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Joint Research Centre

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Coding Primary Site and Tumour Morphology

JRC / ENCR, IARC, Slovenian Cancer Registry

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Outline

- What is coding and why do we need it?
- ICD-10 and ICD-O
- ICD-O-3 Topography coding rules
- ICD-O-3 Morphology coding rules
- How to code?
- ICD-O-3 online

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What is coding and why do we need it?

Coding:

- to assign numerical codes to text descriptions

Example: Malignant neoplasm of the lung = C34

Advantages:

- group cases with similar concepts – site of origin, type of cancer
- complex series of pieces of information can be:
  - conveyed,
  - stored and
  - retrieved in the form of numbers (quickly, easier)

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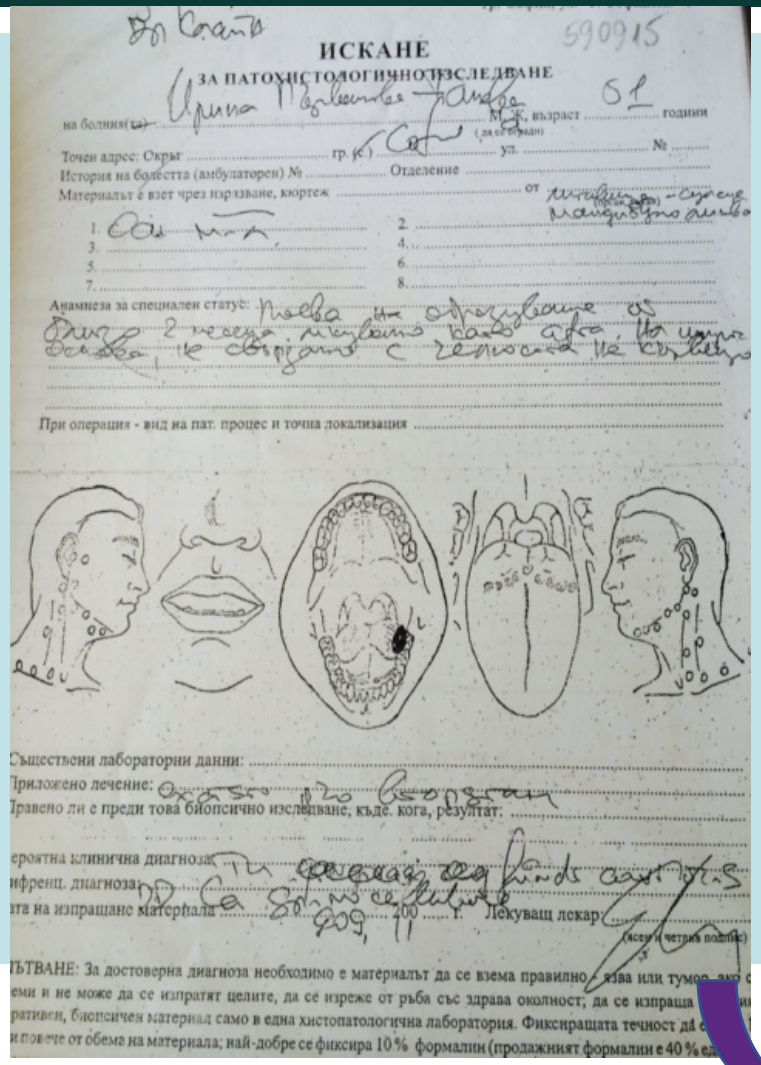
Cancer registry data - example



ИСКАНЕ

ЗА ПАТОХИСТОЛОГИЧНО ИЗСЛЕДВАНЕ

PIN	Incidence date	Site	Morphology and behavior	grade
1011000047	04082000	C419	91803	1
1011000713	22062000	C504	85003	2
1011010324	26072001	C186	84803	2
1011010983	04052001	C56	84503	4
1011020767	30092009	C229	80003	2
1011030136	01032007	C80	80003	9
1011030898	27102005	C64	83103	4
1011040255	04012004	C629	91003	1

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What is coding and why do we need it?

Coding is based on **classification:**

- arrangement of neoplasms or distribution in classes according to a method or system, ensuring **comparability**.

The two most important items of information are:

- **Topography:** the location (site) of the tumor in the body;
- **Morphology** (histology, cytology): the appearance of the tumor when examined under the microscope.

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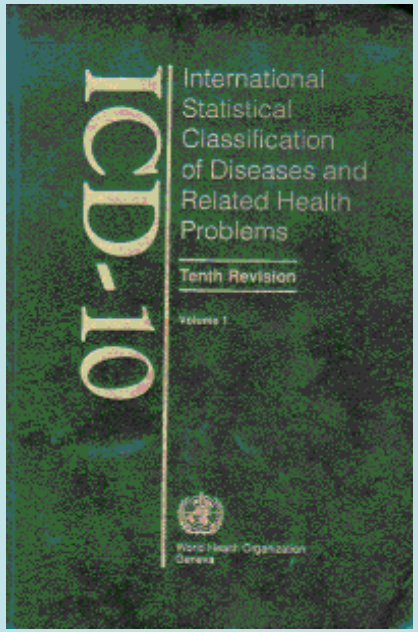
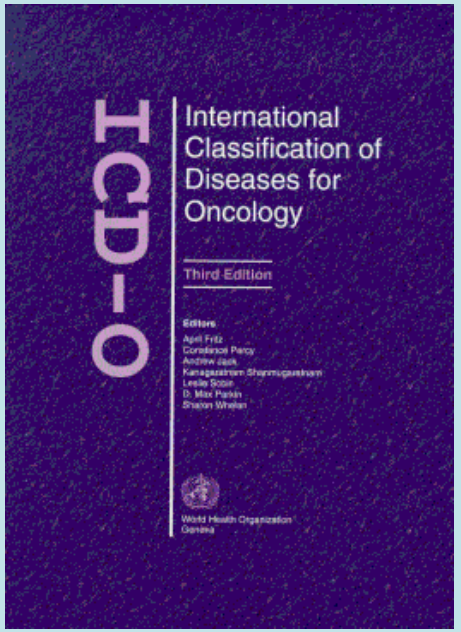
What is ICD-O?

