European Commission

Data linkage and cancer registries

ENCR Scientific Meeting and General Assembly

26-28 September 2018
Copenhagen • Denmark

European Network of Cancer Registries

Joint Research Centre

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Practical information

Official language

The official language of the meeting and side events will be English.

Certificate of attendance

A certificate of attendance can be collected at the registration desk on the third day of the meeting (Friday, 28 September 2018) during the morning coffee break or during lunch.

Social programme

Wednesday 26 September 2018 19:00

Welcome reception, at the premises of the Danish Cancer Society. The Welcome Reception is offered by the European Commission's Joint Research Centre.

Thursday 27 September 2018 19:00

Harbour Cruise, jointly offered by the Danish Cancer Society and the Danish Cancer Registry.

Programme at a glance

	Tue 25 Sep	Wed 26 Sep		Thu 27 Sep	Fri 28 Sep
09:00				Keynote Lecture	Keynote Lecture
09:30	ENCR-JRC Training on Data Coding	ENCR Workshop on Data Protection	Registration	**Scientific Session 3** Estimation and dissemination of cancer burden in Europe – Part 2	**Scientific Session 6** (a) Biobanks and cancer registries (b) Data quality, control, and standards... – Part 1
11:00	*Tea-Coffee break*	*Tea-Coffee break*		*Break & poster viewing*	*Break & poster viewing*
11:30	ENCR-JRC Training on Data Coding	ENCR Workshop on Data Protection		**Scientific Session 4** Clinical databases and population based cancer registries – Part 1	**Scientific Session 7** Data quality, control, and standards for cancer registries – Part 2
13:00	*Buffet lunch*	*Buffet lunch & poster set-up*		*Buffet lunch & poster viewing*	*Buffet lunch & poster pick-up*
14:00	ENCR-JRC Training on Data Coding	Opening Session		ENCR General Assembly	
14:30		**Scientific Session 1** Data linkage methods and cancer registries			
16:00	*Tea-Coffee break*	*Break & poster viewing*		*Break & poster viewing*	
16:30	ENCR-JRC Training on Data Coding	Keynote Lecture		Keynote Lecture	
17:00		**Scientific Session 2** Estimation and dissemination of cancer burden in Europe – Part 1		**Scientific Session 5** Clinical databases and population based cancer registries – Part 2	
17:30					
18:30					
19:00		*Welcome reception*		*Harbour cruise*	

Welcome

The European Commission's Joint Research Centre (JRC), the European Network of Cancer Registries (ENCR), and the Danish Cancer Society welcome you to the 2018 ENCR Scientific Meeting and General Assembly in Copenhagen, Denmark (26-28 September).

This ENCR bi-annual Scientific Meeting has been held regularly since the JRC took over the support (secretariat) activities for the ENCR in 2012. It attracts over 150 delegates and is a unique opportunity for colleagues to meet, compare best practices in cancer registration, and present their research findings. The meeting targets registry experts from the ENCR-affiliated network, as well as clinicians, researchers, epidemiologists and statisticians from cancer research institutions, NGOs, and government organisations. It allows the participants to meet in person the ENCR Steering Committee members, representatives from the European Commission's DG SANTE (Health and Food Safety), and the JRC's Cancer Information team that supports the Network in its quest to provide accurate, reliable, comparable and up-to-date cancer burden indicators at European level.

This year, the meeting will focus on data linkages and cancer registries, and its sessions and keynote lectures will explore a wide variety of topics, including the integration of clinical databases and biobanks with cancer registries, data linkage methods, and related estimation and dissemination issues.

The ENCR General Assembly will take place in the afternoon of 27 September and offer a plethora of interesting topics, including presentations of the new ECIS web-application (launched in February 2018) and the latest version of the JRC-ENCR quality check software (released in September 2018). Full and active participation is warmly encouraged in order to guide the Network, its Steering Committee and the JRC in outlining and deciding priorities for future improvements and developments.

Prior to the scientific conference, some participants will attend a training course on data coding (25 September) and a workshop on cancer registry data protection (26 September, morning).

We thank with particular warmth the Conference Organising Committee (the JRC, the Danish Cancer Society, and the Danish Cancer Registry) for planning and organising this wonderful scientific event. We are confident it will stimulate a creative and fruitful exchange of ideas and provide an opportunity for establishing new collaborations or strengthening existing ones.

We hope that you enjoy your time in Copenhagen.

Anna Gavin
ENCR Chairperson

Otto Visser
ENCR Chairperson

Manola Bettio
European Commission JRC

Paolo Guglielmetti
European Commission DG SANTE

Hans Storm
ENCR SC, Danish Cancer Society

Committees

ENCR Steering Committee

Anna Gavin (Chair, UK)
Otto Visser (Chair, NL)

Freddie Bray (IARC)
Michael Eden (United Kingdom)
Ana Miranda (GRELL)
María José Sánchez (Spain)
Mario Šekerija (Croatia)
Hans H. Storm (ANCR)
Fabrizio Stracci (Italy)
Maciej Trojanowski (Poland)
Elizabeth Van Eycken (IACR)

Danish Organising Committee

Hans H. Storm (Chair)
Lone Rosander Thomsen (Secretary)
Michael Henneberg Pedersen (Head of Finance)
Jens Jepson (Head of Kitchen)
Linda Aagaard Thomsen
Henrik Mulvad Hansen (National Health Data Board/Danish Cancer Registry)

JRC Cancer Information Team

Manola Bettio (Team Leader)

Raquel N. Carvalho
Nadya Dimitrova
Tadek Dyba
Francesco Giusti
Carmen Martos
Luciana Neamţiu
Nicholas Nicholson
Giorgia Randi

JRC Organising Team

Jindra Konopkova (Secretariat)
Brigitte Westrischnig (Secretariat)
Manuel Florensa-Molist (Editorial support)

The European Network of Cancer Registries

The European Network of Cancer Registries (ENCR) was founded in 1990 as the association supporting and promoting cancer registration in Europe. It primarily connects population-based cancer registries, which are the entities collecting data on all new cases of cancer occurring in a defined population, with the final aim of producing statistics on the occurrence and outcome of cancer.

The ENCR builds competences and expertise across registries, promotes collaboration between them, provides training for cancer registry personnel, and defines data collection standards, allowing its members to act as providers of reliable and comparable information on cancer burden in Europe.

The Network was established 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),[1] Association of Nordic Cancer Registries (ANCR),[2] International Association of Cancer Registries (IACR)[3] and Latin Language Registry Group (GRELL).[4] It has been supported by the European Commission, which is currently hosting its Secretariat, and by IARC (1990-2012).

In 2012, two Directorate-Generals of the European Commission (DG SANTE and DG JRC) have established a formal collaboration with the aim of supporting the ENCR and thus paving the way towards further coordination and harmonisation of cancer data in Europe. The support has also ensured the continuity of the ENCR secretariat, including the administrative functioning and networking of the ENCR.

The ENCR is governed by a Steering Committee, currently composed of eleven members: nominated members are the representatives of the IARC, IACR, GRELL and ANCR, five members were elected by cancer registries and two members were co-opted. Members are nominated or elected for a period of three years, with the possibility of one renewal, and the Chair is nominated by the Steering Committee members. The last election of members took place in 2017.

The ENCR Steering Committee

Elected members

Anna Gavin, Graduate of Queen's University Belfast Medical School and London School of Hygiene and Tropical Medicine, Consultant in Public Health and Reader, Centre for Public Health, Queen's University Belfast. Founding director of the N. Ireland Cancer Registry. Currently chair of the European Network of Cancer registries and European representative on the Executive Board of the International Association of Cancer Registries. Member of the Board and various module subgroups of the International Cancer Benchmarking Partnership, a consortium over three continents studying international cancer survival differences.

1. http://www.iarc.fr.
2. https://www.ancr.nu.
3. http://www.iacr.com.fr.
4. https://www.grell-network.org.

The ENCR Steering Committee

Otto Visser, graduated from Medical School in 1984. After several years in basic research, he was employed at the Comprehensive Cancer Centre Amsterdam from 1990-2010, where he was head of the Amsterdam Cancer Registry since 1996. From 2011-2013 he was a cancer registry expert at the Comprehensive Cancer Centre the Netherlands, a new organization resulting from a merger of seven regional organizations. After the merger of the two remaining comprehensive cancer centres in the beginning of 2014, he became director of registration at the Netherlands Comprehensive Cancer Organization, where he is responsible for the Netherlands Cancer Registry (NCR) and the trial data management department. The NCR is one of the most comprehensive populations-based cancer registries in the world including many clinical data. Dr. Visser has an extensive knowledge of all aspects of cancer registration, both as far as the registration process is concerned and in the use of the data. He was involved in the annual publications of the NCR and a large number of epidemiological and clinical studies with cancer registry data. He obtained his doctorate with a thesis on a number of these studies in 2006.

María José Sánchez is Doctor in Medicine and Surgery from the University of Granada (UGR, 1996). Specialist in Clinical Microbiology and Parasitology and Master in Epidemiology and Clinical Research (UGR, 2000) and Master in Health Promotion (UGR, 2018)). Since 2003, she has been a professor at the Andalusian School of Public Health (EASP), assuming the lead of the Research Department from 2007 to 2016 and the Directorate of the Granada Cancer Registry since 2009. She has extensive experience in the design and development of epidemiological studies and research projects related to etiology, health care and survival of cancer patients, having led and/or collaborated in more than 25 European, national or regional research projects. The results of these projects have been reflected in more than 150 publications, indexed in JCR, during the last five years. She currently participates in the Joint Action on Rare Cancers, coordinates the HIGHCARE project (High-resolution project on prognosis and care of cancer patients) and represents Spain on the Board of Directors of the European High-Resolution Studies. She is PI of the EPIC project (nutrition and cancer) and related projects such as EPIC-HEART (cardiovascular disease), EPIC-CVD (ischemic stroke), INTERACT (diabetes mellitus). She has been president of the Spanish Network of Cancer Registries, REDECAN (2014-2017), and is currently a member of the Steering Committee of REDECAN, the European Network of Cancer Registries (ENCR) and the Group for Cancer Epidemiology and Registration in Latin Countries (GRELL).

Fabrizio Stracci graduated in medicine with first class honours at the University of Perugia in 1994, discussing a thesis on the cluster analysis of large bowel incident cancer cases. He attained the master degree in Public Health at the same University in 1998. Dr. Stracci took the Philosophy Doctor degree in 2005. Main research interests of Prof. Stracci are in the field of epidemiology, particularly cancer epidemiology, and public health. He worked at the establishment of the Cancer Registry of the Umbria Italy (IACR member) Region and presently he is the Registry's director. Since 2012, he is Associate Professor in Public Health, University of Perugia. Professor of Public Health, Epidemiology, and Biostatistics in the School of Medicine. Director of the Post-graduate School in Public Health. Coordinator of the Public Health section of the Experimental Medicine Department. Prof. Stracci is the author of over 75 scientific papers published on international peer reviewed journals.

The ENCR Steering Committee

Dr. **Michael Eden** graduated from the University of London and is a Consultant Pathologist at Cambridge University Hospitals and is also Clinical Lead and Associate Caldicott Guardian for the National Cancer Registration and Analysis Service, England. His academic interests include international survival comparisons, cancer registration practice and genomic medicine.

Co-opted members

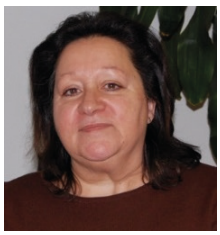
Mario Šekerija is an epidemiologist currently working as the Director of the Croatian National Cancer Registry at the Croatian Institute of Public Health. He is also a post-doctoral researcher at Department of Medical Statistics, Epidemiology and Medical Informatics of the School of Public Health Andrija Štampar of the University of Zagreb School of Medicine. He graduated from the University of Zagreb School of Medicine where he also obtained his PhD degree in the field of diabetes epidemiology. His current scientific interests include cancer epidemiology and application of epidemiological methods in research and he is a member of the working groups in the major international cancer epidemiology studies, including IICC, EUROCARE and CONCORD. He is currently the leader of WP3 (Evaluation) in iPAAC Joint Action and also participates in various other cancer programmes/initiatives in Croatia and Southeastern Europe.

Maciej Trojanowski, M.P.H. (2009) from Poznań University of Medical Sciences, since 2015 he is in the middle of specialization course in epidemiology. For more than ten years he has been involved in the process of cancer registration in Poland, working in the Greater Poland Cancer Registry (GPCR), since 2012 as its Director. On his professional path he went through all the stages of working in the registry from the preparation of data from the paper documentation, by coding data in the electronic database, its verification, preparation of statistics on cancer epidemiology in the Greater Poland region and databases for research projects. On his own or with the Polish National Cancer Registry team he was responsible for preparation and error corrections in the databases for: JRC-ENCR call for data, Concord-2 and 3, EURECCA Breast Study Group, European HR Study (breast and colorectal cancer), HERO-ESTRO Study, IICC-3, NARECHEM (childhood cancers, brain tumors). He is a member of the Polish Society of Social Medicine and OECI Cancer Outcomes Research Working Group. His main interests are in improving the data quality in the GPCR, promoting the use of cancer information especially for outcomes research.

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* (http://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.



Ana Maria Campos Barreiros Pais da Costa Miranda (GRELL)), MS, MSC, the head of National Cancer Registry, has been responsible–since 1988–for the implementation and coordination of the Portugal South Regional Cancer Registry, a population-based registry of about 4 800 000 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 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 she is GRELL representative in ENCR.

Hans Storm (ANCR), MD (1976), Chief Medical Advisor and DPO, Danish Cancer Society (DCS). Medical and surgical trained in oncology 1977-1981, affiliated with the Danish Cancer Registry 1977, Director 1985-1997, Director of Prevention and Documentation, DCS 1997-2014, Medical Vice CEO 2014-2017. Former member the Danish Data Protection Council. ENCR SC member for several periods since 1990. 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 (2 nad 3rd ed.). Over 360 publications in descriptive and analytical cancer epidemiology on treatment, multiple primary cancers, and evaluation of cancer control. H-index (July 2018): 75; Citations (July 2018): 21090.

Elizabeth van Eycken, Nominated representative of the International Association of Cancer Registries (IACR), MD, Trained in Radiation Oncology at the University of Leuven (1992-1997) and Physician Expert Health Data Management (Brussels 2003). She is the director of the Belgian Cancer Registry since 2005 and led the Flemish Cancer Registry Network from 1998 to 2004. The Belgian Cancer Registry is a young, population based registry that covers the country (11 Mio) since 2004. She is engaged in National and European projects related to the evaluation of quality of care in oncology (*e.g.* Eurecca, Rarecarenet, JARC, iPAAC). Linkage with administrative data bases in the context of this type of research, receive her full attention and endorsement. She has a specific interest in TNM classification and radiation oncology related subjects because of her previous work and membership in the International UICC TNM Core Group since 2011. In 2017, both the Belgian and the Dutch Cancer Registry organised the IACR annual scientific meeting in Utrecht, emphasizing on 'Ensuring Quality and Use of Data from Cancer Registries in the 21st Century'.

The Danish Cancer Society

One in every three Danes contract cancer at some point in their lives. Two in three have a relative suffering from cancer. Faced with these figures, the Danish Cancer Society aims to unite the Danish population in a strong, active effort against cancer.

Headquarters of the Danish Cancer Society in Copenhagen.

The Danish Cancer Society has more than 400 000 members – and almost 45 000 volunteers doing what corresponds to around 870 full-time jobs. It has around 690 full-time employees, of which over half is dedicated to research. The Danish Cancer Society has counselling units in the five Regions running the health care system connected to the main oncological centres and have local cancer centres in all communes in Denmark.

We are a democratic membership organisation, whose course is charted by the volunteers and members. The volunteers represent the highest authority of the Danish Cancer Society. They elect the president, set the rules and regulations of the society and identify our main focus areas. We get around 3% of funding from the public and the rest of the approximately 100 m€ collected per year from private donations.

Our vision: A life without cancer.

Our mission: Increasing cancer survival rates; reducing the number of cancer cases, improving life with cancer.

Main purpose: Research; Prevention; Patient support.

The Danish Cancer Society is a national NGO formed in 1928 by the merger of the Medical Unions Committee to fight cancer (1905) and the national Radium Fund (1912) established to treat cancer patients. Two key research institutes were founded and run by the Society – the Danish Cancer Registry established by Johannes Clemmesen in 1942 and the Fibiger laboratories by Jørgen Kieler in 1949, today merged into the Danish Cancer Society Research Center.

National cancer registration has been a strong hold of the Cancer Society linking routine registration with research. In 1997 the responsibility for cancer registration was taken over by the government with the aim of creating a large health data repository available for research and planning. In 2008 with data from 2004 onwards, the new modernised data capture and coding system combining already registered and computerised clinical data, data from pathology and mortality data became operational.

The cancer society has, since the government takeover, supported the running and build of the new system, and maintained the research responsibility on the collected data as well as the development of the tool NORDCAN in collaboration with the ANCR (Association of Nordic Cancer Registries) the IARC (International Agency on Research in Cancer) and the Nordic Cancer Union.

The Joint Research Centre (JRC)

The Joint Research Centre (JRC) is the European Commission's science and knowledge service. Functioning as a Directorate-General of the Commission, the Centre supports a wide range of EU policies by providing evidence and technical know-how independent of all private or national interests.

The JRC Directorate F–Health, Consumers and Reference Materials, in close collaboration with the Directorate-General for Health and Food Safety (DG SANTE), is supporting the creation and maintenance of a cancer information system, to assess and monitor the burden of cancer in Europe.

The JRC has been hosting the ENCR secretariat since 2012, ensuring continued administrative functioning of the network. With the goal of enabling accurate comparisons of European cancer information data, the JRC supports the ENCR in the harmonisation of data and registration processes.

The JRC supporting cancer information in Europe

The Joint Research Centre (JRC) is one of the Directorate-Generals of the European Commission and works in close liaison with DG SANTE (formerly SANCO), which is the Directorate-General primarily responsible for issues relating to health at EU level.

The JRC serves as a key partner to many of the Commission's services in its technical and scientific capacity. In this role, the JRC is working closely with the ENCR steering committee to agree the priorities for enhancing the value and utilisation of cancer data at EU level. The collaboration between the JRC and the ENCR ensures a single, updated, and definitive European cancer-registry dataset that enables computation and dissemination of European statistics on cancer burden.

The priorities of the Commission for the availability of accurate, reliable, comparable and up-to-date cancer indicators (incidence, mortality, survival, prevalence) across Europe are largely aligned with those of the ENCR. With respect to this, the partnership with the ENCR has so far resulted in important achievements for the following aspects:

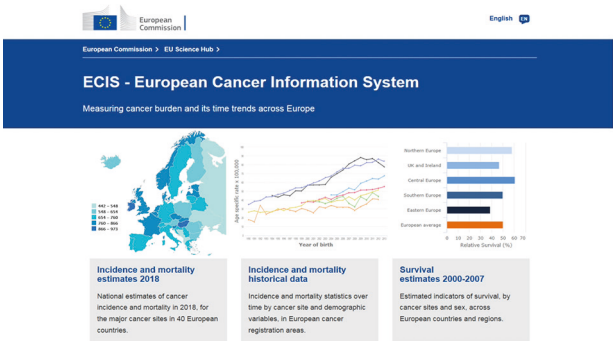
- Harmonisation of data quality–resulting in a JRC technical report in 2014 that was used as the basis for the 2015 ENCR data call; this work is seen as a continuing task to improve the quality of the existing European cancer registry (CR) data variables on the basis of further analyses of the data;

- Development of a data-quality software toolkit for checking the quality of CR data sets, which provides an automatic means for cancer registries to check their data for inconsistencies with the agreed standards prior to sharing them;

- Addressing the efficiency of the data-flow process. Steps were taken for the 2015 ENCR data call to try and remove as many unnecessary overheads as possible on CRs; instead of a number of unsynchronised data calls by different studies, the JRC offers a type of data-broker service, in which a single data call would provide validated data to all requiring entities. The process showed itself workable and will be refined further.

In addition to data collection and harmonisation, the JRC is also in charge of the development and maintenance of the European Cancer Information System (ECIS). ECIS is a comprehensive cancer-information resource for the EU policy makers, researchers, and citizens. At the beginning of 2018, the JRC has released the ECIS web-application–a dissemination tool for reporting on cancer burden indicators for Europe.

The ECIS web-application



The ECIS web-application disseminates cancer burden indicators at European level, namely on incidence, mortality, and survival, derived from data submitted by about 150 European population-based cancer registries for major cancer sites. It displays historical data for incidence and mortality at registry level, by cancer site, sex, age group, calendar year and geographic area, as well as national estimates for incidence, mortality, and survival. The database feeding the ECIS application is dynamic and updated as new data become available.

ECIS was launched in February 2018, on the occasion of World Cancer Day, and can be accessed here: https://ecis.jrc.ec.europa.eu/.

Incidence and mortality historical data

Indicators on cancer incidence and mortality over time that are displayed in ECIS (historical data until the most recent available year) are derived from the ENCR-JRC project 'Cancer Incidence and Mortality in Europe'. The project, in its first edition, makes use of the data from the 2015 data call. As of September 2018, a total of 149 population-based cancer registries from 34 European countries have responded to the call, corresponding to a database with more than 34.5 million cancer cases and with at least 70% of registries providing incidence data up to 2012. The incidence indicators in ECIS are detailed for 60 cancer sites defined according to the International Classification of Disease for Oncology ICD-O-3, and the mortality indicators are presented separately for 43 cancer sites defined according to the International Classification of Diseases, 10th revision (ICD-10).

Incidence and mortality estimates 2018

ECIS also provides national estimates of cancer incidence and mortality for the most recent year. The 2018 estimates are the joint outcome of a collaborative exercise led by the International Agency for Research on Cancer (IARC), in collaboration with JRC, the ENCR, and the International Association of Cancer Registries. The 2018 incidence estimates for 40 European countries are based on the data from the cancer registries participating in IARC's 'CI5: Cancer Incidence in Five Continents series', and the mortality estimates are based on data extracted from the WHO mortality database.

Survival estimates

ECIS includes national survival estimates from the latest published edition of the project EUROCARE-5. EUROCARE (EUROpean CAncer REgistry-based study on survival and care of cancer patients) is the widest collaborative research project on cancer survival in Europe. EUROCARE-5 aims to describe cancer survival differences between European countries and includes data on more than 21 million cancer diagnoses provided by 99 Cancer Registries in 26 European countries.

The JRC-ENCR Quality Checks Software (QCS)

The usefulness and reliability of information provided by cancer registries depends on the quality of the data collected. Therefore, in 2014, the ENCR in collaboration with the JRC has set up a Working Group with the task of establishing a comprehensive and standardised list of data quality checks to be adopted by European registries and projects. The Working Group has produced a proposal for 'One common procedure for data quality checks for European cancer registries' (version 1.0 in 2014, 1.1 in 2018). The proposal includes agreements on case definition, variables to be collected and their format, internal consistency rules, and checks for multiple primary tumours (new feature of the 1.1 version).

Following the rules defined in the above-mentioned report, the JRC has developed a software for data validation, which enables cancer registries to perform quality checks on their own and test their data against the required ENCR-JRC dataset. The JRC-ENCR Quality Check Software (QCS) provides the registries with a user-friendly data-checking and quality-control tool, and aims to standardise the checks to be followed when submitting data, in order to improve their quality and comparability.

The previous version of the JRC-ENCR QCS was released in 2016, and already included checks of the files format (for incidence, mortality, lifetables and population files) and of variables (names and order according to the submission guidelines), verification of the variables' internal consistency and cross-checks among variables. The newly released 2018 version of the software (v. 1.8) includes improvements related mainly to the checks for multiple primary tumours.

The QCS is publicly available and can be downloaded from: https://encr.eu/tools-for-registries.

Working groups to address recommendations

Following the recommendations of the 2015 ENCR-JRC workshop on 'Defining the Roadmap Towards Revision of ENCR Coding Standards and Training for Cancer Registries', the Steering Committee of the ENCR prioritised updates of the guidance on multiple primary cancers and date of incidence:

- 'ENCR guidelines for reporting of multiple primary malignant (invasive) neoplasms'. The new rules provide guidance on the standards for reporting of multiple primary invasive (behaviour 3) neoplasms for the purposes of international comparison. The working group drafted the new recommendations. An evaluation of the impact for the new rules on incidence is ongoing.

- New 'Recommendations for recording and coding Date of Incidence (DoI)'. The working group drafted the recommendations. After the revision of the new rules by the ENCR Steering Committee, the evaluation of the impact on incidence is ongoing.

A new working group on urothelial tumours is working on the revision of the recommendation for bladder tumours coding.

Training, workshop, and roundtable

- How can cancer registries best help cancer patients?–*roundtable*, Ispra, Italy, 1 Feb 2017.

- Cancer Registry Data Collection and Comparability–*course*, Ispra, Italy, 3-4 May 2017.

- Statistical Methods for Analysis of Cancer Registry Data–*course*, Ispra, Italy, 5-6 Jun 2018.

- Data Coding–*course*, Copenhagen, Denmark, 25 Sep 2018.

- Cancer Registry Data Protection–*workshop*, Copenhagen, Denmark, 26 Sep 2018.

ENCR Steering Committee Meetings

A total of six Steering Committee meetings have been held in this time period. Summary minutes of the meetings are published on the ENCR website.

- 66th SC Meeting, March 2018.

- 65th SC Meeting, December 2017.

- 64th SC Meeting, October 2017.

- 63rd SC Meeting, May 2017.

- 62nd SC Meeting, January 2017.

