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European Cancer  
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## Press Release

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Brussels, Belgium

# Value of Innovation in Oncology From CanCon towards the future of cancer care

*“Value of Innovation in Oncology” White Paper and the CanCon Guide  
presented for the first time at the European Parliament*

**Event hosted by MEP Elisabetta Gardini (EPP, Italy)  
in collaboration with MEP Lieve Wierinck (ALDE, Belgium)**

European Parliament, Brussels, April 25, 2017: European cancer patients live a paradox today: scientific research on cancer allowed the development of new treatments and medicines, but these are not equally available to all cancer patients who would benefit from them.

The European Cancer Patient Coalition (ECPC) highlighted this paradox during a meeting at the European Parliament, hosted by MEP Elisabetta Gardini (EPP, Italy). ECPC presented for the first time at the European Parliament two key documents that can help EU countries tackle the unbearable level of inequalities in access to meaningful innovative treatments in cancer:

- The European Guide on Quality Improvement in Comprehensive Cancer Control is the most comprehensive evidence-based set of recommendations to modernise national policies on cancer. It was produced by the Joint Action on Cancer Control (CanCon), a common effort between representatives from 17 EU Member States, co-funded by the European Commission;
- The ECPC Value of Innovation in Oncology White Paper presents ECPC's vision for the future of cancer care, from diagnosis to follow up care. It provides 40 recommendations for sustainable and equitable access to innovative cancer treatments and care pathways.

**For Immediate Release**

Quotes from MEP Elisabetta Gardini

- We know that new health technologies, for example the very promising immuno-oncology treatments, can be incredibly valuable to cancer patients. At the same time, we need to ask ourselves how healthcare systems can provide access to new technologies without breaking the bank. Finding a balance between sustainability and access to innovation will be the main challenge for the future of oncology.
- Europe still lacks a grand vision for the future of oncology. The ECPC White Paper “*Value of Innovation in Oncology*” is a key starting point for Europe and all EU countries to start building a new narrative towards a more accessible, equitable and sustainable innovation in cancer.
- Regarding innovation in the pharmaceutical sector, the European Parliament demonstrated once more to be in pair cooperation with the needs of patients, by supporting a report on access to medicines in Europe last March. I have been very vocal within the Parliament to ensure that the perspective of cancer patients would be taken into consideration: meaningful innovation that can save lives must be made available to patients as soon as possible. I am proud to say that the report reflects this.
- I also welcome the strong stance the Parliament took in favour of harmonising Health Technology Assessment (HTA): it is absurd and unacceptable that in Europe we continue to duplicate the evaluation of the same health technologies in all countries. I hope the Parliament will take the INI report as a base for its future position on HTA, waiting for the *Commission’s* new legislative proposal.

Quotes from MEP Lieve Wierinck

- When you are a cancer patient you only care about one thing: survival. We are stronger if we work in collaboration, government, patients and industry.
- I would like to congratulate the European Cancer Patient Coalition for the highly important White Paper on the Value of Innovation in Oncology.
- *Patients’* safety should remain a high priority in ensuring innovation in cancer care. Collaboration is a win for all.
- I am in favour of adopting adaptive pathways in cancer care, but transparency is a key for success.

Quotes from Prof Francesco De Lorenzo, ECPC President

- CanCon made history by including the *patients’* perspective in the very core of its methodology, work model and final outcomes. The European Cancer Patient Coalition has been involved in the Joint Action since the beginning, providing insight and steering the debate related to several chapters of the Guide.
- CanCon represents the peak of European collaboration on cancer because Member States have been directly involved in the production of the recommendations since the beginning. CanCon gathered not only available and reliable evidence, but also best practices and direct real experiences across EU countries, effectively documenting positive examples of solutions already implemented. This is crucial to show governments that the CanCon recommendations are not only desirable, but also achievable.
- The key future challenge for the European Cancer Patient Coalition will be to ensure that these recommendations will be implemented at the national level. It is up to partners of CanCon, to communicate the

recommendations and spread them within our national networks, conscious that CanCon provides the best harmonised, shared and evidence-based plan to enhance our healthcare *system's* capacity to fight cancer.

