

REGISTRY MANUAL, STANDARD OPERATING PROCEDURES, STAFF TRAINING

Harry Comber, Nadya Dimitrova

OUTLINE

- Registry manual
- Standard operating procedures
- Staff training
- Training materials, tools



REGISTRY MANUAL

- Contains information necessary for the work of the cancer registry staff
 - Description of the registry:
 - Legislative framework
 - Purpose, coverage
 - Organisation
 - Staff
 - Sources of data
 - Classifications and recommendations
 - Software for cancer registration
 - Standard operating procedures
 - Training materials



DESCRIPTION OF THE REGISTRY - EXAMPLE

- The registry became operational in **1953** following an **order** No. 321-4 by the MoH.
- The **structure** of CR includes a National cancer registry and 12 Regional cancer registries.
- CR covers the whole **population** of 9.5 million
- The CR consists of 7 **staff** – 1 head of the registry (engineer), 2 registrars, 1 database manager, 1 programmer and 2 physicians.



SYSTEMS USED FOR CLASSIFICATION AND CODING OF NEOPLASMS - EXAMPLE

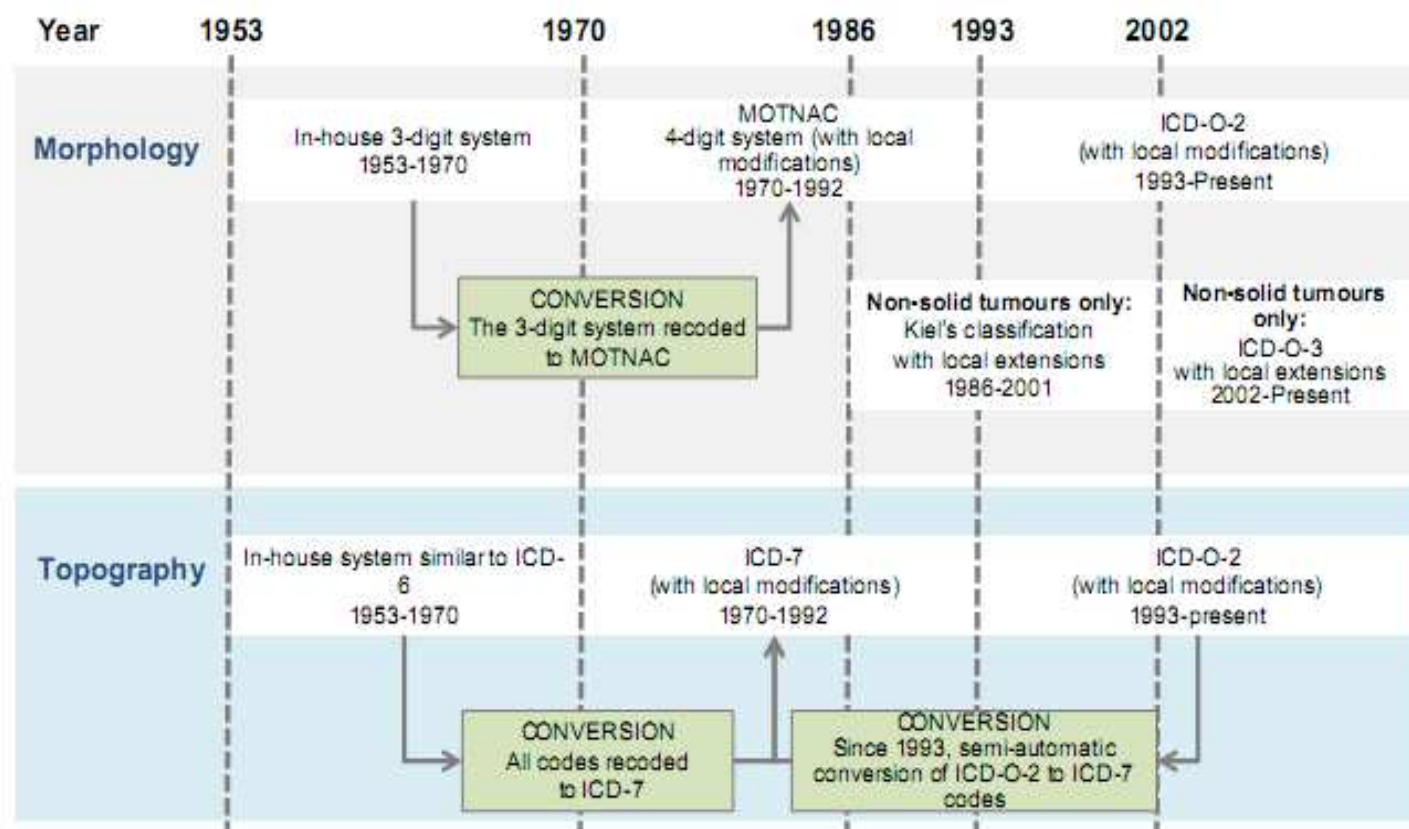


Fig. 1 – The standards of classification and coding of neoplasms followed, Norway 1953–2007.

RECOMMENDATIONS

- Incidence date
- Basis of diagnosis
- Multiple primaries
- Haematological malignancies
- Others



WHAT IS THE INCIDENCE DATE — EXAMPLE (NORWAY)

The in-house rules for the registration of incidence date (for the reporting of new cases or calculating survival) depart from the European Network of Cancer Registries (ENCR) recommendations,¹⁷ as the Registry always registers the earliest incidence dates reported on the sources of notification, whereas the ENCR rules are based upon a hierarchy of possible sources. For the period 2001–2005, 19.7% of the cases had a different date on applying the ENCR rules. For these cases, the median difference between the ENCR-defined date and the in-house incidence date was 10 days.

