Boosting Innovation and Cooperation in European Cancer Control

Key Findings from the European Partnership for Action Against Cancer

Edited by
Jose M. Martin-Moreno
Tit Albreht
Sandra Radoš Krnel
Boosting Innovation and Cooperation in European Cancer Control
Key findings from the European Partnership for Action Against Cancer

Edited by

Jose M. Martin-Moreno, Tit Albreht, Sandra Radoš Krnel
Chapter 6

Information for action: building a unified European Cancer Information System to bolster cancer control

Milena Sant, Riccardo Capocaccia, David Forman, Stefano Rosso, Annalisa Trama, Sabine Siesling, Renée Otter, Camilla Amati, Francesco De Lorenzo

Main messages

- Relevant information on cancer is available, but its organisation and harmonisation is necessary to make it usable for health planners, doctors, patients and other stakeholders.
- Cancer registries should be at the core of a European Cancer Information System (ECIS), providing basic cancer indicators on incidence, survival, prevalence and patterns of care but these data need to be systematically linked to clinical, socioeconomic and population data.
- The first step towards an ECIS, the harmonisation of incidence and survival data, has been taken during EPAAC in order to update European cancer data and construct a common database computing incidence, survival and prevalence data.
- Specific conditions for data use still need to be considered, regulating confidentiality and ownership.

With the economic crisis straining health systems all over Europe, and with cancer incidence rising quickly as the population ages, efficiency and effectiveness are more important than ever, as are analyses on the contribution
made by successful cancer policies to societal well-being. Thus, it is no wonder that cancer information interests everyone committed to the optimisation of cancer control, including citizens, policymakers, public health experts, oncologists, patients, data providers and researchers: it is the only way to provide meaningful responses to population needs.

A large amount of detailed information must be studied in depth to manage the complexities involved in cancer control:

- Multifaceted causal pathways and prevention measures
- Demographic trends (e.g., population ageing)
- Patient and tumour characteristics to determine best course of treatment
- The organisation of clinical pathways
- Increasing cancer incidence rates and improved survival
- Survivorship issues, including long-term toxicity, co-morbidity and recurrence
- Psychosocial and spiritual aspects that add different dimensions to patient care
- Cancer economics, crucial in addressing the rising costs and societal impact

Currently, there is great heterogeneity related to cancer control in Europe: from different cancer-related behaviours, to environmental risks, available resources, cancer care organisation, and comprehensive cancer plan implementation. At the same time, many neighbouring countries also share important characteristics. This variation offers a unique setting for cancer research and its application in health care activities, opening up opportunities to compare cancer policies under both similar and different economic, social, cultural and environmental circumstances. Learning from these differences is essential to developing coordinated European cancer policies, and to improving the effectiveness of the actions undertaken. The will and the rationale for building a common framework for data on cancer in the EU are described in the Portuguese presidency conclusions of 2007 (1), those of the Slovenian Presidency of 2008 (2), the 2009 Communication for an Action Against Cancer (3) by Commissioner Androulla Vassiliou, and the European Commission 2nd Health Programme 2008–2013 (4). Our main aim at EPAAC has been to contribute to the construction of a comprehensive cancer information system for the European Union (ECIS), an essential tool for developing effective public health interventions and addressing health inequities (Box 6.1).
A cancer information system could greatly help national and European policymakers to develop effective cancer control interventions. First of all, it would enable up-to-date monitoring and future forecasting of cancer risks through incidence and mortality data, possibly disaggregated by detailed geographical area and biological disease characteristics. Through existing data produced by the health care system, it could also provide a systematic picture of the available resources and infrastructures deployed to control the cancer burden and to respond to the demands for cancer services. Survival data (possibly analysed by stage at diagnosis), biological characteristics of the tumour and data on type of treatment would allow evaluation of the performance and the final outcome of health services in providing optimal treatments. Linkage of health data with socioeconomic variables could enable measures addressing health inequities. Finally, a dynamic information system with a solid grasp on population-based data, but open to the progressive inclusion of newly relevant information and able to tackle new information challenges, will be necessary to avoid an enlarging gap between cancer research and cancer control activities.

Building a European cancer information system is a complex undertaking and requires political will at all levels: a comprehensive framework should regulate the coordination of the entire process of data gathering, quality control, management, analysis, dissemination and access. These functions must be sustainable over time and progressively implement innovations resulting from research. For these reasons, the process of constructing the future ECIS should be endorsed by each EU Member State involved. In 2009, the EPAAC Joint Action was officially mandated to deliver by 2013 a proposal laying the basis for a future European Cancer Information System, under the consensus of all cancer stakeholders (data providers, health professionals, governments, citizens, patients and researchers). In 2011, the Cancer Policy Support Group of the European Commission Joint Research Centre (JRC) was charged, among other tasks in the framework of the Horizon 2020 goals, with a neutral and technical role in assisting the discussion on an ECIS and in acting as a data

**Box 6.1 Definition of cancer information system**

A ‘Cancer Information System’ is a public health and research infrastructure functionally connecting all institutions, people, procedures and resources; producing meaningful information from cancer data; and working within a common framework of concepts, methods, structures and technical standards. It harmonises the data produced by all these stakeholders and makes the information derived accessible to users under agreed conditions and regulations, providing as much knowledge as possible to facilitate interpretation of the dynamics of cancer in populations.
repository. It is our intention to illustrate here the state of the art in the field and the activities that have been carried out towards an ECIS, as well as those that have been started and will continue after the completion of EPAAC.

**Understanding cancer information: data, registries and cancer information systems**

The major advantage in dealing with cancer information in comparison to other diseases is the wide availability of patients’ data due to the absolute need for specialist care required. These derive mainly from health care facilities, including administrative and clinical hospital records, pathology reports and pharmaceutical data. Cancer registries intercept many of the data flows generated by these sources and, also through their linkage with population sources (census files, household surveys, vital registration systems, organised screening registries), provide cancer indicators on incidence, mortality, survival and prevalence.

Population-based cancer registration is the continuous, systematic collection of a defined data set on all persons diagnosed with cancer, including the tumour characteristics, treatment and outcome, within confidentiality regulations and under quality criteria defined at both EU and global level for comparability of data (7). Information concerning quality of life, survivorship, cancer economics and functional parameters may also be collected. Data refer to an administratively defined population and are frequently sent to the registry from different units (e.g., public hospitals, pathology departments, haematological departments, medical records, radiotherapy databases, cancer centres, hospices, private hospitals, screening registries, other cancer registries, primary care facilities, nursing homes and death certificates) within a single institution or several institutions. Indicators derived from registry data are frequently accessible online or in specific publications and are usually made available by age, sex and type of cancer.

Other information is also available in Europe. Aggregated data on risk factors, early diagnosis, health care resources and socioeconomic variables are available from a number of sources, including the European Health Information Survey (EHIS), the Organisation for Economic Cooperation and Development (OECD) and EUROSTAT (a summary description of cancer data and information sources for European populations is provided in this chapter). However, despite the extensive amount of data collected and the obvious advantages in having access to it, there is no comprehensive platform or system that collates all cancer-specific information, complicating integrated research into this disease. This makes research much more difficult than it should be.
Users of cancer information in the EU

An ECIS would be instrumental for all major stakeholders in cancer control: researchers, clinicians, policymakers and citizens (including patients). First of all, the timely delivery of comparable clinical, biobank and screening data, combined with a more uniform and research-oriented implementation of ethical and data confidentiality standards, could provide a strong boost to cancer research across Europe and worldwide. The European population of 500 million is sufficiently large to enable the analysis of geographic variation and time trends by clinical, biological and demographic characteristics; evaluate the impact of environmental, social and organisational factors on cancer risk and outcomes; shed light on the effect of preventive actions; reliably test hypotheses regarding the role on outcome of health care services organisation and of adherence to national or European guidelines; and benchmark progress with innovative treatments or diagnostic tools in clinical practice.

