

Brussels, 18th January 2018

Subject: Expert Group on Cancer Control

Dear Mr Seychell,

We are writing to express our concern, on behalf of the European Cancer Patient Coalition, over the European Commission's decision to discontinue the current Expert Group on Cancer Control.

The European Cancer Patient Coalition, has been a member of the Expert Group on Cancer Control since its creation in 2014. We are confident that the Expert Group has successfully assisted the European Commission in its work of drawing up guidelines, recommendations on cancer control and other policy documents. The cooperation at the EU-level of multi-stakeholder groups has contributed tremendously in sharing of best practices and, by consolidation of different perspectives, suggesting improvements to the measures affecting public health across the Union. The Expert Group contributed input on the future EU action on rare cancers, the European Reference Networks and continuously collaborated with the Cancer Control Joint Action (CanCon). We have not solved all the challenges yet and the Expert Group on Cancer Control has shown continued commitment and motivation to the engaged support of the Commission's initiatives.

As a patient advocate organisation, the European Cancer Patient Coalition is overwhelmingly concerned that the patients, already often overlooked, will have limited voice in the legislative debate at both the European Union and the Member State level. At the European Cancer Patient Coalition, we believe patients should be acknowledged as equal partners in policy-making, and multi-stakeholder groups such as the Commission's Expert Group on Cancer Control are of paramount importance to convey challenges, but also the opportunities, derived from real-life experiences of cancer patients themselves.

We understand that the Steering Group on Promotion and Prevention aims to enable the European Commission to break-up siloes in the work of the Expert Groups and help the prioritisation of policies. The promotion and prevention can very well be a horizontal policy across all diseases, if the purpose is to break up siloes. However, abolishing the expert groups is not the right solution, since it will dismantle European expertise on various important topics, which took years and considerable resources to build.

On the other hand, the participation of civil society (patients and consumers) in these health policy tables has empowered, educated and enabled them to go back to their national and

European authorities, present the Commission's example of patient inclusion and seek a seat at the table. The Commission's intention to use the online EU Platform Agora, as we understand, for stakeholder involvement cannot replace the in-person interaction of stakeholders on concrete policy topics, nor offer solid and timely feedback from the Commission and other stakeholders.

We would like to highlight the risk presented by the plans so far unveiled to cancer control, as well as other diseases areas, to fall behind the policy discussions and research priorities for extended duration. This poses a tremendous risk to cancer patients' and the cancer policy situation in Europe.

In this context and in agreement with EUROPA DONNA - the European Breast Cancer Coalition and EUROPA UOMO - the European Prostate Cancer Coalition, we would like to ask the European Commission to describe in detail, how the current Expert Group on Cancer Control will be streamlined under the Steering Group and how the civil society will be able to actively be informed and contribute to cancer policy design and planning. We are seeking reassurance that the discontinuation of the Expert Group in the current form will not negatively affect the importance that the cancer policy debate currently has in the Commission's health policy. We hope that the European Commission will continue to actively work for underlining the pivotal importance of active stakeholder involvement to provide evidence with real word experience and more information for policy making on topics of public health.

Kind Regards,

President

European Cancer Patient Coalition



Francesco De Lorenzo
ECPC President