- Subset of *International Classification of Diseases*
- Specific code set for **neoplasms**
- Coding system for **primary site** and **cell type**
  - *Example*: adenocarcinoma of lung = C34, 8140/3
- **ICD-O-3.2** version published in April 2019, to be used from 2020 - http://www.iacr.com.fr





Original - **all diseases** Subset - **neoplasms only**

Differences: **Organization**

- ICD-10 organized by
  1. Behavior
  2. Anatomic site involved
  3. Morphology codes optional

- ICD-O organized by
  1. Anatomical site involved
  2. Morphology + Behavior

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ICD-10 and ICD-O-3

Term	ICD-10	ICD-O-3
Lung tumor, benign	D14.3	C34.9 8000/0
Lung tumor, borderline	D38.1	C34.9 8000/1
Lung tumor, in situ	D02.2	C34.9 8000/2
Lung tumor, invasive	C34.9	C34.9 8000/3
Lung tumor, metastatic	C78.0	C34.9 8000/6
Lung tumor, uncertain if primary or metastatic	D38.1	C34.9 8000/9

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Differences: **Codes**

- Some **special codes** added in ICD-O
- Some ICD-10 codes **not used**
- Some codes used **differently**

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ICD-O **Special Site Codes**

C42 Hematopoietic and reticuloendothelial system

- C42.0 Blood
- C42.1 Bone marrow
- C42.2 Spleen
- C42.3 Reticuloendothelial system, NOS
- C42.4 Hematopoietic system, NOS

- Use as primary site for **leukemia** (C42.1), **multiple myeloma** (C42.1), **Waldenstrom macroglobulinemia** (C42.0)

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ICD-10 **Codes Not Used in ICD-O**
Histology-specific ICD-10 Codes

	ICD-10	ICD-O
C43	Melanoma of skin	**C44**
C45	Mesothelioma	**C38.4***
C46	Kaposi's sarcoma	**C44***
C81-C96	Lymphomas, leukemias, other blood diseases	**C42.1*, C77.***

* For most cases

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Other ICD-10 **Codes Not Used in ICD-O**

	ICD-10	ICD-O
C26.1	Spleen	**C42.2**
C78-C79	Secondary malignant neoplasm of other specified sites	**Code primary site (only) in ICD-O**
C97	Malignant neoplasm of independent multiple primary sites	**Code each primary separately**

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Site Codes Used **Differently**

ICD-10		ICD-O
C77	Lymph nodes (primary and secondary)	Use C77._ as **primary site for nodal lymphomas**. **Do not** code lymph node metastases as primary sites in ICD-O.

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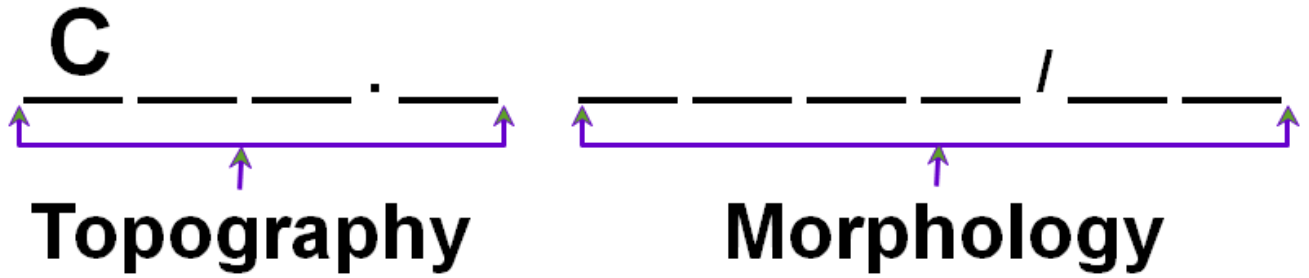
Structure of Code



Digits

Topography – 4

Cell type – 4

Behavior – 1

Grade – 1

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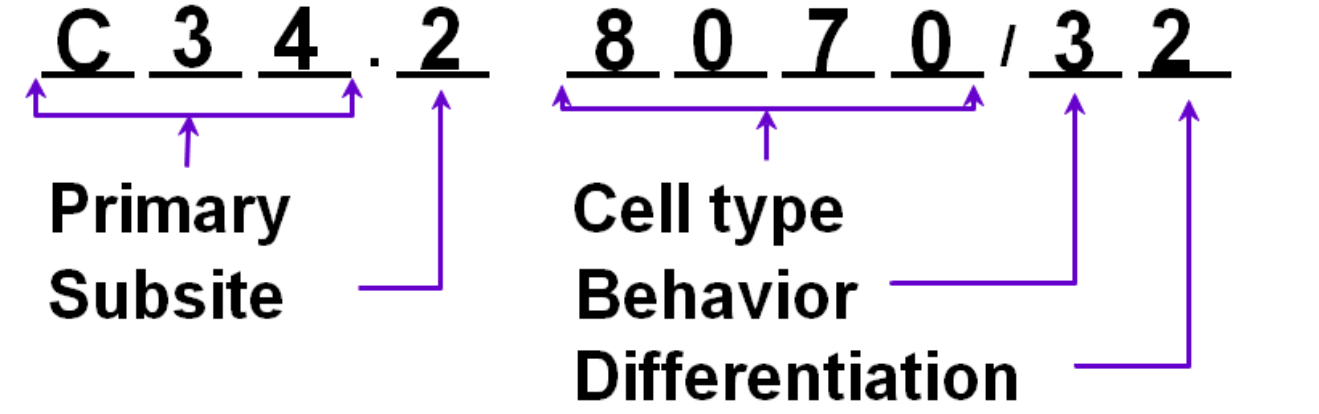
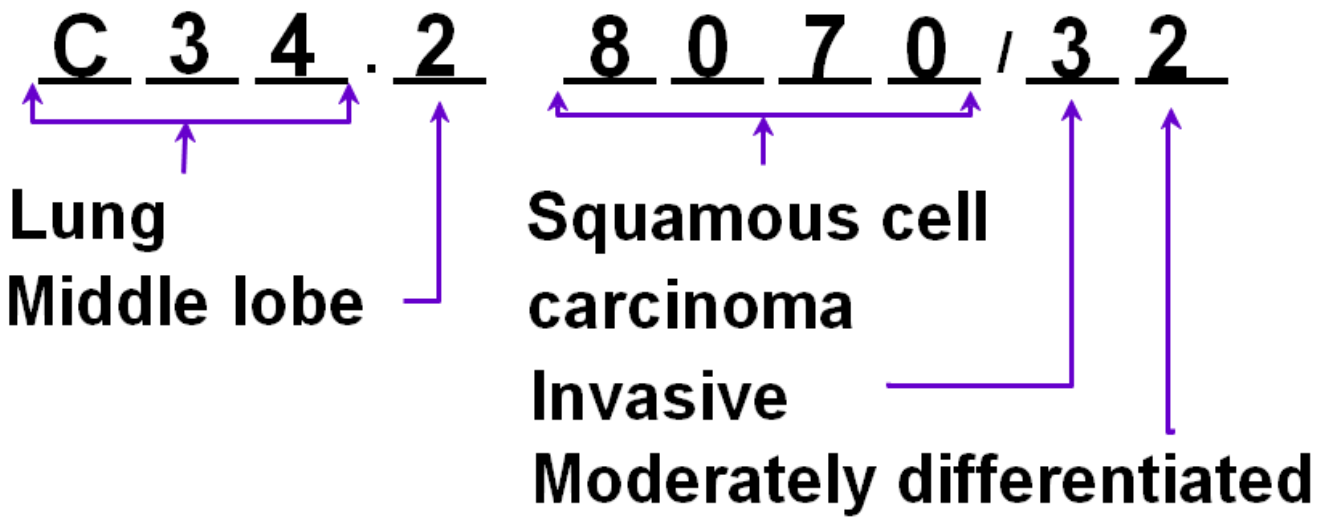
Meaning