For reporting and comparability with other registries it is, however, possible, when needed, to select and give priority to the date when the specimen was taken.



RULES FOR RECORDING AND REPORTING MULTIPLE PRIMARIES – EXAMPLE (NORWAY)

The recording of multiple primary tumours in the main follows the recommendations given by ENCR.¹⁸ The recognition of two or more primary cancers does not depend on time, and the groups of topography codes considered as single sites (from ICD-O-2 and ICD-O-3) are followed, with systemic and multicentric cancers counted only once. The CRN has, however, used a more detailed grouping of specific histologies

constitute a new tumour or a recurrence. For the purposes of incidence reporting, the yearly publication from the CRN includes the first primary tumour within the same three character categories of the topography code in each patient.



REPORTABLE CASES – EXAMPLE (SEER)

- Definition of Reportable: Meets the criteria for inclusion in a registry. Reportable cases are cases that the registry is required to collect and report.
 - **Malignant Histologies (In Situ and Invasive)**
 - Report all histologies with a **behavior code** of **/2 or /3** in the *International Classification of Diseases for Oncology, Third Edition (ICD-O-3)*
 - **Benign/Non-Malignant Histologies**
 - Report **Pilocytic/Juvenile astrocytomas**; code the histology and behavior as 9421/3
 - Report **benign** and **borderline** primary **intracranial** and **central nervous system (CNS)** tumors with a behavior code of /0 or /1 in ICD-O-3, **effective with cases diagnosed 01/01/2004** and later. See the table below for the specific sites.



REPORTABLE CASES – EXAMPLE (NORWAY)

Incident cases in Norway comprise all malignant and *in situ* neoplasms, and the incidence reported in Cancer in Norway (CiN) includes all cases with the 5th-digit behaviour code 3 according to ICD-O-3, for haematological malignancies, and ICD-O-2, for other tumours. Cases with 5th-digit behaviour code 1 are also included for tumours of the central nervous system.



