Coding Incidence Date

Contents

Background

There was both anecdotal and empirical evidence of inconsistency in the application and interpretation of the ENCR incidence date priority list.[1] In particular, there was a need for clarification to incorporate modern diagnostic methods including new imaging and laboratory tests.

Objectives

- Revision of the priority list for incidence date to incorporate modern diagnostic methods, including but not limited to flow cytometry, molecular testing, screening tests and new radiological/imaging techniques.
- The revision should not preclude comparison of survival estimates with tumours registered using the existing priority list, to ensure comparability with historical data.
- Clarify the interpretation of the priority list.

Entering into force

The new ENCR Priority list to determine Incidence Date is published on the website on the (15-03-2022). It is recommended to use this priority list for new cancer diagnoses from the incidence year 2022 onwards.

[1] Eden M, Harrison S, Griffin M, Lambe M, Pettersson D, Gavin A, et al. Impact of variation in cancer registration practice on observed international cancer survival differences between International Cancer Benchmarking Partnership (ICBP) jurisdictions. Cancer Epidemiol. 2019 Feb; 58: 184–92

Priority List

Changes to the previous list[2] are in *italic.* The priority list of the previous ENCR recommendation from 1995 (revised in 1997) is also in Annex 1.

The date of the first event (of the 7 listed below) 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.

Order of declining priority:

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 (see examples)*

3. Date of admission to the hospital because of this malignancy.

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 (includes PET, CT or 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.

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".

[2] Pheby D, Martinez C, Roumagnac M, Schouten L. Recommendations for coding Incidence Date. ENCR; 1997. https://encr.eu/sites/default/files/pdf/incideng.pdf

Priority list: Some examples

2. *Date of first positive genomic/molecular test diagnostic of this malignancy*

Examples of molecular tests that could be used to define incidence date

- T-cell receptor rearrangement – T-cell lymphoma
- BCR-ABL fusion gene (Philadelphia chromosome) – Chronic myeloid leukemia, acute lymphoblastic leukemia, and acute myelogenous leukemia
- JAK2 gene mutation – myeloproliferative neoplasms
- PML/RARα fusion gene – Acute promyelocytic leukaemia
- Circulating tumour DNA (ctDNA) – as part of diagnosis and cancer screening in future

