

2nd European Roundtable Meeting

8th May 2015
Berlin, Germany

'Improving structural development in oncology – transformation of theoretical health care standards and knowledge into a practical approach'



After the success of the first European Roundtable Meeting which took place in Berlin, Germany on 16th May 2014, the German Cancer Society and the Union for International Cancer Control (UICC) organised a second edition, delving further into discussions surrounding the improvement of the Quality of Cancer Care, under the title *"Improving structural development in oncology – transformation of theoretical health care standards and knowledge into a practical approach"*.

The meeting targeted experts concerned with improving the quality of cancer care in the various national health systems of the European Member States.

During the first European Roundtable Meeting (ERTM), participants discussed the benefits of institutional structures that are necessary for the improvement of cancer care. They concluded that the development of National Cancer Control Plans (NCCPs) including quality control by cancer registries is fundamental. Although they may vary from one country to another, NCCPs do exist in many European states. Nonetheless, implementing cancer control plans is considered the most crucial and the most complex process. It has to include an organisational network that provides pathways from diagnosis to treatment rehabilitation and palliative care. Depending on the structure of national healthcare systems, these networks may differ. However, a common issue is the establishment of a multidisciplinary and multiprofessional cooperation.

Which processes can be implemented to provide and ensure opportunities for multi-disciplinary and multiple stakeholder engagement in optimising cancer care and service, responding to patient needs at a population level and at an individual level?

In the long term, it is ensuring robust patient pathways while applying the rules and principles of economics and health systems management.

By organising this second ERTM, the German Cancer Society and UICC wished to encourage the exchange of information on these topics, the sharing of best practices, and learn more about beneficial institutional health structures in Europe.

The Roundtable consisted of a first part, during which representatives from Germany, the Netherlands, Slovenia, Spain and Sweden presented some of the challenges and successes faced by each of their own countries in establishing effective structures and organisational networks to provide quality cancer care. Following the presentations, participants were invited to join one of the three working groups in order to foster discussions and reflections on the three following questions:

1. Which communications strategies are needed between clinical cancer registries and cancer centers in order to improve the quality of care?
2. Which procedures and communications networks are essential in cancer centers to guarantee an optimal interdisciplinary multiprofessional patient care?
3. What is necessary to include the patient's perspective into the structural development of cancer care networks?



KEY PRESENTATIONS OUTCOMES

The key presentations offered different aspects of cancer control, spanning from cancer registry perspectives, to entire cancer control systems. These presentations highlighted that very unique paths were developed by each country, which lead to a variety of structures to implement cancer control systems.

- The political system of a country has a big impact on the ideal structure of the health systems, and coordination between the different levels of government can prove to be challenging. For instance, if decisions are taken at a federal level without proper consideration of budgetary, structural and other general regional circumstances, this can prove unrealistic and/or problematic for implementation.
- These structural issues can, in some cases, have severe impacts on the timely introduction of new essential medicines.
- It was made apparent that cancer registry data collection needs to focus on the essential data. In many cases, the scope of the data collection is too large, which results in inconsistent and incomplete data. Instead, data collection should strive to improve the collection of a targeted and essential subset of data. Moreover, cancer registry data analysis needs to be done more quickly and communicated more efficiently so that processes can be adapted to data results.

Despite the variety in approaches, there are of course common conclusions as to the absolute necessary components of quality cancer control systems. Among them are:

Evidence based clinical guidelines, effective ways to coordinate multidisciplinary care and the implementation of clinical cancer registries (and if possible, population based registries) as indicators of quality of cancer care.

WORKGROUP OUTCOMES

Conclusions of the three groups regarding the three questions they were asked to answer:

1.) Which communications strategies are needed between clinical cancer registries and cancer centers in order to improve the quality of care?

- Clinical cancer registry must be one of the key components of a cancer centre
- National guideline groups should be involved, in order to help determine quality indicators
- Guidelines groups should give advice about the type of data which needs to be collected
- Additionally, a consensus agreement on the criteria of evidence is important, above all when approaching personalised cancer medicine
- Certification of oncology centers should depend on specific outcome data as documented in the registry
- Clinical guidelines should be built on evidence and the clinical cancer registries should collect information on interventions and outcomes according to the clinical guidelines
- Evidence regarding treatment and diagnostic methods should be the outcome of research which takes place in cancer centers
- Evidence should be built on clinical effectiveness and not only clinical efficacy
- There should be close documentary feedback and exchange of patient care results



"The European Roundtable Meetings are ideal opportunities to share information from different oncologic fields and business experience from decades, discuss the challenges and opportunities faced in cancer control and develop strategic solutions. It is our hope that through this network of experts, we will find new and innovative ways to improve the quality of cancer care in a meaningful manner."

Dr Ulrike Helbig,
General Manager of the Section A,
International Coordination, German Cancer Society
Germany

"Setting up an effective network of cancer registries should be done step-by-step, through multi-regional projects of dedicated registries, while remaining open for others to join. Developing success stories early on is an essential factor in consolidating the process."

Professor Jan-Willem Coebergh,
Department of Public Health,
Erasmus MC Rotterdam
The Netherlands



"Preventive, health care and research strategies are not able to balance an increase in cancer incidence. We therefore need new strategies for the prevention and early detection of cancer."

Professor Ulrik Ringborg,
Chairperson of the EUROCAN Platform, Director Cancer
Center Karolinska
Sweden



"With longer-life expectancy and the retirement age constantly being pushed further and further, there is consequently an increase of cancer incidences in the active population. This is why it is essential that we focus on prevention and treatment of highly treatable cancer types."

Professor Tit Albreht,
Head of the Centre for Health Care - National Institute of Public Health, Ljubljana
Slovenia



"The myth of quality assurance cannot be the justification for an exorbitant bureaucracy into the quality measuring, without convincing evidence of the effectiveness."

