

## Authors comments

The EUROCARE project is monitoring cancer patients survival in Europe since over 20 years. The latest EUROCARE-5 study analysed the survival of over 10 million cancer patients diagnosed between 2000 and 2007 and followed up through 2008. The project is based on data of 109 population-based cancer registries from 29 countries, and covers over 50 % of the adult and 77% of the childhood European population.

Survival at 5-year from diagnosis varies remarkably by tumour type, ranging from over 80% for cancers of testis, thyroid, prostate, breast, skin melanoma and Hodgkin's lymphoma, to less than 15% for cancers of the lung, oesophagus, liver, pleura and pancreas. The between-country range of variation for major cancer types, such as colorectal cancers, breast, prostate, skin melanoma and lymphomas, is also high. Survival is usually lowest in Eastern European Countries (Bulgaria, Slovakia, Estonia, Latvia, Lithuania and Poland) and highest in Nordic Countries (with the exception of Denmark) and several Central and Southern European countries (Austria, Belgium, Germany, Netherlands, France, Switzerland, Italy, Portugal, Spain). Survival in the UK and Ireland is lower than average for stomach, colon, ovary and kidney cancers and close to the European average for others (rectum, breast, prostate, skin melanoma and lymphomas).

Cancer survival is generally increasing in the first decennium of 2000's, with highest increases recorded for prostatic and rectal cancers, and for non-Hodgkin lymphomas. Although survival increases in all the European regions, international differences are narrowing only for a few cancer sites (e.g. breast and prostate cancers and cutaneous melanoma).

Childhood cancers are mostly treatable.

The European overall 5-year survival is 78% for children diagnosed in the period 2000-2007, varying, in the main tumour types, from over 95% for retinoblastoma or Hodgkin's lymphoma, to less than 60% for CNS tumours. Between country variations are also large. Attention should be put on some countries of the eastern Europe that show low survival, and also in the limited results of some southern European countries

### *What are the reasons of survival differences ?*

EUROCARE is a European-wide project that can reveal cancer survival differences and assess survival time trends, but has limited possibilities to establish the reasons for such differences. Survival indeed is a complex indicator influenced by many factors, not only by the quality of cancer care services. Population-based survival is more difficult to interpret than survival from clinical randomised trials, because it is difficult to collect for *all* cancer patients the very detailed clinical information influencing the complex clinical pathway of cancer. Cancer registries for instance do not systematically collect information on the extent of disease at diagnosis ( the so called stage), or on the types of performed treatment or on the presence of other illnesses (co-morbidity) limiting the application and the efficacy of treatments.

Broadly speaking survival differences usually reflect differences in the economic resources devoted to health, with low expenditure countries faring worse than those at high expenditure. This is particularly evident for the survival differences between Eastern European countries and the rest of Europe. Nevertheless, there are important differences, even though more limited, also between countries at high-to-medium expenditure on health, indicating that health spending is not the only factor influencing cancer outcome.

In some cases the survival differences may depend on the fact that the nature of tumours is different.

The highest survival of stomach cancer patients in Southern with respect to Nordic countries, for instance, is, at least in part, explained by a highest incidence of less aggressive cancers in the South. Also differences in the implementation of mass screening or in the spread of early diagnostic activities have an impact on the international cancer survival differences, because earlier diagnosis reduces mortality through the identification of less advanced and severe cancers.

This is the case of prostatic and breast cancers and, to a lesser extent, of cutaneous melanoma and colorectal cancers. Prostate cancer incidence and survival, for instance, increased dramatically during the study period in parallel with the increased diffusion of prostate-specific antigen (PSA) testing, which reveals many slow growing tumours. In Eastern Europe, where there are often deficiencies in the implementation and population coverage of mass screening, breast cancer survival is particularly low in the age groups targeted by the mammographic screening.

Cancer registries do not systematically collect information on the stage of tumour at diagnosis, e.g. on the extent of the disease, but diagnostic delay is likely to be a major reason of international differences in survival. Later stage at presentation indeed reduces the efficacy or limit the applicability of the available treatments. Previous EUROCARE analyses on samples of breast and colon cancer cases - for which detailed information on stage was collected - strongly suggested that the survival differences among European countries were largely due to differences in the stage of the disease at the time of diagnosis.