- The European Cancer Patient Coalition asks the European Commission to sustain and increase its engagement in the fight of cancer. The Commission has demonstrated its ability to achieve important results. The implementation of the Cross-Border Healthcare Directive is finally bearing fruits, and the launch of the European Reference Networks show that concrete, effective initiatives to make cures more accessible to cancer patients can start from Brussels. We look with anticipation to the next joint action on cancer, but this is not sufficient to ensure that the CanCon recommendations will be implemented. The Commission lacks legal instrument to bind governments to adopt the CanCon recommendations, and this gap shall be filled up by the *Commission's* explicit political engagement in favour of the recommendations.
- The exceptional results of the Joint Action must correspond with exceptional measures by the European Union as a whole to promote the update of national cancer plans. ECPC will be the *Commission's* ally in this.
- The European Cancer Patient *Coalition's* strongest message goes to the EU Member States. Member States have a great responsibility in implementing the recommendations of CanCon: they cannot turn a blind eye on the outstanding results of this Joint Action. We ask, with strong voice and full confidence, that all 17 Member States involved in CanCon will apply the CanCon recommendations to their national cancer plans and that they will not waste the opportunity provided by the end of the Joint Action to bring back cancer on top of the public health agenda at national and European level.
- ECPC will act as watchdog, monitoring the implementation of the CanCon recommendations at national level.
- European cancer patients should have timely and affordable access to the best treatment and care available, throughout their life. We wrote this report based on our experience, to guide policy makers and the cancer community with real-world recommendations for improving *patients'* involvement in decision-making related to innovation in cancer care and treatment in Europe. There is no meaningful innovation without the involvement of patients throughout the development of new health technologies.

#### Quotes from Prof Tit Albrecht, CanCon coordinator

- CanCon was a common effort between representatives from 17 EU Member States, co-funded by the European Commission (Directorate-General for Health and Food Safety). The European Cancer Patient Coalition was a key partner of CanCon, and contributed to the drafting of the guide and of the policy papers.
- The European Guide on Quality Improvement in Comprehensive Cancer Control presents key recommendations to potentiate EU *countries'* capacity to fight cancer. The recommendations span the whole patient journey from prevention to treatment and survivorship. The Guide explains in detail which measures EU governments should implement to make National Cancer Control Plans more resilient and effective, focusing on key aspects of cancer care: integrated cancer control, community-level cancer control, survivorship and rehabilitation, screening.
- CanCon demonstrated that the European Union can go beyond papers produced “by experts for *experts*” and that it can embrace a more political and efficient way to promote cohesion and collaboration, based on evidence and co-created by European patients.
- Sometimes miracles happen: CanCon ran a pilot in Czech Republic, whereby the key points of the CanCon recommendations were implemented at national level. The pilot was so successful that in three years, the

Czechs managed to change three laws and fully endorse our recommendations within the national cancer plan.

- CanCon worked also on the issue of disinvestment: patients are often exposed to low value care, and it is crucial to use HTA as an instrument to evaluate new and existing medical practices and technologies, and chose which to promote and which to discard.

#### Quotes from Prof Jose Maria Martin Moreno

- This event was an important opportunity to remind our decision makers of the complexity of cancer care, and of the need to implement evidence-based policy recommendations like the CanCon guide;
- The European oncology community, including patients, is able to provide great recommendations to policy makers. The question is: are these recommendations reaching the ears of politicians?
- There is evidence showing that patients and informal caregivers may play a much more prominent role in managing disease and participating in decisions about their treatment. Patients and their caregivers are able to create many different types of innovations which could and should be incorporated by the health care system.
- We need more health brokers, able to communicate to politicians/decision-makers the achievements of the European oncology community, many of which can in fact reduce the cost of care and, more importantly, improve health and quality of life.

#### Quotes from Prof Yolande Lievens, ESTRO President

- The vision of ESTRO is that every cancer patient in Europe will have access to state of the art radiation therapy, as part of a multi-disciplinary approach where treatment is individualized for the specific *patient's* cancer, taking account of the *patient's* personal circumstances.
- More than half of cancer patients will benefit from radiotherapy in the course of their disease, yet only a third of them are receiving proper and timely radiotherapy treatments.
- In radiotherapy, devices are not assessed on their effectiveness prior to marketing authorization, therefore the value of the innovations is difficult to evaluate properly. *It's* only after the investment has been made, the equipment installed, that the effectiveness can be tested, that the costs and cost-effectiveness can be evaluated, that the budget impact can be ascertained. This takes time, and delays reimbursement, sometimes to a moment where the new technology may already have become obsolete. We need to adopt new approaches in HTA to make sure that innovative radiotherapy is given the value it deserves.

#### Quotes from Wim Goettsch, EUnetHTA coordinator

- Cooperation on Health Technology Assessments, such as the one carried out by EUnetHTA, can improve quality, timeliness, efficiency and consistency of the assessments across Europe;
- HTA is more than cost-effectiveness evaluation at the time of launch for a new product. HTA is crucial in several steps of the life cycle of health technologies.
- There are undeniable benefits to HTA collaboration in Europe: higher quality of the evaluation, cutting delays and duplications, but also keep the evaluations consistent with one another.

#### Quotes from Ivana Cattaneo, Novartis & EFPIA

- There are big inequalities in the access to cancer care that have to be addressed in Europe.
- The EFPIA Task Force on Oncology is willing to open a multi-stakeholder discussion in order to tackle the issue of access to innovation in oncology, and we are glad to see that other stakeholders share views and concerns that are similar to the ones we are addressing ourselves.
- In terms of the pricing of new medicines, we need new approaches that could include developing outcome-based models:
- Our aspiration is to work collaboratively in a multi stakeholder format to find the right set of solutions for the future of cancer care in Europe

#### Quotes from Flora Giorgio, European Commission

- In the public consultation about the EU initiative to strengthen cooperation on HTA, 87% of all respondents and 96% of *patients'* organizations expressed they want EU cooperation to be further supported beyond 2020.

