ECC Vienna 2015

The European Cancer Congress was the podium for researchers of EURECCA network to present the various new projects and the progress made in the fields of breast cancer, oesophageal-gastric cancer and colorectal cancer. The first results of the international comparison of older patients with non-metastatic breast cancer were presented on Sunday morning by Marloes Derks. The dataset coming from Belgium, Netherlands, Portugal, Poland, England and Ireland of about 120,000 patients, revealed huge differences in treatment and relative survival. In the coming period Sweden and England will add more patients to this set and the definitive results will be analysed. In short, some countries prescribe more adjuvant endocrine and chemotherapy without improvement in survival data.

During the Special EURECCA session on Saturday, we were very pleased with the update of the Oesophageal-gastric group by Professor William Allum, followed by the International Watch & Wait Database by Dr Nuno Figueiredo and Update of Breast cancer in Europe by Esther Bastiaannet. Esther also presented data of the EURECCA International comparison of treatment and survival for the oldest elderly (80+) with stage III colon cancer.

INSPIRE

INTERNATIONAL NIPPLE SPARING MASTECTOMY REGISTRY

The newest project of EURECCA – is INSPIRE. Patients undergoing nipple sparing mastectomy and immediate reconstruction for breast cancer/DCIS and/or risk reduction will be asked to join this prospective observational database. A patient centered and Modified radical mastectomy and simple mastectomy routinely remove the NAC mostly due to a concern of its possible involvement by malignant cells and the hypothetical increased risk of developing local recurrences with consequent poor cosmetic results. In the last decade, several studies have shown that NAC involvement is not as high as it was thought from historical evidence and more knowledge about the NAC anatomy and the terminal ductal lobular unit in the nipple has spread its practice. Nipple sparing techniques with immediate breast reconstruction may increase the patient’s satisfaction and improve the body image; this may result into psychological benefits for the patients facilitating the recovery process of the breast cancer diagnosis.

EURECCA Breast group is honoured to work with the principal investigators Professor Isabel Rubio, Spain, and Professor Riccardo Audisio, UK. At this moment, the web-based database is being designed for the first version at the end of October 2015. After a period of extensive testing, we will go live!
IWWD

"Paradigm shift a head in rectal cancer treatment is being published the end of 2015 in the European Journal of Surgical Oncology."

The first international prospective database of rectal cancer patients with clinical response to induction therapies in the watch and wait strategy is after 5 months of opening successful. In April the pilot centers from Portugal, Brazil and The Netherlands tested the database extensively, and at present 322 patients are entered in the certified web-based database system ProMiSe of the LUMC. Moreover, more than 18 institutes practicing watchful waiting are registered as participating hospitals. www.iwwd.org

The executive committee; Angelita Habr-Gama, Geerard Beets, Nuno Figueiredo, Rodrigo Perez and Cornelis van de Velde, express their gratitude to all centers with interest to mutually study the pros and cons of this very select patients. It is obviously, crucial to follow these patients prospectively, and impossible to randomise between surgery or watch & wait. We need to find out whether this strategy is a truly equivalent treatment option avoiding rectal resection without increasing oncological outcomes beyond reasonable borders.

EURECCA- ITALY: a multidisciplinary data collection project

Born to reduce the differences among European countries, the international, multidisciplinary, outcome-based quality improvement EURECCA program has been translated into the Italian scenario with the primary goal to create a standardized data collection model in order to obtain a national-based database to support practice survey and to develop and validate multi-factorial prediction models for different treatment outcomes. The three main Italian oncology associations (surgery (SICO), medical oncology (AIOM) and radiation oncology (AIRO) ) endorsed the project. A first prototype of a large heterogeneous database of multi-departmental and/or multi-institutional data is under implementation between five centers. This Standardized Data Collection (SDC) process took advantage of a published ontology, a classification system where each variable related to the domain of interest can be represented using uniform and unambiguous definitions.

The main SDC aims, the procedures and the possible occurring ethical issues are described in an Umbrella protocol and managed by software called "Spider BOA" (System for Patient Individual Data Entry and Recording Beyond Ontology Awareness).