New ENCR website

A new version of the ENCR website has been published in May 2018. The ENCR website has been revamped to make it more user-friendly and to facilitate access to relevant information.

ENCR Newsflash

A periodical e-mail is sent to a large list of contacts to inform and report on the latest news on ENCR activities.

Cancer factsheet

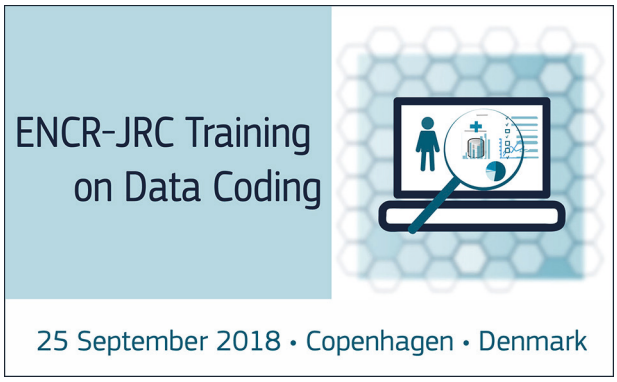
A new version of the cancer factsheet will be soon available in the European Cancer Information System (ECIS) web-application, updated with the latest available data provided by European cancer registries for the ENCR-JRC project on cancer incidence and mortality in Europe.

JRC-ENCR Portal for data submission

New features of the latest version of the JRC-ENCR portal allow both an exchange of information with cancer registries and private access to submitted data, so that data can be reviewed and checked before being released in the public version of the ECIS web-application.

Pre-conference training and workshop

ENCR-JRC Training on data coding



Cancer registry data–
coding topography, morphology, and stage

The aim of this course is to support data coding for European cancer registries by describing the corresponding international classifications and their principles for implementation.

The agenda includes the following topics: Introduction to coding systems (ICD-O); Coding sarcomas, brain tumours, neuro-endocrine tumours and haematological malignancies–specific issues; Coding stage–main principles and selected sites, including the Toronto system for childhood cancers.

At the end of the course, participants should be: (a.) familiar with commonly used cancer coding systems and some of the difficulties in applying these; (b.) confident in coding difficult cases, especially haematological and some rare malignancies; (c.) aware of some on-line resources facilitating the coding of cancer cases and the JRC-ENCR Quality Checks software for consistency of codes.

The course is intended for the cancer registry staff involved in coding and processing coded data. The course will have a number of interactive and individual exercises, which may be followed by a general discussion.

Faculty: Liesbet Van Eycken (ENCR Steering Committee), Otto Visser (ENCR Steering Committee), Nadya Dimitrova (JRC), Carmen Martos (JRC).

ENCR Workshop on data protection

New EU data protection rules (the General Data Protection Regulation–GDPR) regulate the processing of personal data relating to individuals in the EU by an individual, a company, a public administration or another organisation. The ENCR Steering Committee has invited all directors of cancer registries in the EU, cancer registries associations or their representatives, to complete a questionnaire on how the GDPR will impact the running of Cancer Registries' activities in different EU countries. During the workshop the results of the questionnaire will be reported.

Also the cancer registries representatives will be actively involved in group discussions to identify the problems regarding compliance with the new GDPR and to try to find possible solutions. An overview of the data protection principles and the new GDPR will be presented.

Faculty: Hans Storm (ENCR Steering Committee), Luciana Neamțiu (JRC), Raquel N. Carvalho (JRC), Premysl Spicar (JRC), Francesco Giusti (JRC), Carmen Martos (JRC).

Tue

Detailed meeting programme

25 Sep

	TUESDAY	25 September 2018
09:30-11:00	ENCR-JRC Training on Data Coding	
11:00-11:30	*Tea-Coffee break*	
11:30-13:00	ENCR-JRC Training on Data Coding	
13:00-14:00	*Buffet lunch*	
14:00-16:00	ENCR-JRC Training on Data Coding	
16:00-16:30	*Tea-Coffee break*	
16:30-17:30	ENCR-JRC Training on Data Coding	

Detailed meeting programme

Wed

26 Sep

	WEDNESDAY	26 September 2018
09:30-11:00	ENCR Workshop on Data Protection	
11:00-11:30	*Tea-Coffee break*	
11:30-13:00	ENCR Workshop on Data Protection	
13:00-14:00	*Buffet lunch & poster set-up*	
14:00-14:30	**Opening Session** (JRC, Danish Cancer Society, ENCR)	
14:30-16:00	**Scientific Session 1** Data linkage methods and cancer registries	
	Using linked primary care data to investigate patients presenting with non-specific but concerning symptoms	Clare Pearson
	The impact of individual, household and neighbourhood income on lung and colon cancer survival in Belgium	Michael Rosskamp
	Linking the Netherlands Cancer Registry to the Dutch Pathology Registry	Annette Bruggink
	Linkages between cancer registries and administrative data to study late effects in cancer survivors	Alice Bernasconi
	Distributedlearning.ai: towards a distributed learning network for cancer registries	Gijs Geleijnse
	Application of data linkage methods and procedures at the National Cancer Registry of Ukraine	Anton Ryzhov
16:00-16:30	*Tea-Coffee break & poster viewing*	
16:30-17:00	**Keynote Lecture** Les Mery (International Agency for Research on Cancer)	
17:00-18:30	**Scientific Session 2** Estimation and dissemination of cancer burden in Europe – Part 1	
	Cancer of Unknown Primary (CUP): epidemiology in Germany compared to other European countries and the United States	Sylke Ruth Zeissig
	Estimating fractions of cancers attributable to socioeconomic inequalities in Slovenia	Vesna Zadnik
	Hairy cell leukaemia: incidence, prevalence and survival in Europe. Findings from RARECAREnet	Charlene M. McShane
	Incidence trends of hematological malignancies in Belgium 2004-15: impact of the residence on chronic myeloid disorders	Frédéric Calay
	2017 projections of cancer incidence in Granada, southeast Spain	Daniel Redondo-Sánchez
	Childhood cancer incidence in Estonia: time trends since the 1970s	Keiu Paapsi
19:00	*Welcome reception*	

Thu 27 Sep — Detailed meeting programme

	THURSDAY	27 September 2018
09:00-09:30	**Keynote Lecture** Eero Pukkala (Finnish Cancer Registry)	
09:30-11:00	**Scientific Session 3** Estimation and dissemination of cancer burden in Europe – Part 2	
	Prediction of cancer prevalence in Austria up to the year 2030	**Monika Hackl**
	Are melanoma fatal cases decreasing in Europe?	**Roberto Zanetti**
	Identifying and counting people living with treatable but not curable cancer in the England cancer registry	**Rachel White**
	Cancer in the oldest-old–time trends and future burden, a Danish nationwide study	**Klaus Kaae Andersen**
	Life expectancy of Italian cancer patients	**Laura Botta**
	Improvement in cancer survival in the Nordic countries 2001-2015	**Gerda Engholm**
11:00-11:30	*Tea-Coffee break & poster viewing*	
11:30-13:00	**Scientific Session 4** Clinical databases and population based cancer registries – Part 1	
	Pattern of comorbidities among colorectal cancer patients and impact on treatment and short-term survival	**Miguel Ángel Luque-Fernández**
	Risk of developing gynecological cancer in Germany corrected for women no longer at risk after hysterectomy	**Klaus Kraywinkel**
	The use of information on stage and treatment from cancer registries for the evaluation of treatment patterns	**Francesco Giusti**
	Diversity of first-line palliative systemic treatments for esophagogastric cancer patients with synchronous metastases	**Rob Verhoeven**
	Comparison of quality indicators concerning breast cancer care on a national and hospital level	**Jan Nygård**
	Geographic variability in adherence to clinical practice guidelines for skin malignant melanoma in Spain	**Marcela Guevara**
13:00-14:00	*Buffet lunch & poster viewing*	

Detailed meeting programme

Thu

27 Sep

	THURSDAY	27 September 2018
14:00-16:00	**ENCR General Assembly**	
	Welcome and report on ENCR-JRC activities 2017-2018	**ENCR Steering Committee and JRC**
	The ECIS web-application as the dissemination gateway for ENCR data	
	Lesson learnt from the 2015 submissions on data quality and validation, and future plans	
	The JRC-ENCR Cancer Registries Data Quality Check Software new version (QCS 1.8)	
	Addressing national estimates for the countries without a national cancer registry	
	Proposal to update the ENCR SC election rules	
	Award for the best poster	
	Conclusions	
16:00-16:30	*Tea-Coffee break & poster viewing*	
16:30-17:00	**Keynote Lecture** Henrik Møller (Danish Clinical Registries)	
17:00-18:30	**Scientific Session 5** Clinical databases and population based cancer registries – Part 2	
	Endocrine therapy after breast cancer diagnosis: a proof of concept study using the primary care prescription database	**Gabrielle Emanuel**
	Use of cancer registry data to estimate the cancer risk of recipients of liver transplants	**Diego Serraino**
	Comparison of the Danish Cancer Register and the Danish Renal Cancer Database	**Bolette Danckert**
	Emergency admissions for cancer patients in last year of life in Northern Ireland (NI)	**Victoria Cairnduff**
	Metadata in the Cancer Registry of Norway – performing FAIR with ELVIS	**Siri Larønningen**
	Regional differences and trends in mastectomy rates in relation to socioeconomic disparities and screening patterns	**Christian Herrmann**
19:00	*Harbour cruise*	

Fri

Detailed meeting programme

28 Sep

	FRIDAY	28 September 2018
09:00-09:30	**Keynote Lecture** Anne Tjønneland (Danish Cancer Society Research Center)	
09:30-11:00	**Scientific Session 6 (a)** Biobanks and cancer registries	
	The use of biomarkers in treatment patterns and survival outcomes of metastatic non-squamous non-small cell lung cancer	**Rodrigo Murteira**
	Cancers in families with early onset probands	**Janne Pitkäniemi**
	PALGA Portal, the Dutch National Cancer Tissue Portal; a nationwide app for requesting tumor pathology data and tissues	**Annette Bruggink**
	Scientific Session 6 (b) Data quality, control, and standards for cancer registries – Part 1	
	Can we improve and make more useful the urothelial tumours registration? First results of a GRELL collaborative study	**Jaume Galceran**
	Variations in surgical oncology –Improvement through mapping	**Kasper Wennervaldt**
	The challenges, methods and benefits of implementing of ISO27001:2013 in the Northern Ireland Cancer Registry	**Ronan Campbell**
11:00-11:30	*Tea-Coffee break & poster viewing*	
11:30-13:00	**Scientific Session 7** Data quality, control, and standards for cancer registries – Part 2	
	The stage for childhood cancers: the JARC pilot study	**Gemma Gatta**
	Completeness of childhood cancer data in the Finnish Cancer Registry	**Nea Malila**
	Identification of recurrences in the new German cancer registration by example of gynaecological tumours in Hamburg	**Alice Nennecke**
	Comparison of coding diagnosis, localisation and histology via ICD-10 and ICD-O-3 between coders and a gold standard	**Sylke Ruth Zeissig**
	Indicators of data qualiy at the Cancer Registry Zurich and Zug in Switzerland	**Miriam Wanner**
	Automatic extraction of Gleason combined score, primary and secondary grades from written pathology reports	**Kris Henau**
13:00-14:00	*Buffet lunch & poster pick-up*	

Les Mery, MSc, International Agency for Research on Cancer, Lyon, France.

Mr. Les Mery studied mathematics at McGill University in Montreal, Canada, and completed graduate school in the area of statistics from the University of Ottawa. His work has primarily been focused on the application of surveillance and epidemiologic information to help develop cancer control interventions and policy. Over the past twenty years, his appointments have been across several national organizations in cancer–Health Canada, the Public Health Agency of Canada and the Canadian Partnership Against Cancer, including as the Executive Director for the Canadian Strategy for Cancer Control. At the International Agency for Research on Cancer in Lyon, France, Les serves as the Global Manager for the Global Initiative on Cancer Registry Development–a multipartner action plan aimed at improving the quality and coverage of cancer registration. In this capacity, Les oversees the implementation of the GICR and is responsible for technical support in cancer registration to the Caribbean, Pacific Islands and Southern, Eastern and South-Eastern Asia.

Record linkage methods: opportunities and challenges

A critical feature of high quality population-based cancer registries (PBCRs) is the ability to record all cases from residents in a defined geographic area. To allow for this, registries rely on accurate information pertaining to individual patients. In PBCRs, record linkage techniques are used to improve data quality. With the increasing availability of electronic data, linkage also provides opportunities to further develop the cancer registry by including existing computerized data sources and to conduct epidemiologic research by expanding the power of individual data sets by joining them together to study associations, such as between risk factors and outcomes. This presentation will provide an overview of common methods in linkage, together with key considerations in their application.

Professor **Eero Pukkala** (left in the picture) is Director for Research of the Finnish Cancer Registry, Institute for Statistical and Epidemiological Cancer Research, Helsinki, and Professor of Epidemiology at the Faculty of Social Sciences, University of Tampere.

He is author of about 700 peer-reviewed epidemiological publications, including studies on cancer and other health outcomes related to occupational hazards, physical and social environment, and life habits; familial clustering of cancer; evaluations of interventions; studies on factors affecting survival of cancer patients; cancer predictions; cancer atlases; register and biobank data quality; and privacy issues.

Eero is leader of the study network 'Nordic Occupational Cancer (NOCCA)', with a focus on broad selection of work-related hazards, and has coordinated other world-pioneering studies such as 'North-European Studies on Cancer among Airline Personnel (NoESCAPE)' and mapping of cancer-related phenomena in all North-European countries and selected other regions in Europe, America and Asia. He is the Epidemiologist of the year in Finland nominated by the Finnish Epidemiological Society and honorary member of the International Association of Cancer Registries.

Occupational cancer and use of cancer registries

The Nordic Occupational Cancer (NOCCA) project is the largest and in many aspects, also qualitatively, the most unique research study ever done on occupation and cancer incidence. It consists of a follow-up study on the entire working populations of Denmark, Iceland, Finland, Norway and Sweden with three million cancer cases diagnosed 1961-2005, with plans of an extension to more recent years. It described risks of 84 cancer types in 54 occupational categories (astra.cancer.fi/NOCCA) and developed a Nordic Job Exposure Matrix that converts the individual job histories of all Nordic people to quantitative estimates of exposure to potentially cancer-related factors. Many of the results on dose-response associations between exposures and cancers have been novel findings or have confirmed (or not) findings from earlier smaller studies. The NOCCA network still produces about one new publication each month from the old data. Still, not only the NOCCA researcher team but also institutions such as IARC, Nordic Minister Council and occupational health professionals have stressed that it would be important to continue NOCCA research work with updated data. New features in the work life, such as effects of sedentary work, could not be fully studied in the original NOCCA data. There is also an urgent need to follow effects of work safety regulations and operations that were started after the harmful effect of work carcinogens were recognised. For example, restaurant workers who had the highest risk of many cancers are no longer exposed to tobacco smoke in their work environment; this should be seen as a rapid decrease in their cancer risk. It has been proven that combining five entire national populations as a study cohort about 10 years ago was feasible and produced important results. The researchers of the NOCCA network are eager to continue and update the activity, provided that challenges related to funding and data access issues can be won.

Professor **Henrik Møller**, BA, BSc, MSc, Dr.Med., is the Lead Epidemiologist at The Danish Clinical Registries in Aarhus, Denmark. He has academic associations with several medical schools at universities in England and Denmark. Previous employments were as Professor of Cancer Epidemiology at King's College London (since 2000) and Director at the Thames Cancer Registry (2000-2011); Director of Centre for Register-based Research at the Danish National Research Foundation in Copenhagen (1995-1999); as Scientist and Acting Unit Chief in Unit of Carcinogen Identification and Evaluation at International Agency for Research on Cancer in Lyon (1992-1995); and as Epidemiologist at the Danish Cancer Registry in Copenhagen (1986-1992). Henrik's research has a focus on variation in health care provision and associated patient outcomes. In an international research career spanning more than three decades, he has published about 400 peer reviewed research articles in cancer epidemiology and health services research.

Population based cancer registration and clinical databases in cancer epidemiology and health services research

Professor **Anne Tjønneland**, Research Leader at the Danish Cancer Society Research Center, and Professor at Department of Public Health, Faculty of Health and Medical Sciences, University of Copenhagen.

- Anne Tjønneland has 29 years of research experience in nutritional and cancer epidemiology. Anne Tjønneland has established and is head of the Danish prospective cohort study, 'Diet, Cancer and Health'. Diet, lifestyle information, anthropometric measurements and biological material are available for the more than 57 000 participants.

- In 2015-2018, the cohort has been extended to include data from more than 42 000 biological children and grandchildren in the 'Diet, Cancer and Health – Next Generations' study.

- She is Principal investigator and Member of the Steering Committee of the European Prospective Investigation into Cancer and Nutrition (EPIC), a multicenter cohort study with 10 European countries.

Her H-index (June 2018) is 97, and number of citations 43 000 (Scopus). She has been appointed as Highly Cited Researcher 2015, 2016 and 2017 (Thomson Reuters / Clarivate Analytics).

The Diet, Cancer and Health study – a prospective cohort study

The importance of record linkage in Cancer Epidemiology

In my talk, the Diet, Cancer and Health study will be presented including the EPIC collaboration and the Next Generation study.

There will be a focus on the important interaction between prospective cohort studies and data obtained by linkage to Health Registries. Examples from the Danish Cancer Registry, The Causes of Death Registries, Statistics Denmark, and Clinical Databases will be used to give examples from our research on diet and lifestyle in relation to cancer incidence and prognosis.

Perspectives will be given for future research towards a more personalized prevention.

Abstracts

Using linked primary care data to investigate patients presenting with non-specific but concerning symptoms

Clare Pearson,[1,2] Veronique Poirier,[1] Karen Fitzgerald[1]

[1]Cancer Research UK [2]Public Health England Partnership

Background and Introduction

Five 'Accelerate, Coordinate, Evaluate' (ACE) projects are currently piloting Multi-disciplinary Diagnostic Centres (MDCs) in England to address needs of patients with non-specific but concerning symptoms (NSCS). Diagnostic pathway data for similar patients can be obtained from the National Cancer Diagnosis Audit (NCDA). This work aims to compare characteristics of patients with NSCS with those presenting with recognised alarm symptoms to inform the evaluation of the MDCs.

Materials and Methods

The NCDA collected primary care data for 17042 patients diagnosed with cancer in England in 2014. NCDA records were linked at tumour level with national cancer registrations and the routes to diagnosis dataset. Patients with NSCS were identified using the referral criteria developed by the MDCs. The NSCS cohort included patients who only had NSCS recorded by their GP. These patients were compared using statistical tests (ANOVA or Chi2 tests) to the remainder of the NCDA cohort (non-NSCS), specifically characteristics of age, stage, investigation, presentation route and primary care time intervals. Those with no symptoms were excluded.

Results

17% (2865/17042) of patients with only NSCS recorded. The most common NSCS were weight loss and non-specific abdominal pain. The median age for NSCS patients was 71 vs 67 in the non-NSCS patients ($p<0.01$). The proportion of patients presenting as emergency was 34% vs 16% ($p<0.01$). NSCS patients had fewer early stage cancer diagnoses, 23% vs 44% ($p<0.01$). The median primary care interval (presentation to referral) in the NSCS cohort was 11 days vs 2 days and the diagnosis interval (presentation to diagnosis) was 47 days vs 38 days.

Conclusions

The results obtained from the analysis of the NCDA records underline the need for MDC-based referral pathways for patients presenting with NSCS. It demonstrates the usefulness of linking national datasets to expand knowledge of the diagnostic pathway for cancer patients.

The impact of individual, household and neighbourhood income on lung and colon cancer survival in Belgium

Michael Rosskamp, Julie Verbeeck, Liesbet Van Eycken, Harlinde De Schutter

Belgian Cancer Registry

Background and Introduction

Socioeconomic (SE) status is associated with differences in cancer incidence, survival and mortality. Directions and magnitude vary in function of tumour type, outcome and SE parameter. The objective of this study was to assess the relation between income and survival for lung and colon cancer at the Belgian population level. Income was assessed at the individual, household and neighbourhood level.

Materials and Methods

A random sample (1/2) of patients diagnosed between 2004 and 2013 with lung (n=28273) or colon cancer (n=20968) and aged 25 years or older was extracted from the Belgian Cancer Registry. Income data on the year preceding diagnosis were obtained from the Crossroads Banks for Social Security and available at individual, household (increments of EUR 5000 per unit) and neighbourhood level (low, middle and high-income areas). Following univariable analyses, the relation between 5-years observed survival and income was assessed in Cox proportional-hazard regression models, adjusting for age, gender, histology (for lung cancer only), stage and comorbidities.

Results

Higher income at individual, household and neighbourhood level was associated with better survival for patients diagnosed with lung or colon cancer in univariable analyses. After case-mix adjustment, individual (HR:0.91 ; 95% CI:0.87-0.95) and area-level income (HR high vs. low:0.91 ; 95% CI:0.88-0.94) remained significantly associated with survival for lung cancer patients, whereas household (HR:0.98 ; 95% CI:0.97-0.99) and neighbourhood income (HR high vs. low:0.86 ; 95% CI:0.83-0.90) were independently prognostic for colon cancer patients.

Conclusions

Higher income is associated with better survival for lung and colon cancer patients in Belgium, at individual, household and area-level. Further investigations will cover the impact of other SE factors such as education level, employee status, parity and the household type on cancer survival and will include other cancer types.

Linking the Netherlands Cancer Registry to the Dutch Pathology Registry

Dr. Annette Bruggink,[1] Dr. Rinus Voorham,[1] Annemarie Eeltink-Conijn,[2] Prof. Dr. Iris Nagtegaal[3]

[1]PALGA Foundation [2]Netherlands Comprehensive Cancer Organisation IKNL [3]Radboud University medical center, Nijmegen

Background and Introduction

PALGA, the nationwide network and registry of histo- and cytopathology in the Netherlands, contains over 70 million pathology reports from 12 million individuals and is the central access to the pathology material stored in all 45 participating pathology labs in the Netherlands. The nationwide Netherlands Cancer Registry (NCR) is maintained and hosted by the Netherlands Comprehensive Cancer Organisation (IKNL) and contains data on diagnosis, stage and primary treatment of almost all cancers in the Netherlands, as well as on cancer survival

Materials and Methods

Why Linking: data of both registries can be used for scientific research separately, but by combining data of these registries the value of each registry is strongly increased. Combination of both registries enables:

1. studying relations between benign and malignant diseases,
2. following-up (history) cancer patients (*e.g.* metastasis),
3. requesting pathology material (FFPE tissue blocks, slides) from the pathology labs for additional research, such as molecular and DNA research.

Results

The first linkage from NCR to PALGA was established in 2010. At this moment more than 70 linkages have been requested, showing the fulfilled need of the scientific community for this linkage. This also generated al lot of knowhow on linking procedures. Privacy restrictions are met by the use of pseudonyms and the services of a trusted third party.

Conclusions

Combining data and/or material from different registries (and biobanks) to pathology data offers unique opportunities for scientific research and future health care in the Netherlands.

Linkages between cancer registries and administrative data to study late effects in cancer survivors

Alice Bernasconi,[1] Giulio Barigelletti,[2] Laura Botta,[1] Giovanna Tagliabue,[2] Paolo Contiero,[3] Andrea Tittarelli,[2] Anna D'Agostino,[2] Sabrina Fabiano,[2] Gemma Gatta,[1] Annalisa Trama[1]

[1]Evaluative Epidemiology Unit, Fondazione IRCSS Istituto Nazionale dei Tumori, Milan, Italy [2]Cancer Registry Unit, Fondazione IRCSS Istituto Nazionale dei Tumori, Milan, Italy [3]Environmental Epidemiology Unit, Fondazione IRCSS Istituto Nazionale dei Tumori, Milan, Italy

Background and Introduction

In Italy, the project 'Adolescents and young adults with cancer in Italy' (Ada) is developing the first Italian population-based cohort of adolescents and young adult (AYA) cancer survivors. AYAs are defined as those 15-39 years at first cancer diagnosis; survivors if alive 5 years after diagnosis. Ada aims to:

- estimate the burden of late effects in AYA cancer survivors,
- study the association between treatments received and late effects with a special focus on novel targeted therapy.

Materials and Methods

The approach proposed is based on record linkage procedures and not on an ad hoc data collection. All Italian cancer registries (CRs) were invited to join. A survey was performed to assess data sources available in the interested CRs and a protocol was developed to transfer the data according to the results of the survey. CRs provided to our centre (INT) all incident cancer cases in the 15-39 years age group and linked to these cases subsequent tumours and all the other data sources available (*e.g.* hospital discharge records, mortality files, pathological reports, hospital drugs flow).

Results

In Italy, 35 out of 43 CRs are submitting the data to the INT. A cohort of about 70 000 AYA cancer survivors diagnosed from 1978 to 2012 (with mean follow-up of 10 years) was developed. Currently analyses are on going to estimate: mortality excess risk (Standardized Mortality Ratio), secondary neoplasms excess risk (Standardized Incidence Ratio) and hospitalizations excess risk (Standardised Hospitalisation rate Ratio). In addition, from the hospital discharge records we will try to collect information on treatment received (surgery; chemotherapy; radiotherapy) to assess the impact of treatments on late effects.

Conclusions

The AYA cancer survivors cohort will provide knowledge on the burden of late effects and the impact of treatments on the late effects in AYA cancer survivors. This information will be useful to discuss treatment and clinical follow-up guidelines for AYA with cancers to reduce the impact of late effects on this group of neglected patients.

