of IARC, Eurocare, Concord, Rarecare and experts from national networks of CRs, members of the Cancer Information group at the JRC, and other specialists in the field.

Two groups were created, one addressing recommendations and the other focussed on training needs.

In relation to recommendations, the Working Group suggested: updates of current recommendations or new specific ones for the following topics: Multiple primary rules; Staging; Registration/reportability criteria; Death Certificate Only cases (DCO) – Death Certificate Notified cases (DCN); Date of incidence in relation to diagnostic method; 'Complicated' cancers (e.g. bladder, etc.); Haematological cancers; and coding of borderline malignancies.

The group on training suggested that the following issues be addressed: Cancer Registration; Haematological malignancies; Analysis; Stage; Quality; Multiple primaries; many on Specific cancer types; and Grading. For training on specific technical methodology (analysis, data quality) it was suggested that traditional face-to-face courses be provided.

The technical proposals made at the workshop will assist the ENCR SC in prioritising future supporting activities to meet the real needs of CRs.

The report from this Workshop will be available soon.

European Commission

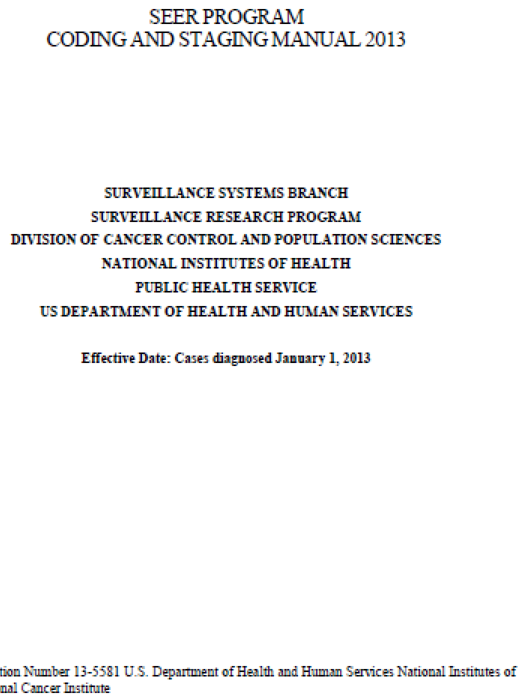
ENCR is hosted by the European Commission's Joint Research Centre

Legal notice

2014 ENCR membership survey

Please find here all the information on the 2014 ENCR Membership Survey

SEER (USA)



SEER PROGRAM
CODING AND STAGING MANUAL 2013

SURVEILLANCE SYSTEMS BRANCH
SURVEILLANCE RESEARCH PROGRAM
DIVISION OF CANCER CONTROL AND POPULATION SCIENCES
NATIONAL INSTITUTES OF HEALTH
PUBLIC HEALTH SERVICE
US DEPARTMENT OF HEALTH AND HUMAN SERVICES

Effective Date: Cases diagnosed January 1, 2013

ublication Number 13-5581 U.S. Department of Health and Human Services National Institutes of
h National Cancer Institute

Routine quality checks

Realtime and episodic

- Consistency checks
  - Site/morphology
  - Sex/site
  - Site/age
  - Rare sites
- Completeness checks
  - % HV
  - Unknown site/morphology
  - % DCI and %DCO

Quality in registration

Registration should be:

- Continuous
- Complete
- Consistent
- Relevant

Relevance

- Communication with stakeholders
- Effective and regular dissemination

Some routes of dissemination

- Reports
  - Annual
  - Commissioned
  - Collaborative
- Atlas
- Fact sheets
- Websites
  - Static and interactive
  - Local and international
  - Data availability
- Peer-reviewed papers
- Responses to queries
- Cluster investigations