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ICD-O-3 Topography Coding Rules

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Coding **topography** using ICD-O-3

- The **topography code**:
  - Indicates the **site of origin** of a neoplasm – where the tumor arose.
  - Has four-characters that run from **C00.0** to **C80.9**
  - A decimal point (.) separates subdivisions of the three-character categories

C _ _ . _

site subsite

C 50 . 2

breast, upper inner quadrant

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ICD-O topography codes - example

C50 BREAST *(excludes skin of breast C44.5)*

C50.0 **Nipple**
Areola

C50.1 **Central portion of breast**

C50.2 **Upper-inner quadrant of breast**

C50.3 **Lower-inner quadrant of breast**

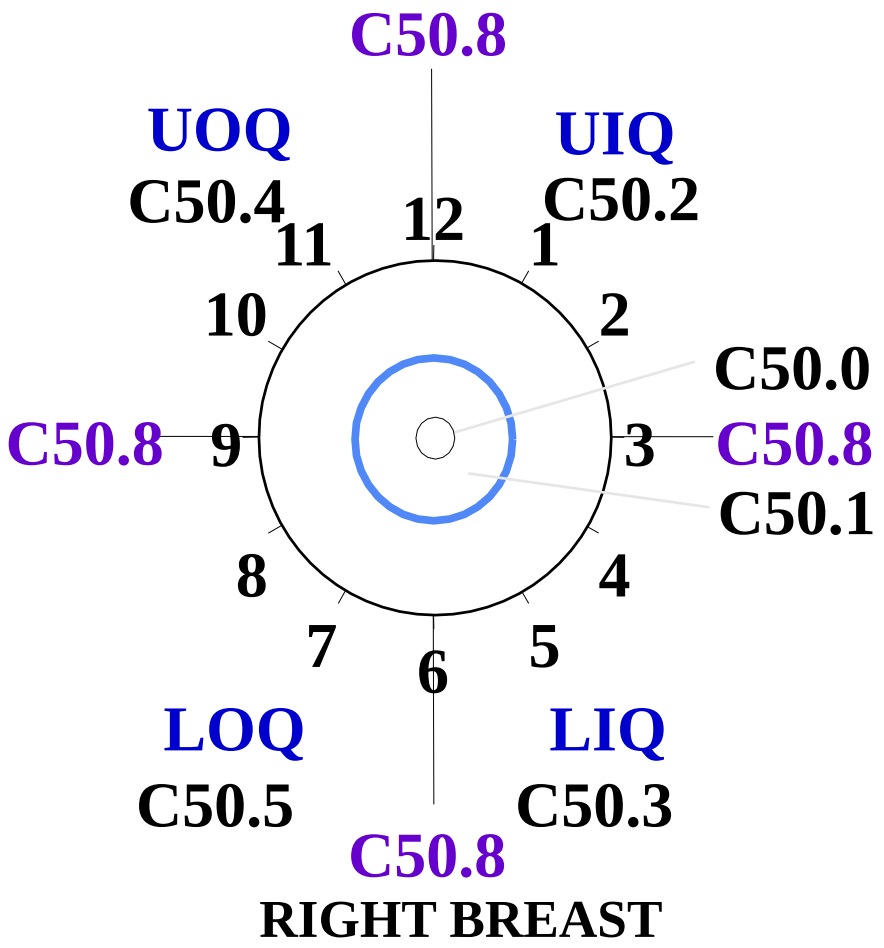
C50.4 **Upper-outer quadrant of breast**

C50.5 **Lower-outer quadrant of breast**

C50.6 **Axillary tail of breast**
Tail of breast, NOS

C50.8 **Overlapping lesion of breast**
(see section 4.2.6)
Inner breast
Lower breast
Midline of breast
Outer breast
Upper breast

C50.9 **Breast, NOS**
Mammary gland



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ICD-O topography codes - example

C18 COLON

C18.0 Cecum
Ileocecal valve
Ileocecal junction

C18.1 Appendix

C18.2 Ascending colon
Right colon

C18.3 Hepatic flexure of colon

C18.4 Transverse colon

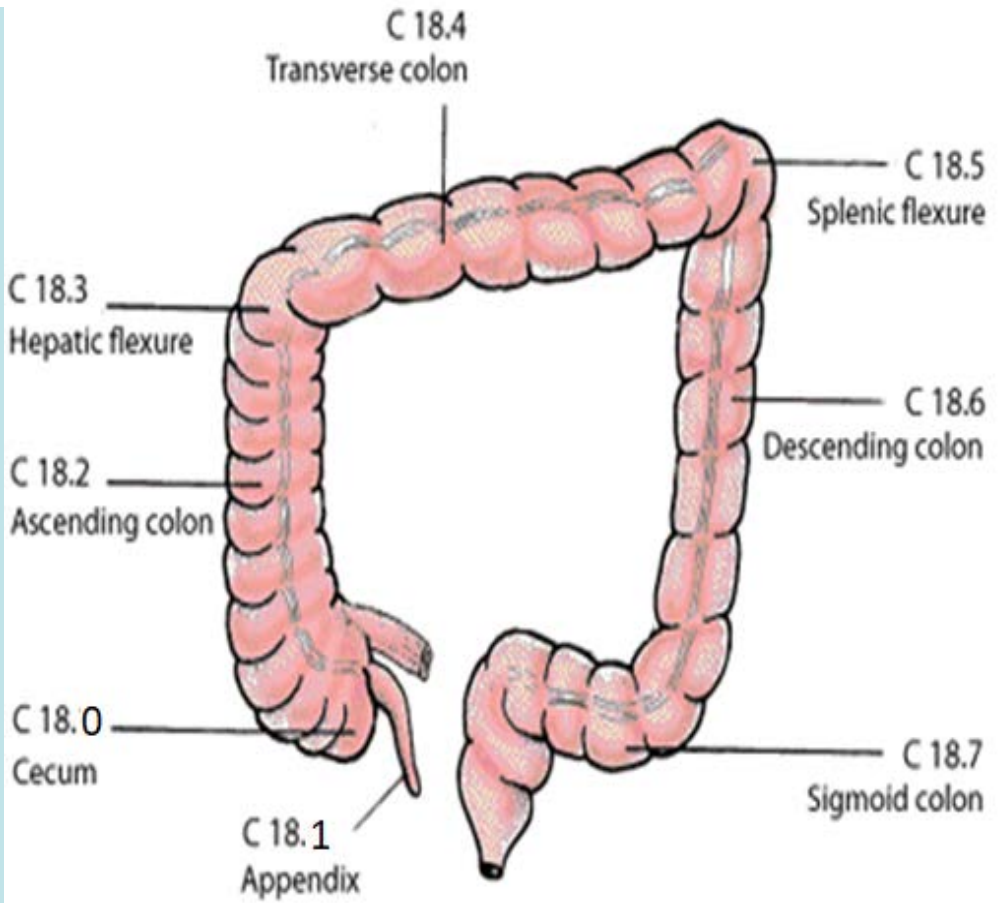
C18.5 Splenic flexure of colon

C18.6 Descending colon
Left colon

C18.7 Sigmoid colon
Sigmoid, NOS
Sigmoid flexure of colon
Pelvic colon

C18.8 Overlapping lesion of colon
(see section 4.2.6)