Distributedlearning.ai: towards a distributed learning network for cancer registries

Gijs Geleijnse,[1] Melle Sieswerda,[1] Melinda Schuurman,[1] Ru Ru Chiang,[2] Anna van der Zalm,[1,3] KC Lee,[4] Johan van Soest,[5] Timo Deist,[5] Andre Dekker,[5] Xander Verbeek[1]

[1]Netherlands Comprehensive Cancer Organisation (IKNL) [2]Taiwan Cancer Registry (TCR) [3]Jeroen Bosch Ziekenhuis (JBZ) [4]Industrial Technology Research Institute (ITRI) [5]Department of Radiation Oncology (MAASTRO), GROW School for Oncology and Developmental Biology, Maastricht University Medical Centre

Background and Introduction

The growing complexity of cancer diagnosis and treatment requires data sets that are larger than currently available in cancer registries. However, sharing patient data is difficult due to patient privacy and data protection needs. Privacy preserving distributed learning technology has the potential to overcome these limitations. Here, we present work-in-progress around the development of a reusable and scalable distributed learning infrastructure for cancer registry data, allowing privacy preserving analysis of data across registries.

Materials and Methods

We are developing distributedlearning.ai, a transparent, open source IT infrastructure. Currently, a distributed Cox proportional hazard algorithm as described by Lu *et al.* [Lu2015], is available for use on the infrastructure. This algorithm iteratively estimates the beta coefficients using only aggregated statistics from each site. Other commonly used statistical analysis algorithms will be made available shortly. To ensure interoperability, the data of the participating organisations will be coded using semantic web standards. This allows the transparent definition of data items according to common standards such as ICD-O and SNOMED.

Results

We have successfully shown the infrastructure can be used to compute hazard ratios on publicly available data sets. As a further proof-of-concept multivariate Cox Regression analyses will be performed to identify possible differences in survival between Taiwan and the Netherlands and their contributing factors. Results will be presented during the congress.

Conclusions

IKNL, TCR, ITRI and MAASTRO are creating an infrastructure and community for the distributed analysis of privacy sensitive data across institutions. This allows the analysis of data as-if they were combined, yet without allowing access to individual patient records. Therefore, distributed learning has the potential to disruptively impact the analysis of cancer registry data within Europe.

Application of data linkage methods and procedures at the National Cancer Registry of Ukraine

Anton Ryzhov, Yevgeniy Gorokh

National Cancer Registry of Ukraine, Ukrainian National Cancer Institute

Background and Introduction

The National Cancer Registry of Ukraine (NCRU) is a network of regional population-based cancer registries (PBCR), operating in each province ('oblast') according to the principles and requirements of the state cancer registration system, but also following international guidelines and recommendations for data quality. The incidence data collected at the NCRU was published in 'Cancer Incidence in Five Continents', vol. X-XI. Due to mainly paper-based communications between regional PBCRs it is important to assess and estimate proportions of duplicates at the national level.

Materials and Methods

The aggregated NCRU's database consists of ~4.5 mln. records of cancer patients (2018). The blocking packages and set of data items and linking functions to be used in linkage procedures were determined to produce a single-value weight for each pair of suspicious records. Patient's personal information (first, last name, sex, birth date, place of residence) as well as tumor (date of diagnosis) were compared. Specific methods were developed to compare Cyrillic names in bilingual cultural environment of Ukraine.

Results

Each regional PBCR in Ukraine uses the same software and linkage procedures while recording new cancer case or updating treatment information/follow up status of existing record. This reduces number of duplicate records in the database of this particular PBCR. Application of data linkage procedures at the national level showed that percentage of potential duplicate records in the whole dataset was less than 2.5%. From this quantity 11.1% had follow-up status 'alive' in both matched records and 2.8% had status 'dead' in one of the matched records.

Conclusions

Our study showed, that despite decentralization of the NCRU's database, the level of duplicates was low. More care must be taken for the recent time period as internal and external migration increased in Ukraine.

Cancer of Unknown Primary (CUP): epidemiology in Germany compared to other European countries and the United States

Sylke Ruth Zeissig,[1] Klaus Kraywinkel[2]

[1]Cancer Registry of Rhineland-Palatinate, Mainz, Germany [2]German Centre for Cancer Registry Data (ZfKD), Berlin, Germany

Background and Introduction

There are only few detailed data about incidence and prognosis of cancer of unknown primary (CUP) in international routine reports of cancer registries (CR). This study presents an overview of the incidence, mortality and survival rates of CUP in Germany in comparison to international data.

Materials and Methods

This study is based on pooled data from the German epidemiological CR (2003-2014). We use official cause of death statistics to describe mortality (ICD-10: C80). Incidence and mortality rates are age standardized using the European Standard Population (1976). To describe 5-year relative survival rates (RSR) period analysis is performed (2010-2014). Incidence rates are compared to those reported for Belgium, Netherlands, Austria and the United Kingdom. Histology and RSR are compared to the SEER 13 Registries.

Results

In Germany approximately 11 000 people per year are diagnosed with CUP, corresponding to 2.3% of all cancers. Age standardized incidence rates are 6,5 per 100 000 women and 9,1 per 100 000 men. Compared to the reported incidence for selected countries the rates in Germany are 30-70% higher. Adenocarcinoma is the leading morphology, but in approximately 30% of cases only unspecific histological codes were given. Age standardized mortality rates were 5,4 per 100 000 women and 7,5 per 100 000 men. RSR of around 18% (18,4% women; 17,5% men) are overall slightly higher than those reported by the SEER Registries (12,1% women; 19,4% men). For younger patients and those with squamous cell carcinoma RSR are considerably higher.

Conclusions

Comparability of data about CUP is difficult, because the registration praxis is different. International comparisons indicate that the incidence of actual CUP in Germany might be overestimated, probably because the differentiation between an actual 'unknown' and merely an 'unspecified' primary site of the tumor is difficult and the term 'CUP' is not well defined in the current ICD-O classification.

Estimating fractions of cancers attributable to socioeconomic inequalities in Slovenia

Vesna Zadnik, Katarina Lokar, Sonja Tomsic, Franciska Skrlec, Tina Zagar

Cancer Registry of Slovenia, Institute of Oncology Ljubljana

Background and Introduction

An unequal distribution of well-known major risk factors in population typically explains much of the variation in the cancer incidence worldwide. Socio-economic deprivation is recognised as one of the important predictors of cancer risk. The aim of this study was to estimate the cancer burden in Slovenia that is attributable to socioeconomic inequalities.

Materials and Methods

For the 2005-2014 period 127 827 incident cases were identified from population-based Slovenian Cancer Registry. Social component of the environment was assessed at an aggregate level using the Slovenian version of European deprivation index (SI-EDI). The smallest geographical census units available (3104 national polling stations) with the average population size of 600 inhabitants were applied in the modelling. Relative risks used in the calculation of population attributable fraction (PAF) were estimated by spatial Bayesian Poisson models. The analysis was prepared for 22 types of cancer.

Results

The affluent population is at higher risk for melanoma (PAF=15.9) and non-melanoma skin cancers (PAF=8.9), prostate (PAF=10.4), breast (PAF=9.5) and rectal (PAF=3.6) cancer as well as for non-Hodgkin lymphomas (PAF=12.9). In contrast, the deprived population is at higher risk for oesophageal (PAF=18.6), stomach (PAF=11.6), cervical (PAF=9.2), lung (PAF=8.6), head and neck (PAF=8.1) and liver (PAF=6.2) cancers. No excess cases because of socioeconomic inequalities has been observed for all cancers together as well as for ovary, testicular, colon, bladder, pancreatic, kidney, thyroid, corpus uteri cancers and leukaemia.

Conclusions

Tackling social inequalities in health is a priority for Slovenian national policy. By estimating the burden of cancers attributable to socioeconomic inequalities, this study enables us to evaluate the gains that could be achieved by implementing targeted public health interventions.

Hairy cell leukaemia: incidence, prevalence and survival in Europe. Findings from RARECAREnet

Charlene M. McShane,[1] Lesley A. Anderson,[2] on behalf of RARECAREnet working group

[1]Centre for Public Health, Queen's University Belfast [2]Northern Ireland Cancer Registry, Queen's University Belfast

Background and Introduction

Limited epidemiological information is available on hairy cell leukaemia (HCL) a rare, indolent form of leukaemia.

Materials and Methods

We used RARECAREnet, an online analysis tool which provides aggregated data from 94 European population-based registries across 27 European countries to investigate incidence, prevalence and survival of HCL diagnosed in Europe during 2000-2007. Crude and age-adjusted incidence rates were estimated. Relative survival (RS) was determined using the Ederer II method.

Results

In 2008, it was estimated that there was n=20 836 patients living with HCL in Europe. During the study period (2000-2007), n=4387 cases of HCL were diagnosed in Europe giving an age-standardised rate of 0.24 (95% CI 0.23-0.25) per 100 000 people. Incidence was higher in males and older adults. Incidence increased slightly overtime but remained relatively stable. Similarly, 5-year RS remained stable throughout the study period [1999-2001: 90% (95% CI 88-93%) to 2005-2007: 89% (95% CI 86-92%)]. Differences in survival were noted by age group and sex with females experiencing significantly poorer 5-year RS compared to males (84% vs 92%). Survival also varied by country with 5-year RS ranging from 58% in Poland to 99% in France.

Conclusions

The majority of HCL patients in Europe can expect to live beyond 5 years, however significant disparities exist by sex, age group and country of residence. International collaborative efforts both at a clinical and research level are required to reduce the disparities experienced by HCL patients' across Europe.

Incidence trends of hematological malignancies in Belgium 2004-15: impact of the residence on chronic myeloid disorders

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Belgian Cancer Registry

Background and Introduction

The Belgian Cancer Registry collects information about all new cancer diagnoses in Belgium since the incidence year 2004. In 2015, hematological malignancies (HM) represent 10.7% of all cancers and are the 3rd cause of death by cancer.

Materials and Methods

We aim to analyse the impact of the residence of patients at time of diagnosis on the incidence trends (age-standardised incidence rate using the world standard population: WSR) and on the relative survival of the main categories of HM over a 12 yr-period in Belgium. Two criteria of residence at time of diagnosis were studied: the three Belgian Regions and the rurality (rural vs non-rural areas defined on municipality).

Results

A total of 71783 HM (lymphoid: 49204; myeloid: 22579) were registered over 2004-15. The slight increase of the WSR incidence rate is mainly explained by an increased incidence rate of chronic disorders (myelodysplastic syndromes (MDS), myeloproliferative neoplasms (MPN), MDS/MPN, and to a lesser extent, chronic lymphocytic leukemia/lymphoma (SLL/CLL)). No major incidence trends are observed for the main categories of lymphoid malignancies. The increased WSR incidence rates for MDS seem to be more important in the Walloon (especially in large Walloon cities) and Brussels-Capital Regions than in the Flemish Region, while the rates are similar between the three regions for MPN, MDS/MPN and SLL/CLL. Regarding the rurality level, no obvious observation except for a trend for a higher incidence of MPN in urban municipalities (not significant). The relative survival for each main category of HM does not differ between the three regions.

Conclusions

In conclusion, the increased WSR incidence over 2004-15 of chronic HM (mainly MDS, MPN, and MDS/MPN) may be at least partly explained by an earlier detection at an asymptomatic stage and/or a better registration by hospitals. However, the disparity of the WSR incidence trend between the three Belgian regions for MDS raises the question of a participation of environmental and/or socio-economic factors on the onset of this myeloid malignancy in Belgium.

2017 projections of cancer incidence in Granada, southeast Spain

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Background and Introduction

Updated cancer incidence data is difficult to obtain, but it is vital for public health managers who require accurate estimation of cancer incidence for cancer surveillance and control. Objective: to estimate the incidence of cancer in the province of Granada for the year 2017.

Materials and Methods

Data were drawn from the Granada Cancer Registry. All incident cases residing in the province of Granada and diagnosed in 2003-2013 for the following anatomical sites were included: colon-rectum, prostate, lung, bladder and stomach in men, and colon-rectum, breast, lung, ovary, corpus uteri and skin melanoma in women. Total cancer except non-melanoma skin was also considered. The incidence projection method was based on GLM, which assumes that the number of incident cases follows a Poisson distribution, with age and year of diagnosis as independent terms, and population as an offset. Then number of new cases, crude and age-standardized rates to the European population (ASR-E) per 100 000 inhabitants were estimated.

Results

4 604 new cases of cancer (except non-melanoma skin) were estimated to be diagnosed in the province of Granada in 2017. The expected number of new cases was 590 per 100 000 men, and 415 per 100 000 women. 58% of estimated cases were men. The standardized rates were 461.2 per 100 000 men and 303.2 per 100 000 women. The most frequent cancers were prostate (ASR-E: 99.7), colon-rectum (ASR-E: 69.2) and lung (ASR-E: 55.8) in men, and breast (ASR-E: 93.1), colon-rectum (ASR-E: 33.1) and corpus uteri (ASR-E: 20.9) in women. Among the analysed sites, the lowest rates were observed in stomach in men (ASR-E: 12.1), and in lung (ASR-E: 10.5) and ovarian cancer (ASR-E: 8.6) in women.

Conclusions

Estimations of cancer incidence in Granada for 2017 confirmed the increasing trend of prostate, breast or colon-rectum cancer, as well as the decreasing incidence of lung cancer cases among men. Cancer projections provide a picture of the current burden of cancer providing evidence for public health policy making.

Childhood cancer incidence in Estonia: time trends since the 1970s

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Background and Introduction

Childhood cancer incidence has been increasing over the past decades, and even though childhood cancer represents a small proportion of all cancers, it is important to monitor the trend to plan and predict the needs of the healthcare system. Estonia has about 35 new childhood cancer cases diagnosed annually, making it a difficult subject to prioritise. As Estonian Cancer Registry (ECR) holds high quality data since 1968, we aimed to examine long-term incidence trends.

Materials and Methods

Data on all cases, diagnosed in children aged 0-14 between 1970-2014, were derived from the ECR (all malignant, CNS non-malignant since 1998). Age-specific and age-standardised (World standard) incidence trends were evaluated by ICCC-3 site groups, calculating annual percentage change (APC) with Joinpoint Regression Program.

Results

ASIR increased significantly over the study period for all sites combined (from 12.5 to 16.5 per 100 000, APC 0.9). Steepest increase was seen for age group 10-14 (APC 1.4). Incidence increased in almost all major site groups, but the increase was not statistically significant for CNS tumors and leukemias. The latter did show a rising trend in all age groups, but the change was significant only for lymphoid leukemias (APC 2.1), and mainly due to the rise in age group 5-9. A slight decline (not significant) was seen for lymphomas, retinoblastomas and renal tumors. The decline was substantial and significant for retinoblastomas in 10-14 year olds (APC -29.2).

Conclusions

Even if the rise in incidence could be explained to some extent by changes in diagnostics and improved registration, the fact that increase was seen in almost all site groups, indicates a real rise, a large part of which still remains ununderstood. On a positive side, the number of unspecified neoplasms decreased, denoting improvements in diagnosing. Efforts must be made to analyse childhood cancer data in more detail in order to understand the underlying mechanisms.

Prediction of cancer prevalence in Austria up to the year 2030

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Background and Introduction
Age is a very strong determinant of cancer risk– the number and proportion of elderly people will rise. Knowledge about further development of cancer prevalence is necessary to allocate the resources required for prevention, diagnosis and therapy optimally.

Materials and Methods
The analysis is based on data of the Austrian National Cancer Registry (query date 15/11/2016). Cancer prevalence comprises all cases diagnosed from 1983 to 2014 and still alive. Cancer prevalence up to the year 2030 is predicted based on the cohort-component method and calibrated to official population projections. Estimated cancer incidence rates were used for 2015 to 2030. The prediction differentiated between persons without a tumor, persons with exactly one and persons with two or more tumors and was performed for 16 groups of tumor sites.

Results
The absolute number of cancer cases will rise by 39% from 2014 to 2030. This future increase in cancer prevalence continues the trend seen since the turn of the millennium: in 2000, about 191 200 persons lived with a prior cancer diagnosis in Austria (2.4% of the population), in 2014 already about 329 200 (3.8%) For 2030 we predict that 457 700 persons (4.9%) will be diagnosed with cancer.

Conclusions
The further development of cancer prevalence is affected by three factors: demographic ageing will result in an increase of cancer prevalence, as cancer mainly shows up in advanced years of life. Then, trends for the individual risk of developing malignant tumors may evolve in different directions, depending on sex and tumor site. Observing all entities together, the individual risk of cancer will decrease in the future, which slows the growth of cancer prevalence. And finally, medical progress improves the relative survival rate of cancer patients, which again leads to an increase of the cancer prevalence. From a health policy point of view, the interaction of these factors shows the importance of preventive measures.

Are melanoma fatal cases decreasing in Europe?

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Background and Introduction

In the period 1995-2012 invasive and in situ melanoma increased in most part of Europe (Annual Percent Change: invasive 4.0% men; 3.0% women; in situ 7.7% men; 6.2% women). The rise in invasive lesions was mainly driven by thin melanomas (8.3% women; 10.0% men). Mortality increased in some areas, but at a much slower pace and not homogenously. In this scenario, it is difficult to disentangle the effects of diagnostic anticipation, true increasing risks, or misclassification. We proposed a different approach: to analyse fatal cases trends according to principal melanoma characteristics.

Materials and Methods

Incidence and mortality data were collected from population based European cancer registries. These data included information on sex, age and year of diagnosis, histological type, tumour location, behaviour (invasive, in situ), lesion thickness, and vital status (dead or alive at up to five years after diagnosis). Trends in the proportion of fatal cases by melanoma and patients characteristics were analysed with multivariate mixed effects log-linear models.

Results

Fatal cases rates occurring within one year after diagnosis were modified by sex, lesion thickness, histology type and body site (more fatal cases in men with thick melanomas of nodular type in the trunk). However, fatal cases occurring in thin melanomas were not a negligible fraction (24%). After controlling for these factors, rates showed a slight decrease in the period (-18% in years 2001-2006 and -21% in 2007-2012 compared to 1995-2000). However, fatal cases at 3 years did not confirm a similar decrease in the last period and other controlling factors in general showed a weaker effect.

Conclusions

The detected decrease in earlier fatal cases over the considered period supports the hypothesis that a higher diagnostic pressure may show a beneficial effect on more aggressive melanoma. However it seems still insufficient on the long run not reducing overall mortality or late case-fatality rates.

Identifying and counting people living with treatable but not curable cancer in the England cancer registry

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Background and Introduction

There is a growing cohort of people, who although they cannot be cured of their cancer, are on treatments that can reduce cancer burden, alleviate symptoms and prolong life. This is a heterogeneous group with different prognoses and treatments. They could be described as living with treatable but not curable cancer (TNCC). This project aims to build a criterion to identify TNCC, using data in the England cancer registry.

Materials and Methods

A set of possible search criteria were developed to be evaluated by 20 oncologists, haematologists and specialist nurses. This will lead to a single search criterion.

Results

Our first set of criteria were based on distant metastatic cancer. There were 76 000 people in England in 2015 at stage IV at diagnosis, with a secondary malignancy or with certain haematological cancers. Our next criteria included metastatic disease developed post-diagnosis. It included 135 000 people identified in inpatient HES and 10 000 from the Cancer Waiting Times dataset. Our next set of criteria focused on treatment. This selected 46 000 people who in 2015 received one of 236 chemotherapy regimens thought to target TNCC; or had a second chemotherapy treatment over a year from first treatment. It found 7 000 people who had a second round of radiotherapy after a six-month gap. Another criterion pinpointed 99 000 people who received palliative chemotherapy or radiotherapy. In the final searches we identified 57 000 people diagnosed with an intermediate survival cancer and 78 000 with a shorter-term survival cancer. McConnell *et al.* (2017) hypothesised that intermediate survival cancers are often long-term conditions. New treatments will make the shorter-term survival group an important part of TNCC.

Conclusions

This is a first attempt which we will refine with clinicians and analyses. It will not cover all circumstances however, it will enable the better understanding and thus influence decision makers and service designers to recognise the group and provide services for them.

Cancer in the oldest-old–time trends and future burden, a Danish nationwide study

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Danish Cancer Society

Background and Introduction
The oldest-old is the fastest growing segment in western populations. Currently, 2% percent of all incident cancers in Denmark are in the oldest-old (persons above the age of 90). This study presents trends in cancer incidence among the oldest-old. Furthermore, we describe trends by demographics, social factors, and comorbidity and predicts the future cancer burden among the oldest-old.

Materials and Methods
We studied all incident cancers in Denmark in the period 2000 to 2015. We included information on demographics, social factors, and comorbidity conditions (Charlson Index) to estimate prevalence ratios hereof using logistic regression models. To estimate the cancer incidence among the oldest-old in Denmark by year 2050 we applied the Lee-Carter model, assuming a linear trend with calendar time, in combination with the projected development of the bio-demographics in Denmark for year 2050.

Results
The oldest-old have experienced a 50% increase in cancer incidence between 2000 and 2015, the highest compared to all age groups. The oldest-old more often live alone and have more comorbidity compared to less old cancer patients.

Conclusions
The proportion of cancer cases among the oldest-old is expected to increase several-fold in Denmark, given the projected development in the aging population. The increase is not only due to an aging population, but is also due to an increased awareness on cancer detection and treatment for the oldest-old. Information is needed on how age-related health problems and social factors, such as multi-morbidity and living alone, affect cancer detection, prognosis, and treatment.

Life expectancy of Italian cancer patients

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Background and Introduction
The loss of life expectancy (LE) of cancer patients with respect to the general population is an indicator of disease burden easily interpretable from patient and informative for long-term survivors as a measure of how much the patients' perspectives of life differ from those of the comparable cancer-free individuals. When such difference becomes small, no further discrimination should hamper normal life actions. We will present for the first time, for Italian cancer patients compared to the general population, LE estimates for all the major cancer sites by age, sex, and time from diagnosis.

Materials and Methods
Data on 722737 cancer patients, diagnosed during the period 1985-2011 and collected from eight Italian population-based cancer registries in the AIRTUM network with more than 18 years of incidence, were analyzed. Period life tables were obtained for each sex, cancer and by five year age class at diagnosis, from 40-44 to 80-84. Excess hazard up to age 119 years, not empirically observable, was estimated by 10-year moving average. The patients' excess hazard due to cancer was added to the general population mortality risk in 2013, so obtaining patients' overall risk for all causes, and calculate their LE. Finally, a smoothing algorithm was applied to stabilize the raw LE values obtained.

Results
The loss of LE of a male patients diagnosed with cancer at 42 years was estimated as 13.6 years at diagnosis and decreased to 7.4, 5.7 and 4.3 for those surviving at 5, 10, and 15 years after diagnosis, respectively. For men diagnosed at 72 years, the corresponding values were 4.2, 2.3, 1.8 and 1.4 years of life lost. For women, the loss of LE at the same time points was higher 13.6, 8.6, 6.5 and 5.0 years, for those diagnosed at 42 years, and 4.7, 3.0, 2.2, and 1.8 for those diagnosed at 72 years of age.

Conclusions
Estimation of LE is very sensitive to random variation in the tail of survival distribution. The main methodological problems and possible solution will be discussed.

Improvement in cancer survival in the Nordic countries 2001-2015

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Background and Introduction

Finland, Iceland, Norway and Sweden are among the countries in the world with highest cancer survival (CONCORD-3). From the 1970s, cancer survival has been much lower in Denmark than in the other Nordic countries, but in the last 15 years improvements are higher in Denmark and the survival gap is closing.

Materials and Methods

The cancer statistics database NORDCAN (www.ancr.nu) started in 2002 and has developed over time. Survival for five Nordic countries, Denmark, Finland, Iceland, Norway and Sweden, was included after a publication in 2010 on cancer survival 1964-2003. The database is updated each year and 1- and 5-year relative survival are now available for ten 5-year periods of diagnosis 1966-2015 for more than 50 cancer sites.

Age-specific and age-standardised (ICSS) relative survival are shown in tables and figures in NORDCAN.

Results

For colon cancer the gap between highest and lowest 1-year survival in the Nordic countries decreased from 9-10 percent point in 2001-2005 to 1 in 2011-2015. For lung from 7-10 to 4 and for breast from 3 to 1 percent points. For 5-year survival the gap in 2001-2005 for colon was 9-10 and decreasing to 4-5 percent points in 2011-2015. For lung from 3-5 to 3 and for breast from 6 to 3 percent point.

Conclusions

The low survival in Denmark prompted national cancer plans in 2000, 2005 and 2011. Surgery has improved and treatment has been centralized. From 2007 cancers have been classified as acute and life-threatening diseases and accelerated site-specific pathways for diagnosis and treatment start were established in 2007-8. Public monitoring of compliance with waiting times in hospitals has followed. Accelerated cancer-specific pathways have now also been introduced in Norway and Sweden. To further monitor the cancer survival the NORDCAN group works on comparing TNM-stage distributions and stage-specific survival from 2004 and on for possible later inclusion in NORDCAN.

Pattern of comorbidities among colorectal cancer patients and impact on treatment and short-term survival

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Background and Introduction

Colorectal cancer (CRC) is the most frequently diagnosed cancer in Spain in both sexes with 41 441 new cases in 2015. There is little evidence regarding the pattern and impact of comorbidities on time from cancer diagnosis to surgical treatment and short-term mortality among CRC patients in Spain. Objective: to describe the pattern of comorbidities and to investigate the extent to which comorbidities influence time-to-cancer treatment and one-year survival in Spain.

