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Introduction

by Ian Banks,
ECCO PAC Chair, Co-Chair Patient Advocacy & Ethics track

Patient care was at the centre of the European Cancer Congress. Improving patient care is about listening to the wishes and needs of patients and combining this input with the patient care insight of all oncology care disciplines and professions.

This was the focus of the 'Patient Advocacy & Ethics' track' of the European Cancer Congress scientific programme under the theme of 'collaboration'. The track was created by experts from the ECCO Patient Advisory Committee (ECCO PAC) and ESMO (European Society of Medical Oncology) with the aim of involving all relevant groups at the multidisciplinary level and stimulating interactions among them, while keeping the focus firmly on the patient. Dynamic and innovative session formats were designed including a thought-provoking mock TV talk show featuring cutting-edge interviews with eminent 'guests' representing the patient advocacy, medical, regulatory and pharmaceutical industry communities.

The track targeted all oncology professions and communities attending the congress. The impressive turnout of participants, the high level of interactions and the clear recommendations that came out of the discussions proved this to be a fruitful approach which should probably be developed further in the next European Cancer Congress in Vienna in 2015.

Executive Summary

A two-day track was devoted to patient advocacy with the overall theme of 'Collaboration' among all stakeholders involved in cancer care, including patient advocates as instrumental partners in the improvement of cancer outcomes. The current summary aims to provide the key messages from the presentations and discussions:

- The culture of research in Europe needs to change to stimulate data sharing and coordination
- The patient advocacy community needs to demonstrate the value of patient involvement
- Adherence to treatment is strongly influenced by the doctor-patient relationship
- More and better-designed studies are needed to arrive at specific recommendations for life after treatment (e.g. in terms of diet), ideally providing tailored advice to different patient groups
- Other key aspects affecting a cancer patient's return to normal life are physical activity, the unlocking of creative potential and cancer support centres treating the person and not only the cancer
- Palliation equals alleviation of symptoms, both physical and psychological, and should be addressed earlier on in cancer care
- Molecular stratification can be successfully integrated into the healthcare system as shown by the French molecular testing initiative
- Healthcare professionals need to engage more closely with patients in discussing treatment options including possible personalised treatment
- Healthcare services should tackle the huge differences in cancer survival between men and women across Europe
- Networks of specialized centres, accreditation schemes and transparent quality criteria may provide robust guidance to patients and reduce the risk of inequality of access to best quality cancer care
- For young cancer survivors, the survivorship passport should be a standard of care

Session 1:

This week on talking about cancer with Richard Sullivan (a mock TV chat show)

Chairs:
Kathy Oliver, International Brain Tumour Alliance
Jana Pelouchovà, ECPC

Session Takeaway Messages:

- ***There is a need to change the culture of research in Europe to stimulate data sharing and coordination and avoid duplication***
- ***There is also a need to better connect basic research and clinical research. Europe is lagging behind in believing in technologies that will lead to a new type of research in life science***
- ***There is a disconnect between what is being talked about in the oncology community and what is out in the media. We should not undersell the benefits of discoveries in basic research or oversell achievements in clinical research***
- ***We have largely underestimated the efforts that it will take to have personalised medicine. In Europe, there is a lack of interest in the development of diagnostic tests***
- ***We will need another, efficient validation model for the biomarkers***
- ***Demonstrating the value of patient involvement is the most important challenge for the patient advocacy community***
- ***Patient advocates need to identify areas where they can take a united stand across Europe***
- ***There is a disconnect between progress made and the feelings of the patients. We are all aware of the power of collaboration but the patient as part of that collaboration is essential***
- ***Public discourse is saturated with the costs of medicines while the most costly part of cancer treatment is the in-patient time in hospital***

Part 1:
Interview with healthcare professionals and regulator

Interviewees (guests):
Martine Piccart, Institut Jules Bordet
Alexander Eggermont, Institut Gustave Roussy
Francesco Pignatti, European Medicines Agency

"Guests" participating in this mock TV chat show format were challenged with a series of questions prompted by Richard Sullivan around the themes of the evolution, the achievements, the expectations and the hurdles in cancer science, care and research.

