3rd European Roundtable Meeting

17 June 2016
Berlin, Germany

'Current developments in cancer care: including the patient perspective'

On 17 June 2016, participants from all over Europe came to Berlin for the third time for an in-depth discussion under the title "Current developments in cancer care: including the patient perspective".

Acknowledging the impressive changes and development in cancer care, the German Cancer Society (DKG) and the Union for International Cancer Control (UICC) were once again able to welcome a group of high-level experts to focus on the role and needs of the patient in cancer treatment.

Addressing the needs of patients during and after cancer treatment was the focus of the previous European Roundtable Meeting in 2015, explained Prof. Ortmann from the German Cancer Society during his introduction. In order to raise the quality of cancer treatment it is necessary to include the patient perspective, not only into the assessment of daily treatment but also while considering cancer care networks and the development of guidelines as well.

While participants discussed the development and need of National Cancer Control Plans (NCCPs) including quality control by cancer registries during the first European Roundtable Meeting (ERTM) in 2014, the second ERTM in 2015 followed up on this. It included discussions on the relevance of cancer registries, spanning from cancer registry perspectives, to entire cancer control systems. The participants highlighted that the political system of a country has a big impact on the ideal structure of the health systems, and that coordination between the different levels of government can prove to be challenging. But participants agreed that the patient view is relevant for the whole cancer continuum as well. Therefore, during the first part of the third ERTM, speakers from Italy, Ireland, Switzerland, Germany and Sweden presented different perspectives of the role of the patient. During the second part, participants split into three different working groups, to discuss new insights and ideas, by reflecting upon the following questions:

1. **How much transparency is needed in patient care, how can it be implemented?**
2. **How does the cancer care system react to new knowledge, how fast can standardised reactions be implemented on the basis of patient needs?**
3. **How can a benchmark for decision-making in partnership with the patient be defined?**

KEY PRESENTATION OUTCOMES

The following key presentations addressed the fact that consideration of patients' needs is fundamental for quality of cancer care and that the patient's needs and views need to be integrated.

- Most relevant for all patients is the access to appropriate treatment as well as innovative drugs. But even in Europe there are disparities in cancer care and the economic situation can't be neglected as this is what limits the access to treatment the most.
- Furthermore, the growing group of cancer survivors brings new challenges to health care sectors but also to society, and employers in particular too. Having said that, speakers highlighted the need to create a new "survivorship-power". For this, the public and politicians need to be sensitised to their needs. Cancer treatment is a busy time for patients and similar to an emotional rollercoaster. Workplaces need to give room to cancer patients' needs and employees should not have the feeling of being tabooed and excluded.
- To establish new structures, it might be helpful to link to other diseases and work in partnership with organisations addressing chronicle and infectious disease with a long term-outcome. The willingness to open and learn from each other could speed up the implementation of the patient's views into the cancer continuum.
- Care-givers, patients and politicians need to be aware that precision medicine, big data and the changes in demographics will lead to rising disparities and complexities in the cancer continuum and will constitute global challenges of cancer care in the future.
- Clinical studies should proceed to include patient reported results but still consider that the best result is improving hard end-points like Overall-Survival and Progression-Free-Survival. Furthermore, it needs to be acknowledged that patients may have another definition of quality of life-parameters.
- To gain patient feedback, participation of patient groups is required in organisations responsible for prevention activities and clinical guidelines, in cancer centers and in the education of care-givers.
- It is absolutely clear that communication is key.

WORKGROUPS OUTCOMES

Task: Analysing how patient needs and voice can be integrated sufficiently into cancer care.

1.a. How much transparency is needed in patient care?