At the clinical level, assessment and outcome tools exist that have been translated and validated in several countries. However, European collaborative efforts are required to develop these tools further and to make them more widely available (see below).

Likewise, assessment is a strategic necessity in public health planning. The availability of epidemiologic and public health indicators is necessary to help policymakers to prepare national cancer plans, but also to evaluate in due course the impact of the planned action at the population level. International comparisons improve knowledge on the effectiveness of cancer plans, particular needs related to specific disease groups or social categories, and accessibility to treatments and the availability of high-quality health care. In summary, without reliable cancer information, policymakers cannot plan appropriate prevention and public health interventions.

Citizens, and particularly patients, have an important stake in progress. Specific problems and needs associated with this have been reported and explained in several European forums, including the initial Europe Against Cancer programme, which was valuable in laying the foundations of a European strategy for cancer control. Patients still face great inequalities between and within Member States in terms of the development of national policies or strategies to tackle cancer and access to specialists, drugs and social services. There are no EU general principles or minimum standards that allow patients and cancer survivors to receive minimum health and social services under a cancer plan. Such principles and standards would help the EU Member States in a meaningful and systematic way to build a framework that is coherent yet flexible enough to take into account the specific requirements of all the diverse
interests. Cancer patient organisations in EPAAC and other EU projects have advocated for the development of a minimum portfolio of essential services for all European patients, with a framework to encourage cooperation and knowledge-sharing between centres of expertise, and a multidisciplinary approach to care to address the complex and diverse conditions that no Member State can address alone (see Chapter 5 on the Network for Information on Rare Cancers, RareCareNet (www.rarecarenet.eu/rarecarenet). Directive 2011/24/EU (8) on the application of patients’ rights in cross-border health care has advanced an EU-oriented approach to the issue of minimum standards. The wide availability of cancer information could facilitate the implementation of minimum standards for health and social services based on good practice from around the continent. Cancer plans that take these standards into account will be better equipped to provide high-quality care for patients and citizens, who would also be enabled to monitor adherence to European norms with absolute transparency.

**Spotlight on SEER: Comparing cancer information in the US and Europe**

An extraordinarily wide spectrum of activities related to cancer information and data is ongoing in Europe, providing all the necessary components for the development of a cancer information system. However, a proportional advance of knowledge in the field of cancer epidemiology is not possible without optimising and integrating our deployment of resources. Perhaps the most relevant experience outside Europe is SEER (Surveillance Epidemiology and End Results programme, run by the National Cancer Institute in the USA, part of the National Institutes of Health (www.seer.cancer.gov). SEER is an authoritative source of information on population-based cancer epidemiology in the United States. It collects, analyses and disseminates cancer incidence, prevalence and survival data on about 28% of the US population. SEER statistics reflect the US population with regard to poverty and education, urban and rural groups, and racial/ethnic diversity (it presently covers approximately 40–50% of Latinos, Native Americans and Asian Americans, and 23% of African Americans). The registries in the SEER programme are required to collect information on demographic indicators, tumour site and morphology, stage at diagnosis, treatment and follow-up, as well as cause-specific mortality data from official US statistics. Annual updates in print and online help thousands of users (including health professionals, policymakers, patient groups and citizens) to obtain an accurate picture of cancer epidemiology. Individual anonymised data may be accessed under the condition that it be used for research purposes, but no information that could identify individual patients can be published. The
wide spectrum of information collected and continuously updated, as well as the accessibility of the data, makes SEER an invaluable source for population-based cancer research worldwide. A widely used measure of impact on research of any activity is given by the number of indexed papers arising from it. The worldwide impact of SEER programme is demonstrated by the 4500 peer-reviewed articles using the SEER Research Database that have been published in indexed scientific journals since the year 2000, generating more 130,000 overall citations (600 of these papers were published in 2012). Over the same period, the number of research papers integrating and jointly analysing registry data from the network of European registries does not exceed 500 (60 in 2012).

There is no reason that this should be so. The European scientific community is at the forefront of methodological research in population-based epidemiology and public health, from analysis and projection of incidence and mortality trends, to survival analysis, prevalence estimation, planning and performance of studies on prognostic determinants, as well as the study of social, organisational and economic inequalities in health. Even though far less funded, the productivity of cancer research in the European Union, measured in terms of scientific publications, is comparable, or even slightly greater, with respect to the United States (9). Moreover, many scientific publications produced in the EU are based on SEER, instead of on European cancer registry data.

The lack of a common framework for cancer information in Europe is a plausible explanation for Europe’s smaller impact on global cancer research. Many different institutions collect different data with a varying degree of coordination. Incidence and mortality databases are maintained by the International Agency for Research on Cancer (IARC), while the EUROCAR project (www.eurocare.it) uses registry data to monitor survival, prevalence and patterns of care. Stage and treatment data are collected by different registries across the EU in the framework of the so-called ‘high resolution studies’. General health-related data, necessary for an appropriate interpretation of cancer indicators, are organised within the EU health portal (ec.europa.eu/health-eu/index_en.htm). General and health specific economic data are collected in the OECD database (stats.oecd.org/).

Another problem we found was the degree of access to patient data. Micro-data at the individual level are the only relevant data in research contexts, as they do not limit study design but do enable the elucidation of the interactions between many causal pathways of disease or outcome as a function of the pattern of care; however, the scientific community’s access to individual data at the European level is not easy. Today, research groups wishing to access individual data from European cancer registry databases for specific aims (e.g., EUROCAR or EUROCIM) can only do so following a request of consent via
relevant protocols among the interested registries, and only data from registries explicitly approving the protocol will be included in the released dataset. Due to the high number of data providers involved, this procedure ends up being quite bureaucratic, with multiple pitfalls that can stop the process. It also requires extra work for the contributing registries, which may become a problem if a high number of requests (as is desirable) reach them. Another disadvantage is the production of ad hoc datasets for each specific request, which may hamper the reproducibility of research results.

The results produced by the SEER system model demonstrate that, with the necessary adaptations to be tailored to the EU context, the potential added value of a unified information system would be enormous in terms of evidence-based public health research, not only for Europe but also for the EU Member States. The SEER experience cannot be immediately applied to Europe, since SEER covers a fraction of one jurisdiction and US federal law regulates SEER activities, whereas the European Union covers 28 countries that organise cancer registration activity in different ways. Moreover, the EU Member States still have different legislation on data protection (a common law should enter in force in the next several years). Finally, the 28 EU Member States present an extremely wide variation in funding for cancer information systems, but nothing as well-funded as SEER. Detailed data on health and cancer determinants in the USA relies on the National Health and Nutrition Examination Survey (NHANES), which doesn't exist in the EU. However, the differences in resources and jurisdictions do not mean, of course, that the same objective is not affordable or achievable in Europe, but that a higher degree of harmonisation and accessibility to cancer information should first become a priority in the European agenda.

