Report on the EORTC 50th Anniversary Conference
Brussels,Belgium March 15th and 16th 2012

We were privileged to attend this conference to celebrate 50 years of the European Organisation for Research and Treatment of Cancer (EORTC).

EORTC/PPI Project

We, along with a number of other members from the NCRN Consumer Liaison Group, are involved in an EORTC/NIHR(National Institute for Health Research) Patient and Public Involvement (PPI) Project . The aim of this project is to:

- improve the quality and relevance of the Patient Information Sheets(PIS) and Informed Consent(IC) given to UK patients considering taking part in EORTC clinical research activities
- ensure information is provided to the patient community about the progress of reviewed projects.

This particular project on patient information is part of a wider initiative currently being developed by the EORTC called 'Cooperation with Patient Organisations and Advocacy Groups' which aims to:

- improve EORTC collaborations with patient organisations and advocacy groups
- raise awareness of the work of the EORTC, its research studies and their results.

As a result the EORTC invited two PPI representatives to attend the conference and we are most thankful to have had funding from the Patient and Public Involvement Program at the NCRN to attend

What Is The EORTC?

The EORTC is an international non-profit research organization created in 1962 by European cancer specialists. It has a co-ordination and analysis centre with 180 staff members from 16 different nationalities. By conducting large, multi-centre clinical trials, EORTC aims to facilitate the passage of experimental discoveries into state-of-the-art treatments by:

- stimulating, developing, conducting and coordinating clinical and translational research in Europe to improve the management of cancer and related problems by increasing survival but also patient quality of life
- improving the standard of cancer treatment through the testing of more effective therapies based on drugs, surgery and/or radiotherapy that are already in use and also through the development of new drugs and other innovative approaches.

The conference was spread over two days, had around 1100 attendees and consisted of a series of talks and lectures (fortunately entirely in English) from some excellent speakers. Some talks primarily celebrated and reviewed 50 years of progress in different areas and considered pan-European cooperation, and others again were looking at future challenges and perspectives. It was not really a conference to discuss the actual individual research projects and so questions and/or discussion groups were not a feature of the conference.

Research in Surgical, Radiation and Medical Oncology

The talks mentioned a number of practice-changing trials that have been achieved over the last 50 years. Some that stood out were EORTC 10801 (1980-1986) comparing breast-conserving surgery to modified radical mastectomy in operable breast cancer over 5cm, Phase III trials over many years studying early-stage Hodgkin's lymphoma, and a number of ovarian cancer studies. The low number of surgical trials, 14 trials from 1980 to 2005, was highlighted by Emiel Rutgers, Professor in Surgical Oncology, Amsterdam. He expressed the view that surgery needs to be standardized and looked at how to measure the quality of surgery.

Over the past 50 years radiotherapy technique has advanced greatly. The progress of quality assurance within radiation oncology (QART) is important for all patients receiving treatment. An example of the importance of QART was EORTC 22281

trial, 1992 – 2012, Boost vs No Boost for patients with a breast cancer diagnosis. 5569 patients recruited to this trial. Initial results would indicate a higher recurrence rate with no boost.

A more recent trial that was discussed several times was MINDACT EORTC 10041 (Microarray In Node-Negative and one to three positive lymph node disease may Avoid Chemotherapy) which is designed to evaluate the clinical utility and added clinical benefit of the Mammaprint™ gene signature in selecting early breast cancer patients for adjuvant chemotherapy. The trial closed in July 2011 with the accrual of 6600 patients and is particularly notable because fresh-frozen samples, paraffin tissue blocks and blood/serum samples were collected and stored for all enrolled patients. Bio- banking was discussed by several speakers and we were told about European biobanking being setup in partnership with EORTC and industry starting with colo-rectal samples. Jean-Yves_Blay (EORTC President) said in his opening talk that one of the questions for the next 20 years is will it be possible to organize bio-banking effectively multi-nationally. Although it was also of note that only 64 patients were enrolled in this MINDACT Trial in the UK compared to for example The Netherlands 2055 and France 1992. The only country with a lower recruitment was Slovenia with 37.

