European Commission

Joining forces for **better cancer registration in Europe**

ENCR Scientific Meeting and General Assembly

5-7 October 2016 • Baveno • Italy

European Network of Cancer Registries

Joint Research Centre

Report EUR 28095 EN

Contact information
Name: ENCR Secretariat / JRC-Cancer Information Group
Address: Joint Research Centre, Directorate F: Health, Consumers and Reference Materials–Health in Society
Via Enrico Fermi 2749, TP 127, 21027 Ispra (VA), Italy
Tel.: +39 0332 78 9926
E-mail: jrc-encr@ec.europa.eu
Web site: http://encr.eu

JRC Science Hub
https://ec.europa.eu/jrc/

JRC102769

EUR 28095 EN

Print	ISBN 978-92-79-61755-3	ISSN 1018-5593	doi:10.2787/99752	LA-NA-28095-EN-C
PDF	ISBN 978-92-79-61756-0	ISSN 1831-9424	doi:10.2787/07824	LA-NA-28095-EN-N

Luxembourg: Publications Office of the European Union, 2016

How to cite: ENCR Scientific Meeting and General Assembly, 5-7 October 2016, Baveno, Italy: Joining forces for better cancer registration in Europe; EUR 28095 EN; doi:10.2787/99752.

Cover image © Maurizio Rovati.

Printed in Italy

Joining forces for better cancer registration in Europe

ENCR Scientific Meeting and General Assembly

5-7 October 2016 • Baveno • Italy

Joint Research Centre

Report EUR 28095 EN

Table of contents

Practical information

Official language

The official language of the meeting will be English.

Internet access

There will be free Wi-Fi access at the Conference Centre.

Certificate of attendance

A certificate of attendance can be collected at the registration desk on the third day of the meeting (Friday, 7 October 2016) during the morning coffee break or during lunch.

Telephone contacts

For general questions, problems or concerns please contact:

JRC Cancer Information Group
+39 0332 789 926/861 (land line)

Social programme

Wednesday 5 October 2016 19:00

Welcome reception at the Grand Hotel Dino, Baveno.

Programme at a glance

	Wednesday 5 October 2016		**Thursday** 6 October 2016	**Friday** 7 October 2016
09:00	ENCR-JRC Training	Registration	Invited Lecture	Invited Lecture
09:30			3rd Scientific Session **Cancer registries and evaluation of cancer care (2)**	6th Scientific Session **Cancer registries and clinical data**
11:00			*Coffee break & poster viewing*	*Coffee break & poster viewing*
11:30			4th Scientific Session **Methods and measures of cancer registry data quality**	Award for best contribution Meeting Closure
12:00				
12:30				*Buffet lunch & poster pick-up*
13:00	*Buffet lunch & poster viewing*		*Buffet lunch & poster set-up*	
13:30				
14:00	Opening Ceremony		5th Scientific Session **Statistical methods and software tools**	
14:30	Invited Lecture			
15:00	1st Scientific Session **Cancer burden in Europe: incidence, mortality, survival and prevalence**			
15:30				
16:00			*Coffee break & poster viewing*	
16:30	*Coffee break & poster viewing*		ENCR General Assembly	
17:00	2nd Scientific Session **Cancer registries and evaluation of cancer care (1)**			
18:30				
19:00	Welcome Reception			
21:30				

Welcome

The European Network of Cancer Registries (ENCR), in collaboration with the European Commission's Joint Research Centre (JRC), welcomes you to the 2016 ENCR Scientific Meeting and General Assembly to be held from 5 to 7 October in Baveno, Italy.

The Scientific Meeting will focus on the collective efforts of European cancer registries in harmonizing their practices and methodologies to provide comparable cancer statistics in Europe. It will be an opportunity for colleagues to meet, compare best practices in cancer registration and present their research findings. The meeting targets staff from ENCR-affiliated cancer registries, as well as clinicians, researchers, epidemiologists and statisticians from cancer research institutions, NGOs and government organisations. The event will also be a chance for participants to meet the Steering Committee of the ENCR and representatives from the European Commission, both from DG SANTE (Health and Food Safety) as well as the JRC's Cancer Information staff who is behind the ENCR Secretariat providing support for cancer registration at European level.

The scientific programme has been tailored to address some important themes in cancer registration in Europe including harmonising coding among affiliated registries, with special emphasis on further progressing the setting up of a European Cancer Information System. The programme also addresses challenges and opportunities ahead such as integrating cancer registry data with clinical information, new methods and measures of data quality, collaboration for research, and data confidentiality.

The ENCR General Assembly will take place Thursday afternoon 6 October. Among other topics, an update on the status of the 2015 Call for Data will be presented. Full and active participation is encouraged. Such contributions and exchanges of view will be beneficial for the Network and its Steering Committee, as well as for the European Commission, in identifying concerns and deciding priorities for future improvements and developments.

In closing, we would like to express our thanks to the conference Organising Committee (the Cancer Information group of JRC's Directorate F – Health in Society Unit) for planning and arranging this Scientific Meeting and the General Assembly. We hope this event will stimulate a creative exchange of ideas and provide an opportunity for establishing new collaborations or strengthening existing ones. We hope that you enjoy your time in Baveno and together we can make this meeting a success.

Alexander Katalinic
ENCR Chairman

Ciarán Nicholl
Head of Unit
Health in Society
JRC

Stefan Schreck
Head of Unit
Health Programme and
Chronic Diseases
DG SANTE

Scientific committees

ENCR Steering Committee

Alexander Katalinic (Chair)

Andrea Bordoni (IACR)
Freddie Bray (IARC)
Carlotta Buzzoni (Italy)
Harry Comber (Ireland)
María Dolores Chirlaque (Spain)
Nadya Dimitrova (Bulgaria)
Ana Miranda (GRELL)
Hans Storm (ANCR)

JRC Scientific Team

Ciarán Nicholl (Head of Health in Society Unit)
Nicholas Nicholson

Cancer Information Group

Manola Bettio (Competence Group Leader)
Raquel N. Carvalho
Emanuele Crocetti
Tadek Dyba
Francesco Giusti
Carmen Martos
Giorgia Randi
Roisin Rooney
Lydia Voti

JRC Organising Team

Secretariat

Chiara Margagliano
Jindra Konopkova
Brigitte Westrischnig

Editorial Support

Manuel Florensa-Molist

The European Network of Cancer Registries

The European Network of Cancer Registries (ENCR) was established in 1989 within the framework of the *Europe Against Cancer* programme of the European Commission on the initiative of the International Agency for Research of Cancer (IARC), the Association of Nordic Cancer Registries (ANCR), International Association of Cancer Registries (IACR) and the Group of Registry and Epidemiology of Cancer in Latin Speaking Countries (GRELL). The ENCR promotes collaboration between cancer registries, defines data collection standards, provides training for cancer registry personnel and regularly disseminates information on cancer incidence and mortality in Europe.

The Network has the following objectives:

- to improve the quality, comparability and availability of cancer incidence data;
- to create a basis for monitoring cancer incidence and mortality in Europe;
- to provide regular information on the burden of cancer in Europe;
- to promote the use of cancer registries in cancer control, healthcare planning, and research.

The Network was directly supported by the European Commission (SANCO) until 31 March 2004. Funding for ENCR activities was also received from Cancéropôle Rhone-Alpes for the years 2007-2008, and again from the Seventh Framework Programme of the European Commission through the EUROCOURSE project in the period 2009-2012. IARC co-funded the ENCR since its inception until the end of 2012; from 2012 onwards the ENCR's secretariat was transferred to the JRC.

The ENCR is governed by a Steering Committee. The Steering Committee is composed of a maximum of 12 members. Nominated members are representatives of IARC, IACR, GRELL and ANCR. Five members are elected by the cancer registries. The last election was held in 2014. Nominees and elected members serve for three years with the possibility of renewal once.

The Chair is nominated by the Steering Committee members.

The ENCR Steering Committee

Elected members

Alexander Katalinic is full professor of epidemiology at the University of Lübeck. He is the director of the Institutes for Social Medicine and Epidemiology and for Cancer Epidemiology (which holds the analysis office of the Cancer Registry Schleswig-Holstein). From 1986 to 1992, he studied medicine at the University Erlangen, Germany. 1994 doctoral degree (MD), 2004 postdoctoral lecture qualification; Vena legendi: social medicine, epidemiology and health care research. He is chairman of the ENCR Steering Committee and of the Association of Population-Based Cancer Registries in Germany (GEKID). His research focus is cancer epidemiology, early detection and health care research. He contributed to more than 240 articles in peer-reviewed journals.

Nadya Dimitrova is associate professor in oncology at the Bulgarian National Cancer Registry (BNCR). She has a master degree in medicine (1997) and a specialty in general medicine (2006) from the Medical University in Sofia, a master degree in health management (2007) from the New Bulgarian University in Sofia and a PhD in oncology (2013) from the National Oncological Hospital in Sofia. Following medical graduation she worked as a general practitioner. In 2007, she joined the staff of the BNCR and during the period 2010-2013 she was its Director. Her main work interests are improving data quality of the registry and increasing the use of cancer information in cancer control activities.

Harry Comber was Director of the Irish National Cancer Registry since its establishment in 1992 to his retirement in 2016. He has a primary degree in chemistry (1971) from University College, Cork, a PhD in biophysics (1974) from the Institute of Cancer Research at the University of London and a medical degree (1978) from University College Cork. Following medical graduation he trained as a general practitioner and worked as a GP and Director of the Cork General Practice Training Programme until 1992. In 1992-1994, he was responsible for setting up the Irish National Cancer Registry, which he has led until 2016. His main interests are in promoting the use of cancer information to improve health service planning and evaluation, and through this, better patient outcomes. His research activity, which derives from these interests, covers topics from determinants of disease to quality of care. He has contributed to over 60 peer-reviewed publications, as well as a large number of reports from the National Cancer Registry. He was a member of the first and second National Cancer Forums and is a former member and Chair of the Scientific Council of the International Agency for Research on Cancer. Most recently, he has led the work package in the EUROCOURSE project which developed the European Cancer Observatory.

The ENCR Steering Committee

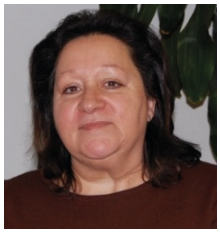
Carlotta Buzzoni has been employed at the Institute for Cancer Study and Prevention in Florence–ISPO–(Italy) since 2005, as a data-manager, statistician and epidemiologist. She contributed to the creation of the Italian Association of Cancer Registries (AIRTUM) database and, currently, she is directly involved in data quality evaluation, maintenance of the database and in the management of the ITACAN website. She is responsible for the analysis of data and co-ordinates Airtum's annual reports. She teaches courses in cancer registration and statistical analysis. She is author/co-author of more than 50 papers in peer-reviewed journals and has presented several talks at national and international conferences. Member of the AIRTUM Steering Committee since April 2016.

María Dolores Chirlaque: Preventive Medicine and Public Health specialist and associated Professor of Murcia University. She has been involved in several aspects of cancer epidemiology like coordination of cancer registration and epidemiological cancer research. Research on patterns of care of breast cancer, accuracy of the hospital administrative databases to identify incident cancer or effect of exposure to endocrine disruptor on cancer related hormones. Active participation in EPIC (European Prospective Investigation into Cancer and Nutrition) from 1993. The scientific production includes statistics of cancer incidence in Murcia region, trend of thyroid cancer, cancer survival in Spain, etc., and more than 150 drafts published on collaborative cancer groups (EPIC, EUROCARE, RARECARE, REDEPICAN, MCC-Spain, CONCORD). She is member of the following scientific societies: REDECAN (Spanish Network of Cancer Registries), ENCR, REDEPICAN (Epidemiology Network and Information System on Cancer), SMMPySP (Murcia Society of Preventive Medicine and Public Health), SEE (Spanish Epidemiology Society).

Nominated members

Freddie Bray (IARC) is Head of the Cancer Surveillance Section at the International Agency for Research on Cancer (IARC), in Lyon, France. He has worked previously at IARC 1998-2005 and at the Cancer Registry of Norway and University of Oslo 2005-2010. He has a PhD in Epidemiology from the London School of Hygiene and Tropical Medicine, and degrees in statistics from the University of Aberdeen and medical statistics from the University of Leicester, U.K. His areas of research revolve around descriptive epidemiology of cancer, including estimation of the global cancer burden and the analysis of time trends including global predictions of the future scale and profile of cancer linked to human development transitions. He has more than 200 book chapters and articles in journals including *The Lancet*, *Lancet Oncology*, *JNCI* and *Nature Reviews Cancer*. In support of the overwhelming need for high quality cancer surveillance systems, given their current paucity and an ever-increasing cancer problem, Dr Bray leads the Global Initiative for Cancer Registration (gicr.iarc.fr), an international multi-partner programme designed to ensure a sustainable expansion of the coverage and quality of population-based cancer registries in LMIC through tailored, localised support and advocacy to individual countries.

The ENCR Steering Committee



Ana Maria Campos Barreiros Pais da Costa Miranda (GRELL) has been responsible–since 1988–for the implementation and coordination of the Portugal South Regional Cancer Registry, a population-based registry of about 4800000 inhabitants, having produced numerous health indicators. In 1978, she took her degree in medicine (University of Lisbon) and in 1995, her Master's degree in Epidemiology at the School of Medical Sciences. Most of the work she has done was developed from research on chronic diseases especially in oncology and in the planning of health. In 2004, she was appointed as Director of the Epidemiology Department of the Lisbon's Portuguese Cancer Institute. In 2005, she was appointed as President of the Research Council of Lisbon's Portuguese Cancer Institute. During the period 2010-2014 she was appointed Secretary of Group for Epidemiology and Cancer Registration in Latin Language Countries–GRELL. Since 2014 is GRELL representative in ENCR.

Hans Storm (ANCR), MD (1976), Medical Vice CEO, Danish Cancer Society (DCS). Medical and surgical trained in oncology 1977-81, affiliated with the Danish Cancer Registry 1977, Director 1985-1997, Director of Prevention and Documentation, DCS 1997-2014. At present, research representative to the Danish Data Protection Council, ENCR SC member for several periods since 1990, and Board member (1994), General Secretary (1997) and President (2000-2004) of the International Association of Cancer Registries. He has been Director of the ANCR Summer School in Cancer Epidemiology since 1993, and initiated the NORDCAN collaboration. Appointed WHO cancer expert and co-author of the European Cancer Code (3rd ed.). Over 350 publications in descriptive and analytical cancer epidemiology on treatment, multiple primary cancers, and evaluation of cancer control.

Andrea Bordoni (IACR), MD, MPH is specialised in cancer registration and cancer epidemiology and is Head of the Ticino Cancer Registry since 1995. He has built up the Ticino Cancer Registry from the beginning, a registry that has expanded and is implementing and organising the Regional mammographic screening programme. The quality and completeness of the registry was accredited by IARC (International Agency on Cancer Research). He is a member of several cancer related committees, is on the board of the Ticino Cancer League, the Fondazione Ticinese Ricerca Cancro and the Scientific Advisory Board of the National Institute of Cancer Registration and Epidemiology. He is also a board member of GRELL and elected European representative on the board of the International Association of Cancer Registries. He is engaged in the promotion and co-operation of several local, national and international scientific networks, particularly related to the study of population-based prognostic and predictive cancer factors in quality of care and survival.

Towards a European cancer information system

Population-based cancer registries systematically collect, store and analyse data on cancers diagnosed in well-defined populations, so that the cancer burden can be assessed and cancer control programmes effectively planned and implemented. Currently, there are several regional and national population-based cancer registries operating in Europe, producing and disseminating cancer burden indicators. These information sources provide cancer statistics at varying degrees of detail and reliability, covering different geographical levels, from local areas (regional cancer registries) to individual countries with full coverage or pooling of regional figures (*e.g.* Itacan for Italy), regions of Europe (*e.g.* Nordcan for Scandinavia), and Europe as a whole (*e.g.* European Cancer Observatory for incidence and mortality data; Eurocare for survival data).

Standardisation of quality evaluation procedures and processing of data across registries is essential for accurate assessment and international reliable comparisons of cancer incidence, mortality, prevalence and survival.

Most recently the European Joint Action EPAAC–European Partnership for Action Against Cancer (2009-2013) highlighted the need for a European Cancer Information System (ECIS) that would integrate the various cancer-burden indicators (incidence, mortality, survival, and prevalence) under a common platform. The need for coordination of the various associated processes, such as data submission, data cleaning, and data management/analysis, in order to provide an optimally functioning resource for cancer-control activities across Europe, was also emphasised.

Whereas an ECIS remains a very valid aim, there are many hurdles to overcome before it can be fully achieved. These include:

- lack of cancer registration coverage in some parts of Europe;
- large differences among registries in data quality, often dictated by large differences in funding levels;
- tapestry of different cancer-registry infrastructures and capacity across Europe (regional/national/regional-national);
- different data reporting and processing standards followed;
- different data-protection regimes based on different interpretations of personal data sensitivity;
- timeliness in provision of quality data–typically 3-4 year time lag in data delivery;
- lack of a formal data-collection mandate at EU level;
- lack of long-term sustainability/continuation plan.

The European Commission services are aware of these constraints and are supporting a package of activities, following the Commission's Health Programme, to address these issues. Not only has this support ensured the continuity of the ENCR secretariat, allowing the administrative functioning and networking of the ENCR, but has also resulted in the on-going development of some of the specific infrastructural elements of ECIS. These include the establishment of a common procedure on cancer data quality checks, the new ENCR-JRC portal enabling a single data-upload mechanism as a unique gateway for European data collection as well as a data-transfer service, the development of open source data-quality check software on the basis of an agreed common procedure, and data-visualisation tools.

The JRC role in cancer information

Cancer is the second most common cause of death in the European Union. In 2009, the European Commission adopted the *Communication on Action Against Cancer: European Partnership* which defines several objectives to successfully reduce the burden of cancer in Europe. Evaluation of measures to implement this goal is critically dependent on accurate and comparable European cancer data available for derivation of incidence, prevalence, survival and mortality statistics. For this purpose, the Joint Research Centre (JRC), in its role as a scientific service to the European Commission, and in close collaboration with the Directorate-General for Health and Food Safety (DG SANTE), is supporting the creation of a cancer information system for Europe that will build upon existing experience, competence and cooperation, whilst recognising the invaluable role of national and regional cancer registries in its development and implementation.

Who we are and what we do

Established in 1957, the JRC serves as the European Commission's in-house science service and has a proven track record in the harmonisation and standardisation of scientific/technical processes and systems. The JRC is independent of all national, commercial and private interests and all of its projects are networked and based on consensus. This extensive experience in managing complex initiatives and collaborations places the JRC as the ideal platform for coordinating healthcare quality systems in Europe towards essential benchmarking standards.

Collaboration with the European Network of Cancer Registries

Data from population-based cancer registries are essential in evaluating the effects of health policy and in comparing practices across regional and national boundaries. The ENCR endorsed the JRC's role in hosting its secretariat, paving the way towards further coordination and harmonisation of cancer data in Europe. The transfer of the ENCR's administrative functions from Lyon (IARC) to the JRC includes, among other tasks, coordinating ENCR Steering Committee meetings, collecting and analysing data from European cancer registries, providing an active information-exchange infrastructure to keep cancer registries abreast of new developments, training, ensuring closer coordination among various stakeholders in defining and agreeing standards, producing or updating recommendations, and initiating and carrying out epidemiological research. This collaboration between the JRC and the ENCR ensures a single, updated, and definitive European cancer-registry dataset that will lead to the development of a comprehensive and harmonised European Cancer Information System.

Overview of the ENCR-JRC activities

The cooperation between the JRC and the ENCR promises many new opportunities for the development, utilisation, and promotion of data. Current and future priorities include the following:

- Further stimulate collaboration between the main stakeholders in cancer registration in Europe, as well as leading research groups in cancer epidemiology;
- Maintain an up-to-date map of European cancer registries and their individual registration processes and needs;
- Update guidelines and recommendations, organise and fund training programmes to help build up competence and expertise across registries, and support working groups to encourage data harmonisation;
- Ensure, on a permanent basis, the management of cancer registry data collection, providing a 'data-brokering' service to ensure integrity of a single European dataset for international studies;
- Streamline data submission and data-usage processes;
- Extend the number of collected variables, and support linkages with other data sources (*i.e.* clinical data as well as environmental, socio-economic indicators, infectious diseases, etc.), in compliance with the EU regulations on personal data;
- Develop an informative and comprehensive web-visualisation tool to display and disseminate statistics on cancer burden;
- Collaborate with international projects and organizations (WHO, IARC, IACR, EORTC, etc.).

In this context, during the period 2014-2016, the close collaboration between the JRC and the ENCR Steering Committee has established the following:

1. development of a portal for uploading data from registries, as a unique gateway for data submission and communication with European cancer registries;
2. launch of the 2015 ENCR-JRC Call for Data, to serve the needs of different European and international projects;
3. launch of the ENCR-JRC project on 'Incidence and Mortality in Europe', to set up a database with updated cancer incidence and mortality data in Europe – currently under validation;
4. publication of the report *A proposal on Cancer Data Quality Checks: a common procedure for European cancer registries*, as an ENCR-endorsed recommendation document addressing the quality standards required by major European and international projects;
5. development and free distribution of the 'JRC-ENCR Data Quality Checks' software, for the implementation of the checks documented in the report above;
6. initiation of activities to address ENCR recommendations and training needs, following a Workshop organized in November 2015 for 'Defining the roadmap towards revision of ENCR coding standards and training for cancer registries';
7. initial development of a new data-visualisation site: a web-based interactive tool to display and disseminate cancer statistics in graphical and tabular ways;
8. issuing of the quarterly *ENCR Newsflash*, as a bulletin to report on ENCR activities;
9. issuing of the *ENCR Cancer Factsheets* – so far these factsheets have addressed colorectal, prostate, lung, breast, melanoma of the skin and cervical cancers;
10. maintenance/update of the ENCR members archive, and collection/update of related information on cancer registration practices;
11. update of the ENCR membership Terms of Reference, to allow for different types of membership differentiating full members from associate members;
12. organization of quarterly ENCR Steering Committee meetings in Ispra, Italy;
13. maintenance and constant update of the ENCR website;
14. contribution to initiatives exploring the linkage of data from population-based registries and clinical registries (*e.g.* PancreOs, on pancreatic cancer);
15. promotion and support to cancer registration for research, planning and policy making including the provision of guidance on the new EU Data Protection regulation and its impact on cancer registration in Europe.

A more detailed description of the main activities in the list above is reported in the following paragraphs.

Overview of the ENCR-JRC activities

1. The ENCR-JRC portal

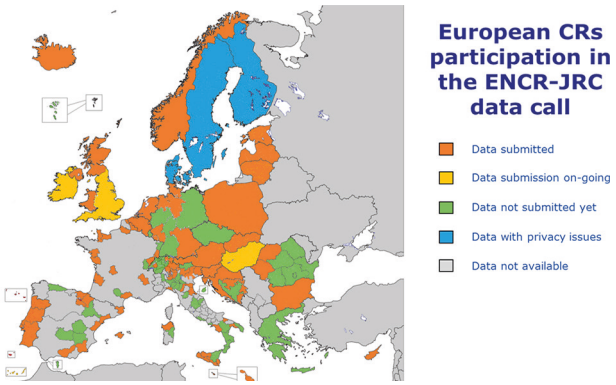
The new ENCR-JRC portal was developed in 2015 with the aim to serve all European and international calls for data addressed to the European population-based cancer registries. In the framework of the 2015 ENCR-JRC Call for Data, European cancer registries were requested to submit their data files, and respond to a data questionnaire, through the ENCR-JRC portal. Using the portal cancer registries benefit from the following features:

- high security and speed of data transfer;
- automated data submission and acknowledgement;
- one submission for several European and international projects;
- built-in mechanisms to read, accept, and sign agreements for participation in studies of their choice;
- track record of all transactions performed to allow for transparency and accountability.

Instructions on portal access, including each step of the data submission procedure, are provided on the ENCR-JRC portal and specific assistance is available on request by contacting the ENCR Secretariat. Using the portal, cancer registries are able to upload and update their data files. The ENCR-JRC portal is continuously being developed to respond to the needs of the cancer registry community.

In the future, extra features will enable cancer registries to update their contact information, receive information from the ENCR (feedback, documents, reports, etc.), receive their error/warning records after data quality checking, participate in ENCR surveys and participate in the ENCR elections.

2. The 2015 call for data



In June 2015 the ENCR and the JRC launched the 2015 Call for Data, addressed to all European population-based cancer registries, in order to build a unique anonymised database of cancer data. This unique archive will give cancer registries the possibility to submit data only once for multiple studies, instead of having to cope with several different data calls and related workload. The ENCR-JRC call, therefore, serves various projects.

The protocol for the 2015 call was jointly drafted by a Working Group involving the ENCR Steering Committee, the JRC and several European and international studies and projects, including members of EUROCARE, CONCORD, and IARC.

The description, format, type of files and variables of the call are detailed in the submission guidelines, available both on the ENCR-JRC portal and on the ENCR website. In addition to requests for data, a questionnaire to collect information on the registration process was drafted in order to facilitate data processing and interpretation. Cancer registries are invited to fill this questionnaire in on-line after submitting data.

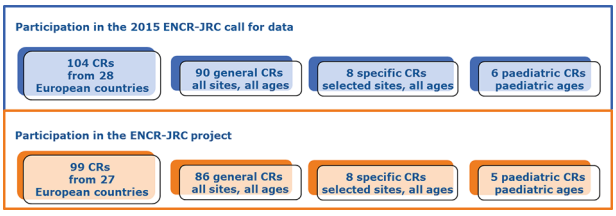
By the beginning of July 2016, 104 cancer registries from 28 European countries responded to the call. Of them, 90 registries cover all sites and all ages, eight cancer registries are site specific, and six cover only paediatric cases.

3. The ENCR-JRC project: incidence and mortality in Europe

The ENCR-JRC project on cancer incidence and mortality aims to create a standardised and comparable database for assessing and monitoring cancer incidence and mortality in Europe. The outputs of this project will consist of cancer incidence and mortality indicators, including specific analyses by cancer site, sex, age group, calendar period, geographic area, and potentially morphology groups. Cancer registries were requested to submit their data through the ENCR-JRC portal. For this specific project incidence data (as a list of individual cancer cases), mortality data from official vital statistics, and population data from the official figures were requested as separate files.

Once data are received, they are stored according to the European Commission's rules on data security. They undergo a quality verification (checking and quality assessment) based on the 2014 cancer data quality checks protocol: 'One common procedure for European cancer registries', approved by the ENCR Steering Committee and other European stakeholders including all major European projects (EUROCARE, CONCORD, RARECARE).

By the beginning of July 2016, participation of European cancer registries in the ENCR-JRC 2015 data call and in the ENCR-JRC project is as follows:



The outputs of the ENCR-JRC project will be disseminated online and will provide a basis for the ENCR factsheets, technical reports on the burden of cancer in Europe, European Cancer atlases and for collaborative peer-reviewed papers that will be drafted jointly by the JRC scientists, the ENCR steering committee and the cancer registries.

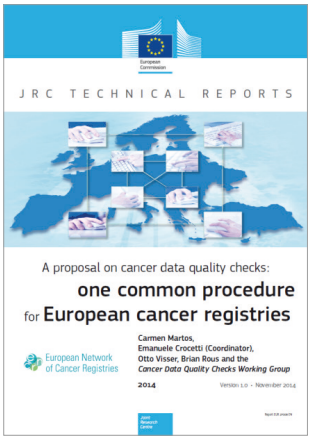
4. Cancer Data Quality Checks: One Common Procedure for European Cancer Registries

The reliability and utility of information provided by cancer registries depends on the quality of the data collected, involving four different dimensions: comparability, completeness, validity and timeliness.

So far, a variety of methods and tools have been used to check data validity in international projects. The ENCR, in collaboration with the JRC, established a standardised list of checks for internal consistency as a first step towards data validation, to be hopefully adopted by all European registries and projects in order to overcome the fragmented, and sometimes conflicting, procedures currently applied.

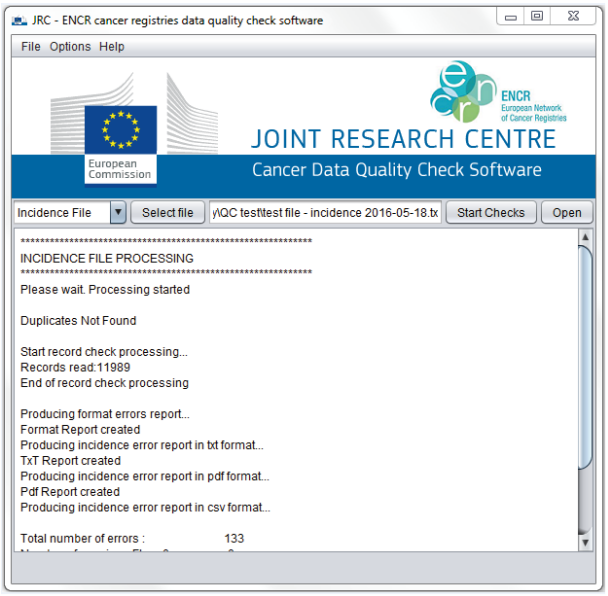
For this purpose, a Working Group consisting of representatives of various stakeholders and field experts was set-up, and three workshops on the topic were held at JRC, Ispra, on 2 July and 15 October 2013, and on 4 June 2014.

The outcome of the first two meetings was an inventory of the data quality checks applied for the different European projects, with final agreement on a common list of mandatory variables and their formats. The third workshop contributed to the finalization of the agreed rules, described in the document: *A proposal on cancer data quality checks: one common procedure for European cancer registries*. This ENCR-endorsed report serves as a guideline for the data quality process.



Future versions of the report will be carried out to incorporate new knowledge. In addition, new checks related to benign and in situ tumours, as well as for those of uncertain behaviour, will be included.

5. The JRC-ENCR data quality check software



Following the rules described in the above-mentioned report, the JRC developed an open-source software in order to test the quality of the data submitted to the ENCR-JRC call. This stand-alone software enables cancer registries to perform data quality checks on their own.

The software represents a first step in the process of providing cancer registries with a user friendly data-checking and quality control tool, and aims to standardise the procedures to be followed when submitting data to improve their quality and comparability. The first version was released November 2015.

A second and more complete version of the *JRC-ENCR cancer registries data quality check software* was released on 18 July 2016, and includes:

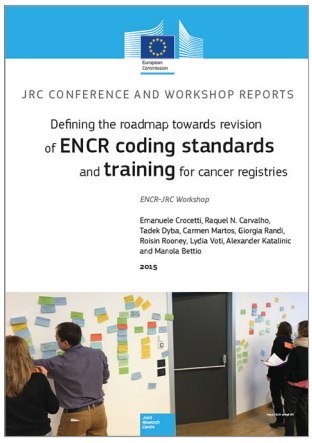
- checks on the format of files (for incidence, mortality, lifetables and population) and on names and order of variables;
- verification of internal consistency of variables;
- cross-checks among variables.

6. ENCR recommendations and training needs

The process to supply valid, complete and comparable data across different European countries implies, among other factors, that cancer registries use common procedures and rules to report and code cancer data. Therefore, providing cancer registry staff with quality, up-to-date recommendations is among the main priorities of the ENCR-JRC. Training, which comes hand-in-hand with issuing recommendations, is of paramount importance to quality cancer registration.

In November 2015, a workshop was organised by the JRC to address urgent needs on these two issues. A group of experts on cancer registration consisting of the ENCR-SC members, representatives from institutions and cancer research projects collaborating with cancer registries (*i.e.* IARC, Eurocare, Concord, Rarecare), representatives from national networks of cancer registries, members of the Cancer Information Group at the JRC and other specialists in the field attended the meeting.

Additionally, to better understand the needs of cancer registries, an anonymous questionnaire was sent to the group of experts and to Directors and staff of cancer registries prior to the meeting. The questionnaire, along with the procedures followed during the workshop, elicited views from participants. A list of topics to be addressed (Metaplan) was agreed. These are summarised in the Report *Defining the roadmap towards revision of ENCR coding standards and training for cancer registries*, available on the ENCR website.



The technical proposals based on the workshop have assisted the ENCR-SC in prioritising future activities to cater to the real needs of cancer registries.