Richard Sullivan (RS): Two hundred years of cancer research. What has been done to advance cancer? What have we done in terms of making the very best advances?

Alexander Eggermont (AE): Everything has changed with the advance of molecular biology. Most cancers are at a systemic level at the time of presentation which causes systemic therapies to increasingly become primary treatment strategies.

Martine Piccart (MP): Most of the progress has come from a multidisciplinary approach using surgery, radiotherapy and adjuvant systemic chemotherapies.

MP: There is a need to change the culture of research in Europe. There is still a lot of duplication, a lack of coordination and data sharing. Very often, by the time the data is published it is outdated. Much more could be done with the data collected both by companies and academics.

RS: By getting more data, are we going to get better at prognostication?

MP: In the clinical trials today we collect precious material which is analysed but the data is not shared soon enough. We could have a system where the prior consent form signed by the patient already ensures the data is made available to the scientific community. Clinical investigators and the pharmaceutical industry could be obliged to share data at an early stage for the controlled arm which represents the standard of care while the same could be done later for the new drugs.

AE: There is a need to better connect basic research and clinical research. Clinical research can only make advances if it embraces fundamental research which brings in the innovations that will change the clinical approaches. Compared to American culture, Europe is lagging behind in believing in technologies that will lead to a new type of research in life science.

RS: What happened to personalised medicine? Has the hype been overplayed?

MP: We have largely underestimated the efforts that it will take to have personalised medicine. In Europe, there is a lack of interest in the development of diagnostic tests.

We will need another, efficient validation model for the biomarkers.

RS: Are we using too many end points in clinical trials that are not validated or irrelevant in terms of incremental clinical benefit?

Francesco Pignatti (FP):We will need different economic models that take into account different fields that will bring their own characteristics in what they may provide either to specific subclasses of tumors or in transversal developments such as immunotherapy. The economics of small subclasses is very difficult as we are looking at about 800 drugs under development.

RS: How do we make sure that the public realizes cancer cure is a long game despite what is sometimes reported in the media?

AE: There is a disconnect between what is being talked about in the oncology community and what is out in the media. We should not undersell the benefits of discoveries in basic research or oversell achievements in clinical research.

FP: There is a need to empower and educate patients as to what a real benefit is as opposed to a marginal one.

Part 2:

Interview with Richard Bergström, Director-General, the European Federation of Pharmaceutical Industries and Associations (EFPIA)

RS: Why is industry in trouble with its reputation? Why has it not caught up with societal demand for more transparency?

RB: In Europe, the reputation of industry among the general public is quite good compared to other sectors. However, this is not the case in the media and among decision-makers. Industry has failed to communicate that it is about knowledge. Industry has to open up. Two years from now, it will open up on all its relationships with healthcare professionals.

To advance science, we need to find the right balance between competition, intellectual property, careers and the sharing of information.

When it comes to transparency, industry is moving in the right direction.

RS: A lot of data is coming out but we are getting less and less for higher and higher prices. Do you think the prices of cancer drugs are justified at the level they are set? Do you think we can continue to afford this as a fair equitable society?

RB: We are underestimating the long term impact of the understanding of the disease. Right now in Europe, drug expenditure is flat and it is expected to be like this for some time, however, there are rearrangements. The oncology expenditure in healthcare may be going up by 10-15% per year in many countries but we are saving elsewhere in the system. Overall, society can manage costs by keeping innovation and generating savings on off-patent medicines. Over time, prices go down.

RS: Do you think that the transition from brands to generics is going to save the drugs budget?

RB: Industry has changed. It does not position the use of branded products as a requirement to support R&D. It recommends increased volumes of generics. Industry is committed to demonstrating the added value of its products.

RS: What do you see Europe doing for global cancer control?