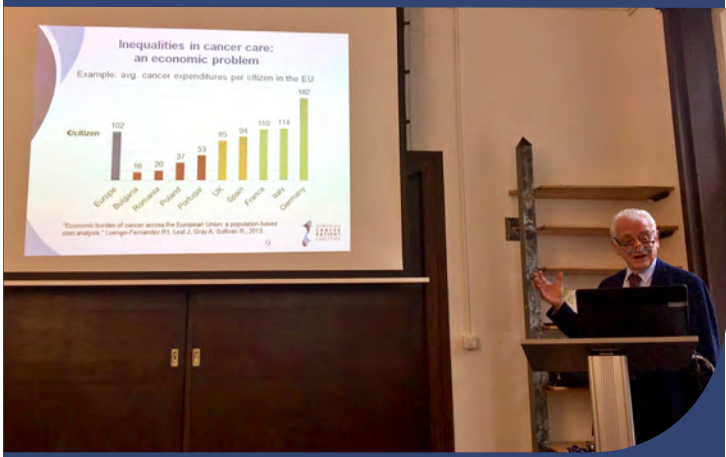
- Transparency means offering choices.
- Transparency means explaining consequences/implications.
- Transparency is not simply information, but is also needed in data collection.
- 100% transparency on all levels, in all related fields needs to be available. The given amount is dependent on how much the patient wishes to be informed and involved (treatment as well as non-treatment and related services).
- Potential barriers against transparency (patient related):
  - limited access to information and choices (limited education and health literacy of the patient)
  - limited regional access to medical services because of long distances and limited mobility

"We tend to have the vision of an ideal patient, who is well-educated about his disease and can handle treatment decisions just in the same way as he would buy a new car or new clothes. However, we have to keep in mind the tremendous impact that cancer can have on the emotions, attitudes, values and the social environment of patients."

Hilde Schulte,
Former President Frauenselbsthilfe nach Krebs,
Haus der Krebs-Selbsthilfe-Bundesverband
Germany

"The chosen type of diagnosis and treatment of cancer patients is mainly driven by providers - however, in order to advance cancer care the perspectives of patients need to be considered, not only to guarantee satisfaction but also to improve outcomes."

Professor Olaf Ortmann,
Vice-President, German Cancer Society (DKG)
Germany



"Survivorship is a ticking bomb: the sights and needs of the growing population of survivors are not sufficiently taken into consideration."

Professor Dr Francesco de Lorenzo,
President of the European Cancer Patient Coalition
Belgium / European Union

"We need to discuss quality of life issues with patient experts and larger patient groups. In our experience, patient cohorts provide excellent opportunities for learning and teaching."

David H.-U. Haerry,
European Aids Treatment Group
Belgium / European Union

"New cancer therapies are really costly and the issue of equal access of all cancer patients to innovative therapies is an ongoing challenge."

Joan Kelly,
Past President of the Association of European Cancer Leagues
Belgium / European Union

"It is important to balance prevention and treatment to combat cancer globally."

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

1.b. How can transparency be implemented?

- Communication on all levels.
- Making data, as well as knowledge, available (also by an independent source).
- Set up a pathway to define the level of transparency and information needed:

1. Explore the degree to which the patient wished to be informed.
   Three groups of patients can be defined:
   A – Very informed, B – Intermediate,
   C –- Uninformed and/or Passive
2. Address insecurity of the patient: address and explain pathway(s).
3. Consider creating financial incentives for communication. Remuneration for bringing information to the patient and interactive decision-making.
4. Include other groups (cancer nurses) into the information, multi-disciplinary approach ("each profession has its own competencies").
5. Care for transfer of information, which stabilises the confidence of the patient in the professionals and the team.
6. Take care in using adequate language and carefully reasoned information.
7. Patient needs to get advice at the strategic decision points and decide upon the treatment strategy.

2. How does the cancer care system react to new knowledge, how fast can standardised reactions be implemented on the basis of the patient needs?

