European funded projects, such as EUROCHIP and EUROCOURSE, have identified the priority information needed to support policy action on cancer control. Such information is however still far from being available at a Europe-wide level. The main objective of this Work Package is to build a comprehensive cancer information system for the European Union.
The WP will bring together the main actors involved in the provision and the use of cancer information: national and regional governmental institutions, cancer registries, research institutes, international institutes, European networks, patient associations, media and citizens representatives. During the second year a conference will be organized in Italy within the Open Forum, aimed to reach an agreement on the priorities identified and to propose the main objectives of the subsequent 2014-2020 programme.

Objective 1: To map the main sources of cancer data in Europe and to identify the priority topics to be supported by the Partnership

The health information useful to support policy action on cancer control has been identified by EU projects, but presently it is not sufficiently available at a Europe-wide level. The main scope of WP9 is to contribute building a shared, advanced and comprehensive cancer information system for European Union.
Cancer registries are the most important population based source of data, and many efforts have been spent to monitor and improve the quality and the coverage of the information they provide. WP9 will maintain a close coordination with ongoing activities on this topic in order: i) to report the Partnership on the progresses made; ii) to optimise the use of cancer registries data for pursuing the other Partnership objectives; iii) to integrate cancer registry data with other sources of information, such as health care system, demographic, socio-economic data. Other sources of data exist in Europe, potentially able to provide relevant information, per se or cross-analysed with cancer registriy data. Statistical Institutes provide data on population structure by age, sex and geographical area, population projections in the future, and general and cause specific mortality. They also collect data on socio-economic variables in European countries and regions that are associated with outcome of health care activity. Administrative sources can potentially provide data on cancer care infrastructures (eg. density of general and specialized doctors, density of imaging machines, number of radiotherapy units, etc), and on drugs and other resources provided for cancer care. Also cancer Institutes often maintain data bases that could provide very detailed, even if not always population-based clinical information. WP9 will map the existence within Europe of these various data sources, and will check on the availability and the quality of these data. A European map of cancer information will be built, using the indicators identified by EUROCHIP and ECHI. The map will identify areas of data availability and data needs. During the second year, a meeting,organized in collaboration with ACC and with the participation of all partners, will provide proposals and recommendation for

the next programme of Community action (2014-2020) in the field of Cancer Information. ACC will be charged to organize this meeting

Objective 2: To unify under a common platform cancer burden indicators (incidence, mortality, survival and prevalence) provided by existing European activities.

Cancer Incidence rates are provided from population-based cancer registries data and are then centralized and regularly published by IARC. Survival rates are currently provided at the European level, by region, country and registry area, by the EUROCARE network and related projects (HAEMACARE, RARECARE). Prevalence can be in principle obtained from cancer registries data. While prevalence data are available from Nordic countries and theoretical estimates of 1-yr and 5-yr prevalence will be provided in Globocan 2008, the most recent European comparative and observation-based data are those pertaining to 1992, provided by the EUROPREVAL project. Mortality data are collected at the national level by official death certificates. Cancer mortality statistics by country and registry area are organized and diffused by IARC. No coordination exists for consistent provision of these indicators as regards definitions, periods of reference, pace of updating, data sources and methods of analysis. High Resolution studies with detailed clinical information collected on representative samples of cases collected by cancer registries are in course or planned in several European countries. WP9 will bring together all the existing European partners working on cancer burden indicators to coordinate the analysis and provision of incidence, mortality, survival and prevalence. Updated incidence and mortality data will be made available in the framework of current activities of the International Organisation of Research on Cancer (IARC) and by the European Network of Cancer Registries (ENCR). Population survival, and high resolution data on stage and treatment from cancer registries, will be available through EUROCARE. Prevalence data will be provided mainly from EUROPREVAL and this task will be developed by ISS (FP), in collaboration with IARC, INT.
A working group will be convened, including IARC (responsible for incidence and mortality statistics), INT and ISS (responsible for survival, high resolution studies and prevalence statistics), and ENCR, to agree common definitions for cancer sites, geographical areas, age classes and time periods. All these indicators will be disseminated through the EU web portal and the Partnership web-site, using the facilities developed so far with the European funds.
The high resolution studies are aimed to explain the differences in cancer survival across areas and overtime, through the collection of more detailed information than that routinely available to cancer registries on tumour stage at diagnosis, clinical characteristics, diagnostic examinations, treatment and clinical follow-up, using representative samples of incident cases.
Between-country coordination of high resolution studies will be made to provide supplementary data useful for the interpretation of survival differences as well as indicators of standard care for cancer (eg. proportion of patients treated in accordance with guidelines).