Professor Dieter Hölzel,
former Director, Tumor Registry Munich,
Germany

"The future of clinical cancer care involves the creation and cultivation of communication platforms where multidisciplinary representatives can discuss the best treatment possible for the patients."

Professor Olaf Ortmann,
Speaker of the Section B,
German Cancer Society
Germany

- Establish mandatory and regular presentation of outcomes data:
 - Regularly update population-based outcome data and its variability and make it accessible via internet and
 - Multidisciplinary teams should provide feedback on the regional results and the quality of the centers and be part of the regular update
- Publication should be distributed to the network of centers and to the centers' associated health care groups (e.g. via internet)
- Encourage openness to work not only with cancer centers associated networks
- Personal contact and exchange is crucial for the better understanding of processes and therefore for increasing the quality of care
- Outcome data should be in line with the corresponding national guidelines
- Establish cancer registries/"service centers" for clinical centers and academic research
- A cancer centre should have an outcomes research unit working with the multidisciplinary/multiprofessional clinical teams
- Implement communication platforms where the discussion of results is possible with multidisciplinary partners and where changes and improvements can be directly introduced to the delivery of the healthcare
- Implementation of central platforms for information collection (research, registries, etc.) as "awareness platforms" (multidisciplinary access)
- Establish early warning system in case of detrimental outcomes of patient care results

2.) Which procedures and communications networks are essential in cancer centers to guarantee an optimal interdisciplinary multiprofessional patient care?

- It is a leadership mission to establish the multidisciplinary/multiprofessional teams in a cancer centre as a part of a comprehensive strategy (integration of prevention, cancer care, research and education)
- The development of a precise description of patient pathways should be a requirement in cancer certification schemes
- There should be a distribution of processes outlines to the different network associates
- Each centre should have updated clinical guidelines and a system for quality assurance of the clinical activities
- Specification of processes and communication should be integrated in guidelines
- There should be a decision that each cancer patient will meet the multidisciplinary team and be discussed at a formal tumour board
- The documentation of processes, treatment courses, examination of results and communication with the patient and between colleagues (informal as well as tumour boards) should be integrated in an easily manageable IT system, which could be accessibly by the multidisciplinary team
- Multidisciplinary teams should take care of the follow-up in patient care
- It is essential to include the patients' perspective, i.e. patients' advocates
- Include trained patients' representatives in the audit teams that perform on-site visits for cancer certification schemes

- Foster opportunities for direct exchange between network associates
- Comparative effectiveness research (“Benchmarking”) should be part of the outcome evaluation of a region
- Foster interdisciplinary research with high recruiting rates and sound timelines
- Allocation of money must support the multidisciplinary



3.) What is necessary to include the patient’s perspective into the structural development of cancer care networks?

- Involve patients in the development of guidelines
- Interpretation of the guidelines should be harmonised between the different disciplines involved
- Collaboration should involve all health providers (e.g. nurses, pharmacists, social workers, psycho-oncologists, dieticians etc.) not only clinicians, and also must include patients
- Receptiveness to patients/survivors needs
- Involve panels of patients/survivors
- Implement patients preferences into multidisciplinary decision-making (e.g. in tumour boards)
- Collection of patients’ feedback on quality of care as a routine quality management indicator
- Documentation and evaluation of patients’ preferences
- Survivorship based research/quality of life research



NEXT STEPS

- A Policy Paper will be drafted by the European Network and disseminated in the coming weeks through the European Journal of Cancer (EJC).
- The discussion will be expanded to a wider network: new organisations will be contacted to give their input and add some key discussion focus points.
- New communication channels will be used by the European Network to communicate on the next steps such as the Stakeholders forum and the Members State Platform.
- Emphasis will be made on advocating for a bottom-up approach.
- The group will set up a third meeting in 2016 to prepare the official launch of the European Network at the UICC World Cancer Congress in Paris in October 2016. This meeting will have a more action-oriented approach with specific projects to be implemented and will potentially focus on best practice.

LIST OF PARTICIPANTS

GROUP 1

- **Dr Sylvia Deandrea**, European Commission Joint Research Centre, Institute for Health and Consumer Protection - Ispra, European Union
- **Dr Markus Follmann**, Head of the Division of Guidelines/EbM, German Cancer Society; German Guideline Program in Oncology (GGPO), Germany
- **Dr Katrin Mugele**, Organisational Communication Specialist, German Cancer Society, Germany
- **Prof. Ulrik Ringborg**, Director Cancer Center Karolinska, Sweden
- **Dr Wendy Yared**, CEO European Cancer League, Brussels, European Union
- **Prof. Olaf Ortmann**, Speaker of the Section B, German Cancer Society, Germany (Rapporteur)

GROUP 2

- **Prof. Tit Albreht**, Head of the Center for Health Care, National Institute of Public Health, Slovenia
- **Dr Johannes Bruns**, Secretary-General, German Cancer Society, Germany
- **Prof. Dieter Hölzel**, former Director Tumor Registry Munich, Germany
- **Isabelle Ladiges**, Policy Officer, European Commission, Directorate-General for Health and Consumers Unit C1 - Programme Management and Diseases, Luxemburg
- **Charles Revkin**, Communications and Marketing Specialist, Union for International Cancer Control (UICC), Switzerland (Rapporteur)

GROUP 3

- **Prof. Jorge Borrás**, Scientific Coordinator Spanish Cancer Strategy / EPAAC, Director Hospital Duran i Reynals, Spain
- **Prof. Jan-Willem Coebergh**, Department of Public Health, Erasmus MC Rotterdam, The Netherlands
- **Prof. Florian Lordick**, Board Member, German Cancer Society, Director University Cancer Center Leipzig, Germany
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