4th European Round Table Meeting (ERTM)

On the 5th of May 2017, participants from European organisations met in Berlin for the fourth in the series of European Roundtable Meetings with a focus of discussion on 'Quality control and improvement of cancer care – what is needed'

In 2014, the German Cancer Society (DKG) and the Union for International Cancer Control (UICC) initiated the European Roundtable Meetings to stimulate more exchange between European cancer organizations and sharing of best practice on key topics relevant to national cancer control planning. Previous meetings have identified the National Cancer Control Plan as a fundamental tool for improved coordination and synergies between key national activities.

Specifically, in this round table, participants were encouraged to share learnings from their own national setting and formulate best practice in optimising communication strategies between parties involved in clinical cancer registries, cancer centres and guideline groups – crucial instruments to both describe and improve quality of cancer care.

Following a set of introductory presentations of frameworks and opportunities at the European level, focus moved to two initiatives at national level linking research and registration and clinical guidelines and registration from Sweden in Germany, before exploring the capacity building challenges at a global level.

Presentations and speakers

- European Union Policy on Cancer – old and new approaches
  Stefan Schreck, European Commission
- How does Europe cope with the processes of Data registration in cancer care and can the EC support?
  Prof. S. Karjalainen, President of European Cancer League
- The role of the Joint Research Centre in developing a European Cancer Information System
  Manola Bettio EU Cancer Information group
- The organization of cancer registry and research in Sweden
  Prof. U. Ringborg, Sweden
- Cooperative network s between cancer centres, clinical cancer registries and Guideline Groups: chances and obstacles
  PD Dr. M. Klinkhammer-Schalk/Prof. Dr. O. Ortmann, Germany
- The Global Initiative of Cancer Registration in developing countries
  Freddie Bray PhD, IARC

Key learnings from presentations and discussions

Stefan Schreck highlighted that the European Union (EU) Policy on cancer was the oldest public health policy in the EU. Despite 30 years' experience he noted that while communication in networks is largely accepted practice, there are deficits in making this work on a day to day level. The European Commission (EC) aims to provide coordination regionally where it is considered a value-add i.e. addressing common problems and sharing best practice on a policy level such as the drive for health in all policies and collaborative research, with the example of the rare diseases initiative where the EC value add is highly appreciated.

> *"Unfortunately, health is not always a policy priority, we in the EU are moving from diplomacy to true collaboration for impact in cancer control."*

Schreck explained that there is change in EC-stance aimed at bridging the implementation gap across the region, looking at cost-efficiencies and financial stability of cancer programmes for sustainability, citing the range in percentage of women in the target population accessing cervical cancer screening as an example of the divide ranging from 25% - 86% across the EU.

New features are the European Research Networks working cross border with 300 hospitals and 900 health units and the European Guide on Quality Improvement in Comprehensive – marking a move away from making new guidelines and towards making current one work in practice, which is aimed at focus for impact on patient outcomes.

Sakari Karjalainen outlined the different and complimentary roles of population-based cancer registries and hospital-based or quality registries, which are both needed for monitoring and evaluation of cancer control plans, ideally in combination with biobanks to support research. Collaboration and harnessing of data at EU has significant potential, also at driving the quality indicators in all countries of: comparability, completeness, validity and timeliness. IT helps address countries these challenges and the EU coordination can be helpful for example in establishing standard template such as structured patient records, e-records and synoptic reporting but also brings challenges as the recent debates on data-sharing across borders exemplifies.

> *"Sharing data is a major challenge, Finland does not require consent for incidence data-sets which supports practical sharing, but transferring data outside of Finland is problematic."*

Karjalainen highlighted how the strengths of some countries can provide policy and programmatic insights for the region for example, the recent costing analysis of cancer services in Finland; Sweden leading the way in development of a national quality registry and the disease registries of selected cancers in Norway.

Manola Bettio shared latest EU statistics, detailing that 1 in 4 deaths (1.3 million people annually) in the EU is due to cancer, which is now the leading cause of death in 12 of the 27 EU countries, surpassing cardiovascular disease, with a healthcare cost of €50 Billion or 5.7% of the total health care cost.

Bettio explained that we have a commitment to reduce the burden of cancer in Europe and importantly, clear recognition that for us to be successful we need accurate and comparable cancer data on incidence; prevalence; survival and mortality. 20 national cancer registries and 111 regional registries collate data from a well-defined geographical region, this generates a dataset which represents 80% of the EU population. The EU is striving towards an integrated and comprehensive approach, overcoming drawbacks to progress such as scattered funding, temporary projects, competition and poor coordination. Investments which are now benefiting monitoring and communicating cancer burden: planning and benchmarking public health interventions; identifying good practices; evaluating strategic decisions (policy impact) and shaping research.