RB: Cancer research in Europe is still very fragmented. Forty percent of the drugs in the pipelines are in the field of oncology. However, surprisingly, there are very few public private partnerships in oncology in the EU IMI programme. The oncology community should think about how to bring oncology into the new EU framework for public private partnerships between industry and academia.

Part 3:
Interviews with patient advocates

Interviewees (guests):
Markus Wartenberg, Sarcoma Patients Euronet
Katie Rizvi, Asociatia Little People Romania
Roger Wilson CBE, Founder and Honorary President, Sarcoma UK

Richard Sullivan (RS): Do you think there is a collegiality to patient advocacy in Europe for the minimum best standards of care across Europe considering the major discrepancies between countries? What do you think the role of patient advocates is in this respect?

Markus Wartenberg (MW): There are discrepancies in the support for patients, in access to treatment and care in Europe. If regulators make different decisions in different countries about access to treatments, this is a very frustrating situation for patients. Patient advocates should play a much more important role in such decisions.

Roger Wilson (RW): There is the potential to establish that patients have the right to certain standards of care starting with the earliest possible diagnosis and continuing right through the introduction of palliative care as a sensible part of the pathway. Palliative meaning alleviating symptoms and not end of life care.

RW: There is a disconnect between progress made and the feelings of the patients. We are all aware of the power of collaboration but the patient as part of that collaboration is essential.

RS: What could be done to improve the engagement of patient groups in policies?

Katie Rizvi (KR): Patient advocates need to look at areas where they can take a united stand across Europe. There should be a lot more brainstorming among patient advocates. The patient community needs to improve collaboration across different diseases.

MW: The patient advocacy community would like industry to engage them in processes such as those of clinical research as early as possible. They would like to be accepted as expert groups by the oncology community. Collaboration with industry is often reduced to funding.

RW: Demonstrating value is the biggest challenge before the patient advocacy community. If we can demonstrate that this movement of patient involvement is delivering value to the entire community decision makers will support it.

RS: What have the patient advocacy groups not done well enough?

KR: Not defining what patient advocacy means is a weakness. There is no place where you can learn the profession of patient advocate.

RS: What is the role of patient advocacy in driving the equity agenda?

MW: Patient advocacy must be better organized in Europe. There is no coordination or a strong common voice.

RS: There are a lot of contradictions between what happens in research and what goes out in the public discourse on patient outcomes. There is a big division between the social determinants of cancer and the prevailing paradigm in research which is very biomedically focused.

Question: What is a clinically relevant end point for the patient and for the doctor?

MW: The cost of cancer care is always reduced to the cost of drugs but patients are kept alive thanks to a multidisciplinary approach. Public discourse is saturated with the costs of medicines while the most costly part of cancer treatment is the in-patient time in hospital.

Session 2:

Adherence to cancer treatment

Chair:
Jola Gore-Booth, EuropaColon

This session focused on patient adherence to cancer treatment in an effort to gain better understanding of this important issue from the perspectives of the medical oncology and nursing areas.

Session Takeaway Messages:

- ***Anticipation and effective management of side effects enhances coping strategies***
- ***Adherence is strongly influenced by the doctor-patient relationship***
- ***Prescribing decisions need to be taken in partnership***
- ***Multi professional strategies are essential***

Speakers:
Robert Glynne-Jones, Mount Vermont Hospital
Giora Sharf, Israeli CML Patients Organisation
Sara Faithfull, University of Surrey

The rates of accidental and intentional non-adherence among cancer patients are alarmingly high. Understanding the key motivators and risk factors behind such behaviour is crucial to the development of strategies for improvement. Better communication and education on side effects is the key to getting the best out of patients. Anticipation of side effects and their effective management can enhance coping strategies.

A large multinational adherence research project has revealed that healthcare professionals need to be careful that permission given to miss medication doses over one or two days is not interpreted as allowance to do so over a longer period. Adherence is strongly influenced by the doctor-patient relationship and by patients' satisfaction with the information provided by their doctors. There is a need to improve communication about adherence between doctor and patient, and raise greater awareness of the implications of non-adherence.