#### KEY MESSAGES ON VALUE OF INNOVATION IN ONCOLOGY

The European Cancer Patient Coalition's White Paper "Value of Innovation in Oncology" makes recommendations for sustainable and equitable access to innovative cancer treatments and care pathways. Each year, over 3 million Europeans are diagnosed with cancer, and over 1 million Europeans die from the disease. With a growing and ageing population, action is urgently needed to address this major global health and societal concern. The White Paper was developed to help policy-makers understand how they can improve access to innovative cancer care and treatment.

- Healthcare reform proposals from the European Cancer Patient Coalition would improve access to innovative oncology care pathways, technologies, and treatments.
- The European Cancer Patient Coalition make 40 policy recommendations for greater emphasis on patient-centred and personalised cancer treatment, based on global evidence and best practice.
- The European Cancer Patient Coalition defined 10 areas for improving access to innovative medicines:

|                                       |                     |
|---------------------------------------|---------------------|
| Development and approval of new drugs | Diagnostics         |
| Health technology assessment          | Radiation oncology  |
| Pricing                               | Surgery             |
| Cancer registries                     | eHealth and mHealth |
| Disinvestment                         | Care pathways       |

The White Paper promotes seven priority recommendations for European Action by EU institutions and Member States:

1. Patients should be routinely involved in decision making processes with regulators, academia and industry in the development of innovative cancer treatments.

2. There should be a centralised, relative effectiveness assessment that is valid in all EU Member States and takes into account patient-reported outcomes.
3. There should be a stronger enforcement of the existing access framework for Member States, i.e. to take the decision of setting a price and reimbursement of a medicine within 180-days from the EMA authorisation and to communicate transparently the criteria.
4. Member States should invest in innovative radiotherapy equipment and workforce training to help overcome inequalities in access to radiation oncology.
5. The focus of development of innovative surgical techniques should be to improve long-term survival and the quality of life.
6. Innovative eHealth and mHealth tools should be used in parallel with innovative care pathways, to increase patient-centricity by design and by default, and should be subject to solid, visible and transparent assessment and governance by an EU-level monitoring body.
7. The performance of standardised cancer patient pathways should be carefully monitored, and strategies to ensure that the pathways are should be included in national cancer plans.

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The European Cancer Patient Coalition gratefully acknowledges the support of AstraZeneca, Merck Group, Pfizer in organizing the meeting at the European Parliament. The scope and content of the event is the sole responsibility of the European Cancer Patient Coalition.

The European Cancer Patient Coalition gratefully acknowledges the support of Bristol Myers-Squibb, Eli Lilly & company, MSD, Novartis, and Roche in producing this white paper. The scope and the content of the white paper is the sole responsibility of the European Cancer Patient Coalition.

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NOTES TO EDITORS:

About Cancer

Cancer is a group of diseases that involves increased cell growth, with the potential to spread to other parts of the body, and it's one of the largest global public health concerns. Each year in Europe, there are an estimated 3.45 million new cases of cancer and 1.75 million deaths from cancer. Of the 17.9 million people living with cancer in the European Union, nearly one quarter (24%) have a rare cancer, equivalent to over 4.3 million people. The most common cancers are breast cancer, colorectal cancer, prostate cancer, and lung cancer. Approximately 28% of all deaths are caused by cancer in the WHO European Region. The most common causes of death from cancer are lung cancer, colorectal cancer, breast cancer, stomach cancer, and pancreatic cancer.

About the European Cancer Patient Coalition

The European Cancer Patient Coalition is an umbrella organisation of over 400 cancer patient organisations in 46 countries. The Coalition works for a Europe of equality, where all European cancer patients have timely and affordable access to the best treatment and care available, throughout their life. The European Cancer Patient Coalition believes that cancer patients are the most important partners in the fight against cancer and against all the cancer-related issues affecting our society. Policy makers, researchers, doctors and industry should recognise cancer patients as co-creators of their own health.

About CanCon

CanCon was a common effort between representatives from 17 EU Member States, co-funded by the European Commission (Directorate-General for Health and Food Safety). The European Cancer Patient Coalition was a key partner of CanCon, and contributed to the drafting of the guide and of the policy papers.

The European Guide on Quality Improvement in Comprehensive Cancer Control presents key recommendations to potentiate EU countries' capacity to fight cancer. The recommendations span the whole patient journey from prevention to treatment and survivorship. The Guide explains in detail which measures EU governments should implement to make National Cancer Control Plans more resilient and effective, focusing on key aspects of cancer care: integrated cancer control, community-level cancer control, survivorship and rehabilitation, screening.

Together with the Guide, CanCon produced also five policy papers regarding hot topics of cancer policy selected and discussed by EU Member States with the support of top European experts on the individual topics.