Recommendations for incidence date and basis of diagnosis

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European Commission

Content of the lesson

- Incidence date
- Basis of diagnosis
- Examples
- Questions

Recommendations for coding the incidence date

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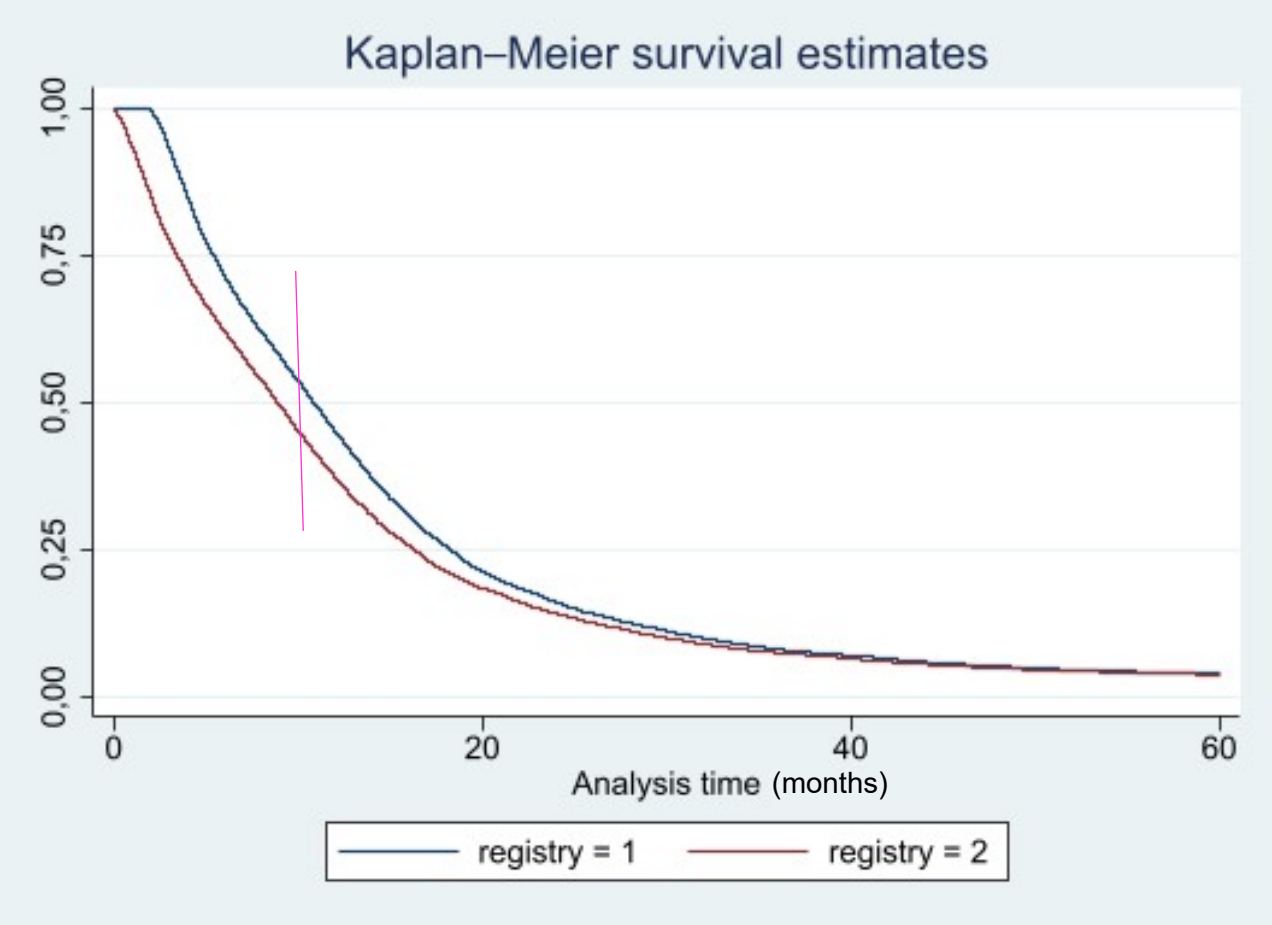
Why rules for coding incidence date?

- For calculating survival time uniformly

- If two registries use different rules and the incidence in registry 1 is two months before registry 2 median survival will also differ by 2 months



Priority list for the incidence date

- The date of the first event (of the six listed in the following slides) to occur chronologically should be chosen as incidence date.
- If an event of higher priority occurs within three months of the date initially chosen, the date of the higher priority event should take precedence.

Priority list for the incidence date

1. Date of first histological or cytological (including flow cytometry, liquid biopsy) confirmation of this malignancy (with the exception of histology or cytology at autopsy). This date should be, in the following order:
   a) date when the specimen was taken
   b) date specimen received by pathologist
   c) date of the pathology report.
2. Date of first positive genomic/molecular test diagnostic of this malignancy
3. Date of admission to the hospital because of this malignancy

Priority list for the incidence date

4. When evaluated at an outpatient clinic only: date of first consultation at the outpatient clinic because of this malignancy.
5. Date of diagnosis, other than 1, 2, 3 or 4, for example:
   a) date of first positive tumour marker test diagnostic for this malignancy
   b) date of first imaging (e.g. PET/CT/MRI) diagnostic for this malignancy
   c) date of multidisciplinary team meeting (MDT) for this malignancy.
6. Date of death, if no other information is available other than the fact that the patient has died because of a malignancy.
7. Date of death, if the malignancy is discovered at autopsy.

Priority list for the incidence date

- Whichever date is selected, the date of incidence should not be later than the date of the start of the treatment, or the decision not to treat, or the date of death.
- The choice of the date of incidence does not determine the coding of the item "basis of diagnosis".

Recommendations for coding the basis of diagnosis

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Why rules for the basis of diagnosis?

- The basis for diagnosis provides the level of certainty of cancer in general or more specifically for the certainty of a specific cancer diagnosis
  - Is it likely that a person has kidney cancer in the absence of pathology?
  - Is it likely that a person has an oligodendroglioma in the absence of DNA diagnostics?
- For comparing data from different cancer registries it is essential to know if there are differences
- Quality indicators are calculated for the basis of diagnosis

Basis of diagnosis 0 – Death certificate only (DCO)

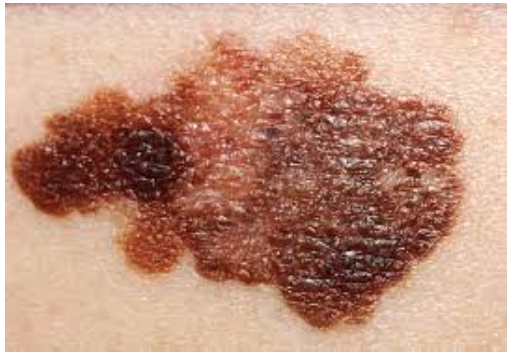
- The only available information of a cancer is from a death certificate
- The proportion DCO's should not exceed 5%
- DCO cases have to be registered with morphology code 8000, unless the morphology code can be derived from
  - the ICD-code (C43 [8720/3], C45 [9050/3], C46 [9140/3] and C81-C96/D45-D47 [9590/3-9989/3])
  - or the text on the death certificate (e.g. 'adenocarcinoma of the stomach' or 'rhabdomyosarcoma').

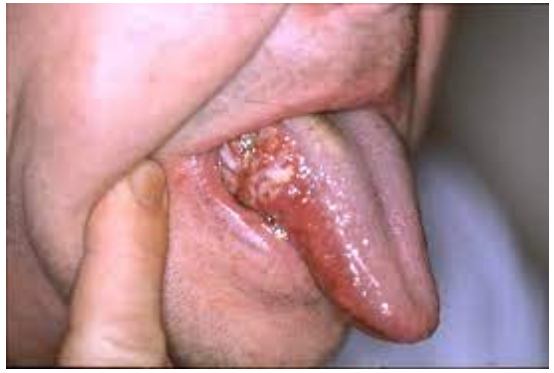
Basis of diagnosis 1 - Clinical

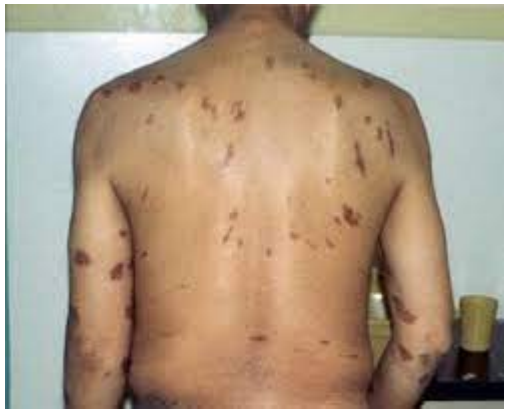
- Diagnosis made before death, but without any of the other options
- By clinical examination (look or feel), without any device
- In Europe, this code should be rarely used, as there is mostly pathology or a clinical investigation
- Possible cancer sites:

