



### Oncopolicy Forum 2011: Inequalities in Quality Cancer Care

The issue of inequalities in quality cancer care is a topic that needs to be addressed by the entire cancer community, said **David Kerr**, president of ESMO. The most useful contribution ESMO can make, he added, is to produce clinical guidelines. Guidelines need to be written that can be applied across the globe, regardless of whether patients live in New York or New Delhi, and also be adaptable to local circumstances.

An important factor to ensure patients receive the best possible standards of care is to keep them informed, thereby enabling them to know the questions they should raise with health care professionals about clinical outcomes.

It is also of great importance that medical oncology is recognised as a distinct speciality. Chemotherapy is a complicated potentially toxic treatment, explained Kerr that should not be administered by amateurs. Yet currently too many under-qualified doctors deliver it.

In the drive to improve clinical standards, competition is an important element that should not be forgotten. If cancer centres discover they have a poor rating in league tables, professional pride should motivate them to improve services.

Cancer care should be safe, effective, accessible, responsive to patient's needs, efficient, equitable and integrated, **Kathy Redmond** told the session. But the reality across Europe, said Redmond, editor of the European School of Oncology's magazine *Cancer World*, is that care of many cancer patients is currently undertaken by amateurs. These include amateurs in chemotherapy, surgery, radiotherapy and nursing. Additionally, patients are not given adequate survivorship support because they are denied access to psycho-oncology services, physiotherapy and occupational therapy. The way cancer services are organised, said Redmond, has a huge influence on patient outcomes and has the power to determine whether people live or die.

Inequities across Europe include differences in the amount of money governments invest in health care, the technology available in different countries, access to specialist doctors and nurses, the number of available hospital beds and reimbursement systems. The bottom line of such discrepancies, said Redmond, is a large difference in cancer mortality that exists across Europe.

Furthermore differences in cancer outcomes exist within European countries, which may be influenced by factors such as gender (women in general do better than men), age (a patient's age influences clinical decisions more than their physical condition), geographical location (patients living in rural areas have difficulty accessing services) and socioeconomic status.

When the Organisation for Economic Co-operation and Development (OECD) explored reasons for differences in cancer survival across Europe at an Open Forum meeting in June 2011 they found 50% of the difference could be explained by financial resources, 33 % by process quality (i.e. whether populations have access to services such as cancer prevention, early detection and evidence based cancer care) and 17% by governance (where countries set specific measurable targets).

Focussing on governance, Redmond said it was important that countries have a national cancer control plan, networks for service delivery, cancer specific targets with timeframes and a mechanism to ensure that targets are being met.

Already a number of European organisations (including OEIC, ESMO and ENETS) have taken up the challenge to improve delivery of cancer care, but to achieve success they will need widespread government support.

Redmond cited the Cancer Quality Index, where cancer service delivery undergoes annual audits, as an example of good practice. Aspects reviewed in the initiative, which has been introduced in Ontario, Canada, include monitoring the percentage of cancer patients undergoing surgery in designated cancer centres, having care discussed in multidisciplinary case conferences, and being treated according to guidelines. In Europe, said Redmond, there is a need for countries to establish clearly defined standards for cancer care and then monitor delivery.

**Nick Fahy**, moderating the panel discussion, opened the debate, stating that while there have been many discussions in the past about what needs to be done to improve quality cancer care, the recommendations have not filtered through to national healthcare systems. He asked the audience why best practice seems to be difficult to transfer from one country to another. 34.2% of delegates said that change requires support from outsiders who are not committed, 23.7% said that data is not available to compare ourselves against others, 23.7% said that unavailability of funds is the problem, 13.2% that senior oncologists did not take well to being criticised, and 5.3% said that we do not really know what best practice is.

Changes to the health care system, said **Regine Haggmann**, head of the German Cancer Information Service at the German Cancer Research Centre, are placing greater responsibility on individual cancer patients to be active participants in decision making. Many patients, however, do not have sufficient information for this role. A survey undertaken in eight European countries revealed that more than half of cancer patients are not satisfied with the communication skills of their doctors or information they had been provided. From this, Haggmann identified a need to improve the communication skills of health care workers, and for understandable, reliable, up to date clinical information to be made available to patients. The German Cancer Information Service is a free public service funded by the German Cancer Research Centre and federal government, with the intention of providing authoritative quality controlled scientific data to help guide patient decision making. Last year the service received 33,000 individual questions and more than 70 million hits to their website.

MEP **Marisa Matias** told delegates in a video link that although recommendations can be made at EU level, national decision-making is of crucial importance to improve healthcare systems. Clinical trials, she said, offer one area where patient access to treatment and the contribution of research can be improved. Getting involved in the revision of the Clinical Trials Directive, which will start in October 2011, is one way in which both researchers and patients could help reduce cancer inequalities.

Before inequalities can be properly documented, a reliable infrastructure is necessary for data collection, said Anna **Kamińska**, from the Polish Ministry of Health. Recounting the Polish experience, five years ago, following the publication of an OECD report which identified problems with reliable data collection, a national cancer registry was established to document inequalities such as waiting times and differences in care.