ENCR recommendations

The workshop identified that updates/issuing of new recommendations are urgently needed for the following topics: multiple primary rules, staging, registration reportability criteria, Death Certificate Only cases (DCO)–Death Certificate Notified cases (DCN), date of incidence, 'complicated' cancers (*e.g.* bladder, etc.), haematological cancers, and coding of borderline malignancies.

As a practical outcome of the workshop, members of the ENCR-SC and staff of the JRC created two working groups to deal with the necessary updates for the recommendations on 'Multiple primaries' and 'Date of incidence'.

ENCR training

The procedures used to prioritise recommendations were also used to prioritise the training needs of cancer registries. These are as follows: cancer registration, haematological malignancies, data analysis, stage, quality, multiple primaries, specific cancer types, and grading.

It was agreed to make available on the web high quality and reliable training-oriented documents approved by the ENCR. For training on specific technical issues (analysis, data quality, etc.) it was suggested that traditional face-to-face courses should be provided. The workshop stressed that recommendations and training are interlinked; any new recommendation/tool/procedure should be issued together with related training material to facilitate its implementation.

A training workshop will take place on 5 October 2016, prior to the start of the conference, to address the evaluation of cancer registries' data quality and to present the new JRC-ENCR quality check software. Sessions of this training will be also recorded and made available as tutorials on the web.

7. Development of a new data-visualisation tool

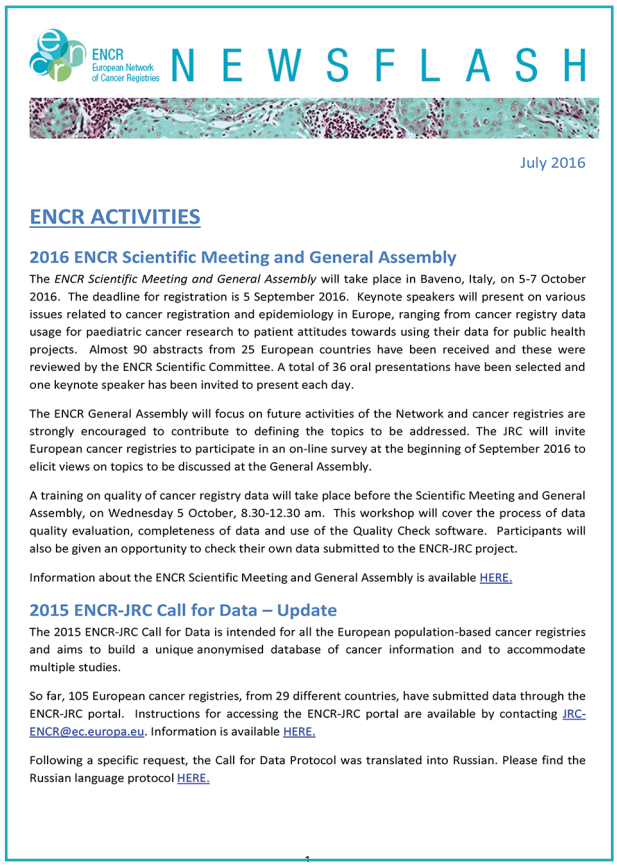
A new version of the European Cancer Observatory (ECO) is under development by the JRC, and this will include a number of interactive data-visualisation tools to facilitate navigation, selection and analysis of cancer-registry data.

The philosophy of the new observatory follows current data-visualisation practices that allow the user to examine and analyse progressively more detailed data from an initial general data overview. The selected dataset will be downloadable in tabular or graphical form.

The initial modules are focused on a cancer atlas. The first general information view will allow an instantaneous update of data at European level when switching across metrics related to cancer site, age distribution, cumulative risk, time trends, etc. The data visualisation tools will be developed using a drill-down approach, allowing the user to navigate from interactive maps to more specific statistics presented in various forms.

It is currently under construction and will become gradually available in 2016.

8. ENCR Newsflash



ENCR European Network of Cancer Registries

NEWSFLASH

July 2016

ENCR ACTIVITIES

2016 ENCR Scientific Meeting and General Assembly

The *ENCR Scientific Meeting and General Assembly* will take place in Baveno, Italy, on 5-7 October 2016. The deadline for registration is 5 September 2016. Keynote speakers will present on various issues related to cancer registration and epidemiology in Europe, ranging from cancer registry data usage for paediatric cancer research to patient attitudes towards using their data for public health projects. Almost 90 abstracts from 25 European countries have been received and these were reviewed by the ENCR Scientific Committee. A total of 36 oral presentations have been selected and one keynote speaker has been invited to present each day.

The ENCR General Assembly will focus on future activities of the Network and cancer registries are strongly encouraged to contribute to defining the topics to be addressed. The JRC will invite European cancer registries to participate in an on-line survey at the beginning of September 2016 to elicit views on topics to be discussed at the General Assembly.

A training on quality of cancer registry data will take place before the Scientific Meeting and General Assembly, on Wednesday 5 October, 8.30-12.30 am. This workshop will cover the process of data quality evaluation, completeness of data and use of the Quality Check software. Participants will also be given an opportunity to check their own data submitted to the ENCR-JRC project.

Information about the ENCR Scientific Meeting and General Assembly is available HERE.

2015 ENCR-JRC Call for Data – Update

The 2015 ENCR-JRC Call for Data is intended for all the European population-based cancer registries and aims to build a unique anonymised database of cancer information and to accommodate multiple studies.

So far, 105 European cancer registries, from 29 different countries, have submitted data through the ENCR-JRC portal. Instructions for accessing the ENCR-JRC portal are available by contacting JRC-ENCR@ec.europa.eu. Information is available HERE.

Following a specific request, the Call for Data Protocol was translated into Russian. Please find the Russian language protocol HERE.

The *Newsflash* is a communication tool of the JRC and the ENCR Steering Committee with the ENCR-affiliated registries. It reports the latest news on ENCR activities, it alerts members about upcoming conferences on cancer epidemiology and it lists the most recent peer-reviewed articles published using cancer registry data. The *Newsflash* also includes news about member-registries and cancer-related information from either EU sources or from outside.

The JRC re-designed the quarterly *Newsflash* as soon as the ENCR secretariat was transferred to JRC (September 2012). ENCR *Newsflash* are usually published four times a year, they are sent via email and they are also available on the ENCR website: http://encr.eu/index.php/publications/newsflash.

Although the target audience of the *Newsflash* is the ENCR members, the contact list of recipients is much wider, and the information is also distributed to cancer research institutions, NGOs, government organisations and anyone interested in the ENCR activities.

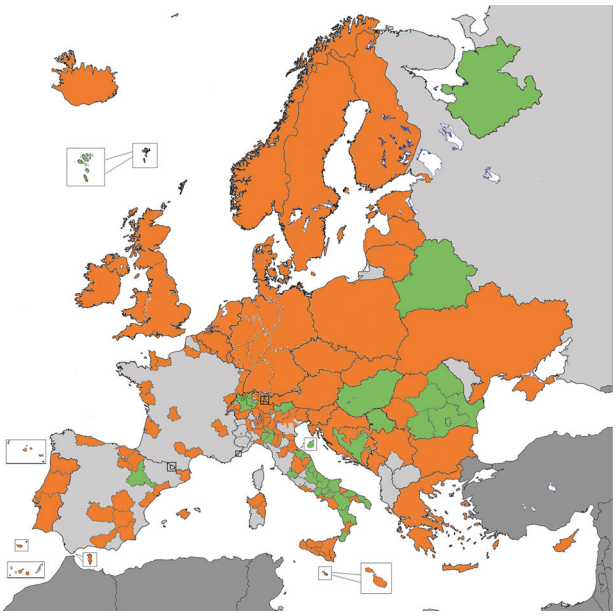
9. ENCR Factsheets

Cancer factsheets provide a quick overview of key facts on specific cancers, reporting summary figures, aetiology, risk factors, screening, if available, and prevention information. Their purpose is to condense and communicate in a clear and concise way relevant information on specific types of cancers. The factsheets are produced jointly by the JRC–Cancer Information Group and the ENCR Steering Committee (SC).

The factsheets are targeted at the general public, although professionals such as medical doctors, epidemiologists, decision makers and healthcare planners may benefit from them, as they present a simple yet up-to-date review of information from different reliable sources in one single document.

The size of the factsheets is limited to two pages, including figures, and the template follows an agreed structure. The first section presents general information, followed by a graphical and numerical presentation of the incidence/mortality in Europe by country. A similar short paragraph related to the worldwide situation is also reported. The section 'Temporal changes in selected European countries' presents figures showing the recent trends in incidence/mortality for specific European countries and related comments. The 'Aetiology' section contains information about the main risk factors, and is followed by a 'Screening and Prevention' paragraph which includes information on European or international guidelines. A summary of the main points is presented in the 'Conclusions' section. A separate linked document contains the full list of references used in the text.

10. ENCR members



Map of full ENCR member registries in Europe, as of July 2016.

In 2010, under the auspices of the EUROCOURSE and EUROCHIP studies (two EU funded projects), a questionnaire on cancer registration practices was sent to all known European cancer registries. In 2014, an abbreviated version of the same questionnaire was sent to the updated cancer registries contact list. The results of the two surveys were supplemented with information gathered through the 2015 ENCR-JRC Call for Data questionnaire. From this information the updated list of ENCR full members was compiled.

Currently, 160 European cancer registries are full ENCR members, representing 38 European countries. Of them, 35 are national and 125 are regional registries; 134 are general registries, recording all cancers in all ages, and 26 are specialised for age and/or cancer.

11. Updated ENCR membership rules

The ENCR Membership criteria have been updated recently by the ENCR SC, introducing a new associated membership category. The criteria for full and associate membership and related benefits are outlined in the table below.

FULL MEMBERSHIP

Cancer registries are eligible for full ENCR membership provided that they:

- are population-based (including site or age-specific registries); population based cancer registries are defined as registries that collect data on all new cases of cancer occurring in a specified population in a defined geographical area;
- currently operate in countries within the UN geographical definition of Europe1, plus Cyprus;
- have completed the ENCR questionnaire within the last five years (*e.g.* the membership questionnaire, or the 2015 ENCR-JRC Call for Data Questionnaire), and update the information on request.

ASSOCIATE MEMBERSHIP

Non-population-based registries, networks of registries, cancer institutes, entities involved in cancer research and organisations supporting cancer registration or cancer research, such as cancer patients' organisations, can apply for Associate Membership. This type of membership can include entities from countries belonging to the WHO European region.

Benefits for ENCR members	Full	Associate
Access to the ENCR-JRC Portal for a unique data submission to several European studies	✓	
Registry data may be included, and displayed, on the European Cancer Observatory	✓	
May propose candidates, from the registry, as ENCR representatives on the Steering Committee, during the elections	✓	
Right to elect the ENCR Steering Committee members	✓	
Inclusion on the ENCR mailing list, which will be kept updated with news from the Network's members and activities	✓	✓
Participate in ENCR activities (meetings, collaborative projects, surveys)	✓	✓
Participate in ENCR training events and, possibly, to request assistance from experts within the Network to enhance capacity at local level	✓	✓
Opportunity to co-author papers, using European cancer registry data	✓	✓

Detailed meeting programme

Wed

5 Oct

	WEDNESDAY	5 October 2016
09:00-13:00	**ENCR-JRC Training**	
13:00-14:00	*Buffet lunch and poster collection*	
14:00-14:30	**Opening Ceremony** (JRC, SANCO, ENCR)	
14:30-15:00	Invited Lecture: **Roberto Zanetti** (International Association Cancer Registries)	
15:00-16:30	1st Scientific Session: **Cancer burden in Europe: incidence, mortality, survival and prevalence**	
	Survival from cancer in the North region of Portugal – Results from the first decade of the Millennium	**Luis Antunes**
	The burden of rare cancer among adults in Austria, 2000-2012	**Monika Hackl**
	Rare cancers prevalence in Europe: the RARECAREnet project	**Sandra Mallone**
	Trends in incidence of childhood cancer in Switzerland, 1985-2014	**Matthias Schindler**
	Time trends and spatial patterns in the mesothelioma incidence in Slovenia, 1961-2013	**Vesna Zadnik**
	Ethnic differences in the incidence of cancer in Norway	**Kirsti Vik Hjerkind**
	Cancer incidence trends in Ukraine, 2002-2012	**Anton Ryzhov**
16:30-17:00	*Coffee break & poster viewing*	
17:00-18:30	2nd Scientific Session: **Cancer registries and evaluation of cancer care (1)**	
	Breast cancer screening effectiveness in Portugal central region	**Joana Bastos**
	Measuring and reporting quality of care at the Belgian cancer registry: pivotal steps of an integrative quality system	**Liesbet Van Eycken**
	Indicators of long-term survival and cure of cancer	**Luigino Dal Maso**
	Monitoring care for female breast cancer patients in N. Ireland (NI) diagnosed 2012 (comparisons to 1996, 2001 and 2006)	**Victoria Cairnduff**
	How European cancer registries can contribute in the assessment of quality of care for cancer patients?	**Luciana Neamtiu**
19:00-21:30	**Welcome reception**	

Thu 6 Oct

Detailed meeting programme

	THURSDAY	6 October 2016
09:00-09:30	Invited Lecture: **Francesco de Lorenzo** (Federation of Cancer Patients Organisations)	
09:30-11:00	3rd Scientific Session: **Cancer registries and evaluation of cancer care (2)**	
	Patterns of care and cost profiles of cancer patients in Italy: the EPICOST study	**Silvia Francisci**
	The volume effect in paediatric oncology: a population based study	**Gemma Gatta**
	Delay in diagnosis and initiation of breast cancer treatment in Belgium	**Liesbet Van Eycken**
	The role of cancer registries in the evaluation of rare cancers care: the joint action on rare cancers	**Annalisa Trama**
	A trans-cultural European Deprivation Index for studying social determinants of cancer incidence and survival in Europe	**Guy Launoy**
	Faking it: Building a Simulacrum of non-identifiable modelled cancer data to support research	**Cong Chen**
11:00-11:30	*Coffee break & poster viewing*	
11:30-13:00	4th Scientific Session: **Methods and measures of cancer registry data quality**	
	Primary brain and central nervous system tumours diagnosed in Girona (Spain) in 1994-2013	**Rafael Marcos-Gragera**
	Completeness and validity of data in the Finnish Cancer Registry	**Nea Malila**
	Completeness of registration in the SCCR as estimated from data exchange with regional cancer registries in Switzerland	**Shelagh M Redmond**
	The impact of under-reporting of cases on the estimates of childhood cancer incidence and survival in Estonia	**Keiu Paapsi**
	Impact of socioeconomic status on breast cancer care patterns and survival: the Italian high resolution study results	**Francesca Di Salvo**
	Cancer incidence rates and Benford's law: a useful liaison	**Emanuele Crocetti**
13:00-14:00	*Buffet lunch and poster viewing*	

	THURSDAY	6 October 2016
14:00-15:30	5th Scientific Session: **Statistical methods and software tools**	
	Evidence-based toolkit of spatial epidemiology and analysis to enhance cancer surveillance	**Dimitra Sifaki-Pistolla**
	Shared mortality from liver cancer and type 2 diabetes mellitus in Puglia	**Enzo Coviello**
	The potential biases for interpreting patients' net survival rate using cancer registries: a literature review	**Ayako Okuyama**
	CanStaging: a cancer staging tool facilitating tumour staging into the future – planned developments and enhancements	**Colin Fox**
	Comparing survival between Belgian haematopoietic stem cell transplant centres using a model based on pseudo values	**Gilles Macq**
	Official/main terms, related terms and conversion between different classifications – renewing the coding manual	**Siri Larønningen**
15:30-16:00	*Coffee break & poster viewing*	
16:00-18:30	ENCR General Assembly	
	Welcome and report on ENCR-JRC activities from 2014-2016	**Alexander Katalinic**
	Towards a European cancer information system: the Data Quality Checks software, the Portal development, the Data Visualization tool	**JRC and ENCR Steering Committee**
	Status of the 2015 ENCR-JRC Call for Data and ENCR-JRC project	
	New data protection regulation and impact on cancer registries	
	Update on the ENCR recommendations	
	Results from the feedback survey to cancer registries	
	General discussion	**ENCR cancer registry members**
	Conclusions	**Alexander Katalinic**

Fri

Detailed meeting programme

7 Oct

	FRIDAY	7 October 2016
09:00-09:30	Invited Lecture: **Kathy Pritchard-Jones** (University College London)	
09:30-11:00	6th Scientific Session: **Cancer registries and clinical data**	
	On the way to a comprehensive cancer registration for Germany	**Alexander Katalinic**
	Electronic reporting of clinical notifications to the Cancer Registry of Norway	**Siri Larønningen**
	Comparison of the old method of record linkage with the new 'system break free' method at the Cancer Registry RLP (D)-	**Katharina Emrich**
	Quality of life according to trial participation among Hodgkin lymphoma survivors: an IKNL-EORTC joint study	**Melissa Thong**
	Collecting clinical and epidemiological data on pancreatic cancer across Europe: PancreOs, a multidisciplinary project	**María-Dolores Chirlaque**
	Survival differences in Hodgkin lymphoma patients treated inside and outside clinical trials–An EORTC-IKNL joint study	**Lifang Liu**
11:00-11:30	*Coffee break & poster viewing*	
11:30-12:30	**Awards for best contribution** **Meeting Closure**	**Alexander Katalinic** **Ciarán Nicholl**
12:30-13:30	*Buffet lunch and poster pick-up*	

Roberto Zanetti graduated in medicine from Torino University in 1978, completed a PhD in Biometrics at Milano University in 1985; he started working at Piedmont Cancer Registry in 1979 as a junior epidemiologist, under the direction of Professor Enrico Anglesio. Dr Zanetti was appointed Director of the Registry following Dr. Anglesio's retirement in 1989. He has been visiting professor at Geneva University, Switzerland (2004-2005). For 1990 and 2003 he was the editor of the Italian monograph on cancer incidence *Cancer in Italy*, and author of the two editions of the dissemination booklet *Facts and Figures of Cancer in Italy*. In 2010 he was editor of the Italian edition of the UICC TNM manual. Between 1987 and 2003 he was principal investigator in the European Melanoma Research Consortium 'Helios', funded within the framework of 'Europe against cancer' programme. He has been (1999-2008) the principal investigator for Italy in the US based melanoma research consortium 'GEM'. In 2009, Roberto was working package leader for the FP 7 Project Eurocourse. In 1997 he promoted the establishment of the AIRTUM, the Italian network of cancer regis-tries. From 1999 to 2003 he was General Secretary of GRELL, the Latin European or-ganisation of Cancer Registries. He served on the Board of Directors of UICC (Union for International Cancer Control) from 2006 to 2010. He represented UICC as an Observer at the IARC Scientific Council (2007-2011). In 2004 Dr Zanetti established the foundation Fondo Anglesio Moroni. He served on the Executive Committee of IACR as European Regional representative (2002-2006), and as President (2012-2016). Presently, he serves as a member in the Scientific Committee of the Concord Project on international Cancer Survival. He has authored more than 150 articles in peer-re-viewed journals and eight ISBN indexed books. He was called as an expert, several times in Court, in judicial litigations relating to cancer aetiology.

Future developments in cancer registration

Modern cancer registration started in the 1930s and progressed steadily with excellent results. Registries expanded worldwide by a factor of around 12 during the following eighty years. The success of cancer registries is probably due to the fact that conceptualisation is simple. On the one hand, standardisation of definitions and methods has evolved coherently over time, and on the other, these systems have the ability to adapt and respond to the need for new information. Besides the expansion of basic indicators for burden of disease (from incidence to survival and prevalence) other milestones have included: a large contribution to aetiological research in the era of classical cohort and case control studies; prompt co-operation with the developments of cancer screening programmes (namely in Europe); quick adaptability to contribute to clinical epidemiology (mainly based on local/hospital opportunities); linkage with bio-banks (EPIC project; large bio-banks in Nordic Countries); linkage with the genomic research milieu; and finally, a contribution to civil society (dissemination of information; information service to advocacy and patient groups). Future developments should include:
- Expanding coverage (worldwide, by continents, by countries) by optimizing the procedures (avoiding proliferation of small isolated units, but networking at the maximum level allowed by IT developments),
- Strengthening organisation as a professional milieu (for example in North America NAACCR, Registrars' Association),
And lobbying to obtain a regulatory framework that facilitates rather than hinders progress,
- Enlarging and enriching partnerships (with medical professionals, researchers (basic and translational), policy makers, advocacy groups, media etc.

Francesco De Lorenzo is a colon cancer survivor, medical doctor and professor of biochemistry at the University Federico II, Naples. He has comprehensive experience in cancer advocacy being the co-founder, former Vice-President and Board member of ECPC. He is also the founder and President of the Italian Association of Cancer Patients (AIMaC), Italy's first Cancer Information Service (CIS), and the Italian Federation of Cancer Patients Organisations (FAVO). Francesco is also active in Italy's governmental network of cancer Institutes (ACC), Italy's National Cancer Plan Committee and the National Volunteer Observatory of the Italian Welfare Ministry. Francesco was also engaged in Italian politics as a Member of Parliament, holding several ministerial mandates (Ministry of Health, 1989-1993). At EU and international level, Francesco is a member of the European Commission Expert Group on Cancer Control; Permanent Member of the European Society for Medical Oncology (ESMO) Cancer Patient Working Group; ECPC representative within CANCON, in several Work Packages; Founding Member of the Elite Oncology Roundtable, created under the auspices of the Society for Translational Oncology–STO, from which the European Cancer Patients' Bill of Rights originated; ECPC Board member responsible for the projects EurocanPlatform and RARECAREnet funded by the 7th Framework Programme; and Co-chair of ECPC Expert Group on Immuno-Oncology.

Patient attitudes to monitoring and use of their data in cancer research

The interest of cancer patients in cancer registries is twofold: better measured cancer survivorship and better measures of incidence and prevalence of rare cancers to improve research.

Cancer survivorship is a ticking bomb: more than 10 million Europeans live today with a cancer diagnosis and increase the socio-economic burden of cancer. Many survivors (around 22% in Italy, for example) can and should get back to a normal life. Registries must play a role in facilitating the identification of survivors by collecting information on their rehabilitation, the level of disability, late effects and capacity to return to work. The final objective would be to have detailed information, at European level, on how many survivors can be considered cured from the disease, *i.e.* those whose life expectancy is equal to the national average. This information would be crucial to ensure better planning of public health policies and resources. The 2014 AIRTUM report can be used as a model. In this way, the registries can provide quick and detailed information to both survivors and public authorities.

Regarding rare cancers, we know that there are differences between the data collected by public cancer registries and hospital-based registries. Nonetheless, rare cancer epidemiological research would benefit greatly from a more in-depth harmonisation of data collected at European level. This need has been raised within Rare Cancers Europe (a multi-stakeholder initiative dedicated to putting rare cancers firmly on the European policy agenda, led by ESMO) and should be the objective of a project to identify a common methodology for the collection of rare cancer patients' data.

Finally, the demands of ECPC and the oncology community, expressed in our position paper *Risk of the New EU Data Protection Regulation* are included in the final text of the General Data Protection Regulation (GDPR). We must ensure that the implementation of the GDPR will respect the final spirit of the text.

Kathy Pritchard-Jones is Professor of Paediatric Oncology at University College London, Institute of Child Health and a consultant oncologist at Great Ormond Street Hospital. She has 25yrs experience of clinical trials and translational research in childhood cancers, particularly kidney cancers. She is a current member of the board of the European Society for Paediatric Oncology (SIOP E) working to deliver the European Cancer Plan for Children and Adolescents (www.siope.eu/SIOPE_StrategicPlan2015/#). This aims to improve survival and quality of survival through research, dissemination of standards of care (www.ncbi.nlm.nih.gov/pubmed/27131152) and reducing inequalities in access to care and innovation (www.expornet.eu/).

Kathy is leading on the cancer outcomes agenda, in particular to improve understanding of the factors that affect the efficacy and safety of first line therapies, strengthen joint working between clinical and population based cancer registry researchers for international collaborative data collection and benchmarking to address the survival differences that currently exist for children with cancer across Europe. Kathy is also the cancer programme director of UCLPartners Academic Health Science Network and chief medical officer for an integrated cancer system, London Cancer, (www.londoncancer.org) that serves a population of 3.5 million in North London. Here, she works closely with commissioners and academic collaborators to develop the means to evaluate outcomes of whole pathways of care and understand the impact of these changes on local population-based health economies.

Childhood cancer outcomes research:
opportunities for integrating clinical and population based cancer registry efforts

Each year in Europe there are ~35 000 new cases of cancer in children and adolescents (15 000 age <15yrs; 20 000 age 15-24yrs). Whilst cancer in young people is rare (~1% total cancers annually), it is a major health issue. One in 600 newborns will develop cancer before turning 20. Age-standardised incidence rates have risen steadily by ~1% per annum from 120/106 children in 1971 to 150/106 in 2010 (preliminary data, ACCIS project). Despite improving survival rates, cancer remains the first cause of death by disease beyond one year of age, with more than 6 000 deaths from cancer annually. 5yr overall survival rates now exceed 80 %, with more than 300 000 survivors of childhood cancer in Europe, estimated to rise to 500 000 by 2020. Two-thirds of survivors of currently available treatments have some late side effects of treatment, impacting on the daily life of half of those affected. SIOPe, the European Society of Paediatric Oncology, has developed a strategic plan to increase the cure rate and quality of survivorship for young people with cancer over the next ten years (http://www.siope.eu/SIOPE_StrategicPlan2015/). This calls for new approaches to prospective clinical research to study effectiveness of first line therapies at a population level. With advances in cancer registration and linkage to hospital data, there is now the opportunity for much closer cooperation between population based cancer registries and the European clinical trial groups who are applying advances in biology to improve diagnostic and prognostic classification and introduce new therapies. Prospective 'non-interventional' clinical studies involving point of care collection of agreed relevant data on patient/tumour demographics, clinical risk stratification and therapies delivered can help to understand the variation in survival seen in some cancer types and between countries and regions. Such studies can support research into surgical, imaging and radiotherapy techniques as well as biology and epidemiological factors that may explain aetiology and prognosis.

Survival from cancer in the North Region of Portugal – Results from the first decade of the millennium

Luis Antunes, Maria José Bento

North Region Cancer Registry of Portugal, Department of Epidemiology, Portuguese Institute of Oncology of Porto, Portugal

Background and Introduction

Net survival is a key epidemiological measure. It allows the evaluation of cancer care practices and a fair outcomes comparison between different regions since it is not dependent on background mortality. Survival from cancer has been improving either due to earlier diagnosis or due to improvements in treatment offered to patients. We aimed to evaluate improvements in net survival from cancer during the period 2001-2010 in the North Region of Portugal.

Materials and Methods

Data has been retrieved from the North Region Cancer Registry of Portugal database. We considered the top twenty cancer sites for patients aged 15 years or older: oesophagus, stomach, colon, rectum, pancreas, liver, larynx, lung, skin melanoma, breast, cervix, corpus uteri, ovary, prostate, kidney, bladder, brain and CNS, thyroid, non-Hodgkin lymphoma and multiple myeloma. Net survival was estimated using Pohar-Perme estimator. Estimates were age-standardized using the International Cancer Survival Standard. Diagnosis years were grouped in two periods: 2001-2005 and 2006-2010. Effect of diagnosis period was evaluated using flexible parametric models adjusted for age and sex where appropriate. Best model for each cancer site was chosen based on lowest AIC.

Results

After excluding cases with missing information (2%), a total of 106774 cases were considered. Thyroid and prostate cancers presented the best 5-year age-standardised survival (>90%) while oesophagus, pancreas, liver and lung cancers the worst (<20%). A significant ($p<0.05$) improvement in survival between the two periods was observed for stomach, colon, liver, pancreas, larynx, melanoma, brain and CNS, thyroid, non-Hodgkin lymphoma and multiple myeloma. For the other cancer sites no significant trends were observed.

Conclusions

Improvements in survival were not universal for all cancer sites. Further studies should be performed to better understand these different patterns in survival trends.

The burden of rare cancer among adults in Austria, 2000-2012

Monika Hackl, Henrike E. Karim-Kos

Austrian National Cancer Registry, Directorate Social Statistics, Statistics Austria, Vienna, Austria

Background and Introduction

Burden of rare cancer is seldom studied, although in Europe rare cancers represent about 22% of all newly diagnosed cancers each year. The aim of this study was to measure the burden of rare cancers among adults in Austria.

Materials and Methods

All malignant cancer cases diagnosed in 2000-2012 in patients aged ≥15 years were derived from the Austrian National Cancer Registry and classified according to the RARECARE entities (65 first and 218 second-layer entities, version December 2015). Cancers showing an average annual crude incidence rate <6/100 000 in 2000-2012 were defined as rare. Relative survival was calculated for 2000-2004 and 2005-2009 based on follow-up until December 31st 2014. Reference date for prevalence was December 31st 2012.

Results

Each year about 7 000 rare cancers were diagnosed, which is 18% of all newly diagnosed cancer cases per year. 84% of all second-layer entities (183) were rare, 13 entities were not observed, and 2 entities (epithelial skin tumours) were not collected. Rare haematological, digestive, and head and neck cancers were most common comprising 57% of all rare cancers. Five-year relative survival remained stable in 2000-2009 at 53% for all rare cancers, varying from 22% (digestive cancers) to 93% (male genital cancers). 60 000 patients with a rare cancer were alive at the end of 2012 (19% of total cancer prevalence).

Conclusions

In Austria, almost one in six cancer cases among adults is a rare cancer. This is in line with the European results. Taking into account that this group consists of at least 183 different entities indicates the challenge that health care faces. Therefore increased awareness among clinicians and policy makers is needed, leading to improvement of diagnostics and treatment by (inter)national cooperation and concentration of care. Preferably, the next national cancer plan should focus on rare cancer.

Rare cancers prevalence in Europe: the RARECARENet project

Sandra Mallone,[1] Annalisa Trama,[2] Riccardo Capocaccia,[2] Roberta De Angelis,[1] Andrea Tavilla,[1] Daniela Pierannunzio,[1] Silvia Rossi,[1] Gemma Gatta[2] and the RARECARENet working group

[1]National Centre for Epidemiology Surveillance and Health Promotion (CNESPS)–National Institute of Health (Istituto Superiore di Sanità), Rome, Italy
[2]Epidemiologia valutativa, Fondazione IRCCS Istituto Nazionale dei Tumori (INT), Milan, Italy

Background and Introduction

This work provides estimates of the rare cancers prevalence (incidence <6/100 000/year in European population) identified by RARECARENet–Information Network on Rare Cancers–project.

Materials and Methods

Complete prevalence (CP) for rare cancers is calculated correcting 15-years (index date 01/01/2008; 26 RARECARENet Cancer Registries-CRs-) prevalence through the completeness index method. Proportions are obtained by dividing CP by the population at risk covered by the RARECARENet CRs. Prevalent cancer patients at 2008 in European Union (EU), European region and Country was estimated by cancer assuming the same CP proportion as in RARECARENet sample and applying it to the corresponding population by gender and age.

Results

Combining all 198 rare cancers, in EU about 5 000 000 people with a previous diagnosis of a rare cancer (1% of population) were alive at 2008. The highest CP proportions were observed for rare haematological and female genital organs tumours (240 and 236/100 000), for head and neck cancers (116). Very low proportions (>10) were observed for rare skin cancers (9), embryonal (8), eye tumours (4). CP proportions were 1052 in Southern Europe, 1038 in Central Europe, 989 in Northern Europe, 965 in United Kingdom and Ireland, 951 in Eastern Europe. Ranking CP by Country, the highest proportion was in Italy (1106) while the lowest was in Ireland (800). In these Countries, ranking CP by cancer the second highest proportions were observed for squamous cell carcinoma with variants of cervix uteri (85 and 60 in Italy and Ireland respectively), and carcinoma of thyroid gland (78 and 58).

Conclusions

These estimates confirm that rare cancers are an important burden to address. Prevalence data for rare cancers should be ensured by CRs to support healthcare planning and facilitate application for the EU orphan drug directive, considering that many rare cancers–neuroendocrine tumours or sarcomas–are not included by current statistics.