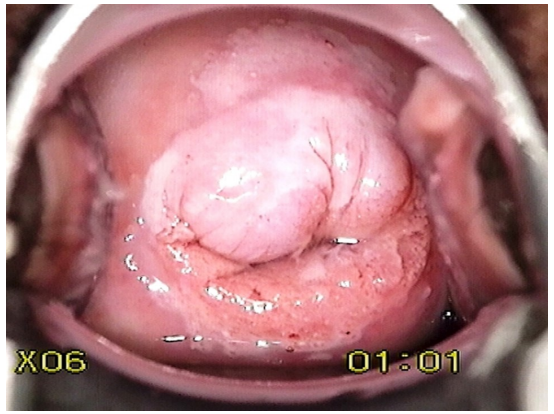
  Oral cavity, eye (melanoma), breast, skin & superficial soft tissues(melanoma, Kaposi sarcoma, angiosarcoma), external genitals, vagina, cervix, penis, anus, rectum and prostate (by digital rectal examination)
- Other sites only possible in exceptional cases

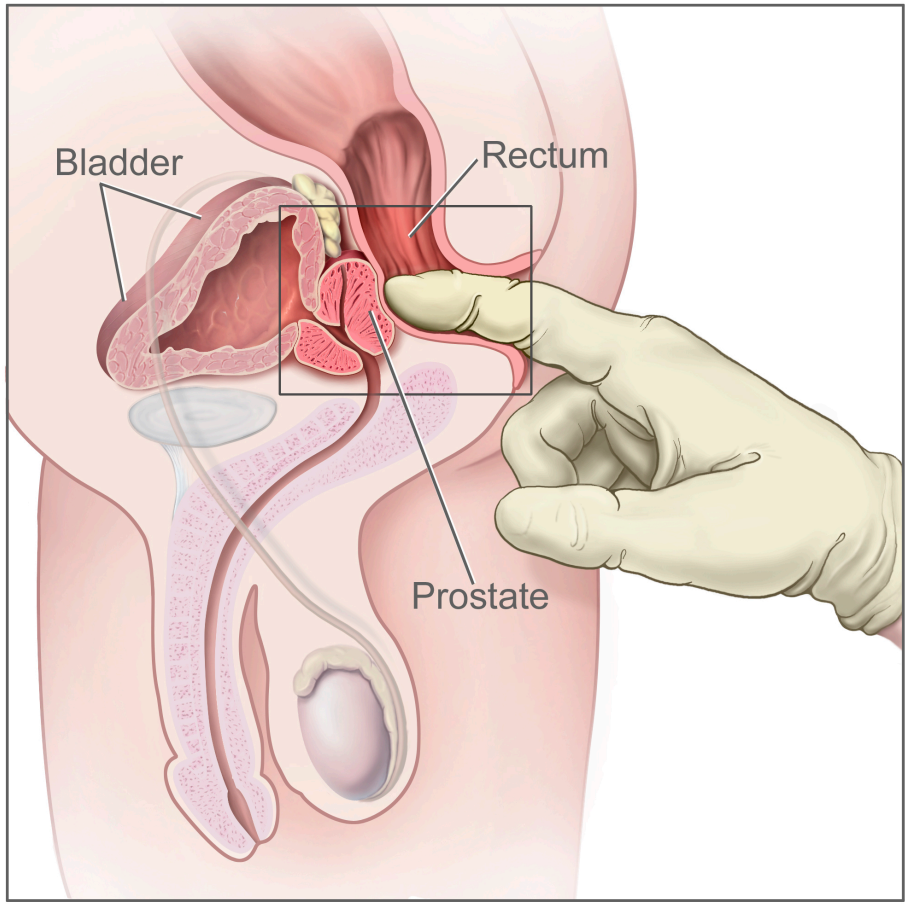
Basis of diagnosis 1 - Clinical









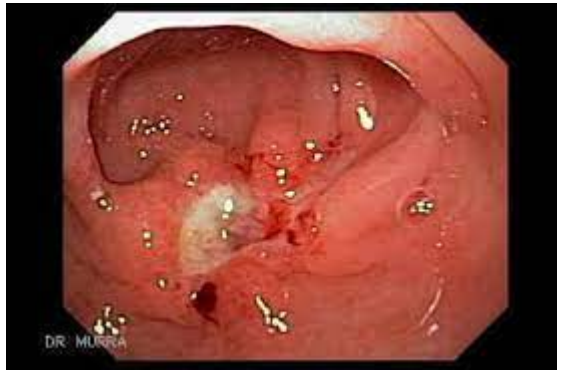


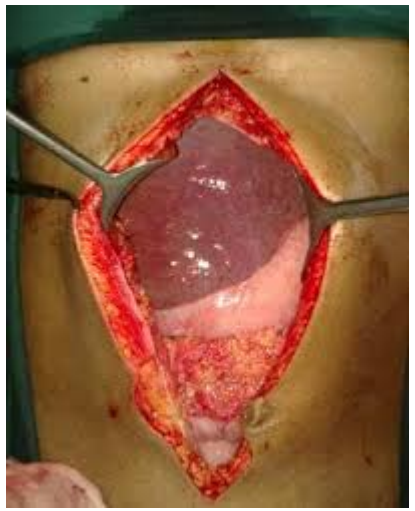
Basis of diagnosis 2 – Clinical investigation

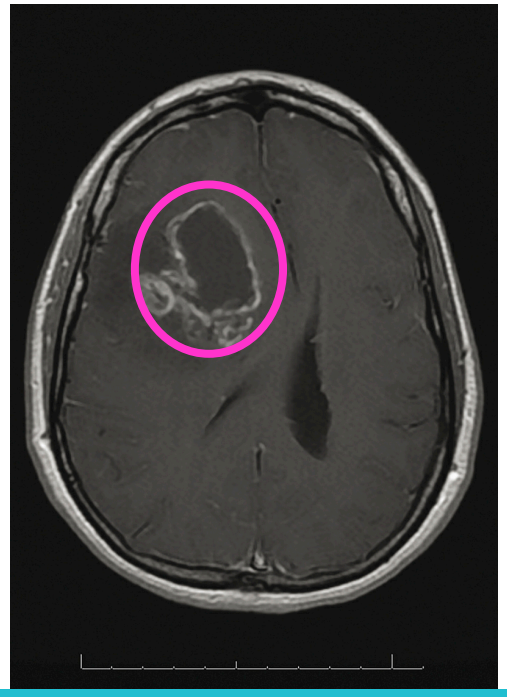
- All diagnostic techniques, including X-ray, endoscopy, imaging, ultrasound, exploratory surgery (such as laparotomy), and autopsy without a pathological diagnosis
- Could be any cancer site, but often used for the diagnosis of cancer of the lung, pancreas, liver, bile ducts, kidney and colon, as well as for tumours of the central nervous system
- Generally not applicable to the diagnosis of haematological malignancies (exceptions: lymphoma of the CNS, Langerhans cell histiocytosis)

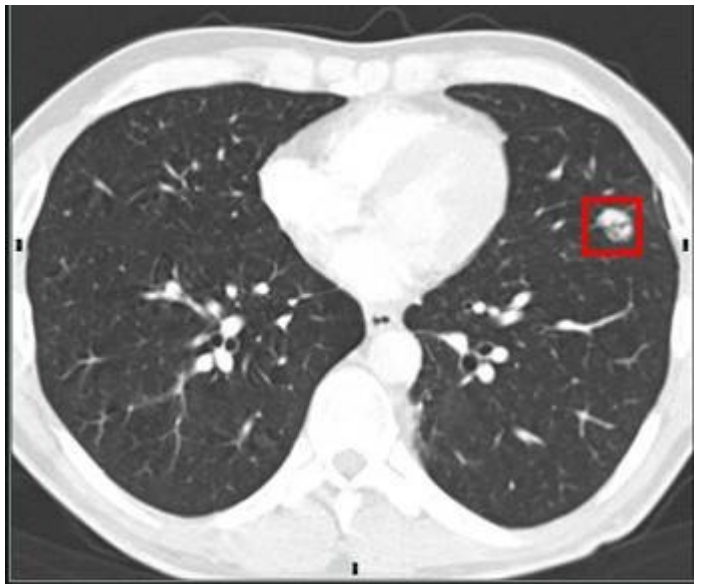
Basis of diagnosis 2 – Clinical investigation