In order to address inequalities of care, Stella **Kyriakides**, chair of the ECCO Patient Advisory Committee, stressed the importance of creating partnerships between patients, professionals and industry. Furthermore, for positive outcomes, "realistic short steps" need to be put in place that can be monitored easily. There is a responsibility, she said, to change the fact that while so much is being achieved at the scientific level so little gets back to patients. Guidelines need adjustment to take into account the individual needs of developing countries. On the subject of cancer plans Kyriakides made a plea for inclusion of survivorship issues, and monitoring to ensure financial investment reaches patients. Kyriakides concluded by raising the issue of how the new directive on cross border healthcare, intended to allow patients to access specialist units outside their own countries, could impact on cancer care. Addressing this point, chairman **Nick Fahy** said that it would be interesting to see if the directive resulted in improved overall care for cancer patients or just for the minority adept at navigating the system.

While one of the key messages from ECCO is that every cancer patient deserves the best, **Cornelius van de Velde**, president of ECCO, explained. He explained the reality that less than 1% of cancer patients in the EU are involved in clinical trials, with some sub-groups, including the elderly, having poor access to clinical trials. Performance feedback, he added, is needed for both hospitals and individual health professionals, together with multidisciplinary guidelines that are based on scientific evidence and real-world outcomes that can be tailored to individual countries.

Nurses, said **Sara Faithfull** from the European Oncology Nursing Society, have a pivotal role to play in helping patients navigate their journey with cancer. Particular help can be offered in the area of drugs, diagnosis and disease, with such issues outlined in cancer plans. Wealthy people, she said, were able to navigate their way through the system whereas more vulnerable groups have poorer access to services. Faithfull highlighted a recent study, published in the *European Journal of Cancer*, demonstrating that cancer patients with less education achieve worse disease outcomes than those with more education.

**Nicole Denjoy**, Secretary General of COCIR, explained that the rising cancer incidence together with the fact that cancer is increasingly becoming a chronic condition is challenging the sustainability of European healthcare systems. E-health can offer integrated technological solutions but it is important that medical professionals view health IT as a solution and not as a threat.

The first comment from the audience was that unless a “new European mood” could be achieved among European member states their ability to work together to find solutions to cancer would be hampered. Guidelines need to be created that can be adapted to individual countries.

Van de Velde acknowledged the need for greater European coordination, adding that every patient should be included in outcome registries, and that care can only be improved with this type of feedback. Mechanisms need to be put in place to acquire reliable data from hospitals to improve care.

When it comes to creating a European vision, said Kyriakides, greater coordination is needed at both the European and national levels. Greater transparency is needed, commented Hagmann, to enable information to reach patients and allow them to be active in demanding the best care.

Initiatives are currently underway, said Van de Velde, which started in colorectal cancer, to judge which hospitals perform best. Such issues are delicate, with decisions needed to be made about whether the medical profession should control the process. Government support will be needed to create infrastructures to make data available, and the resulting processes are likely to vary between countries due to the different health care systems.

Faithfull commented that widespread introduction of such initiatives would result in patients being seen in higher volume centres with social and economic repercussions including that they would be required to travel further for treatment.

Patient advocates, said Kyriakides, have a responsibility to inform patients about the new European cross-border healthcare directive. The directive is only a framework, said Fahy, with implementation in the hands of individual member states.

Wolfram Nolte, a patient representative from the Familienhilfe Polyposis Coli organisation in Germany, commented that no system of transparency currently exists to show patients if they are receiving the best available care. Additionally, he had concerns that quarterly ceilings on drug budgets have recently been implemented in Germany.

Kathy Redmond expressed “100% support” of transparency and added that with patients’ lives at stake professional sensitivities need to be put to one side. When online lists were recently published in Italy of the number of procedures performed in cancer centres, it was apparent that some centres only saw one or two cases each year. Professional bodies, said Redmond, need to lead the push to make such data available and governments need to invest in such initiatives. The bottom line, she added to applause, was that patient lives would be saved.

Van de Velde felt there was a need to define the essential information that should be reported in patients' files for different diseases. On discharge this information should be made easily accessible to both patients and the health care professionals treating them.

In the past Fahy commented, patients have been much more interested in data on hospital food and car park charges than about disease outcomes, demonstrating the need to make clinical information more meaningful to the public. Patients, Kyriakides said, need to be provided with information in a language they can understand. It is everyone's responsibility to ensure they are informed and educated.

Throughout the session, said David Kerr in his concluding remarks, it has been clear that information is of vital importance. The informed patient is the empowered patient.

Transnational comparisons are vitally important since they can be used to engage politicians and drive up standards. Kerr quoted the UK example where poor national cancer survival figures played a major role in influencing former Prime Minister Tony Blair to launch the National Cancer Plan.

In future, Kerr said, it would be important to introduce systems that capture clinical outcomes and make them available to all citizens. Currently in the UK Prime Minister David Cameron is introducing a system to record the five year survival rates of the patients of individual clinicians with the resulting information used to create league tables. The professional pride of clinicians at the bottom of such league tables, Kerr said, should improve standards.

Against this background, he cautioned, many cancer drugs show marginal activity, making it necessary to achieve a "sensible" balance over what agents should be funded. In focusing on targeted medicine, the session has revealed that the poor and disenfranchised may not be served adequately. Patients take uniform quality of cancer care for granted, he said, but once they are shown evidence of the disparities that exist, issues about food and car parks will be forgotten.

**If you have any comments about any of the issues raised in this report or would like further information, please contact ECCO Public Affairs: [EccoPublicAffairs@ecco-org.eu](mailto:EccoPublicAffairs@ecco-org.eu)**