Trends in incidence of childhood cancer in Switzerland, 1985-2014

Matthias Schindler,[1] Verena Pfeiffer,[1] Shelagh Redmond,[1] Marc Ansari,[2] Hugo Ubieto,[3] Gisela Michel,[4] Claudia Kuehni[1]

[1]Swiss Childhood Cancer Registry, Institute of Social and Preventive Medicine, University of Bern, Bern, Switzerland [2]Oncology and Hematology Unit, Department of Pediatrics, Geneva University Hospital, Geneva, Switzerland [3]Division of Hematology and Oncology, Children's Hospital of Eastern Switzerland, St. Gallen, Switzerland [4]Department of Health Sciences, University of Lucerne, Lucerne, Switzerland

Background and Introduction
Several studies have reported increasing incidence rates of childhood cancer. The aim of this study was to describe incidence during the most recent diagnostic period (2005-2014) and to investigate time-trends of childhood cancer incidence in Switzerland from 1985 to 2014.

Materials and Methods
We extracted data of all childhood cancer cases diagnosed at age 0-14 years between 1985 and 2014 in Switzerland. We included ICCC-3 main groups I-XII. We calculated age-standardised incidence rates, cumulative incidence rates and age-specific incidence rates for different diagnostic groups for the period 2005-2014 using data of the Swiss general population. We analysed time-trends of annual age-standardised incidence rates for the period 1985-2014 using the Joinpoint software package.

Results
In total we included 5563 diagnoses. Over the whole study period, 5247 diagnoses (94%) were microscopically verified. The average number of diagnoses per year was 191. Leukaemia accounted for 34%, CNS tumours for 23% and lymphoma for 11% of all diagnoses. Age-standardised incidence was 163 (95% CI 156-171) per million from 2005 to 2014. The cumulative incidence rate before the age of 14 years was 2411 (2383-2438) or one out of 403 children were affected in Switzerland. Annual age-standardised incidence rates increased significantly for all tumours combined by 1% (1985-2014), for CNS tumours by 3.8% (1985 to 2002) and for epithelial tumours by 3.5% (1985-2014).

Conclusions
Trends in incidence were driven mostly by trends among CNS tumours and other malignant epithelial tumours. Trends for CNS tumours levelled off after 2002, which was in line with results from other countries. Based on our results we cannot determine whether change in risk was due to an undetected risk factor or due to diagnostic changes and improved registration procedures.

Time trends and spatial patterns in the mesothelioma incidence in Slovenia, 1961-2013

Vesna Zadnik, Tina Žagar, Katja Jarm, Maja Primic Žakelj

Epidemiology and Cancer Registry, Institute of Oncology Ljubljana, Ljubljana, Slovenia

Background and Introduction
Mesothelioma is a rare cancer except in workers in asbestos industry and in populations living next to asbestos sources exposed indirectly. The asbestos-based manufacture reached its peak between 1970 and 1980 in Slovenia and was banned in 1998, but the population is going to be exposed further on by built in asbestos-containing material and by asbestos dumps. The aim of this study is to evaluate the mesothelioma epidemics in Slovenia in the last 50 years.

Materials and Methods
The temporal trends and geographical variation of mesothelioma burden in Slovenia are assessed by analysing incidence data from the population based Cancer Registry of Slovenia for the period 1961-2013. The incidence time trends are compared with the annual data of asbestos imported to Slovenia (used as a proxy for asbestos exposure in manufacturing areas). The mesothelioma maps produced from the patients' residence geographical coordinates are presented together with the map of Slovenian major asbestos-exposed locations.

Results
From 1970 on the mesothelioma incidence is increasing: the steepest increase can be observed from 1998 to 2003 (APC=13.5), after the year 2004 the mesothelioma time trend curve is stable. The time trend of the asbestos importation shows a great increase between 1965 and 1973 (APC=10.0) and a plateau between 1974 and 1980. It seems that the maximum value of asbestos import curve corresponds to the peak of mesothelioma curve exactly 30 years later. In maps the mesothelioma clusters manifest around known asbestos sources predominately in the years 1980-1990, but in the last years the geographical distribution is more uniform.

Conclusions
The data from our long existing population based cancer registry give a good insight into the on-going mesothelioma epidemic in Slovenia. Our results imply that the mesothelioma peak has already been reached in Slovenia. In the future the new cases will appear more randomly throughout the country.

Ethnic differences in the incidence of cancer in Norway

Kirsti V. Hjerkind,[1] Bernadette Kumar,[2] Samera A. Qureshi,[2] Bjørn Møller,[1] Giske Ursin[1, 3, 4, 5]

[1]Department of Registration, Cancer Registry of Norway, Institute of Population-based Cancer Research, Oslo, Norway [2]Norwegian Centre for Minority Health Research, Oslo, Norway [3]Department of Community Medicine, Faculty of Medicine, University of Oslo, Oslo, Norway [4]Department of Nutrition, Institute of Basic Medical Sciences, University of Oslo, Oslo, Norway [5]University of Southern California, Los Angeles, USA

Background and Introduction
Disparities in cancer risk patterns across ethnic groups and between immigrants and native populations have been reported previously. However, since medical records in Norway do not record country of birth or origin, there has been no monitoring of cancer incidence among different immigrant groups. This study aims to examine cancer incidence among different immigrant groups in Norway.

Materials and Methods
This project links data from the Cancer Registry of Norway with data from Statistics Norway to examine age-specific and age-standardized overall and site-specific cancer incidence rates in different immigrant groups and compare them to rates among persons born in Norway to Norwegian-born parents, using the age distribution from the world standard population.

Results
Analyses of 850 333 immigrants show that 10 334 women and 9158 men developed total minus non-melanoma skin cancer in the period 1990-2012. During this period, the age- and period-standardized incidence rates per 100 000 person-years were 235 for women and 267 for men. Among 4 882 955 persons born in Norway to Norwegian-born parents, 230 099 women and 258 333 men developed cancer during the same period, and the age- and period-standardized incidence rates were 248 women and 298 for men. Cancer in the lung, liver, stomach, prostate, and cervix was more common in specific immigrant groups.

Conclusions
This study found differences in cancer incidence between immigrants and persons born in Norway to Norwegian-born parents. Identifying and monitoring cancer types among immigrants that are rare in the Norwegian population are important for early detection, and to ensure appropriate health care. Additionally, identifying lifestyle-related cancers which are less common among immigrants could help prevent lifestyle changes that may occur after migration.

Cancer incidence trends in Ukraine, 2002-2012

Anton Ryzhov,[1] Zoya Fedorenko,[1] Lyudmyla Goulak,[1] Eugene Gorokh,[1] Olena Soumkina,[1] Lyubov Koutsenko,[1] Jacques Ferlay,[2] Ariana Znaor[2]

[1]National Cancer Registry of Ukraine, National Institute of Cancer, Kiev, Ukraine [2]International Agency for Research on Cancer, Lyon, France

Background and Introduction

The National Cancer Registry of Ukraine (NCRU) collects information on all cancer cases since 2002. Time trends in cancer incidence in 2002-2012 were analysed for major cancer sites in males and females.

Materials and Methods

Information on 1601624 cancer cases (excl. non-melanoma of skin), diagnosed in 2002-2012 was extracted from the NCRU's database. Joinpoint regression analysis was applied to estimate annual percents of change (APCs) and direction of trends in age-standardized incidence rates (ASIRs, European Standard) for major cancer sites.

Results

In males, significant increases were observed for cancers of prostate, ICD-10 C61 (APC=4.2%), kidney, C64 (2.4%), lymphomas combined, C81-85,88,90 (1.7%), colon, C18 (1.6%), rectum, anus, C19-21, (0.9%) and bladder, C67 (0.6%). Significant decreases was observed for cancers of stomach, C16 (-2.4%), trachea, bronchus and lung, C33-34 (-1.7%) and larynx, C32 (-1.1%). The highest increases in women were observed for thyroid cancers, C73 (4.9%), lymphomas (2.3%), corpus uteri, C54 (1.7%), colon (1.6%) and pancreas (1.4%). Significant decreases were observed only for cancers of stomach (-2.2%). The ASIRs for cancers of breast (C50) and cervix uteri (C53) significantly increased from 50.3/100000 in 2002 to 57.3/100000 in 2012 (APC=1.1%) and from 17.5 to 20.1 (APC=1.4%) respectively. The ASIRs for all cancers excl. non-melanoma of skin significantly increased from 328.2/100000 to 340.4/100000 in males and from 217.9/100000 to 246.4/100000 in females.

Conclusions

While incidence rates in Ukraine are increasing for most cancers, decreases were observed for cancers of lung in males and stomach in both sexes. Further strengthening of cancer control activities, screening in particular, is required for reducing the burden of cancer in Ukraine.

Breast cancer screening effectiveness in Portugal Central Region

Joana Bastos,[1] Vitor Rodrigues,[2,3] Ellen Paap,[4] Mireille Broeders,[4,5] Miguel Pina,[6] Dário Cruz,[6] Branca Carrito,[1] Manuel António Silva[1]

[1]Registo Oncológico Regional do Centro, Instituto Português de Oncologia, Coimbra, Portugal [2]Faculdade de Medicina da Universidade de Coimbra, Coimbra, Portugal [3]Núcleo Regional do Centro da Liga Portuguesa contra o Cancro, Coimbra, Portugal and CIMAGO [4]Dutch Reference Centre for Screening, Nijmegen, the Netherlands [5]Department for Health Evidence, Radboud University Medical Center, Nijmegen, the Netherlands [6]Núcleo Regional do Centro da Liga Portuguesa contra o Cancro, Coimbra, Portugal

Background and Introduction
An organized population-based breast cancer screening programme of the Núcleo Regional do Centro da Liga Portuguesa contra o Cancro started in the eighties and covers the entire area of the Central Region of Portugal. We designed a case-referent study to investigate the association of overall mortality with mammographic screening history.

Materials and Methods
The study population (SP) included women aged 50-69 who received at least one invitation to the breast screening programme. A case was defined as a woman from the SP diagnosed with breast cancer between 2000 and 2006 who died before 1/8/2015. Index invitation (IV) was defined as the most recent invitation before diagnosis of the case. For each case, two referents were sampled from the SP. Referents were women free of breast cancer at the IV of the case and alive at time of death of the case. Exposure to screening was the participation in the examination following their IV, or the participation in the screening round preceding the IV. In order to correct for potential self-selection bias (SSB) we calculated a correction factor. We used conditional logistic regression to estimate odds ratio (OR), and 95% confidence intervals (95%CI), for the association between screening history and mortality.

Results
A total of 227 cases and 454 referents were included in this study. Without correction for SSB, the overall OR showed a mortality reduction of 47% (OR=0.53, 95%CI: 0.34-0.77). The estimated correction factor was 1.12 (95%CI: 0.97-1.29). This factor was used to correct the crude odds ratio (OR=0.63, 95%CI: 0.41-0.97).

Conclusions
Even after correcting for self-selection a protective effect of screening on overall mortality has been observed. Comparison to other case-control studies is not straightforward as the other studies looked at breast cancer mortality. Our results support the effect of screening in the decreasing trend in breast cancer mortality in Portugal.

Measuring and reporting quality of care at the Belgian cancer registry: pivotal steps of an integrative quality system

Cindy De Gendt, Geert Silversmit, Viki Schillemans, Jessica Vandeven, Nancy Van Damme, Isabel De Brabander, Harlinde De Schutter, Liesbet Van Eycken

Belgian Cancer Registry, Brussels, Belgium

Background and Introduction

Following the development of evidence-based guidelines, the Belgian Cancer Registry (BCR) plays a pivotal role in measuring quality of care indicators (QCI) covering cancer prevention, diagnosis and treatment. For some cancer types, extended clinical information is available from voluntary-based registration projects. QCI calculations at the population level however rely on a dedicated methodology integrating standard BCR data coupled to administrative data of the health-insurance companies (HIC), enabling the provision of feedback to the Belgian hospitals.

Materials and Methods

For each relevant QCI, a technical definition is established, including an evaluation of measurability. HIC data serve to identify relevant diagnostic and therapeutic acts and the executing centers. Patients are assigned to centers using algorithms based on the exerted diagnostic or therapeutic procedures. A validation phase with clinical data of some centers serves to optimize the algorithms and QCI calculations. Next, all selected QCI are calculated at the national and the center level. Individual feedback allows the center to benchmark its results against the national average and other centers.

Results

QCI assessments have been exerted for testis, breast, rectum, stomach, oesophagus and lung cancer, and are ongoing for prostate and head and neck cancer. While transparency towards a broader public is provided by online publications, reports on the QCI including volume-outcome analyses have yet inspired policy makers to reconsider current health care structures. Regular updates of the QCI measurements enforce centers to improve any suboptimal results.

Conclusions

Devoid of any supplementary registration burden, administrative health care data offer a unique opportunity to assess quality of care for the complete Belgian population. A continuously monitoring system serves caregivers, hospitals and stakeholders to optimize quality of care for cancer patients.

Indicators of long-term survival and cure of cancer

Luigino Dal Maso,[1] Stefano Guzzinati,[2] Roberta De Angelis[3]

[1]Aviano National Cancer Institute-IRCCS, Aviano, Italy [2]Veneto Cancer Registry, Padova, Italy [3]Italian National Institute of Health (ISS), Rome, Italy

Background and Introduction

To provide estimates of indicators of long-term survival and cure for 50 cancer types, presently lacking.

Materials and Methods

Data from 1.6 million of Italian cancer patients diagnosed between 1976 and 2010 (AIRTUM) were included. Validated statistical models had been used to estimate four population-based original indicators of cancer cure, by sex, age and period:

1. Cure fraction: proportion of patients expected to reach the same death rates of the general population.
2. Time to cure: years after cancer diagnosis necessary to eliminate the excess mortality of patients vs the general population. This occurs when 5-year conditional relative survival (CRS, probability of surviving an additional 5 years) becomes >95%.
3. Already cured patients: proportion of patients survived longer than the Time to cure.
4. Cure prevalence: the proportion of all prevalent cases who will not die of that cancer.

Results

The cure fractions ranged from >90% for patients aged <45 years with thyroid and testis cancers to <10% for liver and pancreatic cancers patients. For several cancers types they increased of >10% from the 1980s to 2000s. Five-year CRS >95% is reached in <10 years by patients with cancers of the stomach, colon-rectum, pancreas, corpus and cervix uteri, and Hodgkin lymphoma. Mortality rates similar to the ones reported by the general population were reached after approximately 20 years for breast and prostate cancer patients Five-year CRS remained <95% for > 25 years after cancer diagnosis in patients with liver and larynx cancers, non-Hodgkin lymphoma, myeloma, and leukaemia. Time to cure was reached by 27% (20% in men and 33% in women) of all people living after a cancer diagnosis, defined as already cured. Therefore, the cure prevalence was 67% for men and 77% for women.

Conclusions

The availability of these indicators has a high potential impact on health planning, clinical practice, and patients' perspective.

Monitoring care for female breast cancer patients in N. Ireland (NI) diagnosed 2012 (comparisons to 1996, 2001 and 2006)

Victoria Cairnduff, Deirdre Fitzpatrick, Anna Gavin

N. Ireland Cancer Registry (NICR), Centre for Public Health, Queen's University Belfast, UK

Background and Introduction

Over recent years there have been considerable changes in services provided to cancer patients in NI, with several guidelines produced to specifically improve enhance services and outcomes for breast cancer patients. This audit aimed to document presentation, treatment and outcomes for female breast cancer patients diagnosed in 2012 and compare with data collected in 1996, 2001 and 2006.

Materials and Methods

Data on all breast cancers (n=1279) diagnosed in 2012 were available from the NICR database. Additional clinical information was extracted for patients diagnosed between September and December 2012 (n=411). Chi-Square analysis tested statistically significant differences between audit years and Kaplan-Meier was used to estimate observed survival.

Results

Over half (56%) of patients diagnosed in 2012 came from GP referrals and almost a third (30%) through the breast screening programme. Three quarters (76%) of women were diagnosed at early Stage I or Stage II disease. Seven out of 10 women had a sentinel node biopsy in 2012, an increase from 21% in 2006. As a result the more invasive axillary node clearance fell from 82% in 1996 to 45% in 2012. Use of endocrine treatments increased to 84% in 2012 from 78% in 2006. 90% of women had surgery (49% mastectomy and 51% breast conserving surgery). Regional inequality in breast reconstruction was identified. Two year observed survival improved significantly since 1996 from 84% to 89% Survival improvements were most marked for older ladies (65+) and late Stage IV disease.

Conclusions

Although the number of women diagnosed with breast cancer continues to increase (+1.3%/year), the findings demonstrate improvements in treatment and patient outcomes over time.

Acknowledgments: The NICR is funded by the Public Health Agency of N. Ireland and this audit work was facilitated by the Guidelines and Audit Implementation Network (GAIN) a unit within the Regulation & Quality Improvement Authority (RQIA).

How can European cancer registries contribute in the assessment of quality of care for cancer patients?

Luciana Neamtiu, Zuleika Saz-Parkinson, Liisa Pylkkänen, Anke Bramesfeld, Silvia Deandrea, Aslı Ulutürk, Massimo Ambrosio, Donata Lerda

European Commission, DG Joint Research Centre, Ispra, Italy

Background and Introduction
The European Commission Initiative on Breast Cancer (ECIBC) aims to contribute to improve health and to reduce health inequalities in Europe by ensuring the quality of breast cancer services. Among the ECIBC's main tasks, a new version of the European guidelines for breast cancer screening and diagnosis based on evidence will be developed, together with a platform of high-quality guidelines covering all processes of breast cancer care, both of which will underpin the voluntary European quality assurance (QA) scheme for breast cancer care. This study aims to examine how European population based cancer registries can be used to assess the quality of care for breast cancer patients.

Materials and Methods
Pubmed searches were performed to identify studies published by cancer registries from European countries regarding the quality of care for breast cancer patients. Studies were categorised according to the following domains of quality of care: safety, effectiveness, patient-centricity. Studies in any language published between 1990 and 2016 were included.

Results
31 studies fulfilling the inclusion criteria specified in the methods section were found: the majority assessing effectiveness (mainly adherence to guidelines regarding diagnosis and treatment and quality of outcomes-survival). 21 studies where performed using only data from cancer registries and 10 using linkage of cancer registries data with other databases such as clinical registries, and administrative databases.

Conclusions
Few population cancer registries have published studies which refer to quality of care in breast cancer. Collaboration with cancer registries could exploit the potential of having population level data to assess the quality of care. Cancer registries' support will be crucial for evaluating the impact of the ECIBC at a population level.

Patterns of care and cost profiles of cancer patients in Italy: the EPICOST study

Silvia Francisci,[1] Susanna Busco,[2] Giulia Capodaglio,[3] Luigino Dal Maso,[4] Anna Gigli,[5] Stefano Guzzinati,[3] Sandra Mallone,[1] Andrea Piano Mortari,[5,6] Daniela Pierannunzio,[1] Andrea Tavilla[1]

[1]National Centre for Epidemiology, Surveillance and Health Promotion. Istituto Superiore di Sanità, Rome, Italy [2]Registro Tumori della Provincia di Latina, Latina, Italy [3]Registro Tumori Veneto, Padova, Italy [4]Centro di Riferimento Oncologico di Aviano, Aviano, Italy [5]Institute for Research on Population and Social Policies, National Research Council, Rome, Italy [6]Centre for Economic Studies and International Studies, Rome, Italy

Background and Introduction
Reconstruct and forecast the cancer pathway and the cost-related dynamic according to three phases of care: initial, continuing and final.

Materials and Methods
Profiles of cancer-related costs are built using administrative data (hospital, outpatients and pharmaceutical data) linked at individual level with cancer registry data: each prevalent case is allocated to one of three phases of care and corresponding costs are computed. Forecast are obtained using a dynamic microsimulation model. Cancer sites are colon, rectum and breast; the Italian registries participating in the study are located in eight regions, spanning from North to South.

Results
Preliminary results for colorectal cancer applied to a cohort of patients from Veneto and Tuscany cancer registries show cost profiles with higher costs during the first months of initial phase, then declining until reaching a plateau during continuing phase and then increasing again during the end of life. More advanced stages correspond to higher average costs, in all age classes and particularly among the youngest. This result is consistent with the clinical guidelines, which suggest different treatment strategies according to the tumour stage. Age is also related to costs: younger patients have higher costs in all phases of the disease.

Conclusions
The phase-of-care approach allows estimation of patterns of care and costs at a given date, taking into account the survivors' distribution and their care needs during lifespan. The study confirms that stage at diagnosis has an influence on the therapeutic strategy and related costs. The results confirm the importance of primary prevention and early detection of cancer in a public health perspective, not only in the improvement of patients survival and but also in the economic sustainability of healthcare. The methodology can also be used to compare patterns of care in different countries and settings and to project estimates of costs both geographically and over time.

The volume effect in paediatric oncology: a population based study

Gemma Gatta,[1] Laura Botta,[1] Otto Visser,[2] Maarit Leinonen,[3] Harry Comber,[4] Nadya Dimitrova,[5] Liesbet van Eycken,[6] S. Siesling,[2] Maja Žakelj,[7] Annalisa Trama,[1] Riccardo Capocaccia[1]

[1]Fondazione IRCCS Istituto Nazionale dei Tumori (INT), Milan, Italy [2]Netherlands Comprehensive Cancer Organisation (IKNL), Utrecht, the Netherlands [3]Finnish Cancer Registry, Helsinki, Finland [4]Irish National Cancer Registry, Cork, Ireland [5]Bulgarian National Cancer Registry, National Oncology Hospital, Sofia, Bulgaria [6]Belgian Cancer Registry, Brussels, Belgium [7]Epidemiology and Cancer Registry, Institute of Oncology Ljubljana, Ljubljana, Slovenia

Background and Introduction
A large body of research is available on the volume effect on survival for adult cancers. Childhood cancers are rare, and in many countries the organisation of care for children with cancer has already been concentrated in some form. In addition, most care for childhood cancer is highly protocolised and carried out by specialised caregivers. In the framework of the RARECAREnet study we describe the hospital volume for childhood cancers in six European countries and assess the relation between hospital volume and five-year survival.

Materials and Methods
The study involved six European cancer registries, all with national coverage, who provided individual data on incidence and hospitals of treatment for 4482 children diagnosed with cancer during the period 2000-2007 and followed-up for vital status to the end of 2012.

Results
For all childhood cancers combined, the number of hospitals managing at least one childhood cancer per year ranged between two and 14, by country. The hospitals with the highest volume admitted between 68 and 32 cases per year, across countries. For the haematological malignancies, the major group of childhood tumous, the percentage of children admitted in the highest volume hospital, ranged between 98% and 24%. A relation between hospital volume and five-year survival within country was found only for soft tissue sarcomas ($r = 0.44$).

Conclusions
This analysis described the situation in the first years of 2000 (study period 2000-2007). An animated debate of how centralised childhood cancer and organised efficient network is ongoing in many countries, therefore treatment of childhood cancers can have changed in the most recent years. This study is relevant to show possible progress.

Delay in diagnosis and initiation of breast cancer treatment in Belgium

Pieter-Jan Verhulst,[1] Renée Otter,[2] Gilles Macq,[1] Harlinde De Schutter,[1] Marc Van den Bulcke,[2] Nancy van Damme,[1] Liesbet Van Eycken[1]

[1]Belgian Cancer Registry, Brussels, Belgium [2]Cancer Centre, Scientific Institute for Public Health, Brussels, Belgium

Background and Introduction

Timely diagnosis and treatment are important quality indicators for cancer care. Delays are due to additional diagnostic procedures but also influenced by health care organisation. The goal of this study is (1) to assess the delay between mammography and incidence date and between the incidence date and first therapy for female breast cancer patients in Belgium and (2) to study some possible factors of influence.

Materials and Methods

Female patients with primary invasive breast cancer diagnosed between 2009 and 2011 were retrieved from the Belgian Cancer Registry's database (n=27 092). Information on treatments was obtained from population-based reimbursement data of the health insurance companies. A univariate and multivariate model was constructed to examine the association of different factors (age, clinical stage, treatment and centre volume) with delay.

Results

The median delay between screening mammography and incidence date is 35 days and the delay between diagnostic mammography and incidence date is one day in women who did not undergo screening. Median time from incidence date to first treatment was 21 days. Seven weeks after incidence, treatment was initiated in 90 % of patients, with surgery being the most common first treatment (77 %). Overall, lower stage and younger age were associated with shorter delays. Neo-adjuvant therapy, surgery, radiotherapy and systemic therapy showed a median delay of 23, 20 and 21 and 31 days, respectively. In multivariate analysis, delay was significantly ($P<0.001$) impacted by age, stage, treatment and centre volume.

Conclusions

Our study shows that age, stage, treatment type and centre volume affect the time between diagnosis and start of treatment, with a rather complex relation between these factors. By gaining more insight into the interacting mechanisms, proposals for measures to minimize preventable causes of delay and to increase the quality of life of the patient could be developed.

The role of cancer registries in the evaluation of rare cancers care: the joint action on rare cancers

Annalisa Trama,[1] Gemma Gatta,[1] Riccardo Capocaccia,[1] Laura Botta,[1] María Dolores Chirlaque,[2,3] Carmen Navarro,[2,3] Elena Pardo-Romaguera,[4] Rafael Peris Bonet,[4] Miguel Rodríguez-Barranco,[5] María José Sánchez Pérez[5,6]

[1]Fondazione IRCCS Istituto Nazionale dei Tumori (INT), Milan, Italy [2]Deparment of Epidemiology, Murcia Regional Health Council, IMIB-Arrixaca, Spain [3]CIBER Epidemiología y Salud Pública (CIBERESP), Spain [4]Spanish Registry of Childhood Tumours (RETI-SEHOP), University of Valencia, Valencia, Spain [5]Escuela Andaluza de Salud Pública, Instituto de Investigación Biosanitaria ibs.GRANADA, Hospitales Universitarios de Granada/ Universidad de Granada, Granada, Spain [6]CIBER de Epidemiología y Salud Pública (CIBERESP), Spain

Background and Introduction

Diagnosis and treatment of rare cancers may not reach optimal standards in all EU countries. From the Health Organisation's point of view, in the EU, an opportunity is provided by the creation of European Reference Networks (ERNs). In this framework, the DG SANCO launched the Joint Action on Rare Cancers (JARC) with the following objectives (a) prioritise rare cancers in the EU and MS agendas (b) develop solutions for ERNs on rare cancers, in the areas of epidemiology, quality of care, innovation, education, diagnosis and treatment. Here we present the activities of the JARC WP4 on epidemiology of rare cancers which involve the ENCR.

Materials and Methods

Quality of rare cancers registration. Quality and comparability of morphological details, stage, treatment and place of treatment will be assessed from available datasets (RARECAREnet) and the results will be discussed with ENCR, clinicians and pathologists. Evaluation of the impact of the ERNs. An operational model will be developed and shared across MS for implementing durable electronic linkage between clinical databases and population-based cancer registries (CRs). In addition, the role of high resolution studies to assess the ERNs impact at population level will be discussed to identify pros and cons of these studies and the specific challenges of performing them for the 12 families of rare cancers. Finally, possible ways to assess the implementation of clinical practice guidelines at population level will be discussed with ENCRs.

Results

Recommendations will be developed on possible ways to ameliorate the quality of rare cancers registration in CRs and on the role of CRs to assess the ERN.

Conclusions

CRs will play an essential role in assessing the ERN by monitoring the proportion of eligible cases they capture, tracking rare cancer patients referral through the ERN centres, and assessing the impact of ERNs at the population level in terms of patient outcome.

A trans-cultural Europan deprivation index for studying social determinants of cancer incidence and survival in Europe

Elodie Guillaume,[1] Roberto Lilini,[2,3] Marina Vercelli,[3] Marc Mari-Dell'Olmo,[4,5,6] Carme Borrell,[4,5,6,7] Ana Isabel Ribeiro,[8] Alexandra Mayer,[9] Cyrille Delpierre,[10,11] Bernard Rachet,[12] Guy Launoy[1,13]

[1]French Institute of Health and Medical Research–Caen University, U1086 'Cancers & Préventions', Caen, France [2]Department of Sociology, PhD School in Applied Sociology and Methodology of Research, University of Milan-Bicocca, Genoa, Italy [3]Department of Health Sciences, University of Genoa, Genoa, Italy [4]CIBER Epidemiología y Salud Pública (CIBERESP), Madrid, Spain [5]Agència de Salut Pública de Barcelona, Barcelona, Spain [6]Institut d'Investigació Biomèdica (IIB Sant Pau), Barcelona, Spain [7]Universitat Pompeu Fabra, Barcelona, Spain [8]Universidade do Porto, Porto, Portugal [9]Registro Oncologico Regional Sul, Lisbon, Portugal [10]INSERM, U1027, Toulouse, France [11]Université Toulouse III Paul-Sabatier, UMR1027, Toulouse, France [12]London School of Hygiene and Tropical Medicine, London, UK [13]University Hospital of Caen, Caen, France

Background and Introduction

A growing number of register-based studies highlight the implication of social determinants on the incidence and prognosis of cancer. Measuring and comparing social inequalities in cancer between countries with different economies, social structures, and healthcare systems will facilitate developing more efficient policies to tackle social inequalities in health, and will increase our understanding of the underlying mechanisms and causes of social inequalities. From a European perspective, it is important that the measure of social inequalities becomes comparable, or at least transferable, between different European countries. This contribution will detail the methodological steps for the construction of the European Deprivation Index (EDI).

Materials and Methods

EDI was developed under the Townsend theorization of relative deprivation. In a first step, using the individual questionnaire specially devoted to relative deprivation in EU-SILC survey, fundamental needs associated with both objective and subjective poverty were identified. In a second and third step, a set of weighted variables, selected among variables present in both individual data and national census, best correlated with the lack of at least two fundamental needs, were selected.

Results

EDI was obtained for five European countries with cancer registries: Italy, Portugal, Spain, England, and France. Constructed in this way, the EDI can be used in each country at the smallest geographical level unit for which census data are available.

Conclusions

The European Deprivation Index can now be used to investigate the influence of social environment on cancer incidence, screening, or survival measured at an aggregated level or at an individual level using appropriate multi-level statistical models. Such studies have been already conducted at national level in different countries and have now to be conducted at an inter-country level.

Faking it: building a simulacrum of non-identifiable modelled cancer data to support research

Cong Chen,[1] Christopher Drennan,[1] Brian Shand,[1] Sally Vernon,[1] Georgios Lyratzopoulos,[1,2] Sophie Newbound,[1] Jem Rashbass,[1] Peter Treasure,[1] Matthew Williams[3]

[1]Public Health England (National Cancer Registration and Analysis Service), London, UK [2]University College London, London, UK [3]Imperial College London, London, UK

Background and Introduction

The National Cancer Registry contains data about 15 million cancer patients in England, recording over 200 000 diagnosed tumours each year. The data is confidential and access is stringently controlled by the Office for Data Release. The Simulacrum project aims to create a simulated dataset which matches the real datasets as closely as possible, to make cancer data more widely accessible.

Materials and Methods

We tested key feature variables in cancer data for 2014 statistically for independence, and inferred associations otherwise. Guided by these linkages we sampled from distributions given by real cancer data to produce tumour-level data. This presentation discusses: the tools developed to test the data for realism, methods used to ensure preservation of research-relevant statistical features, steps taken to limit disclosivity risk.

Results

The datasets produced replicate the shape and quality constraints of real cancer data. In testing, low-dimensional statistics correspond closely to those for real-world data–incidence and age profiles by cancer site, stage distribution. Modelling preserves key multidimensional characteristics of the data, such as the influence of age on stage, which are automatically identified from strong correlations in the original cancer registry data set. This correspondence in shape and distributions means that queries run on the test data may expect similar results to queries run on the simulated data, and are also compatible with the real data without significant modifications.

Conclusions

The creation of a non-identifying modelled dataset removes a huge obstacle for research on cancer data. It should support estimates of data quality and size of cohorts, or exploration before detailed investigation. This dataset is a valuable resource for academic and commercial researchers to build their case for further data access and provides a proof of concept for modelling of other cancer datasets.