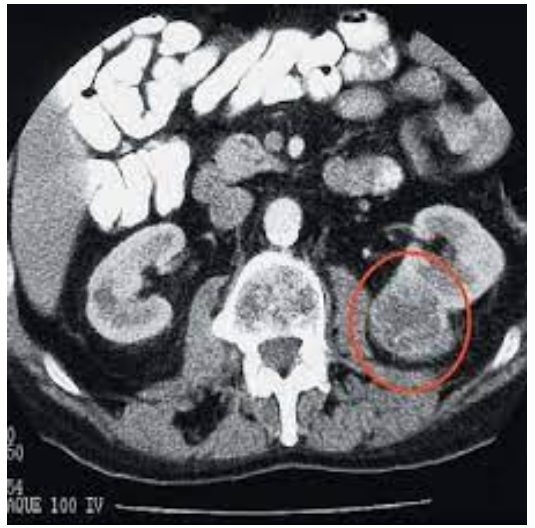
Basis of diagnosis 2 – Clinical investigation











Basis of diagnosis 4 – Specific tumour markers

- Includes biochemical and/or immunologic makers that are specific for a tumour site
- These tumour markers are secreted by tumours cells and can be measured in body fluids (blood, urine, etc.)
- An elevated tumour marker on its own is not enough to diagnose a certain cancer, therefore this finding should always be accompanied by clinical investigations or clinical examinations which support the diagnosis of cancer
- A large number of tumour markers is mentioned in table 4 of the recommendations, but the list is not exhaustive

Basis of diagnosis 4 – Specific tumour markers

- DNA is not included in this category (code as 5)

- Combinations:
  - 1 + 4 = 4
  - 2 + 4 = 4
  - 4 → not enough evidence for cancer

Basis of diagnosis 4 – Specific tumour markers

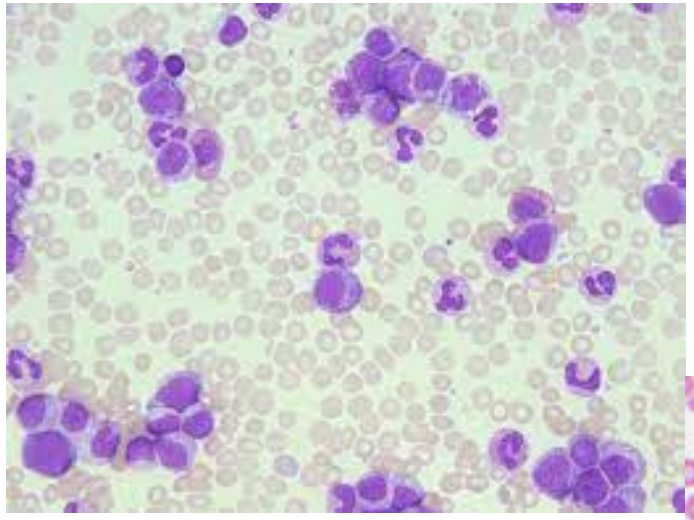
Examples of tumour markers:

- PSA (protein) → prostate cancer
- Prolactin (hormone) → pituitary adenoma (prolactinoma)
- IgM (immunoglobulin) → Waldenström's macroglobulinaemia or multiple myeloma

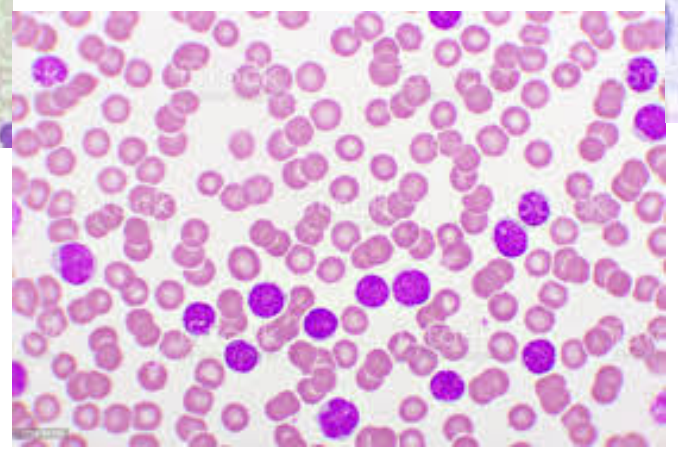
Basis of diagnosis 5 – Cytology

- Examination of cells from a primary or secondary site, including fluids aspirated by endoscopy or needle; also includes the microscopic examination of peripheral blood and bone marrow aspirates, immunophenotyping by flow cytometry and a liquid biopsy in the absence of pathology.
- Immunophenotyping is often used for diagnosing leukaemia by using specific markers at the cell surface
- A liquid biopsy is a sample of blood or another body fluid (liquor, etc.) for the detection of cancer cells or DNA-fragments of these tumour cells

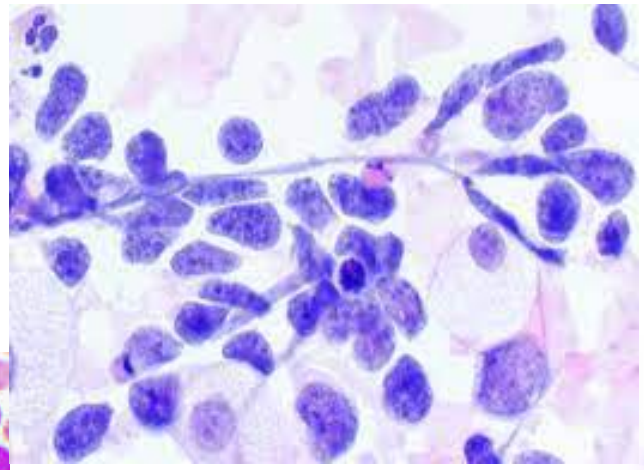
Basis of diagnosis 5 – Cytology



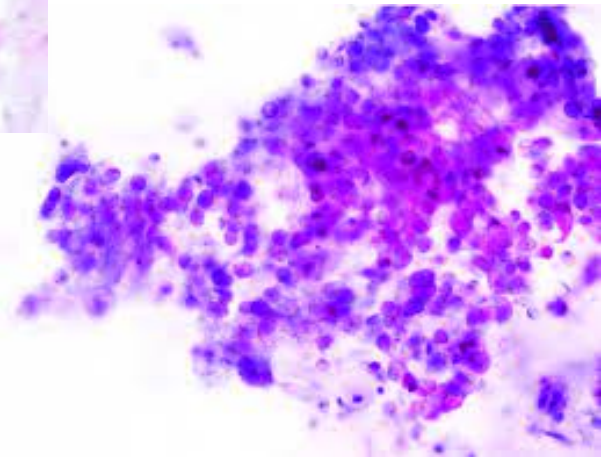
CML
(blood smear)



ALL
(blood smear)



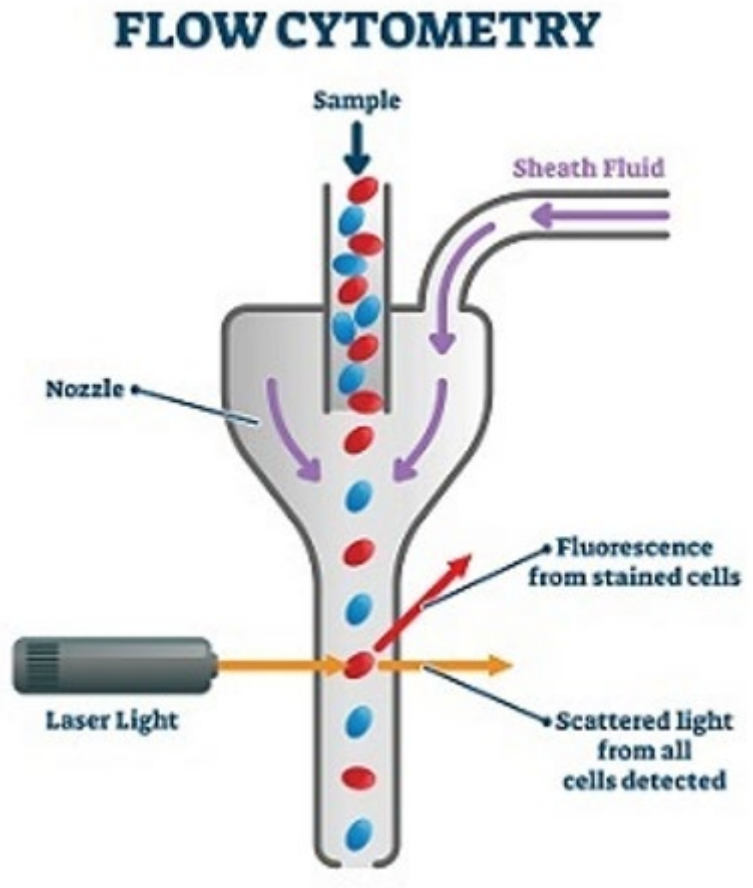
SCLC
(fine needle aspiration)