Important efforts towards better coordination in Europe have been promoted in recent years. For example, the FP7 ERA-net project EUROCOURSE (www.eurocourse.org) had among its deliverables the development of a European Cancer Observatory (ECO) (10), including the formation of a comprehensive programme of work on cancer intelligence. This website for the dissemination of registry-based indicators was built on the existing GLOBOCAN platform (globocan.iarc.fr) and the former ECO site, hosted by IARC. The ECO website, now publicly available, also provides user-friendly and timely access to data on European cancer registries, with considerable potential for exploring similarities and differences in cancer epidemiology (incidence, mortality, 5-year prevalence and survival) according to predefined groupings and formats, at national level or at regional/registry level. It allows geographical comparisons by cancer site, age and time period. In several cases, registries are also enriched by linkage between clinical registries (good examples can be found in Nordic countries
and in the Netherlands). Despite these laudable initiatives, however, researchers still lack access to a single quality-controlled information system integrating all relevant data in a systematic and continuous way.

Finally, in the year 2011 the European Commission Joint Research Centre (JRC), the Commission’s in-house science service, was identified to help coordinate and improve cancer prevention, control and care processes across the EU via the standardisation and harmonisation of good practices and the establishment of a cancer information system. JRC is independent of all national, private and commercial interests and has a proven track record (since 1957) in the harmonisation and standardisation of scientific/technical processes and systems. It will coordinate the implementation of ECIS in full collaboration with all the major stakeholders to leverage maximum impact and build on the foundations laid by earlier projects. In particular, it will support the governance and technical coordination processes and will take on the responsibility of releasing the official cancer statistics in liaison and agreement with the stakeholder community.

**Current hurdles in creating a shared system**

Despite its undeniable benefits, and the recent actions carried out at the EU level toward a cancer information system, there are a number of scientific, technical and – even more challenging – policy and legal difficulties that must be addressed in order to develop it (Table 6.1).

As described in full in Chapter 1, the scientific challenges have been at the centre of our work in EPAAC, and a number of pivotal steps have been made in the areas of data availability, data harmonisation and linkages, and consensus discussions to develop the basis for an ECIS. The next step is to pool existing resources and experiences in that line of action.

As for policy-related issues, the EU Parliament’s Directive 95/46/EC on Data Protection was developed to safeguard online privacy rights more tightly in 2012 following comprehensive reform (11). In response, the EUROCOUSE produced a position paper (12), and guidelines were released by the European Network of Cancer Registries (ENCR) to offer an ethical framework for interpretation also to clinical registries. If the ECIS could link a recognised scientific authority to an explicit commitment from national authorities, these issues would be much more easily tackled. US SEER Data access conditions do not differ much from conditions to access the European Surveillance System (TESSy (13)) on infectious diseases maintained by the European Centre for Disease Prevention and Control (ECDC). Here, under the EU directive 851/04/EU (14) and decision 2119/98/EU that governs the ECDC and its relationship
with national notification systems, data on infectious diseases in Europe are collected, analysed and disseminated based on the compulsory notification by the physician or hospital. To request an extraction of case-based/aggregate data from TESSy, a signed request with applicant details and a description of the proposed study protocol is necessary. Likewise, in the EU, difficulties could be solved by an institutional mandate for sharing cancer data. Conditions already in place that balance privacy regulations and data access for research in the framework of infectious diseases comprise a working example that could be used for developing regulation to improve accessibility of cancer data (Box 6.2).

### Building a European Cancer Information System

**Where to start? Sources of cancer data and their availability in the EU**

As a first step in our work in EPAAC, we undertook a review of European activities (including EU and international projects\(^1\) on health and cancer information and databases) to map the availability and sources of relevant cancer indicators in Europe according to the list originally proposed by EUROCHIP (www. tumori.net/eurochip) (Table 6.2).

\(^1\) ECHI, EUROCHIP, EUROCOURSE, RARECARE, HAEMACARE, ECN, WHO, OECD, IARC, EUROSTAT, ECO, ENCR
Prevention indicators

Information on the behavioural determinants of cancer is provided by the European Health Interview Survey (EHIS). The EHIS collects information from the general population on health status, health care and health determinants as well as background information on demographic and socioeconomic variables. Among the large set of indicators are several of those propounded by EUROCHIP-1: cancer screening, body mass index, smoking habits, alcohol intake, and fruit and vegetable intake. Managed by EUROSTAT, the EHIS will be conducted every five years, with a detailed analysis of the results of each wave to assure more comparable results and complete time series in the future.

A summary of the problems that occurred during the first wave of EHIS are included in a report (16). In general, the questionnaire was long, complicated and full of skips, causing difficulties, mistakes and lengthy interviews. Questions could be misunderstood, and comparison was impaired by linguistic or health system differences. Too long or too many reference periods applied in one questionnaire caused memory recall problems. There will be always a place for improving the quality of the current health surveys, and the national problems faced during the first wave of EHIS should be taken into consideration to obtain the best possible harmonisation for future implementation of the surveys.

Complementary to the EHIS, the European Health Interview & Health Examination Surveys Database presents an inventory of national and multi-country health surveys implemented in EU Member States as well as EFTA countries, EU Candidate Countries and the USA, Canada and Australia. The types of surveys in the database include Health Interview Surveys (HIS), Health

Box 6.2 Addressing policy-related obstacles to an ECIS

To address policy-related issues, we highlight the following needs:

Improved coordination among countries to share resources and transfer good national experiences

Harmonisation of research projects at EU level, considering continuity, sustainability and data ownership (see information on pilot projects 2 and 3 in Chapter 7)

Establishment of legal and institutional basis (under the consensual decision of single countries) to develop an ECIS, enabling it to receive and redistribute the relevant data and information. One first step in this direction would be the joint agreement of a number of pioneer Member States to develop a common free access database, including a limited number of health and economic indicators, as a starting point towards the construction of an ECIS
Table 6.2 EUROCHIP cancer indicators