Primary brain and central nervous system tumours diagnosed in Girona (Spain) in 1994-2013

Rafael Marcos-Gragera,[1] Loreto Vilardell,[1] Rafael Fuentes-Raspall,[2] M. Carme Carmona-Garcia,[1,4] Sònia Del Barco,[3] Marta Solans,[1,5,6] Montse Puigdemont[7]

[1]Epidemiology Unit and Girona Cancer Registry, Oncology Coordination Plan, Department of Health, Autonomous Government of Catalonia, Catalan Institute of Oncology, Girona, Spain [2]Radiation Oncology Service, Catalan Institute of Oncology, Girona, Spain [3]Medical Oncology Service, Catalan Institute of Oncology, Girona, Spain [4]Emergency Department, University Hospital Dr Josep Trueta, Girona, Spain [5]CIBER in Epidemiology and Public Health (CIBERESP), Spain [6]Research Group on Statistics, Econometrics and Health (GRECS), Universitat de Girona, Girona, Spain [7]Catalan Institute of Oncology (ICO), Hospital Cancer Registry, Hospital Universitari Dr Josep Trueta, Girona, Spain

Background and Introduction

According to ENCR international guidelines, the registration of all intracranial and intraspinal cases is recommended irrespective of their behaviour (benign, uncertain and malignant). However, information on benign tumours is collected by relatively few European Cancer Registries and the proportion of such cases varies widely between them. The aim of the present study was to estimate the population-based incidence and survival of primary malignant and non-malignant brain and central nervous system (CNS) tumours by histology, sex and age at diagnosis.

Materials and Methods

We included cases of primary malignant and non-malignant brain and CNS tumours. All pathological reports were revised in order to classify them according to the 2007 World Health Organization (WHO) Classification. Incidence was calculated as crude rate (CR) and European age-standardized rate (ASRe). The follow-up was available until 31st December 2014. Death certificate only (DCO) cases were excluded for the survival analysis. We will estimate five-year net survival with the Pohar-Perme estimator.

Results

From 1994 to 2013, 1964 patients diagnosed with CNS tumours were registered in the area covered by the Girona cancer registry (north-east Spain). The ASRe (malignant and non-malignant) was 14.3 in males and 16.1 in females. The distribution of malignant and non-malignant was 55% and 45% respectively. The most frequently reported histology overall was meningioma (30%, ASRe=4.3), followed by glioblastoma (23%; ASRe=3.6). Incidence rates and net survival estimates by histology will be presented.

Conclusions

With these preliminary results and compared with other published series (Ostrom QT et al, Neuro-Oncology, 2015), we found an incomplete registration of non-malignant brain and CNS tumours. Taking into account that during this year the 2016 WHO Classification of Tumours of the CNS has been published, an update of the ENCR guidelines would be required.

Completeness and validity of data in the Finnish cancer registry

Nea Malila, Maarit Leinonen, Joonas Miettinen, Tiina Hakanen, Anni Virtanen, Janne Pitkäniemi

Finnish Cancer Registry, Finland

Background and Introduction
The Finnish Cancer Registry (FCR) has passive data collection with a long tradition of monitoring the cancer burden in Finland. The Cancer Society of Finland is taking care of the national register as agreed with the National Institute for Health and Welfare. Completeness, accuracy and timeliness of registering cases is of key importance. We aim to study data quality of the FCR comprehensively updating the previous report from 1994.

Materials and Methods
Cancer cases diagnosed in 2009-2013 will be retrieved from the FCR and from the hospital care register (HILMO). Cases missing from either of the registers will be estimated and explanations for the discrepancies studied.

Results
The FCR's database for the period 2009-2013 comprised 149 025 incident cases. Overall, 93 % of all incident cancers were morphologically verified. There was great variation according to primary site. An independent case ascertainment using hospital discharge data and mortality to incidence ratios revealed that a substantial amout of solid tumors without histological verification, such as brain tumors eye malignancies were missing from the FCR. Also, hematological malignancies are still not properly covered by the FCR.

Conclusions
Registration and coding routines in place at the FCR are mostly based on national guidelines (incl. ENCR and WHO) and these yield comparable data of high guality. Registration of tumors with no histology is still incomplete and warrants an active trace-back procedure using external data sources like hospital discharge data.

Completeness of registration in the SCCR as estimated from data exchange with regional cancer registries in Switzerland

Shelagh M Redmond,[1] Verena Pfeiffer,[1] Matthias Schindler,[1] Nicolas von der Weid,[2] Ivka Avellina,[3,*] Bertrand Carney,[4] Joachim Diebold,[5] Andrea Jordan,[6] Isabelle Konzelmann,[7] Claudia E Kuehni,[1] for the Swiss Pediatric Oncology Group (SPOG)

[1]Institute of Social- and Preventive Medicine (ISPM), University of Bern, Switzerland [2]Pediatric Hematology/Oncology Unit, Children's Hospital Basel (UKBB), Switzerland [3]Cantonal Cancer Registry of Basle City and Land, Switzerland [4]Cantonal Cancer Registry Fribourg, Switzerland [5]Cantonal Cancer Registry of Central Switzerland, Switzerland [6]Cantonal Cancer Registry Bern, Switzerland [7]Cantonal Cancer Registry Valais, Switzerland *Cantonal Cancer Registry authors in alphabetical order

Background and Introduction

Completeness of registration is important for cancer registries and can be used as a quality indicator. Incomplete registration leads to *e.g.* an underestimation of incidence rates. A previous study based on death certificates showed that completeness of the Swiss Childhood Cancer Registry (SCCR) has improved from 85% in 1985-1989 to >95% since 2005. We now compared the completeness of cancer registration using a different approach: comparing cases registered in the SCCR and five regional population-based cancer registries (CCRs).

Materials and Methods

The SCCR is a national population-based cancer registry, including children and adolescents diagnosed with leukaemia, lymphoma, central nervous system tumors, malignant solid tumors or Langerhans cell histiocytosis living or treated in Switzerland (CH). We compared data for 0-14 year olds registered in the SCCR with five CCRs for varying time periods between 2006-2014, according to the date the CCRs were founded and up to which years they had registered cases. As the inclusion criteria for the SCCR and the CCRs differ, we compared only malignant neoplasms and benign CNS tumours in children aged 0-14. The SCCR data were linked to those in the CCRs using the canton of residence, date of birth, first and last name and sex.

Results

Preliminary analysis shows that compared with registries A, B, C, D and E: 91% (of 43, 39 in SCCR), 99% (of 99, 98 in SCCR), 95% (of 66, 63 in SCCR), 90% (of 61, 55 in SCCR) and 60% (of 55, 33 in SCCR) of all registered cases were present in the SCCR, and 63% (of 43, 27 in CCR), 79% (of 99, 78 in CCR), 95% (of 66, 63 in CCR), 89% (of 61, 54 in CCR) and 78% (of 55, 43 in CCR) in the respective cantonal cancer registry. The number of missing cases not recorded by either registry cannot be determined.

Conclusions

Registration by the SCCR for children aged 0-14 is better or equal to most CCRs. SCCR and the CCRs can both profit from regular data exchanges to improve and complete their data sets.

The impact of under-reporting of cases on the estimates of childhood cancer incidence and survival in Estonia

Keiu Paapsi,[1] Tiiu Aareleid,[1] Margit Mägi,[1] Sirje Mikkel,[2] Kadri Saks,[3] Kaire Innos[1]

[1]National Institute for Health Development, Estonia [2]Tartu University Hospital, Estonia [3]Tallinn Children´s Hospital, Estonia

Background and Introduction

About 35 new childhood cancer cases are diagnosed in Estonia (population 1.3 million in 2011) every year. It is obligatory by law to notify all cases to the Estonian Cancer Registry (ECR). However, decreasing incidence and poor survival rates lead us to a hypothesis that some non-fatal cases might be missing from the ECR. A study was carried out to evaluate the completeness of case ascertainment of childhood tumors in the ECR and its impact on the estimates of cancer incidence and survival.

Materials and Methods

All cancer cases diagnosed in 2000-2011 among children aged 0-17, eligible for registration in the ECR, were included in the study. Data completeness was analyzed, using independent case ascertainment method. For all cases, a notification form was reabstracted from the hospital data. Collected data were linked with the ECR and eligible cases found to be missing, were added to the database. Incidence rates (2000-2011) and period-hybrid estimates of five-year survival (2010-2014) were calculated for children aged 0-14 years before and after adding the missing cases. All analyses were done with STATA.

Results

Overall, 56 cases were found to be missing from the ECR. Under-reporting was associated with year of diagnosis ($p<0.001$) and primary site ($p=0.017$). Overall completeness of case ascertainment was estimated to be 89%. Overall incidence rate rose from 12.8 to 14.8 per 100 000, after adding the missing cases. The five-year survival rate (all sites combined) increased from 70% to 76%. Greatest improvements in survival estimates were seen for leukaemias (from 70% to 81%), lymphomas (from 89% to 91%) and CNS tumors (from 67% to 72%).

Conclusions

The under-reporting of childhood cancer cases caused considerable underestimation of incidence and survival rates in Estonia. Although a substantial improvement was seen in the five-year survival for all sites combined, it still did not reach the European average for 2005-2007.

Impact of socioeconomic status on breast cancer care patterns and survival: the Italian high resolution study results

Francesca Di Salvo,[1] Nicola Caranci,[2] Fabrizio Stracci,[3] Mario Fusco,[4] Fabio Falcini,[5] Claudia Cirilli,[6] Giuseppina Candela,[7] Rosanna Cusimano,[8] Rosario Tumino,[9] Milena Sant[1] and the The 'Socioeconomic inequalities and oncological outcomes' Italian Study Working Group

[1]IRCCS Istituto Nazionale dei Tumori Foundation, Milan, Italy [2]Agenzia Sanitaria e Sociale, Regione Emilia-Romagna, Bologna, Italy [3]Umbria Cancer Registry, Italy [4]Napoli Cancer Registry, Italy [5]Romagna Cancer Registry, Italy [6]Modena Cancer Registry, Italy [7]Trapani Cancer Registry, Italy [8]Palermo Cancer Registry, Italy [9]Ragusa Cancer Registry, Italy

Background and Introduction
Socioeconomic differences in survival are known to exist for women diagnosed with breast cancer. The aim of this study is to investigate impact of socioeconomic status (SES) on five-year relative (RS) and disease-free survival (DFS), adherence to clinical guidelines and tumor characteristics.

Materials and Methods
3434 malignant breast cancer patients, diagnosed in 2003-2005, in seven Italian cancer registries: Modena, Romagna and Umbria (Centre-North Italy), Napoli, Trapani, Palermo and Ragusa (South Italy) were included in the analysis. SES was assessed by the Italian deprivation index based on census data and categorized in three classes, from 'less deprivated (LD)' to 'most deprivated (MD)'. Regression models adjusted by age, registry and subtype were used to investigate: a) impact of SES on DFS and RS; b) association between SES and sentinel lymph node biopsy (SLNB) vs axillary dissection only or other; c) how SES may affect adherence to ESMO guideline (breast conserving surgery associated with radiotherapy (BCS+RT) vs mastectomy or other, for T12NoMo cases).

Results
In women younger than 60 years, 43% of LD cases and 50% of MD cases had a more advanced stage; 7% of LD cases and 10% of MD cases had a triple-negative tumor. DFS was 86.6% in LD and 82.7% in MD. No relevant differences in terms of stage, subtype and DFS were found in women older than 60 years. RS was 86.3% and 84.8% respectively in LD and MD class. 36% of the LD women against 30% of the MD underwent SLNB (ORMD vs LD = 0.7, p = 0.02). 62% of the LD cases and 58% of the MD followed ESMO guidelines (BCS+RT) (ORMD vs LD = 0.7, $p<0.01$).

Conclusions
This analysis shows that patients with higher socioeconomic conditions seem to be more likely to receive SLN, to be diagnosed with a less advanced tumor stage, a less aggressive subtype and consequently a higher DFS. Methodological assessment of SES needs to be developed especially at the European level in order to let international comparisons.

Cancer incidence rates and Benford's law: a useful liaison

Emanuele Crocetti, Giorgia Randi, Raquel Carvalho, Tadeusz Dyba, Francesco Giusti, Carmen Martos, Roisin Rooney, Lydia Voti, Manola Bettio

European Commission, DG Joint Research Centre, Ispra, Italy

Background and Introduction

In 1938 Benford described an odd distribution of the first significant digit (FSD) in many numerical collections: the probability to have 1 as FSD is 30.1% then it slightly and consistently lowers up to 9 which is least frequent FSD. This pattern is already used to identify possible violations in numerical data (*e.g.* in accounting). We evaluated whether population-based cancer incidence rates follow Benford's law (BL), to detect possible violations during data quality assessment of cancer registry (CR) data.

Materials and Methods

We randomly sampled from CI5C-X web site the detailed databases of two population-based CRs for each of the following regions: Africa, north and south America, Asia, Europe and Oceania. The distribution of the FSD of crude incidence rates was evaluated for each separate registry, and for all of them together in a single dataset. The observed FSD distribution was plotted against the Benford theoretical one, and the following statistics were computed: Person's r, distances' measures, and Chi2/n to check if the data are well-modelled by BL. A summary index was also computed (the lowest the index, the best the fitting).

Results

The distributions of FSD of crude incidence rates (overall on 40 493 observations) showed a mean greater than the median and a positive skewness, typical of Benford-like distributions. In fact, it fitted almost perfectly Benford distribution ($r = 0.997$; $m = 0.01$; $d^* = 0.02$; $Chi2/n = 0.05$). Individual selected CRs (from 779 to 5 376 observations) had generally very good fitting; however, one registry had all the four statistics in the worst duo-decile ($p = 0.00005$).

Conclusions

Crude cancer incidence rates adhere to BL. This suggests using BL as a quick, easy and objective screening tool for assessing CR data quality. The CR with the worst adherence to BL had a warning also in CI5C-X. We propose to use the BL as a screening tool in cancer data quality evaluation, identifying anomalies worthy of further inspection.

Evidence-based toolkit of spatial epidemiology and analysis to enhance cancer surveillance

Dimitra Sifaki-Pistolla,[1] Vasiliki-Eirini Chatzea,[1] Elpiniki Frouzi,[1] Vassilis Georgoulias,[2] Sofia Aggelaki,[2] Phaedon Kyriakidis,[3] Christos Lionis,[1] Nikos Tzanakis,[3] on behalf of the Cancer Registry of Crete

[1]Clinic of Social and Family Medicine, School of Medicine University of Crete, Heraklion, Greece [2]Department of Medical Oncology, School of Medicine, University of Crete, Heraklion, Greece [3]Department of Civil Engineering and Geomatics, Cyprus University of Technology, Limassol, Cyprus [4]Associate Professor of Epidemiology, School of Medicine, University of Crete, Heraklion, Greece

Background and Introduction

Geographical Information Systems (GIS) are accredited by cancer registries as powerful tools. However, there is not yet a cancer oriented toolkit for spatial analysis that could be utilized by cancer registries. The current study aims to propose an evidence-based cancer-oriented toolkit for spatial analysis.

Materials and Methods

A triangulation of approaches was used; systematic review of the literature, previous experience of the authors, and testing the selected methods on 'training' databases. The systematic review was conducted in PubMed, the Cochrane library and Scopus database, by three independent reviewers. This systematic approach guided the development of a toolkit that was subsequently tested on 'training data' of cancer cases. Data on cancer cases were obtained from the Cancer Registry of Crete. Three scenarios were utilized: a) low prevalence cancers, b) high prevalence cancers, c) cancer data jointly with risk factors.

Results

The final toolkit covered the whole spectrum of spatial epidemiology: data preparation/testing for randomness, data protection, mapping/visualizing, geographic correlation studies, clustering/surveillance, integration of cancer data with socio-economic, clinical and environmental factors. Some of the proposed methods included in the toolkit are: aggregation techniques for data protection, buffer and proximity analysis, exploratory spatial analysis, spatio-temporal statistics and modeling, spatial interaction models, spatial diffusion, regression models and smoothing techniques. All suggested statistical models were found to fit well ($R2=0.72-0.96$) in 'training data': a) low prevalence cancers ($R2=0.72-0.85$), b) high prevalence cancers ($R2=0.81-0.96$), c) cancer data jointly with risk factors ($R2=0.78-0.93$).

Conclusions

The proposed toolkit provides to cancer registry professionals a robust methodological framework along with recommendations for assessing different types of research questions.

Shared mortality from liver cancer and type 2 diabetes mellitus in Puglia

Enzo Coviello, Francesco Cuccaro, Annamaria Nannavecchia, Lucia Bisceglia

Puglia Cancer Registry, Italy

Background and Introduction

Many diseases share risk factors (FR) and shared component models (SC) are used to fit together the geographical distribution of the risk of two or more diseases. HCV infection is a FR for hepatocellular carcinoma and type 2 diabetes mellitus (DM2). We applied a SC model to the geographical distribution of mortality from liver primary cancer (LC) and DM2 in Puglia to investigate their correlation and better defining the areas of the region with highest risks.

Materials and Methods

Mortality data of Puglia inhabitants from 2008-2012 was provided by ISTAT, disaggregated by cause, sex, age and town of residence. For each municipality we calculated deaths for LC (C220, C229) and DM2 (E11, E14) and expected deaths based on regional mortality rates. We adapted the model proposed by Besag *et al.* (BYM) separately to LC and DM2 mortality data and the SC model, proposed by Knorr-Held *et al.*, to both mortality data at once.

Results

From 2008 to 2012 in Puglia we observed 2948 deaths for LC and 7984 for DM2. In the LC and DM2 maps (BYM model) the municipalities of the BAT province and of the neighbouring part of the province of Bari show relative risks (RRs) higher than the rest of the Puglia. About in the same area the map obtained with the SC model points out higher RRs shared between both diseases. The shared variance of the RRs captures the 68% and 47% of the total variance of the RRs for LC and DM2. The shared FR has an association twice stronger with the risk of LC than with the risk of DM2.

Conclusions

The SC model demonstrated the correlation between mortality for LC and DM2 and the importance of HCV infection as common FR of both diseases in Puglia. The SC models represent a progress in disease mapping techniques because delineate risk areas with greater precision and highlight the importance of particular FR in specific areas. Cancer registries can take advantage of the SC models by applying them to incidence data of better quality than mortality data.

The potential biases for interpreting patients' net survival rate using cancer registries: a literature review

Ayako Okuyama, Akiko Shibata

National Cancer Center in Japan, Tokyo, Japan

Background and Introduction
Net survival rate is used to develop cancer control plan. It is necessary to bear in mind that there are limitations and biases within interpreting the data on patient survival rate. This study aims at identifying and accounting potential biases and/or limitations on estimating net survival rate, so as to control cancer more effectively.

Materials and Methods
We searched PubMed from December 2010 to December 2015 for articles that investigated or described biases of estimating patient survival rate using cancer registries. Articles only described the tendency of survival and investigated relationships between patients' characteristics, treatment and survival were excluded.

Results
In total, 50 articles were met the inclusion criteria. The identified potential biases were categorised to the three areas: 1) the quality of registry data (*e.g.*, the completeness of cancer patients, accuracy of data, follow-up rates), 2) the limitations related to estimated methods for net survival (*e.g.*, misclassification of cause of death for cause-specific survival, a lack of comparability of background mortality for relative survival), and 3) the comparability of net survival among different groups (*e.g.*, age-adjustment, dealing with multiple cancers).

Conclusions
Cancer prognosis measures are suited to answer questions related to health policy and research. Several factors should be considered for interpreting net survival which was estimated using cancer registries. Firstly, we should show the proportion of death-certificate only cases (DCOs) and followed-up cases. Ideally, both survival rates using methods of 'excluded DCOs' and 'correct for DCOs' should be presented. Secondly, explain the reasons why cause-specific or relative survival analysis was used. Finally, for the purpose of enabling the comparison between net survival rates among different groups, we should use age-adjustment and should not exclude patients with a previous cancer diagnosis.

Canstaging: a cancer staging tool facilitating tumour staging into the future – Planned developments and enhancements

Colin Fox,[2] Giulio Napolitano,[1,2] Morten Ervik,[3] Carlos A. Velasco,[4] Lisa Ranaghan,[5] James Brierly,[6,7] Anna Gavin[2]

[1]Institute of Medical Biometry, Informatics and Epidemiology, University Hospital Bonn, Germany [2]Northern Ireland Cancer Registry, Belfast, UK [3]Section of Cancer Surveillance, International Agency for Research on Cancer, Lyon, France [4]Fraunhofer Institute for Applied Information Technology FIT, Sankt Augustin, Germany [5]Belfast Health & Social Care Trust, Belfast, UK [6]Princess Margaret Cancer Centre, Toronto, Canada [7]Union for International Cancer Control, Geneva, Switzerland

Background and Introduction

The staging of cancers is an important and necessary activity which has a significant impact on treatment strategies and patient outcomes, including screening, survival and assessment of new diagnostic techniques. CanStaging (http://go.qub.ac.uk/CanStaging) has been available online since 2014. The objectives of this current work are: to evaluate the use of CanStaging so far; to identify and communicate future developments which will maximise the usability of the tool and expand its availability to a wider global audience.

Materials and Methods

CanStaging access has been monitored after its official release. We invited existing users to provide feedback and requests for additional functionality. We also assessed potential technical barriers to accessibility and availability, such as internet connectivity. The initial consortium (the Northern Ireland Cancer Registry, the IARC Global Initiative for Cancer Registry Development and the UICC TNM Core Group) was expanded to include the Institute of Medical Biometry, Informatics and Epidemiology (Bonn University) and the Fraunhofer Institute for Applied Information Technology.

Results

As of May 2016, 94 organisations and individuals from 51 countries have requested access to CanStaging and, on average, the tool recorded 20 access sessions per month, mostly for the staging of breast (43 %) and cervix (29 %) tumours. The access frequency, however, shows a declining trend. Based on user feedback, a number of enhancements will be developed, including more stable connectivity and the conversion of CanStaging into a multilingual instrument, with the capability to add new languages in a matter of days.

Conclusions

CanStaging is being used globally on a regular basis. It is hoped that the planned enhancements to functionality and the removal of language barriers along with more stable connectivity will increase usability. Thanks to the UICC, the tool is available at no cost for non-profit use.

Comparing survival between Belgian haematopoietic stem cell transplant centres using a model based on pseudo values

Gilles Macq,[1] Evelien Vaes,[1] Geert Silversmit,[1] Marijke Vanspauwen,[1] Liesbet Van Eycken,[1] Yves Beguin[2]

[1]Belgian Cancer Registry, Brussels, Belgium [2]Université de Liège & CHU de Liège, Department of Hematology, Liège, Belgium, on behalf of the Steering Committee of the Belgian Transplant Registry of the Belgian Haematological Society

Background and Introduction

Centre-specific survival rates cannot be compared as such if the centres' patient case mix is different. Especially if characteristics have a direct impact on survival. As a solution, centres' results are adjusted for case mix by standardisation techniques based on regression model predictions. This study applies an indirect standardisation technique based on a logistic regression model on pseudo values. This type of logistic model allows to directly model survival probability at a fixed time point and does not require the proportional hazards assumption to hold. We applied this technique to compare survival among the Belgian haematopoietic stem cell transplant centres. In addition, the indirect and direct standardisation techniques based on the pseudo values logistic model were compared via a simulation study.

Materials and Methods

Our example includes Belgian auto-transplanted patients (n=2735) and allo-transplanted patients (n=2346) who received their transplant in 2007-2013. Patients are distributed across 18 auto-transplant and 13 allo-transplant centres. Observed survival at three years was modelled. The simulation study was conducted in order to compare the two standardisation approaches according to power and type I error in a variety of situations: parameters such as proportion of censoring, proportion of under/over performing centres, etc. were varied.

Results

Indirect standardisation seems to be more powerful than direct standardisation. Naturally, type I errors (probability of falsely identifying an average centre as over/under performing) are larger for indirect versus direct standardisation. However, type I errors of the indirect standardisation never exceed 5%.

Conclusions

The presented indirect standardisation technique is powerful and beneficial in some situations, as was the case for the Belgian Transplant centres. Moreover its output is easily interpretable from a clinical point of view.

Official/main terms, related terms and conversion between different classifications – Renewing the coding manual

Siri Larønningen, Petter Topp, Jan F. Nygård, Tom Børge Johannesen

Cancer Registry of Norway, Oslo, Norway

Background and Introduction

Keeping track of changes in the ICD-O-classifications, for instance new codes, changed main terms, new related terms and codes that are no longer in use, is a troublesome and time-consuming task. This is also the case for conversions between different classifications and/or versions of classifications. In-house codes increase the complexity.

Materials and Methods

The Cancer Registry of Norway (CRN) has developed a tool for structuring all morphology codes used in the CRN. Each morphology code is placed in the correct classification (ICD-O-2, ICD-O-3, WHO, in-house), and assigned a main term and a set of related terms (both general and topography-specific). In addition, the code is correctly grouped according to both the ICD-O-classification and the IARC-groups. There is also a possibility to give the corresponding code in other classifications, such as ICD-O-2, ICD-O-3, SNOMED and MoTNaC.

Results and Conclusions

The tool is used to do the manual ground works that is needed both for the new coding manual in the CRN (replacing the old HTML-manual), for the management of rules in the new coding and registration system, and for data extractions from the planned data warehouse. Preliminary tests of the new coding manual show an improvement in both accessibility and readability of the codes, and the structuring will make the update and editing of codes easier.

On the way to a comprehensive cancer registration for Germany

Alexander Katalinic

Association of Population-based Cancer Registries in Germany

Background and Introduction
In 1995 there was a first national cancer registration law in Germany that forced all 16 federal states to implement epidemiological cancer registries. In the year 2013 a new national law came into force to implement clinical cancer registration all over Germany. The main issue of the law is to use cancer registry data for quality assurance, for verification of adherence to therapy guidelines and for more transparency in oncological health care.

Materials and Methods
Actual information of the status of the implementation was collected directly from the cancer registries including a review of new cancer registry laws and actual results.

Results
The new national law made some important points obligatory for all federal states. Notification to the cancer registry should be mandatory and electronically. The dataset was standardized and includes now a broad range of clinical variables, as detailed information on therapy and follow-up events (*e.g.* relapse). Per incident cancer case the cancer registry will receive about 140; notifying institution will receive a fee per notification (5-18€). In all federal states new legislations for cancer registration are in process or have already passed the parliaments. Existing structures of epidemiological or clinical cancer registries will be used to develop a comprehensive clinical-epidemiological cancer registration. A key issue is the development of a new IT-infrastructure and new registration software. The goal is the development of a unique, internet-based registration and feedback portal. About half of the federal states started to register cancer under the new legislation end of 2015/early 2016.

Conclusions
With the extension to clinical data, cancer registration in Germany will play an important role in evaluation and quality assessment of cancer care, not only on the population level but also on the level of care providers.

Electronic reporting of clinical notifications to the cancer registry of Norway

Siri Larønningen, Huidong Tian, Basit Ahmed Khan, Therese Hüber, Bjørn Møller, Jan F. Nygård

Cancer Registry of Norway, Oslo, Norway

Background and Introduction

A main goal of the clinical registries is to provide data for quality assurance of treatment of cancer patients. The large amount of manual work with coding and registration of cancer notifications delays access to such data and makes the clinical registries less useful for the health providers. Getting structured, electronic information from the clinicians is a key element to make clinical registries more timely and useful.

Materials and Methods

Since 2012, clinicians have had access to a web based reporting system (KREMT) to report clinical information structured and electronically to the Cancer Registry of Norway (CRN). KREMT is accessible through the secure Norwegian Health Network. It contains all the twelve different types of clinical notifications used in the CRN; ten cancer specific notifications and two for the remaining solid tumours and non-solid tumours, respectively. In addition to submission of notifications, KREMT provides lists of reminders for missing notifications, receipts for notifications submitted electronically, administrative statistics and clinical statistics, as well as the possibility for temporary storage of notifications that have not been fully filled out. The clinical statistics contains data derived directly from the clinical forms, and it is therefore possible to present day-old statistics to the users, for their own hospital, and compared to total numbers for Norway. The reporting system consists of a Vaadin web application-framework, Microsoft InfoPath and SharePoint for generation of notifications in XML-format, and the statistical package R with the Shiny package for Web-presentation.

Results

In 2015, 44105 notifications were submitted through KREMT – 66 % of all clinical notifications. The total number of notifications reported electronically is per June 2016 120088, 29000 so far in 2016.

Conclusions

Based on the success of KREMT, electronic reporting from clinicians was made mandatory from January 1st 2016.

Comparison of the old method of record linkage with the new 'system break free' method at the cancer registry RLP (D)

Katharina Emrich, Gerhard Seebauer

Cancer Registry Rhineland-Palatinate, Mainz, Germany

Background and Introduction

German cancer registries match new records using pseudonymisation and manual linkage processes. The Cancer Registry Rhineland-Palatinate uses the following programs (database, SAS, MTB) to prepare its data. However, this process is inefficient and time consuming. Due to the incorporation of clinical registry in the epidemiological registry, we have created a new record linkage software (identity service) to match records automatically. We compared both softwares with each other, using the available matches from our 'clerical review' software.

Materials and Methods

Decision rules for matching personal records:
Stochastic weights of Record-Linkage are combined with filter rules.

a) weights < lower limit: reject match
b) weights > upper limit or (pseudonyms or phonetic codes of all identity data concur: names, surnames, sex, month + year of birth, place of residence): accept match
c) lower limit < weights < upper limit and some identity data do not concur: clerical review

We tested the new algorithm, using the clerical reviewed cases of our database. The chosen rules are to minimize the rate of homonym and synonym errors as well as to reduce the number of cases in the clerical review system.

Results

Old method: from 37577 records (30124 persons) inputted, 10752 were rejected as matches, 19372 persons were clerically reviewed (most of those were already matched preliminary).
New method: results of optimised decision rules (lower limit = 24, upper limit = 55):

a) 10669 records were rejected (synonym error 0.2%, 28 persons)
b) 17401 persons were accepted (homonym error 0.01%, 1 person)
c) 2054 persons were clerically reviewed, *i.e.* 94.6% (1944 persons) were true matches.

Conclusions

The new (identity service) software works quite well. We have optimised this method in order to embed it in our new database. Cancer registries try to minimise matching errors, however minor errors are acceptable due to multiple notifications per person we get in future.

Quality of life according to trial participation among Hodgkin lymphoma survivors: an IKNL-EORTC joint study

Melissa S.Y. Thong,[1] Michal Kicinski,[2] Corneel Coens,[2, 3] Francesco Giusti,[2, 4] Lonneke van de Poll-Franse,[5, 6] Jan Bogaerts,[2] Lifang Liu[2]

[1]Department of Medical Psychology, Academic Medical Center University of Amsterdam, Amsterdam, the Netherlands [2]Department of Statistics, European Organisation for the Research and Treatment of Cancer, Brussels (EORTC), Belgium [3]Department of Quality of Life, European Organisation for the Research and Treatment of Cancer, Brussels (EORTC), Belgium [4]Current affiliation: European Commission, DG Joint Research Centre, Ispra, Italy [5]Netherlands Comprehensive Cancer Organisation (IKNL), Utrecht, the Netherlands [6]Division of Psychosocial Research and Epidemiology, The Netherlands Cancer Institute, Amsterdam, the Netherlands

Background and Introduction
The highly controlled setting of clinical studies challenges the external generalization of clinical trial results. Most attention is given to outcomes such as survival. Patient-reported outcomes are less researched as key outcome measures. The current study aims to describe differences in quality of life (QoL), and healthcare use and satisfaction of Hodgkin Lymphoma (HL) patients treated in- and outside clinical trials using data from the population-based Patient Reported Outcomes Following Initial treatment and Long-term Evaluation of Survivorship (PROFILES) registry.

Materials and Methods
All HL survivors diagnosed 1989-1998 in South Netherlands were selected from the Netherlands Cancer Registry (IKNL) for the PROFILES survey in November 2004. As IKNL/PROFILES does not register trial participation, a deterministic data linkage with European Organisation for Research and Treatment of Cancer (EORTC) early (H6-H9) and advanced (H3b4 and H34) stage HL trials was performed in November 2014. EORTC provided demographic and clinical trial data to IKNL to facilitate patient identification and linkage.

Results
The study sample included 65 trial (TP) and 67 non-trial participants (NTP). Both groups had comparable demographic and clinical characteristics. Unadjusted and adjusted models indicated no association between trial participation and QoL. There was no difference in healthcare satisfaction. TP reported 48% more visits to specialists in the past year than NTP (adjusted 95% CI: 10%-99%). No difference in cancer-related contacts was observed.