Materials and Methods

We developed a population-based high-resolution cohort study, including all CRC cases in Granada and Girona diagnosed in 2011. Data were drawn from two cancer registries and hospital digital medical records. We describe the pattern of comorbidities by patient, tumor and healthcare factors using radar-plots and heatmaps. Then, we used nonparametric methods to study the impact of comorbidities on time to surgical treatment and short-term mortality. Finally, we developed a web app: watzilei.com/shiny/CoMCoR/.

Results

The most common comorbidities were diabetes (24%), COPD (17%) and congestive heart failure (15%). Dementia was the most common comorbidity among older patients (75+ years) showing a higher proportion (30%) of late cancer diagnosis. The median time from diagnosis to surgical treatment was 35 days. Overall, patients with 2+ comorbidities had an increased time to surgery of 17 days, 95% CI 12-34. However, patients aged 75+ years having 2+ comorbidities showed a higher prevalence of emergency hospital admission followed by surgery the same day or the day after admission (37%). Overall, the presence of 2+ comorbidities increased two-times the risk of short-term mortality one-year after diagnosis.

Conclusions

Results from our study allow identifying patterns in the frequency and distribution of comorbidities among CRC patients and their impact on time from diagnosis to surgical treatment. Thus, this web application is meant to serve as a scientific tool supporting evidence-based policymaking to improve CRC patients outcomes.

Risk of developing gynecological cancer in Germany corrected for women no longer at risk after hysterectomy

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Background and Introduction
Incidence rates from population based cancer registries generally underestimate average risk of developing cancer of the cervix or other gynecological sites in the population, as a relevant proportion of women is no longer at risk after a hysterectomy, but still contributes to the denominator for the calculation of these rates. First estimates for corrected age specific incidence rates for cervical cancer were recently published based on data of a national health survey, where women had been asked if they ever had a hysterectomy. As hysterectomy rates for non-malignant indications are steadily declining in Germany, it can be assumed that these correction factors are not permanently valid.

Materials and Methods
Based on the age specific prevalence of hysterectomies as determined from the national health survey (DEGS-1 2008-2011), we used publically available nationwide hospital data on incident hysterectomies to calculate dynamic correction factors for the incidence of cancer of the cervix, corpus and ovary between 2005 and 2015. Population statistics including deaths were additionally incorporated in the calculations.

Results
Compared to official incidence statistics, the corrected age specific incidence rates, restricted to women 'at risk', were up to 65% higher, while incidence trends were slightly more favorable after correction.

Conclusions
With the proposed method, more realistic estimates of age specific cancer risks for gynecological tumors can be given for Germany. These results are relevant for women's decision to attend cervical cancer screening, but also for the evaluation of cervical cancer incidence trends in the light of HPV vaccination and changing screening methods. We also conclude that using data from different sources can be useful for public health research even when direct data linkage is not possible.

The use of information on stage and treatment from cancer registries for the evaluation of treatment patterns

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Background and Introduction

Some population-based cancer registries (CR) are gathering data on stage and treatment (TRT). Such data could be used for the assessment of cancer care patterns among regions. The current analysis reports on stage and TRT patterns for female breast cancer in Europe.

Materials and Methods

Data from CRs included in the European Cancer Information System (ECIS) which submitted data on stage and TRT for the ENCR-JRC project were analysed. Proportion of cases by TRT type: surgery (SG), radiotherapy (RT), systemic therapy (ST), by stage, age (19-74, 75+), period (1999-2005, 2006-13) and region were calculated.

Results

848320 cases from 20 CRs were analysed. TRT for stage I patients aged 19-74 in 1999-2005 was SG alone (22%), SG+ST (13%) SG+RT (31%), SG+RT+ST (32%), other (*e.g.*, ST alone) 1%, none <1%, unknown 1%. SG alone decreased to 18% and SG+RT+ST rose to 37% in 2006-13. High regional variability was observed: in Eastern Europe (EE) SG alone was 31%, SG+ST 17%, SG+RT 24%, SG+RT+ST 23% in 2006-13, in Western Europe (WE) SG alone was 12%, SG+ST 13%, SG+RT 31%, SG+RT+ST 43%. For age 75+ in 1999-2005 SG alone (37%) and SG+ST (20%) were higher than in 19-74 patients while SG+RT (17%) and SG+RT+SG (15%) were lower. SG alone decreased to 31%, SG+RT+ST rose to 20% in 2006-13. Untreated patients were 3% in both periods. For the regional comparison, in 2006-13 SG alone was 50% in EE vs 25% in WE; SG+RT+ST was 9% in EE, 24% in WE. In 2006-13, for younger stage IV patients SG alone was 7%, ST alone 29%, SG+ST 18%, SG+RT+ST 14%, no TRT 9%, unknown 7%. For 75+ patients SG alone was 11%, ST alone 30%, SG+ST 12%, SG+RT+ST 7%, no TRT 15%, unknown 14%.

Conclusions

In this exploratory study variability in TRT patterns was observed by stage, age, period, region. Clinical information from CRs should be routinely used to monitor clinical care patterns, according to national and international recommendations, to compare levels of compliance and discuss the reasons for changes and differences.

Diversity of first-line palliative systemic treatments for esophagogastric cancer patients with synchronous metastases

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Background and Introduction
Optimal palliative systemic treatment for metastatic esophagogastric cancer is not well defined, causing variation in treatment. Aim of this study was to explore diversity in first-line systemic treatment in metastatic esophagogastric cancer patients in a real world setting and assess the effect on overall survival (OS) and progression-free survival (PFS).

Materials and Methods
In a retrospective cohort study (2010-2016), esophagogastric cancer patients (n=2295) with synchronous metastases treated with systemic therapy were included. Systemic therapy was divided in monotherapy, doublets, triplets (all without trastuzumab), and regimens with trastuzumab. Kaplan-Meier curves and Cox proportional hazards regression, with adjustment for age, gender, tumor and metastatic locations, year of diagnosis and performance status, was used to analyze OS and PFS (PFS only available for 2010-2014 patients, n=1392).

Results
Up to 69 different systemic treatment regimens were administered, with a median OS of 8.7 and PFS of 4.8 months. Nearly half of patients (48.2%) were treated with doublet therapy, while 752 patients (32.5%) received triplet and 230 (10.0%) monotherapy. Median survival was highest in patients with trastuzumab (OS: 12.5 & PFS: 7.6 months) and lowest in patients who received monotherapy (OS: 5.8 & PFS: 2.8 months). For patients not treated with trastuzumab, triplet therapy did not show difference in OS and PFS compared to doublet therapy in and multivariable analyses (OS HR: 0.98 95%CI 0.98-1.12 & PFS HR: 0.89 95%CI: 0.77-1.02).

Conclusions
Esophagogastric cancer patients with synchronous metastases are treated with a wide variety of palliative systemic treatment. In our cohort we found that patients treated with a trastuzumab regimen had the best survival, and that doublet therapy provided similar overall and progression-free survival compared to triplet chemotherapy.

Comparison of quality indicators concerning breast cancer care on a national and hospital level

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Background and Introduction

In recent years, the quality of health care has become a subject of public debate. This has given rise to the need of hospitals to openly provide indicators of the quality of their diagnostics and treatment. Both the Netherlands and Norway have clinical breast cancer registries. Aim: this study aims to compare six quality indicators defined by Nabon Breast Cancer Audit (NBCA) between the Netherlands and Norway.

Materials and Methods

All female patients diagnosed in the Netherlands or Norway between 2012 and 2016, with DCIS or Invasive breast cancer were included. Six quality indicators were calculated on a national level and for all the institutions in both countries and given with a 95% confidence interval. Case-mix adjustment for baseline characteristics of the patient (*i.e.* age and stage) were performed.

Results

Breast cancer care is given in 92 hospital in the Netherlands, and 65 in Norway. The Dutch data contains 78126 breast tumors; 10764 DCIS and 67362 invasive breast cancer. In Norway, the data contains 19428 breast tumors; 1753 DCIS and 17675 invasive breast cancer. For indicator 9, percentage of patients with an immediate breast reconstruction by plastic surgeon for DCIS, an average rate of 44% (95% CI 42-45) and 44% (95% CI 41-46) was observed in the Netherlands and in Norway, respectively. For indicator 10, percentage of patients with an immediate breast reconstruction by plastic surgeon for invasive breast cancer, an higher rate was observed in the Netherlands 21% (95% CI 20-21) than in Norway 14% (95% CI 12-16). Results on the other indicators will be given in the presentation.

Conclusions

For most quality indicators the results are similar for both countries. The findings of the outcome, support the continued development of treatments and guidelines and can start a discussion about differences, which could in turn could be input for improvement projects within breast cancer care.

Geographic variability in adherence to clinical practice guidelines for skin malignant melanoma in Spain

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Background and Introduction

Studies on care patterns for melanoma patients are scarce. The aim was to assess and compare the adherence to clinical practice guidelines (CPG) for skin melanoma patients in three Spanish regions.

Materials and Methods

A population-based study conducted in Girona, Granada and Navarra. Cases with invasive skin melanoma diagnosed in 2009-2013 were included. We compared the proportion of patients receiving recommended care according to European CPG.

Results

A total of 934 cases were included, with a mean (SD) age of 60 (18) years. The proportion of pathology reports that mentioned the essential pathological features required for T staging was 93%, ranging across regions from 81% to 98% ($p<0.001$). We observed a different pattern of use of imaging for staging in each region: 1) chest & liver imaging for most of the patients regardless the risk of metastasis, 2) increasing imaging studies from only chest to chest+liver+bone & brain, according to the patient's risk, and 3) increased imaging also according to risk but with higher use of imaging in all risk groups; thus, *e.g.* the proportion of high-risk patients receiving at least three imaging tests varied from 8% to 85% ($p<0.001$). The proportion of patients cN0M0 with Breslow >1mm receiving sentinel lymph node biopsy (SLNB) was 68%, ranging among regions from 61% to 78% ($p=0.02$). The factors independently associated with undergoing SLNB in these patients were age, comorbidity, anatomic location and region. Interferon adjuvant treatment was given to 20% and 63% of the patients in stage IIB/IIC and in stage III, respectively, with no differences among regions.

Conclusions

This study revealed wide geographic variability in adherence to melanoma CPG in Spain. The use of a standardized pathology report could improve the quality of the pathology reporting. More specific recommendations on the use of imaging for staging in the CPG would reduce its variability. These results will serve as feedback to help hospitals improve the quality of care for melanoma patients.

Endocrine therapy after breast cancer diagnosis: a proof of concept study using the primary care prescription database

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Background and Introduction

Although endocrine therapy (ET) treatment for breast cancer patients is usually initiated within secondary care, the majority of repeat prescriptions are given in primary care. A partnership between NHS Business Services Authority and the National Cancer Registration and Analysis Service has linked cancer registration data with the Primary Care Prescription Database (PCPD). We aimed to use this linked data to identify the level of ET prescribing in women with breast cancer and assess the epidemiological research potential of the PCPD.

Materials and Methods

Cancer registrations for women diagnosed with breast cancer during 1995-2015 who survived to 1 April 2015 were anonymously linked to ET prescriptions issued during April-July 2015. Summary statistics were used to investigate ET prescribing.

Results

Among 369 280 survivors of breast cancer diagnosed during 1995-2015, 37% were prescribed ET during April-July 2015. ET prescribing was highest in oestrogen receptor positive (ER+ve) patients (81%) and lowest in ER-ve patients (6%) for those diagnosed five years prior to the prescription period. Prescribing varied by time: the proportion of ER+ patients prescribed ET was highest for those diagnosed during the year before (59%), the 2nd (90%), the 3rd (88%), 4th (87%) and 5th (85%) years before the prescription period, and lowest for those diagnosed 13 years before (7%). This was expected as ET treatment is usually recommended for five years. Younger women usually received tamoxifen and older women usually received aromatase inhibitors.

Conclusions

The linkage of the PCPD to cancer registry data in England has allowed the investigation of ET prescriptions in women with breast cancer. Prescribing was as expected, in accordance with ER status, patient age and anticipated treatment duration. The PCPD, linked to cancer registry data, should bridge a substantial gap in the knowledge of therapies that are not hospital based.

Use of cancer registry data to estimate the cancer risk of recipients of liver transplants

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Background and Introduction
This cohort study assessed, in Italy, the risk for de novo malignancies following liver transplantation (LT) by using baseline cancer incidence rates from all the Italian population-based cancer registries (CRs).

Materials and Methods
The study group included 2832 individuals who underwent LT between 1985 and 2014 in nine centres throughout all of Italy. Person-years (PYs) at cancer risk were computed from 30 days after LT to the date of cancer diagnosis, to the date of death, or to the end of follow-up. The number of observed cancer cases among LT recipients was compared to the expected one computed from age, sex, and type specific incidence rates from CRs for broad Italian geographic area. Excess cancer risk was statistically estimated using standardized incidence ratios (SIRs) and 95% confidence intervals (CIs).

Results
During 18642 PYs, 246 LT recipients developed 266 de novo malignancies, corresponding to a 1.8-fold higher cancer risk (95% CI: 1.6-2.0). SIRs were particularly elevated for virus-related malignancies, including Kaposi's sarcoma (SIR=53.6, 95% CI: 30.0-88.5), non-Hodgkin lymphomas (SIR=7.1, 95% CI: 4.8-10.1), and cervix uteri (SIR=5.4, 95% CI: 1.1-15.8). Among virus-unrelated malignancies, elevated risks emerged for head and neck (SIR=4.4, 95% CI: 3.1-6.2), oesophagus (SIR=6.7, 95% CI: 2.9-13.3), and adrenal gland (SIR=22.9, 95% CI: 2.8-82.7). Borderline statistically significant elevated risks were found for lung cancer (SIR=1.4, 95% CI: 1.0-2.1) and skin melanoma (SIR=2.6, 95% CI: 1.0-5.3). A reduced risk emerged for prostate cancer (SIR=0.1, 95% CI: 0.0-0.5).

Conclusions
These findings stress the methodological importance of using poulation-badsed cancer data it assess the cancer risk of selected population groups. In the specify area, they underline the need of preventive interventions and early detection of malignancies, specifically tailored to LT recipients.

Comparison of the Danish Cancer Register and the Danish Renal Cancer Database

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Background and Introduction
The Danish Cancer Register (DCR) and the Danish Renal Cancer Database (DaRenCaData) are both population-based registers upon which statistical analyses of renal cancer are based. However, there is variation between the inclusion criteria of the two databases leading to some discrepancies between them. The significance of these differences on survival estimates is important to address in order to qualify the analyses based on the two registers. Yet, it has not previously been investigated.

Materials and Methods
The study will use descriptive statistics to compare data from DCR and DaRenCaData during the period 2010-2014. It will apply the inclusion criteria from DCR to the DaRenCaData and vice versa. Moreover, the study will compare 1-year survival estimates (based on Cox proportional hazard models and relative survival) for renal cancer patients figuring in a) both in DCR and DaRenCaData, b) DCR only, and c) DaRenCaData only.

Results
The study will report results of descriptive statistics related to DCR and DaRenCaData and compare relevant 1-year survival estimates.

Conclusions
The present study aims to provide valuable insights regarding the differences between DCR and DaRenCaData, and regarding how these differences affect survival estimates. The study will conclude by discussing the consequences, including how the findings can qualify analyses based on either of the two databases.

Emergency Admissions for Cancer Patients in last year of life in Northern Ireland (NI)

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Background and Introduction

There is increased interest in the place and timing of end-of-life care for people dying from cancer. Emergency admissions for end-of-life cancer patients may indicate gaps in routine cancer care. This project aims to examine the demographic, disease and environmental characteristics of people dying with cancer admitted as an emergency in the last year of life to provide information to improve services, for example by improving end-of-life care training received by ambulance staff.

Materials and Methods

Data on all cancer deaths in N.Ireland (NI) in 2015 (n=4353) were extracted from the population based cancer registry and linked with hospital episodes relating to emergency admissions in the last year of life.

Results

Of 4353 people dying of cancer in NI in 2015, almost three of four (73.7%; n=3212) had at least one emergency admission recorded. The proportion of people having an emergency admission recorded was 60.0% for people aged 0-24 years, 80.4% for those aged 25-39 years and 66.2% for those people aged 80 years and over ($p<0.001$). Over a third (35.5%) of people with at least one emergency admission, died before discharge on their last admission. No differences by deprivation quintile were observed ($p=0.064$). Further information on clinical and environmental factors (tumour type, treatment and rurality) will be presented.

Conclusions

A large number of cancer patients have at least one emergency admission in their last year of life and while differences exist by age, no differences by deprivation were observed. These findings will help inform future changes in emergency care for cancer patients at end-of-life in NI.

Acknowledgements

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Metadata in the Cancer Registry of Norway–performing FAIR with ELVIS

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Background and Introduction

With increasing amount of variables in the CRN, especially in clinical registries, the workload of providing metadata is huge. A tool for keeping track of all attributes for variables is necessary for both systems and humans. The CRN therefore develop ELVIS–Electronic List of Variables in Systems. ELVIS contains metadata, CRN coding manual and lookup-tables for the registration system and rule-engine.

Materials and Methods

Needs and requirements for ELVIS are identified through discussions and brainstorming with user groups. The project group systematized, refined and specified the requirements and sorted basic needs of version 1.0 from needs to be covered in later versions. ELVIS is performing on a Java platform with Javascript libraries as front end. Data is stored in a MySQL, and RESTful APIs are used for interoperability. Security is covered through LDAP authorization, HTTPS and SSL-certificates.

Results

The first incarnation of ELVIS is a web-based tool developed which promises to give users an overview of variables and quality of data accessible in the CRN, and to order variables/datasets. Metadata can be exported to other metasystems. An external version available on the Internet will provide researchers easy access to metadata and easy data request to the Data delivery unit. An internal version also provides coding manual, additional metadata-attributes and user-friendly tools for updating information. ELVIS will be available in both English and Norwegian, but could easily be updated with additional languages.

Regional differences and trends in mastectomy rates in relation to socioeconomic disparities and screening patterns

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Background and Introduction

In Switzerland, breast cancer is the most frequently diagnosed cancer in women. Important regional disparities in patterns of care in breast cancer have been recently described. In Switzerland, nationwide data on hospitalisations have been collected since 1998. They have not been used up to now to explore space-time patterns and trends of breast cancer healthcare related procedures for control and health planning purposes.The objective of this study was to assess geographical and temporal variation of mastectomy rates.

Materials and Methods

Bayesian Poisson spatio-temporal models have been applied on hospital-based data with national coverage to describe disparities in breast cancer surgery patterns. Covariates included patient characteristics as provided in the hospital data, as well as data on mammography screening programme duration and surgeon and gynaecologist density.

Results

We analyzed more than 70 000 patients. Mastectomy rates declined from 43 % to 30 % in Switzerland between 2000 and 2012 for patients aged 50-69 and from 61 % to 43 M for those 70 + and remained stable for those under 50. Important geographical differences in rates were present. Rates were significantly influenced by age (Relative Rate Ratio (RR) 50-69: 0.92, RR 70 +: 1.25), differences in co-morbidity (RR one comorbidity: 1.17, RR more than one: 1.35). Regions with higher surgeon or gynaecologist density had significantly higher rates of mastectomies (RR surgeons: 1.01, RR gynaecologists: 1.06), whereas regions in the French-speaking part or with mammography screening programmes showed significantly lower rates (RR French language region: 0.72, RR screening: 0.87). No difference was found for patients in different socio-economic groups or with different insurance types.

Conclusions

This research unveiled important information which was not available for the whole country before. The results play an essential role in the identification of regions where special attention is required.

The use of biomarkers in treatment patterns and survival outcomes of metastatic non-squamous non-small cell lung cancer

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Background and Introduction

In metastatic non-small cell lung cancer (NSCLC) the presence of anaplastic lymphoma kinase (ALK) gene rearrangements or epidermal growth factor receptor (EGFR) gene mutations allows treatment with target-specific agents, such as EGFR tyrosine kinase inhibitors (TKIs) and ALK inhibitors. In this study we investigate treatment outcomes in patients with metastatic non-squamous NSCLC harboring EGFR mutations, ALK rearrangements and both EGFR and ALK wild-type (wt).

Materials and Methods

A historical population based cohort study was designed considering all patients aged ≥18 years, diagnosed with stage IV non-squamous NSCLC during 2013-2014, resident in Southern Portugal Cancer Registry influence area at diagnosis and that received systemic treatment. Analysis of overall survival (OS) was performed by Kaplan-Meier method. The end of follow up was 22 May 2018.

Results

A total of 684 patients were included. Median age was 64 years, 64.62% were male and 68.67% had a performance status of 0-1. EGFR and ALK molecular testing was performed for 64.77% and 37.13% of patients, respectively. Out of tested patients, 122 (27.54%) were EGFR mutated, 115 of which received EGFR-TKIs, 16 (6.30%) had ALK rearrangements, seven of which received ALK inhibitors and 201 (29.39%) were EGFR and ALK-wt. Median follow-up was 11.77 months. The median OS of patients harboring at least one mutation and treated with targeted therapy was superior compared to wt-treated patients (17.16 vs 10.06, $p=0.01$). The difference between OS of EGFR mutated patients treated with TKIs as first-line therapy and those treated with chemotherapy was not statistically significant (17.20 vs 21.47 months, $p=0.058$).

Conclusions

In 2013 and 2014 molecular testing was sparse, limiting the number of patients eligible for targeted therapy. Patients eligible and treated with target-specific agents had a better OS, however, when comparing first-line treatment between chemotherapy and EGFR-TKIs, the results showed no significant difference in OS.

Cancers in families with early onset probands

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Background and Introduction

Exploring cancer risk in population-based series of families with early onset cancers may reveal new cancer sites with strong familial aggregation.

Materials and Methods

A population-based family cohort, with 42 969 families and 430 063 subjects with at least one cancer patient diagnosed between 1970 and 2012 under the age of 40 years, was established. Familial aggregation was estimated by standardized incidence ratio (SIR) using Poisson regression. Analysis was stratified by relatedness to proband and the age at onset (any age or <=40). We correct for the ascertainment and immortal bias introduced by the study design. Cancers of brain and central nervous system (CNS, 14% of the probands), breast (14%), melanoma of the skin (7.5%), thyroid (7%) and colorectum (5%) were chosen for the analysis of familial aggregation.

Results

When considering familial cases at any age, the familial risk for breast cancer was 1.66 and it was 3.51 when restricting to familial cases with young onset cases only. In cancers of the brain and CNS, familial relative risk was 1.65 for any age at onset and 3.06 for early onset. In thyroid cancer, the SIRs were 4.81 and 6.37, respectively. In colorectal cancers the familial risk for first degree relatives was 2.3, but increased to 13.5 when including only young onset familial cases. Familial risk of melanoma did not vary significantly by relatedness to proband nor age at onset. All SIR's for spouses were at the population level.

Conclusions

The familial risks were elevated in all studied cancers and were highest in siblings with parental cancers of the brain and CNS, colorectum, and thyroid. The increase in familial risks were even more pronounced if all familial cases were early onset. Our findings support further research on the role of environmental or genetic factors which are non-equally shared by family members or transmitted within family. Most interestingly, our results suggest a larger than assumed role of environmental factors in breast cancer, and accordingly, smaller than assumed in colorectal cancers.

PALGA Portal, the Dutch National Cancer Tissue Portal; a nationwide app for requesting tumor pathology data and tissues

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Background and Introduction

PALGA, the Dutch pathology registry contains over 70 million pathology records from over 12 million individuals. Most cases involve oncology, and the accompanying tumor tissues, mainly paraffin-embedded, are stored in more than 45 pathology labs. To facilitate and stimulate secondary use of the tumor tissues and data for research, PALGA developed the PALGA Portal. The PALGA Portal allows fast, easy and safe access to the data and tissues, possibly combined with linked data from the Netherlands Cancer Registry (NCR).

Materials and Methods

The PALGA Portal is a web-based portal that allows researchers to request pathology data and/or material (from different diagnostic pathology labs), with the possibility to request linked NCR data. Requests are automatically forwarded to the designated labs and HUB-employees, stationed in every academic hospital, aid in picking, registering and sending the requested tumor materials.

Results

Since launch in 2015, the number of requests increased and so far, the PALGA Portal has facilitated over 500 requests, involving more than 49 000 cancer pathology records. For example, the Portal enabled identification and collection of data and material from sporadic cancer patients spread over the Netherlands. It also allowed the collection of thousands of tumor/normal tissue pairs for the creation of tissue microarrays. Further, it has fulfilled more than 40 NCR-linked requests. The increased re-use of tumor tissues led to increased scientific publications. Besides facilitating researchers, the PALGA Portal supports the diagnostic labs in tracing their material, and provides information on the use of cancer pathology data and material for research.

Conclusions

The PALGA Portal has streamlined and professionalized the (NCR-linked) request, delivery and use of cancer pathology data and tumor tissues for research. It has shown to increase efficiency and transparency for both the requesting researchers and providing diagnostic labs.

Can we improve and make more useful the urothelial tumours registration? First results of a GRELL collaborative study

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Background and Introduction

Due to the differences in the definition, criteria of inclusion and coding of urothelial tumours (UT), data of different cancer registries (CRs) are not comparable and studies on incidence and survival difficult to understand. Objectives: 1. to conduct a survey on current practices of recording and reporting of UT in the CRs of GRELL countries; 2. to propose recommendations to record and to report these UT in the calculation of incidence and survival.

Materials and Methods

A questionnaire has been finalized to assess whether non-invasive (NI) UT, multiple UT, UT occurring outside or before the operating period and time between UT are currently taken into account in tumour recording and reporting. This questionnaire was first sent to 91 European GRELL CRs and 42 of them participated.