<table>
<thead>
<tr>
<th>Prevention</th>
<th>Epidemiology &amp; Cancer Registration</th>
<th>Screening</th>
<th>Treatment &amp; Clinical Aspects</th>
<th>Macro-social and Economic Variables</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lifestyle</td>
<td></td>
<td>Screening examinations</td>
<td>4.1. Delay of cancer treatment</td>
<td>Social indicators</td>
</tr>
<tr>
<td>1.2.</td>
<td>Consumption of alcohol</td>
<td>2.2. Cancer-incidence rates, trends and projections</td>
<td>4.3. Distribution of diagnostic CATs in the population</td>
<td>5.2. Gini index</td>
</tr>
<tr>
<td>1.3.</td>
<td>BMI* distribution in the population</td>
<td>2.3. Cancer relative survival-rates, trends and projections</td>
<td>4.4. Distribution PETs** in the population</td>
<td>5.3. GDP</td>
</tr>
<tr>
<td>1.4.</td>
<td>Physical activity attitude</td>
<td>2.4. Cancer prevalence proportions, trends and projections</td>
<td>4.5. Distribution of magnetic resonances in the population</td>
<td>5.4. Total social expenditure</td>
</tr>
<tr>
<td>1.5.</td>
<td>Tobacco survey: prevalence of</td>
<td>2.5. Cancer mortality rates, trends, projections and person-years of life lost due to cancer</td>
<td>4.6. Compliance with best oncology practice</td>
<td>5.5. Total national expenditure on health</td>
</tr>
<tr>
<td></td>
<td>a. tobacco smokers among adults</td>
<td>Stage at diagnosis – % of cases with:</td>
<td>4.7. Use of morphine in cancer patients</td>
<td>5.6. Total public expenditure on health</td>
</tr>
<tr>
<td></td>
<td>b. tobacco smokers among 10–14 year olds</td>
<td>a. early diagnosis</td>
<td>4.8. % of patients receiving palliative radiotherapy</td>
<td>5.7. Anti-tobacco regulations</td>
</tr>
<tr>
<td></td>
<td>c. ex-smokers</td>
<td>b. metastases</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Environment &amp; occupational risk</td>
<td>2.6.</td>
<td>Screening examinations</td>
<td>3.1. % of women that have undergone mammography (breast cancer)</td>
<td>5.8a. Public expenditure for cancer prevention on anti-tobacco activity</td>
</tr>
<tr>
<td>d. exposure to environmental tobacco smoke</td>
<td>3.2. % of women that have undergone cervical cytology examination (cervical cancer)</td>
<td>3.3. % of persons that have undergone a CRC* screening test</td>
<td>5.8b. Total expenditure for population-based cancer registries</td>
<td></td>
</tr>
<tr>
<td>1.6.</td>
<td>Exposure to sun radiation</td>
<td>3.4a. Organised screening coverage</td>
<td>5.8c. Total expenditure for organised cancer-screening programmes</td>
<td>5.8d. Public expenditure for cancer drugs</td>
</tr>
<tr>
<td>1.7.</td>
<td>PM10† emissions</td>
<td>3.4b. Screening recall rate</td>
<td>5.8e. Total expenditure for cancer research</td>
<td>5.8f. Estimated cost for one cancer patient</td>
</tr>
<tr>
<td>1.8.</td>
<td>Indoor exposure to radon</td>
<td>3.4c. Screening detection rate</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>3.4d. Screening localized cancers</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>3.4e. Screening positive predictive value</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>3.4f. Screening benign/malignant biopsy ratio</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Environment &amp; occupational risk (contd)</td>
<td>Epidemiology &amp; Cancer Registration</td>
<td>Screening</td>
<td>Treatment &amp; Clinical Aspects</td>
<td>Macro-social and Economic Variables</td>
</tr>
<tr>
<td>----------------------------------------</td>
<td>-----------------------------------</td>
<td>-----------</td>
<td>------------------------------</td>
<td>-----------------------------------</td>
</tr>
<tr>
<td>1.9. Prevalence of occupational exposure to carcinogens</td>
<td></td>
<td>National evaluation in HMP of organised mass-screening process indicators (contd)</td>
<td></td>
<td>Demographic indicators</td>
</tr>
<tr>
<td>1.10. Exposure to asbestos: mesothelioma incidence and mortality trends</td>
<td></td>
<td>3.4g. Screening interval cancers</td>
<td></td>
<td>5.9. Age distribution in 2010, 2020 and 2030</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3.4h. Screening specificity</td>
<td></td>
<td>5.10. Life-table indicators</td>
</tr>
</tbody>
</table>

Medicaments

1.11. Prevalence of use of HRT‡ drugs

Source: (15)

*BMI: body mass index; †PM: particulate matter; ‡HRT: Hormone Replacement Therapy; §CRC: Colorectal cancer; ** positron emission tomographies
Examination Surveys (HES) and combined HIS/HES Surveys. In 2011 there were 218 HIS, 14 HES and 27 combined HS/HES Surveys in the database. HIS surveys included in the database have mainly been executed in 1991–2009, HES in 1999–2008 and combined HIS/HES in 1995–2009. With regard to other cancer-related prevention indicators, all but two are available in the sources mentioned in this section: exposure to sun radiation and prevalence of occupational exposure to carcinogens.

**Epidemiology and cancer registration**

Cancer registries are the main (often the only) source for incidence, survival and prevalence indicators. Given that comparable disease-specific sources of data are not available for any other major disease, national and local registries are a unique and valuable source of health information. Indeed, the few examples of structured health databases in Europe today are largely based on cancer registry experiences or have been set up under their initiative. Traditionally used in aetiological research as a means of enhancing our knowledge on risk factors for cancer, registries also provide statistics on incidence for the purposes of assessing and controlling the impact of cancer in the community as well as a means to monitor and assess the needs for screening and early detection programmes within a population. Moreover, they are used to evaluate and monitor screening programmes already in place. Population-based cancer registration constitutes an effective and relatively cost-efficient method for providing information for planning, monitoring and implementing cancer control measures and care guidelines and highlighting differences in survival and quality of care. It offers a huge opportunity for public health research, bridging the gap between administrative control and research; since the early 1940s, cancer registries have been acknowledged as an important tool for cancer research and control across Europe.

Given the importance of cancer registries, many efforts have been spent to monitor and improve the quality, type and coverage of the information they provide. In order to optimise comparability of cancer incidence data, promote cancer registration in Europe, form the basis for the continuous monitoring of the cancer burden and foster the use of cancer information for research and planning, the ENCR was constituted in 1990 under the European Commission’s Europe Against Cancer programme (17), jointly with the Association of Nordic Cancer Registries (ANCR), the International Association of Cancer Registries (IACR), the Latin Language Registry Group (GRELL), and IARC, where the secretariat was first established (Figure 6.1).
In order to better support the Joint Research Centre coordinating role in cancer control activities and the development of ECIS, the secretariat of ENCR was transferred to JRC in 2012. As a first concrete action aimed at creating a harmonised network of cancer registry data, an ENCR Workshop on cancer registry quality checks was organised and hosted at JRC. The workshop focused on protocols for cancer registry data – including but not limited to survival data quality checks – with the overall goal of designing a common tool for checking prevalence, incidence and survival data.

Today, more than 200 cancer registries are active under ENCR in Europe. Data collection systems in the EU reflect the specific organisation of national health systems, and barriers persist in data access, so it is difficult to move from the national to the European scale as not all indicators are comparable across the EU. Registries presently provide most epidemiologic data on cancer, yet they are underfunded, mostly understaffed, struggling with national and European laws on protection data, or launched without proper planning. Therefore, data are not easily accessible to everybody (see EUROCOURSE for more information).

In recent years, the successful collaboration of the cancer community and policymakers has ensured greater attention towards population-based cancer registration, and this is reflected in the public health agendas across the EU. After the European Council Conclusions for the new European Health Strategy...
in 2008 indicated that EU Member States should develop National Cancer Control Programmes, with cancer registration highlighted as a statutory requirement, important developments in the establishment of cancer registries have been observed (Figure 6.2).

In Romania, since 2008 following Ministry of Health Order no. 2027/26, regional cancer registries for each of the eight development regions work in alignment with ENCR standards for data collection, classification and codification (20); in 2009 the Cyprus Cancer Registry became a Ministerial organ (21); in 2012, Greece started the Hellenic Cancer Registry as the first action of the fifth axis of intervention of its National Cancer Plan 2011–2015 (22), and the National Cancer Registry of Luxembourg started in 2013 (23). Today, cancer registries cover the entire population in 23 of 31 (28 EUMS+3 EEA/EFTA) countries: Austria, Bulgaria, Belgium, Croatia, Czech Republic, Cyprus, Denmark, Estonia, Finland, Ireland, Latvia, Lithuania, Luxembourg, Malta, the Netherlands, Slovakia, Slovenia, Sweden, the United Kingdom, Hungary, Portugal, Iceland and Norway. For different reasons, in Italy, Spain, France, Germany, Poland, Switzerland, Romania and Greece, there is only partial population coverage, varying from one to nearly all regions. According to the results of EUROCARE-5, in 2000–2007, 50% of the population was covered by cancer registration.
The overall quality of data was satisfactory: less than 1% of total cases were excluded from the EUROCARE database due to major errors, cases with death certificate only were around 3%, and cases lost to follow up were 1% overall; 90% cases were microscopically verified, and approximately 1% overall had a poor morphology specification. By contrast, information on stage was inadequate and varied according to tumour site and registry: the highest figures, not exceeding 50% of cases with available stage were for breast cancer; for colorectal cancers stage was available for approximately 35% of cases, whereas for other solid cancers stage was available in less than 20% of cases. Gradually, gaps in coverage and quality are being filled thanks to the proactive collaboration with several EU initiatives, including EPAAC, and scientific support is continuously provided at EU level to ensure the best standards (Box 6.3).