Conclusions
TP and NTP had comparable long-term QoL. Although TP reported more specialists visits, healthcare satisfaction and the number of cancer-related visits were not statistically different between the two groups. Data linkage between clinical trials and population-based cancer (PRO) registry data provides an innovative methodology to study the external generalizability of clinical findings.

Collecting clinical and epidemiological data on pancreatic cancer across Europe: PancreOs, a multidisciplinary project

María Dolores Chirlaque,[1,2] Carmen Martos,[3] Núria Malats,[4,5] María José Sánchez,[1,2] Eva Ardanaz,[1,2] Rafael Marcos-Gragera,[1,2] Carmen Alberich,[1] Ester Molina,[4,5] Manola Bettio,[3] Alfredo Carrato[4,5]

[1]REDECAN (Registro de Cáncer de Murcia, Granada, Navarra, Girona y Castellón/Comunitat Valenciana), Spain [2]CIBER of Epidemiology and Public Health (CIBERESP), Spain [3]European Commission, DG Joint Research Centre (JRC), Ispra, Italy [4]EUPancreas COST Action (BM1204) [5]EU-Multistakeholder Platform on Pancreas Cancer

Background and Introduction

Aim: to elaborate a common protocol for registration of patients diagnosed with incident PC including clinical and epidemiological variables across Europe.

Materials and Methods

A protocol for collecting data on PC cancer is being developed in a multidisciplinary team by PancreOs (European Pancreatic Cancer Registry), an initiative supported by EU Multi-Stakeholder Platform and COST Action EUPancreas, with collaboration of JRC (Joint Research Centre) and population-based cancer registries (PBCRs). Protocol includes socio-demographic information, risk factors, cancer family and patient history, tumour characteristics, diagnosis and treatment procedures, palliative care and survival. The team is composed mainly of clinician, epidemiologist, biologist and geneticists. Several meeting of working group have been realized in the last year. Spanish PBCRs have been invited to joint this initiative and are actively involved on it.

Results

Ongoing preparation of manual procedures to collect variables considering several questionnaires including PancreOs and following international and European recommendations (ENCR). JRC is coordinating the manual. Issues discussed in the working group have been: inclusion criteria, microscopical confirmation, date of incidence, morphology-topography (ICDO-3), rules for multiple primary; familiar and personal history of diseases including cancer, and risk factors (smoking, alcohol or BMI). Detailed report on clinical aspects: specific PC cancer history, physical examination and clinical laboratory test at first oncology visit, disease diagnosis including initial diagnosis and metastatic diagnosis; also diagnostic procedure (TAC, RMN, PET, ecoendoscopy), radiotherapy, chemotherapy.

Conclusions

This study will provide a common procedure for registration clinical and epidemiological aspects of PC. A joint collaboration between PancreOs and European PBCR, ENCR, JRC could be essential for a better understanding of PC and improve their health.

Survival differences in Hodgkin lymphoma patients treated inside and outside clinical trials – An EORTC-IKNL joint study

Lifang Liu,[1] Francesco Giusti,[1,2] Michael Schaapveld,[3,4] Berthe Aleman,[5] Pieternella Lugtenburg,[6] Paul Meijnders,[7] Martin Hutchings,[8] Valery Lemmens,[3] Jan Bogaerts,[1] Otto Visser[3]

[1]Department of Statistics, European Organisation for the Research and Treatment of Cancer, Brussels (EORTC), Belgium [2]Current affiliation: European Commission, DG Joint Research Centre, Ispra, Italy [3]Netherlands Comprehensive Cancer Organisation (IKNL), Utrecht, the Netherlands [4]Division of Psychosocial Research and Epidemiology, the Netherlands Cancer Institute (NKI), Amsterdam, the Netherlands [5]Department of Radiation Oncology, the Netherlands Cancer Institute (NKI), the Netherlands [6]Department of Hematology, Erasmus MC Cancer Institute, Rotterdam, the Netherlands [7]Department of Radiation Oncology, ZNA Middelheim and University of Antwerp, Antwerp, Belgium [8]Department of Haematology, Rigshospitalet Copenhagen University Hospital, Copenhagen, Denmark

Background and Introduction

Survival of patients diagnosed with Hodgkin lymphoma (HL) has steadily improved in subsequent European Organisation for Research and Treatment of Cancer (EORTC) clinical trials from 70% in the 1970s to 90% in the 1990s. However population-based data show lower survival. The study aims to assess the survival differences between trial- and non-trial participants and the associated factors.

Materials and Methods

In this retrospective cohort study data from six EORTC phase-III randomized clinical HL trials were linked to data on all Dutch HL patients diagnosed in 1986-2004 derived from the Netherlands Cancer Registry to identity trial participation. We assessed overall survival (OS) and used Proportional Hazard-Cox models to study associated factors.

Results

In 1986-2004, 27% of all HL patients aged 15-70 years were entered on an EORTC clinical trial. Compared to non-trial participants, trial participants were younger (median age, 31 versus 34 years), had staging registered more accurately, and had an 8% higher 20-year OS (73% versus 65%). After adjusting for baseline differences, no survival differences remained (hazard ratio (HR) = 0.96, 95% confidence interval (CI) 0.82-1.12), also not in subgroup analysis according to stage. Over time, an increased administration of chemotherapy in combination of radiotherapy as well as a decreased radiotherapy alone was observed among trial population. This trend was followed by non-trial participants later in time, coinciding with a similar 'take-up' in survival: the age standardized OS of non-trial participants diagnosed 1996-2004 was similar to that of trial participants in 1986-1995.

Conclusions

The observed superior survival among patients with HL treated in clinical trials can be largely explained by the differences in baseline characteristics, in particular, younger age. High trial participation rate and centralized expertise facilitates the implementation of trial findings to real-world practice.

Theme: **Cancer burden in Europe**

Recent trends in cancer incidence, mortality and survival in Estonia

Mari-Liis Zimmermann,[1] Kaire Innos,[2] Margit Mägi,[1] Pille Härmaorg,[1] Tiiu Aareleid,[2] Aleksei Baburin[2]

[1]National Institute for Health Development, Estonian Cancer Registry, Tallinn, Estonia [2]National Institute for Health Development, Department of Epidemiology and Biostatistics, Tallinn, Estonia

Background and Introduction

The aim of this study was to analyse 20-year trends in incidence and mortality, and recent relative survival for selected cancer sites in Estonia.

Materials and Methods

Temporal trends in age-standardised (World) incidence (1994-2013) were examined using Cancer Registry data on cases of colorectal, lung, breast (women), cervical and prostate cancer and skin melanoma. Trends in age-standardized mortality (1994-2014) were analysed using data from the Causes of Death Registry. Five-year relative survival ratios (RSR) for 2010-2014 were calculated using period-hybrid analysis (cases diagnosed in 2005-2012 and followed through 2014).

Results

Since 1994, both the incidence and mortality of male lung cancer have declined steadily, while among women, the incidence has increased slightly during recent years. Breast cancer incidence has increased continuously, while mortality has been decreasing since 2000. Cervical cancer incidence is still rising with no change in mortality. Continuous upward trends are apparent in the incidence of prostate and colorectal cancer as well as skin melanoma, while there is no significant change in mortality. The age-adjusted five-year RSR 2010-2014 was 87% for prostate cancer, 81% for skin melanoma, 77% for breast cancer, 66% for cervical cancer, 57% for colorectal cancer and 14% for lung cancer.

Conclusions

Among cancer sites amenable to prevention, positive trends in incidence and mortality were seen only for male lung cancer. Compared to Western and Northern European countries, the five-year RSRs revealed a marked deficit for malignancies in which early diagnosis combined with adequate treatment may lead to high survival rates (skin melanoma, breast and colorectal cancer).

Theme: **Cancer burden in Europe**

Survival of solid cancer patients in France, 1989-2013: a study from FRANCIM registries

Anne Cowppli-Bony,[1,2] Zoé Uhry,[3,4] Laurent Remontet,[3] Anne-Valérie Guizard,[1] Brigitte Trétarre,[1] Anne-Marie Bouvier,[1] Marc Colonna,[1] Nadine Bossard,[3] Anne-Sophie Woronoff,[1] Pascale Grosclaude,[1] and the French Network of Cancer Registries (FRANCIM)

[1]FRANCIM (French Network of Cancer Registries), Toulouse, France [2]Loire-Atlantique and Vendée Cancer Registry, Nantes, France
[3]Hospices Civils de Lyon, Biostatistics Service, Lyon, France [4]French Institute of Public Health, Saint Maurice, France

Background and Introduction
The objective of this study was to provide estimates of net survival at one, three, five, and 10 years after cancer diagnosis and survival trends. Survival at 15 years was also estimated for the first time in France.

Materials and Methods
Data were provided by FRANCIM registries. The study included all new cases of solid cancers diagnosed between 1989 and 2010 in people aged 15 or over in 19 metropolitan departments; a total of 502 063 cases. Vital status was updated at 30/06/2013. Net survival was estimated with the unbiased Pohar-Perme method. The results are reported by sex, age class and period of diagnosis, for 37 cancer sites (all stages combined).

Results
The net survival of solid cancer patients varied considerably with cancer site. Over the period 2005-2010, the five-year net survival ranged from 4% (pleural mesothelioma) to 96% (testis) in men and from 7% (pancreas) to 98% (thyroid) in women. The most frequent cancers had the highest net survivals: 88% and 94% at five years respectively for breast and prostate cancer. Poor-prognosis cancers (five-year net survival of less than 33%) were more frequent in men (31% of cancers vs 17% in women) while good-prognosis cancers (five-year net survival of 66% or more) were more frequent in women (57% of all cancers vs 44% in men). For all cancer sites, survival decreased also with age. In most cancers, net survivals at 15 years were lower than 10-year net survivals. Improvements of net survivals were observed for most cancers between 1989 and 2010, less pronounced in elderly patients.

Conclusions
This study showed the unfavorable role of age at diagnosis in prognosis. Survival increases over the last decades are probably related to the general improvement of cancer management. However, over-diagnosis and lead-time bias due to screening may partly explain these trends.

Education predicts cervical cancer survival: a Lithuanian cohort study

Ieva Vincerževskienė,[1,2] Domantas Jasilionis,[3] Donatas Austys,[4] Rimantas Stukas,[4] Augustė Kačėnienė,[1,2] Nadežda Lipunova,[2] Giedrė Smailytė[1,3,4]

[1]Laboratory of Cancer Epidemiology, National Cancer Institute, Vilnius, Lithuania [2]Lithuanian Cancer Registry, National Cancer Institute, Vilnius, Lithuania [3]Centre for Demographic Research, Vytautas Magnus University, Kaunas, Lithuania [4]Institute of Public Health, Faculty of Medicine, Vilnius University, Vilnius, Lithuania

Background and Introduction

Reproductive, lifestyle, and behavioural factors may vary in socioeconomic groups and therefore affect cervical cancer risk. We aim to assess the extent of inequalities in cervical cancer survival in Lithuania by education and place of residence and to quantify the proportion of these inequalities that are attributable to the extent of disease at diagnosis.

Materials and Methods

Our study was conducted using data from the 2001 Census and Cancer registry on women aged 25-64. Study population consisted of 1866 women, which were followed up through record linkages with Statistics Lithuania until the end of 2009. Education was classified as higher, secondary, and lower than secondary. Place of residence was reported as urban or rural. The Kaplan-Meier method was used to estimate the overall survival. Log-rank based tests were used to assess the crude effect of socioeconomic variables on cervical cancer survival. Cox's proportional hazards regression models were used to estimate the adjusted hazard ratio (HR) and 95% confidence interval (CI).

Results

There were 671 deaths corresponding to a five-year survival proportion of 64.13%. Urban residents had higher five-year survival than rural residents (68.61% and 55.93%). Highest survival was observed in highest education group (79.77%) and decreased to 64.85% and 50.48% in groups of secondary and lower than secondary education. In the multivariable-adjusted model, education was statistically significantly associated with survival, with HR of 1.83 and 2.04 in secondary and lower than secondary education groups, respectively.

Conclusions

Place of residence and education had strong impact on cervical cancer patients' survival. Women living in urban areas had higher cervical cancer survival. Higher survival was observed in women with higher education. In the multivariable-adjusted model, education had a statistically significant effect on cervical cancer survival.

Theme: **Cancer burden in Europe**

Incidence and time trends of childhood lymphomas in 14 Southern and Eastern European cancer registries and SEER, US

Marios K. Georgakis,[1] Maria A. Karalexi,[1] Emmanuel Hatzipantelis,[2] Maria Kourti,[3] Maria Moschovi,[4] Sophia Polychronopoulou,[5] Eftichia Stiakaki,[6] Apostolos Pourtsidis,[7] SEE working group, Eleni Th. Petridou[1]

[1]Department of Hygiene, Epidemiology and Medical Statistics, School of Medicine, National and Kapodistrian University of Athens, Athens, Greece [2]Second Department of Pediatrics, Aristotelion University of Thessaloniki, AHEPA General Hospital, Thessaloniki, Greece [3]Department of Pediatric Hematology and Oncology, Hippokration Hospital, Thessaloniki, Greece [4]Haematology-Oncology Unit, First Department of Pediatrics, Athens University Medical School, "Aghia Sophia" Children's Hospital, Athens, Greece [5]Department of Pediatric Haematology-Oncology, 'Aghia Sophia' Children's Hospital, Athens, Greece [6]Department of Pediatric Hematology-Oncology, University of Crete, University Hospital of Heraklion, Heraklion, Greece [7]Department of Pediatric Hematology-Oncology, 'Pan. & Agl. Kyriakou' Children's Hospital, Athens, Greece

Background and Introduction

Geographical discrepancies have been described regarding the incidence of childhood lymphomas, that are thought to be attributed to environmental factors, mainly including infectious agents. Aim of the current study was to describe epidemiologic patterns of childhood (0-14 years) lymphomas in the Southern and Eastern European (SEE) region comprising variable ethnic groups in comparison to the Surveillance, Epidemiology and End Results (SEER), US and explore tentative discrepancies pointing to etiologic mechanisms.

Materials and Methods

Childhood lymphomas were retrieved from 14 SEE registries (N=4702) and SEER (N=4416), during the period 1990-2012; incidence rates were estimated and time-trends were evaluated.

Results

Overall age-standardized incidence rate (ASR) was higher in SEE (16.9/106) compared to SEER (13.6/106), due to a higher ASR of Hodgkin (HL, 7.5/106 vs. 5.1/106) and Burkitt lymphoma (BL, 3.1 vs. 2.3/106), whereas ASRs of non-Hodgkin lymphoma (NHL) were overall identical (5.9/106 vs. 5.8/106), albeit variable among SEE. Incidence increased with age, except for BL which peaked between 5-9 years. The male preponderance was more pronounced for BL and attenuated with increasing age for HL. Increasing trends were noted in SEER for total lymphomas, NHL and marginal for HL, as contrasted to the decreasing HL and NHL trends generally observed in Belarus, Serbia Ukraine with the exception of increasing HL trends in central Portugal; of note, BL incidence trend increased in Bulgaria, Croatia, North Portugal and Ukraine.

Conclusions

Registry-based data reveal variable patterns and time trends of childhood lymphomas in SEE and SEER during the last decades, possibly reflecting diverse early life exposure/immune patterns prevailing in the multiple ethnic groups residing in these areas; optimization of registration process may allow further exploration of molecular characteristics of disease subtypes.

Theme: **Cancer burden in Europe**

Incidence, time trends and survival of childhood pilocytic astrocytomas in Southern-Eastern Europe and SEER, US

Marios K. Georgakis,[1] Maria A. Karalexi,[1] Eleni I. Kalogirou,[1] Anton Ryzhov,[2] Anna Zborovskaya,[3] Nadya Dimitrova,[4] Apostolos Pourtsidis,[5] SEE Working Group, NARECHEM-BT Working Group, Eleni Th. Petridou[1]

[1]Department of Hygiene, Epidemiology and Medical Statistics, School of Medicine, University of Athens, Athens, Greece [2]National Cancer Registry of Ukraine, National Institute of Cancer, Ukraine [3]Belarusian Research Center for Pediatric Oncology, Hematology and Immunology, Childhood Cancer Subregistry of Belarus [4]Bulgarian National Cancer Registry, National Oncology Hospital, Sofia, Bulgaria [5]Department of Pediatric Hematology-Oncology, 'Pan. & Agl. Kyriakou' Children's Hospital, Athens, Greece

Background and Introduction

Pilocytic astrocytomas (PA) represent the most common childhood central nervous system (CNS) tumor. We exploited publicly-available registry-based data derived from Southern and Eastern European countries (SEE) and SEER, US in order to compare incidence, time trends and survival of this non-malignant tumor and explore tentative outcome disparities by sociodemographic and clinical features.

Materials and Methods

Childhood PA were retrieved from 12 SEE registries (N=552), circa 1983-2014, and SEER (N=2723; 1973-2012). Age-standardized incidence rates (ASR) were estimated and temporal trends were explored via Poisson and Joinpoint regression analyses; survival was examined using Kaplan-Meier analysis and Cox proportional hazard models.

Results

The overall ASR of childhood PA during 1990-2012 in SEE was 4.2/106 and double during the same time period in the US (8.2/106). Same size increasing annual trends, more prominent during the earlier registration years, were recorded in both areas (SEE: +4.1%, USA: +4.6%). Cerebellum was the most common location, apart from infants in whom supratentorial tumors were dominant. Of note, age at diagnosis was one year later in SEE vs. SEER; likewise, the 10-year survival was 87% in SEE and 96% in SEER, improving over time, due to better outcome of non-cerebellar PA. Significant outcome predictors were age <1 year at diagnosis (Hazard Ratio, HR: 3.99), female gender (HR: 1.38), non-cerebellar locations (HRs: 9.35-12.86), residence in SEE (HR: 4.03) and rural areas (HR: 2.22).

Conclusions

The largest to date study on childhood PA, showed incidence variations between SEE and USA, increasing trends and significant survival discrepancies by geographical region and urbanization, implying healthcare access inequalities. Non-modifiable factors affecting survival were also identified; the dismal outcomes among infants and females merit further consideration, as they might point to treatment adjustment needs.

Theme: **Cancer burden in Europe**

Cancer-survival in Granada (South Spain), 2004-2008: estimates for five major cancers

Elena Molina-Portillo,[1,2,3] Miguel Rodríguez-Barranco,[1,2] Yoe-Ling Chang,[1,2] Daniel Redondo-Sánchez,[1,3] Elena Salamanca-Fernández,[1,2,3] Emilio Sánchez-Cantalejo,[1] María José Sánchez Pérez[1,2,3]

[1]Andalusian School of Public Health, Granada Cancer Registry, Granada, Spain [2]Biosanitary Investigation Institute ibs.Granada, University Hospital Complex of Granada/University of Granada, Granada, Spain [3]CIBER of Public Health and Epidemiology (CIBERESP), Spain

Background and Introduction

Cancer survival is an important performance indicator of the health care system in a geographical area, reflecting mainly access to diagnostic and treatment facilities. In Spain, cancer survival is slightly higher than the European mean, with differences between regions and type of tumour. The aim was to estimate five years survival in the province of Granada for all cancers combined, except non-melanoma skin cancer and for five major sites in men and women.

Materials and Methods

Data were obtained from Granada Cancer Registry, a population-based cancer registry located in the south of Spain covering a population close to 900 000 inhabitants. All incident cases diagnosed of primary cancer, except non-melanoma skin cancer, during 2004-2008 in Granada province were included and followed up to December 2014. Cases only known by death certificate and diagnosed at autopsy were excluded from the analysis. For all cancer combined, except non-melanoma skin cancer, and for the five most common anatomical sites by sex, age-standardized five-year net-survival (ASNS) was estimated by Pohar-Perme approach.

Results

A total of 18 593 new cancer cases, except non-melanoma skin cancer, were diagnosed in Granada province over the period 2004-2008 (58.4% in men). Survival was higher in women than in men (57.7% and 50.5%, respectively). In men, five-year ASNS was very low for lung cancer (8.3%). Stomach and colorectal cancer five-year survival was 20.7% and 50.7% respectively. Bladder (73.3%) and prostate cancer (83.9%) had the highest ASNS. In women, the lowest five-year ASNS was for stomach cancer (28.8%), followed by ovarian (42.4%) and colorectal cancer (56.8%) while corpus uteri (71.7%) and breast cancer (81.0%) had the highest survival.

Conclusions

Granada's ASNS were similar to those estimated for Spain, showing differences by anatomical site and sex, being higher in women. The worst prognosis was for lung cancer in men and the best for breast cancer in women.

Theme: **Cancer burden in Europe**

Comparison of thyroid cancer incidence rates in Austria, Switzerland and Germany

Ina Schönfeld,[1] Klaus Kraywinkel,[1] Monika Hackl,[2] Henrike Karim-Kos,[2] Matthias Lorez,[3] Volker Arndt[3]

[1]Robert Koch Institute, Berlin, Germany [2]Austrian Cancer Registry, Wien, Austria [3]Foundation National Institute for Cancer Epidemiology and Registration (NICER), Zürich, Switzerland

Background and Introduction

In recent years, age-standardized incidence rates for thyroid cancer have increased considerably in many industrialised countries, predominantly in younger adults. To show similarities and differences in three neighbouring countries where similar diagnostic standards can be assumed, we compared recent developments of thyroid cancer in Austria, Switzerland and Germany.

Materials and Methods

We analysed thyroid cancer incidence using pooled data from population-based cancer registries stratified by sex, age group and histologic subtype: Follicular, papillary, medullary and anaplastic carcinomas. Rates were age-standardised using the old European standard population (1976). Data from four different regions was analysed: Austria (AUT, 1991-2012), Switzerland (SUI, pooled data from 10 cantons, 1996-2012), Bavaria (BAV, 2002-2012) and other German federal states (GER, 1998-2012).

Results

Age-standardised incidence rates have been steadily rising in all three countries. Rising trends were only observed for papillary carcinomas, predominantly at a younger age. In all regions, age standardised incidence rates have almost doubled within ten years, reaching a peak around the year 2008, with incidence rates for women of 10-12 per 100 000 in BAV and AUT and 6-8 per 100 000 in SUI and GER (papillary type only). Rates for men were about three times lower in all four regions, but showed a similar relative increase as in women. Similarities between the rates in Austria and adjacent Bavaria are striking, whereas the rates in the northern/central region of Germany correspond to slightly lower rates in Switzerland.

Conclusions

The results underline the similarities in thyroid cancer incidence trends in Central Europe. Papillary carcinomas in younger age groups are predominantly responsible for the rising numbers of cases. The reasons still remain unclear, but improved imaging techniques may play a major role.

Theme: **Cancer burden in Europe**

Childhood lymphomas: geographic and age-specific disparities of mortality & survival in Southern-Eastern Europe and US

Maria A. Karalexi,[1] Marios K. Georgakis,[1] Emmanuel Hatzipantelis,[2] Maria Kourti,[3] Maria Moschovi,[4] Sophia Polychronopoulou,[5] Eftichia Stiakaki.[6] Apostolos Pourtsidis,[7] SEE Working Group, Eleni T. Petridou[1]

[1]Department of Hygiene, Epidemiology and Medical Statistics, School of Medicine, University of Athens, Athens, Greece [2]Second Department of Pediatrics, Aristotelion University of Thessaloniki, AHEPA General Hospital, Thessaloniki, Greece [3]Department of Pediatric Hematology and Oncology, Hippokration Hospital, Thessaloniki, Greece [4]Haematology-Oncology Unit, First Department of Pediatrics, Athens University Medical School, 'Aghia Sophia' Children's Hospital, Athens, Greece [5]Department of Pediatric Haematology-Oncology, 'Aghia Sophia' Children's Hospital, Athens, Greece [6]Department of Pediatric Hematology-Oncology, University of Crete, University Hospital of Heraklion, Heraklion, Greece [7]Department of Pediatric Hematology-Oncology, 'Pan. & Agl. Kyriakou' Children's Hospital, Athens, Greece

Background and Introduction

Advances in chemotherapy and radiotherapy have led to significant advances in lymphoma survival among children (0-14 years); these gains have not been equally shared, however, by young patients. We used readily available cancer registration data to assess mortality and survival disparities among children residing in Southern-Eastern Europe (SEE) and those in the US.

Materials and Methods

We calculated average age-standardized mortality rates and time trends of Hodgkin (HL) and non-Hodgkin (NHL) including Burkitt (BL) lymphomas, using national data from 12 SEE countries (1990-2014) and the Surveillance, Epidemiology and End Results Program (SEER, US; 1990-2012). Survival data were available from 14 SEE cancer registries distinguishing also BL. Kaplan-Meier curves and multivariate Cox regressions were used to assess survival in a total of 8918 cases.

Results

Decreasing mortality trends were noted, albeit of variable magnitude among SEE. Rates were overall higher compared to those in SEER (1.02/106), which presented a sizeable (-4.8%, $p=0.0001$) annual change. Remarkable were also the 10-year survival in SEER reaching 96%, 86% & 90% for HL, NHL & BL, respectively; survival was again lower, yet diverse in SEE for every lymphoma subtype. Particularly, NHL was associated with a poorer outcome following an age-specific pattern; noticeably, compared to 10-14 year-old, prognosis was inferior in <5 year-old SEE children (HR: 1.58, 95%CI: 1.28-1.96) and superior in 5-9 year-old SEER children (HR: 0.63, 95%CI: 0.46-0.88).

Conclusions

Higher SEE mortality rates compared to SEER, but overall decreasing trends were found. Despite remarkably improved outcomes in childhood lymphomas over the last two decades, there are still substantial geographic, disease-and age-specific outcome disparities. Optimizing childhood cancer registration and accurate risk stratification based on linkage with clinical and national mortality records would further facilitate research at population level.

Theme: **Cancer burden in Europe**

Survival of childhood chronic myeloid leukemia: determinants and disparities between Southern-Eastern Europe & the US

Maria A. Karalexi,[1] Marios K. Georgakis,[1] Margarita Baka,[2] Sophia Polychronopoulou,[3] Eftichia Stiakaki,[4] Maria Moschovi,[5] Emmanuel Hatzipantelis,[6] Maria Kourti,[7] SEE working group, Eleni T. Petridou[1]

[1]Department of Hygiene, Epidemiology and Medical Statistics, School of Medicine, University of Athens, Athens, Greece [2]Department of Pediatric Hematology-Oncology, 'Pan & Agl. Kyriakou' Children's Hospital, Athens, Greece [3]Department of Pediatric Haematology-Oncology, 'Aghia Sophia' Children's Hospital, Athens, Greece [4]Department of Pediatric Hematology-Oncology, University of Crete, University Hospital of Heraklion, Heraklion, Greece [5]Haematology-Oncology Unit, First Department of Pediatrics, Athens University Medical School, 'Aghia Sophia' Children's Hospital, Athens, Greece [6]2nd Department of Pediatrics, Aristotelion University of Thessaloniki, AHEPA General Hospital, Thessaloniki, Greece [7]Department of Pediatric Hematology and Oncology, Hippokration Hospital, Thessaloniki, Greece

Background and Introduction

Molecularly directed target therapy, notably imatinib mesylate, a tyrosine kinase inhibitor (TKI), has revolutionized outcomes from chronic myeloid leukemia (CML) among adults; yet, its introduction has been delayed in this rare type of cancer among children (0-14 years). We considered it of clinical value to use routine registration data as to assess trends in survival of children with CML, as well as tentative geographic disparities between the US and the less affluent Southern-Eastern European (SEE) countries before and after the introduction of TKIs and contrast them to those of acute lymphoblastic (ALL) and acute myeloid (AML) leukemia.

Materials and Methods

We calculated survival among children with CML, ALL, AML in 14 SEE (1990-2014) cancer registries and the US Surveillance, Epidemiology and End Results Program (SEER, 1990-2012). Kaplan-Meier curves and multivariate Cox regression models assessing hazard ratios (HR) with 95% confidence intervals (CI) were derived.

Results

Among 369 CML cases, substantial improvements were noted in two-year survival during post-TKI (range: 81-89%) compared to pre-TKI (range: 49-66%) period (HR: 0.37, 95% CI: 0.23-0.60). Risk of death was 56% higher for those living in SEE vs US (95% CI: 1.01-2.42). Regardless of geographic area and period of TKI administration, however, age seems to be a significant determinant of CML prognosis, specifically three times higher for <5 year-old children vs. those aged 10-14 years (95% CI: 1.85-4.94). Noticeably, post-TKI survival in CML overall approximates that for ALL, whereas therapeutic advancements for AML remain modest.

Conclusions

Registry data show dramatic survival gains following introduction of molecular CML therapies in children, approximating the high curable rates of ALL. The considerably higher death rates in SEE countries seem amenable to optimized medical interventions, as contrasted–presently–to those on account of younger age at diagnosis, which need to be further explored.

Theme: **Cancer burden in Europe**

Second malignancies following leukemia diagnosis: preliminary results from the 20-year nationwide registration in Greece

Maria A. Karalexi,[1] Marios K. Georgakis,[1] Margarita Baka,[2] Sophia Polychronopoulou,[3] Eftichia Stiakaki,[4] Maria Moschovi,[5] Emmanuel Hatzipantelis,[6] Maria Kourti,[7] Helen Kosmidis,[8] Eleni T. Petridou[1]

[1]Department of Hygiene, Epidemiology and Medical Statistics, School of Medicine, University of Athens, Greece [2]Department of Pediatric Hematology-Oncology, 'Pan & Agl. Kyriakou' Children's Hospital, Athens, Greece [3]Department of Pediatric Haematology-Oncology, 'Aghia Sophia' Children's Hospital, Athens, Greece [4]Department of Pediatric Hematology-Oncology, University of Crete, University Hospital of Heraklion, Greece [5]Haematology-Oncology Unit, First Department of Pediatrics, Athens University Medical School, 'Aghia Sophia' Children's Hospital, Athens, Greece [6]2nd Department of Pediatrics, Aristotelion University of Thessaloniki, AHEPA General Hospital, Thessaloniki, Greece [7]Department of Pediatric Hematology and Oncology, Hippokration Hospital, Thessaloniki, Greece [8]Oncology Department, 'Mitera' Childrens Hospital, Athens, Greece

Background and Introduction

Intensive chemotherapy and supportive care have improved survival of children with hematological malignancies. Evaluation of late effects is vital for the growing population of survivors with likely longevity. We aimed to present preliminary data on secondary malignancies (SMN) among children with leukemia during almost two decades (1996-2014) of registration by the Nationwide Registry for Childhood Hematological Malignancies (NARECHEM).

Materials and Methods

Active follow-up of cases comprised clinical data on disease-and treatment-specific characteristics of SMNs; Last follow-up date was considered the death date, lost to follow-up date or June 30th, 2015. Differences in distributions of SMN characteristics were assessed using t-test. Cox regression analyses were also run to explore the effect of potential predictors on survival following a SMN.

Results

At a mean follow-up of 88.7 months (standard deviation, SD: +54.2), 16 childhood leukemia (0-14 years) patients developed SMNs, 14 during or after completion of front-line therapy and 2 while in second complete remission after relapse. In 14 cases the primary diagnosis was acute lymphoblastic, in one acute myeloid and in one chronic myeloid leukemia. Overall, the most common SMN was central nervous system (CNS) tumor (N=5), followed by sarcoma (N=2), acute myeloid leukemia (N=2), non-Hodgkin lymphoma (N=2), myeloid sarcoma (N=2), Hodgkin lymphoma (N=1), malignant Warthin tumor (N=1) & thyroid carcinoma (N=1).Three out of 5 patients with CNS-SMN had received cranial irradiation following leukemia diagnosis. Overall, mean time to death since SMN diagnosis was 13.5 months (SD: +8.3).

Conclusions

The patterns and timing of SMNs among leukemia survivors of NARECHEM follow those expected from previous studies. Late follow up of cancer patients is needed to explore the potential risk factors of a leukemia child to develop SMN and assess survival to their counterparts who've been successfully treated for the primary tumor.

Theme: **Cancer burden in Europe**

Trends in prostate cancer incidence (1968-2013) and mortality (1960-2014) in Croatia: a joinpoint regression analysis

Mario Šekerija,[1] Kristina Sekulić[2]

[1]Croatian National Cancer Registry, Croatian Institute of Public Health, Zagreb, Croatia [2]Institute of Public Health of Karlovac County, Karlovac, Croatia

Background and Introduction
Prostate cancer incidence is increasing; however limited data is available on trends in pre-1990s period for many European countries. Data on prostate cancer trends in Croatia is currently available for the 1988-2008 period and we aimed to broaden the investigated study period.