Pancreatic carcinoma
(brush)

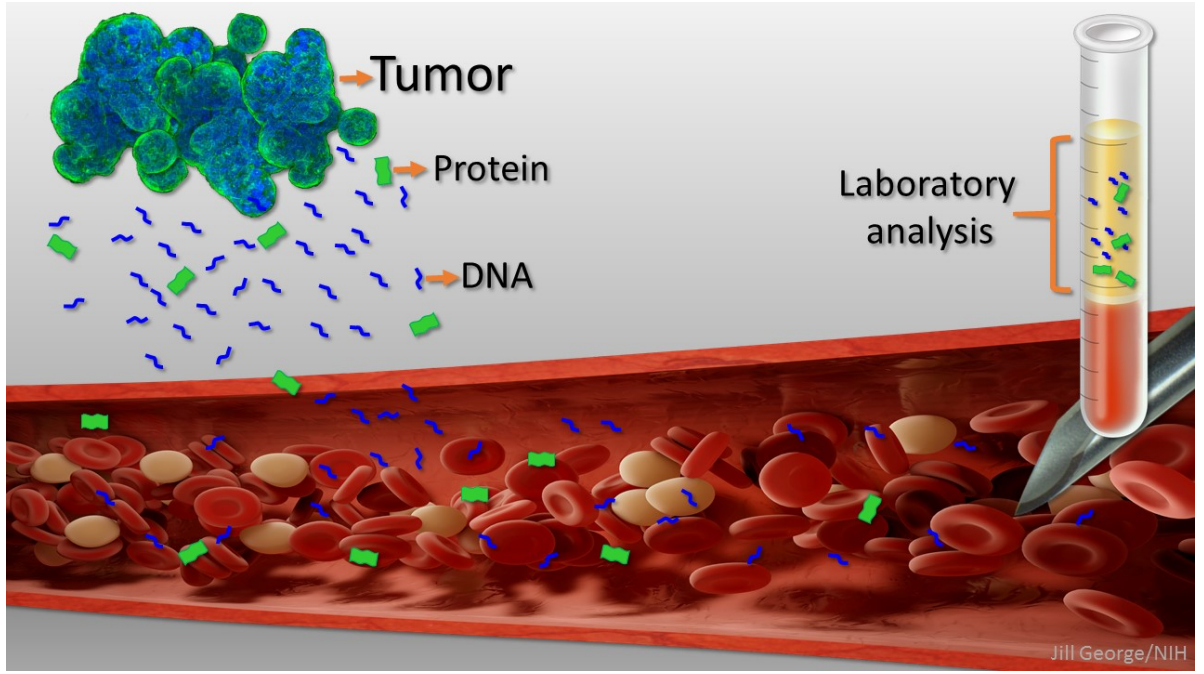
Basis of diagnosis 5 – Flow cytometry (for cells)

- Flow cytometer is an instrument measuring multiple physical characteristics of a single cell such as size and granularity as the cell flows in suspension through a measuring device
- Its working depends on the light scattering features of the cells under investigation, which may be derived from dyes or monoclonal antibodies targeting either extracellular molecules located on the surface or intracellular molecules inside the cell
- This approach makes flow cytometry a powerful tool for detailed analysis of complex populations in a short period of time.



Basis of diagnosis 5 – Liquid biopsy

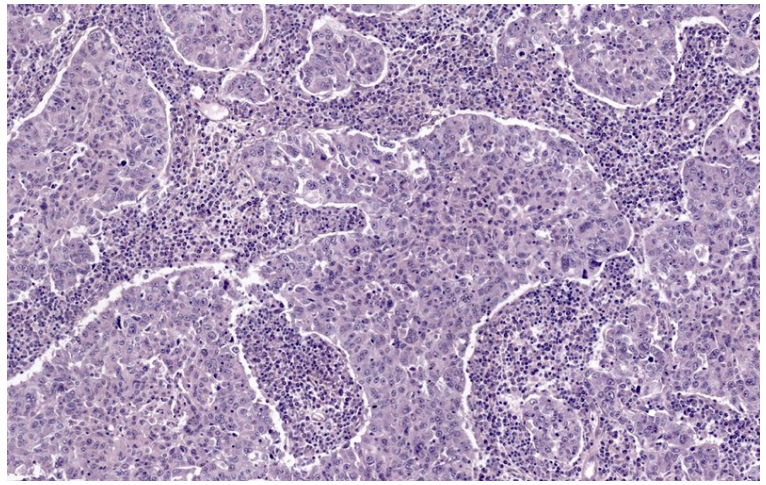
- In case of metastatic disease circulating tumour cells can be detected in blood or other fluids
- Circulating tumour DNA (not in cells) can also be detected with sequencing techniques
- Liquid biopsies are mostly performed on peripheral blood, but other fluids are possible (liquor)
- Already used for the diagnosis of NSCLC (with NGS)
- Might be used for screening purposes in future



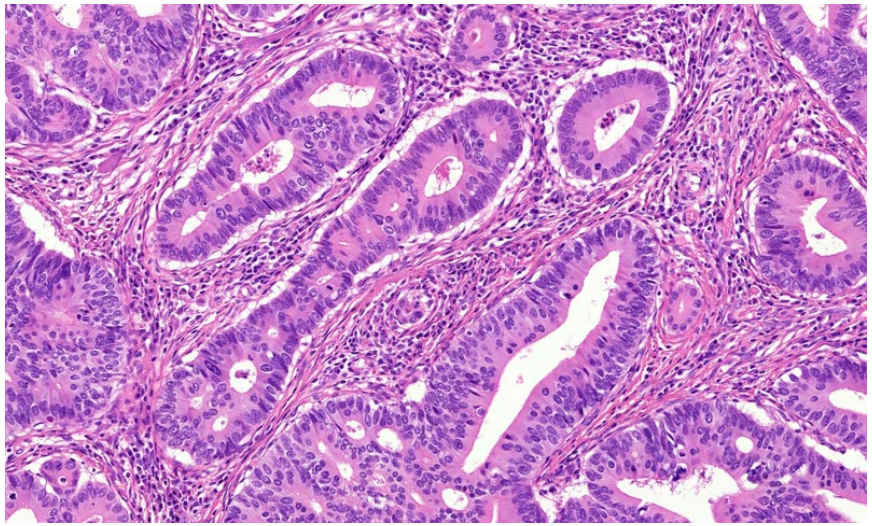
Basis of diagnosis 7 – Histology

- Histologic examination of tissue from the tumour (primary or metastatic), however obtained, including all cutting techniques and bone marrow biopsies; also includes autopsy specimens of the tumour.
- Optional:
  - Histology of the primary tumour
  - Histology of a metastasis
  - Histology at autopsy

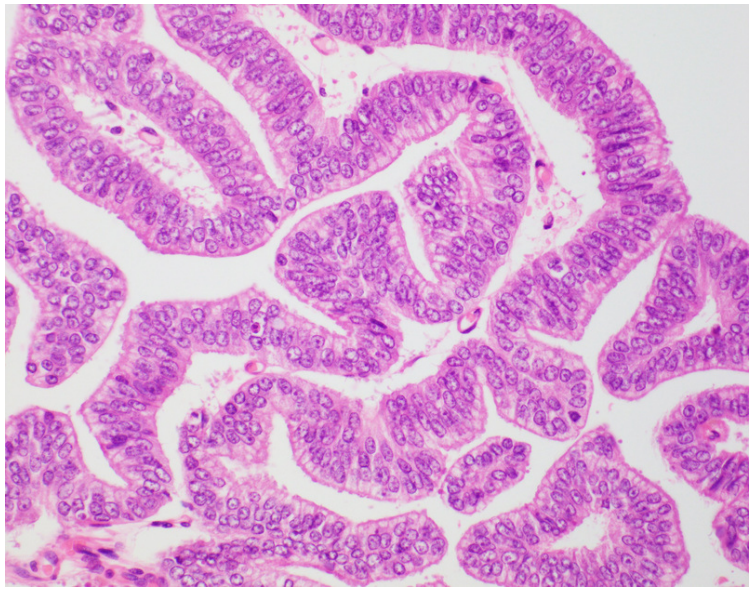
Basis of diagnosis 7 – Histology



Breast carcinoma NST



Colorectal adenocarcinoma



Prostatic ductal adenocarcinoma

Basis of diagnosis 8 – Cytogenetic and/or molecular testing

- Detection of tumour-specific genetic abnormalities or genetic changes in the tumour, including techniques such as karyotyping, FISH (fluorescent in situ hybridization), PCR (polymerase chain reaction), DNA sequencing
- Should be accompanied by cytology/histology (if not: code 5)

Basis of diagnosis 8 – Cytogenetic and/or molecular testing

- Many tumours have genetic abnormalities. Only a few are specific for the diagnosis of a certain cancer.
- Only when the genetic abnormality is specific for that cancer, basis of diagnosis 8 should be used.
- In most cases the abnormality should be present (e.g. CML, BCR-ABL1+ is 9875/3), but there are also cancer diagnoses which are characterized by the absence of a genetic abnormality (e.g. glioblastoma IDH wild type is 9445/3).