An up-to-date analysis of the situation in all European cancer registries and their potential role in cancer information is available through the results of the ENCR questionnaire, ‘Overview of Cancer Registration in Europe’ (Box 6.4).

**Main indicators provided by cancer registries**

**Incidence**

Incidence refers to the number of new cancers occurring in a specified population over a year, usually expressed as the number of cancers per 100,000 population at risk (i.e., ovarian cancer incidence refers to incidence per 100,000 females). The ninth volume of *Cancer Incidence in Five Continents* (CI5) covers new diagnoses of cancer from 1998 to 2002 in 100 Registries in 29 countries of the European Region (24). Inclusion in the series is a good marker of the quality of an individual registry’s data. The online CI5 databases provide access to detailed information on the incidence of cancer recorded by registries (regional or national) worldwide in two formats:

- CI5 I-IX basic data published in the nine volumes of CI5
- CI5 plus annual incidence for selected registries published in CI5 for the longest possible period

In addition, ECO provides contemporary estimates (from 2008) on the incidence, mortality, prevalence and disability-adjusted life years (DALYs) for all major types of cancer in all 28 EU Member States and EEA/EFTA.

**Survival**

Population-based survival data can provide insight into the effectiveness of health care systems. They usually provide ‘relative survival’, which is adjusted by the competing causes of death in the same area, gender and age group to
Box 6.3 Spotlight on cancer registries in Greece, Luxembourg and Bulgaria

The Hellenic Cancer Registry (HCR), based at the Hellenic Centre for Disease Control & Prevention, connects all public and private hospitals in the country, registering all incident cancer cases with official permission (Decision No. 1116/13-7-2012) by the Hellenic Data Protection Authority for the lawful processing of personal sensitive patient data as regards its purposes. Cancer notification at the time of going to press was based on paper, but it will switch to electronic notification by the end of 2013. The restructuring of the HCR has received funding from the National Strategic Reference Framework Programme 2007–13. Part of the National Cancer Plan 2011–15, the HCR aims to produce reliable information on the burden of cancer so that effective policies for cancer control may be developed, implemented and evaluated in Greece.

In Luxembourg, implementation of the cancer registry began in 2011 and is now complete*. The registry is based at the Centre for Public Health Research. As of 2013, all cancer incident cases are registered, (incidence on breast and colorectal cancer began on 1 January 2012). The aims of the cancer registry are to provide information for strategic planning and evaluation of the screening programmes and the national cancer plan, as well as to give feedback to clinicians concerning quality of care and to facilitate collaborative research with other countries.

In Bulgaria, on the other hand, a national cancer registry and 13 regional registries have been active since the 1960s and have been providing cancer data of good quality with numerous international collaborations. However, a reorganisation of cancer care that started in 2011 may lead to deterioration of registry data in the country, lack of interest from the policymakers, lack of vital funding and limited use of cancer registry data for cancer control purposes (personal communication with Nadia Dimitrova, Director of the Bulgarian Cancer Registry).

*These include the set of data to be collected (using definitions available at EU level), the IT system in hospitals and clinics (public and private) to collect and deliver the data, the IT system for collecting the data at national level, the trained cancer registrars, the organisation of the CR with a scientific board, a surveillance board, the information leaflet for the patients, a website and a law (Reglement Grand Ducal) was awaiting approval in April 2013 by the highest responsible civil state body

which the patient belongs. However, survival is a complex indicator: it may reflect earlier diagnosis, over-diagnosis or later death. A potential artefact influencing population-based survival data and the interpretation of differences across areas and over time is that of lead time bias. Diagnosis at an earlier stage can increase survival by simply anticipating the date of diagnosis, without postponing the date of death. In this case, longer survival associated to a more favourable stage distribution is not an advantage for the considered population. In 1989, EUROCARE² started to monitor, analyse and explain between-

country differences and trends in cancer survival, and it still provides the most systematic data available on the patterns of cancer survival in Europe (25). The most recent study (EUROCARE-5) has collected incidence data up to 2007 for 29 countries in Europe (EU and EEA+ EFTA), along with last known vital status as of 31 December 2008 or later (Figure 6.3).

More detailed information is available on the EUROCARE website (www.eurocare.it). The EUROCARE-4 project also provides detailed information on incidence, prevalence and survival on haematological malignancies and on rare cancers in the framework of the Cancer Registry Based project on
Haematologic malignancies (HEAMACARE) and Surveillance of rare cancers in Europe (RARECARE) projects, respectively.
**Prevalence**

**Complete prevalence** refers to the number of persons living with a previous diagnosis of the disease, regardless of how long ago the diagnosis was or whether the patient is still under treatment or is considered cured. **Partial prevalence** limits the number of patients to those diagnosed during a fixed time in the past. GLOBOCAN provides prevalence of cancers based on cases diagnosed within one, three and five years, as they are likely to be of relevance to the different stages of cancer therapy, namely, initial treatment (one year), clinical follow-up (three years) and cure (five years). Data is available for the adult population only (≥15 years) in 40 European countries (26). The EUROPREVAL study provides complete prevalence data on stomach, colon, rectum, lung, breast, cervix uteri, corpus uteri and prostate cancers, as well as skin melanoma, Hodgkin’s disease, leukaemia and all malignant neoplasms combined for the end of 1992 in Austria, Denmark, Estonia, Finland, France, Germany, Iceland, Italy, Poland, Slovakia, Slovenia, Spain, Sweden, Switzerland, the Netherlands and the United Kingdom (27). The RARECARE project provides partial and complete prevalence for rare and common cancers in Europe at the end of 2002 (28).

**Mortality**

Mortality refers to the yearly number of cancer-specific deaths over the whole population in an administratively defined area. The available mortality data are more comprehensive than incidence data – the WHO mortality databank contains national cancer mortality data for 35 countries in the European Region, available over extended periods of time for many of those countries. However, mortality data are affected by several problems, for instance the degree of detail and accuracy of the recorded cause of death and the completeness of death registration. These are known to vary considerably between countries and over time. In addition, mortality statistics include deaths occurred in a given year, regardless of length of survival, from a few months to many years after diagnosis. Detailed mortality data at a regional level, as available from EUROSTAT, provide valuable information of uniform quality which at present is not sufficiently known or adequately utilised.

**Screening**

The EHIS provides information on participation in organised or voluntary screening tests (mammography in the past two years, Pap smear test in the past three years and a colorectal cancer screening in the past two years). Information on breast and self-reporting cervix screening uptake are available for 18 of the 20 countries participating in the EHIS (information missing in Switzerland and...
Norway), while colorectal screening rates are available in 16 (all but Austria, Estonia, Switzerland and Norway). Administrative sources based on screening programme data or registry-based information would be preferable to EHIS-based data, as the latter will be influenced by recall and sampling biases.

