



Hearing of the European Parliament's Special Committee on Beating Cancer (BECA)
Beating cancer - empowering patients and their caregivers
Monday 11 January 2021, 13:45-18:45

Welcome and opening remarks by [Bartosz Arlukowicz MEP](#), BECA Chair

In opening remarks BECA Chair **Bartosz Arlukowicz MEP**:

- announced that the Special Committee will soon hold a hearing dedicated to the intersection of cancer with other health challenges, including COVID-19 and AMR.
- informed that the Commissioner for Health and Food Safety, Stella Kyriakides, has been invited to join the [Committee's meeting on February 4th](#) to present the just published proposals from the European Commission for a Europe's Beating Cancer Plan to the Committee members (not confirmed yet if she will).

Introducing the hearing on Patient Empowerment he referred to foundational statements of the rights cancer patients including European Cancer Patient's Bill of Rights and the [European Code of Cancer Practice](#), developed by the European Cancer Organisation.

Part 1: Patients' Rights

Dr. Jan Geissler, Workgroup of European Cancer patient Advocacy Networks (WECAN):

- There are huge inequalities across Europe regarding patient access to information, prevention, diagnosis, treatment, follow-up and reintegration.
- Recommended to synergize past and current EU initiatives relevant to cancer in order to address cancer patients' needs and advance patient access to relevant information.
- Models promoting excellence centres and knowledge sharing, such as the European Reference Networks, need to be strengthened through adequate funding.
- Patients and patient organisations have a crucial role but are still the most the most underfunded and unempowered part of the healthcare system.

Full presentation [here](#).

Willy Palm, Unit Head, Regional Governance and Languages at World Health Organization:

- The increasing incidence of chronic diseases and complexity of healthcare require more active engagement of patients in their care and health policy design.



- Patient-centredness is key to good quality and modern healthcare; it requires to: listen to patients' voice when shaping health policy, take account of their preferences and engaging them in the co-production of their own care.
- Legal protection of patients is needed against information asymmetry, vulnerability, and inequalities; Netherlands can provide an example in that respect.

Full presentation [here](#).

Prof. Françoise Meunier, leader of the project "Right to be Forgotten", European Cancer Patient Coalition:

- 4 EU Member States (France, Belgium, Netherlands, Luxembourg) have taken legal measures to counter discrimination faced by cancer survivors when trying to access financial services such as loans and insurance
- The EU has legal basis to harmonise legislation in this area and should act on it
- Implementation of the "Right to be Forgotten" is a concrete goal that can be achieved as part of Europe's Beating Cancer Plan

Stefan Gijssels, Chief Executive Officer of "Digestive Cancers Europe":

- The burden of colorectal cancer makes optimal early detection crucial. This requires political will and best practice sharing via a European platform of screening agencies.
- A European Cancer Dashboard is needed to put an end to the current data fragmentation and deploy the data needed to design quality cancer care policies.
- The [Essential Requirements for Quality Cancer Care](#) of the European Cancer Organisation should be used by health systems to achieve multidisciplinary cancer care.
- Patient organisations are the only stakeholder group which really understand the whole patient journey. They must be recognized for their value for patients and society and actively involved to make health systems more effective and efficient.

Full presentation [here](#).

Dr Stanimir Hazardzhiev, Chairperson of the Bulgarian National Patients' Organisation:

- Europe's Beating Cancer Plan should provide guidance for effective implementation.
- Revised pricing and reimbursement models are needed so that all European citizens gain timely access to quality healthcare.
- The Beating Cancer Plan should be a roadmap to serve as an example to all other disease areas to ensure that no one is left behind by 2030.

Full presentation [here](#).



Q&A session: During the ensuing discussion, the members of the Special Committee voiced their support for the inclusion of strong provisions relating to patients' rights in Europe's Beating Cancer Plan. Key topics that were raised by the MEPs included:

- **The implementation of the « Right to be Forgotten»:** Cindy Franssen MEP (EPP, Belgium); Nicolae Ștefănuță MEP (Renew, Romania); Dolors Montserrat MEP (EPP, Spain); Katarina Konecna MEP (GUE/NGL, Czech Republic); Tomislav Sokol MEP (EPP, Croatia); Tilly Metz MEP (Greens/EFA, Luxemburg);
- **The EU's role in guaranteeing access of all patients to quality cancer care:** Alessandra Moretti MEP (S&D, Italy); Katarina Konecna MEP (GUE/NGL, Czech Republic); Andrey Slabakov (ECR, Bulgaria);
- **Cancer patients' return to work:** Dolors Montserrat MEP (EPP, Spain); Cindy Franssen MEP (EPP, Belgium); Bronis Ropé MEP (Greens/EFA, Lithuania);
- **Patients' rights to cross-border healthcare:** Alessandra Moretti MEP (S&D, Italy); Tomislav Sokol MEP (EPP, Croatia);
- **Patient-centredness and patient empowerment:** Joanna Kopcińska MEP (ECR, Poland); Romana Jerković MEP (S&D, Croatia).