C18.9 Colon, NOS
Large intestine *(excludes rectum, NOS C20.9 and recrectosigmoid junction C19.9)*
Large bowel, NOS



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Special topography codes

Divisions of the Esophagus – two incompatible systems and both are included.

- C15 Esophagus
- C15.0 Cervical esophagus
- C15.1 Thoracic esophagus
- C15.2 Abdominal esophagus

radiographic and intraoperative descriptors

- C15.3 Upper third of esophagus
- C15.4 Middle third of esophagus
- C15.5 Lower third of esophagus

endoscopic and clinical descriptors

- C15.**8 Overlapping** lesion of esophagus
- C15.9 Esophagus, **NOS**

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ICD-O-3 Topography Coding Rules

- Rule A. Topographic regions and ill-defined sites
- Rule B. Prefixes
- Rule C. Tumors involving more than one topographic category or subcategory
- Rule D. Topography codes for lymphomas
- Rule E. Topography code for leukaemias

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Rule A

Topographic regions and ill-defined sites

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Rule A
Topographic Regions and Ill-defined Sites

How to use the topography codes for ill-defined sites?

"If the diagnosis **does not specify** the **tissue of origin**, code the **appropriate tissues** suggested in the **alphabetic index** for each **ill-defined site** in preference to the "**NOS**" category."

***Ill-defined site**:* term for area of the body used in a **general sense** - arm, ankle, face

NOS: Not otherwise specified

- Not elsewhere classified
- Term used in a general sense
  - When there are more specific codes
  - To encompass an organ as a whole

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Rule A
Topographic Regions and Ill-defined Sites

- *Example*: Osteosarcoma of **ankle**
- *Issue*: Primary site not fully identified in diagnosis
- *Several non-specific codes available in the **alphabetic index***
  - C76.5 **Ankle**, NOS
  - C40.3 Bone of **ankle**
  - C44.7 Melanoma of **ankle**
  - C49.2 Soft tissue of **ankle**
- Use information from the cell type to code primary site.
  - **Osteo**sarcoma of ankle
  - Code: C40.3 **bone** of ankle

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Rule A
Topographic Regions and Ill-defined Sites

Implied rule:

- Code **as specifically as you can** with the information you have
- Avoid using ill-defined site/NOS codes if possible.

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Rule B

Prefixes

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Rule B. Prefixes

- "If a topographic site is modified by a prefix such as **peri-para-**, or the like which is **not specifically listed** in ICD-O, code to the appropriate ill-defined subcategory **C76**, unless the type of tumour indicates origin from a particular **tissue**".
- Prefix terms in ICD-O index:

Term	ICD-O code
Periampullary	C24.1
Periadrenal or perirenal	C48.0
Retrocecal or peripancreatic	C48.0
Supratentorial brain	C71.0

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Rule B. Prefixes

- When term is not listed, determine **the location** it describes and code that.
- *Examples*

  Paraspinal—along the spine:

  C76.7 Ill-defined site of back

  Perigastric—near the stomach:

  C76.2 Ill-defined site of abdomen

  Peribiliary—near the biliary tract:

  C76.2 Ill-defined site of abdomen

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Rule B. Prefixes

- Implied rule: When you can't find a code for the anatomic site term in the alphabetic index, use "ill-defined site of …" **C76._**
- Do not code to primary site mentioned (such as spine, stomach, bile duct) when tumor is described as "near" that organ.

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Rule C

Tumours involving more than one topographic category or subcategory

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Rule C. Tumors Involving More Than One Topographic Category or Subcategory

- "Use **subcategory ".8"** when a tumor overlaps the boundaries of two or more categories or subcategories and its point of origin cannot be determined."

- Implied rule: If you can't tell where a single tumor started in an **organ** or **system**, use an "overlapping site code, C_ _ . 8.

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Rule C. Overlapping Sites - examples

Overlapping lesion of	ICD-O code
Tongue	C02.8
Major salivary glands	C08.8
Lip, oral cavity and pharynx	C14.8
Rectum, anus and anal canal	C21.8
Biliary tract	C24.8
Digestive system	C26.8
Female genital organs	C57.8
Male genital organs	C63.8

