



*European Cancer  
Patient Coalition*

# Press Release

## **European cancer patients call for full and fast implementation of new EU guide on cancer control**

*For media release*

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*On the 14<sup>th</sup> and 15<sup>th</sup> February, the new European Guide on Quality Improvement in Comprehensive Cancer Control was presented during the final conference of the Joint Action on Cancer Control (CanCon) in Malta.*

*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.*

*The European Cancer Patient Coalition President Prof De Lorenzo was invited to the Final Conference to present the patients' perspective on the CanCon Guide and Policy Papers. As he was unable to travel due to*

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recent surgery, the European Cancer Patient Coalition was represented by Vice-President Kathi Apostolidis, Head of EU Affairs Francesco Florindi.

**Note from Prof Francesco De Lorenzo, President of the European Cancer Patient Coalition and contributor to the CanCon Guide**

**CanCon: a landmark achievement for all European cancer patients**

For more than 30 years, the European Union worked alongside its Member States and stakeholders to fight cancer. The European Cancer Patient Coalition is thankful to European Commission for this continuous engagement, and for having involved patients in all other cancer-related initiatives, such as the *European Commission's Expert Group on Cancer Control*, the *Initiative on Breast Cancer Screening*, the *European Network of Cancer Registries* and the *European Medicines Agency*. This level of commitment should be a model for all Member States on how to involve and interact with patient organisations. The *Joint Action CanCon*, which ends today, marks a new apex in the European struggle to fight this disease, for two key reasons.

First and foremost, 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. This factor enriches the value of the Joint Action's outcome: 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 citizens affected by cancer. CanCon is a milestone for all European cancer patients because of the arguments that the European Cancer Patient Coalition brought forward. Many of the in the final Guide and policy papers come directly from the people fighting against cancer every day, and we can proudly say that its achievements are also the achievements of the European cancer patient community.

The second reason why CanCon represents the peak of European collaboration on cancer is because Member States have been directly involved in the production of the recommendations since the beginning. In the future, I hope we will find out that the most important deliverable of CanCon is not on paper, but the fruitful relationship that CanCon facilitated between national institutes of health, academia and patients, effectively building a community of likeminded cancer experts across most EU Member States. All the partners involved in CanCon retain clear and direct links with the healthcare authorities of all 17 countries represented in CanCon. 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. Furthermore, the Expert Group on Cancer Control closely monitored the production of the CanCon deliverables and contributed to streamline and perfect the recommendations. In brief, the results of CanCon stem from a true collaboration among decision-making bodies, which were fully integrated, when not directly involved, in the production of the recommendations. This is a game-changing factor: those responsible for the implementation of the CanCon recommendations are also co-creators of the same

recommendations, cutting down obstacles to the formal and complete acceptance of the recommendations by the 17 countries involved.

### **Key recommendations for Cancer Patients**

The effects of the economic crisis have exacerbated the existing, unacceptable inequalities in cancer care and survivorship in Europe. CanCon recognised these issues and brought together all stakeholders in cancer control to define reliable solutions.

[Chapter 7 “Survivorship and rehabilitation: policy recommendations for quality improvement in cancer survivorship and rehabilitation in EU Member States”](#) will be a valuable source for all EU countries to provide actionable solutions to the rising number of patients surviving cancer. Survivorship is a ticking bomb: more than 7 million Europeans survive the disease for more than 5 years since diagnosis, but almost all EU countries do not have sufficient policies in place to ensure that these citizens receive appropriate physical, psychological, sexual, nutritional rehabilitation, or can return to work, or access loans, mortgages and health insurances. Based on the experience of our French colleagues at the *Institut National du Cancer* (INCa), the chapter defines the pillars of a model National Cancer Survivorship Plan, which was designed on the express needs that cancer patients flagged throughout the production of the document.