Results

All participating CRs record NI bladder UT in sole occurrence. In the case of a progressive bladder UT, 98 % of the CRs record at least one NIUT but 19 % do not record the invasive progression of this tumour, 17 % of the CRs do not record an invasive pelvic tumour that occurs after a NI bladder UT. The occurrence of an infiltrating UT on the urinary tract other than the bladder masks the recording of the invasive progression of a bladder UT for 17 % of the CRs. 19 % of CRs do not record an invasive bladder UT that followed a NI tumour occurring outside the zone or period of time. The recording of two synchronous UT is carried out with the grouping code C68.9 for 36 % of the CRs. The same analysis was conducted about the reporting of the UT in incidence and shows also heterogeneity between CRs.

Conclusions

These first results show that there is an urgent need to define clear rules for the recording and reporting of UT. They must now be discussed with pathologists and clinicians to elaborate a proposal of recommendations to GRELL CRs. The proposal will then be discussed with the Steering Committee of the European Network of Cancer Registries. The study will be then extended to all Latin CRs.

Variations in surgical oncology–Improvement through mapping

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Background and Introduction

With +30 000 surgical cancer operations annually, the surgical modality and the surgical units are at the core of modern cancer treatment. Concurrently, there is an increased demand for clinicians and decision makers to produce data-driven improvements. Quality assurance in surgical oncology requires a model with a transparent and systematic approach that favors both the organizational, clinical and the patient's perspective. Presently, no such model exists. Objectives: the main objective is to build a model for quality assurance and monitoring of outcomes in surgical oncology across different specialties. The aim is to provide key personnel with a meaningful overview of the services and with a tool for prospectively monitoring the effect of changes made.

Materials and Methods

The register-based model is constructed with eight key variables: admission, procedures, readmissions, mortality, diagnosis, age and gender, co-morbidity, and TNM. From this data, information can be extracted on admission time and type, transfers, readmissions, diagnosis, tumor stage, age, co-morbidity, mortality (short and long), and hospital production volume. Data sources are the Danish National Patient Registry and the National Pathology Data Bank. Data are cross-referenced by combing the two databases.

Results

We present selected examples of the model applied in different surgical areas: pancreatic cancer surgery (high risk, low volume) and kidney cancer surgery (low risk, moderate volume), with illustrations of variation within each specialty. For pancreatic surgery, we found a skew in production volume, and for kidney surgery, we found a difference used modality. In both specialties, we found variations in admission, readmissions, disease stage, and mortality.

Conclusions

The model provides a framework for extracting and monitoring meaningful and relevant outcomes on cancer surgery from readily accessible data sources. It enables key personnel to monitor variations, identify challenges and define quality levels.

The challenges, methods and benefits of implementing of ISO 27001:2013 in the Northern Ireland Cancer Registry

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Northern Ireland Cancer Registry

Background and Introduction

The Northern Ireland Cancer Registry (NICR), relies heavily on sensitive data received from a variety of sources which comes with a responsibility to protect this data, ensuring confidentiality and protecting the reputation and longevity of the NICR as provider of official statistics and data rich environment for effective and meaningful cancer research. Building on existing Information Security Management Systems (ISMS) the registry investigated the accreditation of its ISMS to an independently approved and internationally recognised certification, ISO 27001 which focusses on the principles of Confidentiality, Integrity and Availability(CIA).

Materials and Methods

The proposed presentation will focus on the identification of information assets present in a cancer registry; the risk assessments and treatments of vulnerabilities and threats to both the common and unique sets of information held within the registry; the input from all staff in the successful implementation; the implementation steps and challenges; and the benefits received during and after the successful accreditation of ISO 27001 including:

- Training and assigning a staff member to manage the project.
- Ensuring buy-in from senior management, developing a business case outlining the costs and benefits.
- Enlisting the assistance of externally experience body to assist with the implementation.
- Identification of information assets and the assessment of threats and vulnerabilities to these assets.
- Developing a Risk Assessment matrix with the appropriate course of action.
- Communication and staff awareness workshops.
- Testing by means of internal and external audits, monitoring and management review.

Results

Focussing the attention of staff and management to the best practices in information security; enhancing the reputation of the NICR amongst supplier and peer organisation; supporting documentation when applying for grants.

The stage for childhood cancers: the JARC pilot study

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Background and Introduction

The 'Toronto consensus principles and guidelines' (Lancet Oncology, 2016) provides recommendations on which staging system should be adopted by population-based cancer registries for each of the major childhood malignancies. Within the European Joint Action on Rare Cancers (JARC), a pilot study is now testing how the Toronto recommendations can be applied by population-based cancer registries in order to perform survival analysis by tumour stage.

Materials and Methods

Along with the cancer registries a protocol has been agreed to collect stage and information for the definition of stage for consecutive samples of neuroblastoma and Wilms tumours, diagnosed in the period 2010-2015 (or more for small populations). Up to now, registries from 12 European countries contributed to the study.

Results

From the preliminary analyses, about 94% of both tumours were staged, according to the more detailed staging criteria (tier 2). Clinical and pathological records were used for about 90% of cases. Eleven percent of Wilms tumours and 56% of neuroblastoma were diagnosed with stage IV or distant metastases at diagnosis. Actually, localized disease for Wilms tumours and metastatic disease for neuroblastoma were the most prevalent stages in each country. However, differences in the distribution of stage by country were notified.

Conclusions

The interest of the international community of paediatric oncologists is increasing towards population based studies. Since there are now specific recommendations (Toronto guidelines), the inclusion of stage in routine data collection will facilitate research between epidemiologists and clinicians. We suggest to 1) collect stage at diagnosis, in a prospective way for childhood cancers, which are rare tumours, according to the Toronto guidelines and 2) promote within the ENCR initiatives to facilitate the collection of and quality of staging information.

Completeness of childhood cancer data in the Finnish Cancer Registry

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Background and Introduction

The Finnish Cancer Registry (FCR) has a long tradition since 1953 of collecting incident cancer cases and monitoring the cancer burden nationally. Completeness for all cancers was evaluated at 95% of cases diagnosed in 2009-2013 and the estimate was 80 % for childhood cancers. We aimed to validate the childhood cancer case completeness of the FCR.

Materials and Methods

The FCR database for the period 2009-2013 comprised in all 762 incident childhood cancers (diagnostic age 0-14 years) with a valid ICCC3-code. Around half of the patients were aged 0-4 years at diagnosis and of all childhood cases, 95% were morphologically verified. Cancer cases were independently retrieved from the national Hospital Discharge (HD) register based on the hospital visit diagnostic code. Each hospital outpatient visit or in-patient episode is recorded with at least one ICD10-diagnosis code.

Results

We originally identified 116 diagnoses of solid cancers in the HD that were missing from the FCR and 63 non-solid cancers. After checking original hospital records of all potentially missing cases, 50 cases were found to be absent from the FCR, of these 10 were retinoblastomas of the eye and 5 other eye cancers. Other commonly missing diagnoses were CNS tumors, especially non-malignant ones. Additionally, some borderline cases (such as ovarian borderline tumors) were coded as invasive cancers in the HD and truly not missing from the FCR. The final completeness of the FCR thus increased from 80% to 94% in 2009-2013.

Conclusions

We could indicate missing notifications especially in eye tumors that were not morphologically confirmed and benign or borderline cases of the CNS. After checking hospital records for potentially missing cases the completeness was increased to 94%. We find, however, independent case ascertainment using hospital discharge data relevant in order to ensure complete registration of all childhood cancers. FCR yields comparable data of high guality.

Identification of recurrences in the new German cancer registration by example of gynaecological tumours in Hamburg

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Hamburg Cancer Registry

Background and Introduction

Recurrences of malignant neoplasms are vitally important for patients and for oncological care. However, there is hardly up-to-date and sufficiently representative information on cancer recurrence available and serious shortcomings are stated with regard to cancer registration and monitoring. As the German states are legally obliged to establish comprehensive clinical cancer registration based on a national data set since 2014 there is now an option to generate data in this respect. The objectives of our study are to identify recurrences in gynaecological malignancies within the first two years after diagnosis by means of information ascertained by the Hamburg Cancer Registry (HCR) and to evaluate the relevant data quality and completeness.

Materials and Methods

We include malignant tumours of the vulva, cervix, uterus and ovaries primarily diagnosed in 2014 and 2015 in patients who have been treated in Hamburg, reported to the HCR, followed up until 31.12.2017, and who survived at least six months. Recurrences are identified using data on diagnosis, course of disease, TNM stage, therapy and possibly second tumours. The information extracted from the reports on various items will be compared and the results assessed on the basis of currently available literature.

Results

Recurrence rates are presented by tumour entities, time elapsed since diagnosis, type of recurrence and source of information. According to the current state of data recurrences occur in 25% to 40% of the affected patients in Hamburg within two years after diagnoses of a gynaecological tumour.

Conclusions

Four years after starting the population-based Hamburg Cancer Registry's conversion into a comprehensive clinical registry there are both encouraging and fragmentary observations concerning cancer recurrence rates.

Comparison of coding diagnosis, localisation and histology via ICD-10 and ICD-O-3 between coders and a gold standard

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Background and Introduction

Correct coding of neoplasms in cancer registries is essential. However, only few studies give information about comparisons of coding on neoplasms via ICD-10 and almost no results are available for the ICD-O-3 coding. The main aim of this study is to compare coding of localisation and histology of neoplasms in pathology reports via ICD-O-3 and diagnosis via ICD-10 between coders of the Cancer Registry of Rhineland-Palatine (CRRP) and the correct codings (gold standard) which were developed by study-intern experts.

Materials and Methods

11 coders of the CRRP coded the same 35 pathology reports each (30 randomly selected for the main analysis and 5 with a higher degree of difficulty for an extra analysis). For analysing the agreement between coders and the gold standard, categories of agreements were pre-defined to take the multi digits of ICD-coding into account. Sub analyses of work experience in the field of tumour documentation and experience in coding of pathology reports are performed. Weighted Kappa Coefficients will be calculated to show the inter-observer agreement.

Results

Overall 330 coded pathology reports were available for the main analysis. 253 (76.7%) of the codings of localisation, 265 (80.3%) of the histology and 242 (73.3%) of the diagnosis completely agreed with the gold standard on the highest level. 200 (60.6%) reports were coded with complete agreement to the gold standard over all items. The group of persons with more than three years of work experience and a regularly coding of pathology reports showed a higher percentage of complete agreement than those with less work experience and non-regularly dealings with the reports (74.4% vs. 50.0%).

Conclusions

Overall results show that further effort is needed to improve the quality of coding in the future. Tightly focussed trainings for employees with lower work experience who do not code pathology reports constantly should be performed regularly as a part of quality assurance.

Indicators of data qualiy at the Cancer Registry Zurich and Zug in Switzerland

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Cancer Registry Zurich and Zug, Switzerland

Background and Introduction

Data quality is an important issue in cancer registration. We provide a comprehensive overview of the four main data quality indicators (comparability, validity, timeliness, completeness) for the Cancer Registry Zurich and Zug in Switzerland, which was established in 1980 and covers roughly 20% of the Swiss population.

Materials and Methods

We extracted all malignant cancer cases (C00-C99 according to ICD-10, excluding non-melanoma skin cancer (C44)) diagnosed between 1980 and 2014 in the canton of Zurich. Methods include the proportion of DCN (2009-2014) and DCO cases (1997-2014), the proportion of morphologically verified cases (MV%, 1997-2014), and cases with primary site uncertain (PSU%, =C80 according to ICD-10, 1980-2014). Furthermore, we present the stability of incidence rates over time (1981-2014), mortality:incidence (MI) ratios (1980-2014), age-specific incidence rates for childhood cancer (1981-2014), and the comparison of incident cases published in annual reports in different years (incidence data 2012-2013 published in 2014-2016).

Results

The DCO rate decreased from 6.4% in 1997 to 0.8% in 2014 and was <5% since 2000. MV% was 89.7% in 1997 and 95.5% in 2014. PSU% was <3% over the whole period. The incidence rate of all tumours increased over time with site-specific fluctuations. The overall M:I ratio decreased from 0.58 in 1980 to 0.37 in 2014. The age-specific incidence of childhood cancer was within reference ranges. About 2.5% of cases were registered one year later than intended (*i.e.*, with more than two-year delay).

Conclusions

Overall, data quality of the Cancer Registry Zurich and Zug was good according to the methods presented in this review. Most indicators improved over time with low DCO rates, high MV%, low PSU%, relatively low M:I ratios and age-specific incidence of childhood cancer within reference ranges.

Automatic extraction of Gleason combined score, primary and secondary grades from written pathology reports

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Belgian Cancer Registry

Background and Introduction

The Belgian Cancer Registry (BCR) registered 105672 cases of prostate cancer between 2004 and 2015. One important factor in the management of prostate cancer is the Gleason score and grading. This is however not readily available in the cancer registration but can be obtained from the written pathology reports. The present work explores the possibility to automatically extract the Gleason score and grades.

Materials and Methods

An algorithm (VBA-Excel using regular expressions) was created to automatically extract the Gleason score, primary and secondary grades from text reports written in Dutch or French. In addition, the algorithm differentiates between biopsy and prostatectomy and indicates the absence of a Gleason result due to limited amount of tissue. To validate the automatic extraction, 1000 random prostate cancer reports from 79 pathology laboratories were read and any Gleason score or grade was extracted. The output of the automatic extraction was then compared with the manual extraction and accuracy was calculated.

Results

The result on all available prostate cancer reports (2004-2015: N = 136003) resulted in 90% of cases with extracted Gleason score or grades. A manual review was indicated for 3186 reports (2%) where the algorithm could not distinguish between a score or a single grade and for 173 cases (0.1%) where only the keyword 'Gleason' was detected. The remaining 7% (N=9563) of the reports did not mention 'Gleason'. On the random set of 1000 manually reviewed reports, we achieved a complete automatic extraction of Gleason score, primary and secondary grades with 98% accuracy.

Conclusions

The developed algorithm is able to automatically extract the Gleason score and grades from text in pathology reports with a very high accuracy. The methodology will be applied to all reports received by the BCR and results will be used in descriptive statistics as well as in projects on quality of care.

Theme: **Data linkage methods and cancer registries**

Low education level and cancer: incidence and mortality risk pattern

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Background and Introduction
The aim of this study was to analyse cancer incidence and mortality risk in low education group during the period 2001-2009, using population-based census-linked registry data covering the entire population of Lithuania.

Materials and Methods
The study was based on linkage between all records of the 2001 population census, and all records from Lithuanian Cancer Registry (cancer incidence) and Statistics Lithuania (deaths) for the period of 6 April 2001-31 December 2009. Incidence and mortality risk was analysed in low education group compared to the group of higher education. Low education group was defined as up to 9 years of schooling, high education as at least 14 years of schooling. Incidence rate ratios (IRR) and mortality rate ratios (MRR) for education were estimated by means of multivariate Poisson regression models. Separate models (controlling for age) were estimated to calculate relative rate ratios by education using high education as a reference category.

Results
IRR for all cancer sites in low education group for males was not significantly different, as for females low education was associated with lower cancer risk. The highest IRRs among males were found for lip, oral cavity and pharynx, esophagus, larynx and lung cancers. Higher risk for lung and cervix cancer was found among females. Melanoma risk and skin cancer risk in both sexes, prostate cancer risk among males and breast cancer risk among females was lower in low educated group. Cancer mortality risk was higher in low education group for both sexes. The highest MRRs among males were found for larynx, lung, stomach and lip, oral cavity and pharynx cancers, and for cervix cancer among females. MRR for melanoma of skin was lower for both sexes. Despite low IRR for prostate cancer, MRR for that site was significantly higher.

Conclusions
The study based on the census-linked cancer register data covering the entire population of Lithuania showed different incidence and mortality risk pattern as compared to high education group.

Theme: Data linkage methods and cancer registries

Evaluation of a national lung cancer awareness campaign in Wales

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Background and Introduction

Lung cancer is the leading cause of cancer mortality in Wales.To promote earlier diagnosis, a four week Be Clear on Cancer mass-media campaign ran during July 2016 to encourage people to visit their GP with a cough lasting for three weeks or more. Evaluation assessed behavioural awareness, NHS activity and clinical outcome data.

Materials and Methods

Representative pre-campaign (n=1001) and post-campaign (n=1013) population samples were surveyed in 2016 to assess symptom awareness and perceived barriers to help seeking. Numbers of GP visits for cough symptoms in patients 50+ years, urgent suspected cancer (USC) referrals, GP radiology requests, and new lung cancer diagnoses and stage for 2016 pre-campaign, campaign and post-campaign periods were compared with corresponding periods in 2015.

Results

Increases in recall (pre-campaign 28%, post-campaign 41%, $p<0.001$) and recognition of cough (82%-87%, $p<0.01$) as a symptom of lung cancer was observed. Fewer respondents agreed with 'if I had a cough, I would be worried about wasting the GP's time' (49%-43%, $p<0.001$) post-campaign.There was a 24% increase in cough symptom GP visits during the campaign, compared to the corresponding 2015 period (17297-21507, $p<0.001$). GP-ordered chest X-rays increased by 23.4% (19107 in 2015−23585 in 2016 $p<0.001$), whilst there was no statistically significant change in USC referrals. Increases in new diagnoses (401 cases in 2015−412 cases in 2016, $p<0.700$) were not statistically significant.

Conclusions

Increased public awareness, GP visits for cough, and GP-ordered radiology did not translate into statistically significant increased USC referrals, new diagnoses or stage shift. However, it was a relatively low intensity/short duration campaign, and small numbers of new cases during the short campaign and control periods could have hampered effect detection. Earlier diagnosis might be achieved by more intensive, sustained population-based campaigns supported by targeting, by improving GP diagnostic and referral systems.

Theme: **Data linkage methods and cancer registries**

The Castile and Leon Childhood Cancer Registry (CLCCR). Using several electronic sources for quality standards

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Background and Introduction

The CLCCR is a population-based registry established in 2010 which primary purpose is to collect data of new cancer cases in patients younger than 15 years throughout the Castile and Leon region in Spain. In order to report all childhood tumours, we implemented a mixed system combining a passive reporting and an active search for cases from different information sources which is analysed.

Materials and Methods

The CLCCR uses multiple data sources: 1) an electronic passive notification from Paediatric Hospital Units and 2) an active search for cases from other sources: hospital discharge diagnoses, patients referred to hospitals outside Castile and Leon (SIFCO-information system), the Spanish Registry of Childhood Tumours (RETI), patient's demographic information and Death Certificates. A specific software (TUIN) has been developed for the loading of electronic sources, data validation and tumour matching. Some of the records need data corrections and manual resolution.

Results

Each year about 60 childhood cancers are reported. The main information source is the electronic notification of tumours by paediatricians from the 14 Castile and Leon public hospitals (97% of all reported tumours). Discharge diagnoses from public and private hospitals provide 2% of all cancer cases. SIFCO and RETI only contribute with a 1% of all cases however, both are important sources for retrieving information on patients from Castile and Leon who have been diagnosed and treated outside our region. In some cases, RETI also provides additional information such as tumours site and morphology, treatments received by the patient or tumour's stage. Using linkage procedures, we could confirm that all cases of childhood cancer reported from the death certificates were already included in our registry database.

Conclusions

These results suggest that the mixed methods yields appropriate coverage and quality standards (completeness and validity) for the CLCCR and a high level of ascertainment.

Theme: Data linkage methods and cancer registries

Using English Cancer Registry linked data to assess diagnostic pathway variation for colorectal and lung cancers

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Background and Introduction

Understanding factors contributing to longer diagnostic pathways could help improve pathway efficiency and could provide evidence for a new diagnostic metric in England. This analysis used linked cancer registration data to define diagnostic pathway (DP) length and examine variation by presentation route and stage for two major cancers. It also identified factors associated with longer DPs.

Materials and Methods

English Cancer registrations (2014-15) for colorectal and lung cancer patients (C18-20, C33-34) were linked to routine health datasets: Hospital Episode Statistics, Diagnostic Imaging Dataset, Cancer Waiting Times. To calculate DP length, a start date was derived by defining the earliest event deemed relevant to the diagnostic process (comprised of referral into/secondary care appointment or diagnostic procedure) in the six months before the diagnosis date (DP end point). The DP length was compared by stage, presentation route and patient characteristics. Regression analysis produced Odds Ratios (OR) of a long DP (over the site median), controlling for factors including age, sex and comorbidities.

Results

The median DP length (days) was 26 for colorectal and 35 for lung. DP length decreased with later stage (stage 1-4 colorectal: 35 to 20, lung: 75 to 25) with variation also by presentation route and comorbidity score. Patients on a routine GP referral route had an increased odds of a long DP compared to the urgent GP referral (colorectal OR: 4.5, lung OR: 2.5). Patients presenting via the Emergency route had reduced OR of a long DP (colorectal OR: 0.2, lung OR: 0.4).

Conclusions

Substantial variation exists in DP length by stage and presentation route for both sites, often exceeding 28-days (colorectal: 45%, lung: 56%). Vague symptoms, comorbidities and other patient characteristics may make cancer more difficult to diagnose. Factors associated with longer DPs could support the creation of targeted initiatives to reduce the DP length.

Survival in the Central region of Portugal in some selected topographies: 2003-2010

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Background and Introduction

Survival analysis using population-based data is vital for the evaluation of cancer care practices. Survival from cancer has been improving in Europe. We aimed to compare cancer survival in the Central region of Portugal between 2003-2007 and 2008-2010 for some selected topographies.

Materials and Methods

Data on 38 021 individuals (>14 years old) with a diagnosis of an invasive cancer of the breast, cervix, ovary, prostate, stomach, colon, rectus, liver and lung were collected from the Registo Oncológico Regional do Centro and followed until 31/07/2015. The five-year net survival (NS) stratified by period of diagnosis, 2003-2007 (P1) and 2008-2010 (P2), and the correspondent 95% confidence intervals (CI) were estimated by the method proposed by Pohar-Perme. Mortality tables were those produced by the CONCORD-2 project.

Results

Women: breast, NSP1=0.87 (CI:0.86-0.88) vs. NSP2=0.89 (CI:0.87-0.90); cervix, NSP1=0.67 (CI:0.63-0.71) vs. NSP2=0.87 (CI:0.61-0.72); ovary, NSP1=0.47 (CI:0.42-0.52) vs. NSP2=0.45 (CI:0.39-0.51); stomach, NSP1=0.44 (CI:0.40-0.48) vs. NSP2=0.35 (CI:0.30-0.39); colon, NSP1=0.65 (CI:0.62-0.68) vs. NSP2=0.63 (CI:0.59-0.66); rectus, NSP1=0.60 (CI:0.56-0.65) vs. NSP2=0.61 (CI:0.56-0.66); liver, NSP1=0.13 (CI:0.05-0.20) vs. NSP2=0.14 (CI:0.05-0.23) and lung, NSP1=0.29 (CI:0.25-0.33) vs. NSP2=0.26 (CI:0.21-0.32). Men: prostate, NSP1=0.91 (CI: 0.89-0.92) vs. NSP2=0.93 (CI:0.92-0.95); stomach, NSP1=0.31 (CI:0.29-0.34) vs. NSP2=0.32 (CI:0.28-0.36); colon, NSP1=0.61 (CI:0.58-0.64) vs. NSP2=0.59 (CI:0.56-0.62); rectus, NSP1=0.60 (CI:0.57-0.63) vs. NSP2=0.60 (CI:0.55-0.64); liver, NSP1=0.21 (CI:0.16-0.26) vs. NSP2=0.20 (CI:0.15-0.26) and lung, NSP1=0.17 (CI:0.15-0.19) vs. NSP2=0.14 (CI:0.11-0.16).

Conclusions

No notorious differences were found between the two periods, except for stomach cancer in women. Maybe more aggressive tumours are being diagnosed, although lack of information on tumour stage at diagnosis limits the interpretation of the results.

Theme: Estimation and dissemination of cancer burden in Europe

Increasing kidney cancer incidence and survival in Estonia: role of gender, age and stage

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Background and Introduction
Kidney cancer incidence and mortality in Estonia are among the highest in Europe. The aim was to examine long-term trends in incidence, mortality and survival of kidney cancer in Estonia, with special focus on gender, age and TNM stage.

Materials and Methods
Estonian Cancer Registry provided data on all incident cases of kidney cancer (ICD-10 C64), diagnosed in adults (age ≥15 years) in Estonia in 1995-2014. Joinpoint regression modelling was used to study incidence (1970-2014) and mortality (1995-2016) trends. Age-specific incidence rates were examined by birth cohort and period of diagnosis. Five-year relative survival ratios (RSR) were calculated by gender, age and TNM stage.

Results
Incidence increased significantly in both sexes, with the steepest rise seen for stage I/II disease. Cohort effects were particularly noticeable in men, while period effects from mid-1980s to mid-1990s were seen in both sexes. Mortality decreased significantly in men throughout the study period, but female rates have plateaued since 2002. A significant shift towards older age and earlier stage was observed. Age-standardized five-year RSR for total kidney cancer increased from 53% to 65% over the study period. Women had higher RSR than men and their survival gain was also larger. Improvement was most pronounced for the youngest patients (age <55 years). RSR increased about 5 percent units for stages I/II and III.

Conclusions
Estonia remains among countries with the highest incidence of kidney cancer. The results suggest a combined effect of changing risk profiles in successive birth cohorts and increasing diagnostic activity around 1990. Large survival increase can mostly be attributed to earlier detection, but improved diagnosis and treatment have probably influenced stage-specific survival. High proportion of tumors with unspecified morphology and those with unknown stage among the elderly warrants further investigation of diagnostic and treatment practices.