Materials and Methods
We analysed the incidence data from Croatian National Cancer Registry (CNCR) for the 1968-2013 period, as well as mortality data for the period 1960-2013 period from the official mortality statistics. We analysed the trends in age-standardised rates (1976 European standard population) of incidence and mortality using joinpoint regression analysis.

Results
Trends in incidence showed four joinpoints; no significant change from 1968-1982, a significant annual percentage change (APC) of 1.4 (95% CI 0.7-2.1) from 1982-1997, a steep increase from 1997-2002 (APC 11.5; 95% CI 7.5-15.7), an APC of 3.5 from 2002-2009 (95% CI 1.9 to 5.1) and no significant trend in 2009-2013 period. Average APC for the 1968-2013 period was 1.9 (95% CI 1.3 to 2.5). Trends in mortality indicated one joinpoint; in the period from 1960-2010 mortality increased with an APC of 1.2 (95% CI 1.0-1.4), while the trend from 2010-2014 was not statistically significant. The average APC for the entire 1960-2014 period was 1.0 (95% CI 0.7 to 1.4).

Conclusions
The incidence rates of prostate cancer in Croatia sharply increased in 1997, probably due to a wider acceptance of PSA testing and increased awareness among Croatian male population. The mortality trends are more stable, showing a 1% annual increase since the 1960s. A discontinuation of increasing trends noticed in both incidence and mortality data warrants further attention.

Incidence trends and survival of skin melanoma and squamous cell carcinomas in Cluj County Romania

Ofelia Suteu,[1,2] Luminita Blaga,[1] Florian Nicula,[1] Patricia Suteu,[1,2] Ovidiu Coza,[1,2] Patriciu Achimas-Cadariu,[1,2] Daniela Coza[1]

[1] 'Prof. Dr. Ion Chiricuţă' Institute of Oncology, Cluj-Napoca, Romania [2] 'Iuliu Haţieganu' University of Medicine and Pharmacy, Cluj-Napoca, Romania

Background and Introduction

Skin cancers registered in the last decades an increasing incidence worldwide. In Cluj County in 2011, cutaneous melanoma (CM) ranked eight in men and five in women, in the age group 25-49 years, whereas for skin squamous cell carcinoma (SCC), there is little information about their incidence and time trends. The aim was to study trends of the incidence of CM and SCC in Cluj County, from 1998 up to 2011, and to examine five-year net survival between 2006-2010.

Materials and Methods

Data concerning all cases of CM and SCC, diagnosed between 1998 and 2011, were obtained from the Cluj Cancer Registry. Incidence rates were standardized by the direct method (ASIR), using the world standard population. Trends and annual percentage change (APCs%) of incidence rates were calculated by joinpoint regression analysis. Pohar-Perme estimator was used to examine the five-year net survival of cases, diagnosed during 2006-2010 and followed-up until 31 of December 2015.

Results

A total of 580 cases of CM (56% in female) and 397 cases of SCC (50.6% in female) were reported. For the period 1998-2011, ASIR for SCC was 2.40/100 000 in men, respectively 1.85 in women and for CM-3.84/100 000 respectively 4.3. The ASIR of melanoma increased significantly by 7.8% and 7.42% APCs in males and females, respectively. For SCC, the incidence increased with APCs of 9.40% in males and during the interval 2002-2011, by 12.65% APCs in women. The survival rates showed an improving trend during 2006-2010, and they were generally lower in men. Survival for SCC as well as CM decreased with age and was lower in rural areas and in more advanced stages, in both sexes.

Conclusions

This study reveals a rising incidence of cutaneous cancers in concordance with international trends. These data support the important role for primary and secondary prevention of skin cancers, focused not only on melanoma, due to its lower survival, but also on SCC, in order to reduce their incidence and mortality.

Theme: **Cancer burden in Europe**

Cancer incidence in young people in Montenegro, 2013 – Where are we comparing with the region?

Rajko Strahinja,[1] Veselinka Beatović[2]

[1]Registry of Malignant Neoplasms of Montenegro, Institute of Public Health of Montenegro, Podgorica, Montenegro [2]Institute of Public Health of Montenegro, Podgorica, Montenegro

Background and Introduction

Morbidity and mortality of malignant neoplasms are one of the most significant public health problems, at global and national levels. Although the share of newly diagnosed malignant neoplasms among young people is generally low (global incidence rate for adolescents is 9-30/100 000), it does not lessen their public health significance. Projections indicate that number of newly diagnosed cases will rise significantly at global level by 2035 (by 75 %).

Materials and Methods

Epidemiologically descriptive; unpublished data of the Cancer Registry in 2013 in Montenegro (founded on 01.01.2013), and corresponding annual reports from countries in the region.

Results

In 2013, a total of 2277 new cases of malignant neoplasms (C00-C96 according to ICD-10) were registered in Montenegro. There were 19 registered cases in young people of both gender (0.83 % out of total vs. Slovenia – 0.48 %, Croatia – 0.51 %, Serbia – 0.84 %). There were 13 cases among males and six cases among females, M:F = 2.17). Age specific incidence rate per 100 000 for age group 15-24 years was 21.9, which is also standardized incidence rate according to the European standard population (TASR 15-24-E) (Croatia – 20.9, Slovenia – 28.6, Serbia – 31.4). Out of total number of cases, Hodgkin lymphoma and testicular neoplasms were the most common malignant neoplasms (with 21 % each), followed by neoplasms of CNS and thyroid gland (with 10 % each).

Conclusions

For the first time in Montenegro, it is possible to analyse malignant neoplasms morbidity in young people by using data from the population cancer registry at the national level. The share of newly diagnosed cases among young people, in the total number of newly diagnosed in all age groups in Montenegro, ranges within the same values as in the comparing countries as well as the TASR 15-24. Indirectly, it can be concluded that, although it is the first year of Registry, these data indicate its satisfactory quality.

Theme: **Cancer burden in Europe**

Thyroid cancer in Puglia: heterogenity of incidence and mortality in four provinces

Danila Bruno,[1] Anna Maria Nannavecchia,[1] Francesco Cuccaro,[2] Antonino Ardizzone,[3] Anna Melcarne,[4] Antonia Mincuzzi,[5] Lucia Bisceglia,[6] Cinzia Tanzarella,[1] Antonio Chieti,[1] Vanna Burgio Lo Monaco[1]

[1]Cancer Registry of Puglia–Coordination centre, Cancer Institute IRCCS Giovanni XXIII, Italy [2]Cancer Registry of Puglia–Local Health Unit of Barletta-Andria-Trani, Italy [3]Cancer Registry of Puglia–Local Health Unit of Brindisi, Italy [4]Cancer Registry of Puglia–Local Health Unit of Lecce, Italy [5]Cancer Registry of Puglia–Local Health Unit of Taranto, Italy [6]Cancer Registry of Puglia–Health Regional Agency of Puglia, Italy

Background and Introduction

We used Cancer Registry of Puglia (RTP) data, a regional population-based cancer registry, to investigate incidence and mortality distribution of thyroid cancer. We included four of the six sections (Barletta-Andria-Trani, Brindisi, Lecce and Taranto) that are at present accredited by AIRTum and cover more than 50 % of regional population.

Materials and Methods

2 213 incident cases, defined by the topographic code C73 in ICD-O3, concern the accredited RTP sections. We calculated age-adjusted rates (ref. European Pop.) per 100 000 pop. (DSR) and we deepened the geographical differences, studying rates of the main morphologic groups (papillary, follicular, medullary anaplastic). We also investigated mortality rates.

Results

Our results show the heterogeneity of incidence: TA shows the highest incidence (DSR 10.6 M and 33.8 F, 2006-2011), followed by BR (DSR 8.5 M and 28.3 F, 2006-2009), LE (DSR 6.3 M and 23.4 F, 2003-2008), BT (DSR 4.7 M and 21.0 F, 2006-2010), Italy AIRTum (DSR 7.3 M and 22.2 F, 2006-2009) and South Italy AIRTum (DSR 7.5 M and 24.6 F, 2006-2009). We calculated morphology rates by province in histological confirmed cases. The most represented group is papillary type: the highest morphology rate was found in TA for both sexes. Mortality rates by provinces do not show statistically significant differences.

Conclusions

This study is a pioneering investigation about the geographic distribution of thyroid cancer incidence in Puglia. Papillary type, less aggressive and with a better prognosis, is the most frequent, in particular where the incidence is higher. This situation may suggest that the highest incidence in areas like TA can be related to a high pressure diagnostic and screening opportunistic, encouraged by the presence of high attention to environmental pollution and its potential effects on health. In support of this hypothesis, TA mortality rates do not show a statistically significant excess respect to other areas.

Cancer risk in Basel by municipality and district: a population-based cancer registry 1981-2010

Seyed Mohsen Mousavi, Ivka Avellina, Maria Caterina Cammarota, Désirée Lüscher

Cancer Registration Office, Licenses and Supports, Department of Medical Services, Basel Department of Public Health, Basel, Switzerland

Background and Introduction

Basel cancer registry was established by Krebsliga in 1969. The cancer data has been registered in an electronic Database since 1981. We aimed to define cancer risk in Basel city and country by municipality and district.

Materials and Methods

We used Basel cancer registry database from 1981 to 2010. Cancer data is coded by the International Classification of Disease for Oncology (ICD-O). We calculated age-standardized incidence rates (ASRs per 100 000 populations at risk). The European population was used for standardization. The ASRs were adjusted by age (five-year bands), period (five-year bands) and sex. The confidence interval (95 % CI) was calculated by making a Poisson approximation of the binomial variance of the age-specific incidence rate. The municipalities in Basel city are Basel, Riehen and Bettingen. There are five districts in Basel country: Arlesheim, Liestal, Sissach, Waldenburg and Laufen. The Laufen was not included.

Results

We observed 21 140 male and 19 366 female cancer cases in Basel, 2 628 and 2 491 cases in Riehen and Bettingen, 14 560 and 12 177 cases in Arlesheim, 4 449 and 3 690 cases in Liestal, 2 398 and 1 849 cases in Sissach, and 1 178 and 944 cases in Waldenburg, respectively. An increase in the cancer rate was seen among all Basel residents from 1981-1985 to 2006-2010: Basel (male: ASR from 627.6 to 692.4; female: 377.0 to 491.0), Riehen and Bettingen (male: 486.7 to 611.2, female: 358.7 to 453.8), Arlesheim (male: 535.8 to 608.6 , female: 357.8 to 467.3), Liestal (male: 511.1 to 528.8, female: 325.4 to 446.6), Sissach (male: 488.3 to 481.2, female: 300.7 to 384.8), and Waldenburg (male: 464.3 to 547.4, female: 358.4 to 396.9).

Conclusions

Our study shows increased risks up to 26 % in Riehen and Bettingen males and 37 % in Liestal females. Implementing cancer control program should be a high health-priority in Basel department of health.

Trends in incidence, survival and mortality of childhood and adolescent cancer in Austria, 1994-2011

Monika Hackl,[1] Henrike E. Karim-Kos,[1] Monika Hackl,[1] Georg Mann,[2] Christian Urban,[3] Adelheid Woehrer,[4] Irene Slavc,[5] Ruth Ladenstein[2]

[1]Austrian National Cancer Registry, Directorate Social Statistics, Statistics Austria, Vienna, Austria [2]Children Cancer Research Institute, St.Anna Children's Hospital, Vienna, Austria [3]Department of Paediatrics and Adolescent Medicine, Division of Haemato-Oncology, Medical University of Graz, Austria [4]Institute of Neurology, Medical University of Vienna, Austria [5]Department of Paediatrics and Adolescent Medicine, Medical University of Vienna, Austria

Background and Introduction

This is the first study on trends in cancer incidence, survival and mortality for children and adolescents in Austria. The aim was to assess to what extent progress has been made in Austria since childhood cancer treatment has been centralized in the 1990s and neuroblastoma screening took place in 1991-2003.

Materials and Methods

All malignant neoplasms and non-malignant tumours of the Central Nervous System (CNS) in patients aged <20 years and diagnosed in 1994-2011 (N=3582 children: 0-14 years; N=1842 adolescent: 15-19 years) were derived from the Austrian National Cancer Registry. Incidence and mortality trends were evaluated using average annual percentage change (AAPC). Observed survival rates were calculated based on follow-up until December 31st 2013 and changes over time were evaluated applying Poisson regression modelling.

Results

Childhood cancer remained stable with 182 cases per million in 2011, but rose among girls by 1.4% (95% CI: 0.1, 3.6) annually. Overall, non-malignant CNS tumours and Non-Hodgkin lymphoma increased. Neuroblastoma increased to 22.5 per million children in 2002 followed by a decline to 13.8 in 2011. Adolescent cancer rose by 1.5% (95% CI: 0.4, 2.6) annually, from 182 cases per million in 1994 to 269 in 2011, mainly due to an increase of leukaemia, non-malignant CNS and epithelial tumours. Five-year survival improved by 5-7% reaching 86% for both groups (p<.05). Mortality declined by -2.4% (95% CI: -3.7, -1.2) among children and -2.0% (95% CI: -4.6, 0.5) among adolescents. The strongest decline was seen for childhood leukaemia.

Conclusions

Progress is demonstrated by improved survival and declined mortality most likely related to improved diagnostic techniques, more effective therapeutic regimes, supportive care and central advisory function of experts in the Austrian paediatric oncology. Increases of not notifiable non-malignant CNS tumours were caused by the introduction of Austrian Brain Tumour Registry since 2005.

Theme: **Cancer burden in Europe**

Lung cancer and annual mean exposure to outdoor air pollution in Crete, Greece

Dimitra Sifaki-Pistolla,[1] Vassilis Georgoulias,[2] Sofia Aggelaki,[2] Christos Lionis,[1] Nikos Tzanakis,[3] on behalf of the Cancer Registry of Crete

[1]Clinic of Social and Family Medicine, School of Medicine University of Crete, Greece [2]Department of Medical Oncology, School of Medicine, University of Crete, Greece [3]Department of Medicine, School of Medicine, University of Crete, Greece

Background and Introduction

The increasing burden of Lung Cancer (LC) in Crete, Greece has raised concern about potential association of environmental risk factors with LC. Aim of this study was to assess Outdoor Air Pollution (OAP) and the risk for LC, for the first time in Crete using LC primary data.

Materials and Methods

5000 LC cases (diagnosed from 1992 to 2013) were obtained and followed-up from the CRC's database. The Age-Adjusted Incidence Rates (AAIR) and the Age-Standardized Mortality Rates (ASMR) were calculated. Data on outdoor air concentrations of particulate matter [PM2.5, between 2.5 μm and 10 μm (PM2.5-10) and PM10], PM2.5 absorbance (black carbon measure), nitrogen dioxide (NO_2) and nitrogen oxides (NOx) were derived from the European Environment Agency (EEA). Spatio-temporal statistics were used to explore association between LC and OAP, and develop a multivariate model of future risk. All tests were conducted at a=0.05 in STATA and ArcMap 10.3.1.

Results

LC in Crete accounts for 40.2 new cases/100 000/year for both genders (AAIRmales=73.1 new cases/100 000/year; AAIRfemales=11.8 new cases/100 000/year). The annual median estimates of environmental concentrations in Crete were the following: PM2.5=20.7 (±1.5) μg/m3, PM10=38.9 (±2.5) μg/m3, PM2.5-10=59.6 (±3.7) μg/m3, PM2.5 absorbance=1.2 (±0.3)×10-5 per m, NO_2=15.2 (±3.8) μg/m3 and NOx=20.1 (±4.9) μg/m3. A strong positive association (mean Correlation Coefficient=0.75; Pvalue<0.05) was found between LC and PM2.5, PM2.5-10), PM10, pM2.5 absorbance, NO_2 and NOx. The highest risk for LC mortality was observed in the major urban centers and several south-east and north-west rural regions of Crete (RR=3.2, 95% CI=1.638-4.765). A general increase of LC and the observed RRs is estimated for the next 10 years, especially in north-west rural regions (RRexpected=3.9, 95% CI=1.372-6.428).

Conclusions

OAP seems to be an important determinant of LC. Targeted interventions have to be performed in the current and future risk areas.

Theme: **Cancer burden in Europe**

Cancer registries should additionally provide information on cancer incidence geographical variability

Emanuele Crocetti, Giorgia Randi, Raquel Carvalho, Tadeusz Dyba, Francesco Giusti, Carmen Martos, Roisin Rooney, Lydia Voti, Manola Bettio

European Commission, DG Joint Research Centre, Ispra, Italy

Background and Introduction

The frequency of cancer in a defined population and in a certain period is reported by cancer registries (CR) as a rate, age-standardised to allow for reliable comparisons. This is the standard statistic computed by all CRs independent of the size of the population at risk. The measure of variability provided – standard error – refers to the precision of the estimator and does not reflect the heterogeneity in cancer incidence within the area. Some national CRs are publishing incidence rates at a lower geographical level providing thus more insight into intra-CR incidence variability.

Materials and Methods

We retrieved from Nordcan (http://www-dep.iarc.fr/NORDCAN) the European age-standardised incidence rates (ASR) for Denmark and Finland in 2013, at national level as well as for five regions in each country, for all sites excluding non-melanoma skin cancer, for men. Differences between and within countries were evaluated.

Results

The national ASR for Denmark was 479.4, and for Finland 422.2 per 100 000 py. The standard errors, 3.68 and 3.46, were negligible due to a big number of incident cases considered, 17 582 and 15 517 respectively. ASRs for the Danish regions ranked from 458.7 in Zealand to 495.9 in Southern Denmark (range: 37.2). As regards Finland, regional ASRs varied between 362.1 in Turku to 490.4 in Tampere, with a range of 128.3. Significant differences were observed both between and within countries.

Conclusions

Although both Danish and Finnish ASRs are correct, the analysed example demonstrates that the national ASR may reflect more (Denmark) or less accurately (Finland) the incidence of cancer in the different regions of a country. When heterogeneity is present regional rates are more informative than the national ones. The unavailability of a unique population-unit for sub-areas makes comparisons difficult. However, CR should start to deal with the need to provide information on internal cancer incidence variability as well as just incidence.

Theme: **Cancer burden in Europe**

Bayesian estimates of incidence rates and number of cases by country for the rare cancers in Europe

Laura Botta,[1] Ramon Clèries Soler,[2, 3] Trama Annalisa,[1] Gemma Gatta,[1] Riccardo Capocaccia[1]

[1]Evaluative Epidemiology Unit, Fondazione IRCCS Istituto Nazionale dei Tumori (INT), Milan, Italy [2]Plan for Oncology of the Catalan Government, L'Hospitalet de Llobregat, Barcelona, Spain [3]Departamento de Ciencias Clínicas, Facultad de Medicina, Universitat de Barcelona, Barcelona, Spain

Background and Introduction

Rare cancers are an important issue in clinical research, clinical practice and public health. The RARECARENet project provided for the first time systematic estimates of epidemiological indicators of rare cancers incidence by country. To this aim small-area estimation using full Bayesian methodology was tested.

Materials and Methods

We analyzed data on rare cancer patients diagnosed in 27 countries during the period 2000-07. For each cancer we smoothed the standardized incidence rate with a log-linear model, made of a fixed part (global average relative risk) and a random part (unstructured residual for each country). The latter was assumed to follow a Normal distribution with 0 mean and a precision following a non-informative Gamma prior distribution. For each country and for each rare cancer, we provided the Bayesian estimates of incidence rates (BIR). We also defined the waiting time needed to observe 1 case to communicate incidence estimates for exceptionally rare cancers.

Results

BIRs were in many cases similar to the classical ones. However, for very rare entities (such as for example adenocarcinoma of trachea), the Bayes and classical estimates are in most countries different and closer to the European average by more than 10 %. For 124 entities the observed number of cases was not included in the credible interval of the Bayesian estimated number for at least one country thus we recommend the use of the produced BIRs. With the Bayesian method we also overcome the problem of incidence estimates with 0 cases observed in a country during a limited time period. As an extreme example, we could estimate a waiting time of 68 years to see one case of adenocarcinoma of trachea in Iceland.

Conclusions

We give practical indications on when Bayesian method actually provides different results with respect to the classical estimation. Thanks to a simple and informative indicator we communicate the burden for exceptionally rare cancers.

Theme: **Cancer burden in Europe**

Incidence of lip malignancies in Germany – Data from nine population-based cancer registries

Meike Ressing,[1,2] Sylke Ruth Zeissig,[1,2] Katharina Emrich,[1,2] Bernd Holleczek,[3] Klaus Kraywinkel,[4] Robert Mischkowski,[5] Hans-Joachim Schulze,[6] Susanne Singer[1,7]

[1]Institute of Medical Biostatistics, Epidemiology and Informatics, University Medical Centre, Johannes Gutenberg University Mainz, Mainz, Germany [2]Cancer Registry Rhineland-Palatinate, Mainz, Germany [3]Saarland Cancer Registry, Saarbrücken, Germany [4]German Centre of Cancer Registry Data, Robert Koch Institute, Department of Epidemiology & Health Monitoring, Berlin, Germany [5]Department of Maxillofacial Surgery, Ludwigshafen, Germany [6]Department of Dermatology, Fachklinik Hornheide, Germany [7]University Cancer Centre Mainz (UCT), Germany

Background and Introduction
The objective of this study was to analyse the incidence of lip malignancies in Germany and its different federal states.

Materials and Methods
Data from nine population-based cancer registries covering a population of 39.17 million inhabitants from 14 federal states were pooled. Lip malignancies were classified according to the International Classification of Diseases, 10th edition (ICD-10). The number of cases of lip cancer (ICD-10 code C00), melanoma of the lip (C43.0), and non-melanoma skin cancer of the lip (C44.0) were counted. Age-standardised incidence rates (per 100 000) as well as annual percentage changes (APC) in the incidence trends for the years 2003 to 2012 were calculated.

Results
Lip cancer (C00) incidence rate was 0.65/0.18 per 100 000 (men/women) in 2003 and 0.57/0.20 in 2012. In women, the change was statistically significant. Melanoma lip cancer (C43.0) incidence rates both in men and women were 0.02 in 2003 and 0.01 in 2012. Incidence rates of non-melanoma skin cancer of the lip (C44.0) significantly increased from 1.8 in 2003 to 2.2 in 2012 in men and from 1.6 in 2003 to 2.5 in 2012 in women. In lip cancer (C00), the vast majority (92% in men/84% in women) were squamous cell carcinomas and 2%/7% were basalioma. In men, 55% of non-melanoma skin cancers (C44.0) were squamous cell carcinoma, whereas these were only 27% in women. Nearly all other non-melanoma skin cancers were basalioma.

Conclusions
The incidences of non-melanoma skin cancer of the lip increased over time in Germany in both sexes. Lip cancer incidence increased in women, while it stayed stable in men. Melanoma of the lip did not change in incidence. The distribution of histology in non-melanoma skin cancer of the lip differed by sex.

Theme: **Cancer burden in Europe**

Sustaining progress towards early detection of cervical cancer in Romania

Camelia Nicoleta Claici and The West Romania's Cancer Registration Working Group

Timisoara Regional Cancer Registry, National Institute of Public Health, Romania

Background and Introduction

Cancer is a major cause of suffering and death in the western region of Romania; its high incidence and mortality, the psycho-social impact on patients and their families, jeopardizing the well-being of the entire society. Burden of disease in our development region is dominated by lung, colon-rectal, breast, stomach, cervical and prostate cancers, which represent more than 53% of all incident cases. West Regional Cancer Registry is one of eight population-based Romanian cancer registries. The purpose of this study is to identify critical high incidence of the cervical cancer, per counties, in the western region of Romania, in order to emphasize that more cancers should be diagnosed via Screening and Early Detection.

Materials and Methods

The information used, regarding new cases of cervical cancer notified since 2008, was provided by West Regional Cancer Registry's database. Population denominators come from the Romanian National Institute of Statistics.

Results

We described the estimated number of cervix uteri cancer cases, the number of cervical cancer deaths and the corresponding crude and age-standardized rates with the world standard population, as reference for the western development region of Romania. In the western region of Romania, high mortality rates were noted 11.0/100 000. The standardized incidence rate is more than 17.0/100 000. Romania is one of the most affected countries in Europe, with almost 3 200 cases and more than 1 800 deaths per year. The world-age standardized mortality rates is >12.0/100 000 women-years.

Conclusions

We have highlighted the elevated burden of cervical cancer in the western region of Romania. Our matter of concern is the increasing mortality rate, in younger women. The public health experts will have to define, to measure and to evaluate the contribution of the immunization and population-based early detection in tackling this highly preventable disease.

Citizens' initiative for epidemiological study of cancer disease in the VCO province

Giulio Barigelletti, Sergio Cozzi, Sergio Montanara

Associazione AMICI DELL'ONCOLOGIA ONLUS–Ospedale di Verbania, Verbania, Italy

Background and Introduction

Worrying 'voices of the people', indicated the presence of an excess of cancer cases in Verbano Cusio Ossola [VCO] (Verbania province–Piedmont–Italy), area was not covered by a Cancer Registry (CR). Under the auspices of several non-profit organizations and Local Health Units (ASL) the activation of the 'Epidemiologic Study Retrospective Standing on Neoplastic Disease in the ASL VCO' was promoted.

Materials and Methods

After a set up phase started in 2011, the study was able to resume with all the information sources and with the approval of the Inter-Corporate Ethic Committee in July 2013. It was made like any other cancer registry in Italy and working in accordance with the rules of recordings proposals organizations [AIRTUM, ENCR, IARC]. In Dec. 2014 the final results were published:

- Old age Index analysis of the resident population
- Crude and ASR rates (EU, World)
- Tumor incidence between years 2007-2011
- Mortality from all diseases during the Year 2011
- Tumor mortality years between 2011-2013
- five-year survival observed and relative
- Spatial analysis
- WEB Site www.registrotumorivco.org.

Results

The results showed a surplus in crude incidence rates compared with the registers of the neighboring areas. At the same time it showed the presence of a particularly elderly population. The standardization of rates has enabled a reduction to values close to those of the national average or slightly better than the neighboring areas.

Conclusions

In areas not covered by CR, the increase of diagnosed cancer, due to aging population, can often cause unjustified alarmism. Hoping that the authorities take care of the necessary coverage of the territories currently not covered by an institutional CR, independent studies, may give the answers to the concerns. Respecting the rules and operating methods used by CR allows the comparison of the calculated values and the work may be prodromal to the realization of an institutionalized CR.

Theme: Cancer registries and evaluation of cancer care

Colorectal cancer incidence: an increasing trend under 50 years of age?

Adele Caldarella, Alessandro Barchielli, Antonella Corbinelli, Pietro Paolo Di Dia, Teresa Intrieri, Gianfranco Manneschi, Libuse Nemcova, Carmen Visioli, Marco Zappa

Istituto per lo Studio e la prevenzione Oncologica (ISPO), Florence, Italy

Background and Introduction

Colorectal cancer is the second most commonly diagnosed cancer in Italy. Although the overall incidence appears to be stable or decreasing, recent literature suggested a trend of rising incidence in young people. We analyzed the colorectal cancer incidence rates by age among patients collected by Tuscan Cancer Registry (RTT).

Materials and Methods

We retrieved all patients with colorectal cancer diagnosed from January 1, 1985 to December, 31, 2008 and collected by RTT, a population based registry active from 1985 in the area of Florence and Prato, about 1 200 000 inhabitants. Information on sex, age at diagnosis, date of diagnosis, morphology, pathological stage, were retrieved from the archive of RTT. Age-adjusted incidence rates per 100 000 and confidence intervals at 95% are calculated. The Annual Percent Changes (APCs) were calculated by fitting a least squares regression model to the logarithm of the rates.

Results

Among the 24 000 patients with colorectal cancer diagnosed in the 1985-2008 period, 4.8% were diagnosed in younger than 50 years of age (incidence rate 14.7). After the initial stable incidence, a significant decreasing trend was found (APC 2000-2005: -1.7, CI -3.2, -0.1; APC 2006-2008: -6.4, CI -9.6, -3). When age was considered, the decrease was confirmed among people older than 50 years of age (APC 2000-2005: -3.2, CI -0.2, -7.1; APC 2006-2008: -11.1, CI -5.2, +26.9). Among younger people, however, an increasingly incidence was recently found, although without statistically significance (APC 2000-2005: -0.9, CI -8.5, +7.4; APC 2006-2008: +20.8, CI -14.4, +70.7).

Conclusions

In a population based analysis we found different trend for colorectal cancer by age, with a rising incidence in young patients, as recently reported in literature. Although the rarity of young colorectal cancer, these observations could suggest that health policy attention and further research on clinico-pathological characteristics of these tumours are needed.

Theme: Cancer registries and evaluation of cancer care

Dying with cancer: perspectives of bereaved friends and relatives

Victoria Cairnduff, Deirdre Fitzpatrick, Conan Donnelly, Janine Blaney, Anna Gavin

N. Ireland Cancer Registry (NICR), Centre for Public Health, Queen's University Belfast, Northern Ireland, UK

Background and Introduction

Over the past decade there has been increased interest surrounding the place where cancer patients die to inform planning of end-of-life (EoL) care. Aim: To establish key factors that influence place of death, specifically those enabling cancer patients to die at home.

Materials and Methods

Bereaved relatives/friends who registered the death of a cancer patient in previous five to nine months were mailed a questionnaire (based on that of the QUALYCARE study, Cicely Saunders Institute, King's College London) which collected information on care received in the last three months of life, place of death, socio-demographic characteristics, Quality of life and respondent's grief response.

Results

467/1495 questionnaires returned. Home was preferred place of death for 75% of patients, however only 38% achieved this with 41% dying in hospital. High service use was observed with 3/4 patients having overnight stay in hospital and over 1/2 patients attending A+E and/or using ambulance services in last three months. 9/10 patients received informal care from family/friends at home and a higher proportion of patients who died at home had informal care at home from 6+ relatives/friends.1/5 of patients did not have a key worker to co-ordinate care with key worker being shown to play important role in achieving home death. 1/3 of respondents felt they did not receive enough information. Satisfaction with communication differed across settings and health care professions (HCPs) with the highest rating for HCPs specifically trained to provide Specialist Palliative Care. Better information giving was associated with achieving a home death. No significant differences in palliative outcomes or respondent's grief response were observed by place of death.

Conclusions

The findings highlight the importance of good communication in EoL care and the critical role that key healthcare workers play in communication and co-ordinating access to services.

Acknowledgments: This work was funded by Cancer Focus, NI.

Theme: Cancer registries and evaluation of cancer care

Presentation, referral and management of oral cavity cancer in Northern Ireland–2013

Conor McKenna,[1] Eileen Morgan,[2] Gerry McKenna,[3] Anna Gavin,[2] Ramzan Ullah,[1] Frank Kee[3]

[1]Belfast Health and Social Care Trust, UK [2]Northern Ireland Cancer Registry, UK [3]Centre for Public Health, Queen's University Belfast, UK

Background and Introduction

Oral cavity cancers include cancers of the lip, oral tongue, gum, floor of mouth, hard palate and other parts of the mouth. We audited the presentation and treatment of these rare cancers during 2013.

Materials and Methods

Cases diagnosed between 1/1-31/12/2013 were identified from the Northern Ireland Cancer Registry using ICD-10 codes pertaining to oral cavity cancer diagnoses. Clinical data were collected in Microsoft Excel and analysed using SPSS.

Results

73 oral cavity cancers were diagnosed in 2013 (50 males, 23 females). The largest subsite was oral tongue (n=37, 51%). The most common presenting symptom was an ulcer/lesion (n=50, 68%). General medical practitioner was the most common referral source (n=32) however a significant proportion (n=26) had initial referral by community dentistry. 95% of patients had primary site imaging (CT n=38, MRI n=37). 96% had chest imaging (Chest XR n=35, CT Chest n=35). 32 patients had Stage 4 disease. 100% of patients were discussed at the regional Multi-Disciplinary Team. 58 patients (79%) had radical treatment with 45 patients having surgical management (primary surgery n=15, primary surgery + neck dissection n=30). Reconstruction was used in 13 patients with radial forearm free flap the most common option. 44 patients had radiotherapy (22 as post-operative RT/13 as primary RT/9 as palliative RT). 6 patients had chemotherapy (concurrent chemoRT).

