

EUROCIM – 2

Description

The European Network of Cancer Registries (ENCR) in the past developed a joint software and database called EUROCIM (European Cancer Incidence and Mortality database). This database allowed contributing member registries to analyze international cancer registry data at a level of detail previously impossible based on public use data. The database included families of major morphology groups in addition to site and it was based on anonymous individual records coded according to the ICD-O, combining topography and morphology. The use of the data was regulated by a set of rules: only researchers in registries or linked to registries were allowed to use the data, and any publication on data from individual registries required pre-warning of the registries whose data was used. The ENCR urged members to contact and discuss results with the individual registries, both to avoid publication of registration artifacts, and to establish collaboration on descriptive epidemiology across European cancer registries.

The data submitted for the EUROCIM, in addition to the software itself, was in the past used for studies going beyond the level of detail in the software, upon explicit consent of the registries whose data were involved in a specific analysis. No examples of misuse and breach of the established rules were seen.

The software is now outdated, and by decision of the ENCR Steering Committee it will not be developed further. Firstly, the concept of families of major morphology groups was restrictive since they reflect known factors. Further, the data structure limited analysis of data to mortality and incidence. Studies on survival, prevalence and predictions were not feasible. The database, however, will be renewed and become available to the participating registries and it will include additional data items to enable a wider range of studies.

The development of a data submission layout will be the basis for even more and detailed collaboration on the data. The use of data submitted is limited to projects where a protocol exists, is posted on the ENCR website, and the project is acceptable to the registry. The current protocol or terms of reference for use of the EUROCIM-2 dataset is based on the idea to return the data to the data providers and enable each of them to analyze European data including survival and prevalence and allowing one to carry out time trends and predictions.

The EUROCIM-2 dataset will be provided to contributing registries under the rules listed in section 1 and at the level of detail described in section 2. As with the original EUROCIM database publications will require the explicit consent of the registries whose data is used and a protocol for the study published on the ENCR web site.

Rules of use of the EUROCIM-2 dataset

- The EUROCIM-2 dataset is for internal use by the organizations providing the data and researchers designated by them, with written consent to adhere to the rules laid out in this protocol.
- No attempt should be made to identify information pertaining to particular individuals or to contact individuals.
- The data must be kept secure at all times.
- The data must not be linked to other datasets without explicit permission.
- No data of a nature breaching confidentiality of individuals may be published, and users are obliged to check confidentiality issues with the registries whose data are used.
- No data relating to single registries may be published without the explicit consent of the registries in question.
- Registries may publish their own data compared to the European pool of data, upon consent of the ENCR steering committee.
- Registries may publish their own data compared to grouped data from regions of Europe when consent is given either from associations covering the regions or from the individual registries within the region.
- Copies of the given consent must be provided to the ENCR secretariat in all instances.
- Users are urged to establish collaboration with other contributors in analysis and presentation of data from the EUROCIM-2 dataset.
- Users of the EUROCIM-2 dataset must provide a copy of any resulting manuscript to the ENCR steering committee, and to registries whose data are presented in a form that identifies the registry when submitting to a journal.
- For any resulting publication, the registries must provide a written statement to the ENCR steering committee that the above rules were followed, and also provide a copy of the manuscript