- What kind of research knowledge?
  Knowledge of illness, diagnostics, treatment, recognition of side-effects (pain), adherence to therapy and medication, knowledge of non-pharmacological measures, to decrease cognitive barriers of patients to cancer therapy and therapy to the side-effects. But also knowledge of improving the self-management, self-care abilities & self-observation of the patients.
- There is a gap between research results and transfer into daily practice, especially between basic research and clinical research.
- Research process analysis needed
- Analysis of bottlenecks and solution development needed.
- Follow-up new treatments after admission and create population-based data.
- Exchanges between data gaining institutions (e.g. CC, CCC, CCR) needed (data, results, knowledge).
- Fast knowledge transfer to guidelines and patient guidelines.
- Integration of patient groups into research groups and study design development.
- Patient groups need to be independent (by non-industrial financing).
- Research groups need to be independent (by non-industrial financing or other financing models including the pharmaceutical industry).
- Defining of relevant outcomes research to assess clinical effectiveness and cost-effectiveness of new diagnostics and treatments before adoption by the healthcare systems.
- Prioritisation of cost-allocation to treatment procedures.

3. How can a benchmark for decision-making in partnership with the patient be defined?

- Specific time for decision-making process needs to be implemented into process.
- Mutual respect for different positions.
- Providing information is necessary.
- Offering of decision aids right from the beginning.
- Educational process if wanted.
- Principles of patient-centred communication have to be established in clinical settings.
- Patient experience needs to be measured.
- Establishment of a structured decision-making process.
- Involvement of patient representatives into decision-making process.
- Measurement of patient satisfaction with enablement and therapeutic process.
- Comparison to other institutional peers.

KEY CONCLUSIONS AND FUTURE PROSPECTS

The participants agreed on the value of patient views and perspectives in the whole continuum of cancer care. Access to treatment, high-level of communication and transparency, as well as the inclusion of patients into the developing-process of guidelines were identified as relevant aspects.

Survivorship will be a new challenge not only for the health-care-sector but for society and the workplace as well. More awareness to the needs of this group is required.

Results of the Meeting will be disseminated in the coming weeks through the European Journal of Cancer (EJC).

The German Cancer Society (DKG), in cooperation with UICC, will organise a fourth meeting in 2017.

"Our overall goal in the development of new therapies should be to achieve normal life expectancy with a good quality of life and minimal side effects. The isolated use of single endpoints in clinical trials does not address the complexity of new therapies."

Professor Dr Michael Hallek,
Director and Chair of the Department of Internal Medicine at the University of Cologne
Germany

"The integration of patient groups into the planning process of study designs can integrate the benefit of goal directed innovation."

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

LIST OF PARTICIPANTS

GROUP 1

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- **Prof. Dr Francesco de Lorenzo**, President of the European Cancer Patient Coalition, Belgium / European Union
- **Prof. Dr Michael Hallek**, Director and Chair of the Department of Internal Medicine at the University of Cologne, Germany
- **Prof. Dr Margarete Landenberger a.D.**, Institute of Health and Nursing Science, Medical Faculty of Martin-Luther University Halle-Wittenberg, Germany
- **Prof. Olaf Ortmann**, Vice-President, German Cancer Society (DKG), Germany
- **Dr Wiebke Rösler**, Global Resources Manager, Union for International Cancer Control (UICC), Switzerland/Global
- **Dr Wendy Yared**, Director of the Association of European Cancer Leagues, Brussels / European Union

GROUP 2

- **Prof. Josep M. Borras**, Director, Catalan Cancer Plan, Spain
- **Anke Bramesfeld**, Scientific/Technical Project Officer, DG Joint Research Centre, Institute for Health Policy Support Unit, Healthcare Quality Team, Italy
- **Dr Johannes Bruns**, Secretary-General, German Cancer Society (DKG), Germany
- **David H.-U. Haerry**, European Aids Treatment Group, Belgium / European Union
- **Joan Kelly**, Past President of the Association of European Cancer Leagues, Belgium/ European Union
- **Dr Katrin Mugele**, Press Officer, German Cancer Society (DKG), Germany

GROUP 3

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