

HAEMACARE - Cancer Registry Based project on Haematologic malignancies

Background and Rationale

Haematological malignancies (lymphomas, leukaemias and multiple myeloma) constitute a large fraction of blood diseases in adults. Leukaemias and non-Hodgkin's lymphomas (NHL) are the commonest haematological malignancies (HMs), accounting for 6% of all cancer deaths in the EU. In 1995 estimated *incidence* in the EU was 6 per 100,000 person/year for NHL; 2 for Hodgkin lymphoma (HL), 4 for multiple myeloma (MM), and 10 for leukaemias. However incidence varies, being generally higher in northern and western European countries, and lower in the southern and eastern countries.

Mean European 5-year *relative survival* ranges from 80% for HL, to 33% for MM. In general, HM survival is lowest in eastern Europe and highest in France, Spain and Austria. Importantly, there are inter-country survival differences for potentially curable HMs such as HL. The differences can be due to different stage at diagnosis, variation in treatment quality (at least for curable HMs such as HD) and also in part to variations in the case mix of morphological subtypes. However, because of the lack of standardisation of diagnostic criteria and coding practices it is difficult to interpret regional and overtime differences in survival and incidence for HMs.

Many HMs are chronic, requiring repeated treatment cycles and associated with long-term sequelae. In recent years, important developments have occurred in diagnosis and treatment of HMs, that are likely to modify the natural history of these diseases, and improve prognosis in the near future. Survival and prevalence are important indicators of outcomes and the resources required for planning public health provision. Most studies on HM are hospital-based, and therefore are on selected series of patients, so that results may not generalisable to the entire population.

Public health planning therefore requires *population-based information*, such as that provided by cancer registries. The problem is that the classifications of HMs used by cancer registries are not always up-to-date or compatible with clinical classifications, which now make use of molecular information (cell surface markers, cytogenetics, tumour gene mutations). This project aims to bridge the gap between clinical research and public health information systems. It will be based on the EURO CARE-3 and EUROPREVAL networks, and will profit from the collaboration of the EUROCHIP project.

Aims of the project

- 1) To **increase the standardisation and comparability** of indicators provided by population cancer registries, i.e. incidence, survival and prevalence, on HM.
- 2) To **revise coding practices** of cancer registries with the aim to increase availability and standardisation of morphology data, ensuring a strict adherence to ICD-O classification, and making them consistent with clinical classifications
- 3) To **integrate the information** currently available to population cancer registries with that derived from clinical data bases
- 4) To estimate **survival** according to specific morphology groups, instead of the large categories of HM usually provided by cancer registries. This will help interpreting survival differences (particularly those between Eastern and Western European countries).
- 5) To estimate the **prevalence** of HM in Europe, i.e. the number of persons diagnosed with HM alive at a fixed date. These persons represent a part of population with specific health needs, thus this indicator can help planning resources.
- 6) To tentatively estimate the proportion of **'cured' patients** among the overall survivors, by mixture survival models, which divide survivors in 'cured' and bound to die after a certain time since diagnosis.
- 7) To provide **indicators of clinical activity** on HM, by country, using information available in clinical data bases