Educational platform – e-CRC

The e-learning project of EURECCA has been delayed due to unsuccessful fundraising so far. Because this project would reach patients and health care professionals globally, we do believe it is vital to keep searching for budget. The exposure of a free accessible website with 'state of the art' modules with standards of cancer care written by dedicated key opinion leaders and patients for patients would reach many! EUROPACOLON would provide patient summaries of treatment recommendations and explanations to aid in shared decision making.

The structure and design of the educational platform and contents for colorectal as for Oesophageal-Gastric cancer are ready to be built as we are lacking the finances to go ahead. Any suggestions to get this great initiative funded are very welcome! Please, contact PG Boelens.
Octogenarians can be fit or frail, with or without comorbidities, and with or without polypharmacy, in summary a very heterogeneous group of patients and therefore at risk of undertreatment or overtreatment. Esther Bastiaannet presented the analysis of the international comparison of treatment and relative survival of this age group at the ECC 2015 in Vienna. Evidence from randomised controlled trials concerning treatment of colon cancer stage III in patients aged 80 years or older is scarce. Adjuvant chemotherapy in stage III colon cancer, showed to be advantageous in 24 trials with 33,574 patients, however, only 0.8% of these patients randomised were 80 years or older. Given the peak incidence of colon cancer is at 75 years, we need to unravel best practices in this vulnerable group. For this purpose, data was collected from Denmark, Sweden, Belgium, Netherlands, and Germany. Treatment strategies, relative survival and cancer specific survival were analysed using the instrumental variable method, in which country was used as variable that mimics treatment allocation. The proportion adjuvant chemotherapy in stage III colon cancer in patients older than 80 was 23% in Belgium and least in Sweden with 0.9% and The Netherlands 1.2%. Treatment strategy with a higher proportion of chemotherapy (equal proportion surgery) may not be associated with relative survival or cancer specific survival in older patients having stage III colon cancer. The full manuscript and definitive results are expected soon. We thank all countries for participating!

It remains a political difficulty to get countries to share their data on patient characteristics, treatment and outcome. Again the upcoming publication of Mathieu Messager and Wobbe de Steur is a great example of feasibility of international collaboration. Summarizing their results; Adenocarcinoma is the most common cancer in all countries. Earlier stages are found in France and Ireland. Neoadjuvant chemoradiation is preferred in the Netherlands and Ireland for Oesophageal cancer while neoadjuvant chemotherapy is for the UK. Postoperative mortality is ranging between 1 and 7% between the five countries. The manuscript is accepted in the European Journal of Surgical Oncology. It seems that national produced randomised trials impact on national guidelines and patterns of care as detected from this paper. Longterm follow up would be able to detect treatment to outcome tools. Another project studies the international variance in clinical pathways of oesophageal and gastric cancer, showing lots of variation in approaches to staging, centralisation in oesophageal cancer care, consistent approaches in pathology among the countries, differences in composition of the Multidisciplinary boards (MDTs). Moreover, audit and registry is differently handled. Many hypothesis to study have been discussed and more activities are anticipated by the active group of William Allum. 

“Multidisciplinarity is key to improve cancer care, standardized audit and registry will reflect on performance and outcome.”
About PROMISE

ProMISe (Project Manager Internet Server) is a web-based relational database management system for the design, maintenance and use of (clinical) data management. This ProMISe system provides in custom made databases for scientific medical research as well as an application for online data entry, quality checks and reporting. It also provides a tool for data retrieval to facilitate statistical analysis. ProMISe can be applied for single- as well as for multi-center studies. ProMISe is developed within the Leiden University Medical Center (LUMC) by Ronald Brand, professor of Good Research Datamanagement. Ronald Brand is head of the Section Advanced Data Management (ADM), which is responsible for the development and maintenance of new ProMISe-projects. New ProMISe-databases are developed in consultation with the researcher(s) concerned, keeping in mind the scientific goal of the new database. ADM works in close collaboration with the statistical staff of the department of Biostatistics & BioInformatics of which it is an integral part.