Most adherence issues stem from the absence of the patient's own perspective from the prescribing decision process. This needs to be managed as a partnership and decisions need to be jointly considered by the patient and the healthcare professional. Clinicians should invite patients to discuss their views of medication and adapt treatment strategies to include adherence assessment.

Session 3:

Cancer: now what? Returning to normal life

Chair:
Joan Kelly, ECL

This session discussed survivorship and the return to normal life and included the viewpoints of patients, researchers and healthcare professionals. The aim of the session was to show how those who have had cancer can live a healthy life through diet and exercise. It explored the area of employment following treatment and survivors who had made the transition back into normal life shared their experiences.

Session Takeaway Messages:

- ***Cancer treatments can have major side effects with considerable impact on quality of life (fatigue, loss of confidence)***
- ***Physical activity can help reduce such major side effects***
- ***Major changes to the services set up are required to ensure patients are less affected by cancer and its treatment***
- ***Better-designed studies can help create specific recommendations (e.g. on diet)***
- ***Other key aspects are the unlocking of creative potential in patients and cancer support centres focusing on the person behind the cancer***

Speakers:

Shirley Bianca, breast cancer survivor
Anna Campbell, University of Dundee
Rachel Thompson, World Cancer Research Fund International
Nathalie Doyle, the Royal Marsden NHS Foundation Trust
Linda Sharp, the Irish National Cancer Registry
Sarah Walshe, cancer survivor

The unlocking of their creative potential can help patients heal body and soul.

There is convincing evidence that physical activity reduces the risk of certain cancer types including colon, breast and endometrial cancers.

There is also emerging evidence suggesting that physical activity after cancer diagnosis has a protective effect. It is established that physical activity can help reduce major side effects of treatments that impact on quality of life such as fatigue and lack of confidence.

Data suggests that dietary supplements are unlikely to improve prognosis or survival and might in fact be harmful. It is best to receive nutrients through a healthy diet where possible. Unintentional weight loss should always be seen as a warning sign. More evidence is becoming available, but we need more and better-designed studies in order to develop specific dietary recommendations ideally tailored to the needs of different groups of patients.

The first national cancer survivorship initiative was undertaken in 2008. Major changes to the services set up are required to ensure that the degree to which cancer and its treatment affect patients is as low as possible. There is an urgent need to rigorously develop and evaluate appropriate interventions that improve time to recovery and rates of work resumption in order to restore cancer survivors to their desired level of work participation and minimize economic losses to employers and society as a whole.

Trying to carve out a new sense of self after cancer may be even more challenging than undergoing cancer treatment. Cancer support centres treat the person and not just the cancer and aim to help the patient heal at their own pace. Real healing begins with an empathic connection with the person behind the patient.

Session 4:

Best Practices: didn't we do well?

Chairs:

Sema Erdem, Europa Donna

Jan Geissler, Leukemia Patient Advocates Foundation

Patient advocacy organisations had the opportunity to share best practices and successful initiatives with their peers. Projects were selected through a competitive application process and focused on three areas under the overarching theme of collaboration: 'patient advocacy', 'patient support services' and 'awareness and communication'.

Speakers:

Ingrid Kössler, Swedish Breast Cancer Association

Anemone Bogels, the Dutch Federation of Cancer Patient Organisations

Elisabetta Iannelli, Italian Federation of Volunteer based Cancer Organisations

Margaret Wilcox, the Independent Cancer Patients Voice

Stefania Vallone, the Women Against Lung Cancer in Europe Organisation (WALCE)

Evelyne Manten-Horst, St Radboud UMC & the AYA Platform

Susan Barber, European Men's Health Forum

Teodora Kolarova, APOZ and Friends

The collaboration among patient advocacy organisations was behind their contribution to the establishment of a national cancer control strategy in Sweden.

Through a survey addressed to the political parties ahead of elections, patient advocacy organisations raised awareness about key issues in cancer care such as long waiting times and the small budget allocated to cancer in the total budget of healthcare. Three years later the Swedish government took the decision to put a national cancer control strategy in place.