Alessandra Moretti MEP (S&D, Italy): *"A European Health Union with binding measures across the EU is needed to ensure that we have minimum healthcare service provision applied to all European citizens regardless of where they live."*

Nicolae Ștefănuță MEP (Renew, Romania): *"Europe is a place famous for ensuring that its citizens have equal rights in their relations with banks and financial institutions. I urge Stella Kyriakides to take account of these various aspects in Europe's Beating Cancer Plan."*

Dolors Montserrat MEP (EPP, Spain): *"People who had a cancer diagnosis face physical and mental problems, but also social, economic and job-related problems. Everyone should have social and employment protection of adequate levels in Europe."*

Tomislav Sokol MEP (EPP, Croatia): *"It is very important to have the same set of patients' rights across all EU Member States."*

Romana Jerković MEP (S&D, Croatia): *"Patients' knowledge, skills and experience are extremely valuable not only for themselves and their physicians, but also for politicians and policy-makers."*



Rapporteur **Véronique Trillet-Lenoir** emphasised the importance of providing funding to patient organisations and expressed her strong support to the rights enshrined into the [European Code of Cancer Practice](#) developed by the European Cancer Organisation. She described it as a *“guarantee for the provision of best available care”*, calling for further work within EU institutions towards their effective implementation. Finally, she repeated her agreement with the importance of implementing a harmonised “Right to be Forgotten” across the EU.

Part 2: Survivorship, Quality of Life and Caregivers

Introducing the session, BECA Chair **Bartosz Arlukowicz** stressed the importance of the numerous caregivers and of the informal care they deliver, who he said *“account for great savings for health systems, but are facing increasing pressure.”*

Dr Matti Aapro, President of the European Cancer Organisation:

- Cancer patients’ rights enshrined within the [European Code of Cancer Practice](#) must be made a reality across all EU Member States.
- The Beating Cancer Plan should cover all bases on Survivorship and Quality of Life, including cancer co-morbidities, workplace reintegration, cancer distress, pain management and sexual health needs.
- The report [Free From Cancer: Achieving Quality of Life for All Cancer Patients and Survivors](#), developed by the European Cancer Organisation’s [Survivorship and Quality of Life Network](#) provides concrete recommendations in this aim.

See Matti Aapro’s full presentation [here](#).

Katie Rizvi, Co-Founder & Executive Director, Youth Cancer Europe:

- The EU must put an end to the huge inequalities in access to sexual and reproductive healthcare for young people living with cancer across Europe, and include adoption rules within their right to be forgotten.
- Late effect surveillance and long-term follow-up should be an integral part of Europe's Beating Cancer Plan. European guidelines must be translated into care at national level.
- Mental health support for cancer patients and their caregivers needs to be part of routine care and covered within health insurance programs.
- EU funding instruments need to be extended to the capacity building of patient organisations for EU cancer policy initiatives to become part of cancer patients’ reality.

See Katie Rizvi’s full presentation [here](#).



Dr Nicolò Battisti, Medical oncologist, President-Elect of the International Society of Geriatric Oncology:

- Older individuals have higher cancer incidence and mortality, and represent an increasing share of the total cancer patient population.
- Older cancer patients are extremely heterogeneous; the management of their cancer is complex and needs to be multidisciplinary, with a focus needs moving from survival to quality of life. France provides an example of good practice in this respect.
- Concrete steps for the EU to take to banish age discrimination in cancer care include: improving access to healthcare professionals trained in geriatric oncology, ensuring inclusion of older patients in clinical trials, and responding to the comorbidity challenge.

See Nicolò Battisti's full presentation [here](#).

Prof. Andreas Charalambous, President of the European Oncology Nursing Society:

- Today's challenge in cancer is not only to put years in survivors' lives, but also to put life in the survivors' years. Health systems need to do more to ensure sustained quality of life.
- Multidisciplinary is key to improving quality of life for cancer patients. This requires more political will for effective implementation.
- EU action is needed to ensure that an adequately trained workforce is made available to care for patient needs, by minimising workforce shortages and leveraging the EU Professional Qualification Directive.