> *"At €0.27 per capita, cancer registration is low cost and the community is starting to see the benefits of the regional led, integrated cancer information system of the joint research centre of the European Commission with close proximity to policy makers and Independent of all national/ private/commercial interests."*

Ulrik Ringborg shared the information that Sweden has had a national cancer registry since 1959 and that since 1974, regional registries have augmented the data set. Rinborg explained that the positive attributes of the Swedish system are that the regional coordinated oncology centres work with regional clinical guidelines and these cancer registries. In addition, he noted the advantages of common approaches of no private profit cancer care, multidisciplinary treatment, early detection programmes which are all contributing to the positive outcomes in terms of survival and mortality which stand up to international comparison.

Ringborg went on to note missing elements in the Swedish system, for example, treatment of recurrent disease is not included in clinical registries; missing data on quality of life, psychosocial oncology, rehabilitation or palliative care and long term follow-up, emphasising the potential for strategic innovation if these elements were routinely collected and available to researchers. Currently, assumptions on the effects of anti-cancer therapies are usually based on results from clinical trials i.e. the clinical efficacy, we need data to validate these findings on a population based patient cohort to really understand the clinical utility of new interventions.

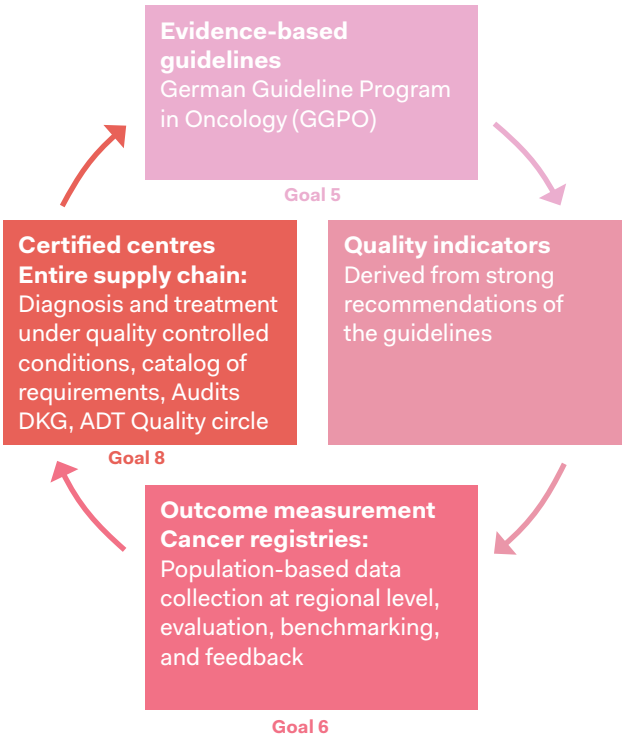
> *"Quality of care and innovation are two sides of the same coin, which overtime should become more integrated, but we need new criteria defining evidence and an effective dissemination of innovations are a key role for Comprehensive Cancer Centres."*

Olaf Ortmann and Monika Klinkhammer-Schalke continued with discussion of the task of building cooperative networks between cancer centres, clinical cancer registries and Guideline Groups in Germany as a key objective in the further development of cancer care services and quality assurance in the National Cancer Control Plan for Germany. While outlining the challenges of navigating systems that span national, federal and regional governance, Ortmann presented the Network of Quality Management Cycle in which the German Guideline Programme in Oncology has led to the development of a set of quality indicators, which are now embedded in the certification processes of the German Cancer Society network of certified cancer centres and directly linked to the benchmarking of outcome measures through clinical registries, which in turn inform the guidelines.

Klinkhammer-Schalke went on to illustrate the complex nature of this network in just one region of Germany – Regensburg, which comprises a Network of 56 regional hospitals, university clinic and 1000 general practitioners, follow-up documentation of all 450.000 cancer patients in the region (2.3m inhabitants), Certified Centres (42) for Breast-, Colorectal-, Prostatic Cancer, project groups for quality management for each tumour entity, quality circles for general practitioners and a group of 20 postgraduates. Despite the challenges, Klinkhammer-Schalke explained that neutral evaluation of new structures of care and reporting of data to the guideline committees is already having impact with providers of care, patients and politics benefiting from systematic reduction of redundant documentation and innovative health services research.