Conclusions

This study details the presentation and management of oral cavity cancers in Northern Ireland. The finding of a significant proportion of referrals from community dentistry could inform public health initiatives and local referral pathways. Variability exists in the imaging workup of oral cavity cancers. The majority of patients were treated with curative intent, with surgery the most common initial therapy. Radial forearm free flap is the reconstructive surgery of choice following resective oral cavity surgery in Northern Ireland.

Theme: Cancer registries and evaluation of cancer care

Geographical variation and modulation factors of lung cancer survival in Southern Spain

Miguel Rodríguez-Barranco,[1,2,3] C. García-Díez,[4] Yoe-Ling Chang,[1,2] María Luisa Fajardo,[5] Isabel Linares,[6] Elena Molina-Portillo,[1,2,3] Juana Tallón-Lobo,[5] José Luis Gurucelain,[5] E. Bayo-Lozano,[7] María José Sánchez[1,2,3]

[1]Andalusian School of Public Health, Granada Cancer Registry, Granada, Spain [2]Biosanitary Investigation Institute ibs.Granada, University Hospital Complex of Granada/University of Granada, Spain [3]Public Health and Epidemiology CIBER (CIBERESP), Madrid, Spain [4]Complejo Hospitalario Universitario de Huelva, Huelva, Spain [5]Delegación Territorial de Salud de Huelva, Huelva, Spain [6]Complejo Hospitalario Universitario de Granada, Granada, Spain [7]Plan Integral de Oncología de Andalucía, Consejería de Salud, Junta de Andalucía, Sevilla, Spain

Background and Introduction
Lung cancer (LC) is the leading cause of cancer death worldwide. The aim was to analyze presentation, treatment and survival for LC in Granada and Huelva, and identify factors influencing survival.

Materials and Methods
Data were obtained from the population-based cancer registries located in Granada and Huelva, two regions in Southern Spain. All newly diagnosed cases of primary LC over the period 2010-2012 were included. Data regarding diagnostic procedures, stage at diagnosis and treatment were collected from clinical records. Two-year age-standardized net survival was estimated by means of Pohar Perme method. Relative Excess Risks (RER) of death was estimated through generalized linear models with a Poisson error structure.

Results
1196 cases of LC were included (760 from Granada and 436 from Huelva). 83% were men and 62% over 65 years old. Microscopic verification was obtained in 80% of cases. 34% were adenocarcinoma, 29% squamous cell, 18% small-cell and 19% other types. 15% were stage I-II and 61% were stage IV. Surgery was performed on 15% of patients, chemotherapy on 44%, and radiotherapy on 33% of cases. Two-year net survival was 20.7% in Granada and 16.5% in Huelva. After adjustment, two-year risk of death was 21% higher in Huelva than Granada. Tobacco consumption (RER=1.9 smoker vs non-smoker), advanced stage (RER=10.1 stage IV vs I), small-cell carcinoma (RER=1.3 vs adenocarcinoma) and not receiving surgery (RER=3.3), chemotherapy (RER=2.6) or radiotherapy (RER=1.6) were significant risk factors for survival.

Conclusions
Huelva population had higher risk of death due to LC compared with Granada population. Diagnosis at late stages and the low percentage of cases that can be surgically treated are key factors affecting survival in lung cancer. Therefore, efforts should be focused on early diagnosis since this factor could improve the effectiveness of treatments and thus the overall survival of lung cancer patients.

Theme: **Cancer registries and evaluation of cancer care**

A population level investigation of cancer clinical trials participation in a UK region

Conan Donnelly, Melanie Morris, Richard Wilson, Victoria Cairnduff, Amy Wotherspoon, Amy Devlin, Anna Gavin

N. Ireland Cancer Registry, Queen's University Belfast, UK

Background and Introduction

To document cancer trial participation since establishment of Cancer Trials Network and investigate population and disease factors associated with trial participation.

Materials and Methods

An independent cohort of 50 400 cancer patients from the cancer registry covering the same population (2007-2012) was linked to a database of 1316 interventional cancer trial participants in a UK region. The primary outcome measure was participation in an intervention clinical trial. Patients were followed up until 31 December 2013. Kaplan Meier tests and Cox proportional hazard models using person days at risk to allow for death were used to investigate factors associated with trial participation. Multivariate analysis assessed the impact of age, cancer type and stage, distance from the cancer centre (radiotherapy), marital status, deprivation quintile and rurality. Participation was analysed separately for children (aged <15 years).

Results

Trial recruitment increased three-fold with establishment of a network. Participation was highest for children at 21% but relatively low at 2.05% for adults, highest for haematological malignancies (4.5%). Lower likelihood of trial participation in adults was associated with female sex, older age, distance from regional Cancer Centre and stage 1 disease.

Conclusions

The introduction of a regional Cancer Trials Network increased participation, however, trial participation remains relatively low at population level especially among elderly patients. Linkage of clinical trials and cancer registry database provide an easy mechanism to monitor trial representativeness at population level.

Theme: **Cancer registries and evaluation of cancer care**

Trends in patterns of care for breast cancer patients in Navarre, Spain. A population-based high resolution study

Marcela Guevara,[1,2,3] Jorge Díaz-González,[1,3] Rosana Burgui,[1,2,3] Erkuden San Román,[1,3] Mª Josefa Urbina,[1,3] Conchi Moreno-Iribas,[1,3,4] Esteban Salgado,[3,5] Alicia Córdoba,[3,5] Concepción de Miguel,[3,5] Eva Ardanaz[1,2,3]

[1]Instituto de Salud Pública de Navarra, Pamplona, Spain [2]CIBER Epidemiología y Salud Pública, Spain [3]Navarra Institute for Health Research (IDISNA), Pamplona, Spain [4]Red de Investigación en Servicios de Salud en Enfermedades Crónicas (REDISSEC), Spain [5]Complejo Hospitalario de Navarra, Pamplona, Spain

Background and Introduction
This population-based study aims at evaluating temporal trends in patterns of care for breast cancer patients in Navarre, Spain, according to major recommended treatment options.

Materials and Methods
From the Navarre Cancer Registry all women diagnosed in 2005 and from Jan-2013 to Feb-2014 with primary invasive, non-metastasized breast cancer were selected. Cases with breast cancer other than carcinoma (*i.e.* sarcoma) were excluded. Locoregional treatment was considered guideline-adherent when a patient had breast-conserving surgery and radiotherapy (RT) or mastectomy with or without RT, in all cases with any axillary surgical procedure. The receipt of systemic therapy was also analyzed. Patterns of care in 2013-14 were compared to 2005.

Results
A total of 731 breast cancer cases were included, 300 of 2005 and 431 of 2013-14. The mean age was 60±14 years in both periods. The proportion of patients receiving guideline-adherent locoregional treatment did not change significantly and were 90% in 2005 and 87% in 2013-14 ($p=0.240$). There was a trend towards increased use of BCS in the last period vs. 2005. Sentinel node biopsy was carried out in 56% and 79% of the cases in 2005 and 2013-14, respectively ($p<0.001$), while the proportion of patients with lymphadenectomy declined from 47% to 27% ($p<0.001$). Among cases with oestrogen receptor positive 97% in 2005 and 94% in 2013-14 received endocrine treatment ($p=0.09$); and among patients with node-positive disease or hormone receptor negative or HER-2 positive tumours 71% in both periods received chemotherapy. The percentage of patients with HER-2 positive tumours that received targeted treatment increased from 39% in 2005 to 68% in 2013-14 ($p=0.002$).

Conclusions
Adherence to standard care for breast cancer in Navarra is high. Knowledge of changes in patterns of care may help evaluate the effects of guidelines.

Funding: FIS (PI07/0700), La Caixa 2015, CIBERESP.

Theme: Cancer registries and evaluation of cancer care

Improving survival of patients with hepatocellular carcinoma between 2005 and 2012 in the Finistere area, France

Alice Billot-Grasset,[1,2] Mélanie Cariou,[1] Mathilde Calament,[3] Florence Tanné,[3] Michel Robaszkiewicz,[1,2,3] Jean-Baptiste Nousbaum[1,2,3]

[1]Digestive Tumors Registry of Finistère, Brest, France [2]ERCR SPURBO, University of Western Brittany, Brest, France [3]Department of Hepatogastroenterology, University Hospital, Brest, France

Background and Introduction

Relevant diagnostic procedures and advanced treatments have been introduced in the management of hepatocellular carcinoma (HCC). The aim of the study was to assess the effect of treatment procedures evolution on survival between 2005 and 2012 in the Finistere area.

Materials and Methods

All cases of HCC (n=971) diagnosed from January 1st, 2005, throughout December 31st, 2012, were registered in the database of the Finistere registry of digestive cancers. Diagnostic circumstances, medical background, type of diagnosis confirmation, Child-Pugh score and BCLC staging classification, treatment and AFP levels have been tested for their effect on survival. Patients were divided into two groups according to the diagnosis date. The five-year cancer specific survival (CSS) was calculated using Kaplan-Meier method and a multivariate analyse was performed.

Results and Conclusions

Overall, the five-year CSS significantly increased during this eight-year period, from 12.9% for cases diagnosed between 2005 and 2008 to 21% for cases diagnosed from 2009 onward ($p<0.05$). Patients diagnosed during screening procedures had a five-year survival rate of 25.5% vs 7.6% in case of symptomatic diagnosis ($p<0.001$). They underwent more curative or interventional treatment in 67% of cases whereas it dropped to 22.2% in case of symptomatic diagnosis. We observed a strong association between the AFP level and prognosis, CSS being 25.9 months (IC95 20.5-30.8) for AFP level below 14 ng/mL, as compared with 9.7 months (IC95 7.3-11.5) and 3.1 months (IC95 2.6-3.8) for levels between 14 and 199 ng/mL or above 200 ng/ml respectively. In the multivariate analysis, clinical presentation, tumor size, AFP level, Child-Pugh score, BCLC stage and treatment were independent prognostic factors for the five-year CSS. Cancer specific survival rate significantly increased during this eight-year period in HCC patients, mostly in patients diagnosed during screening. A low level of AFP is a significant prognostic factor.

Theme: Cancer registries and evaluation of cancer care

Impact of the decline in colorectal cancer participation screening

Alice Billot-Grasset,[1,4] Mélanie Cariou,[1] Carole Picart,[2] Françoise Bommelaere,[3] Jean-Yves Le Reste,[4] Jean-Baptiste Nousbaum,[1,2,4] Michel Robaszkiewicz[1,2,4]

[1]Digestive Tumors Registry of Finistère, Brest, France [2]Department of Hepatogastroenterology, University Hospital, Brest, France [3]Cancer prevention coordination center (ADEC29), Brest, France [4]ERCR SPURBO, University of Western Brittany, Brest, France

Background and Introduction

The objectives were: a) to measure the evolution of participation rate during the three first colorectal (CRC) screening campaigns organized in the Finistere area between 2004 and 2010; b) to assess the impact of decline in participation on diagnosis stage and five-year survival; c) to compare CRC patients characteristics according to each screening status [screen-detected cancer (SDC), screen-excluded cancer (SEC), interval cancer (IC) and non-responders cancers (NRC)] with a control group of patients diagnosed between 2002 and 2004.

Materials and Methods

This retrospective study covered the first three CRC screening campaigns (C1,C2,C3) organised in the Finistere area in France. We matched all cases diagnosed during the three campaigns registered from the Finistere registry of digestive cancers with those from cancer prevention coordination center database in order to specify the screening status for each patient. Descriptive analyses of age at diagnosis, gender, stage, and subsite have been conducted. Incidence rate and disease-specific survival have been estimated. The screening campaign participation rate was 47.6% for C1 (2004-2006), 34.6% for C2 (2006-2008) and 33.7% for C3 (2008-2010). A total of 2842 CRC were identified (SDC=547, SEC=231, IC=436, NRC=1628) and 687 in the control group. The proportion of in situ CRC was significantly higher in C1 (21.9%) than in C2 (14.0%) and C3 (17.8%). The proportion of stage III CRC was higher in C2 (27.3%) vs C1 (19.7%) and C3 (21.3%). There was no significant difference between the three campaigns regarding age at diagnosis, gender, subsite, the overall survival nor the disease-specific survival.

Results and Conclusions

Despite a decrease in CRC screening participation over time, it remained an important benefice to CRC screening by permitting more early CRC diagnosis when the compliance was higher. Moreover, we showed that the decrease in participation had no significant impact on disease-specific five-year survival.

Theme: Cancer registries and evaluation of cancer care

Investigating the characteristics of breast cancer patients assigned to self-directed aftercare programme

Victoria Cairnduff, S. Lardner, Deirdre Fitzpatrick, Anna Gavin

N. Ireland Cancer Registry (NICR), Centre for Public Health, Queen's University Belfast, UK

Background and Introduction

In recent years there has been increased interest in new models of cancer follow-up due to the pressure that increasing cancer survivorship places on the healthcare system. A self-directed aftercare (SDA) programme which initially focused on patients diagnosed with breast cancer was established in N. Ireland (NI) in 2013. This study aims to investigate the characteristics of breast cancer patients who were assigned to the SDA programme with comparisons to the total population of patients diagnosed with breast cancer in NI.

Materials and Methods

Data on the disease and socio-demographic characteristics for invasive breast cancer patients (ICD-10 C50) assigned to the SDA programme between 2013 and 2015 were extracted from the N. Ireland Cancer Registry database. Chi-square analysis was carried out to investigate statistical differences in disease and socio-demographic characteristics between patients assigned to the SDA programme and all patients diagnosed with breast cancer over the same time period.

Results

Preliminary findings have shown that a higher proportion of patients on the SDA programme (n=1365) were diagnosed at stage I and II (93%) when compared with average of all patients (73%) diagnosed with breast cancer in NI between 2010 and 2014. The patients on SDA were also more likely to be younger with 77% patients aged less than 70 years at diagnosis when compared with 68% of total breast cancer population. No significant differences in receipt of SDA were observed across deprivation quintiles.

Conclusions

Overall the findings show differences in age and stage of patients assigned to SDA. Further analysis to investigate differences estimated survival between patients assigned to the SDA programme and those in the total breast cancer population is now required

Acknowledgements: The N. Ireland Cancer Registry is funded by the Public Health Agency of N. Ireland and this research work has been funded by Macmillan Cancer Support.

Theme: **Cancer registries and evaluation of cancer care**

The analysis of hospitals of referral and treatment in rare cancer patients

Riccardo Capocaccia,[1] Laura Botta,[1] Liesbet van Eycken,[2] Nadya Dimitrova,[3] Sabine Siesling,[4] Maarit Leinonen,[5] Harry Comber,[6] Eva Ardanaz,[7] Maja Primic Žakelj[8]

[1]Fondazione IRCCS Istituto Nazionale dei Tumori (INT), Milan, Italy [2]Belgian Cancer Registry, Brussels, Belgium [3]Bulgarian National Cancer Registry, National Oncology Hospital, Sofia, Bulgaria [4]Netherlands Comprehensive Cancer Organisation (IKNL), Utrecht, the Netherlands [5]Finnish Cancer Registry, Helsinki, Finland [6]Irish National Cancer Registry, Cork, Ireland [7]Navarra Cancer Registry, Pamplona, Spain [8]Epidemiology and Cancer Registry, Institute of Oncology Ljubljana, Ljubljana, Slovenia

Background and Introduction

The hospitals in which cancer patients are diagnosed and treated are usually available in the cancer registry datasets (CR). A pilot study has been carried out by the RARECARENet project to evaluate the referral patterns for rare cancers and to give insight in the possible systematic use of hospital of diagnosis or treatment.

Materials and Methods

The study involved seven European CRs, who provided individual data on incidence and hospitals of treatment for 225 000 patients diagnosed with rare cancers during the period 2000-2007 and followed-up for vital status to the end of 2012.

Results

Different indicators have been defined and were applicable on at the individual, hospital and national level to measure the degree of centralization in rare cancers treatments. All of them show large heterogeneity, both between countries and between cancers. For some cancers (*e.g.* head and neck cancers, CNS tumours, bone sarcomas, uveal melanoma, retinoblastoma) there was a clear effort to centralize treatment, for others (such as ovarian, biliary and urinary tract rare cancers) a high degree of dispersion of treatment was observed. At the aggregated level, there is a positive correlation between the degree of centralization and five year survival observed among countries, for most of the considered cancers. The relation between hospital volume and survival estimated at the individual level indicated a better prognosis of patients referred to high volume hospitals for head and neck cancer and for soft tissue sarcomas, depending from stage at diagnosis.

Conclusions

The information on hospital of diagnosis and/or treatment collected by CR provide important insights on cancer care organization and its relation with outcome. However, they have to be cautiously interpreted in connection with information on the existence of networks, the resources available, stage and other tumour characteristics, and the frequency of the cancer in the population considered.

Theme: Cancer registries and evaluation of cancer care

Survival of hematological malignancies in France between 1989 and 2013: a population-based study from FRANCIM network

Alain Monnereau,[1,2] Zoé Uhry,[3,4] Xavier Troussard,[1] Anne Cowppli-Boni,[1] Emilie Marrer,[1] Florence Binder,[1] Patricia Delafosse,[1] Bénédicte Lapôtre-Ledoux,[1] Nadine Bossard,[3] Marc Maynadié[1] on behalf of the French Network of Cancer Registries (FRANCIM)

[1]FRANCIM (French Network of Cancer Registries), Toulouse, France [2]Hematological Malignancies Registry of Gironde, Bordeaux, France
[3]Hospices Civils de Lyon, Biostatistics Service, Lyon, France [4]French Institute of Public Health, Saint-Maurice, France

Background and Introduction
This study aims to provide updated estimates of 1, 3, 5 and 10-years net survival and survival trends in patients diagnosed with hematological malignancy (HM). We also provide 15-year survival estimates for the first time in France.

Materials and Methods
The present study included 35520 incident cases diagnosed between 1989 and 2010 with one of the 16 HM distinct clinical entities, aged 15+ in 16 metropolitan departments. The data were collected by the French population cancer registries (FRANCIM network). The vital status was registered according to a standardized procedure (last update 30/06/2013). Net survival was estimated with the unbiased Pohar-Perme method.

Results
For 2005-2010, the 5-years standardized net survival (5ys SNS) varies dramatically from 22% for acute myeloid leukemia to 87% for marginal zone lymphoma. Seven out of the sixteen HM studied (45.5% of incidence cases) have a good prognosis with 5ys SNS of 75% or more. Reversely, two HM have a poor prognosis with 5ys SNS less than 33% (10% of incidence cases). We observe upward trends in 5ys SNS for several HM, significant (+18% or more) for chronic myelogenous leukemia, follicular lymphoma and diffuse large B-cell lymphoma. These trends are observed in both sexes and in all age categories except for follicular lymphoma (cases aged 55 years or more). For other HM, upward trends in survival are less important but still detectable also for aggressive diseases such as in youngsters with acute myeloid leukemia or lymphoblastic leukemia/lymphoma.

Conclusions
Most of the HM included in this analysis have shown better survival over time. For three specific HM entities, the progresses issued from clinical research seem to translate in better survival outcome in the general population. The access and usage of highly efficient novel treatments with low toxicity could largely explain these observations.

Theme: Cancer registries and evaluation of cancer care

Trends in survival of childhood cancer in Osaka, Japan, 1975-2009

Kayo Nakata, Isao Miyashiro, Toshitaka Morishima, Yuri Ito, Masami Inoue, Junichi Hara, Keisei Kawa, Nariaki Matsuura

Center for Cancer Control and Statistics, Osaka Medical Center for Cancer and Cardiovascular Diseases, Osaka, Japan

Background and Introduction

Although a dramatic improvement of childhood cancer survival has been reported in Europe, population-based evaluation of childhood cancer survival is scarce in Japan. We investigated trends in survival for childhood cancer using population-based cancer registry data in Osaka, Japan.

Materials and Methods

Study subjects were 6405 children (0-14 years) registered in the Osaka cancer registry, diagnosed with cancer during the period 1975-2009. Cancers were divided into 12 categories based on the International Classification of Childhood Cancers (ICCC) third edition. We estimated the five-year observed survival for each ICCC using the Kaplan-Meier method, over four decades, 1975-1979, 1980-1989, 1990-1999, 2000-2009.

Results

Five-year observed survival of all childhood cancer was 36.4% (95% CI 33.3-39.4) in 1975-1979 and had improved to 82.8% (95% CI 80.8-84.7) in 2000-2009. Improvement was remarkable in leukemia (from 20.0% to 82.9%), lymphoma (from 30.2% to 89.9%), and bone tumor (from 16.1% to 75.9%). However, survival of brain tumor and soft tissue sarcoma was still low (73.1% and 73.7%) in 2000-2009.

Discussion

Our results indicated that Japanese childhood cancer survival improved dramatically in these four decades. This is resulting in an increased population of long-term survivors who need long-term follow-up and efforts to minimize morbidity and prevent secondary cancer. In addition, the trend in survival was different for each cancer type. Because cancer biology or treatment strategy may differ in each cancer type, it is necessary to evaluate their survival separately.

Conclusions

Population-based cancer registry data shows a dramatic improvement of childhood cancer survival in Japan, in the long term.

Theme: **Cancer registry data: quality, methods, and tools**

Thyroid cancer risk in the Palermo province: a spatial analysis

Walter Mazzucco,[1] Barbara Ravazzolo,[1] Rosalba Amodio,[1] Maria Angela Brucculeri,[1] Rita Mannino,[1] Giuseppa Rudisi,[1] Maria Antonietta Cascio,[1] Rosanna Cusimano,[1,2] Francesco Vitale[1]

[1]Registro Tumori di Palermo e Provincia AOUP 'Paolo Giaccone', Palermo, Italy [2]UO Sanità Pubblica Epidemiologia e Medicina Preventiva ASP Palermo, Palermo, Italy

Background and Introduction

Sicily documents a higher incidence for thyroid cancer than the remaining Italian regions. Aims of the study are to scan the geographical distribution of incident cases and to identify areas at risk of thyroid cancer in the Palermo province.

Materials and Methods

The 1653 incident cases (366 males and 1287 females) of malignant thyroid cancer (ICD10 C73) diagnosed between 2003 and 2011 and registered by the population-based cancer register were georeferenced at the municipal level, through record linkage with vector cards provided by the Italian Statistical National Institute. SatScan GIS spatial analysis software was used, assuming a Poisson distribution model adjusted for age and conditioned to population density. LLR and the corresponding p-value were obtained by performing Monte Carlo simulation. As maximum cluster size, it was assumed the 30% of the population at risk and a high level of not compactness.

Results

Three risk clusters were identified. The first cluster (A1) included 19 municipalities with 138 incident versus 89 expected cases (RR=1.61; p=0.0029). The second one (A2), considering only females, was almost comparable to cluster A1 and included 22 municipalities with 133 incident versus 86 expected cases (RR=1.60; p=0.0037). A third cluster (A3) related to malignant tumors with papillary histology was identified in a subarea within the A2 cluster area, by using the available 92.6% cases microscopic verifications. A3 cluster included 14 municipalities, with 107 incident versus 62 expected cases (RR=1.80; p=0.001); considering females only, it documented a RR=1.90 (p=0.0015), with 88 incident versus 48 expected cases.

Conclusions

All of the identified risk clusters belonged to a specific mountains area. Thus, the lack of iodine has to be considered. The results are in line with previous studies and, in the absence of known environmental exposures, appear to be independent from health surveillance related to benign thyroid disease.

Theme: **Cancer registry data: quality, methods, and tools**

Step by step towards the implementation and quality of the Castile and Leon population-based Cancer Registry (CLPBCR)

Pilar Gutiérrez, Rufino Álamo, Isabel Carramiñana, Isabel González, Adriana del Villar, Pilar Álvarez, Inmaculada Gil, José Antonio Iglesias and José Miguel Cobo

Castile and Leon Population-based Cancer Registry, Public Health Office, Castile and Leon Government, Valladolid, Spain

Background and Introduction

Castile and Leon is the largest region in Spain, divided in nine provinces, with about 2.5 million population. The progressive implementation of the CLPBCR and the process to improve quality of the collected data between 2004-2014 is described.

Materials and Methods

Aimed to achieve a Population-based Cancer Registry covering 100% of the Castile and Leon population and getting acceptable international indices of quality, the CLPBCR has followed a process to improve registry coverage and completeness, validity and comparability of the data. During this process have been necessary updates in definitions, classification and coding in addition to train all registry personnel.

Results

The first step was to collect in the CLPBCR information of 14 Hospital-based cancer Registries from public hospitals (main source of information), which are preparing with a mixed method: automatized procedures of data collection from databases and manual review of critical points. In addition, other sources available were recorded as private hospitals, other care centres and laboratories (36 altogether).The CLPBCR started in 2004 in three provinces (covering 44% of the Castile and Leon population). The rest of the provinces set off their participation gradually and 100% coverage was achieved in 2010. During this time were updated the classification and coding (ICD-O 3rd edition and later 2011 Updates) and were implemented in the CLPBCR software the main cancer quality checks propose by European Network of Cancer Registries (consistency between variables). After that the CLPBCR converted and checked their data. Other important critical point was to get access to death certificates with mention of cancer as one of the causes. This issue was resolved and these dates are available from 2010 and forward.

Conclusions

This ten years process to improve of the CLPBCR has enabled the data included to give acceptable indices of quality nowadays.

Theme: **Cancer registry data: quality, methods, and tools**

Software tool for increasing cancer data quality within Northwestern Regional Cancer Registry from Romania

Luminita Blaga,[1,2] Daniela Coza,[1,2] Alexandru Todescu,[1,2] Jan Nygård,[3] Ofelia Suteu,[1,4] Anton Bereschi,[1,2] Florian Nicula,[1] Adela Moldovan,[1,2] Ciprian Turcu,[1,2] Patriciu Achimas-Cadariu[1,4]

[1]The Oncology Institute 'Prof. Dr. Ion Chiricuta', Cluj-Napoca, Romania [2]Northwestern Regional Cancer Registry, Cluj-Napoca, Romania
[3]Cancer Registry of Norway, Oslo, Norway [4]'Iuliu Haţieganu' University of Medicine and Pharmacy, Cluj-Napoca, Romania

Background and Introduction

The Northwestern Regional Cancer Registry (RRCNV), hosted by the Oncology Institute from Cluj-Napoca, covers six Romanian counties accounting for 14% of surface and 12.7% of population. RRCNV started a project funded within the EEA Grants framework, in collaboration with the Cancer Registry of Norway (CRN), aiming to build a web-based synoptic reporting application (OncReg) in order to enhance quality and completeness of cancer data collected by RRCNV.

Materials and Methods

We developed a streamlined data collection and communication system, in a .NET environment, to meet an eclectic multi-source information system.

Results

OncReg is designed to provide various health care units with an easy to use tool but with enhanced capabilities for saving time and human resources in activities such as performing classification or information extraction from free text reports. Our software tool has been integrated easily in the daily activities of health professionals involved in cancer care and the feedback from various stakeholders is very favorable. Behind the user-friendly interface a complex data processing is developed to improve consistency and accuracy of case abstraction and to enhance the minimum data set with high resolution site specific data and geographic data. OncReg also connects with screening databases. Confidentiality, protection and security of data are addressed.

Conclusions

We expect to observe an improvement in completeness and timeliness of regional cancer data and figures as well as an accurate assessment of the efficiency of screening programs on specific target populations and provide an assessment tool for cancer burden in our region. This is expected to lead to improved governance in health care in the NW region, also creating premises and acquired experience for enhancement at national level, regarding one of the major health problems in Romania, namely cancer.

Theme: **Cancer registry data: quality, methods, and tools**

Evaluation of completeness of case ascertainment in Swiss cancer registration

Matthias Lorez,[1] Andrea Bordoni,[2] Christine Bouchardy,[3] Bertrand Camey,[4] Silvia Dehler,[5] Silvia Ess,[6] Harald Frick,[6] Isabelle Konzelmann,[7] Mohsen Mousavi,[8] Sabine Rohrmann,[5] Volker Arndt[1]

[1]Foundation National Institute for Cancer Epidemiology and Registration (NICER), Zürich, Switzerland [2]Ticino Cancer Registry, Locarno, Switzerland [3]Geneva Cancer Registry, Geneva, Switzerland [4]Fribourg Cancer Registry, Fribourg, Switzerland [5]Zürich Cancer Registry, Zürich, Switzerland [6]St. Gallen-Appenzell Cancer Registry, St. Gallen, Switzerland [7]Valais Cancer Registry, Sion, Switzerland [8]Basel Cancer Registry, Basel, Switzerland

Background and Introduction

The value of population-based cancer registries (CRs) depends strongly on completeness of case ascertainment, *i.e.* the extent to which all diagnosed neoplasms are included in the registry database. This is the first comprehensive evaluation of completeness in Swiss cancer registration.

Materials and Methods

We applied simple quality measures, such as the proportion of cases for whom the death certificate is the first notification (DCN%), or the proportion of cases based on histology or cytology (MV%), as well as more developed methods such as the MI-Surv method of comparing the ratio of crude mortality and incidence rates with relative survival (RS) and the Flow method, which estimates the exact number of missed diagnoses. All 10 Swiss CRs in operation since at least 2006 are included. Diagnosis period was 2006-2011.

Results

Death certificates played a minor role for case finding (DCN≤6%) in all CRs for most types of cancer, except hepatic and pancreatic cancer. They were thus flagged as potentially under-registered in 8 of 10 CRs. Comparison of registry-specific MV% with all 10 combined CRs flagged a single unusual high value for hepatic cancer in one CR. For the MI-Surv method, the complement of five-year RS proportion (1-RS) was subtracted from the corresponding MI ratio. One type of cancer, lymphoid leukaemia, was systematically flagged in 6 of 8 CRs. The Flow method estimates completeness depending on year since diagnosis. The only diagnostic group which was systematically flagged in 6 of 7 registries at 3 years after diagnosis was lymphoid leukaemia.

Conclusions

Focusing on findings replicated by several methods, we identified only lymphoid leukaemia as potentially under-registered by most Swiss CRs. This was due to the high proportion of chronic types of leukaemia. As next steps, we will follow up flagged cancer types in individual CRs to substantiate these findings and identify ways of improvement.

Theme: **Cancer registry data: quality, methods, and tools**

The Finnish Cancer Registry description

Tiina Hakanen, Henna Degerlund, Nea Malila

Finnish Cancer Registry, Institute for Statistical and Epidemiological Cancer Research, Helsinki, Finland

Background and Introduction

The Finnish Cancer Registry (FCR) was founded in 1953 by the Cancer Society of Finland in collaboration with the National Board of Health. FCR covers also the Mass Screening Registry, which was founded in 1968. This report is only focused on the Cancer Registry data content.

Materials and Methods

The nation-wide database contains all persons resided in Finland whom have been diagnosed with cancer. The cancer notifications submitted to the FCR, and the information from Statistics Finland as well as the Finnish Population Register center are modified into a suitable database for statistical use. All Finnish hospitals, practising physicians and other relevant institutions must send a clinical notification to the FCR. Before 2016 year the notifications could only be able to fill manually and submit to the FCR by post. At the beginning of the year 2016 FCR introduced the electronic clinical notification. In addition, pathological and haematological laboratories are requested to report all cancer cases that come to their attention to the FCR. At the end of the 1980s the laboratory notifications started to become electronically and currently the major of laboratory notifications are obtained automatically from laboratory data systems. In year 2014 approximately 32 000 cancer cases was registered in the FCR.

Results

Since 1967 everyone resided in Finland has been assigned a personal identity code (PID), which is stored in the FCR database and is the key in all practical registration procedure. After that the FCR database is regularly linked with Population Register Center and Statistics Finland (based on (PID)) where the cancer patients' personal information is checked. Also complements like dates and causes of death, time of emigration and immigration, person's socioeconomic status etc. are obtained.

Conclusions

This report contains the FCR database description which is important to know since the data is widely used for statistical and research purposes.