The Dutch Federation of Cancer Patient Organisations defined patient-driven quality indicators for standards of care.

Working with professional associations, it developed patient guides defining minimum conditions for good care. Hospitals were evaluated on the basis of patient feedback structured around these quality indicators and that evaluation was made public on the Dutch Federation website. These patient guides empowered patients by raising their awareness of the standards of care they could expect and by enabling them to make informed choices. Since patients are usually treated in the hospital where they are diagnosed, these guides also help general practitioners with their decision making during the referral process. In the long term, the objective of the Federation is to combine the patient feedback in these guides with data from professional cancer registries and in this way move towards integrated transparency. A national observatory for cancer treatment and care was established in Italy in 2008 through the initiative of an alliance uniting healthcare professionals, patients and authorities. This observatory led to the adoption of new laws which reduced the time of disability recognition for cancer patients and made innovative drugs immediately available all over Italy. Several examples demonstrated that partnerships between patient organisations, healthcare professionals and institutions are effective in improving the health and life of people with cancer.

By encouraging groups collecting tissues to work together, the Independent Cancer Patients Voice stimulated the creation of a large tissue bank and managed to bring about changes to tissue access policies.

Patient advocates played a key role in educating health professionals on approaching potential donors and in raising public awareness of the need for tissue donation.

The Women Against Lung Cancer in Europe organisation (WALCE) designed a lung cancer clinical trial database in order to increase access to information for patients but also for health professionals who are not always aware of certain trials.

The initiative required strong cooperation with the centres and pharmaceutical companies conducting clinical trials. Another key task was to evaluate what information would be relevant to patients. Patient advocacy groups have a key role in helping patients become responsible users and in positively impacting the patient recruitment in clinical trials.

The AYA Expertise platform is an initiative of the St Radboud University Medical Center (The Netherlands) to unite Adolescents and Young Adults (AYAS).

The platform seeks to create an AYA-centred healthcare vision and implementation supported by research and education. It is advised by an AYA task force in which patients and professionals work together towards a patient-centred healthcare system. This collaboration has led to concrete achievements including a hospital-wide integrated AYA-centred care concept, an AYA outpatient multidisciplinary clinic and the online AYA4 community. A nationwide AYA platform was established in February 2013 and the first national seminar for AYAs and healthcare professionals will take place in February 2014.

The European Men's Health Forum initiated a service delivered though an online tool where men could ask questions about any aspect of their healthcare or make enquiries prior to receiving care for prostate health.

The initiative was planned by a multi-stakeholder group including healthcare professionals and patients.

Rare diseases are rare because we rarely talk about them.

The zebra turned into the international symbol of neuroendocrine tumors (NET) and inspired the international neuroendocrine cancer alliance (INCA) as the hero of the NET Cancer Awareness Day on 10 November.

Session 5:

Panel Discussion: quality of life / palliative care - do patients perceive quality of life the same way their doctors do?

Chair:
Tom Hudson, Europa Uomo
Moderator:
Kathy Redmond, Cancer World Magazine

Session Takeaway Messages:

- ***The treatment strategy developed by the multidisciplinary team should address all aspects of care***
- ***Clinical studies should look beyond adverse events and incorporate a valid quality of life instrument***
- ***It is recommended that palliative care forms a part of the consultation team rather than being managed separately by palliative care units in hospitals***
- ***Palliation equals alleviation of symptoms, both physical and psychological and should be addressed earlier on in cancer care***

Panelists:
Nathan Cherny, Shaare Zedek Medical Center
Irene Higginson, King's College London
Phil Larkin, University College Dublin
Roger Wilson, CBE, Founder and Honorary President, Sarcoma UK

Surveys among medical oncologists show low referral rates to palliative care services. Palliative care is associated with end of life care and therefore oncologists do not feel it appropriate to refer to palliative care patients who are not considering end of life care.

It is essential to work on changing existing attitudes towards the benefits palliative care can offer earlier on in the disease journey.