Basis of diagnosis 8 – Cytogenetic and/or molecular testing

Other examples:

- Acute myeloid leukaemia, inv(16)(p13;q22)
- Acute myeloid leukaemia with t(8;21)(q22;q22); RUNX1-RUNX1T1
- Medulloblastoma, SHH-activated and TP53-wildtype
- Oligodendroglioma, IDH-mutant and 1p/19q-codeleted
- Myeloid neoplasm with PDGFRB rearrangement

not yet in ICD-O:

- *CIC*-rearranged sarcoma
- Round cell sarcoma with EWSR1-non-ETS fusions

Basis of diagnosis 8 – Cytogenetic and/or molecular testing

Basis of diagnosis 8 is especially relevant if no specific morphology code is available

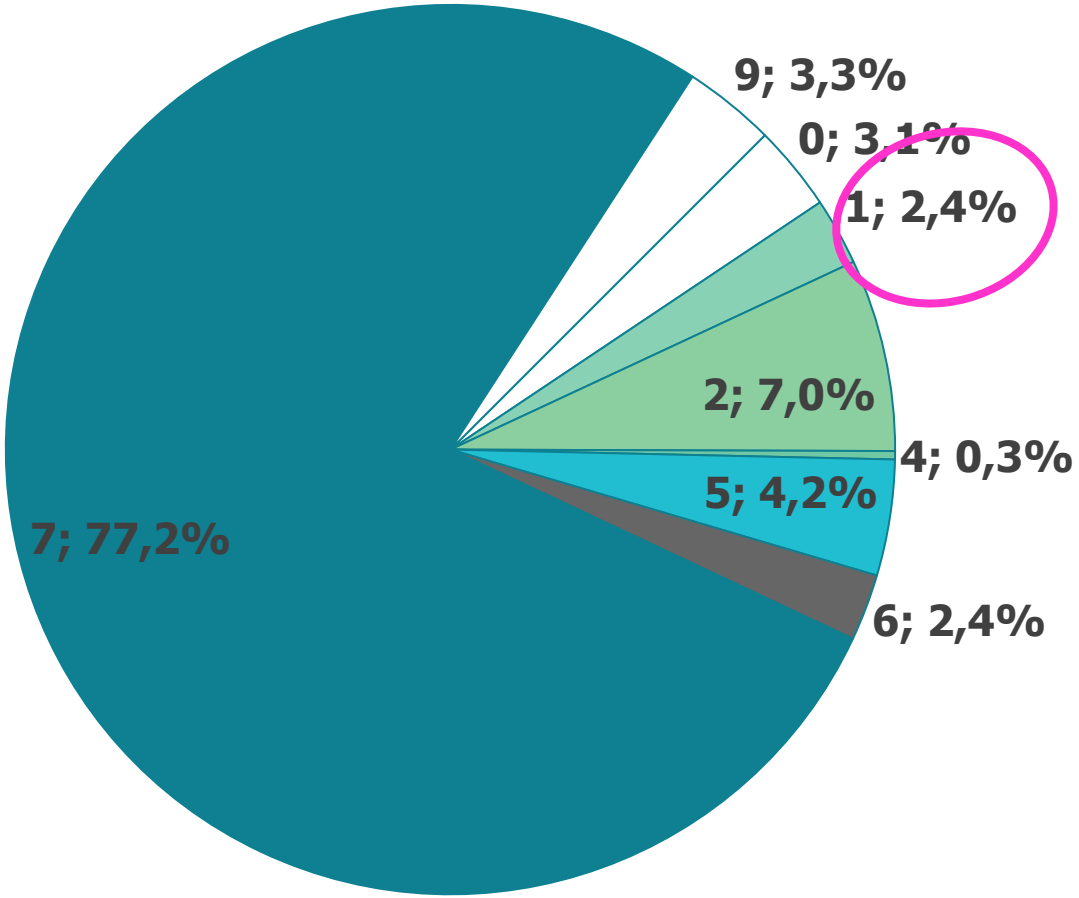
As soon as there are specific morphology codes for all relevant cytogenetic abberations this code may become redundant

For now, the code als also menat for drawing attention to look for cytoegentic/molecualr tests

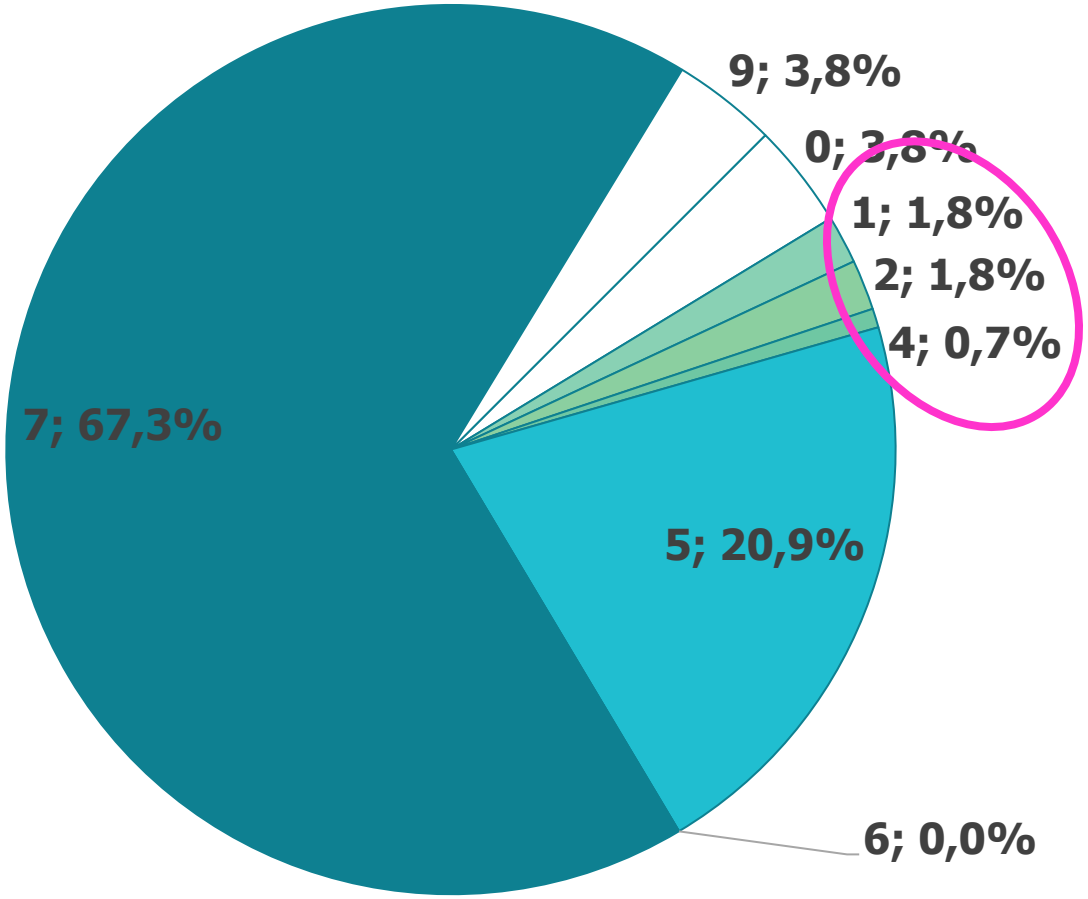
Basis of diagnosis 9 – Unknown

- There is no information about the basis of diagnosis
- Could be used for hospital notifications for which pathological information is not accessible to the registry