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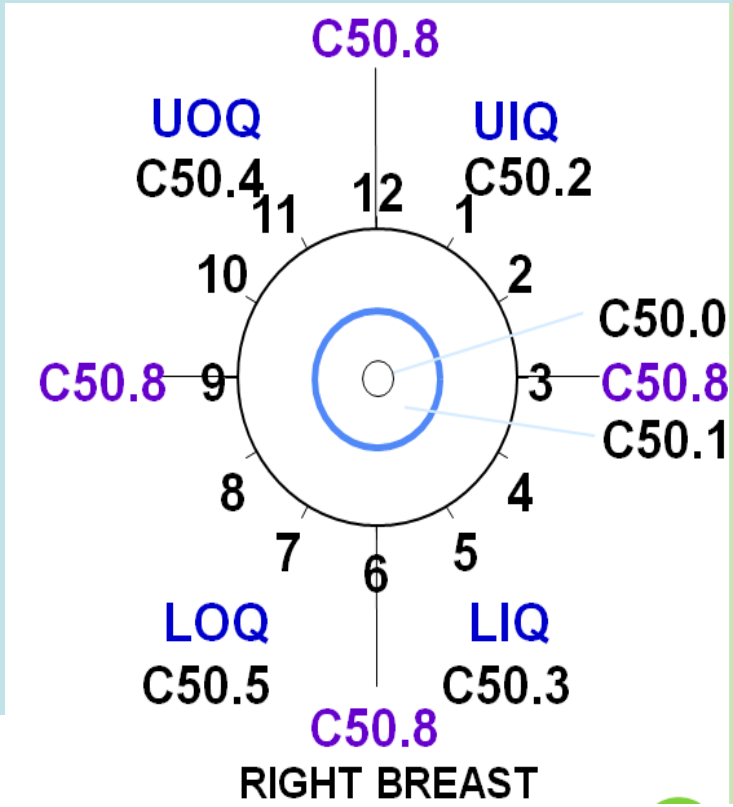
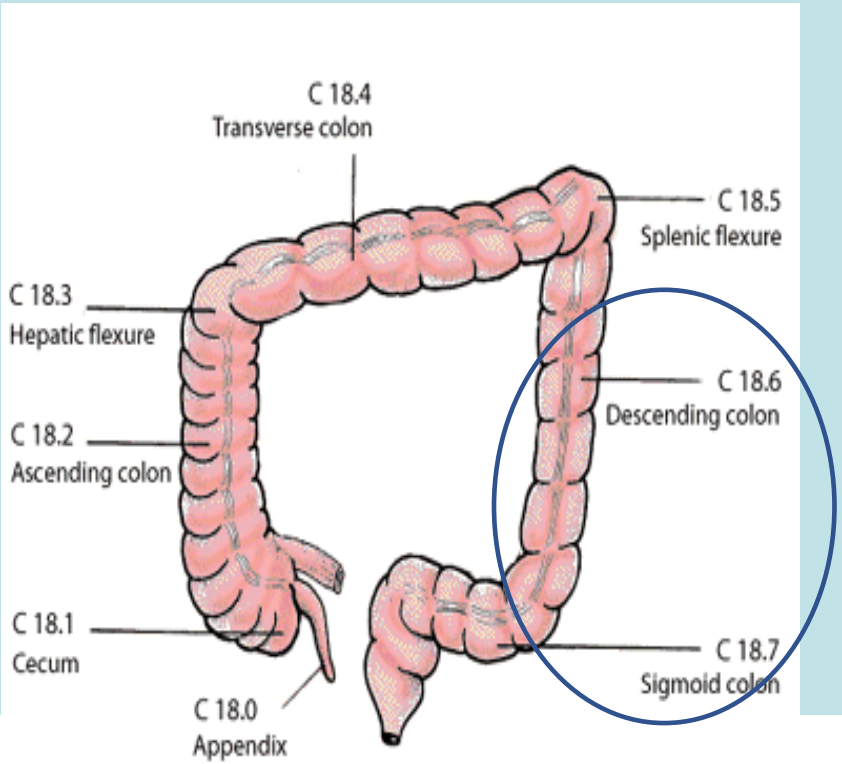
Rule C. Overlapping Sites - examples

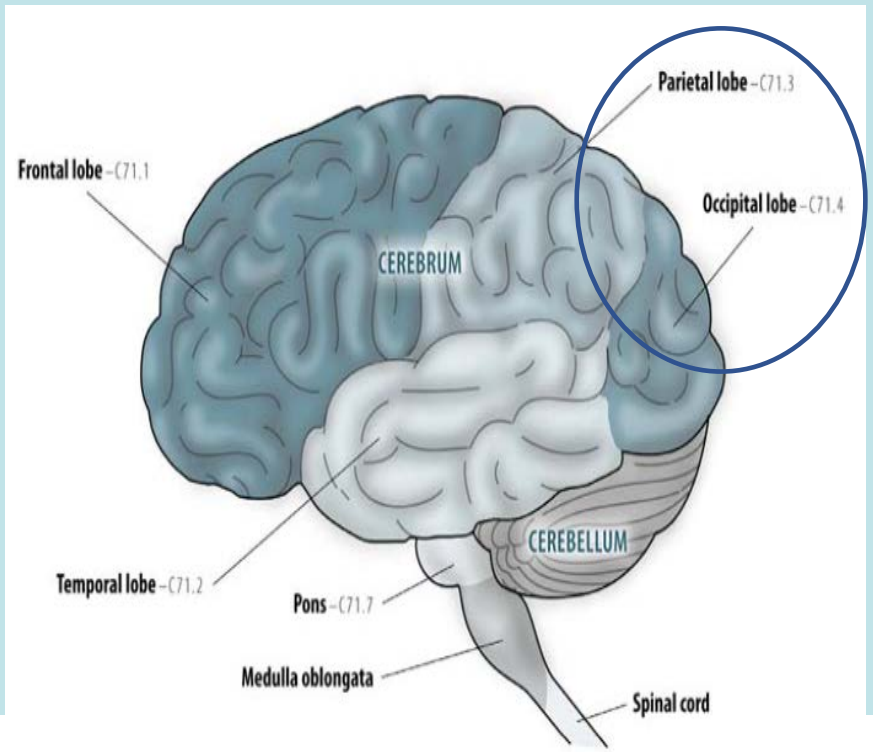
Tumor of breast at 12:00 – C50.8



Large neoplasm of descending and sigmoid colon – C18.8



Glioma involving parietal and occipital lobes – C71.8



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Rule C. Overlapping Sites

Does not apply to non-adjacent sites

- *Example*: Squamous cell carcinoma of skin of forehead and skin of forearm
  - Primary site: C44.**9** Skin, NOS

    Forearm and forehead are not adjacent sites.

Does not apply to separate lesions

- *Example*: Separate tumors in UIQ and LOQ of breast
  - Primary site: C50.**9** Breast, NOS (or according to the rules for multiple primaries)

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Rule D

Topography codes for lymphomas

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Rule D. Topography Codes for Lymphomas

Lymphomas arising in lymph nodes	Extranodal lymphomas
Code **C77._**	Code to the **site of origin**, which may not be the site of the biopsy.
If **multiple lymph node regions** are involved, code to **C77.8** (lymph nodes of multiple regions).	If **no site** is indicated for a lymphoma and it is suspected to be extranodal, code to **C80.9** (unknown primary site).
If **no site** is indicated for a [nodal] lymphoma, code to **C77.9** (lymph node, NOS).	

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Rule D. Topography Codes for Lymphomas

Implied rule: Code a lymphoma to its site of origin.