The language of palliative care discourse has become confusing – it includes terms such as "life threatening", "life limiting", "terminal care" and we have a responsibility to cut through the confusion.

Palliation equals alleviation of symptoms, both physical and psychological.

In order to change mindsets and attitudes, personalised medicine should be redefined as medicine that targets the specific needs of a person and the treatment strategy developed by the multidisciplinary team should address all aspects of care.

Evidence of the benefit of palliative care especially early on in the disease journey is lacking and needs to be gathered.

Appropriate education of healthcare professionals is also crucial as a driver of positive change.

If palliative care is a part of the consultation team it will be optimally incorporated into the overall treatment and decision-making process as opposed to the scenario where palliative care is managed by centralized units in hospitals.

Patient advocates need to advocate with professionals, professional associations and governments for the concept of integrated multidisciplinary care to be put into practice in all cancer centres.

In addition to reporting on adverse events, a clinical study should incorporate an appropriate instrument for the evaluation of quality of life .

It is important for nurses to be empowered to share their own perspective on quality of life which they witness through their daily experience with patients.

The perception of quality of life issues differs considerably among members of the clinical community, patients, regulators and policy makers. Such differences make it even more difficult for patients to access appropriate treatments.

There are a number of quality of life assessment instruments available – some may be too long, others too short and not including the right questions. Some of these instruments have an advantage over biomedical markers in terms of identifying when a patient's condition begins to deteriorate.

Session 6:

Personalised medicine

Co-chairs:
Sarper Diler, Myeloma Patients Europe
Raphael Catane, Sheba Medical Center

Session Takeaway Messages:

- ***The French molecular testing initiative has shown that molecular stratification can be successfully integrated into the healthcare system and that it is also an opportunity to improve patient accrual onto new types of clinical trials***
- ***There is still a long and complicated journey before every cancer patient can receive the right drug in the right dosage at the right time***
- ***Healthcare professionals need to engage more closely with patients in discussing treatment options including whether personalised treatment would be beneficial to the patient, whether it might represent a chance for a cure and the side effects which may result from it***

Speakers:
Herbert Pinedo, Vrije Universiteit Amsterdam
Agnes Buzyn, Institut National du Cancer
Jola Gore-Booth, EuropaColon

Chemotherapy used to attack the nucleous of the cell but now we are aware of the proteins and their kinases (biology) that have an important role in the functioning of the cell. In oncology, we will be seeing radio immunotherapy and chemo radiotherapy more and more. Specific cells and their environment can be radiated by adding radiotherapy to a monoclonal antibody through a linker.

With the advance of new antibody drugs, it becomes increasingly important to understand how they work.

In future, imaging will become better at telling us if a drug reaches a tumour.

All cancer centres and laboratories in France are being organized to offer targeted therapies to all cancer patients with a companion test i.e. the identification of a biomarker. In France, all patients have access to molecular testing as soon as the targeted therapy is available.

At this stage, it would be more appropriate to refer to personalised medicine as precision medicine or stratified medicine because it is based on a tumour-centred approach rather than a patient-centred approach. Molecular alterations can be shared in several types of cancers.

Currently, there are 20 target therapies available but more than 900 are under development worldwide.

At this moment, 1 to 7 biomarkers can be tested for each tumour but in future there may be more than 50 biomarkers. Therefore, the companion test approach will become more complex. The alternative is the sequencing of the entire DNA of the tumour, which is also referred to as next generation sequencing, but at this stage it is not known which of these two approaches would work at the national level.

It is driver mutations that contribute to the progression of a tumour and it is important to understand that a targeted drug will only be effective if it attacks a driver mutation rather than a common one.

Tumours can be heterogeneous in the expression of the abnormality.

As a result of improved understanding of their specificity, cancers are turning into orphan diseases.

Studying a target therapy in a single disease is an inefficient use of resources.

