## ECPC (European Cancer Patient Coalition): Cancer patients contribute to Cancon

Cancon brings together 17 EU health ministries and their representatives, plus Europe's most important cancer patients associations and stakeholders, and therefore it certainly represents the most relevant and concrete attempt to ameliorate the way we all fight cancer in Europe.

But is Cancon a patient-oriented initiative? The European Cancer Patient Coalition (ECPC) was present since the beginning of the joint action, and contributed also to Cancon's predecessor, EPAAC. As a collaborative partner of Cancon, we are fully integrated in the drafting and work of several work packages deliverables, most notably those of WP 4 (Guide coordination), WP 5 (Member States Platform), WP 7 (Community-level cancer care) and WP 8 (Survivorship).

What was our concrete impact on Cancon's work? The next Cancon Policy conference in Rome will provide several great examples of how cancer patients are contributing to the Cancon's deliverables, therefore showing how Cancon and its partners are taking into consideration the patients' perspective.

## **Cancon Policy paper on Equity in cancer care**

First of all, ECPC was directly involved into the conceptualisation and definition of the Cancon Policy conference. Together with the European Cancer Leagues (ECL) and the Italian Ministry of Health we have defined the objectives of the event. We agreed that the Policy conference could be a great chance to give visibility and recognition to two of the Cancon deliverables where the role and contribution of cancer patients was the most effective: the WP5 policy paper on equity and the WP8 recommendations on survivorship and rehabilitation.

The policy paper on equity in cancer control, produced by the WP 5 is a clear example of Cancon's adaptability to the changing policy environment. The idea for the policy paper came from ECPC and was quickly supported by a large number of partners, during the successful 2015 Stakeholders' forum in Brussels.

Under the leadership of the Italian Ministry of Health (leaders of WP 5), W P5 put together a core writing group coordinated by FISABIO (Spain) and enjoying the contribution of three Cancon associate and collaborative partners (ECPC; the Epidemiology Unit of the ASL TO3 of the Piedmont Region, Italy; the Belgian Cancer Centre in the Belgian Scientific Institute of Public Health, Belgium) plus the key contribution of several experts, including the direct involvement of Prof Mark Lawler, Dean of the Queen's University Belfast (UK) and Prof Michel Coleman and Prof Claudia Allemani, the leading researchers of the CONCORD Group (UK).

ECPC was directly involved in the writing of the paper: we strongly advocated for a solid and comprehensive position against inequalities in cancer care, which, once approved and endorsed by all Cancon partners as a final deliverable of the project, will truly represent the strongest position against inequalities in cancer care.

The document provides key recommendations that, if duly implemented, will have a formidable impact on the life of millions of Europeans affected by cancer today.

## A new European strategy on survivorship

The second keynote presentation of the Policy conference is dedicated to the work done by WP 8 on survivorship and rehabilitation. Cancer survivors in Europe are a ticking bomb: every year more than 3.5

million people are diagnosed with cancer in Europe, and thanks to the increasing quality of the treatments, more and more people survive cancer, often 5 or more years after diagnosis.

We know that there are more than 10 million cancer survivors in Europe, but very few of them have been provided the instruments to return to a normal life, or to better manage the effects of cancer on their long-term survival.

Under the leadership of the French National Cancer Institute (InCA), we have finally provided specific and clear guidelines to all EU countries on how to develop sustainable cancer survivorship plans and policy strategies. This is a landmark achievement, in which ECPC has played a great role

## From paper to action: implementing the Cancon recommendations

The exceptional results of WP 5 and WP 8, together with the other achievements of the other Cancon WPs must not remain on paper. It is necessary that the EU ministries which have supported Cancon will take the lead to implement Cancon's recommendations, therefore giving the example to all EU countries.

We are confident that national and EU policy makers will recognise the value of the recommendations: throughout the duration of the project, Cancon managed to adapt its role and responsibilities to the dynamics and neds of EU policymaking. Thus demonstrating that all Cancon partners are ready to pick up the fight when and where it is most needed.

For example, the launch of the works for the policy paper on equity came in the heat of the pan-European discussion on inequalities in access to essential and innovative medicines, led by the activity of the European Parliament on the same topic (March 2016). The equity paper will provide EU decision makers with a coherent position of the Cancon partners, not only on the crucial issue of access to innovative medicines, but more in general on the causes and nature of inequalities in cancer care.

The equity policy paper's recommendations are perfectly in line with the comments made by Commissioner Andriukaitis and the EMA Director Prof Guido Rasi on the need to harmonise the way we evaluate new drugs and on the way we reimburse and buy medicines (click <a href="here">here</a>), which are also in line with the ground-breaking amendments introduced by several MEPs (most notably those of MEP Gardini, who will be present at the Rome meeting) calling for more harmonisation of the HTA process at the European level, to cut inefficiencies, delays and costs.

During the meeting in Rome, the Chair of the ENVI Committee of the European Parliament, MEP Giovani La Via will showcase the whole array of initiatives of the European Parliament in favour of patients' access to innovation and to fight inequalities in cancer care, further strengthening on the importance of the WP 5's recommendations

In this perspective, the Cancon policy paper on equity **connects the dots among national and local needs of patients, EU health ministry policies and EU decision makers**. The top-end quality of Cancon contributors and partners ensures that the paper is equilibrate and scientifically validated.

The equity paper is just an example of the exceptional political and clinical impact that Cancon can have on European and national cancer policy. We are looking forward to explore the full potential of Cancon's recommendations with all the participants to the Cancon Policy conference in Rome, next 16<sup>th</sup> September.