Examples:

- Hodgkin lymphoma of cervical lymph nodes → C77.0
- MALT lymphoma of stomach → C16.9
- B-cell lymphoma of inguinal and femoral nodes → C77.4
- Primary lymphoma of femur → C40.2

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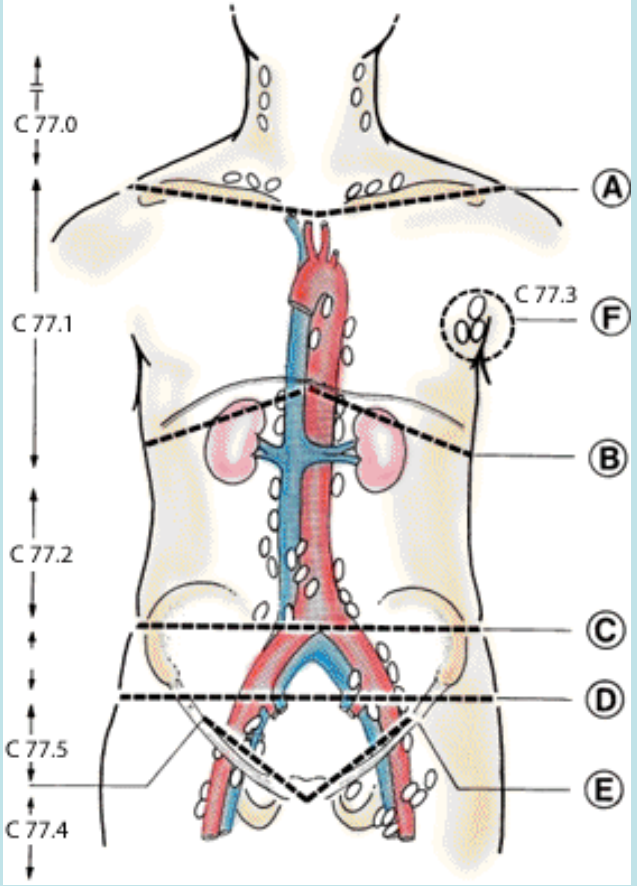
Rule D. Topography Codes for Lymphomas

C77.8 Special Rule: Involved lymph node chains do not have to be adjacent.

Examples:

Cervical and mediastinal nodes → C77.**8**

Axillary and periaortic nodes → C77.**8**



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Rule E

Topography code for leukaemias

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Rule E. Topography Code for Leukemias

"Code all **leukaemias** except myeloid sarcoma (M-9903/3) to **C42.1, bone marrow**."

- Myeloid sarcoma: a deposit of malignant myeloid cells in soft tissue. Code to location of lesion.

- The following are also coded to bone marrow, C42.1
  - Multiple myeloma
  - Refractory anemias
  - Polycythemia vera
  - Myelodysplastic syndrome
  - Other hematopoietic diseases

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ICD-O-3 Morphology Coding Rules

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ICD-O-3 Morphology Coding Rules

- Rule F. Behavior code in morphology
- Rule G. Grading or differentiation code
- Rule H. Site-associated morphology terms
- Rule J. Compound morphology diagnoses
- Rule K. Coding multiple morphology terms

Note: **ICD-O-3.2** includes about 100 new terms, some of them with new codes

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Rule F

Behavior code in morphology

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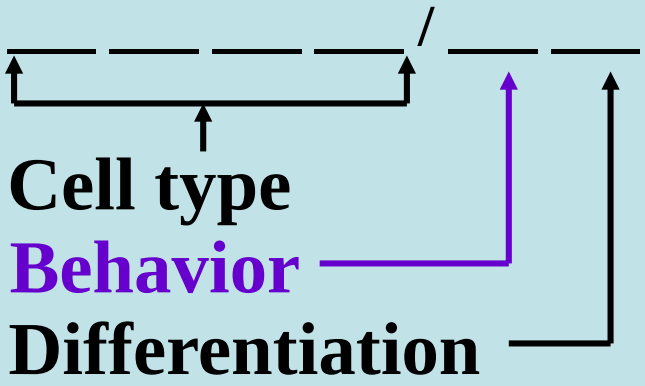
Rule F. Behavior Code in Morphology

- "Use the appropriate **5th digit** behavior code even if the exact term is not listed in ICD-O."



Behavior of a tumor is the way it acts within the body

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Rule F. Behavior Code in Morphology

- Codes:
  - ***/0*** – benign – the tumor grows in place without the potential for spread;
  - ***/1*** – uncertain whether benign or malignant
  - ***/2*** – noninvasive or in situ – the tumor is malignant, but still growing in place
  - ***/3*** – malignant, primary site – the tumor invades surrounding tissues
  - ***/6**** – malignant, metastatic site – the tumor disseminates from its point of origin and begin to grow at another site
  - ***/9**** – malignant, uncertain whether primary or metastatic site
  - * **Not used by cancer registries, but by pathologists**

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Rule F. Behavior Code in Morphology

- **The Matrix principle**

  8010/0 Epithelial tumor, benign

  8010/1* Borderline epithelial tumor

  8010/2 Intraepithelial carcinoma, NOS

  8010/3 Epithelial tumor, malignant (Carcinoma, NOS)

  8010/6 Metastatic carcinoma

  8010/9 Carcinomatosis

* 8010/1 is not printed in ICD-O-3, but can be constructed if the pathologist diagnoses a borderline epithelial tumor.

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Rule F. Behavior Code in Morphology

Implied rule: It is OK to change the behavior code to accurately report what the pathologist said.

Example:

- Pathology report states “adenoid squamous cell carcinoma *in situ*”

ICD-O-3 only lists 8075/3 Adenoid squamous cell carcinoma.

Change behavior code to **8075/2** to indicate in situ.

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Rule F. Behavior Code in Morphology

- **ICD-O-3.2**
  - About 65 changes (or new) of behavior code
  - May impact on the definition of a reportable case

  Examples:

Change of behavior code (from 1)	8150	3	Pancreatic endocrine tumour, NOS (C25.4)
Change of behavior code (from 1)	8580	3	Thymoma, NOS (C37.9)
Change of code and behavior (was 8508/3)	8500	2	Cystic hypersecretory carcinoma (C50._)
Change of behavior code (from 3)	8832	1	Dermatofibrosarcoma, NOS (C44._)

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Rule F. Behavior Code in Morphology

Note: Most cancer registries collect only

/2 Carcinoma in situ; noninvasive; noninfiltrating; intraepithelial

/3 Malignant, primary site (invasive)

- If diagnosis comes from a metastatic site, **the cancer registry records primary site and morphology with behavior /3.**

Example: Pathology report says: “metastatic adenocarcinoma in lung biopsy.” Coded as C34.9 8140/6 on report.

Cancer registry reports case as unknown primary site, C80.9 8140/3

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Rule G

Grading or differentiation code

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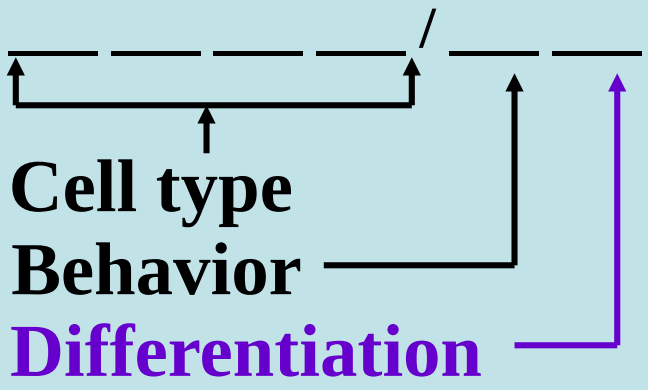
Rule G. Grading or Differentiation Code

- "Assign the **highest grade** or differentiation code described in the diagnostic statement."