HINT

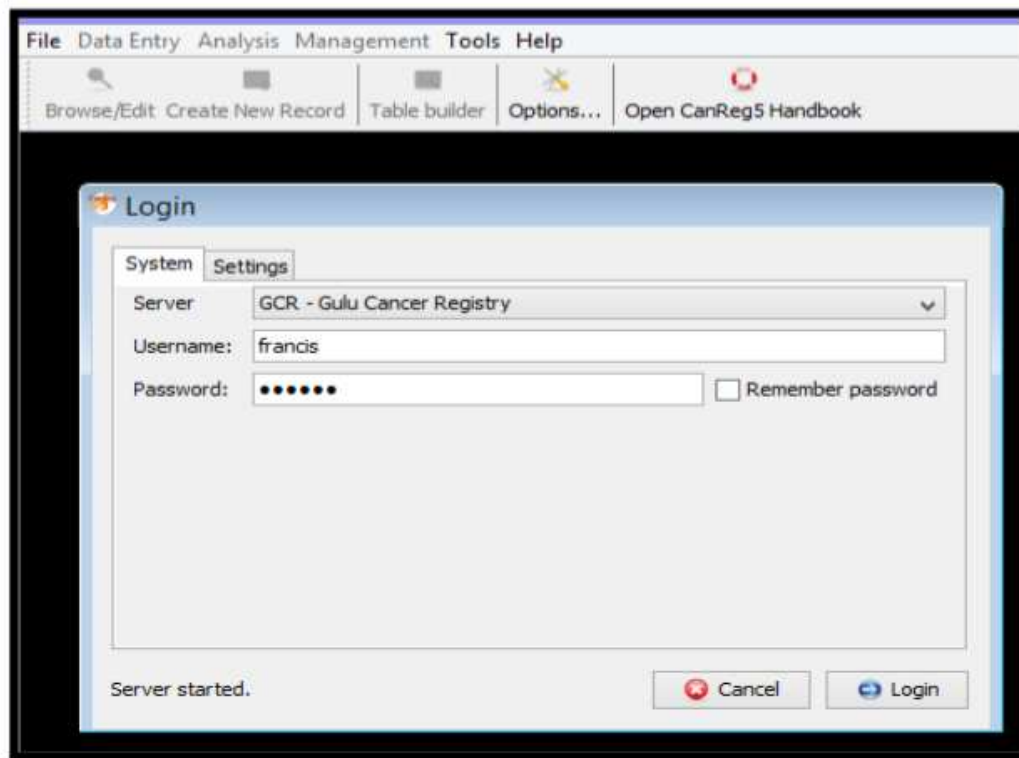
- Have all of these details **written down in a Manual.**
- Don't rely only on the historical memory of the staff.
- Document all changes/interpretations at the time they are made and keep the registry manual **updated annually.**



SOFTWARE FOR CANCER REGISTRATION - EXAMPLE

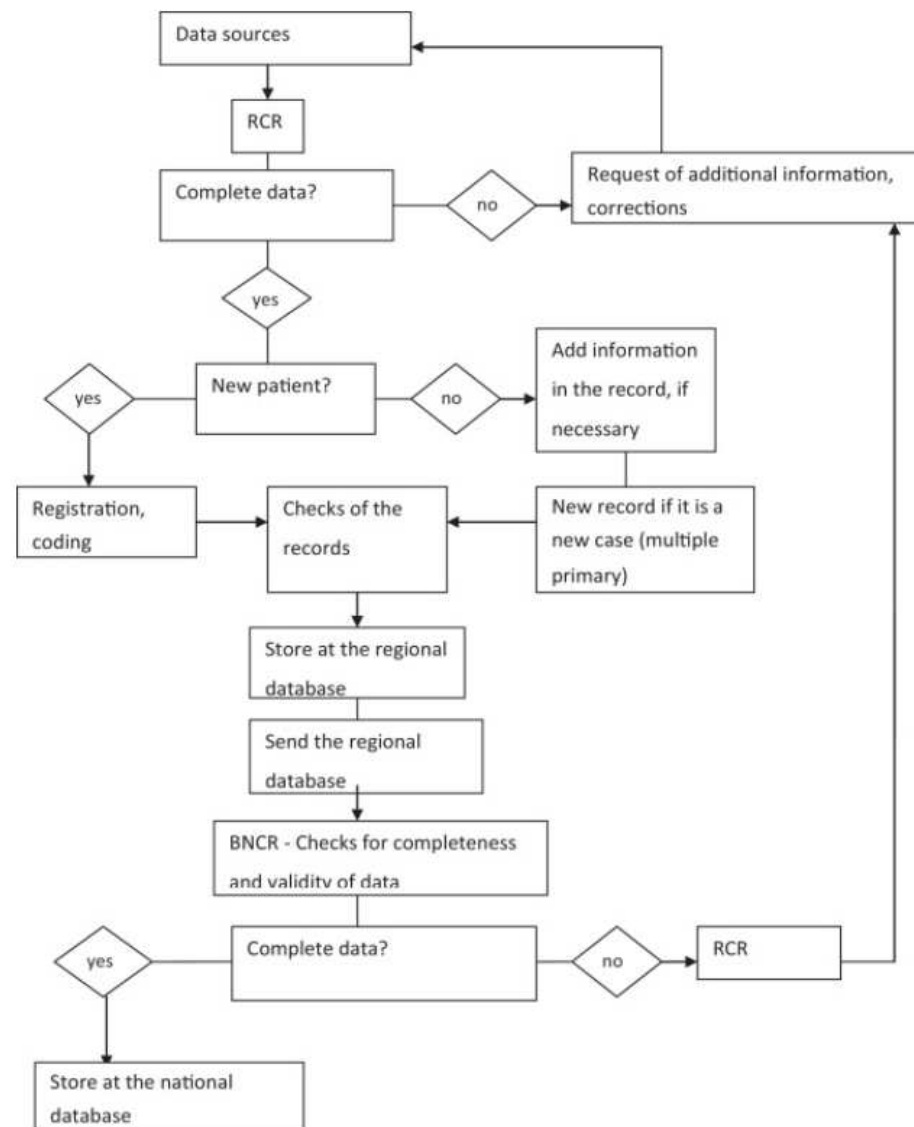
Gulu Cancer Registry uses CanReg5 system to enter, clean and analyzed data on cancer cases.

