



# 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

	<b>Tue</b> 25 Sep	<b>Wed</b> 26 Sep	<b>Thu</b> 27 Sep	<b>Fri</b> 28 Sep
09:00			Keynote Lecture	Keynote Lecture
09:30	ENCR-JRC Training on Data Coding	ENCR Workshop on Data Protection	Registration	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
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
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	
17:30		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	
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 GUGLIEMMETTI  
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 NEAMȚIU  
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),<sup>1</sup> Association of Nordic Cancer Registries (ANCR),<sup>2</sup> International Association of Cancer Registries (IACR)<sup>3</sup> and Latin Language Registry Group

(GRELL).<sup>4</sup> 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>.

8 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

## The ENCR Steering Committee

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<sup>nd</sup> and 3<sup>rd</sup> 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. Eureka, 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 take-over, 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:

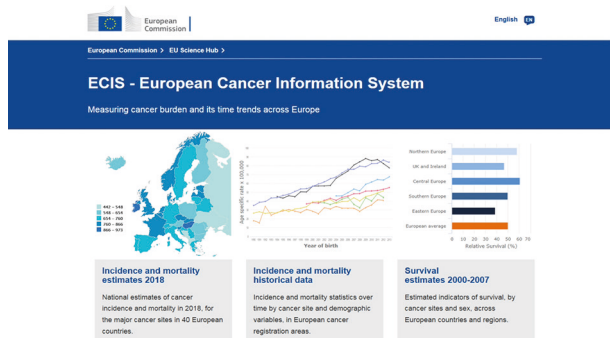
- Harmonisation of data quality—resulting in a JRC technical report in 2014 that was used as the basis for the 2015 ENCR data call; this work is seen as a continuing task to improve the quality

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, 10<sup>th</sup> 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 EURO-CARE-5. EURO-CARE (EUROpean CANCER REgistry-based study on survival and care of cancer patients) is the widest collaborative research project on cancer survival in Europe. EURO-CARE-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.

- 66<sup>th</sup> SC Meeting, March 2018.
- 65<sup>th</sup> SC Meeting, December 2017.
- 64<sup>th</sup> SC Meeting, October 2017.
- 63<sup>rd</sup> SC Meeting, May 2017.
- 62<sup>nd</sup> 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

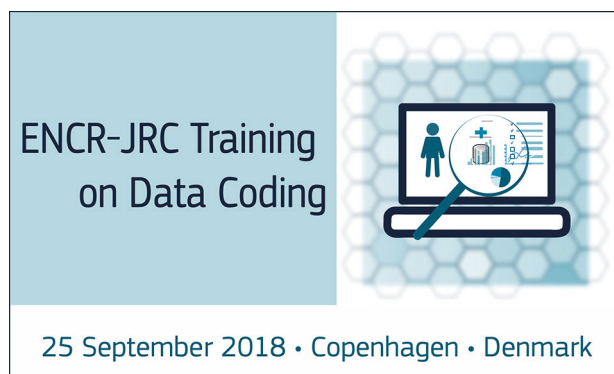
A new version of the cancer factsheet will be soon available in the European Cancer Information System (ECIS) web-application, updated with the latest available data provided by European cancer registries for the ENCR-JRC project on cancer incidence and mortality in Europe.

## 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**

	<b>TUESDAY</b>	<b>25 September 2018</b>
09:30-11:00	ENCR-JRC Training on Data Coding	
11:00-11:30	<i>Tea-Coffee break</i>	
11:30-13:00	ENCR-JRC Training on Data Coding	
13:00-14:00	<i>Buffet lunch</i>	
14:00-16:00	ENCR-JRC Training on Data Coding	
16:00-16:30	<i>Tea-Coffee break</i>	
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	<i>Tea-Coffee break</i>	
11:30-13:00	ENCR Workshop on Data Protection	
13:00-14:00	<i>Buffet lunch &amp; poster set-up</i>	
14:00-14:30	<b>Opening Session</b> (JRC, Danish Cancer Society, ENCR)	
14:30-16:00	<b>Scientific Session 1</b> 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	<i>Tea-Coffee break &amp; poster viewing</i>	
16:30-17:00	<b>Keynote Lecture</b> Les Mery (International Agency for Research on Cancer)	
17:00-18:30	<b>Scientific Session 2</b> 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	<i>Welcome reception</i>	

**Thu****Detailed meeting programme****27 Sep**

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

# Detailed meeting programme

Thu

27 Sep

	THURSDAY	27 September 2018
14:00-16:00	<b>ENCR General Assembly</b>	
	Welcome and report on ENCR-JRC activities 2017-2018	<b>ENCR Steering Committee and JRC</b>
	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	<i>Tea-Coffee break &amp; poster viewing</i>	
16:30-17:00	<b>Keynote Lecture</b> Henrik Møller (Danish Clinical Registries)	
17:00-18:30	<b>Scientific Session 5</b> 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	<b>Gabrielle Emanuel</b>
	Use of cancer registry data to estimate the cancer risk of recipients of liver transplants	<b>Diego Serraino</b>
	Comparison of the Danish Cancer Register and the Danish Renal Cancer Database	<b>Bolette Danckert</b>
	Emergency admissions for cancer patients in last year of life in Northern Ireland (NI)	<b>Victoria Cairnduff</b>
	Metadata in the Cancer Registry of Norway –performing FAIR with ELVIS	<b>Siri Larønningen</b>
	Regional differences and trends in mastectomy rates in relation to socioeconomic disparities and screening patterns	<b>Christian Herrmann</b>
19:00	<i>Harbour cruise</i>	

Fri

# Detailed meeting programme

28 Sep

	FRIDAY	28 September 2018
09:00-09:30	<b>Keynote Lecture</b> Anne Tjønneland (Danish Cancer Society Research Center)	
09:30-11:00	<b>Scientific Session 6 (a) Biobanks and cancer registries</b>	
	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 Pitkaniemi
	PALGA Portal, the Dutch National Cancer Tissue Portal; a nationwide app for requesting tumor pathology data and tissues	Annette Bruggink
	<b>Scientific Session 6 (b) Data quality, control, and standards for cancer registries – Part 1</b>	
	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	<i>Tea-Coffee break &amp; poster viewing</i>	
11:30-13:00	<b>Scientific Session 7 Data quality, control, and standards for cancer registries – Part 2</b>	
	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 quality 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	<i>Buffet lunch &amp; poster pick-up</i>	





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](http://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.