In several cases, improved therapeutic protocols were established during the study period and this may explain the improved survival time trends, as well as part of between-country differences. Survival has improved particularly for non-Hodgkin lymphoma (most likely because of more effective drugs becoming available in the study period) and for rectal cancer (most likely because of improved surgical techniques). The lack or shortage of public funds for health care services causes a sub-optimal access of the whole population to standard care and it is plausibly related to the frequently poor survival in Eastern European countries. This may explain the dramatically lower survival of childhood cancers and of lymphoma. In some cases, the survival gap of the Eastern countries is particularly large in young patients, e.g. for rectal cancer, and for lymphomas, and this suggests inadequacy of care.

In some cases, survival differences may persist even after controlling for stage at diagnosis and treatment, as for instance documented by studies analysing the differences in breast cancer patients' survival between Denmark and Sweden. Screen detected cases might receive better care due to well established protocols and multidisciplinary team case management. However other factors, such as lifestyle and socio-economic differences, most likely have to do with these differences. There is increasing evidence that the general health status, metabolic factors (e.g. metabolic syndrome), or the co-existence of other diseases, affect cancer patients' survival.

## FAQ

*What is population-based survival and why it is important to monitor it*

The highest achievable survival is obtained in randomised controlled clinical trials comparing new treatments with the best available treatments. Trials for most adult cancers involve only *small and selected* groups of patients and their results are extremely useful to identify new treatment protocols with potential to improve survival for all cancer patients. Conversely population-based survival is based on data collected by population-based cancer registries. It does not measure the best achievable survival but the survival achieved by *all* cancer patients residing in a given area and diagnosed in a given period of time. Population-based cancer survival is thus an indicator of the overall efficacy of health care systems in cancer control and care.

Monitoring population based survival is useful to identify areas, within a country or in international comparisons, where cancer patients survival can be improved. Monitoring population-based survival over time allows to measure progress in cancer management and to assess the impact of changes in the delivery or organization of cancer care services.

#### *Current issues in cancer registration*

Since population-based cancer survival is based on data collected by population-based cancer registries, it is very important to address the issues which hamper their efficient work.

One of the main issues is *outdated legal framework* for cancer registration, which doesn't reflect the current organization of the oncology health care in many countries and allows some hospitals (especially private ones) to have a very low and optional participation in cancer registration. Even when the cancer registration is compulsory, there are no penalties for low compliance of health care providers to cancer reporting, which leads to delays in data processing.

Another issue is that policy makers and governors continue to disregard the work of cancer registries, which results in allocating very limited budgets for their activities, but at the same time requesting quicker production of cancer reports, including the most recent accurate data. Some registries face restrictions in accessing demographic information, that are necessary for their analyses, mostly due to data protection laws. Data integrity and safety are in fact determined and guaranteed by the epidemiologic methodology, including ethics and serving to patients and populations at risk on the one hand, while also serving the medical, multi-disciplinary teams and community on the other hand, making maximum use of up to date and validated knowledge of the various cancers.

At the same time, using of e-resources and technologies is increasing, but still there are standards, recommendations and data certification procedures for cancer registration, which have to be considered and all data collectors must comply with them.

With the support not only of the responsible government institutions, but also of medical and patient societies, and non-governmental organizations, interested in cancer prevention, treatment and research, cancer registries have the potential to expand their role in cancer control

#### *Does better survival imply higher quality of treatment?*

Not only this, but also better access of all the population to the appropriate treatments.

#### *Is it true that cancer in the young are more aggressive?*

Not necessarily, this depends upon the type of tumour.

#### *May the international differences in survival depend on different age of the populations?*

No, because the methods used in the study allow to eliminate the influence of this factor

#### *May international differences depend on different quality of survival data?*

The data sets used in the study have been checked through quality indicators and cancer registries that did not match the appropriate standards were rejected. Possible residual problems of quality in survival data are addressed in the discussion and interpretation of results.