EURECCA & ProMISe

The two prospective databases of EURECCA IWWD and INSPIRE are designed in ProMISe. Moreover, the RAPIDO, SCRIPT, TEAM and many other multinational studies harbour their data in the ProMISe system. ADM is NEN7510 certified and ProMISe meets the requirements for data-safety and privacy set by international law. Due to this certification the ProMISe system facilitates the availability, integrity and confidentiality of your data. ProMISe facilitates you to store, exchange and retrieve data according to the security conditions demanded by GCP.

For more information please visit the website https://www.msbi.nl/promise/

EURECCA Breast update

The EURECCA Breast group was started in 2012, with the chair Riccardo Audisio.
As a first initiative, EUSOMA and EURECCA, collaborated in unravelling the adherence to quality indicators (QIs) of 27 EUSOMA certified breast units. In this dataset of over 40,000 patients patterns of care were analysed. Mandy Kiderlen, first author on this publication in the European Journal of Cancer 2015 found the highest compliance to adhere to QI’s in patient group aged 55-64 years. Lowest compliance in the oldest patient group. Moreover, lots of variation in compliance to EUSOMA Qis is found and lower than predefined minimum standards for the youngest and oldest group. Mandy Kiderlen published an international comparison between Ireland and the Netherlands in PLosOne this year. In a dataset of approximately 47,000 patients treatment and survival were compared for patients above 65 years.
The International comparison of Marloes was introduced and the latest project INSPIRE. Please, see the corresponding updates of these projects.
EURECCA Pancreatic cancer

The EURECCA-pancreas group has been informed about the manuscript describing the minimum common data set that should be feasible. Of the 36 pancreas registries or audits 16 has responded, and 11 has participated in the definition of the common data set. Eleven complete lists of items were received from the collaborators; Austria, Belgium, Bulgaria, Denmark, Germany, The Netherlands, Slovenia, Spain, Sweden, Ukraine and the United Kingdom. The number of data items in the datasets varied between 16 and 285. A total of 25 items was marked present in seven out of eleven datasets. The next phase will include a call to share data from 2012-2013, to study treatment patterns among the European countries as was agreed upon in the call of agreement. Capturing clinical relevant international benchmarks is not challenged before in pancreatic cancer and would provide tools for feedback and improvement of health care infrastructures. Combining forces to obtain robust population-based data will generate the reflection of real life of pancreatic cancer care, more than results from clinical trials or from expert centers only. International comparisons are the superlative measure to effectively benefit patients with pancreatic cancer. Please, keep in the loop about the next call coming up to participate in EURECCA Pancreatic cancer.

EURECCA publications 2013-2015

van den Broek CB, Boelens PG, Breugom AJ, van de Velde CJ. Improving the Outcome of Colorectal Cancer: The EURECCA-Project. Colorectal Cancer (2013) 2(4), 1-6


EURECCA (acronym for EUropean REgistry of Cancer CAre or EUropEan CanCer Audit), started in 2007 as an ECCO/ESSO initiative. EURECCA is an international multidisciplinary platform of clinicians and epidemiologists aiming to improve the quality of cancer care by data registration, feedback, forming plans for improvement and sharing knowledge of performance and science. EURECCA is registered as a foundation, based in Leiden. Relevant background: Still considerable variation exists in Europe in cancer management and outcome. Moreover, there is an urgent need for transparent uniform international data collection and analysis, in order to monitor and learn from all aspects of cancer care and to provide feedback and education. Uniform datasets are necessary, and not existent yet.

Support EURECCA

We are a non-profit foundation, with active network of dedicated health care professionals, epidemiologists and patients. Most of our work is done for free. One of our weaknesses is that we could do so much more if we would be able to increase our financial support. Any form of support that could help built our financial structure to a more sustainable structure is very welcome. Endorsement of multidisciplinarity and international collaboration are key to detect patient-treatment to outcome patterns to improve cancer care. Prospective auditing and registry is costly and some human resources to keep the network running is very much needed. Please, consider supporting us in more ways.

Mission of EURECCA

The mission of EURECCA is achieving and assuring high quality of multidisciplinary cancer management in Europe, accessible to all patients through the development and support of an international quality assurance structure, which is an audit structure, using anonymous patient data and compliant with national and international laws. Feedback and education are key. Moreover collaboration and prospective standardized data collection are vital.

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