The database is installed and run from an internet server for purpose of data back in the cloud



server. The accounts is accessible by namely; Supervisor, Registrars and Analyst all of whom have different level of rights to accessing the features and

STANDARD OPERATING PROCEDURES - EXAMPLE



STANDARD OPERATING PROCEDURES - EXAMPLE

SEER Program Coding and Staging Manual 2016 – Revised Coding Instructions

- b. Record the tumor size as **one mm more than stated when** tumor size is reported as “more than x mm” or “more than x cm”
 - i. For example, if size is > 10 mm, code size as 011
 - ii. Often measurements are given in centimeters and must be converted to millimeters such as: > 1 cm (> 10 mm), code as 011; or > 2 cm (> 20 mm), code as 021
 - iii. Code 989 when described as anything greater than 989 mm (98.9 cm)
- 5. Record “between” tumor sizes as the midpoint between the two measurements when tumor size is reported to be between two sizes; i.e., add the two sizes together and divide by two.

Example: Tumor size is “between 2 and 3 cm.” Code size as 025 since $2 + 3 = 5$ divided by 2 = 2.5 cm (25mm).



STAFF TRAINING

- Initial and ongoing training
 - At work, on the job
 - Training courses:
 - Formal training courses and use of standard manuals - to **avoid the establishment of individualized practices** by single staff members, as well as individualized practices by single registries deviating from standard procedures.
 - Attendance at international training courses--who decides and **who should go!**



STAFF TRAINING

- Standard operating **procedures**
- **IT** training
- Training on **confidentiality**, local laws on data etc.
- Training and audits on **document handling and security**
- Joint training **with data processing/analysis staff** on problems, interpretation



STAFF TRAINING

- Training materials - examples

- The IARC–IACR *Manual for Cancer Registry Personnel* (Esteban *et al.*, 1995), (<http://www.iarc.fr/en/publications>)
- *Pathology of Tumours for Cancer Registry Personnel* (Buemi, 2008), (<http://www.iacr.com.fr/PathologyManualApr08.pdf>). It explains in simple terms the genesis of tumours and the techniques used for pathological diagnosis, and contributes to the understanding of the terminology used.
- The Surveillance, Epidemiology, and End Results (SEER) Program of the USA (<http://seer.cancer.gov/>).



TRAINING TOOLS



Registry Resource

In addition to online learning opportunities, publications and articles, and in-person programs, the Center for Cancer Registry Education strives to deliver valuable information to help them to succeed. These items are complimentary.

New Resource! Informational Abstracts

The abstract is the basis of all registry functions. It is a tool used to help accurately report cancer data. An abstract must be complete, containing all the information needed to provide a complete picture of the cancer case. To assist registrars in preparing abstracts, NCRA's Education Committee has developed a presentation titled *Using the Informational Abstracts in Your Registry* that shows how specific abstracts provide an outline to follow when determining what text to include.