We need to re-think clinical research in order to better allocate resources. In France, two options are under consideration: clinical trials on several diseases sharing the same abnormalities (basket studies) or sequencing the tumours of patients with one diagnosis (e.g. lung or breast) and allocating treatment depending on the abnormalities expressed (umbrella trials).

The French molecular testing initiative has shown that molecular stratification can be successfully integrated into the healthcare system. It is also an opportunity to improve patient accrual onto new types of clinical trials.

A long and complicated journey lies ahead of us before every cancer patient can receive the right drug in the right dosage at the right time.

In most of Europe, knowledge of personalised medicine among clinicians should be improved through better education.

Healthcare professionals need to engage more closely with patients in discussing treatment options. Such discussions should transparently address the reality that not every patient can benefit from personalised treatment, that it is not always a cure and that there are side effects accompanying targeted treatment.

New pricing methods need to be tested to reward the manufacturer's R&D effort and investment while ensuring fair prices for healthcare payers.

Session 7:

Some patients are more equal than others / Satnav cancer: where do I find the best?

Co-chairs:
Ian Banks, European Men's Health Forum
Jan Geissler, Leukemia Patient Advocates Foundation

Session Takeaway Messages:

- ***In light of the existing inequalities, healthcare services should ensure that the huge differences in cancer survival between men and women across Europe are taken into account***
- ***There is also a risk that personalised medicine becomes more exclusive in addition to being more personalised***
- ***Patient organisations have a crucial role to play in helping patients navigate this complex new environment***
- ***Debates and initiatives around networks and centres of reference are driven by factors like the specialization of cancer care, the complexity of technologies and the need to concentrate resources as required by the high costs of treatment***
- ***Networks could be the right organisational models to respond to these challenges. National networks of centres of reference might be the starting point because these require external accreditation of the centres***
- ***Networks of specialized centres, accreditation schemes and transparent quality criteria may provide robust guidance to patients and reduce the risk of inequality of access to best quality cancer care***

Speakers:

Mark Lawler, European Cancer Concord
Ian Banks, European Men's Health Forum
Jan Geissler, Leukemia Patient Advocates Foundation
Mahasti Saghatchian, OECI
Josep Borras, European Partnership Action Against Cancer

The European Cancer Concord is a new initiative aiming to improve access to an optimal standard of cancer care and research for European citizens. Through a partnership between patient advocates and healthcare professionals, the European Cancer Concord drafted a Patient Bill of Rights aiming to empower equity and innovation on cancer care and research for Europe's citizens.

The European Cancer Patients' Bill of Rights calls for the right of every European citizen to receive the most accurate information, to be proactively involved in his/her care and the ability to have shared decision-making between the healthcare provider and the citizen. It also calls for equal and timely access to appropriate care including clear pathways to clinical innovation and the right to be treated in healthcare systems that ensure improved outcomes and patient rehabilitation.

Healthcare services should work to take into account the enormous gender differences in cancer survival across Europe. For example, studies have shown that there are considerable differences between men and women with regard to symptom awareness and the use of health services.

Patients are excited about progresses in tackling cancers with more targeted or personalised medicines, but this also brings challenges in areas like validated companion diagnostics, health technology assessment, clinical trials endpoints and healthcare budgets.

Biomarker based medicine may also create new access barriers. Regulators may seek to limit access to expensive therapies to those who need them the most or those who have access to appropriate diagnostics, leaving behind others who might still benefit. There is a risk that personalised medicine becomes more exclusive in addition to being more personalised.

Patient organisations need to work together and be included in the decision-making process when priorities are set. The current, very restrictive approach to providing information to patients needs to be completely reconsidered in view of the complexity of personalised cancer care. Patient organisations have a crucial role in helping patients navigate their journey in this new environment.