Basis of diagnosis in ECIS



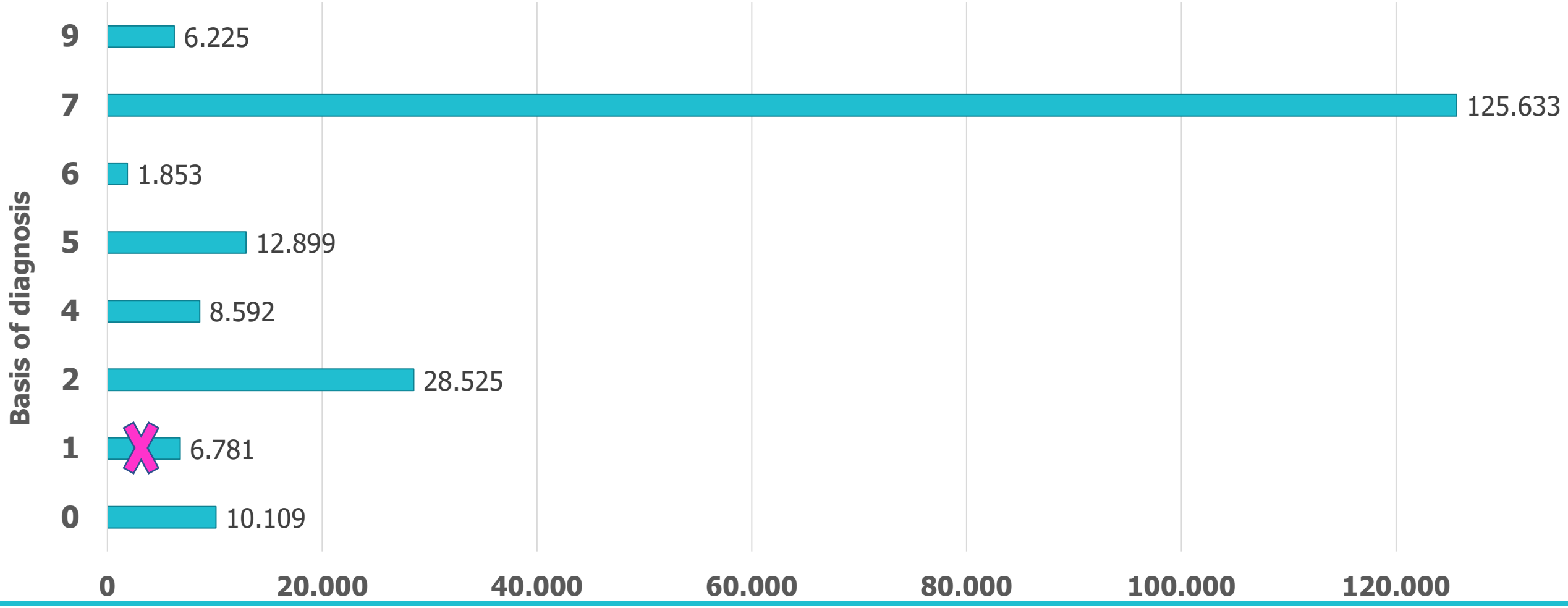
Solid cancers (/3)