Objective 3: Task force on population-based cancer cost investigation in Europe

Cancer incidence is increasing and fortunately prognosis is also tending to improve. Pharmaceutical, clinical and diagnostic costs are increasing faster than the available resources of most countries, thus costs are a fundamental aspect of cancer control. However population-based cancer cost analysisare rarely performed at European level and standardized and comparable data are scarce. The task force, which will include cancer experts, epidemiologists, health planners, economist and stakeholders, will produce an inventory of ongoing, reported and published population-based studies on cancer costs in order to evaluate the comparability of available data across Europe. A discussion on best methodology to be applied in order to collect comparable data on cancer costs at population level across Europe will also be promoted.
A standardised approach to the routine collection of survivorship data using population based cancer registries in various European countries will be studied. Survivorship research focuses on the health and life of a person with a history of cancer beyond the acute diagnosis and treatment phase. Survivorship research addresses quality of life of cancer survivors and their families and caregivers, including social, familiar, sexual and emotional aspects, as well as late effects of treatment. This task will be carried out in collaboration with with patients' organizations (FAVO, ECPC), international and national networks (OECI, ACC) and stakeholders.

Objective 4: To develop an inventory of statistical methods to analyse population based cancer data.

Sound statistical analysis is important for the full exploitation of population based cancer data. Many excellence experiences exist in Europe for the various fields of statistical analysis, such as trend and projections analysis, national estimates of incidence in countries with limited registry coverage, survival analysis, prevalence estimates, cross- analysis between incidence and survival indicators and Health Care System and socio-economic indicators. The establishment of a European network on data analysis will allow to better coordinate the efforts, to provide scientists with wide pan-European datasets, and to start build a European capacity for statistical analysis, projections and forecasting epidemiological cancer indicators. A panel of experts in population based data analyses, projections and forecasting will be identified by ISS and IARC in consultation with ENCR and other subjects. ISS will be the focal point of this

action, in collaboration with with ENCR, FRANCIM, IARC, IKNE, INT

Deliverables linked to each objective:

Objective 1: Report on data availability (Map of cancer information available in Europe)
Objective 2: Common on-line data resource, containing most up-to date cancer incidence, survival, prevalence and data in Europe
Updated European High resolution study protocol for the collection of cancer registry based data on cancer care and outcomes
Objective 3: Report on methodology to estimate cancer cost in Europe
Inventory of survivorship data to be collected by cancer registries
Objective 4: Report on statistical methodologies to analyse population based data

Work Package Leader on Cancer Information and Data:
Fondazione IRCCS Istituto Nazionale dei Tumori
milena.sant@istitutotumori.mi.it

PROPOSAL FOR EUROPEAN CANCER INFORMATION SYSTEM (ECIS)

We are proud to present the proposal for European Cancer Information System (ECIS). This updated version was created as a result of Work Package 9 (Information and Data) disccussions with EUROCARE, ENCR, IARC, OECI, JRC and DG SANCO and is in line with the EU health strategies of recent years.

The ECIS proposal was presented at the EPAAC OPEN FORUM in Rome, on 19 - 20th June 2012, and a specific open session on Cancer Information & Data was scheduled on June 20th.

To see the ECIS proposal please click here.

To see the Annex of the proposal, please click here.

Related Content

1. European High Resolution Study Workshop

High Resolution studies are carried out using population Cancer Registry (CR) data on a sample basis, involving the collection (and study) of detailed information on diagnostic, therapeutic and follow up procedures that are not usually routinely collected by CRs. The Workshop was held on 06.11.2012 at the Malpensa Center of Milan, Italy.

To see the Minutes of the Workshop please click here.