Survival and quality of life of cancer patients often depend on receiving best quality care in a timely manner. The increasing complexity and specialization of cancer care makes it especially challenging for patients to identify specialized centres and experienced experts in their specific disease. Networks of specialized centres, accreditation schemes as well as transparent quality criteria may provide robust guidance to patients and reduce the risk of inequality of access to best quality cancer care.
Debates and initiatives around networks and centres of reference arise from a series of factors and challenges including the specialization of cancer care, its

complex technologies and high costs that require a concentration of resources. Networks as organisational models could be a way to respond to these challenges. There are several national and international initiatives but they lack consistent quality criteria. In addition, there is a lack of external evaluation of excellence. Excellence tends to be self-declared.

The 2011 EU Directive on the application of patients' rights in cross-border health lists the criteria that cancer centres must fulfill in order to be part of European reference networks.

National networks of centres of reference might be the starting point because these require external accreditation of the centres.

Multidisciplinary teams have been defined in the context of the European Partnership Action Against Cancer (EPAAC) as "An alliance of all medical and healthcare professionals related to a specific tumor disease whose approach to cancer care is guided by their willingness to agree on evidence-based clinical decisions and to coordinate the delivery of care at all stages of the process, encouraging patients in turn to take an active role in their care".

The OECI Accreditation and Designation Programme was launched in 2008. It focuses on the planning and organisation of global care (from prevention to follow-up) on the basis of quality standards and quantitative data. Improving comprehensiveness and quality is the main purpose of the programme which helps patients make informed choices.

Session 8:

Empowering young people with cancer - a passport for survivors

Chair:
Gerlind Bode, International Confederation of Childhood Cancer Parent Organisations

Session Takeaway Messages:

- ***General practitioners need support in order to provide adequate long-term follow-up***
- ***The survivorship passport should be a standard of care***

Speaker:
Sabine Karner, Österreichische Kinder-Krebs-Hilfe

Currently, there are approximately 300.000 to 500.000 childhood cancer survivors in Europe. General practitioners do not have enough information and experience about the needed long-term follow-up of childhood cancer survivors.
The survivorship passport provides the patient with advice and guidance on specific long-term follow-up of possible late effects. It contains cancer history and therapy information. The survivorship passport should be a standard of care in the follow-up of childhood cancer survivors. It is a tool for information transfer and a tool for education of the survivors. Those who understand the reasons behind it will be more likely to pursue follow-up care.

Patient Advocacy Square (PAS) and Patient Advocacy Lounge

The Patient Advocacy Square and Lounge areas were considered by most organisations as an excellent opportunity to share their initiatives and interact with others

For the first time at the European Cancer Congress, a dedicated exhibition area for cancer patient advocacy organisations called "Patient Advocacy Square" was set up. It aimed to give European patient advocacy organisations the opportunity to promote their resources and services to the professional oncology community, hold meetings and network with new and existing contacts.

Twenty one booths were manned by patient advocates representing various cancer-site specific, Europe-based organisations. They were selected on the basis of a competitive application process. In future, there should be a focus on significantly increasing the number of visitors to these areas.

About fifty scholarships were granted to patient advocates from Europe-based cancer patient groups to enable them to travel to Amsterdam to take part in the European Cancer Congress 2013.

Protest of patient advocates

Patient advocates were banned from entering the main exhibition hall adjacent to the Square due to a newly-imposed Dutch Regulation governing the separation of pharmaceutical companies from anyone who wasn't a "prescriber". This was a consequence of the transposition of the EU pharmaceutical legislation 2001/83/EC, 2004/27/EC on "information to the general public on medicinal products" into the Dutch legislation.

By signing a petition, patient advocates from all across Europe strongly objected to the Dutch Regulation.

Patient Advocacy & Ethics Track Committee 2013

Ian Banks, ECCO PAC Chair & Co-chair Patient Advocacy & Ethics Track - EMHF

Kathy Redmond, Co-chair Patient Advocacy & Ethics Track – Cancer World Magazine

Gerlind Bode, ECCO PAC member - ICCCPO

Rafael Catane, ESMO cancer patient working group

Sarper Diler, ECCO PAC member - Myeloma Patients Europe

Sema Erdem, ECCO PAC member - Europa Donna

Jan Geissler, ECCO PAC member - Leukemia Patient Advocates Foundation

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