In Europe, most programmes for cancer screening have developed their own screening information systems for running day-to-day operations, managing quality, monitoring and evaluating services, with no explicit priority on promoting an exchange of information between programmes in different countries.

The European Network for Information on Cancer (EUNICE) has proposed a monitoring tool capable of calculating a selection of key performance parameters and early impact indicators from the European Guidelines, which could be used to compare screening programmes across Europe on a regular basis. The web-based data warehouse EUNICE Breast Cancer Screening Monitoring (EBCSM) was tested for its initial application in 10 national and 16 regional programmes in 18 European countries. The results demonstrate the feasibility of pan-European screening monitoring using the EBCSM data warehouse, although further efforts to refine the system and to harmonise standards and data collection practices will be required to fully include all European countries (29).

Apart from the EHIS, information on screening programme coverage at the EU level, like information on screening programme implementation, varies among the different screening programmes available in each country. Thus a comprehensive overview of cancer screening programme coverage and implementation in Europe is mainly provided by the periodic report on the implementation of the Council Recommendation on cancer screening. Organised screening programmes are presently recommended (breast, colorectal and cervix uteri cancers) and are in place or planned in many countries, and their implementation in other regions is encouraged by EU recommendations. While the quality of mass screening should be supported by professional training (see Chapter 4) and continuously monitored by specific process indicators within the programme, the existence of a population-based cancer registry is indispensable for evaluating the efficacy of the programme in terms of reduction of mortality and incidence of invasive lesions.

The evaluation of screening programmes would be greatly facilitated by the availability of screening indicators in an ECIS, which would allow the joint analysis of screening indicators with trends in incidence, mortality, patterns of care in the population. For other cancers, such as prostate and lung, there are no recommended tests for early diagnosis. However, the prostate specific antigen
Information for action

(PSA) for early diagnosis of prostate cancer has been widely used in Europe, leading to a change in the prostate cancer epidemiology (26). Information on PSA testing use in Europe is not available. It could be important to monitor the use of such testing, and the EHIS could be a way to collect such information. Although the stage at diagnosis is not a tool to monitor the efficacy of screening, its systematic collection in the cancer registry regions where screening activities are ongoing would help monitor the screening programmes. Additional indicators should be identified by means of the cancer information system and should comply with the European quality assurance guidelines for breast, cervical and colorectal cancer screening as well as with recommendations by ENCR, EUNICE and EUROCORES workgroups on screening.

**Treatment and clinical aspects**

Information on medical equipment (computed axial tomography, magnetic resonance imaging unit, positron emission tomography scanners, radiation systems) and frequency of surgical procedures (hysterectomy, prostatectomy, breast conserving surgery, mastectomy) is available from EUROSTAT (30) and OECD (31). These data come from administrative sources and are not always collected according to uniform criteria (administrative data depends on the organisation of the health care system in each country), raising question on comparability. Only in very few cases (e.g., Belgium since 2005) are national data available on multidisciplinary teams responsible for treating the patient, although the Organisation of European Cancer Institutes (OECI) has data for some hospitals in different countries as part of the audit system. For example, regarding the medical technology devices for United Kingdom, data refer only to devices in the public sector; they do not include equipment in the private sector (resulting in an underestimation). For Spain, the data relate only to devices available in hospitals; they do not include equipment in other health care facilities (also leading to an underestimation).

Information on stage and treatment is not routinely available from cancer registries, clinical or administrative files. However, for a limited number of registries the questionnaire ‘Overview of Cancer Registration in Europe’ includes items dealing with stage, diagnostic and treatment delay and compliance with selected clinical guidelines. In some countries, extra work and funds are needed especially to provide information on compliance with cancer guidelines. To promote the collection of variables for the three indicators in European Registries, EUROCHIP-3 has published the following recommendations (32):

- To further study the cancer registries reporting collection of stage, diagnostic and treatment delay, and compliance with selected clinical guidelines in
order to determine their practice and to encourage other registries to follow their lead.

- To promote collection of data generating stage, diagnostic and treatment delay, and compliance with selected clinical guidelines according to the ENCR rules and definitions, in order to make useful and relevant comparisons over the years between EU countries.

The EUROCare group has published several high-resolution studies on stage at diagnosis, diagnostic procedures and treatment. As mentioned above, these data, not routinely collected by most registries, can help to explain the differences in survival on the basis of disparities in diagnosis and/or major treatments between regions. These studies have provided information on breast (33), colorectal (34), lung (35), prostate (36), stomach (37), testicular cancers (38), and melanoma and lymphoma (39) management in participating countries. Presently, high-resolution and patterns-of-care (POC) studies are ongoing in several Member States, focusing on different cancer types. POC studies aim to evaluate the dissemination of state-of-the-art cancer management into community practice and to explain differences in outcomes.

Within EPAAC, collaborations were developed for the constitution of an Outcome Research Forum, to describe, interpret, and predict the impact of interventions and other factors on final outcomes of importance to decision-makers, including the pilot launch of European High Resolution Studies (see description in Chapter 7). Within an eventual ECIS, it will be essential to ensure the systematic provision of information on stage and treatment (similar to what is presently available within the individual records included in the SEER database). Information on resources (medical equipment and surgical procedures) should also be available, with a clear description of the sources of the information. The limitations arising from data incompleteness and low comparability should be clearly mentioned.

**Macro social and economic variables**

EUROSTAT provides information for all EU MS on GDP and total public expenditure on health as a percentage of GDP, while WHO provides an overview of the anti-tobacco regulations in its tobacco control country profiles (40). Information on estimated **cost per cancer patient** is not presently available. However, the OECD has proposed a methodology to collect such data in the System of Health Accounts framework (41) using national health accounts as sources, and it is also performing studies on these sources across Europe to estimate comparable direct cancer costs. At present, the direct costs which can realistically be collected and compared refer to hospital costs.
Eurostat aims to produce data on expenditure by disease at EU level and obtain patient-level data with information on patient and treatment characteristics, actual resource use and reliable price/cost data, including the provision of sound data on private expenditure. It would also address the collection of indirect costs data, such as linkage to years of life lost/loss of potential years of work. Data on expenditure by disease can contribute to health systems’ performance analysis through the provision of data on how much money is spent on preventing and treating particular diseases, differentiated by age and gender. The action should take into consideration the increasing health care needs of ageing populations in Europe.

Additional indicators that were not included in the EUROCHIP list but should be part of an ECIS relate to the area of cancer survivorship, including all aspects of cancer care and survival occurring after diagnosis and first course treatment phase. Standardised quality-of-life indicators are collected by most clinical studies, as there is evidence they can influence cancer outcomes and patients’ prognosis; however, information on quality of life is not readily available to cancer registries. The feasibility of collecting standardised indicators of psychosocial distress using the IPOS (42) tool (developed for screening and diagnosis) should be investigated. It will also be essential to identify data needs for ongoing follow-up and confidential monitoring of cancer survivorship issues (e.g., treatment course and outcomes, quality-of-life indicators, long-term effects of diagnosis and treatment) and to increase the capacity of surveillance systems (including cancer registries) to track such information.