> *"Despite the challenges and obstacles in implementation, due to the complexity of our work, clear communication and early insights for the benefit breast cancer patient outcomes and quality of life advice has united clinicians, practitioners and registry personnel as they see this work is for benefit of patient care."*

Network of Quality Management Cycle (PDCA)



Fred Bray closed this first segment by reminding participants of the global status in cancer surveillance with inequities in both the future global cancer burden and data availability for local cancer planning – only 67/184 countries (36%) report high quality incidence data to IARC and only 34 of 178 countries (19%) report high quality mortality data to WHO. Bray went on the present the Global Initiative of Cancer Registration and the improvements which this long-term commitment to building capacities nationally towards population based cancer surveillance www.GICR.org is already making in improving the accuracy of our global picture of the cancer burden as well as generating new tools and support such as the essential TNM staging tool, aimed and encouraging documentation of stage at diagnosis.

> *"A great network of 6 regional expert hubs provide training, mentorship and direct support, networking and advice for cancer control planning and research and are truly having an impact, sadly sustainable funding for this work is a challenge."*

Key learnings from the interactive session

The aim of the interactive session was to identify useful models and principles that have proven to be effective in supporting collaboration of these stakeholder groups that do not always have natural touch points work together and finding common ground around the shared goal of both improved outcomes and quality of care for cancer patients. Using the key questions:

- How does the data flow need to be described?
- How do communication processes between institutions need to be described?
- How does result-communication need to be described?

There was a general acknowledgement that this work needs to build on the solid foundation of cancer registration, harnessing regional structures and care networks for maximum coordination and collaboration. The decentralized model of data collection, close the to the patient and care giver enhances quality, but there was also a clear role for governments at the regulatory level and a need for central coordination for the definition of mandatory datasets, indicators and standard setting, as well as education, training and quality control. Specifically, with respect to quality indicators, there is recognition of the data management burden and therefore a call for sound research before adoption of indicators into a core mandatory set for the cancer registry. In addition, acceptance from the clinical community should be sought through a consensus process, which in the experience of those that had done so, enhanced mutual recognition of differing perspectives, needs and drivers of the different players in the network.

Communication between stakeholders is considered the major challenge but fundamental for sustainability, ranging from the challenge of overcoming lack of motivation for routine documentation, which some felt could be overcome with trained data managers that are integrated into the multidisciplinary teams, to management of benchmarking reports. Establishing mechanisms for learning and making improvements over time are considered critical in this regard. Ideas included formalized feedback from registries to clinic boards on a quarterly basis, institutional benchmarking reports for immediate single site feedback and peer comparison and options to revise data, as well as reflection in certification and accreditation processes with external review. Equally, participants acknowledged that this work is defining a new level of evidence, which needs work to become established a high level of quality that is replicated at local, regional and national level. This will also require new ways of understanding the inter-linkage of data and therefore also new ways of communicating outcomes.

Recognition of broader stakeholder access to the data by insurers and patients for example requires simple and clear language, explaining how and why data was collected. Here the trust in the independence and quality of the data and the auditors was considered critical. Patient engagement in the work as also recommended, especially from the perspective of quality of life indicators. Generally, patient groups were considered as supportive and sharing the vision of the potential for real-time benchmarking reports with the opportunity for patients to view their own data. A challenge here is the variation in need for patient consent, with the recommendation that there is a legal obligation to share data, although this is hard to realize. Most are mandated to advise patients that their data will be used in this manner and a patient opt-out system is considered best practice.

List of participants

Association of European Cancer Leagues

Prof. Dr. Sakari Karjalainen, President of the Association of European Cancer Leagues, Secretary General, Cancer Society Finland, Helsinki, Finland

European Commission

Manola Bettio, Group Leader, Directorate General Joint Research Centre, Ispra, Italy

Dr. Stefan Schreck, Head of the Health Information and Scientific Comittees Unit of the Directorate -General for Health and Consumers (DG-SANTE), Luxembourg,

France

Dr. Freddy Bray, Head of Section of Cancer Surveillance, International Agency for Research on Cancer, Lyon

Slovenia

Prof. Dr. Tit Albreht, Head of the Centre for Health Care – National Institute of Public Health, Lubljana

Sweden

Prof. Dr. Ulrik Ringborg, Chairperson of the EUROCAN Platform, Director Cancer Center Karolinska, Stockholm

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The Netherlands

Prof. Dr. Jan-Willem Coebergh, former Head of the Department of Public Health, Erasmus MC Rotterdam

Prof. Dr. Sabine Siesling, Dept. of Registration and Research, Comprehensive Cancer Care Centre of the Netherlands, Utrecht

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Prof. Dr. Henrik Møller, Head of Cancer Epidemiology, King's College, London

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