Haematological malignancies

Source: ECIS
Courtesy to Carmen Martos

Basis of diagnosis of hepatocellular carcinoma

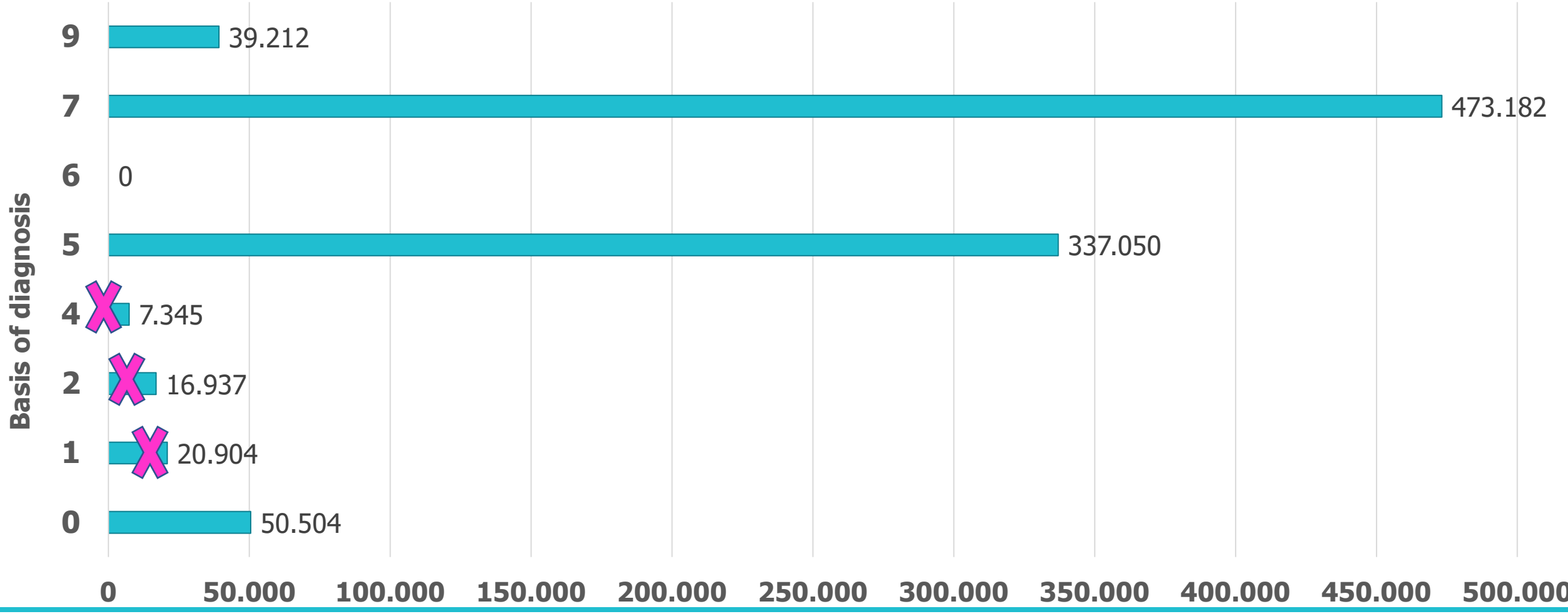


European Network of Cancer Registries

Source: ECIS
Courtesy to Carmen Martos

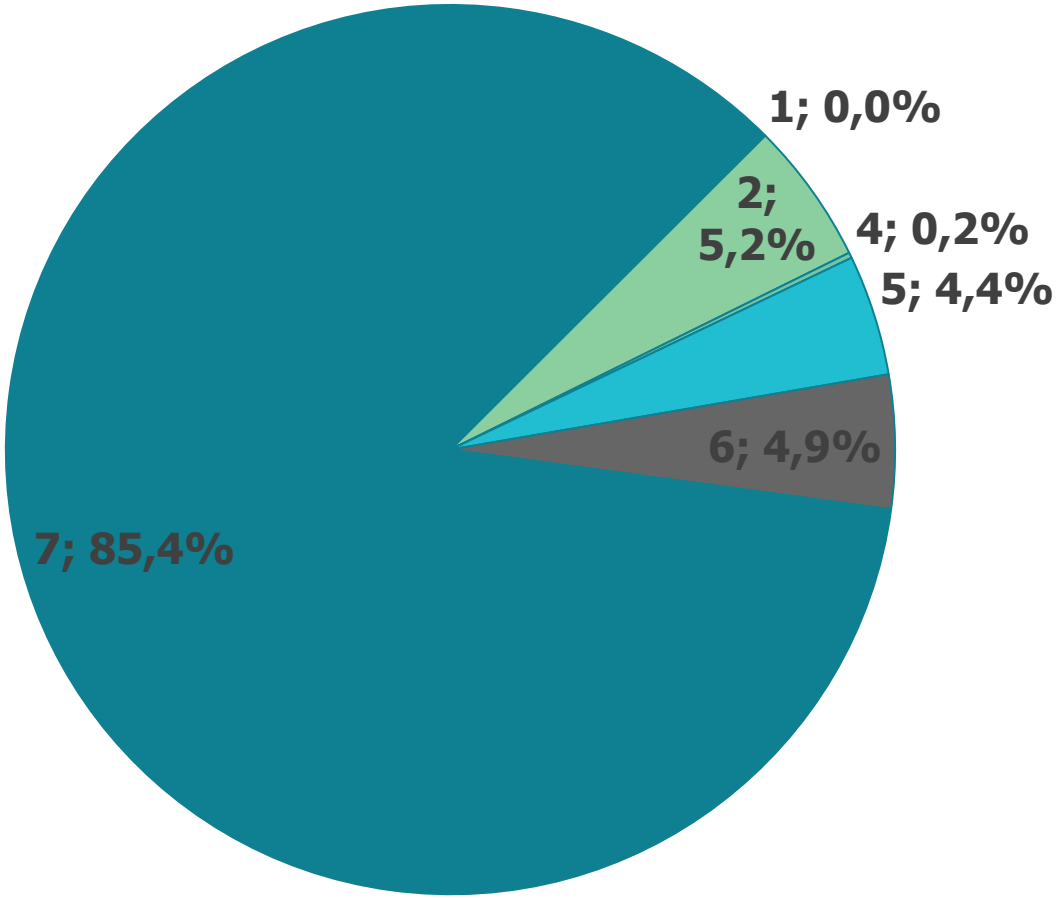
European Commission

Basis of diagnosis of leukaemia

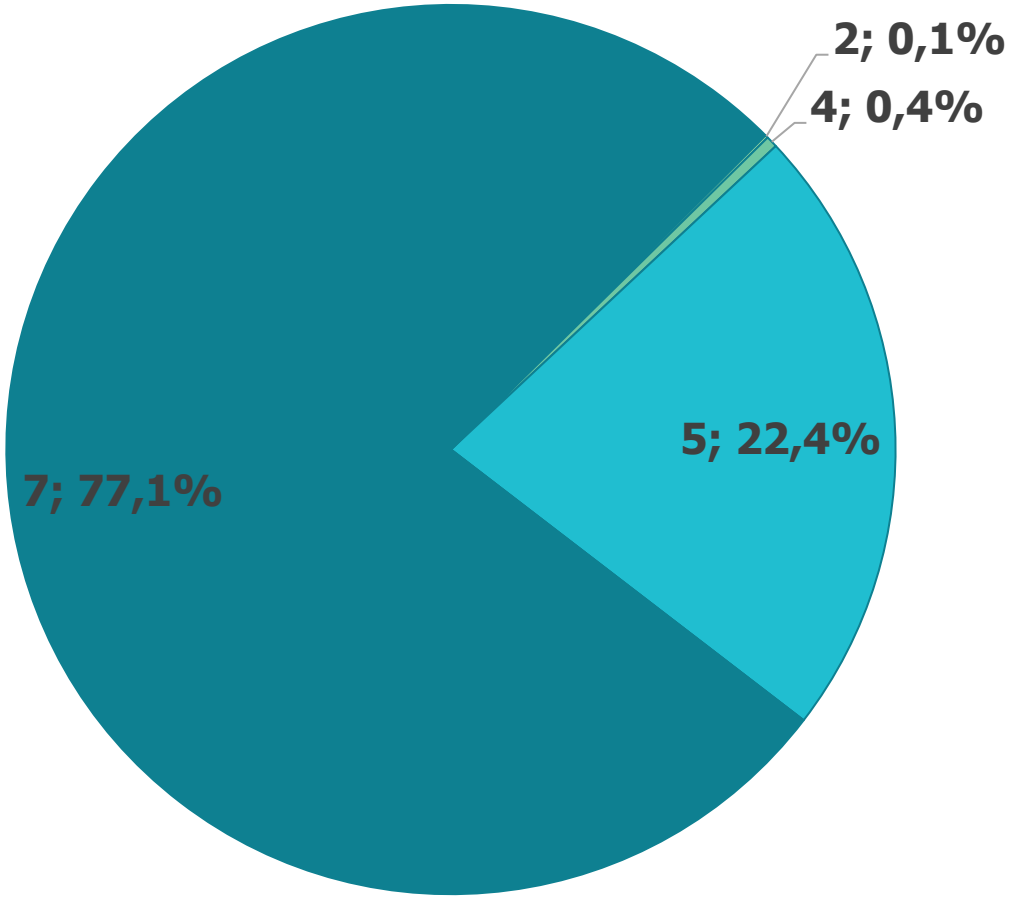


Source: ECIS
Courtesy to Carmen Martos

Basis of diagnosis in the Netherlands



Solid cancers (/3)



Haematological malignancies

Source: NCR

Rule 1

- Use the highest code from the range 1-8, unless
  - it is a DCO (basis of diagnosis 0)
  - the basis of diagnosis cannot be determined (basis of diagnosis 9)

Rule 2

- Codes 1 and 2 may be used when a diagnosis of cancer is at least likely ('probably cancer').
- If clinical examinations or investigations reveal that a cancer diagnosis is possible, the case should not be registered in the absence of pathological confirmation (basis of diagnosis 5-8).

Rule 3

- Cancers registered with basis of diagnosis 1 or 2 should be registered with morphology code 8000/3 (8000/0 or 8000/1 for benign and borderline malignant tumours of the central nervous system)
- Exceptions to this rule are listed in table 3. These exceptions only apply to cases for which the specific diagnosis is at least likely.
- If a specific diagnosis is only 'possible' or more than one diagnosis is mentioned in the clinical file or report, the case should be registered with morphology code 8000/3 (8000/0 or 8000/1 for benign and borderline malignant tumours of the central nervous system).

Rule 3

- Cases that may be registered with a specific diagnosis include:
  - Paediatric solid tumours
  - CNS tumours (including lymphoma and teratoma)
  - NET
  - Sarcoma
  - Melanoma
  - Hepatocellular carcinoma
  - Cholangiocarcinoma

Examples

European Commission

Example 1

- You have a DCO with C50

→Basis of diagnosis 0

→Morphology 8000/3

Example 2

- You have a DCO with ductal carcinoma of the breast

→Basis of diagnosis 0

→Morphology 8500/3

Example 3

- You have a DCO with C92.1 (chronic myeloid leukaemia, BCR/ABL+)

→Basis of diagnosis 0

→Morphology 9875/3

Example 4

- A patient was admitted to hospital at June 2nd 2021 for the evaluation of jaundice
- The CT-scan of the pancreas: tumour in the head of the pancreas
- No treatment was given
- The patient dies at July 13th 2021

→Incidence date June 2nd 2021

→Basis of diagnosis 2

Example 5

- A patient was admitted to hospital at June 2nd 2021 for the evaluation of symptoms of polycythaemia vera
- Several laboratory investigations are done on that same day
- Among other results, there is a positive JAK2 blood test
- Based on the results the haematologist confirms the diagnosis polycythaemia vera

→Incidence date June 2nd 2021

→Basis of diagnosis 5

Example 5

- *JAK2+ is basis of diagnosis 5 when you only have a blood test*
- *When also a bone marrow biopsy is available, it is basis of diagnosis 8*

Example 6

- A patient was admitted to hospital at June 2nd 2021 for the evaluation of jaundice
- The CT-scan of the pancreas is inconclusive, it may be pancreatitis or a malignancy
- No treatment was given
- The patient dies at July 13th 2021

→Incidence date you should not register this patient

Example 7

- A patient was admitted to hospital at June 2nd 2021 for the evaluation of a potential malignancy
- On the basis of a CT-scan (June 4th 2021) lung cancer is diagnosed
- No treatment was given
- The patient dies at July 13th 2021

→Incidence date June 2nd 2021

→Basis of diagnosis 2

Example 7

- *Admission to hospital (3) has a higher priority than imaging (5b)*

Example 8

- A patient was admitted to hospital at June 2nd 2021 for the evaluation of a potential malignancy
- On the basis of a CT-scan (June 4th 2021) lung cancer is diagnosed
- No treatment was given
- The patient dies at July 13th 2021 and at autopsy the lung cancer is histologically confirmed

→Incidence date June 2nd 2021

→Basis of diagnosis 7 (7.3)

Priority list for the incidence date

1. *Date of first histological or cytological (including flow cytometry, liquid biopsy) confirmation of this malignancy (with the exception of histology or cytology at autopsy). This date should be, in the following order:*
   a) *date when the specimen was taken*
   b) *date specimen received by pathologist*
   c) *date of the pathology report.*
2. *Date of first positive genomic/molecular test diagnostic of this malignancy*
3. *Date of admission to the hospital because of this malignancy*

Example 9

- A patient was admitted to hospital at June 2nd 2021 for the evaluation of a potential malignancy
- On the basis of a CT-scan (June 4th 2021) lung cancer (stage I) is diagnosed
- Stereotactic radiotherapy starts a June 28th 2021
- On December 6th 2021 there is a recurrence in a supraclavicular lymph node; histology reveals an adenocarcinoma

→Incidence date June 2nd 2021

→Basis of diagnosis 7 (7.2)

Priority list for the incidence date

- *The date of the first event (of the six listed in the following slides) to occur chronologically should be chosen as incidence date.*
- *If an event of higher priority occurs within three months of the date initially chosen, the date of the higher priority event should take precedence.*