Informational Abstracts

- [Informational Abstract: Bladder](#)
- [Informational Abstract: Breast](#)
- [Informational Abstract: Cervical](#)

Video Presentation Materials

- [PowerPoint Slides](#)
- [Where to Find Informational Abstract Various Data](#)

Resources for International Registries

NAACCR is pleased to announce the **NAACCR International Fellowship Program**.

This program will provide hotel accommodation and conference registration for staff of cancer registries from low and middle income countries to attend the NAACCR Annual Conference in Albuquerque, New Mexico, June 20-22, 2017.

Please click [here](#) for details and application.

INTERNATIONAL AND GLOBAL CANCER SURVEILLANCE

Welcome to the North American Association of Central Cancer Registries' International and Global Cancer Surveillance Hub. The purpose of this Global Cancer Registry-Centered Surveillance site is to:

1. Build and enhance ties with cancer surveillance organizations in the international arena.
2. Improve the worldwide availability of cancer registry-centered surveillance data, strengthen regional cancer surveillance networks, and improve resource sharing between high quality cancer surveillance systems and middle/low resource environments.
3. Facilitate communications and knowledge transfer through NAACCR members to provide a direct and tangible benefit for low resource countries.
4. Enhance engagement and provide training tools for building capacity and enhancing cancer registry-centered surveillance in middle and low resource countries.



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EDUCATIONAL RESOURCES

GLOBAL CANCER REGISTRY EDUCATIONAL RESOURCES

TRAINING TOOLS

Cancer Statistics

[Statistical Summaries](#)[Interactive Tools](#)[Publications](#)

For Researchers

[Datasets and Software](#)

For Cancer Registrars

[Coding Rules, Training and Support](#)

About SEER

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Data Submission Requirements

Reporting Guidelines

[\[+\] Casefinding Lists](#)[\[+\] SEER Coding Manual](#)[Grade Coding Instructions 2014+](#)[\[+\] Hematopoietic Project](#)[Historical Staging and Coding Manuals](#)[ICD-O-3 Coding Materials](#)[\[+\] MP/H Rules](#)

Staging

[Registrar Staging Assistant \(SEER*RSA\)](#)[\[+\] Collaborative Stage](#)

Cancer Registrar Training

The following training resources are available for cancer registrars.

- [Hematopoietic & Lymphoid Neoplasms Online Training](#) – Educational recordings of presentations for the hematopoietic and lymphoid neoplasms project
- [Multiple Primary and Histology Coding Rules Training](#) – Recordings of the online MP/H Rules Training sessions.
- [SEER*Educate](#) – Online training platform for cancer registry professionals
- [SEER Self Instructional Manuals for Cancer Registrars](#) – A collection of instructional manuals in PDF format.
- [SEER's Training Web Site](#) – Web-based training modules for cancer registration and surveillance.

[SEER Advanced Topics for Registry Professionals](#) – An annual event that provides advanced training in data collection and coding.

Learn more about [Becoming a Cancer Registry Professional](#).



TRAINING TOOLS



Search SEER Training:

Enter Keyword(s)

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Cancer Registration & Surveillance Modules

Site-specific Modules

Colorectal Cancer

Introduction

Anatomy of Colon and Rectum

Abstracting, Coding, & Staging

ICD-O Site Codes

Morphology & Grade

Extent of Disease

Staging

Abstracting Keys

Treatment

For hands-on exercises, please go to [SEER*Educate](#).

Resources

Archived Modules

Updates

MORPHOLOGY & GRADE

ICD-O-3 Morphology Codes

If the diagnostic term in the pathology report is not in the following list, be sure to consult your ICD-O manual.