Theme: Estimation and dissemination of cancer burden in Europe

Are there differences in treatment and survival between men and women with colorectal cancer?

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Background and Introduction

For both men and women in Switzerland, colorectal cancer (CRC) is within the five most common cancer incidences and causes of death. Several studies have shown that female CRC patients have a better overall survival. To support aspects of gender medicine, we investigated if differences in treatment decision and survival by sex exist in Switzerland.

Materials and Methods

We included data of 591 men and 489 women diagnosed with CRC in 2000 and 2001 from the Cancer Registry Zurich and Zug in Switzerland. The Charlson Comorbidity Index (CCI) defined the severity of the comorbidities at time of cancer diagnosis. Missing data for comorbidities was completed with multiple imputation methods. We estimated with binomial logistic regression models the probability of receiving surgery versus other primary treatment depending on sex, subsite (left-sided colorectal cancer, LCRC, vs. right-sided colon cancer, RCC), CCI, stage and age. Univariable and multivariable Cox proportional hazards regression models stratified by sex assessed the effects of age, subsite, CCI, stage and treatment on survival.

Results

LCRC was more common in males (62%) and RCC in females (54%). Treatment decision was independent of sex and CCI. Increasing tumor stage favored other primary treatment than surgery. The probability to receive other primary treatment than surgery was higher in LCRC for either sex. Female patients had no better survival than males (hazard ratio 1.00, 95% confidence interval 0.85-1.18). Survival decreased with higher age and tumor stage in both men and women and with CCI ≥1 in men. In the univariable analysis, patients with LCRC had better survival than those with RCC. However, this association was attenuated in the multivariable model.

Conclusions

Our results indicate that in the canton of Zurich, men and women with colorectal cancer had equal survival considering CCI and other factors. In addition, there was no sex difference in the treatment decision.

Theme: Estimation and dissemination of cancer burden in Europe

Pilot study on patient experiences in Germany using an adaptation of the Danish National Cancer Patient Questionnaire

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Background and Introduction

InnoCan is an on-going EU-Interreg project. Part of the project is the comparison of German and Danish cancer registry data. During the preceding Fehmarn Belt project, extensive analyses on survival of colorectal cancer patients were conducted for the regions Zealand and Schleswig-Holstein using cancer registry data in order to examine if diagnosis, treatment and follow-up can be adequately studied by these means. Threats to comparability were identified and solutions were suggested. InnoCan aims to extend the data basis and update the results by including more recent years, an additional region and an additional cancer site.

Materials and Methods

Registry data on breast and colorectal cancer were extracted for the regions Southern Denmark, Zealand and Schleswig-Holstein from 2005 to 2014 (N = 88765). Survival analyses are going to include Kaplan-Meier estimator, Cox regression and relative survival. Also a comparison of German and Danish clinical guidelines was performed and results will be used for interpreting findings.

Results

Results of the survival analyses will be presented. The guideline comparison showed that, despite a somewhat different presentation of guidelines, the literature used to develop these was the same. The guidelines did not point at any major difference between the regions, which indicates no underlying systematic difference in the treatment offered to the studied populations.

Conclusions

Creating a common database involves overcoming many hurdles. The new EU General Data Protection Regulation makes data exchanges difficult. Nevertheless, cross-border analyses are important for unravelling differences in treatment quality as well as in registration practices. Despite potential pitfalls concerning comparability (*e.g.* varying proportion of cases known only from death certificates), survival analyses taking into account stage and treatment variables allow a valid comparison for international benchmarking.

Theme: **Estimation and dissemination of cancer burden in Europe**

Myeloproliferative neoplasms–incidence, prevalence and survival across Europe

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Background and Introduction

Incidence, prevalence and survival of myeloproliferative neoplasms (MPNs) vary internationally. Whilst it is thought that environmental risk factors play a role in MPN development, their aetiology is currently unknown. Survival is often good for some MPN subtypes however many patients confer significant morbidity.

Materials and Methods

Using data from RARECAREnet, we investigated incidence, prevalence and survival of MPNs (excluding chronic myeloid leukaemia) diagnosed across 94 European population-based cancer registries between 1995 and 2007.

Results

Across Europe it was estimated that there were 12384 new cases of MPNs (excluding chronic myeloid leukaemia) and 109915 people living with these MPNs. MPNs increased in incidence from 1.27 per 100000 in 1995-1998 to 2.09 per 100000 in 2003-2007. Incidence was highest in the UK and Ireland (2.83 per 100000), in particular England (4.24 per 100000) and lowest in Eastern Europe (0.67 per 100000). Incidence also increases with increasing age, disproportionately affecting the 65 and above age category. Prevalence was highest in Southern Europe and lowest in Eastern Europe. Survival overall was good at 91%, 82% and 75% for one-, three- and five-year relative survival respectively with modest improvements over time with as expected, the greatest five-year survival occurring in the 15-24 age group. Central Europe had the highest one year survival with lowest survival rates reported in Northern Europe which also had the lowest five-year survival rates.

Conclusions

Incidence of MPN was increasing over this time period; registration of MPNs may not have been uniform across Europe with reclassification of MPNs in 2001 as a neoplasm. While survival overall was good in these patients, new treatments are likely to improve survival but regional variation in incidence, prevalence and survival was apparent warranting further investigation.

Theme: Estimation and dissemination of cancer burden in Europe

Epidemiology of cervical dysplasia and carcinoma after the onset of an HPV vaccination programme in Navarra (Spain)

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Background and Introduction

Persistence of high-risk human papillomavirus (HPV) infections plays a crucial role in the development of cervical cancer (CC). However, vaccination could prevent most of these infections. This work aims to evaluate the incidence rates of mild to moderate dysplasia (MMD) (CIN1+CIN2 lesions), in situ (ISC) and invasive cervical carcinoma (ICC) from 2007 to 2012 after the beginning of an HPV vaccination programme in Navarra.

Materials and Methods

A descriptive longitudinal study including all data available regarding CC from the population-based cancer and mortality registries of Navarra was performed to estimate the crude and age-adjusted annual incidence rates (IRs) for MMD, ISC and ICC. The direct method was used for the standardization taking the world standard population as reference. The CC specific mortality rates were also analyzed and regression joinpoint models were used to estimate the IRs trends and annual percentage change (APC).

Results

We found 1271 new MMD cases (69.1%), 458 (24.9%) of ISC and 109 (5.9%) of ICC from 2007 to 2012. The median age of diagnosis for MMD was similar to the one observed for ISC (34 vs. 36 years), whereas the one observed for ICC was higher 51 years) than the other two ($p < 0.001$). The age-adjusted IR for each category (MMD, ISC, and ICC) was 68.9, 23.0 and 4.2 cases per 100 000 women respectively. The incidence of MMD steadily increased from 59.8 in 2007 to 86.1 in 2012 with an APC of 9.37%; CI95% [4.22, 14.77] ($p = 0.02$). On the contrary, the adjusted incidence of ICC showed a decreasing tendency with an APC of -17.58%. The age-adjusted specific mortality rate was 2.7 per 100 000 women during the study period.

Conclusions

Low CC incidence and mortality rates were observed in Navarra. Cancer registry data are useful for providing a global picture of CC epidemiology, which could be of great assistance in the future evaluation of the impact of the HPV vaccination on this disease.

Theme: **Estimation and dissemination of cancer burden in Europe**

Regional differences in 5-year net survivals of selected cancers in Poland

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Background and Introduction

In CONCORD 3 programme five-year net survival rates for whole Poland, including its 16 provinces, were published for the first time. The objective of our study was to analyse differences in survival in all 16 provinces of Poland for invasive cancers: breast (C50-C50.6, C50.8-C50.9), colon (C18-C18.19, C19.9), and rectum (C20.9, C21.2, C21.8) in 2000-2014, and most recently in 2010-2014.

Materials and Methods

Five-year survival rates were extracted from the world-wide CONCORD 3 study results, based on data from Polish national and regional cancer registries.

Results

Breast cancer survival in Poland in 2010-2014 was 76.6%. Despite the low diversity in survival, higher rates than for Poland (in general) were in three provinces: Mazowieckie (79.8%), Zachodniopomorskie (78.1%), Dolnośląskie (77.8%). In 2000-2014 the five-year net survival improvement was in all provinces but the greater change was in Łódzkie province (9.8% points). Survival rates in colon cancer for Poland was 52.9%. Despite the low differentiation between provinces survival higher than for whole Poland were in Pomorskie (57.8%), Lubuskie (56.1%) and Podkarpackie (56.4%). In all Polish provinces were improvements in survival. The largest change was in Lubuskie -13.4% points. In 2010-2014 survival rate for rectal cancer in Poland was 48.4%, but in several provinces it was higher: Mazowieckie (54.2%), Podlaskie (51.9%), Zachodniopomorskie (51.0%). Survival rate for rectal cancer increased in 2000-2014 in all provinces but the largest improvement was in Podlaskie province (16.0% points).

Conclusions

Our analysis showed a systematic increase in five-year rate net survival in colon, rectum and breast cancers in all 16 provinces in Poland in 2000-2014. Despite the increase, there are differences between provinces in survival rates. The highest survival rates in two cancers (breast and rectum) were in Mazowieckie province.

Theme: Estimation and dissemination of cancer burden in Europe

Is high socioeconomic status associated with earlier detection of breast cancer in young women in Norway?

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Background and Introduction

Higher educated women have higher incidence, but lower mortality of breast cancer before age 50 in Norway, compared to lower educated women. Earlier detection could possibly explain lower mortality among higher educated women. We investigated stage-specific incidence of breast cancer by education and income, to determine whether higher socioeconomic status is associated with earlier detection of breast cancer.

Materials and Methods

We compared stage-specific breast cancer incidence by education level and personal income quintile among all Norwegian residents aged 30-48 years during 2000-2015. We calculated stage-specific age-standardized incidence rates per 100 000 person-years (World standard) and used Poisson regression to assess stage-specific relative risk of breast cancer by education and income level, adjusting for age, year and immigration status.

Results

Higher educated women had higher rates of early-stage (localized and regionally spread) breast cancer, but no difference in rates of late-stage (distally spread) cancer compared to lower educated women. The stage-specific incidence rate ratios (IRR) for the highest versus lowest educated women were: localized stage: 1.40 (95% CI: 1.25-1.57), regional spread: 1.25 (1.15-1.35), distal spread: 0.91 (0.65-1.28). Higher income was associated with higher rates of early-stage and lower rates of late-stage breast cancer. Women in the lowest income quintile had more distally spread cancer than women in all other income quintiles. The stage-specific IRRs for women with the highest versus lowest income were: localized stage: 1.66 (1.45-1.91), regional spread: 1.25 (1.13-1.37), distal spread 0.69 (0.47-1.02).

Conclusions

Higher education and income were associated with earlier detection of breast cancer. However, socioeconomic differences in stage at diagnosis were greatest for income. Only high income was associated with lower rates of late-stage cancer, where mortality is highest.

Theme: **Estimation and dissemination of cancer burden in Europe**

Reliable comparisons of basis of diagnosis among registries needs age standardisation: harmonising actions necessary

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Background and Introduction

The level of diagnostic aggressiveness varies according to the age of patients. Therefore, age may be a possible confounder when Basis of Diagnosis (BD) are compared across different cancer registries (CR).

Materials and Methods

16 833 336 incident cases in 2004-2013 were analysed, provided by 59 CRs included into the European Cancer Information System (ECIS) – 6 operating in Northern Europe (NE), 26 in Western Europe (WE), 4 in Eastern Europe (EE) and 23 in Southern Europe (SE). The crude proportion (CP) of cases for each category of BD – DCO, Clinical (CL), Clinical investigation (CI), Specific tumour markers (TM), Cytology (CY), Histology of a metastasis (HMT), Histology of a primary tumour (HPT) – was calculated for liver, pancreas, lung and colorectal cancer. Moreover, proportions were age-standardised according to the International Cancer Survival Standard. Chi-squared test was performed to compare CP and standardised proportions (SP).

Results

For pancreas the distributions of BD across areas were significantly different using CP or SP. CI was the BD for 34% of the cases in NE and 39% in EE as CP; it was 29% and 39% respectively as SP. BD was HPT for 33% of cases in NE, 42% in EE, 57% in WE as CP and 39%, 42%, 62% respectively as SP. For lung the CP of DCO was similar to the SP: in SE DCOs were 3% both as CP and SP, in WE the CP was 11% and the SP was 10%. HPT had instead different distributions; it was 57% in NE and 58% in EE as CP, 61% in NE and 56% in EE as SP. For Ovary HPT was the BD of 80% of the cases in EE and 81% in SE as CP, whereas SPs were 74% for EE and 83% for SE.

Conclusions

Crude and age-adjusted proportions of BD differ significantly across geographical areas for the considered cancers, confirming the varying intensity of diagnostic pathways in different geographical areas. Therefore, the comparison of crude BD proportions may be not reliable. We recommend a harmonisation action for the international comparisons of proportions.

Theme: Estimation and dissemination of cancer burden in Europe

Impact of comorbidities at diagnosis on prostate cancer treatment and survival

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Background and Introduction

For Switzerland, it is currently unclear in which way comorbidities influence the choice of primary treatment in prostate cancer (PCa) patients and how comorbidities affect long-term survival of PCa patients. Thus, the aim of this study was to assess the associations of comorbidities with primary treatment of PCa patients and of comorbidities with PCa-specific mortality (PCSM) compared to other-cause mortality (OCM) in Switzerland.

Materials and Methods

We included 1527 men diagnosed with PCa in 2000 and 2001 in the canton of Zurich. Comorbidities at time of diagnosis were based on the Charlson Comorbidity Index (CCI). Multiple imputation methods were applied to missing data for stage, grade and CCI. Multinomial logistic regression analyses were used to explore the associations of comorbidities with treatment. Cox regression models were used to estimate all-cause mortality, and Fine and Gray competing risk regression models to estimate sub-distribution hazard ratios for the outcomes PCSM and OCM.

Results

Increasing age was associated with a decreasing probability of receiving curative treatment, whereas an increasing CCI did not influence the treatment decision as strongly as age. The probability of OCM was significantly higher for patients with comorbidities compared to those without comorbidities (CCI 1: 2.07 [95% CI 1.51-2.85], CCI 2+: 2.34 [1.59-3.44]); this was not observed for PCSM (CCI 1: 0.79 [0.50-1.23], CCI 2+: 0.97 [0.59-1.59]). In addition, comorbidities had a greater impact on the patients' mortality than age.

Conclusions

The results of the current study suggest that the chronological age is a stronger predictor of treatment choices than comorbidities. This study supports the inclusion of comorbidities in treatment choices in order to offer more appropriate treatment for PCa patients to counteract over- or undertreatment.

Theme: Estimation and dissemination of cancer burden in Europe

Just how rare are rare lymphoid malignancies in Europe? Findings from RARECAREnet

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Background and Introduction

Rare cancers contribute to just under a quarter of the total cancer burden in Europe. Many have poorer survival when compared to more common cancers with regional and international variation apparent.

Materials and Methods

Using data from RARECAREnet, which collates data from 94 European population-based registries, we investigated incidence, prevalence and survival of rare lymphoid malignancies diagnosed in Europe.

Results

In 2008, an estimated n=931855 individuals were living with a rare lymphoid malignancy in Europe. During 2000-2007, n=282288 new rare lymphoid malignancies were diagnosed; age-adjusted incidence rate (ASR): 15.2 per 100000 people. Hodgkin lymphoma nodular lymphocyte predominance (n=1483; ASR 0.09 per 100000) and prolymphocytic B-cell leukaemia (n=804; 0.04 per 100000) were the least commonly diagnosed malignancies accounting for less than 1% of total cases respectively. Across all subtypes, slight increases in five-year relative survival were observed between 1999 and 2007 with the largest increase observed for prolymphocytic B-cell leukaemia (+11%). Despite this increase, patients with prolymphocytic B-cell leukaemia had the poorest five-year relative survival of all malignancies investigated (31%). Survival was only marginally better for multiple myeloma/plasmacytoma (including heavy chain disease; 35%) and 'other T-cell lymphomas' and Natural Killer cell neoplasms (38%). Differences in survival were noted by sex and European region.

Conclusions

Increased efforts are needed to improve survival outcomes for patients with rare lymphoid malignancies in Europe. Research focusing on prevention, early detection and treatment is warranted to ensure adequate service provision is made available to patients.

Theme: Estimation and dissemination of cancer burden in Europe

Mortality trends of breast and cervical cancers in Poland during the first decade of the national population screenings

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Background and Introduction

In many European countries breast and cervical screenings were implemented in the 90s or earlier. Following the EC recommendations (2003) in Poland screenings on the population level were implemented in 2006. Published CONCORD-3 results disclosed that in Poland is no sufficient increase in cancer survival, neither breast nor cervical cancer. Therefore we decided to analyse the mortality trends in the first decade since the screening was implemented in Poland.

Materials and Methods

Based on the published data by the National Cancer Registry, we calculated mortality trends in breast and cervical cancers. We applied Joinpoint Regression Analysis and calculated APC (Annual Percentage Change) for the period of 2000-2015.

Results

Contrary to our expectation breast cancer mortality trend was steadily increasing during 2000-2012 (APC=1.3% per year) and accelerated later up to 4.4%. Cervical cancer mortality was steadily decreasing the whole analysed period of time on average -1.19% per year. The national screening programme could effect in a slight increase in the five-year cancer survival from 2000-2014: in breast cancer about 5.3% and in cervical cancer about 3.5% as it was presented in CONCORD. However, detailed report on the health effect of screening has not been published yet. A possible explanation of the increase in breast cancer mortality could be a large increase of number of patients due to early detection, including national screening, and eldering of the population. That could overload the healthcare system and adversely affect access to treatment. To countervail this problem in 2015 the so-called 'fast oncological patient pathway' (DiLO) was implemented by law. The decreasing mortality trend in cervical cancer in Poland seems to be related to natural trends in Europe, therefore, the influence of the screening is difficult to assess.

Conclusions

The evaluation of health effectiveness of screening programmes in Poland is difficult in the present situation.

Theme: **Estimation and dissemination of cancer burden in Europe**

European countries with partial cancer registration coverage: how to estimate national incidence?

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Background and Introduction

European public health policies and epidemiological cancer surveillance widely refer to national cancer incidence indicators. Six European countries (France, Germany, Italy, Romania, Spain, and Switzerland) have only regional cancer registries (CRs) not covering the national population and other two countries (Portugal and UK) have complete population coverage for certain years only. Their national cancer incidence has been estimated using different methodological approaches. This study aims at comparing national incidence estimates based on the most frequently applied methodological approaches.

Materials and Methods

The methods considered for estimating national incidence are two. The 'local data' method assumes that national age-specific incidence crude rates are the same of the covered region and computes the national incidence from the national population; the 'I:M method' assumes that incidence to mortality ratio (I/M) at national level is the same of the covered region and estimates the national incidence from the national mortality. The incidence data of the regional CRs included in the European Cancer Information System (ECIS) were used in this comparison exercise.

Results

The incidence estimates obtained with the two approaches are quite similar for many cancer sites (relative changes between -5% and 5%), with the exception of some sites (*e.g.* oesophageal and thyroid cancer, and Hodgkin's lymphoma) showing bigger discrepancies (relative change lower than -20% or higher than 20%).

Conclusions

Besides the different methods, the discrepancies observed between the two set of estimates can be attributed to several factors, including the representativeness of the available CRs as compared to the national territory, the selection of the CRs among those available and the definition of the cancer sites in the analysed period. The results of this comparison are expected to improve the estimation of national incidence in these European countries.

Theme: Estimation and dissemination of cancer burden in Europe

The software COMPREV 3.0: a tool to quantify cancer burden by means of Complete Prevalence estimation

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Background and Introduction

Complete Prevalence (CP) is important to evaluate the cancer burden and survivorship and direct costs of cancer care. It represents the proportion of people alive on a certain date who have been previously diagnosed, regardless of how long ago the diagnosis was.

Materials and Methods

CP includes people with a range of health service needs, from recently diagnosed patients requiring initial treatment to people who require extensive care in their last year of life or long-term survivors who need only minimal care. Therefore, estimating prevalence by phase of care (initial care, monitoring and last year of life) is useful to provide evidence-based guidance for health service planners and policy makers and resource allocation (Mariotto, 2006). CP includes also people who were diagnosed in their childhood and are still alive. The ChildPrev method (Simonetti, 2008) allows estimating prevalence even when no observation is available (typically older patients alive at the prevalence date may have been diagnosed before the introduction of the registry). CP is not easily estimated from cancer registry data over a limited time span, and to this scope the COMPREV software (http://surveillance.cancer.gov/comprev/) was developed by the NCI in collaboration with Italian researchers including the authors of the present abstract, who developed the methodology.

Results

The software calculates CP based on limited-duration prevalence statistics from cancer registries. It contains incidence and survival models estimated for a combination of cancer sites, sex and races. These models are used to calculate the completeness index (Capocaccia, 1997), that represents the percent of 'completeness' of limited duration prevalence.

Conclusions

A new revised version COMPREV 3.0, with improved graphical interface and more functions, is about to be released and includes four sessions:
1) Completeness index estimation;
2) Complete Prevalence estimation;
3) Childhood Prevalence estimation;
4) Phase of care Prevalence estimation;
which will be illustrated through a set of examples.

Theme: **Clinical databases and population based cancer registries**

Cancer clinical research should join forces with registries on long-term outcome research – a showcase of EORTC-IKNL

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Background and Introduction

In Europe, more than half of cancer patients survive five years after diagnosis. With the ever improving survival rate, research on long-term care and outcome become increasingly important. Both clinical trial organizations and cancer registries perform long-term outcome research. However, due to operational, regulatory, or methodological constraints this particular research field has not reached its full potential.

Materials and Methods

The current study used an empirical case study to show the level of agreement of variables between two databases of the same patients diagnosed with Hodgkin Lymphoma treated in the European Organisation for Research and Treatment of Cancer (EORTC) H1-H9 trials: one database is the clinical trial database from the EORTC and the other is the Netherlands Cancer Registry (IKNL).

Results

The study showed a high level of agreement between the two datasets in most of the variables. However the vital status was more complete in the registry database, in particular for survivors diagnosed with cancer more than 10 years ago whereas treatment registration was more complete and more accurate in the EORTC clinical trial database.

Conclusions

Based on the case study, we envisaged several actionable collaboration activities between clinical research organizations and population-based registries in long term outcome and survivorship studies in the future, including data linkage, joint methodology development, data quality cross-check and improvement program.

Theme: Clinical databases and population based cancer registries

High resolution registry of melanoma and care pathways monitoring in the Veneto Region, Italy

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Background and Introduction

In 2016 the Veneto Region issued the care pathways for patients with melanoma. The Veneto Tumour Registry, in collaboration with the Veneto Oncology Network, started the high-resolution recording of melanoma for the 2013 incident cases. This study evaluates the use of cancer registry data to calculate indicators for care pathways monitoring.

Materials and Methods

Information was collected on diagnostic procedures, tumour characteristics, surgical therapy, medical therapy and follow-up. The care pathways indicators that can be calculated using the regional administrative data were distinguished from those calculated only through registry data.

Results

The high-resolution registry includes 403 melanomas diagnosed in 2013 in the provinces of Belluno, Padova and Rovigo (28% of the Veneto Region). Of these, 78% were diagnosed in stage I, 11% in stage II, 8% in stage III and 2% in stage IV, with a three-year survival of 99.3%, 90.5%, 86.5% and 11.1%, respectively. Fifty-nine percent of cases showed vertical growth and 18% ulceration.
A BRAF mutation was recorded in 21 out of 36 tested patients. Sentinel lymph-node biopsy (BLS) was performed in 34% and lymphadenectomy in 8% of cases, with positive lymph-nodes in 10%. Nine percent of patients performed medical treatment, of which 35% immunotherapy, 23% systemic chemotherapy, and 19% target therapy. Among the analysed care pathways indicators, BLS not performed if Breslow <0.8 mm without ulceration = 0%; more than 12 excised axillary lymphnodes = 76%; more than six inguinal lymphnodes = 80%; interval between biopsy and wide excision <60 days = 68%; evaluation of mutational status if stage IV = 58%; lymphadenectomy if BLS positive = 69%.

Conclusions

The quality of melanoma care before the introduction of care pathways was medium-high. The Cancer Registry was essential for calculating almost all the process indicators and made it possible to define the sources of information necessary for monitoring also the care pathways for other cancers within the Veneto Oncology Network.

Theme: **Clinical databases and population based cancer registries**

Supporting local NHS decision-making in Wales with profiles of cancer incidence and prevalence at Cluster Network level

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Background and Introduction

There are 60 Cluster Networks in Wales across seven health boards. These groups of neighbouring GP practices and partner organisations have a role in supporting local health needs assessments, allocating appropriate resources and forecasting potential future demand on primary care. Analysis of linked data at cluster level has been conducted to support clusters' decision-making and understanding of their cancer burden.

Materials and Methods

We extracted cancer data from the Welsh Cancer Intelligence and Surveillance Unit's Cancer Registry for two diagnosis periods–2011-2015 for incidence and 1995-2015 for prevalence. We linked each case to a Cluster Network. We used the Welsh Index of Multiple Deprivation 2014 to assign a deprivation quintile to patients and the 2011 Rural Urban Classification to assign two rurality categories. For incidence, we calculated the proportion of patients in each category for Cluster Networks by cancer type, sex, four age bands, deprivation quintile, rurality and stage at diagnosis. We calculated the percentage prevalence of people living on the 31st December 2015 with a cancer diagnosis in the 21 years previously for Cluster Networks by cancer type, sex, four age bands, deprivation quintile and rurality.