Example 10

- A patient was admitted to hospital at June 2nd 2021 for the evaluation of a potential malignancy
- On the basis of a CT-scan (June 4th 2021) lung cancer (stage I) is diagnosed
- Stereotactic radiotherapy starts a June 28th 2021
- On August 6th 2021 there is a recurrence in a supraclavicular lymph node; histology reveals an adenocarcinoma

→Incidence date June 28th 2021

→Basis of diagnosis 7 (7.2)

Priority list for the incidence date

- *Whichever date is selected, the date of incidence should not be later than the date of the start of the treatment, or the decision not to treat, or the date of death.*
- *The choice of the date of incidence does not determine the coding of the item "basis of diagnosis".*

Example 11

- A patient with lung cancer is screened for brain metastasis
- The Ct scan (date: May 17th, 2021) of the brain shows no signs of metastasis, but a small parietal meningioma is found
- The meningioma is not treated

→Incidence date May 17th, 2021

→Basis of diagnosis 2

→Morphology 9530/0

Example 12

- You have a notification from a hospital of a leukaemia, NOS (date: September 21st, 2021)
- You have no pathology
- You have information regarding treatment with chemotherapy, starting August 7th, 2021

→Incidence date August 7th, 2021

→Basis of diagnosis 9

Example 13

- You have a notification from a hospital of a leukaemia, NOS (date: September 21st, 2021)
- You have access to the pathology, but there is no pathology record of this patient
- You have information regarding treatment with chemotherapy, starting August 7th, 2021

→Incidence date August 7th, 2021

→Basis of diagnosis 5

Example 12/13

The difference between 12 and 13 is that in 12 you do not have information about pathology while in 13 you are certain that pathology was not performed. If there is pathology was not performed the only way to diagnose a leukaemia is a blood smear and that is coded as basis of diagnosis 5

Example 14

- You have a notification from a hospital of an AML, PML-RARA+ (date: September 21st, 2021)
- You have no pathology
- You have information regarding treatment with chemotherapy, starting August 7th, 2021

→Incidence date August 7th, 2021

→Basis of diagnosis 8

Example 15

- A patient with a history of alcohol abuse and liver cirrhosis is admitted to hospital for evaluation at October 21st, 2021
- alfa-fetoprotein (AFP) is increased
- An MRI is made in October 21st, 2021. Conclusion: solitary lesion in the liver, hepatocellular carcinoma (Li-RADS 5)
- The patient is treated with radiofrequency ablation (RFA)

→Incidence date October 21st, 2021.

→Basis of diagnosis 4

→Morphology 8170/3

Example 16

- A patient is brought to the first aid department because of a collapse
- A CT scan (September 7th, 2021) of the brains reveals a lesion in the temporal lobe
- The exact nature of the lesion is unclear, it could be a vascular malformation, a stroke or a brain tumour (possibly a glioblastoma)
- The patients dies 5 days later

→Incidence date this tumour should not be registered

Example 17

- A two year old child is admitted to hospital on April 6th, 2021
- Clinical examination of the child reveals a retinoblastoma of the left eye
- Radiotherapy starts at April 15th, 2021

→Incidence date April 6th, 2021

→Basis of diagnosis 1

→Morphology 9510/3

Example 18

- You have a histology diagnosis of anaplastic oligodendroglioma
- Cytogenetic/molecular diagnostics were not performed

→Basis of diagnosis 7

→Morphology 9451/3

Example 19

- You have a histology diagnosis of anaplastic oligodendroglioma
- Cytogenetic/molecular diagnostics: IDH-mutant and 1p/19q-codeleted

→Basis of diagnosis 8

→Morphology 9451/3

Example 20

- You have a histology diagnosis of glioblastoma
- Cytogenetic/molecular diagnostics: not performed

→Basis of diagnosis 7

→Morphology 9440/3

Example 21

- You have a histology diagnosis of glioblastoma
- Cytogenetic/molecular diagnostics: IDH-mutant

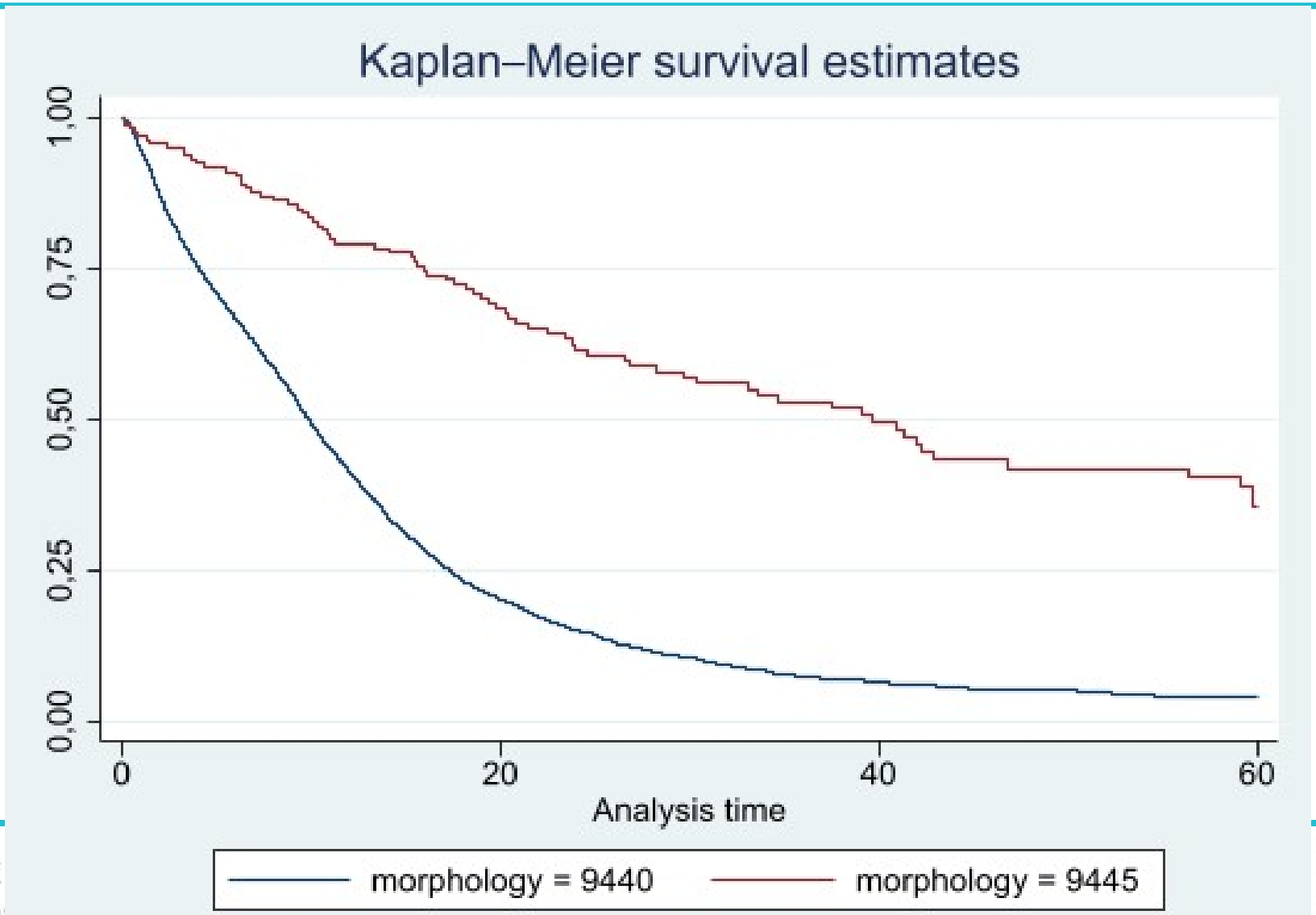
→Basis of diagnosis 8

→Morphology 9445/3

In basis of diagnosis 8 both pathology and cytogenetic/molecular diagnostics should be available

Survival of glioblastoma

9440 = IDH-wildtype
9445 = IDH-mutant



Q&A

- *Is increased PSA included in 5a of the incidence data priority list → yes, but increased PSA should be combined with a clinical examination/investigation*
- *Is it allowed to use the new rules for the basis of diagnosis before 1-1-2023 → yes, that is allowed*
- *How do I code cell block (cytoblock) → as basis of diagnosis 5*
- *How do I code a Klatskin tumour on imaging→ basis of diagnosis 2, topography C24.0, morphology 8162/3*
- *How do I register IPMN on imaging→ If the disease is not classified as malignant (8453/3), you should be able to differentiate between low grade (8453/0) and high grade (8453/2); if the grade is not mentioned, it is better not to register the case*

Questions?

Please be aware that any question on coding can be submit at the website of the ENCR:
https://www.encr.eu/ask-an-expert

European Commission