Given the increasing consensus across European health care institutions that proceedings should incorporate the patient perspective in all disease phases, survivorship is a field of major interest for patients’ organisations. However, the research area could also benefit from the involvement of patients by developing studies based on their stated needs. The role of patients in this process needs to be better defined in order to allow them to be actively engaged in the relevant aspects. In EPAAC, the involvement of cancer patients’ organisations has highlighted the need for identifying a minimum set of services that should be provided to all EU patients. The availability of an open access ECIS will help in this effort by contributing to define standards of minimum health and social services that should be included in cancer plans. Member States can then take into account the needs of cancer patients and survivors in their policies more effectively. In particular, international standards for care and rehabilitation are very relevant given the growing expenditure on health care in a context of economic crisis.
Unifying definitions and presentation of epidemiologic indicators to facilitate comparison of data in the EU

Simultaneous consideration of incidence, prevalence, survival and mortality indicators is of tremendous informative and interpretative value, and observed and/or estimated values of these indicators should be made available as much as possible at the national or sub-national levels. However, this requires that all indicators refer to the same population, which is not presently the case in Europe. Here, these four indicators are provided by different sources, with different coverage and inconsistent tumour definitions. Furthermore, they are only available to the public from different publications and websites. As part of its activities, EPAAC is taking steps to overcome this situation, building a dataset of indicators defined on exactly the same populations and time periods and with the same disease definitions. IARC and EUROCARE agreed on a protocol for convening their data to build such a dataset and for disseminating it in one location: the ECO website at IARC (Table 6.3).

The European Cancer Observatory

A web-based tool for the dissemination of cancer indicators derived from registry data have been developed by ENCR and IARC, largely within the EUROCOURSE project. The ECO is structured to provide a comprehensive system of information on the cancer burden in Europe. Its design and functionalities are an excellent and advanced starting point for the dissemination, through the progressive inclusion of a wider set of indicators, of the cancer data collected and organised by ECIS. ECO is presently made of three distinct websites: EUCAN (national estimates), EUREG (registry data) and EUROCIM (downloadable data):

- EUCAN presents national estimates of cancer incidence, mortality and prevalence for 24 major cancer types in 40 European countries for 2012. The standard methodology used may have produced results different from those developed by national bodies.

- EUREG permits the exploration of geographical patterns and temporal trends of incidence, mortality and survival observed in European population-based cancer registries for 35 major cancer entities in about 100 registration areas.

- EUROCIM will allow the user to define, extract and request data sets provided by the participating cancer registries. At time of going to press it was under construction.
**Creating consensus among national, sub-national and supranational stakeholders**

In order to provide a framework for the ECIS proposal design under the aegis of the Joint Action EPAAC, our team on cancer information formed a writing committee, involving the key cancer data stakeholders to ensure a proactive communication flow and mutually beneficial objectives. The ECIS writing committee included the EPAAC coordination representatives from Slovenia, the Information coordination group, the IARC, the ENCR, the project EUROCAN platform (43), and observers from political authorities. The JRC
participated from the beginning in the writing committee meetings as well as in the drafting of the ECIS proposal. The group gathered twice a year in 2011 and in 2012. Dissemination of material for comments among all EPAAC experts was regularly ensured; subsequent drafts of the ECIS were presented at the EPAAC Steering Committee of Berlin in March 2012, and at the Rome Open Forum 2012. On this occasion, the most relevant cancer registration experts from almost all of the EU+EEA and EFTA countries participated. An updated version of the ECIS document was circulated to all EPAAC partners in July 2012 and to the registries of the ENCR in August 2012. The document was further discussed in September 2012 at the ENCR meeting in Cork, Ireland. Technical, political and scientifically relevant inputs were sent from Austria, Germany, Finland, the Netherlands, France, Poland, Spain and the United Kingdom to enrich the process. An updated version of the document was presented to DG SANCO and JRC in January 2013, and the proposal was approved as an EPAAC output. Thanks to the EPAAC platform, close coordination among all ongoing activities was maintained, with the objective of sharing any progress made during the EPAAC contractual time by the cancer data community (i.e., the optimisation of the use of cancer registry data, the integration of registry data with other sources of information, such as the health care system or demographic and socioeconomic data). EPAAC has collaborated with all relevant DG SANCO projects: the Joint Action’s European Community Health Indicators (ECHI), the Cross-Border Patient Registries (PARENT) and the European Union Committee of Experts on Rare Diseases (EUCERD), as well as the European Organisation for Rare Diseases (EURORDIS).

A roadmap to ECIS

During the course of our work, it has become clear that ECIS activities must be implemented as much as possible by pooling existing resources and experiences from European institutions that are already involved in cancer information and data dissemination, most of which have already developed the knowledge, skills and instruments to carry out the tasks foreseen. The main tasks of an ECIS, then, do not imply collection of new data, but rather reorganisation and better coordination of existing activities. We identify five main types of tasks to be carried out under ECIS, and summarised in the list below.

Data management: Each dataset (i.e., a collection of data containing the same information for many individuals or individual data units) flowing into ECIS needs to be organised according to a unique and coherent structure. This task requires close interactions with the many data providers (i.e., the institutions
that collect and submit the same data from different populations or geographical areas).

**Data quality control**: Continuous improvement of both quality and data standardisation are crucial for reporting, planning, research and comparative analysis, as these measures are the only means to obtaining reliable data.

**Datasets organisation**: A user-friendly pathway should be implemented to structurally connect different datasets (e.g., cancer incidence and risk factors distribution across populations, or provision of health care services and survival) and allow the user to access them from a shared platform.

**Data analysis**: A plan of analysis for the main outcomes should be systematically and periodically laid down. Efficient management of problems related to the variability of data and definitions often require statistical modelling and ad hoc methods (e.g., incidence and mortality analysis, survival analysis, prevalence analysis, high resolution studies, national estimates for countries with partial cancer registry coverage, time trend analyses, cancer burden forecasts, joint analyses).

**Data dissemination**: The ECIS would be a key epidemiologic infrastructure for the European Research Area. Results should be dissemination through many channels: general and specialised publications, press, leaflets, and web-based tools. The datasets included in ECIS should be available to different users, according to specific permissions and credentials. Three level of dissemination should be foreseen:

- a set of core pre-calculated cancer indicators presented mainly in graphic format, with explanatory notes directed to the general public, policymakers and media;

- a wider set of pre-calculated indicators, of the highest level of detail, including metadata on sources, data quality and comparability, estimation methods, and underlying assumptions, to be used by health professionals;

- quality-checked individual records: the only data fully adequate for in-depth research activities and which do not suffer the severe limits of data tabulated according to pre-defined variables and categories.

**Possible organisational options**

For each of the ECIS functions envisaged, a set of practical options was formulated and analysed according to advantages and disadvantages (Table 6.4).
**Table 6.4** ECIS organisational options and considerations, by function

**Table 6.4a** Database management

**Database Management**
The data flowing into ECIS need of course to be organised conforming to a unique and coherent structure. This does not necessarily imply building a single centralised data repository. Use of web-based remote connection to distributed data repositories is a possible alternative.

<table>
<thead>
<tr>
<th>Description</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Centralised</td>
<td>Simpler and well-experienced implementation</td>
<td>Possible progressive difference (drift) between central and local data</td>
</tr>
<tr>
<td></td>
<td>Easier to keep consistency among registry-specific datasets (periodic cleaning, updating and definitions)</td>
<td>Needs wide political consensus</td>
</tr>
<tr>
<td></td>
<td>Well defined responsibility</td>
<td></td>
</tr>
<tr>
<td>Distributed</td>
<td>Avoids formal data submission of data to a third party</td>
<td>More labour demanding for all those involved, intensive networking and computationally complex</td>
</tr>
<tr>
<td></td>
<td>Providers keeps strict control on the use of their data</td>
<td>Any necessary change indicated by the CDM must be applied by providers in the accessible area</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Intense interaction between data providers and CDM needed</td>
</tr>
</tbody>
</table>

**EPAAC conclusions**
The two solutions imply trade-off between practical and policy-related considerations. The final resolution has to be identified for each type of data through agreement between ECIS management and data providers.