Results

There was wide variation in incidence and prevalence between Cluster Networks when considering sex, deprivation and stage at diagnosis. Cancer diagnoses were most common in the 75+ age group, with proportions ranging from 29% to 43%. However, two Cluster Networks in Cardiff were found to have high proportions of diagnoses in the youngest age group (0-49 years) at 15% and 17%. One year prevalence ranged from 9%-18% for men and 7%-15% for women. However, 21 year percentage prevalence in women (23%-36%) was higher than in men (18%-31%).

Conclusions

Further analysis for this project is ongoing as more work is needed to develop a fuller picture of the cancer population in Wales.

Theme: Clinical databases and population based cancer registries

Development of an algorithm using administrative data to estimate recurrence of ovarian cancer in Belgium

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Background and Introduction

In contrast to primary cancer incidences, recurrences are currently not systematically registered in most population-based cancer registries, including the Belgian Cancer Registry (BCR). Recurrence data for ovarian cancer could give an estimation of cancer burden and effectiveness of therapy. Algorithms based on administrative to obtain recurrence information at the population level have been built in other countries before, but with variable performances related to the lack of treatment details available, and the limited size of validation cohorts. The aim of our study is to create administrative data-based algorithms to estimate recurrence and progression for ovarian cancer in Belgium.

Materials and Methods

First, we retrospectively collected recurrence data of ovarian cancer patients from medical files from UZ Leuven. 100 cases (with a recurrence) were matched to 100 controls by tumour and patient characteristics. Following transfer of these data to BCR, we deterministically linked health insurance data containing charged medical acts for every patient. The cohort was used as a training set to develop the algorithm. Later, a test set will be used to validate the accuracy of the algorithm. Since chemotherapy is the recommended treatment for recurrent ovarian cancer, a switch in chemotherapy regimen or additional chemotherapy lines after a disease-free window was taken into account, as they could indicate recurrence or progression of cancer.

Results

The training set yielded preliminary results of the algorithm, which estimated recurrence or progression for ovarian cancers with 91.0% sensitivity and 96.7% specificity.

Conclusions

Using an algorithm on administrative data, we could estimate ovarian cancer recurrences with a high sensitivity and specificity. When further refinement of the algorithm is completed and the validation of the algorithm in the test set is satisfactory, it will be used to identify recurrence/progression for all Belgian ovarian cancer cases.

Theme: **Clinical databases and population based cancer registries**

Investigating characteristics of women with Breast Cancer Recurrence in Northern Ireland (NI)

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Background and Introduction

Little is currently known about prevalence of recurrence within the NI Breast Cancer population. We aim to report the characteristics of women developing a breast cancer recurrence.

Materials and Methods

Disease and socio-demographic characteristics of women (n=1109) diagnosed with Invasive Breast Cancer (ICD10 C50; excluding stage IV) in 2009 were extracted from the NICR database. Electronic healthcare databases were used to follow up for disease recurrence to 2017.

Results

145 (13.1%) women diagnosed with Invasive Breast Cancer (excluding stage IV) had a recurrence with a mean time to recurrence of 3.4 years (95% CI: 3.1-3.7 years).For women with recurrence, 17.2% had a local/regional recurrence, two thirds (64.1%) had recurrence of distant site(s) and 18.6% had both local/regional and distant site recurrence. A lower proportion of women of screening age (50-70 years; 9.9%) and over 80 years (10.4%) at diagnosis had a recurrence recorded when compared with other age groups (20-49 years; 20.2% and 70-79 years; 16.5%). Recurrence was related to stage at diagnosis with 34.2% at Stage III, 16.0% at Stage II, 6.0% at Stage I and Unknown stage 3.2%.

Conclusions

The findings show differences by age and as expected stage in the proportion of women with a recurrence of breast cancer. Further investigation of the disease and patient socio-demographic characteristics (including deprivation quintile, hormone receptor status and treatment) is now planned to provide information for patients and clinicians and also to inform future improvements in breast cancer care in NI.

Acknowledgements

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Theme: **Clinical databases and population based cancer registries**

Characteristics of pancreatic cancer and survival by stage: a population-based study from the Girona cancer registry

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Background and Introduction

Pancreatic cancer (PC) is a major health problem in our society due to its high mortality rate and its increasing incidence. The aim of this study was to present the clinical characteristics and survival according to stage of PC registered in the Girona cancer registry in the 2010-2013 period.

Materials and Methods

Data were extracted from the population-based Girona cancer registry. Incident cases were classified using the ICD-O-3 Third Edition, fist revision. The period study was from 2010 until 2013. Age-adjusted incidence rates (ASRE) to the European standard population were obtained. For survival analysis (follow-up available until 31/12/2017), observed and relative survival were estimated with Kaplan-Meier and Ederer II methods, respectively.

Results

388 PC incident cases were included (54.9%men). The most frequent histology was adenocarcinoma with 135 cases (34.8%) and the second one was infiltrating duct carcinoma with 48 cases (12.4%). The most frequent subsite was head (39.2%). Only in 28.4% of cases (110) was a histological diagnosis of the primary tumor obtained. In a large part of the cases (36.1%) only clinical diagnosis obtained. In the remaining cases (15.5% diagnosis by metastasis biopsy, 15.5% by cytology). The majority of cases were diagnosed in stage IV (49.5%); 10.3% were stage III, 16.2% were stage II and only 1.5% were stage I. In 22.4% (87) of cases the staging could not be obtained. The PC CR was 10.47 and ASRE was 11.77 (95% CI 10.63;13.01). CR in male was 11.38 and ASRE was 14.12 (95% CI 12.28;16.22) and CR in female was 9.54 and ASRE was 9.53 (95% CI 8.13;11.12). There was a male predominance. 69% of cases were >65 years old at diagnosis. Observed survival was 20.9% at the end of first year and only 6.2% at the fifth year. Relative survival will be presented.

Conclusions

The incidence in Girona is within the European average. The majority of cases are adenocarcinomas, with histological confirmation in only 59.4% of the cases and the majority being diagnosed in advanced stages, hence their poor survival.

Theme: **Clinical databases and population based cancer registries**

Quality indicators for lung cancer care in canton Ticino (southern Switzerland), 2015-2016

Laura Ortelli, Alessandra Spitale, Paola Mazzola, Simona Peverelli, Andrea Bordoni

Ticino Cancer Registry

Background and Introduction

Lung Cancer (LC) is one of the most common cancers in the world and it is the leading cause of cancer mortality worldwide. Stage and morphology of LC are of fundamental importance in the therapeutic decision making. Aim of this study is to analyse evidence-based quality indicators (QIs) for LC care in a population-based setting in order to provide important feedback to providers, regulators and purchasers of care.

Materials and Methods

All patients diagnosed with LC in canton Ticino (southern Switzerland) during the period 2015-2016 are selected. Lymphomas, carcinoids and NOS neoplasms are excluded from the analysis. QIs are defined according to the ESMO Clinical Practice Guidelines for LC (2017) and are computed for available information as proportion with corresponding 95% confidence interval (95%CI).

Results

420 LC are diagnosed in canton Ticino during the study period: 87% of them are non-small-cell LC (NSCLC) and 13% small-cell LC (SCLC). Average age at diagnosis is 70.3±9.8 years. LC stage distribution is the following: 19% stage I, 8% stage II, 19% stage III, 50% stage IV and the remaining 4% are not classifiable. Patients with non-metastatic (M0) LC have a pre-treatment pathological diagnosis before curative treatment in 84% (95%CI: 79%;90%) of cases (QI1). 88% (95% CI: 82%;94%) of stage I-II NSCLC patients undergo surgery within 4 months from the date of diagnosis (QI2), while the proportion of NSCLC patients (all stages) undergoing surgery with free margins (R0) is 94% (95% CI: 90%;99%) (QI3). Metastatic SCLC are treated with chemotherapy in 83% (95% CI: 70%;95%) of cases (QI4).

Conclusions

Although improvements are possible, results for LC care in canton Ticino are generally positive and encouraging. Further national and international population-based data are needed for comparative analysis.

Theme: Clinical databases and population based cancer registries

Quality evaluation of breast cancer screening canton Ticino in southern Switzerland through cancer registry data

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Centro Programma Screening Ticino, Ticino Cancer Registry

Background and Introduction

The breast cancer screening program of canton Ticino, southern Switzerland, is a public service offering every two years a free and quality-controlled screening mammography to all women aged 50-69 years and resident in the mentioned area (about 48000 women). A specific regional law allocates the screening centre within the Ticino cancer registry, thus permitting data linkage for quality control issue of the screening program. The program activity started progressively in 2015 and 2016 represents the first year of full activity. Aim of the study is to present the results of quality indicators for the breast cancer screening program in canton Ticino in 2016.

Materials and Methods

Quality indicators are calculated as proportion and they are compared with reference values of the European Guidelines for quality assurance in breast cancer screening and diagnosis (EU). Whenever possible data are compared with 2012 Swiss data (CH). Data collection is performed by trained data managers working on both screening and cancer registry database.

Results

In 2016, 25716 women are invited, 22540 of them are eligible for a screening mammography and 13558 perform a mammography. The corrected activity rate of the program is 60%. 92.8% of women receive the result within four working days from the date of the exam (EU: >90% within 10 days). 7.1% of cases are discussed in a Consensus Conference in case of discordance between first and second reading (EU: <7-15%). 14 women (0.1%) repeat the exam due to technical reasons (EU: <1-3%), while 530 women (3.9%) are recalled for additional investigations following a 'positive' result (EU: <3-7%; CH: 3.4-7.8%). The false positive rate is 3.2% (CH: 2.9-7.2%), while 97 women (7.2‰) have a diagnosis of invasive or in-situ breast cancer (CH: 4.9-6.5‰).

Conclusions

The quality control for 2016 of the activity of the breast cancer screening program of canton Ticino shows encouraging results reflecting Swiss data and the recommendations of the European Guidelines.

Theme: **Clinical databases and population based cancer registries**

Second malignant neoplasms after a childhood cancer in the Comunitat Valenciana region, Spain

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Background and Introduction

Children cancer survivors are at markedly increased to develop a second malignant neoplasm over the years. This study aims to analyse second malignant neoplasm among children diagnosed of a cancer over the period 1983-2015 in the C. Valenciana. The catchment population comprises 10.5% of the Spanish population in this age range.

Materials and Methods

Descriptive and prospective epidemiological study. Data were obtained through the Cancer Information System of our region. We have registered 3336 patients with cancer among children who survived six month or more from 1983 to 2015.We followed up them until 31st of December 2015. Tumours with benign and uncertain behaviour were excluded and patients with incomplete follow up. We estimate the time between the 1st and 2nd tumours, overall and by main groups diagnostic ICCC3. We calculate probability the second tumours by sex, age groups and period of incidence. The software used in analyse was R.

Results

A total of 3336 children with cancer who survived six month or more have had 38 second malignant neoplasm in this period. The average of years in appears second tumour is 12 year (range maximum Leukaemia 20 year and minimum for renal tumour two year). Probability of developing a second tumour is higher in girls (13.9) than boys (9.3). By age groups the highest probability is noted at 10-14 yr. (16.4) and 5-9 yr. (13.6) and the lowest at 1-4 yr. (6.8). By period diagnostics, although the first has higher probability of second tumour than others there are not comparable. By group of first primary cancer, Lymphomas produced 26% of second tumours. The most frequently second malignancies were Leukaemia 31.6% and breast carcinoma 18.4% respectively.

Conclusions

New primary cancers were higher in older children than in younger ages. The probability was higher among girls than boys. Lymphoma was the initial group with more second tumours following a childhood cancer. Longer series will be required to learn what is occurring.

Theme: **Clinical databases and population based cancer registries**

Odisseia, an oncology disease information system – integrating information from different sources

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Background and Introduction

The basic traditional information collected by population-based cancer registries (age, sex, topography, morphology, behaviour) no longer satisfies the needs of researchers and health policies decision-makers. More and more, there is a demand for information on clinical characteristics of the disease (biomarkers, genetic mutations...), characteristics of the patient (comorbidities, risk behaviours...), detailed treatment information and response to treatment and follow-up information (relapses, progression, death).

Materials and Methods

Gathering all this information constitutes a great challenge. An information system was designed at IPO-Porto and it is now being implemented. Nowadays, much information is registered electronically in different systems. The main aim was to endow the cancer registry with an integrated system that aggregates information from these different sources. The system will integrate information from: anatomy pathological reports; clinical pathology and genetic results; imaging exams; surgery reports; drugs administered (both injectable and oral) including chemo, immuno and hormone therapy; radiotherapy; primary care information on life-style and comorbidities; death certificate national information system. A rule engine will be set-up to handle the integrated information automatically. A set of dictionaries will ensure the validity of the information collected. Nevertheless, to guarantee the quality and consistency of the registered information a set of regular validation procedures are foreseen.

Conclusions

In conclusion, the system being developed will allow a much more automated and faster collection of complete information on the care pathway of cancer patients. The evaluation of associations between patient and disease characteristics, the care delivered and outcomes will be easily achievable.

Theme: **Clinical databases and population based cancer registries**

Systemic treatment in non metastatic breast cancer in Belgium: does age influence intercenter heterogeneity?

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Background and Introduction

The Belgian Cancer Registry (BCR) conducts studies on quality of care indicators (QCI) including individual feedback to all hospitals, intending to compare and ultimately improve quality of care. In the present study, QCI on systemic treatment for non-metastatic breast cancer patients were calculated, taking into account an age cut-off of 75 years.

Materials and Methods

Data on females with unique clinical stage I-III breast cancer diagnosed in 2010-2014 was selected in the BCR (n=35631), and linked with administrative data. Following QCI were calculated at national and hospital level for elderly (≥75 yrs; n=7497) and non-elderly (<75 yrs; n=28134) patients: administration of upfront endocrine treatment without surgery, adjuvant endocrine treatment and (neo-) adjuvant chemotherapy.

Results

Elderly received more upfront endocrine treatment without surgery than their younger counterparts (19% (range 0-67%) vs. 1% (0-12%)). On the contrary, less adjuvant endocrine treatment was administered to the elderly (63%, 0-85%) compared to the non-elderly population (79%, 53-100%). Neo-adjuvant chemotherapy was given to only 3% (0-25%) of the elderly versus 12% (0-39%) in younger patients, and the administration of adjuvant chemotherapy showed the same trend with 10% (0-46%) of elderly patients treated vs. 38% (0-64%) of non-elderly patients.

Conclusions

Elderly non-metastatic breast cancer patients received more upfront endocrine treatment, but less adjuvant endocrine treatment and (neo-)adjuvant chemotherapy than their younger counterparts. Substantial intercenter variability in systemic treatment was noted for both age classes, but was more pronounced in elderly for endocrine treatment and, inversely, in non-elderly for chemotherapy. Additional analyses will take patient (comorbidities, performance status) and tumor (stage, differentiation grade, molecular subtype) characteristics into account. Also, we will refine our methods to quantify intercenter variability.

Theme: Clinical databases and population based cancer registries

Mortality among non-operated colon cancer patients in Denmark

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Background and Introduction

A previous study has shown that the proportion of non-operated colon cancer (CC) patients is increasing. In 2001-2004 the proportion of non-operated CC patients included in the Danish Colorectal Cancer Group database (DCCG.dk) was 8%, and increased to 15% in the period 2009-2012. The relative survival (RS) of non-operated CC patients decreased during these periods. The aim of the study was to describe characteristics of non-operated CC patients in Denmark, and evaluate how these characteristics effected one-year mortality.

Materials and Methods

The study is based on patients diagnosed and registered with CC from 2009 to 2015 in DCCG.dk. DCCG.dk includes among others information on age at time of diagnosis, comorbidity, stage, MDT conference, reason for not operating, and referral to oncological treatment. Descriptive statistics will be used, and one-year mortality will be calculated using RS and Cox proportional hazard models.

Results

The study includes 2861 non-operated CC patients. For both periods, 2009-2012 and 2013-2015, the proportion of non-operated patients was 14%. For the period 2009-2015, the primary reason for deselecting an operation was disseminated cancer (72%), patients opting out (13%) and comorbidity (10%). Half of the patients were 75 years or older (51%) and 81% had stage IV CC. Estimates for one-year RS and Cox proportional hazard models will be presented.

Conclusions

The present study did not find an increase in the proportion of non-operated CC patients from the period 2009-2012 to 2013-2015. Further conclusion will be drawn from the RS and Cox proportional hazard models.

Theme: **Clinical databases and population based cancer registries**

Recent trends in incidence of non-melanoma skin cancers pathology reports in Northern Ireland

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Background and Introduction

Suspected skin cancers account for a significant proportion of dermatology referrals received from primary care. Due to limited resources, it is common practice for registries to report only the first Basal Cell Carcinoma (BCC) or Squamous Cell Carcinoma (SCC) per person. This leads to under-reporting of the true burden of NMSCs on the health system. This study examines trends in the incidence of NMSCs and of all pathologies in N.Ireland (NI).

Materials and Methods

Joinpoint analysis was used to investigate changes in the age-standardised incidence rates of first recorded NMSC by subtype. Pathology reports during 2010-2015 were extracted from the NI Cancer Registry and incidence of all reports examined. A sample of reports were checked to ensure accurate recording.

Results

Significant increases in the annual age-standardised incidence rates of first recorded SCC and BCC were detected. In total, there were 10 664 SCCs and 30 209 BCCs NMSCs reported. during 2010-2015. There were 13 846 patients with one pathology report and 9 640 patients with more than one pathology report. Validation of pathological reports is currently underway.

Conclusions

With an aging population, multiple primary tumours in affected individuals and the increasing incidence of NMSC there is an urgent need to plan future services. This data will assist in the commissioning of Dermatology services to meet current and future needs.

Theme: Clinical databases and population based cancer registries

Higher values of five-year survival as an advantage resulting from starting treatment in the oncological center

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Background and Introduction

In 2015, the Province of Lower Silesia, Poland had 2 900 000 inhabitants and 13 093 new cancer cases were registered.

Materials and Methods

The five-year relative survival of patients, including data from the cancer registry and clinical database for the Lower Silesia Voivodship with breast and ovary cancer for women, rectum and malignant melanoma for both sexes was calculated for patients who fell ill during the five years of 2000-2004, 2005-2009 and in the years of 2010-2012, including clinical advancement.

Results

The five-year survival rates were higher for patients treated with surgery at the Lower Silesian Oncology Center (LSO). The rates for women with breast cancer during the study period: treated in LSO 83 - 87% - on average 85% and respectively outside LSO 69 - 87% on average 82%. In addition, the cases reported to the registry for LSO`s patients had a lower stageing of the operated tumors. For patients with rectal cancers despite the similar stage in the analyzed period, rates were: at LSO 58 - 64% on average 61% and outside LSO 36 - 59% on average 48%. For patients with melanomas during the study period: LSO 56 - 73% - 67% on average and for the second group 34 - 66% - on average 58%. In 2011 the difference of 10% in favor of those operated outside the LSO was due to differences in advancement: the metastatic stages were 45.5% in the LSO and 27.8% outside. In 2012, at the similar level (stages with metastasis were 31.6% in LSO and 33.3% outside LSO), patients operated in LSO showed an increase of indicators of 7.6%. Cases of ovarian cancer during this period : at LSO 43 - 53% - on average 48% and respectively autside LSO 30 - 53% - on average 44%.

Conclusions

The differentiation of five-year survival apart from the differences in advancement, is mainly due to availability, so also easy access to the oncological center and thus high-quality medical care. The study showed that treatment in a high specialized oncology center such as Lower Silesian Oncology increases the chances of survival.

Theme: **Clinical databases and population based cancer registries**

Population-based incidence of lymphoid neoplasms according to WHO 2008 classification: results from the Girona province

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Background and Introduction

Changing classifications and few complete available epidemiological data hamper international comparisons of lymphoid neoplasms (LNs) data. The aim of this study was to present incidence and survival of LNs in the Girona province (1994-2014) according to the WHO 2008 classification, and to predict the number of LNs in Spain during 2020.

Materials and Methods

Data were extracted from the population-based Girona cancer registry. Incident cases were classified using the ICD-O-3 first revision and grouped according to the WHO 2008 classification scheme. Age-adjusted incidence rates (ASRE) to the European standard population were obtained and incidence trends were modeled using Joinpoint. For survival analysis (follow-up available until 31/12/2015), observed and relative survival were estimated with Kaplan-Meier and Ederer II methods, respectively, and trends tested with a log-rank test.

Results

4376 LNs incident cases (57.2% men) were diagnosed in the Girona province. There were 372 (8.5%) Hodgkin-lymphoma, 218 (5.0%) precursor lymphoblastic leukemia/lymphoma, 3395 (77.6%) mature B-cell neoplasms, 255 (5.8%) matureT/NK-cell neoplasms, 3 (0.1%) composite Hodgkin and no-Hodgkin lymphoma, and 133(3.0%) lymphoma NOS. The median age at diagnosis ranged from 25 to 75.6 years according to the major LNs subtypes. Overall in both sexes, the top five most frequent subentities were: plasma cell neoplasm (828), chronic lymphocytic leukemia/small lymphocytic lymphoma (739), diffuse large B-cell lymphoma (735), follicular lymphoma (427) and marginal lymphoma (339). The LNs CR was 32.7 and ASRE was 36.4 (95% CI 35.4;37.5).There was a marked male predominance; the incidence sex ratio (M/F) ranged from 1.1 for follicular lymphoma to 5.3 for hairy cell leukemia. Incidence trends, the expected number of LNs in Spain in 2020, and survival will be presented.

Conclusions

This is the first study to present epidemiological data from LNs in Spain according to the WHO 2008 classification.

Theme: Clinical databases and population based cancer registries

Involvement of European cancer registries in measuring Patient Reported Outcome Measures in colorectal cancer

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Background and Introduction

The burden of colorectal cancer in Europe is still increasing. The disease and treatment can have profound impacts on the patients' quality of life (QoL), emphasizing the importance of measuring QoL. An important tool in this process is Patient Reported Outcome Measures (PROMs). The goal of this study is to give an overview on the use of PROMs throughout the colorectal cancer care pathway in Europe, and to describe the role of the cancer registries (CR) in this process.

Materials and Methods

Studies were searched via Pubmed until end of April 2018 regarding the involvement of CRs in measuring PROMs in colorectal cancer, focusing on the whole care pathway, *i.e.*, screening, diagnosis, treatment, follow-up, and palliative care. Only studies conducted in Europe were included.

Results

Our search retrieved 49 studies and 19 studies (39%) involved CRs. Most of the studies were conducted in the Netherlands (n=10). Other studies used data from Germany (n=3), United Kingdom (3), Denmark (1), Ireland (1) and Czech Republic (1). Concerning care processes, most studies focused on treatment (*i.e.* surgery, systemic therapy). Only one study assessed PROMs in the screening settings. There is a great variation in the PROMs instruments used, as well as in the domains included in them (physical function, symptoms, psychological distress, general QoL, financial aspects, patient satisfaction). The most used standardised instrument was EORTC QoL C30, sometimes in combination with other colorectal cancer specific questionnaires. CR were used to identify the cancer cases in 13 studies, to link clinical data or other information with PROMs in 5 studies and to audit the screening in 1.

Conclusions

In Europe, the use and content of PROMs in colorectal cancer varies but is still limited. Cancer registries are mostly used to identify patients. In future CRs could play a fundamental role in routine collection of PROMs and linking with clinical data to provide unbiased and comprehensive results.

Theme: **Clinical databases and population based cancer registries**

A national, prospective collection of patient reported outcomes for prostate cancer: infrastructure and response rates

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Background and Introduction

To gain knowledge on adverse effects and quality of life after diagnosis/treatment, the Cancer Registry of Norway collects patient reported outcomes on prostate cancer (PCa) shortly after diagnosis and after one and three years in a nationwide, prospective pilot study. Compliance rates are important for the validity of the project, and we present early response rates.

Materials and Methods

All Norwegian men diagnosed with PCa from 2017-2019 (n≈15 000) are invited to a survey on men's health. Controls with no history of PCa are frequency matched on age and geographical region of residence. Men with an official digital mailbox are invited electronically, and the remaining by regular mail with the questionnaire and a pre-paid return envelope included in the invitation. Regardless of how they were invited, participants can submit their questionnaire either online or by regular mail. Those participating electronically log on using the highest level of electronic identity authentication, which is familiar to Norwegians through public and private digital services.

Results

For men invited until mid-September 2017 (n=5 253), the response rate among PCa patients was 59%, and 36% among controls. Among patients, he response rates were evenly distributed across age groups (18-60: 59%, 60-69: 60% and 70+: 57%). Respectively, the response rates for controls were 27%, 40% and 36%. Men invited by digital mailbox were more likely to respond than those invited by regular mail, with response rates at 65% and 51% for patients and 44% and 31% for controls. Multivariable logistic regression analysis confirms that age, invitation method and case/control status were associated with participation.

Conclusions

The infrastructure for sending invitations and receiving questionnaires both digitally and on paper makes it feasible to reach all patients and controls on a nationwide level. We are currently planning to apply the infrastructure on other groups of cancer patients.

Theme: **Clinical databases and population based cancer registries**

Model to evaluate the impact of ERNs by linking PBCRs and CDBs. The JARC study

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Background and Introduction

Within the Joint Action on Rare Cancer (JARC) (WP 4 Epidemiology. Task 4.4) a pilot study is testing the feasibility of a model to evaluate the impact of European Reference Networks (ERNs) by means of the linkage between clinical databases (CDBs) and population-based cancer registries (PBCRs).