Colon and Rectum

- Adenocarcinoma (814_3; 98% of tumors a
- Mucinous (colloid) adenocarcinoma (8480.
- Signet ring adenocarcinoma (84903)
- Adenocarcinoma in adenomatous polyps (
- Adenocarcinoma in adenomatous polyps
- Adenocarcinoma in villous adenoma (8261
- Other carcinomas
- Lymphoma (many cell types)

Appendix

- Carcinoids (82401)

Anal Cancer

- Squamous cell carcinoma of the anus (807
- Cloacogenic (81243; transitional cell 8120.
- ano-rectal junction
- Basal cell cancer (809_3)
- Extramammary Paget disease (85423)
- Bowen disease (80812)
- Malignant melanoma (872_3)
- Sarcomas and lymphomas of the perianal

QUIZ: INTRODUCTION TO COLORECTAL CANCER

1. It is estimated that 147,500 new cases of colorectal cancer will be diagnosed in 2003, 2/3 in men and 1/3 in women.
☐ True ☐ False
2. Some 30 percent of colorectal malignancies occur in those who are under age 40.
☐ True ☐ False
3. The exact cause of colorectal cancer is unknown, but at least eight different genes can be traced to dietary fat, particularly animal fat.
☐ True ☐ False
4. People over 65 are at risk of developing colorectal cancer.
☐ True ☐ False
5. Familial or multiple polyposis is a disease occurring in some families that consists of multiple adenomatous polyps of the colon which have high malignant potential.
☐ True ☐ False
6. Women are more likely to develop anal cancer than men.
☐ True ☐ False
7. The early signs of colorectal cancer are very different from those symptoms caused by other gastrointestinal illnesses, such as influenza, ulcers, and colitis (an inflammation of the colon).
☐ True ☐ False



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Training on Quality of Cancer Registry Data

A Training Workshop on Quality of Cancer Registry Data took place on 5 October 2016, as a side event to the Scientific Meeting and General Assembly. About 50 participants attended the workshop which covered the process of data quality evaluation, methods for assessing the completeness of data, use of the JRC-ENCR Quality Check software and reading outputs. The JRC provided feedback on the ENCR-JRC project and the further processing and feedback that will be sent to the registries.

For further details, see below the presentations given at the training.

Speaker	Presentation
Nadya Dimitrova	The Process of Cancer Registry Data Quality Evaluation
Carlotta Buzzoni	The Completeness of Cancer Registry Data
Carmen Martos/ Fancesco Giusti	From Harmonization of Quality Check Project to the Development of the JRC-ENCR Quality Check Software


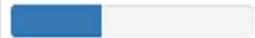
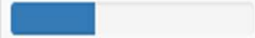
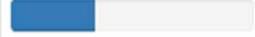

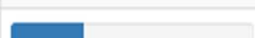
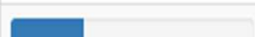
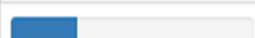
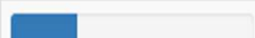
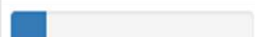
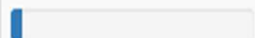
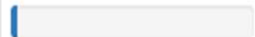
Download [here](#) the test dataset used at the training to illustrate the use of the JRC-ENCR Quality Check Software (QCS). More information on the QCS can be found [here](#).



ENCR-JRC SURVEY ON ISSUES TO DISCUSS AT THE ENCR GA 2016


○ Results – overview

The issues my registry wants to have addressed are:

		Answers	Ratio
Quality Control processes		21	52.50 %
Legislation		15	37.50 %
Funding		14	35.00 %
Interaction with policy makers, clinicians & other specialists		14	35.00 %
Data analysis		13	32.50 %
Data collection		12	30.00 %
Recommendations		12	30.00 %
Cancer control-related activities		11	27.50 %
Training		11	27.50 %
Reporting		6	15.00 %
No Answer		2	5.00 %
Other		1	2.50 %



COMMENTS - TRAINING

- 90% of the personal who work at the Registry **has not been trained**.
 - **no training** for the involved personnel, so far
 - **coding** training programmes should be re-scheduled to keep the harmonization alive of procedures and guides.
 - We need training in **coding and data analysis**
 - training as for **basic themes** on registration as for **more detailed** topics.
 - training in **data collection** and in **data analysis**. We would like to have opportunities to **attend courses** or to **visit other registries**
 - New methodologies for **data analysis**, **staging systems** other than TNM
 - Training programme for **IT specialists or non-cancer specialists** working with cancer data.
 - How to get **funding** to train all registry personnel? How do you organise this training? What about ENCR **on line courses**?
- 

THANK YOU!