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Rule G. Grading or Differentiation Code

Histologic grading and differentiation for malignant tumors – describes how much or how little a tumor resembles the normal tissue from which it arose (**codes 1 to 4** and 9).

Codes:

1 – Grade I, well differentiated

2 – Grade II, moderately differentiated

3 – Grade III, poorly differentiated

4 – Grade IV, undifferentiated, anaplastic

9 – grade, differentiation or cell type not determined, not stated or not applicable

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Rule G. Grading or Differentiation Code

- **Cell origin / lineage** for leukemias and lymphomas (**codes 5 to 8** and 9)

Codes:

5 – T-cell

6 – B-cell

7 – Null cell, Non T-non B

8 – NK cell

9 – grade, differentiation or cell type not determined, not stated or not applicable

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Rule G. Grading or Differentiation Code

Implied rule: Code to the **higher grade**.

Example: moderately to poorly differentiated adenocarcinoma of prostate

- Moderately differentiated = grade 2
- Poorly differentiated = grade 3
- Code diagnosis as 8140/33

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Rule G. Grading or Differentiation Code

- Implied rule: "**double code**" any statement of grade in the diagnostic term.

Example: undifferentiated carcinoma

- Undifferentiated carcinoma= 8020/3
- Undifferentiated = 4
- Code diagnosis as 8020/34

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Rule G. Grading or Differentiation Code

Central Nervous System tumours follow a different system (table 27 in ICD-O)

WHO Grade I (benign or borderline malignant)

WHO Grade II ('low grade')

WHO Grade III ('anaplastic')

WHO Grade IV

Examples:

oligodendroglioma, NOS → 9450/32

anaplastic astrocytoma → 9401/33

glioblastoma → 9440/34

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Rule G. Grading or Differentiation Code

Implied rule: For **haematological malignancies** use **cell origin**, not the differentiation (grade), if both are stated.

Example:

- Poorly differentiated B-cell nodular lymphocytic lymphoma
  - Poorly differentiated = grade 3
  - B-cell origin = code 6
  - Code diagnosis as 9693/36

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Rule H

Site-associated Morphology Terms

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Rule H. Site-associated Morphology Terms

"Use the topography code provided when a topographic site is not stated in the diagnosis.

This topography code should be disregarded if the tumor is known to arise at another site."

Suggested site code

- In parenthesis ( ) after morphology term
- Most common site associated with neoplasm

Examples:

M-8330/3 Adenocarcinoma, follicular (C73.9 {thyroid})

M-9700/3 Mycosis fungoides (C44._ {skin})

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Rule H. Site-associated Morphology Terms

Examples of terms that include a root word mentioning a site

- Nephroblastoma, NOS (C64.9 – kidney)
- Thymoma, NOS (C37.9 – thymus)
- Bronchiolar carcinoma (C34._ – bronchioles of lung)
- Hepatocellular carcinoma (C22.0 – liver)

No suggested site code is listed when malignancy could appear in many sites, such as adenocarcinoma, NOS

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Rule H. Site-associated Morphology Terms

If a site is given that is different from the site indicated by the suggested site code, use the site code appropriate to the diagnosis.

Example: infiltrating duct carcinoma, head of pancreas

- 8500/3 Infiltrating duct carcinoma (C50._) *Suggested site code is breast—ignore this based on diagnosis!*
- Head of pancreas = C25.0
- Code diagnosis as C25.0 8500/3

Implied rule: Use the suggested site code as a guide to code the primary site. If the site stated in the pathology report is different, code what the pathology report states (note: metastatic site).

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Rule J

Compound Morphology Diagnoses

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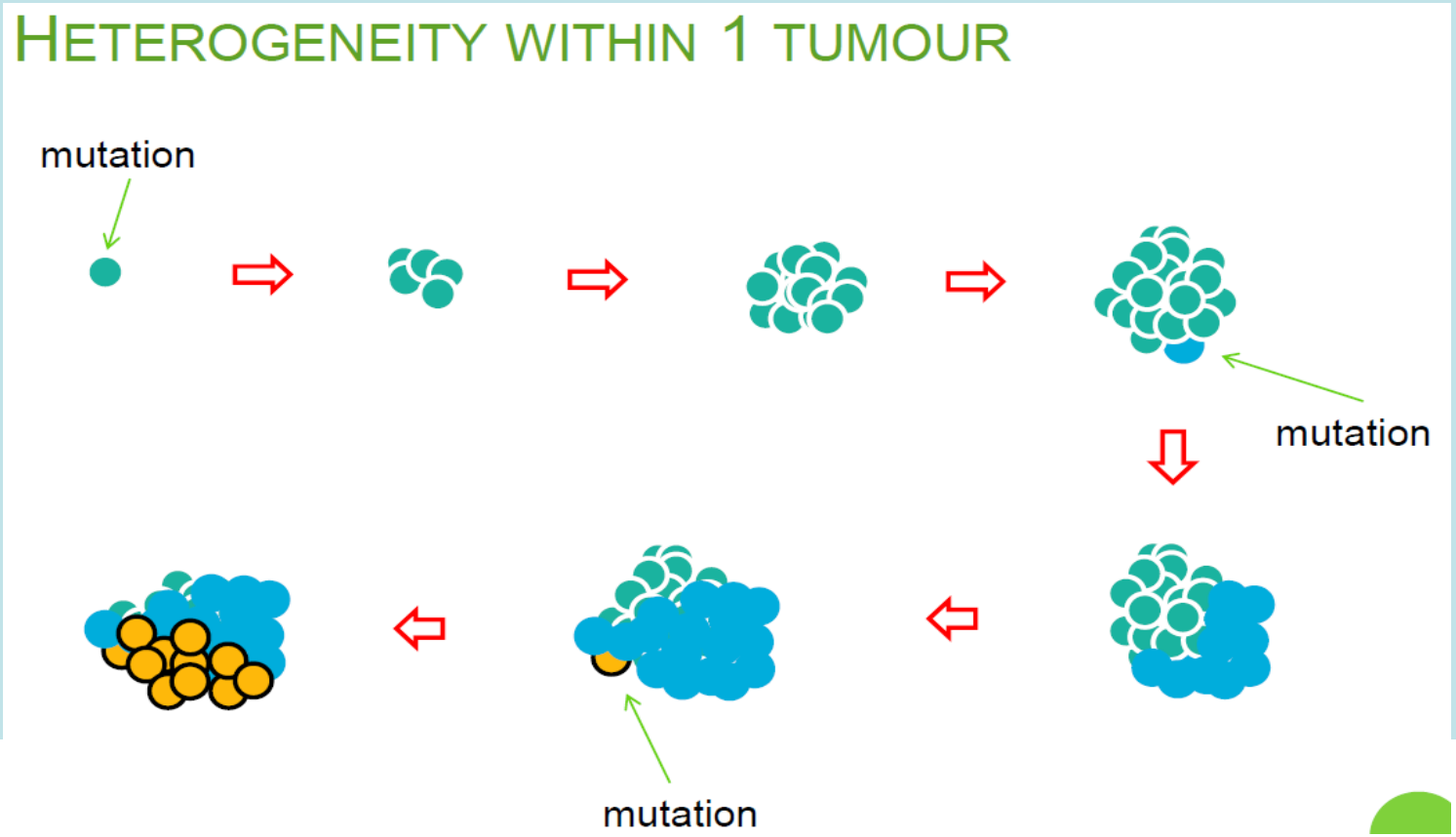
Rule J. Compound Morphology Diagnoses

"Change the order of word roots in a **compound term** if the term is not listed in ICD-O-3."