**Conclusions**
The potential benefits entailed in the development of a European Cancer Information System are tremendous. Research – so essential to broader efforts of cancer control – is a cumulative effort, guided by knowledge acquired by predecessors and peers. In this context, data and information are the most precious of commodities; the more information researchers have, the better equipped they are to enrich the knowledge base on the causes of cancer, the mechanisms of carcinogenesis, and most important, effective options for prevention and treatment. Likewise, an ECIS would strengthen the political commitment to cancer control, providing accessible information on the progress that countries are making in comparison to the past and to neighbouring countries. The delivery of evidence-based approaches to cancer control would be facilitated, and health system responses to cancer control would be strengthened.
In particular, Europe has much to gain from better coordination and collaboration. The plurality of cultures, health systems and policy approaches is fertile ground for all kinds of cancer research, from basic and clinical to translational and epidemiologic, and the establishment of global, national and regional networks will not only help to identify the best practices in the continent, but also to implement them at low cost in the countries struggling the most to meet this challenge.

Despite this unarguable promise, the development of the European cancer information system will need constant and vigorous efforts. The road towards an integrated and comprehensive ECIS seems to be quite challenging, but it is important to acknowledge certain positive prospects, including developments promoted by the JRC in close cooperation with ENCR, IARC and other key stakeholders, including our EPAAC Cancer Information team (44).
Table 6.4c Data analysis

Data Analysis
The systematic analyses aimed at providing indicators, specific reports, and data descriptors on a regular basis require some form of centralised planning. This could be achieved via several forms of organisation.

<table>
<thead>
<tr>
<th>Description</th>
<th>Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Centralised</td>
<td>Analyses carried out by an epidemiologic and statistical team working at the ECIS coordinating centre (the team would have unrestricted access to the ECIS database, using a set of agreed data analysis procedures to calculate the set of indicators necessary to update the ECIS website annually, to draft periodic reports and to provide the more general description of the latest data). Particularly appropriate for the provision of core, consolidated indicators (e.g., point estimates of incidence, prevalence, survival and mortality)</td>
</tr>
<tr>
<td>Distributed</td>
<td>Analyses could fall under the responsibility of a group of partners organised into a Data Analysis Network to be considered as part of the ECIS. Partners would have access to the central database to carry out a specific set of analyses with the appropriate quality controls on the entire European dataset and to deliver the planned set of statistics and indicators. Appropriate for systematic and periodic complex analyses that require statistical modelling, other advanced methods, or for the development of new methods</td>
</tr>
<tr>
<td>Ad hoc</td>
<td>Analyses carried out by entrusted external bodies Appropriate for well-delimited tasks, to be carried out in response to specific requests (such as experimental analysis of new datasets included in ECIS, or reports on very specific topics)</td>
</tr>
</tbody>
</table>

EPAAC conclusions
The three types of ECIS data analysis organisational modalities are not mutually exclusive. They should be combined where necessary to implement any given programme of data analysis in the most appropriate and effective way, thus optimising the use of knowledge and time in cancer research.

It will be conditioned by available resources, time constraints, and institutional limitations and concerns. These factors will influence the technical configuration of ECIS, and it is up to the European Commission, Member States and cancer information institutions to analyse the options we have formulated and to build on the conclusions reached over the course of EPAAC (a detailed report of our findings will be published following the conclusion of EPAAC). However, as part of a multidisciplinary and multinational partnership, the our team on cancer information is strongly in favour of solutions capable of promoting the widest participation among different specialties, countries and institutions, to perform the anticipated ECIS activities and to access ECIS data and information. The Joint Research Centre (JRC), the European Commission in-house science
Table 6.4d  Individual data dissemination

**Individual data dissemination**

ECIS will be a key epidemiologic research infrastructure for the European Research Area. As such, it will have to make data available at the highest level of detail possible. Three main different mechanisms for data release can be envisaged.

<table>
<thead>
<tr>
<th>Description</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consent from data providers</td>
<td>Current system; no modifications required</td>
<td>Heavy bureaucratic and organisational load at both ends</td>
</tr>
<tr>
<td>In order to release individual patients’ data from EU databases, provider consent is requested via the circulation of relevant protocols, and only data from registries explicitly approving the protocol can be included in the released dataset.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Approval by a central committee</td>
<td>More effective use of time and resources than asking consent from each data provider</td>
<td>Appropriate mechanism for committee definition and rules of operation have to be agreed</td>
</tr>
<tr>
<td>A committee is delegated by data providers to evaluate research study protocols requests under general and pre-defined criteria. The positive evaluation by the committee is the sufficient condition for the delivery of the requested dataset.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Free public use</td>
<td>The availability of individual records for driven analyses will constitute a major advance with respect to the data now available from EU projects, which are accessible only in tabulated form.</td>
<td>Data privacy regulations are different across the EU, and in many EU countries they are more restrictive than in the USA.</td>
</tr>
<tr>
<td>An online, public use dataset (similar to that provided by the US-SEER). Variables to be included in such a dataset and their level of detail should be carefully designed to avoid the possibility of disclosing individual patients’ data. It should be possible for the provider to refuse public data access.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**EPAAC conclusions**

The three outlined procedures are of course schematic and can be combined in several ways. They do not differ from each other with respect to data privacy and protection issues, since all of them foresee the delivery of individual patients’ data. Rather, they provide different practical solutions with different trade-offs between an increasing level of openness and distribution of the data and a decreasing control of providers on the use of their own data. Data to be included in research datasets must be consistent with the privacy protection laws in all the contributing countries. Rules for assuring confidentiality must be developed in accordance with EU legislation.

In order to test practical solutions and the feasibility of an open access database, a pilot version of the database could be implemented on a voluntary basis. Providing that a critical mass is reached, the spread of this instrument may encourage all European registries to participate. The dataset could be periodically updated with an allowance for including newly adhering registries.

service, is an important instrument for ensuring the fundamental sustainability of ECIS and coordinating its further development. JRC is working in close collaboration with all the major stakeholders, including ENCR, other networks of European scientific institutions (such as those involved in EUROCARE), and IARC, to define the best effective options on all the major ECIS functions.
In our exploration of the panorama of cancer information, the importance of utilising and coordinating European expertise on cancer has become abundantly clear. Building on the most comprehensive existing cancer registry network, we can together improve geographical coverage and data quality, as well as facilitate a variety of European collaborations in epidemiologic and clinical cancer research. To achieve these goals, cancer information stakeholders need a clear framework and ground rules in order to work in synergy for the optimal use of existing databases for cancer monitoring and cancer research. A European repository with updated and timely data and optimally trained health scientists will provide a necessary tool in combating cancer, thereby elevating the quality of services available to cancer patients to the highest possible level and facilitating long-term planning and decision-making. Perhaps more than any other issue attracting calls for better coordination and cooperation among Member States and partners, information without borders will be key to unlocking European potential to cancer control.

The authors of this chapter would like to acknowledge the valuable support of the Italian Ministry of Health during this project.

References


14. Decision of the EU-Republic of Latvia Association Council on the Addition of Annexes to the Protocol to the Europe Agreement on