CanCon demonstrated to be reactive also on the problem of inequalities in access to quality cancer care. [“Tackling Social Inequalities in Cancer Prevention and Control for the European Population”](#) benefitted from the direct input of top European scientists in the field of cancer epidemiology and inequalities, such as Prof Mark Lawler, Prof Michel Coleman and Prof Claudia Allemani, as well as the committed CanCon partners and patient representatives. It provides a balanced, evidence-based roadmap to tackle the causes of inequalities in cancer care in Europe. Cancer patients are living in a paradox today: scientific research is finally delivering on several effective new treatment strategies, but those new treatments are not available to most European patients, alongside essential quality cancer care. The policy paper cast a light on the main issues on which EU governments must act promptly to guarantee access to adequate, quality and effective cancer care to all European citizens.

Inequalities are intertwined with socio-economic issues and with the overall healthcare systems' resilience. That is why the European Cancer Patient Coalition took a strong stance in support of the policy paper [“Enhancing the Value of Cancer Care Through a More Appropriate Use of Healthcare Interventions”](#). Our contribution helped to define the methodology to identify and act upon those healthcare interventions that simply do not provide sufficient value to healthcare systems and cancer patients. To make room for effective innovation, there is an urgent need to get rid of old and non-effective treatments. The policy paper sets a patient-oriented method not only to make room for new treatments and investments, but also to better allocate the scarce resources available into those interventions that make a real difference to cancer patients.

### **Our joint future challenge: implementing the CanCon recommendations**

**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 to be able to achieve important results. The implementation of the Cross Border Healthcare Directive is finally bearing fruits, and the launch of the European Reference Network show that concrete, effective initiative 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 lack of legal means by the Commission to bind governments to adopt the fruits of our collaboration shall be filled up by the Commission's explicit political engagement towards Member States, the Council and the European Parliament. **To the exceptional results of the Joint Action must correspond exceptional measures by the European Union as a whole to promote the update of national cancer plans.** We 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.**

The European Cancer Patient Coalition strongly agrees with the key general recommendations set by the CanCon policy paper "[National Cancer Control Programmes \(NCCPs\)/Cancer Documents in Europe](#)", which sets the scene for the implementation of the whole Guide. In particular, a first, fundamental step in all Member States is to identify a body (national agency, institution) which will be responsible for cancer control at national/regional level. If such an institution does not already exist, it should be immediately created, to ensure fast implementation of the CanCon recommendations.

The European Cancer Patient Coalition has already kicked off a key initiative to implement the recommendations on survivorship and rehabilitation. Together with the European Society of Medical Oncology (ESMO), the European Cancer Patient Coalition is creating the first European patient guide on survivorship, complete with a checklist for patients and oncologist to help them reach all the objectives for a successful follow up and rehabilitation process, which would include all the aspects

identified in the [CanCon model for national survivorship care plan](#). In this way, the European Cancer Patient Coalition wants to act as a bridge between high level political commitment (the CanCon recommendations) and daily fight against cancer (ESMO-ECPC guide and checklist). Initiatives such as this must be supported by Member States and by the European Commission, as they act to directly implement the recommendations.

CanCon represents also an opportunity for Member States. Too many EU countries are experiencing great disaffection for the EU values and the European ideal, which are fundamental for cancer patients. The European Cancer Patient Coalition strongly believes in Europe and is glad to be also Europe's advocate, creating added value for all our Members and encouraging them to engage at the EU and national level. All 408 members of the European Cancer Patient Coalition believe that together we can achieve more for people with cancer. Member States have the opportunity to demonstrate to their citizens that, by collaborating with other countries, together they can devise and implement practical and effective solutions to fight cancer. To those governments, public officials and other stakeholders who believe in the potency of the CanCon recommendations, the European Cancer Patient Coalition pledges our commitment to support you and your work for a better future for all people with cancer.

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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 is 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 (officially European Guide on Quality Improvement in Comprehensive Cancer Control or CanCon; Cancon for short) is a joint action initiative, co-funded by participating organisations, institutes, universities and health care units, and the European Union. Cancon is co-funded by EU Health Programme. Cancon aims to contribute in different ways to reducing the cancer burden in the EU by creating a European Guide on Quality Improvement in Comprehensive Cancer Control. The Guide is meant for governments; parliamentarians; health care providers and funders, and cancer care professionals at every level.*