Theme: **Cancer registry data: quality, methods, and tools**

Optimisation of malignant mesothelioma registration at the Belgian cancer registry

Michael Rosskamp,[1] Harlinde De Schutter,[1] Mia Slabbaert,[1] Kris Henau,[1] Marleen Praet,[2] Jan Van Meerbeeck,[3] Kristiaan Nackaerts,[4] Liesbet Van Eycken[1]

[1]Belgian Cancer Registry, Brussels, Belgium [2]Belgian Mesothelioma Registry, University Hospital of Ghent, Ghent, Belgium [3]University Hospital of Antwerp, Antwerp, Belgium [4]KU Leuven, University Hospital of Leuven, Leuven, Belgium

Background and Introduction

Malignant mesothelioma (MM) is a rare but aggressive cancer mostly caused by asbestos exposure, and for which diagnosis is difficult to make. Completeness and correctness of MM registration at the Belgian Cancer Registry (BCR) is assessed using information from three independent national databases, *i.e.* the standard cancer registration, the population-based mortality statistics (death certificates, COD) and the Belgian Mesothelioma Registry (BMR).

Materials and Methods

The study cohort includes all MM diagnoses reported to BCR (2004-2012; n=2344), all patients reviewed by the pathology commission of BMR (2004-2012; n=2019), and COD data for all Belgian citizens (2004-2013). All available data are compared for diagnosis and immunohistochemical (IHC) tests as derived from the available pathology reports (APD) at BCR or registered by BMR.

Results

Preliminary analyses (n=1927; 81% of the study cohort) showed that 94% of diagnoses were concordant between BCR and BMR. The proportion of MM without specified histological diagnosis (28% before project start) could be reduced to less than 1%. IHC results derived from APD and/or BMR were available for 86% of the cases. The most commonly performed markers were calretinin, CEA, CK5/6 and TTF1, as expected. Different IHC patterns could be distinguished in concordance with MM histology. MM was mentioned in 165 COD between 2004-2011 that remained uncoupled to BCR. For 139 patients registered at BCR with a different diagnosis, COD indicated MM as cause of death.

Conclusions

This projects aims to achieve a complete and correct registration of MM diagnoses in Belgium by comparing information from three independent national databases. Discordant cases will be explored in detail and if necessary, a pathology revision will be performed. Once a definitive database is obtained, further analyses will be conducted including in-depth profiling of long-term survivors and description of treatment patterns.

Theme: **Cancer registry data: quality, methods, and tools**

The small-area cancer atlas Schleswig-Holstein, Germany

Ron Pritzkuleit, Nora Eisemann, Alexander Katalinic

Institute of Cancer Epidemiology, University of Lübeck, Lübeck, Germany

Background and Introduction

Schleswig-Holstein is the northernmost federal state of Germany. It is bordering to Denmark, the Baltic Sea, and the North Sea. It has 2.8 million inhabitants, about 50 % of them living in rural areas. The state is divided in more than 1100 municipalities (min 5, median 721, max 78 000 inhabitants) and on the next higher administration structure there are 173 departments (mean 15 000 inhabitants). The Schleswig-Holstein Cancer Registry started the area-wide registration in 1998, has a completeness of more than 95 %, and registered on the spatial level of municipalities. The population-based cancer registration is predestined for small-area analyses and mapping. But three important points have to be considered – data privacy, data stability and the trust of the population to the analyses. In this context we started to develop a small-area cancer atlas for our region and found a lot of inspirations and suggestions in the All-Ireland-Cancer Atlas and the Queensland Cancer Atlas.

Materials and Methods

The atlas includes the ten-year-period 2001 to 2010. We used two spatial levels – the municipality-level with a Bayesian spatial smoothing model (BYM) and the department level without smoothing. For 20 cancer sites we calculated three indicators – incidence and mortality ratios (SIR, SMR) and excess survival (RER). A quasi-continuous scale was used for maps. On the level of departments we used incidence data as direct age-standardized rate with an absolute scale.

Results

Maps and charts for selected cancers are presented. The visualization of cancer patterns is feasible and useful.

Conclusions

The combination of small-area smoothed data and a quasi-continuous scale enables to observe spatial patterns of cancer. It is helpful to evaluate the possible cancer causes and cancer care with small area maps to generate hypotheses and use them for risk communication. A discussion of the results with clinicians and stakeholders will be initiated.

Cancer specific Potential Years of Life Lost (PYLL(75)) in Belgium

Geert Silversmit, Evelien Vaes, Liesbet Van Eycken

Belgian Cancer Registry, Brussels, Belgium

Background and Introduction

Besides incidence, mortality, and survival, 'Potential Years of Life Lost' (PYLL) is another measure to quantify the impact of cancer. PYLL is defined as the number of years not lived before a given reference age and can most easily be calculated using a fixed reference age, a_ref, for all individuals, noted as PYLL(a_ref). For a cohort of cancer patients PYLL(a_ref) has a few drawbacks: (1) it depends on the choice of the reference age, (2) as a consequence it is a comparative quantity only, and (3) it cannot be fully assigned to the cancer as deaths not related to the cancer will also contribute to the observed life years lost. A method to estimate the expected PYLL for a matched group from the general population is proposed. Comparison to the observed PYLL allows to estimate the actual PYLL fraction that can be assigned to the cancer.

Materials and Methods

Belgian residents older than 14 years diagnosed in the period 2004-2013 were considered. Vital status was obtained from the Belgian Crossroads Bank for Social Security up to the 1st of July 2015. A reference age of 75 years was applied, resulting in PYLL(75). The framework of the calculation of the relative survival by the actuarial and the Ederer II method was used to estimate the number of expected deaths by age, which allows to calculate the expected PYLL*(75). The fraction 1-PYLL*(75)/PYLL(75) of the observed potential life years lost can then be assigned to the cancer.

Results

The mean PYLL(75) and its cancer-specific fraction at the Belgian national level for a selection of cancers sites are: colon: 1.9 year, 88.9 %; rectum: 2.3 year, 87.4 %; pancreas: 6.4 year, 98.6 %; lung: 6.9 year, 97.9 %; breast: 1.4 year, 78.7 %; prostate: 0.6 year, 20.5 %; and testis 1.5 year, 75.3 %.

Conclusions

Cancer-specific PYLL(75) can be obtained via the framework of relative survival and Ederer II matching to the general population. The PYLL(75) is limited to a comparative quantity.

Theme: **Cancer registry data: quality, methods, and tools**

Estimating cancer incidence from drug prescriptions, outpatient data, and hospital discharges

Giovanna Tagliabue,[1] Andrea Tittarelli,[1] Sabrina Fabiano,[1] Paolo Contiero[2]

[1]Cancer Registry Unit, Fondazione IRCCS Istituto Nazionale dei Tumori (INT), Milan, Italy [2]Environmental Epidemiology Unit, Fondazione IRCCS Istituto Nazionale dei Tumori (INT), Milan, Italy

Background and Introduction

Cancer incidence data produced by cancer registries is delayed by two-three years or longer. However health authorities need incidence data that is as recent as possible for planning and evaluation. To provide more recent estimates of cancer incidence we developed a method that estimates incidence from information on individuals (hospital admissions for cancer, prescriptions of anti-neoplastic medications, etc.) available from health databases in combination with cancer registry prevalence data. For each person identified from health databases the method assigns a probability that the person really has cancer. The estimates are produced for macro-groups of cancer sites.

Materials and Methods

We used data up to 2009 from the Varese section of the Lombardy Cancer Registry (LCR) to identify prevalent cancer cases. We used files of hospital discharges, outpatient data and drug prescriptions for the years 2010 to 2012 persons with a cancer diagnosis during the years 2010 and 2011, subtracting cancer cases prevalent in 2009 and previously. For each combination of data items from the health databases we estimated the probability that a person with that combination of items had cancer, using the LCR cancer incidence data for 2010-2011 as gold standard.

Results

13307 cancer cases incident in 2010-2011 were identified from the LCR (gold standard). The incidence estimated by our method was 6% lower. Most of the cases lost to our method were identified by the LCR only from pathology reports–an information source not used by our method and most were cases from a limed number of sites (mainly skin). Estimated individual probabilities of cancer were in the range 67-100%.

Conclusions

It is possible to estimate the actual persons recently diagnosed with cancer in a population from health databases in combination with cancer registry prevalence data.

Theme: **Cancer registry data: quality, methods, and tools**

Cancer incidence estimation method: an Apulian experience

Anna Maria Nannavecchia,[1] Ivan Rashid,[1] Danila Bruno,[1] Vanna Burgio Lo Monaco,[1] Antonio Chieti,[1] Cinzia Tanzarella,[1] Francesco Cuccaro,[2] Lucia Bisceglia[3]

[1]Cancer Registry of Puglia—Coordination centre, Cancer Institute IRCCS Giovanni XXIII, Bari, Italy [2]Cancer Registry of Puglia—Local Health Unit of Barletta-Andria-Trani, Barletta, Italy [3]Cancer Registry of Puglia—Health Regional Agency of Puglia, Bari, Italy

Background and Introduction

Cancer Registry of Puglia (RTP) was instituted in 2008 as a regional population-based cancer registry. It consists of six sections (FG, BT, BA, BR, LE and TA) and cover more than 4500000 inhabitants. At present, four of six sections have got accreditation by AIRTum (53% of regional population). To point out possible regional geographic variability in cancer incidence and also in order to support health services planning, we developed an original estimation method to ensure a complete territorial coverage.

Materials and Methods

Incidence data of the four accredited RTP sections for the shared incidence period 2006-2008 and the 2001-2013 hospitalization regional data have been considered. In order to take into account specific health features of different provinces, we realized an estimate of cancer incidence rates in not accredited cancer registry areas (NACRA), adjusting the rates of accredited cancer registry areas (ACRA) with a factor that consists in a ratio between NACR and ACR hospitalization rate. We checked results comparing the adjusted rates of NACRA with data of the two sections (Bari e Foggia), available for 2006. Finally, we estimated regional cancer rate as sum of ACR rates and NACR adjusted rates.

Results

Our estimates are close to real incidence data of NACR. They are also in agreement with expected health pictures for each area, for example a known higher rate of liver cancer in Bari province. For some site, as pancreas and prostate, results are not very close to real incidence data.

Conclusions

This method could be useful to assess cancer incidence when cancer registration data are not available, but hospitalization and neighboring incidence data are available. In this case, the aim is reached: we estimated cancer rates for the whole Apulian region. However, in the case of pancreas and prostate, whose estimates are very conditioned by survival, mortality information could be considered to improve the adjustment factor.

Theme: **Integrating cancer registry data and clinical practice**

ROR-Sul Platform: an innovative tool for cancer research and clinical practice

Ana Miranda, Alexandra Mayer, Cláudia Brito

IPOLFG EPE Lisbon Cancer Institute, Lisbon, Portugal

Background and Introduction

South Regional Cancer Registry (ROR-Sul) was created 1988 and regulated by law. It is a population based cancer registry with 4.8 million inhabitants.

Materials and Methods

ROR-Sul developed as network since 2007, however this Platform is a step ahead, since it is base in record linkage system, allowing the integration of data from different independent databases (we have a unique identifier for health system). There are three types data being linked: patient complete identification (from national citizens database, which is updated every fortnight), clinical data including exams, topography, morphology, staging and treatment modality (these data coming from different databases – pathology Lab, hospital pharmacy, radiotherapy system, etc are integrated by steps). This system allows the monitoring of each cancer case since presentation until death, which has enormous applications. Confidentiality is not compromised and we have different levels of access defined according to the user profile and data circulates in a private network.

Results

This platform allows clinicians to see the case as a whole and to update information concerning his patient. The central information processing ensures it is permanently available for research purposes.

Conclusions

In summary this platform may be seen namely as:

a) working tool for clinical purposes
b) a research tool on patterns of cancer care and pharmacoepidemiology
c) a research tool on monitoring the outcome and the effectiveness of new molecules.

Theme: **Integrating cancer registry data and clinical practice**

40 Years of collaboration between the Swiss Childhood Cancer Registry (SCCR) and Swiss Paediatric Oncology Group (SPOG)

Verena Pfeiffer,[1] Shelagh M. Redmond,[1] Matthias Schindler,[1] Gisela Michel,[2] Claudia E. Kuehni[1]

[1]Institute for Social and Preventive Medicine (ISPM), University of Bern, Bern, Switzerland [2]Department of Health Sciences and Health Policy, University of Lucerne, Lucerne, Switzerland

Background and Introduction

The SCCR is a population-based cancer registry including children diagnosed with leukaemia, lymphoma, central nervous system tumors, malignant solid tumors or Langerhans cell histiocytosis before age 21. The SPOG founded the SCCR in 1976. Here we describe the collaboration between the SCCR and the SPOG.

Materials and Methods

Data managers at all 9 specialized pediatric cancer centers (SPOG Stations) directly notify incident cases to the SCCR with detailed data on tumor and therapy. Follow-up information (remissions, relapses, therapies, toxicities) is received annually for at least five to 10 years after diagnosis (Dx). The SCCR codes this data according to ICCC-3. Childhood cancer (CC) patients are included in clinical studies (SP) or treated according to study protocols (NA) whenever possible. The SCCR reports to all SPOG Stations detailed information about their patients (code and date of Dx, type, protocol name of study, date of study informed consent, reason of being a non-study patient). SPOG Stations check accuracy and notify any mistakes. Annually, the SCCR reports the number of cancer cases in patients diagnosed or treated per individual center to the SPOG.

Results

By 12/2015, the SCCR included information on about 10325 neoplasms in 10103 patients, including 7926 neoplasms in 7846 children aged 0-14 years. 1764 children had at least one relapse five years after Dx. 95% of CC patients are treated by SPOG Stations. Among these 77% are included in clinical studies (SP: 51%), or treated according to study protocols (NA: 26%). Since 1995 registration of children with cancer in the SCCR is complete.

Conclusions

Close collaboration between the SCCR and the SPOG allows compiling a rich dataset for CC, which facilitates and enables joint research in CC epidemiology and long-term outcome. It guarantees quality control and clinical use of registered data, feedback to treating pediatric oncologists and contributes to improve CC therapy and survival.

Theme: **Integrating cancer registry data and clinical practice**

Establishing a population-based register of monoclonal gammopathy of undetermined significance in Northern Ireland

Charlene M. McShane,[1] Liam J. Murray,[1] Anna T. Gavin,[2] Eve Roman,[3] Han-I Wang,[3] and Lesley A. Anderson[1]

[1]Centre for Public Health, Queen's University Belfast, UK [2]Northern Ireland Cancer Registry, Queen's University Belfast, UK [3]Epidemiology and Statistics Research Group, University of York, UK

Background and Introduction

Monoclonal gammopathy of undetermined significance (MGUS), the most prevalent of the plasma cell dyscrasias precedes almost all cases of multiple myeloma (MM), an incurable blood cancer. Previous observational studies have reported an annual progression rate of 1% to MM and associated lymphoproliferative disorders and this risk has been reported to remain elevated beyond 25 years of observation. We aim to establish a population-based register of MGUS within Northern Ireland (NI) to investigate important patient outcomes.

Materials and Methods

To identify MGUS cases, all serum and urine protein electrophoresis investigations with a detectable paraprotein carried out in NI are being retrospectively reviewed and linked to the NI cancer registry. As MGUS can be caused by a number of haematological malignancies, individuals with a previous or concurrent lymphoproliferative malignancy (up to 12 months following MGUS diagnosis) will be excluded. Once established the MGUS register will be linked to a number of existing databases housed within the NI cancer registry to investigate important patient outcomes.

Results

The newly established register will be used to determine the incidence and prevalence of MGUS within NI and to investigate the rate of MGUS evolution during the follow-up period. The register will also be analysed to investigate the impact of MGUS on patient survival and medical resource use.

Conclusions

The proposed NI MGUS register will provide an excellent population-based resource to investigate the impact of a relatively common pre-malignant condition for which there is currently limited population-based data/registers available.

Theme: **Integrating cancer registry data and clinical practice**

Cancer risk among patients with type 2 diabetes mellitus: a population-based cohort study in Northeastern Italy

Ettore Bidoli,[1] Loris Zanier,[2] Antonella Zucchetto,[1] Jerry Polesel,[1] Saverio Virdone,[1] Martina Taborelli,[1] Luigino Dal Maso,[1] Elena Clagnan,[2] Michele Gobbato,[2] Diego Serraino[1]

[1]Unit of Cancer epidemiology, CRO National Cancer Institute, Aviano, Italy [2]Friuli Venezia Giulia Central Health Direction, Udine, Italy

Background and Introduction
Diabetes mellitus (DM) is associated with an elevated risk of cancer. The study aim was to assess cancer risk and survival of individuals with type 2 DM (T2DM) living in Friuli Venezia Giulia (FVG), Northeastern Italy.

Materials and Methods
A retrospective population-based cohort study on 32247 T2DM patients, aged 40-84 years, was conducted through a record linkage of FVG health-care databases and the FVG cancer registry for the 2002-2009 period. Standardized incidence ratios (SIR) with corresponding 95% confidence intervals (CI), and five-year survival probabilities were computed.

Results
The SIR for all cancer types (N=2069, 6.4%) was 1.28 (95% CI: 1.23-1.34). The highest SIRs were observed for liver, female genital organs, small intestine, and pancreatic cancers. After an initial three-year period, the risk for colorectal, liver, pancreatic, and kidney cancers remained significantly elevated and a reduced risk of prostate cancer (SIR=0.73, 95% CI: 0.54-0.96) was found in men aged 65-74 years. The overall five-year survival was 88.7%. T2DM patients with breast cancer showed lower five-year survival probabilities than those without diabetes.

Conclusions
This population-based study confirmed that T2DM patients are at increased risk of several cancers and of premature death. Specific primary and secondary cancer prevention programs are a priority among T2DM patients.

Theme: **Integrating cancer registry data and clinical practice**

Net survival of Hodgkin lymphoma by stage and histological subtype in Girona (Spain): a population-based study 1985-2013

Marta Solans,[1,2,3] Laura Serra,[1,2,4,5] Gemma Osca-Gelis,[2,3,6] Raquel Comas,[3] Gemma Renart,[1,2] Loreto Vilardell,[3] Joan Buch,[7] David Gallardo,[7] Rafael Marcos-Gragera[2,3]

[1]CIBER in Epidemiology and Public Health (CIBERESP), Spain [2]Research Group on Statistics, Econometrics and Health (GRECS), Universitat de Girona, Girona, Spain [3]Epidemiology Unit and Girona Cancer Registry, Oncology Coordination Plan, Girona, Spain–Department of Health, Autonomous Government of Catalonia, Catalan Institute of Oncology, Girona, Spain [4]Center for Research in Occupational Health (CiSAL), Department of Experimental and Health Sciences, Pompeu Fabra University, Barcelona, Spain [5]IMIM Parc Salut Mar, Social Epidemiology and Occupational Health Group, Barcelona, Spain [6]Institut Català d'Oncologia, Pla Director d'Oncologia, Hospital Duran i Reynals, L'Hospitalet de Llobregat, Spain [7]Hematological Service, Catalan Institute of Oncology, University Hospital Dr. Josep Trueta, Girona, Spain

Background and Introduction

Survival reported for men diagnosed with Hodgkin lymphoma (HL) in the province of Girona (Spain) during the last three decades was lower compared to European registries data. To determine if these disparities would be explained by defined prognostic factors, clinical data were retrospectively recollected in collaboration with clinicians. The aims of the present study were to estimate population-based incidence and five-year net survival of HL according to sex, age, histological type and stage.

Materials and Methods

Data were obtained from the Girona population-based cancer registry. 445 cases diagnosed with HL during 1985-2013 were included in this study. Incidence was calculated as the crude rate (CR) and the European age-standardized rate (ASRE). The follow-up was available until 31/12/2013. Death certificate only (DCO) cases were excluded for the survival analysis. five-year net survival was estimated using the Pohar-Perme method.

Results

Between 1985 and 2013, 445 HL cases were recorded in the province of Girona (273 men; 172 women), with a median age (min-max) of 38 (3-92). CR was higher in men than in women (3.0 and 1.9, respectively) and corresponding ASRE were 2.6 and 1.7, respectively. There were significant differences by sex considering stage, histology and B-symptoms presence, but not for age or tumour site. five-year net survival was 70.3% (95% CI: 63.9-77.3) for men and 80.5% (95% CI: 73.5-88.0) for women. Parameters negatively influencing this survival in the multivariate analysis were as follows: age at diagnosis of >70 years for both men and women and advanced (III/IV) clinical stage for men.

Conclusions

HL incidence in Girona was similar to European registries data. Differences in five-year net survival for men could be explained by a different case-mix of clinical parameters compared to Europe. This is the first study to assess five-year net survival of HL in Spain according to clinical prognostic factors.

Theme: **Integrating cancer registry data and clinical practice**

Physical after-effects reported by men undergoing prostate biopsy. Results from an all-Ireland study

Eileen Morgan,[1] Frances J. Drummond,[2] Catherine Coyle,[3] Anna Gavin,[1]* Linda Sharp,[2, 4]*
*Joint last authors

[1]N. Ireland Cancer Registry, Centre for Public Health, Queen's University Belfast, UK [2]National Cancer Registry Ireland, Cork, Ireland [3]Public Health Agency, Belfast, Northern Ireland, UK [4]Institute of Health and Society, Newcastle University, Newcastle, UK

Background and Introduction
In developed countries, prostate cancer is the most common cancer diagnosed in men than any other cancer. A proportion of these men, and others, will have undergone a prostate biopsy. It is important to understand the after-effects experienced in men following this common procedure. We investigate physical after-effects following prostate biopsy undertaken in men in routine practice.

Materials and Methods
811 men received questionnaires 4-6 weeks post-biopsy in six cancer centres (Republic of Ireland, 4; Northern Ireland, 2). Questions included pre-biopsy symptoms and comorbidities. Men were asked about whether they experienced specific physical after-effects post-biopsy (raised temperature/pain/bleeding/erectile dysfunction/urinary retention), their severity and duration, and any associated healthcare utilisation. Binomial and ordinal logistic regression was used to investigate factors associated with presence of post-biopsy after-effects and number of after-effects reported, respectively.

Results
Post-biopsy after-effects were common with 88.1% of 335 respondents having reported at least one after-effect; 21% reported at least three. The odds of reporting any after-effect was lower in men over 65 compared to younger men (adjusted OR = 0.50, 95% CI 0.25, 1.01). The odds of increasing number of after-effects were over two-fold higher in men with higher levels of health anxiety and for men who had had multiple biopsies. 11.5% with after-effects reported contacting their doctor or local pharmacy; 14.6% contacted hospital services; and 3.1% of men were admitted to hospital with an average stay of 5.4 nights (SD 6.3).

Conclusions
Physical after-effects following prostate biopsy in routine practice are commonly reported. Men undergoing this common procedure should be adequately prepared and those with increased health anxiety or previous biopsies should be offered additional support.

Authors' index

Authors' index

Authors' index

Authors' index

Authors' index

ENCR and JRC would like to thank all the oral and poster presenters for their contributions to the meeting. Their abstracts have been published as submitted.

Working Group list

RARECAREnet working group (*page 30*): Monika Hackl, Zdravka Valerianova, Margit Mägi, Nea Malila, Bernd Holleczek, Jón Gunnlaugur Jónasson, Stefano Ferretti, Gianbattista Spagnoli, Maria Michiara, Fabio Falcini, Neville Calleja, Tom Børge Johannesen, Jadwiga Rachtan, Stanisław Góźdź, Jerzy Błaszczyk, Maja Primic-Zakelj, Mohsen Mousavi, Christine Bouchardy, Silvia M. Ess, Isabelle Konzelmann, Otto Visser, Julia Verne, Anna Gavin, David H Brewster, Dyfed Wyn Huws.

Swiss Paediatric Oncology Group (SPOG) Scientific Committee (*page 31*): Prof. Dr. med. R. Ammann, Bern; Dr. med. R. Angst, Aarau; PD Dr. med. M. Ansari, Genf; PD Dr. med. M. Beck Popovic, Lausanne; Dr. med. E. Bergstraesser, Zurich; Dr. med. P. Brazzola, Bellinzona; Dr. med. J. Greiner, St. Gallen; Prof. Dr. med. M. Grotzer, Zurich; Dr. med. H. Hengartner, St. Gallen; Prof. Dr. med. T. Kuehne, Basel; Prof. Dr. med. K. Leibundgut, Bern; Prof. Dr. med. F. Niggli, Zurich; PD Dr. med. J. Rischewski, Lucerne; Prof. Dr. med. N. von der Weid, Basel.

Swiss Paediatric Oncology Group (SPOG) (*page 109*): Dr. med. R. Angst, Aarau; Prof. Dr. med. M. Ansari, Genf; PD Dr. med. M. Beck Popovic, Lausanne; Dr. med. P. Brazzola, Bellinzona; Dr. med. J. Greiner, St. Gallen; Prof. Dr. med. K. Leibundgut, Bern; Prof. Dr. med. F. Niggli, Zurich; PD Dr. med. J. Rischewski, Lucerne; Prof. Dr. med. N. von der Weid, Basel.

West Romania's Cancer Registration Working Group (*page 84*): Stefan Curescu, Ana Szekely, Melania Bengulescu, Tiberiu Rugea.

Southern-Eastern European (SEE) working group (*page 67*): Anton Ryzhov (National Cancer Registry of Ukraine, National Institute of Cancer, Ukraine); Anna Zborovskaya (Belarusian Research Center for Pediatric Oncology, Hematology and Immunology, Childhood Cancer Subregistry of Belarus); Nadya Dimitrova (Bulgarian National Cancer Registry, National Oncology Hospital, Sofia, Bulgaria); Snezana Zivkovic (Institute of Public Health of Serbia, Belgrade Serbia); Sultan Eser (Izmir Cancer Registry, Izmir Hub, Izmir & Hacettepe University Institute of Public Health, Turkey); Luis Antunes (North Region Cancer Registry of Portugal, RORENO, Portuguese Oncology Institute of Porto); Mario Sekerija (Croatian National Cancer Registry, Croatian Institute of Public Health, Zagreb); Tina Zagar (Cancer Registry of Republic of Slovenia, Institute of Oncology); Joana Bastos (Central Region Cancer Registry of Portugal, ROR-Centro, Portuguese Oncology Institute of Coimbra, Portugal); Anna Demetriou (Cyprus Cancer Registry-Health Monitoring Unit, Ministry of Health, Nicosia, Cyprus); Domenic Agius (Malta National Cancer Registry, Department of Health Information and Research, Malta); Margareta Florea (Regional Cancer Registry of Iasi, National Institute of Public Health, Iasi, Romania); Daniela Coza (Regional Cancer Registry of Cluj, Oncological Institute 'Ion Chiricuta', Cluj Napoca, Romania); Evdoxia Bouka (Department of Hygiene, Epidemiology and Medical Statistics, School of Medicine, National and Kapodistrian University of Athens, Greece); Prodromos Kanavidis (Department of Hygiene, Epidemiology and Medical Statistics, School of Medicine, National and Kapodistrian University of Athens, Greece); Helen Dana (Oncology Department, 'Mitera' Childrens Hospital, Athens, Greece); Maria Kantzanou (Department of Hygiene, Epidemiology and Medical Statistics, School of Medicine, National and Kapodistrian University of Athens, Greece).

Southern-Eastern European (SEE) working group (*page 68, 71, 72*): Anton Ryzhov (National Cancer Registry of Ukraine, National Institute of Cancer, Ukraine); Anna Zborovskaya (Belarusian Research Center for Pediatric Oncology, Hematology and Immunology, Childhood Cancer Subregistry of Belarus); Nadya Dimitrova (Bulgarian National Cancer Registry, National Oncology Hospital, Sofia, Bulgaria); Snezana Zivkovic (Institute of Public Health of Serbia, Belgrade Serbia); Sultan Eser (Izmir Cancer Registry, Izmir Hub, Izmir & Hacettepe University Institute of Public Health, Turkey); Luis Antunes (North Region Cancer Registry of Portugal, RORENO, Portuguese Oncology Institute of Porto); Mario Sekerija (Croatian National Cancer Registry, Croatian Institute of Public Health, Zagreb); Tina Zagar(Cancer Registry of Republic of Slovenia, Institute of Oncology); Joana Bastos (Central Region Cancer Registry of Portugal, ROR-Centro, Portuguese Oncology Institute of Coimbra, Portugal); Anna Demetriou (Cyprus Cancer Registry-Health Monitoring Unit, Ministry

of Health, Nicosia, Cyprus); Domenic Agius (Malta National Cancer Registry, Department of Health Information and Research, Malta); Margareta Florea (Regional Cancer Registry of Iasi, National Institute of Public Health, Iasi, Romania); Daniela Coza (Regional Cancer Registry of Cluj, Oncological Institute 'Ion Chiricuta', Cluj Napoca, Romania).

NARECHEM-BT Working Group (*page 68*): National Registry of Childhood Hematological Malignancies and Brain Tumors (NARECHEM-BT) working group: Evdoxia Bouka (Department of Hygiene, Epidemiology and Medical Statistics, School of Medicine, University of Athens, Athens, Greece); Charis Bourgioti (First Department of Radiology, Aretaieion Hospital, Medical School, University of Athens, Athens, Greece); Helen Dana (Oncology Department, 'Mitera' Childrens Hospital, Athens, Greece); Emmanuel Hatzipantelis (Second Department of Pediatrics, Aristotelion University of Thessaloniki, AHEPA General Hospital, Thessaloniki, Greece); Maria Kourti (Department of Pediatric Hematology and Oncology, Hippokration Hospital, Thessaloniki, Greece); Maria Moschovi (Haematology-Oncology Unit, First Department of Pediatrics, Athens University Medical School, 'Aghia Sophia' Children's Hospital, Athens, Greece); Savvas Papadopoulos (Department of Pathology, Hygeia Hospital, Athens, Greece); Evgenia Papakonstantinou (Department of Pediatric Hematology and Oncology, Hippokration Hospital, Thessaloniki, Greece); Sophia Polychronopoulou (Department of Pediatric Haematology-Oncology, 'Aghia Sophia' Children's Hospital, Athens, Greece); Spyros Sgouros (Department of Neurosurgery, 'Mitera' Childrens Hospital, Athens, Greece); Kalliopi Stefanaki (Histopathology Department, 'Aghia Sophia' Children's Hospital, Athens, Greece); Eftichia Stiakaki (Department of Pediatric Hematology-Oncology, University of Crete, University Hospital of Heraklion, Heraklion, Greece); Katerina Strantzia (Histopathology Department, 'Pan. & Agl. Kyriakou' Children's Hospital, Athens, Greece); Basilios Zountsas (Department of Neurosurgery, St. Luke's Hospital, Panorama, Thessaloniki, Greece); Eustratios Patsouris (Department of Pathology, National and Kapodistrian University of Athens, Medical School, Athens, Greece).

The 'Socioeconomic Inequalities and oncological outcomes' Italian Study Working Group (*page 50*): Teresa Spadea, Nicolàs Zengarini and Paolo Carnà (Servizio Sovrazonale di Epidemiologia ASL TO3, Grugliasco, Tourin); Giuseppe Costa (University of Tourin); Milena Sant, Pamela Minicozzi, Francesca Di Salvo and Hade Amash (IRCCS Istituto Nazionale dei Tumori Foundation, Milan); Nicola Caranci (Agenzia Sanitaria e Sociale, Regione Emilia-Romagna, Bologna); Adriano Giacomin (Biella Cancer Registry); Alessandro Barchielli and Gianfranco Manneschi (Toscana Cancer Registry), Claudia Cirilli (Modena Cancer Registry), Fabio Falcini and Alessandra Ravaioli (Romagna Cancer Registry), Lucia Mangone, Paolo Giorgi Rossi, Enza Di Felice and Massimo Vicentini (Reggio Emilia Cancer Registry); Fabio Pannozzo and Francesca Calabretta (Latina Cancer Registry), Fabrizio Stracci, Fortunato Bianconi and Valerio Brunori (Umbria Cancer Registry), Mario Fusco and Valerio Ciullo (Napoli Cancer Registry); Rosaria Cesaraccio (Sassari Cancer Registry); Rosanna Cusimano, Maurizio Zarcone (Palermo Cancer Registry); Rosario Tumino and Carmela Nicita (Ragusa Cancer Registry); Giuseppina Candela and Tiziana Scuderi (Trapani Cancer Registry).

LA-NA-28095-EN-C

JRC Mission

As the science and knowledge service of the European Commission, the Joint Research Centre's mission is to support EU policies with independent evidence throughout the whole policy cycle.

EU Science Hub
ec.europa.eu/jrc

@EU_ScienceHub

EU Science Hub - Joint Research Centre

Joint Research Centre

EU Science Hub

Publications Office

doi:10.2787/99752
ISBN 978-92-79-61755-3