There was an interesting talk on the difficulties of using progression-free survival as a primary end-point in trials and the work of the EORTC statistics department in reassessing methodology particularly in the light of new imaging techniques, which may be used as surrogate end-points.

We were given a copy of the European Journal of Cancer Supplements vol 10, No.1 2012 (EORTC 1962-2012 50 years of Progress Against Cancer) which has proved to be a readable reference to EORTC studies across all the site-specific tumour groups.

A Pan-European Collaboration

A number of talks focused on pan-European collaboration and future challenges. It was particularly interesting to hear R.Draghia-Akli (Director of the Health Directorate at the Research DG of the European Commission). She talked of the EU vision for pan-European research, so important given the increasing numbers who will be affected by cancer across the EU as the population ages. She said that the EU's strategic objectives were to produce evidence based solutions and shorten the innovation life-cycle for new treatments, developing international collaboration for rare disease. The Commission has recognized the need to revise the Clinical Trials Directive (CDT) to ensure high standards and quality in clinical research across Europe. There have been two rounds of public consultation and adoption of commission proposal is due in mid 2012.

Professor Francoise Meunier, Director General,EORTC, spoke of the necessity to move research forward in Europe with the need to understand EU Legislation in relation to national laws. She posed the question – does legislation protect the researchers or the patients? Professor Meunier gave the example of Patient Information Sheets(PIS). In 1995 / 1999 the PIS median was three pages, in 2010 / 2011 it was twelve pages. She believes the way forward is to streamline, simplify and harmonise with the ongoing revision of the CDT.

Patient Voice

There was an excellent presentation from Peter Kaptein, President and Patient Advocate of Inspire2Live. Apart from very eloquently reminding us that research is for the patient, he pointed out that it isn't patients who talk about privacy but lawyers. He talked about the rights of patients to get better treatment and to decide what purposes their own data is used for "use everything I got – tissue, data, everything to help me and others". Peter concluded his very challenging talk with a quote from Martin Luther King:"what do you do for other people". Throughout the conference many of the speakers referred to the impact of Peter's presentation, highlighting the importance of the patient perspective within research.

Quality of Life

EORTC has researched in the area of health-related Quality of Life for 30 years and developed the widely-used modular system of HRQOL measurement known as EORTC-QLQ-C30. We were told of the on-going research in this area, including cross-cultural differences between populations, computer-adaptive testing and electronic administration. Professor Galina Velikova presented her work in this area. She leads a Cancer Research UK funded group studying implementation of routine measurement of patient reported outcomes and QL in oncology practice. She is funded by the NIHR to develop a web based

system for collecting patient reported data on toxicity during cancer treatment, integrating it with electronic patient records. We were given the Quality of Life Group Newsletter. Members of the group are from 31 different countries with the UK, Germany, Austria, Italy and The Netherlands the five "top contributors". The Newsletter also highlighted two new grants where the UK is taking part in the research: development of measures to assess quality of life in lymphopoliferative disorders and development of the EORTC testicular cancer module (QLG-TC26), a Phase IV study.

The Future

Several speakers discussed a variety of challenges for the future for research both at the EORTC, and beyond. One speaker looked at the economics of innovative cancer treatments and policy implications. They recognized that modern clinical research cannot be addressed without specific partnerships, and that in fact a third of EORTC activities are now inter-group trials. Liaison offices have now been opened in several countries including the UK. They also discussed the changing methodology of modern clinical trials and the need for research in this area. They noted the need to improve and expand relationships with patient organisations and advocates. The EORTC Mission and Structure Handbook talks of exploring other forms of PPI through specific working meetings, apart from the limited areas of using patient expertise to edit leaflets and information.

Our Learning Points

- The need for collaboration in translational and clinical research projects to ensure progress in surgery/drugs/radiotherapy treatment for people diagnosed with cancer
- This collaboration means large, multicenter, phase III clinical trials can move experimental discoveries into treatment
- Also dependent on EU legislation and national laws
- Need for revision of Clinical Trial Directive
- Importance of QOL issues both during and post treatment
- Financial issues
- Patient voice in use of data, tissue samples etc
- PPI involvement in EORTC in all aspects of research cycle

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