Materials and Methods

Based on the previous experience in Spain in the frame of ENCCA (Task 11.4), this pilot study includes the CDBs of neuroblastoma in 9 European countries and the PBCRs covering the same geographical areas. First, a survey has been sent to obtain a description of their characteristics to evaluate possible linkage. Next, the feasibility will be tested by linking the CDBs and the corresponding PBCRs. As part of the feasibility studies, an updated and enlarged linkage between the complete CDB of the Spanish neuroblastoma network (at IISLaFe) (1999-2017) and the Spanish Registry of Childhood Tumours (including collaborating regional PBCRs) for infant neuroblastoma is in progress.

Results

Nine countries (one CDB per country) and 68 registries were invited. The response rate from CDBs was 88% (Belgium, Bulgaria, Germany, Hungary, Italy, Spain, Switzerland, United Kingdom (England)) and from PBCRs 83%. For the new Spanish infant-neuroblastoma linkage, expected cases for Spain are 680 (95% of estimated coverage prior linkage with the regional PBCRs). Detailed analysis of the questionnaires and of the infant-neuroblastoma linkage will be shown at the meeting.

Conclusions

A good response to the survey was obtained. The feasibility of the linkage, its completeness and overall quality will be ascertained. If successful, the linkage will provide a measure of the population coverage of the CDBs within the selected resident population. Such a model may be applied to the CDBs of the ERNs to monitor the proportion of eligible cases they capture, to track the rare cancer patients moving through the ERN centres, and to assess by observational studies the impact of ERNs at the population level.

Theme: **Biobanks and cancer registries**

The role of viral agents in the progression from Barrett's oesophagus to oesophageal adenocarcinoma

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Background and Introduction

Oesophageal adenocarcinoma incidence is increasing. Infectious agents have a causal role in the development of a number of neoplasms including those of the head and neck. Recent evidence suggests that human papilomavirus (HPV) is associated with an increased risk of oesophageal adenocarcinoma and its precursor, high-grade dysplasia. John Cunningham virus (JCV) has also been implicated in oesophageal adenocarcinoma pathogenesis and herpes simplex virus-1 (HSV-1) in achalasia. The study aims to investigate the presence of a range of infectious agents in Barrett's oesophagus biopsy tissue from patients who progressed to high grade dysplasia/oesophageal adenocarcinoma and in a subgroup of non-progressors.

Materials and Methods

Barrett's oesophagus patients who progressed to oesophageal adenocarcinoma (cases, n=180) and Barrett's oesophagus patients who did not progress (controls, n=358) were identified through linkage of the Northern Ireland Cancer Registry to the NI Barrett's oesophagus register. Formalin-fixed paraffin-embedded tissue from cases and controls were retrospectively collected by each Trust (and by the Northern Ireland Biobank). Sections were cut utilising strict guidelines to ensure non-contamination. Viral DNA was assessed using a Luminex-based platform. Conditional logistic regression analysis odds ratios and corresponding 95% confidence intervals will be calculated comparing virus status (present/absent) in cases and controls with adjustment for potential confounders.

Conclusions

This research will clarify the role of infectious agents in Barrett's oesophagus and their involvement in the development of oesophageal adenocarcinoma. If a pathogen is identified this could instigate development of preventive strategies, such as vaccination, use as a prognostic indicator and/or differential therapy.

The NICRs experience of the TNM8 Oropharyngeal p16+ Staging System

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Background and Introduction

The new UICC TNM8 staging system clinically commenced in Northern Ireland on 01/01/2018. In line with the rest of the United Kingdom, the Northern Ireland Cancer Registry (NICR) has decided to collect UICC TNM7 and TNM8 data items for head and neck cancer staging simultaneously. The UICC TNM8 staging system includes p16 immunohistochemistry (IHC) alone as a marker of HPV status in oropharyngeal squamous cell carcinoma cases (OPSCC). However, second line testing for HPV, such as in situ hybridisation, is suggested as many OPSCCs are p16+ but HPV- with differential prognosis. The NICR reviewed regional molecular data available and the training implications of implementing the UICC TNM8 staging system.

Materials and Methods

The Tumour Verification Officer (TVO) team re-staged all the 2016 NICR OPSCC cases registered in the NICR and recorded molecular data associated with OPSCC.

Results

In Northern Ireland on average 323 cases incident head and neck cancer cases were diagnosed annually (2012-2016). In 2016 there were 78 pathologically verified incident cases of OPSCC with 69 (88.4%) had a p16 IHC test. Of those given an IHC test 45 cases (65.2%) were p16+ positive. Only six p16+ cases (8.7%) were given a second line test to verify HPV driven disease. There were OPSCC tumours were down-staged from versions TNM7 to TNM8, advanced Stage 3+4 reduced from 84.6% to 51.3%.

Conclusions

Ascertaining the site of origin of head and neck tumours can be quite difficult and this is particularly evident in advanced stage tumours where annotations often differ. Taking into account p16+ increased the complexity of staging OPSSCs. The TVO team found the language used for molecular testing difficult as brand names were used for testing as opposed to the technical name of the procedure. Summary: second line testing of p16+ tumours are not standard procedure in Northern Ireland. More specialist training is required to ensure high quality TNM8 aTNM8 OPSCC registrations. Significant staging differences could impact survival statistics.

Automatic extraction of Gleason combined score, primary and secondary grades from written pathology reports

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Belgian Cancer Registry

Background and Introduction

The Belgian Cancer Registry (BCR) registered 105 672 cases of prostate cancer between 2004 and 2015. One important factor in the management of prostate cancer is the Gleason score and grading. This is however not readily available in the cancer registration but can be obtained from the written pathology reports. The present work explores the possibility to automatically extract the Gleason score and grades.

Materials and Methods

An algorithm (VBA-Excel using regular expressions) was created to automatically extract the Gleason score, primary and secondary grades from text reports written in Dutch or French. In addition, the algorithm differentiates between biopsy and prostatectomy and indicates the absence of a Gleason result due to limited amount of tissue.

To validate the automatic extraction, 1000 random prostate cancer reports from 79 pathology laboratories were read and any Gleason score or grade was extracted. The output of the automatic extraction was then compared with the manual extraction and accuracy was calculated.

Results

The result on all available prostate cancer reports (2004-2015: N = 136 003) resulted in 90% of cases with extracted Gleason score or grades. A manual review was indicated for 3186 reports (2%) where the algorithm could not distinguish between a score or a single grade and for 173 cases (0.1%) where only the keyword 'Gleason' was detected. The remaining 7% (N = 9563) of the reports did not mention 'Gleason'. On the random set of 1000 manually reviewed reports, we achieved a complete automatic extraction of Gleason score, primary and secondary grades with 98% accuracy.

Conclusions

The developed algorithm is able to automatically extract the Gleason score and grades from text in pathology reports with a very high accuracy. The methodology will be applied to all reports received by the BCR and results will be used in descriptive statistics as well as in projects on quality of care.

United Kingdom and Ireland Association of Cancer Registries (UKIACR) performance indicators 2018 report

Ceri White, UKIACR Analysis Group, UKIACR Executive Committee

United Kingdom and Ireland Association of Cancer Registries

Background and Introduction

All five UK and Ireland cancer registries extract data relating to a number of performance indicators to allow comparisons of the timeliness, quality and completeness of their data. This information is collated centrally and an annual report is published. For the 2018 report, Wales and Ireland have not participated due to delays in 2016 registrations from implementation of new systems in their respective countries.

Materials and Methods

The measures are broken down by cancer type and some indicators measured are as follows:

- Stability of incidence in the current year compared to the average of the three previous years.
- Completeness of data items such as known date of diagnosis, date of birth, identification number, ethnicity and tumour behaviour code.
- Completeness of screening category for breast, bowel and cervical cancers.
- Completeness of stage at diagnosis by cancer type and morphology.
- Proportion of death certificate only (DCO) cases.
- Proportion of patients whose morphology code is non-specific, proportion of microscopically verified cases, the mortality to incidence ratios.
- Proportion of tumours that have any treatment where treatment would be expected (i.e. childhood, early stage).

Results

Comparing 2010 data with that for 2016 this comparison has documented:

- An increase in staging from 41.4% to 77.9%.
- An increase in completeness of hormone therapy for breast cancer from 29.6% to 55.0%.
- An increase in completeness of hormone therapy for prostate cancer from 31.8% to 53.0%.
- A decrease in DCO rates from 1.5% to 0.4%.

Conclusions

The quality and timeliness of data held by cancer registries in the UK and Ireland has been documented over the past few years with areas for action highlighted and data quality improved.

Theme: **Data quality, control, and standards for cancer registries**

Quality checks after automated cancer coding

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Background and Introduction

Finnish Cancer Registry made the first computer program for automated prostate cancer coding in the new cancer register database in January 2018. Our aim was to find out potential errors in the automated coding.

Materials and Methods

All new notifications in Cancer Registry database in January 2018, mainly from year 2016, were processed by using the automated coding program. It included three separate processes: identified and marked irrelevant notifications, created new pre-cancer and invasive prostate cancer cases, and updated earlier coded prostate cases.

Results

Altogether 5519 persons with one or more new notifications were handled. 3676 new pre-cancer or invasive cases were created and 1843 persons with earlier coded cases were updated. Some unexpected errors in the automated coding of time of diagnosis or in method of confirmation were found. In ten cases, the date of autopsy was used as diagnosis date, even though it was after date of death. In some pathology notifications, autopsy was recorded as histological specimen (not an autopsy), and such an error is impossible to trace. Creating a duplicate of a case was expected if a person had earlier unknown cancer (C80.9): three out of 11 cases were corrected. Errors in stage of cancer were expected. Because of conflicting TNM-value with earlier staged case, 34 cases were corrected. We also checked cases, where TNM was updated and the latency from time of diagnosis to submitting the notification was more than two years. Only few cases needed correcting. Pathology notifications, which were marked as non-cancers were checked and no errors were found.

Conclusions

Only 0.9% of all automatically coded prostate cancer cases included errors. We could identify some of those errors beforehand and some were discovered in the manual check after automated coding. Finding and correcting the cases with errors was a quick process. Co-operation between cancer coders and system specialists is required.

Theme: Data quality, control, and standards for cancer registries

Role of cancer registry workers in improving the documentation of cancer staging data

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Background and Introduction

Gathering cancer staging data is an important task in many cancer registers. Cancer staging is crucial for epidemiological analyses involving effectiveness of primary prevention programs, screening methods, and oncological treatment outcomes. In the Greater Poland Cancer Registry, the main source of information on cancer staging is the cancer notification form (CNF). Additionally, in some cases this information is also gathered by studying medical records and pathology reports. The comparison of cancer staging data on cards sent in by physicians with data verified and entered into the database by cancer registry workers helps assess the role of cancer registry staff in documenting staging data.

Materials and Methods

The proportion of entrees into the register with documented cancer staging filed in by physicians was compared between the cancer registry database for cases diagnosed in 2014 (13 407 records) and cases awaiting verification by the cancer registry team identified in 2016 (12 341 on-line NCR applications). Statistical significance was analysed using the chi-squared test with a P value of <0.05.

Results

Analysis of cancer staging data showed a significant difference between information gathered and verified by cancer registry workers and information submitted by doctors, awaiting verification. In the first group, cancer staging data was fully documented in 59.19% of entrees, while in the second group only 36.40% of entrees were accurately completed. The difference was statistically significant ($p<0.000001$).

Conclusions

This study has shown that the CNF cannot be the only source of information on cancer staging for the cancer registry, as data provided by the form is less comprehensive compared to staging data provided by the registry team. The work, knowledge and experience of the registry staff, who use various sources of information such as medical records and pathology reports, significantly improve the accuracy and level of documentation of data on cancer staging.

The lack of clinical notifications in Finnish Cancer Registry

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Cancer Society of Finland, Finnish Cancer Registry

Background and Introduction

The Finnish Cancer Registry is established in 1952. It is obligatory for health care organizations to register all diagnosed or suspected cancer cases in Finland since 1961. The regular sources of cancer information are physicians (clinical notifications), hospitals and pathological laboratories as well as Statistics Finland and Population Registry. Since 2011 the amount of clinical notifications has decreased dramatically. Over 50% of notifications considering year 2015 is missing.

Materials and Methods

We surveyed all Finnish Cancer Registry's cancer cases from 1985 to 2015 and observed how many of those had a clinical notification. The registered cancer cases and cases which were accepted for official statistics were observed separately. We also compared the hospital districts and different cancer types (ICD-10) concerning received clinical notification.

Results

The amount of clinical notifications has decreased significantly. At the year 1985 87% of registered cases (N=20140) and 96% of cases which were accepted for official statistics (N=16548) got a clinical notification (one or more). At year 2015 only 41% registered cases (N=43597) and 49% of cases which were accepted for official statistics (N=32330) had a clinical notification. The major deficiency was with diagnosis C44 (skin cancer), C43 (melanoma of the skin), C73 (cancer of thyroid), C64-68 (cancers of urinary system) and C60-63 (cancers of male genitals). With diagnoses C44 81%, C43 77%, C73 61%, C44-68 60% and C60-63 55% of clinical notifications were missing.

Conclusions

The lack of clinical notifications has an influence on counting the diagnose specific predictions and survival rate. By getting clinical notifications we'll have more accurate data about date of diagnosis and spreading of the tumour at the time of the diagnosis. Clinical notifications are needed to ensure the quality of data in our registry.

Theme: **Data quality, control, and standards for cancer registries**

DCN, DCI and DCO in the Cancer Registry of Norway

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Background and Introduction

Using death certificates (DCs) as a source of information is important to cancer registries as a means of ensuring completeness and evaluating validity. Both DCN, DCI and DCO is important. The theoretical background is given for instance in Parkin and Bray (2009) and Bray, Kohler and Ferlay (2014).

Materials and Methods

We estimated the percentage DCN, DCI and DCO in the Cancer Registry of Norway (CRN). All DCs with a cancer case as an underlying or contributing cause of death in the period 2011-2015 were included.

Results

From the total of 64308 cancer cases from DCs in the period 2011-2015, 12.6% can be regarded as DCNs and 7.4% as DCIs, whereof 3.1% was DCOs. Of the 8093 DCNs, a trace-back was performed for about 60%. The remaining 40% (n=3105, 4.8% of the total cases) was manually evaluated at the CRN to be an erroneous diagnosis at the DC. The reasons were either that the diagnosis at the DC represented a benign case or that the diagnosis was an extension of an already registered case–for instance that the DC-diagnosis was primary tumor in the lung (ICD-10: C34), but the diagnosis really represented a lung metastasis from another primary tumor (already registered at the CRN). For 87.1% of the cancer cases, information on the case already existed in the cancer registry, and for an additional 0.3% another notification was received during the wait (within 30 days after the DC was registered). In 0.4% of the cases, the information in the trace-back lead to the cancer case registered from the DC being changed to a pre-malignant case or deleted. The DCI/DCN-proportion is 58.5%.

Theme: Data quality, control, and standards for cancer registries

High Resolution Studies–an opportunity to increase data quality in the Greater Poland Cancer Registry

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Background and Introduction

Cancer epidemiology statistics in Poland focus primarily on morbidity and mortality. Although Polish registries gather information on cancer stage at diagnosis, tumour morphology and grading, there is a lack of research concentrating on statistics of this data. This may stem from low quality of collected data. Greater Poland Cancer Registry (GPCR) collects data both passively and actively. Participation in international research improves the quality and comprehensiveness of gathered data, and strengthens cooperation with clinicians. It encourages the use of new sources of data such as medical records or pathology reports.

Materials and Methods

TNM staging, tumour morphology and grading data selected for the European High Resolution (HR) study–colorectal cancer (503 cases), and recorded by the GPCR, were compared with data obtained from medical records and pathology reports.

Results

The HR-colorectal cancer study examined 503 cases. On initial analysis 236 cases (47%) did not have a defined T, 242 (48%) lacked N, 252 (50%) lacked M staging. The specific morphology code was not recorded in 42 cases (8%), and 280 cases (56%) were undefined in terms of tumour grading. After analysis, the quality and comprehensiveness of the GPCR database significantly increased *i.e.* the number of records with a defined T increased by 7%, there were 17% more records with defined N, and 23% more records with defined M. There was a 25% increase in records with defined tumour grading.

Conclusions

This study has shown that participation in international research improves the quality and comprehensiveness of a database. It encourages participants to further their knowledge on cancer registration and promotes cooperation with clinicians. Another benefit of taking part in international research is the external assessment of data quality by participating institutions. Improving data comprehensiveness opens up the possibility of conducting detailed statistical research on cancer epidemiology.

Theme: **Data quality, control, and standards for cancer registries**

The impact of breast cancer screening on cancer staging at diagnosis in the Greater Poland region

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Background and Introduction

The Early Detection Breast Cancer Program was implemented in Poland in 2005. Software used to run the program does not collect data on cancer staging at diagnosis, as required by the European guidelines for quality assurance in breast cancer screening and diagnosis. Therefore, population-based epidemiological studies on the effectiveness of breast cancer screening in Poland depend on data gathered by Cancer Registries, *i.e.* cancer staging at diagnosis and participation in screening.

Materials and Methods

Cancer staging at the time of diagnosis was compared in 9568 patients aged 50-69 participating and not participating in screening between 2005 and 2014. The 'Cochran-Armitage test for trend' was used in statistical analysis with a 0.05 significance level. Calculations were performed using PQStat v1.6.6.

Results

In the study population most patients were diagnosed with stage I breast cancer (4588; 48%), and patients with stage IV breast cancer at diagnosis were the smallest group (483; 5%). Overall 30% of women diagnosed with breast cancer participated in screening. Screening participation varied significantly ($p<0.0001$), and was correlated to disease severity at diagnosis: for stage I 59% (screening) vs. 43% (no screening), stage II 13% vs. 13%, stage III 13% vs. 17%, stage IV 1% vs. 7%.

Conclusions

The purpose of screening is reduction of mortality. The most important prognostic factor in breast cancer is staging at diagnosis. Our results indicate that women who participated in screening were diagnosed with less advanced cancer, this applies especially to stage I and stage IV patients. It is worth noting that the above-mentioned results were obtained despite the lower than recommended by the EC screening participation rate of 70% (51% for Greater Poland).

Theme: Data quality, control, and standards for cancer registries

The impact of administrative reforms on quality of cancer registration: an example of Latvian Cancer Registry

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Background and Introduction

Latvian Cancer registry (LCR) was established in 1993. Until 2006, information for the registry was provided by district oncological cabinets. In the wake of the financial crisis these cabinets were phased out. In addition, in 2006 a decision was made to combine all disease registries in Latvia. Since 2009 cancer registry data is a part of Patients Suffering from Certain Diseases, owned by the Centre for Disease Prevention and Control. The aim of this study was to determine whether administrative changes have had an impact on the quality of cancer registration.

Materials and Methods

LRC's data with 35322 cases of breast, colorectal and cervical cancer incidents for 2000-2014 were analysed. Established qualitative and semi-quantitative methods were used to assess the completeness and validity of the data from the LCR with special attention to the registration period 2006-2009.

Results

Proportion of morphologically verified cases (MV%) increased from 80.5% in 2000 to 85.4% in 2014 with no significant difference for 2006-2009. MV% for colorectal cancer was 78.2%, for breast cancer 85.0% and 91.9% for cervical cancer. Proportion of death certificates only (DCO%) cases was significantly higher for the time period 2006-2009, 6.2%. DCO% was significantly higher in this period for all examined cancer sites: 8.4% for colorectal cancer; 4.6% for breast cancer and 3.5% for cervical cancer cases. Proportion of unknown stage was significantly higher in 2006-2009: 13.8% overall; 19.7% and 12.0% for colorectal and cervical cancers, respectively. Cancer incidence over time was gradually increased for all three cancer sites, however sharp drop of incidence observed in 2008 for colorectal and cervical cancers.

Conclusions

In the time period of 2006-2009 data quality significantly suffered due to changes in the Latvian health administration. The present evaluation of the quality of data suggests that the registry has a good degree of accuracy; however, data quality varies by the cancer site.

Theme: **Data quality, control, and standards for cancer registries**

Improving registration of rare cancers: the proposal of the Joint Action on Rare Cancers (JARC)

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The RARECARE project reported that the quality of rare cancers registration could improve. The JARC included the quality of rare cancers registration among its objectives. Funnel plots were used to detect excessive variation in rare cancers incidence across countries. Based on such excess, a working group of experts identified rare cancers with registration heterogeneities hampering comparability: soft tissue sarcomas (STS), gastrointestinal stromal tumours (GIST), head and neck, neuroendocrine (NET) and central nervous system tumours. Here, we report about GIST, sarcomas and NET of the digestive tract (GEP). The malignant potential of GIST is defined based on tumour size and mitotic count, data which are not routinely collected by cancer registries (CR). CR staff find it difficult to record malignant GISTs and small GIST can be under reported. Experts do not differentiate between benign and malignant GIST. A consensus workshop involving CRs and sarcoma experts (pathologists and clinicians) will be organised to reach a consensus on GIST malignant potential and how to describe it in the pathological report. STS are usually analysed based on the ICD-O topography (C49). However, exclusion of STS arising in specific organs leads to an underestimation of about 50% of STS incidence. It is recommended to check the proportion of STS arising in specific organs before performing STS analyses and to privilege analyses based on the STS morphological codes of the RARECARE list. Regarding NET, we noticed that in some countries the number of poorly differentiated NET was higher than that of the well differentiated not functioning of the GEP suggesting a possible misclassification. In Italy, a review of 500 pathology reports performed by expert NET pathologists changed the diagnosis in 40% of cases registered as poorly differentiated NET, emphasizing the need for uniform registration guidelines. Simple rules based on grading, Ki-67 and mitotic count were proposed to differentiate well and poorly differentiated NET.

Theme: Data quality, control, and standards for cancer registries

Evolution and differences in coding basis of diagnosis among European Cancer Registries

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Background and Introduction

Basis of Diagnosis (BD) is an important variable for data quality evaluation. The objective of the study is to highlight variations in BD coding between different periods and geographical areas in Europe.

Materials and Methods

8 812 587 cases provided by 34 registries (CR) – 4 operating in Northern Europe (NE), 15 in Western Europe (WE), 3 in Eastern Europe (EE) and 12 from Southern Europe (SE) – which are contributing to the European Cancer Information System (ECIS) were analysed. The proportion of cases for each category of BD (except DCO) was calculated for periods 1994-2003 and 2004-2013 for liver, pancreas, lung and colorectal cancer. Proportions were age standardized according to the International Cancer Survival Standard.

Results

Histology of primary tumour (HPT) was the BD in 34% of liver cancers in EE and 74% in NE in 1994-2003, and 55% and 68% respectively in 2004-2013. HPT decreased from 44% to 38% in SE and from 60% to 52% in WE. Clinical investigation (CI) increased from 37% to 44% in SE and from 21% to 29% in WE. HTP was stable for pancreas in NE (47% and 51% in the two periods), SE (41% and 43%), WE (42% and 38%), and increased in EE (34% and 52%). For lung, HPT or histology on metastasis (HMT) was higher in NE (73% in 1994-2003, 85% in 2004-2013) than in SE (62% and 68%) and EE (60% and 62%) while it was 78% and 74% in WE. Cytology (CL) was higher in SE (20% and 17%) and WE (15% and 18%) than in NE (12% and 6%) and EE (11% in 1994-2003, 7% in 2004-2013). HPT was more than 90% in all countries for colon-rectum in 2004-2013.

Conclusions

Differences in BD distribution were observed in the selected cancer sites, except for colon-rectum. The observed CI increase in liver could be due to the improvement of imaging technology, lowering the proportion of cases with HPT diagnosis. Low HPT in pancreas could be due to the difficulty to perform biopsies. Different proportion of HPT and CL for cancer sites such as lung could derive from different diagnostic approaches.

Theme: **Data quality, control, and standards for cancer registries**

Digital Archiving for improving data quality management in Cancer Registries

Begoña Sanchez-Royo, David P. Anderson, Jaime Kaminski, Janet Anderson

E-ARK4ALL

Background and Introduction

Re-using research data generated by Horizon 2020 plays a critical role in building a strong future for European Science. The Digital Service Infrastructures (DSIs) known as building blocks provide basic and re-usable digital services. Building blocks can be integrated into other DSI and ICT projects and can be combined with each other. 'E-ARK for all' 2018 is the new eArchiving Building Block DSI in the Connecting Europe Facility (CEF), under the direction of DG CNECT and in collaboration with DIGIT. E-ARK for all is developing associations and synergies between the eArchiving and the other Building Blocks and ICT projects in eHealth. These include electronic health registries and databases such as the European Cancer Information System (ECIS). Cancer is the second largest cause of death in Europe. Population-based cancer registries are the most important source of data in this arena, and the potential benefits entailed in the development of the ECIS are tremendous. eArchiving activities are integral in the Database Management of ECIS, each dataset flowing into the ECIS needs to be preserved over the long-term according to a coherent structure for digital archiving. This reduces costs in the operational database and risks of degradation of the quality of the data.

Materials and Methods

The question addressed here is how do we preserve cross-border access in large-scale cancer-related dataset? Using qualitative research methods the following results were obtained.

Results

E-ARK for all not only offers practical tools for digital archiving workflows but it also offers a CHOICE of tools. The study shows some benefits of the E-ARK for all CEF eArchiving framework for ECIS in terms of standards for quality in metadata (OASIS, METS and PREMIS); file extension (EAD, MARC and Dublin Core expressed in XML syntax) and storage (open Source software: RODA-in and RODA).

Conclusions

The study provides guidance on how to develop synergies for long-term preservation that creates value for ECIS.

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