5. Date of diagnosis, other than 1, 2, 3 or 4, for example:

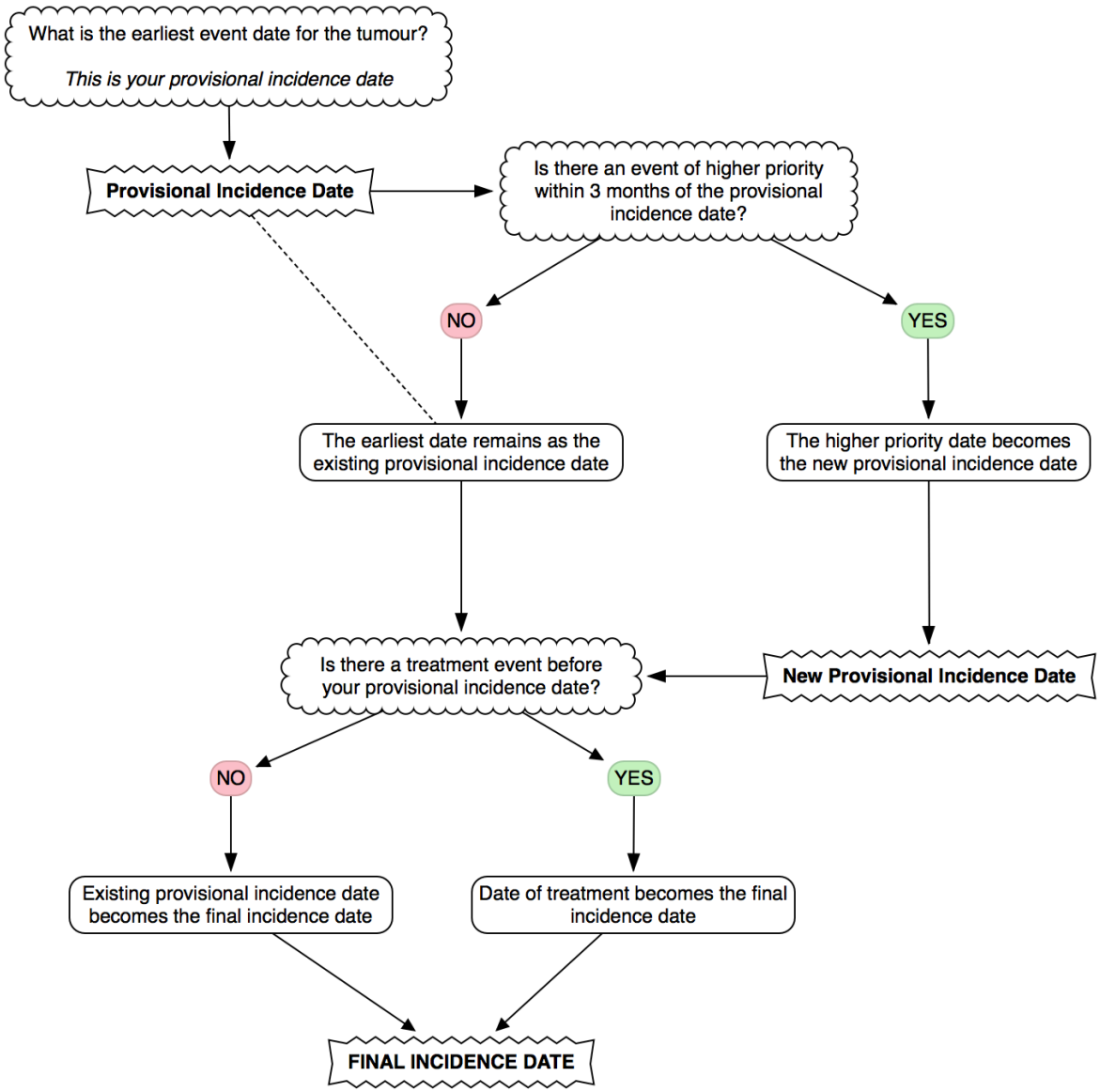
a) date of first positive tumour marker test diagnostic for this malignancy

Examples

- AFP in liver cancer
- Calcitonin in medullary thyroid carcinoma
- Chromogranin A in neuroendocrine tumours
- …

Incidence Date Decision Pathway

The proposed priority list can be used in conjunction with the incidence date decision pathway to provide clarification on how the rules should be interpreted.



Annex 1: Priority list in previous ENCR recommendation (1997)

The date of the first event (of the six listed below) 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.

Order of declining priority:

1. Date of first histological or cytological 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 (biopsy)
    b) date of receipt by the pathologist
    c) date of the pathology report.
2. Date of admission to the hospital because of this malignancy.

3. When evaluated at an outpatient clinic only: date of first consultation at the outpatient clinic because of this malignancy.

4. Date of diagnosis, other than 1, 2 or 3.

5. Date of death, if no information is available other than the fact that the patient has died because of a malignancy.

6. Date of death, if the malignancy is discovered at autopsy.

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

Annex 2: Working Group Members

This work was continued over time by consecutive Steering Committees. Michael Eden was responsible for the finalization of the current version, based on the work initiated by previous Steering Committees, under guidance of Emanuele Crocetti and the Working group.

Michael Eden, Emanuele Crocetti, Elizabeth Van Eycken, Maria Dolores Chirlaque, Alexander Katalinic, Ana Miranda, Maja Primic Zakelj, Michel Velten, Ariana Znaor, Antonio Mateos, Carmen Martos, ENCR Steering Committee 2014-2017[3], ENCR Steering Committee 2018-2020[3].

[3] https://encr.eu/previous-encr-steering-committees