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Rule J. Compound Morphology Diagnoses

Compound terms have **multiple root words**

Example:

- Myxofibrosarcoma – not in ICD-O-3.1 (added to ICD-O-3.2)

  Break into word roots

  Myxo / fibro / sarcoma

  Change around word roots, then look up new term

  Fibromyxosarcoma 8811/3

- Chondro-osteosarcoma ➔

  Osteochondrosarcoma 9180/3

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Rule K

Coding Multiple Morphology Terms

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Rule K. Coding Multiple Morphology Terms

"When no single code includes all diagnostic terms, use the **numerically higher** code number if the diagnosis of a single tumor includes two modifying adjectives with different code numbers."

Implied rule: Code to higher code number if there is no combination code.

For haematological malignancies - code **the most specific code** (not necessarily the highest code), take into account specific diagnostics, such as immunohistochemistry and cytogenetics.

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Rule K. Coding Multiple Morphology Terms

Examples:

- "**Adenoid cystic spindle cell carcinoma**"

  No combination code

  Spindle cell carcinoma 8032/3

  Adenoid cystic carcinoma 8200/3

  Code morphology to higher number 8200/3

- "**Papillary and tubular adenocarcinoma**"

  Papillary adenocarcinoma 8260/3

  Tubular adenocarcinoma 8211/3

  There is a singe code: 8255/3 (Adenocarcinoma with mixed subtypes)

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Rule K. Coding Multiple Morphology Terms

Look for a **code that represents the combined morphology**:

Mixed embryonal carcinoma and teratoma = teratocarcinoma 9081/3

Ductal carcinoma and lobular carcinoma 8522/3

- Compound terms

Carcinosarcoma 8980/3

Adenocarcinoma and squamous carcinoma = adenosquamous carcinoma 8560/3

Small cell-large cell carcinoma 8045/3

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How to Code

- Break phrase into topography and morphology
- Look up morphology first
- Use up all the words in the phrase
- Add 5th and 6th digit codes
- Look up topography

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Coding example 1

Diagnosis: Poorly differentiated hepato-cellular carcinoma of right lobe of liver

- What is it (morphology and behavior)?

  Hepatocellular carcinoma, NOS (C22.0): 8170/3

- Suggested site code is included in index

  Liver, right lobe: C22.0 Liver, NOS

- What else do we know?

  Poorly differentiated: /_3

- Complete codes: C22.0 8170/33

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Coding example 2

Diagnosis: Moderately differentiated adenocarcinoma of prostate

- What is it (morphology and behaviour)?

  Adenocarcinoma [not otherwise specified]: 8140/3

- What else do we know?

  Moderately differentiated: /_2

- Where did it start (topography)?

  Prostate: C61.9

- Complete codes: C61.9 8140/32

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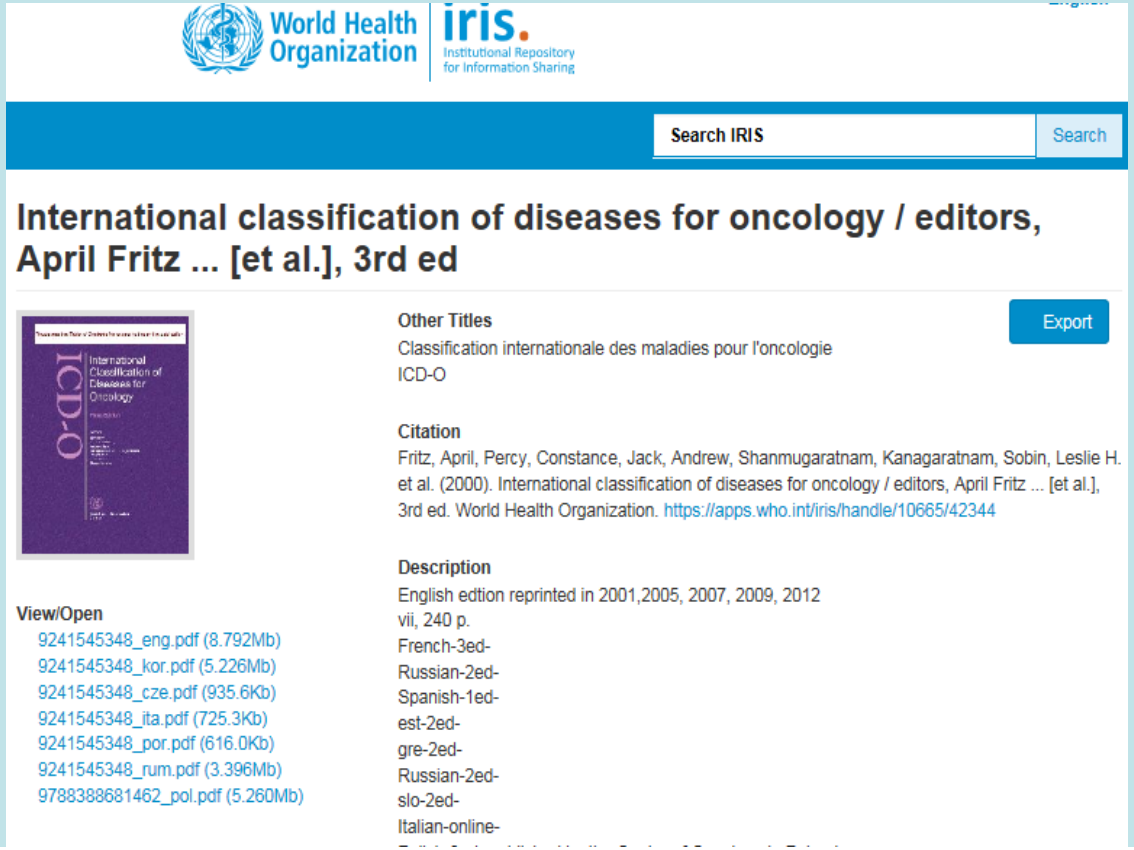
ICD-O-3 online: http://www.iacr.com.fr

http://www.iacr.com.fr

https://apps.who.int/



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