See Andreas Charalambous' full presentation [here](#).

Claire Champeix, Policy and Project Officer at Eurocarers:

- Carers, i.e. persons providing care - usually unpaid - to someone with a chronic illness, disability or other long lasting health or care need, outside of a professional or formal framework, are central to the sustainability of health systems and have a crucial role for the quality of life of the patients.
- Carers support cancer patients in all aspects of their care and their life.
- An ambitious and comprehensive EU-level initiative is needed to support and empower carers, ensuring their access to information and training, recognising their role and the challenges they face, preserving their health and enhancing their social rights.

See Claire Champeix's full presentation [here](#).

Q&A session: During the ensuing discussion, the members of the Special Committee voiced their support for elevating cancer patients' quality of life during and after treatment, and protecting them against all forms of discrimination. Key topics that were raised by the MEPs included:



- **Access to supportive care, rehabilitation and psycho-oncology** (including insurance coverage): Katarina Konecna MEP (GUE/NGL, Czech Republic); Nathalie Colin-Oesterlé MEP (EPP, France); Bronis Ropé MEP (Greens/EFA, Lithuania); Tilly Metz MEP (Greens/EFA, Luxembourg);
- **Recognition and protection of cancer carers:** Monica Semedo MEP (Renew, Luxembourg); Tilly Metz MEP (Greens/EFA, Luxembourg); Chiara Gemma MEP (Non-attached, Italy);
- **Care for older cancer patients and the fight against age discrimination:** Alessandra Moretti MEP (S&D, Italy); Katarina Konecna MEP (GUE/NGL, Czech Republic);
- **Cancer patients' long-term follow-up** (Survivorship passports and coverage by health insurance): Cindy Franssen MEP (EPP, Belgium); Nathalie Colin-Oesterlé MEP (EPP, France);
- **Childhood cancer care and the support to reintegration of childhood cancer survivors:** Alessandra Moretti MEP (S&D, Italy); Monica Semedo MEP (Renew, Luxembourg).

Cindy Franssen MEP (EPP, Belgium): *"Survivorship and Quality of Life are issues in which big steps can be made and more cooperation is needed."*

Joanna Kopcinska MEP (ECR, Poland): *"Oncological nurses are highly skilled professionals fulfilling very important roles in hospitals and in their local communities."*

Alessandra Moretti MEP (S&D, Italy): *"We need to offer the best possible care to older cancer patients. Being an elderly person should not be seen as a problem, but as a value for society."*

Monica Semedo MEP (Renew, Luxembourg): *"Not all Member States give the option to carers to take leave in order to take care of their child. This might mean making a choice between giving up your career and financial situation or not being able to really take care of your child. No one should face this choice."*

Rapporteur **Véronique Trillet-Lenoir** stressed the need to ensure the reintegration of increasingly numerous cancer survivors in their emotional, social, professional and family lives. Areas which she mentioned as of particular interest were:

- the access to psychological, nutritional, social and sexual health services;
- specific needs of particular age groups, such as older cancer patients;
- long-term follow-up through a Survivorship passport, and its financial coverage;
- cancer survivors' return to school and work; and
- education, training and empowerment of caregivers.



Address by John Ryan, European Commission, Director of Public Health, Country Knowledge and Crisis Management

Reflecting on the hearing, John Ryan said it is clear that *“Europe’s Beating Cancer Plan must cover areas which go beyond the health sector”*. Areas such as patients’ rights, including the Right to be Forgotten, patient-centred health systems, the rights of carers and the reintegration of cancer patients into normal life, including their return to work, were cited as *“key elements to patient’s recovery and dignified end of life”*. Mr. Ryan also said the Plan would include provisions pertaining to the education of health professionals and to psychological support.

Importantly, Mr. Ryan talked about the idea of a **Cancer Inequalities Registry**, which would be included in Europe’s Beating Cancer Plan and aim at *“better map and analyse differences between and within the Member States”* in respect to access to cancer treatment and care.

Regarding funding, Mr. Ryan explained that Europe’s Beating Cancer Plan would use resources from the EU4Health program, the Horizon Europe’s Cancer Mission and structural and cohesion funds. Finally, Mr. Ryan announced that the Plan would also include proposals for its governance, with follow-up mechanisms involving Member States, the European Parliament and the stakeholder community.