

European Network of Cancer Registries: Recommendations for Registration of Haematological Malignancies

1. Multiple data sources such as blood, bone marrow, flow cytometry, molecular and cytogenetic tests from haematology and designated molecular laboratories in addition to histopathology, cytology, clinical records and death notifications should be used to register haematological malignancies (HM).
2. When additional information is received on the same HM patient the option exists to record as a transformation, same tumour or new tumour
 - a. Allocate as **Transformation** if first HM transforms into a new morphological entity (different diagnostic group) after a three month window of first registration,
 - only the first tumour's morphology and date of diagnosis to be considered as incident for analysis and reporting
 - the transformed tumour must **not** be counted as a new tumour and therefore not be included in the incidence statistics.
 - b. Allocate as **same tumour** with more specific /revised morphology,
 - if within same diagnostic group, date of diagnosis remains unchanged.
 - if a transformation occurs within three months after the incidence date, the morphology code of the transformed malignancy should replace that of the first tumour and be recorded as the first primary and not a transformation. Date of diagnosis remains unchanged as that of the first tumour

- c. Allocate as a **new tumour registration** with new incident date when
- HM with malignant behaviour (code /3) occurs after a previous haematological disease with uncertain behaviour (code /1) or
 - the change is not a transformation or a revised diagnosis of an existing tumour or
 - clinical opinion regarding a new tumour is available and the detail of that decision is recorded.
3. Regular survival analysis methods do not necessarily apply in the case of patients with HM where transformations have occurred as the patient has to be alive until the diagnosis of multiple tumour or transformation occurs. The information of these changes may be used as time-dependent covariates. There are special methods for such multiple tumour analyses¹.
4. The ENCR recommendations for coding of incidence date should be followed².
5. Basis of diagnosis should follow the ENCR recommendations³
6. Record all dates and diagnoses of transformations in the registry.

References

1. Heinävaara S, Teppo L, and Hakulinen T, Cancer-specific survival of patients with multiple cancers: an application to patients with multiple breast cancers. Stat. Med 2002; 21: 3183-95.
2. European Network of Cancer Registries. Recommendations issued by ENCR. Available from: <http://www.enccr.eu/index.php/activities/recommendations>.
3. Tyczynski JE, Démaret E, Parkin DM. Standards and guidelines for cancer registration in Europe. The ENCR Recommendations, Volume 1. IARC Technical Publication No 40. Also available from <http://www.enccr.com.fr/incideng.pdf>.

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