

Recommendations from ‘the Cancer Related Complications and Comorbidities Initiative’ for the **Consultation on ‘*Europe’s Beating Cancer Plan*’**

The Cancer Related Complications and Comorbidities Initiative brings together relevant stakeholder on the EU level.ⁱ We define a comorbidity as the co-existence of disorders in addition to a primary disease (cancer) and a cancer complication as a complication resulting from the underlying malignancy or its treatment.ⁱⁱ We all believe that cancer-related complications and comorbidities are a highly significant burden on patients across Europe that is all too often neglected in policy and research.^{iii,iv} Cancer associated thrombosis alone is the second leading cause of death in cancer patients. One in five of all cancer patients develop VTE (venous thromboembolism) and their 1 year survival is reduced to one-third of that of other cancer patients. Depression affects 15-25 % of cancer patients^v, and cancer often affects the nervous system and can result in significant neurological morbidity and mortality. Around 15-20 % of cancer patients have neurological complications.^{vi} People living with obesity have an increased risk of developing several types of cancer,^{vii} and the percentage of new cancer cases attributable to overweight and obesity is higher in Europe than the global average.^{viii} We seek to shed light on this significant burden and call on the EU to make cancer-related complications and comorbidities a central part of the cancer plan as comorbidities can only be dealt with through a multidisciplinary and holistic approach that ensures better and integrated care for cancer patients.

1. We would like the plan to prioritise patient safety and appropriate early detection and prevention in order to reduce overall mortality and disability among cancer patients. As cancer treatments improve, many cancer patients do not have just one disease or one outcome anymore, therefore measures to reduce the rates of all preventable complications in cancer patients must be emphasized in order to reduce mortality and increase patients’ quality of life.
2. Ensure that the management of cancer patients with comorbidities is defined by integrated care, that is the care is shared between relevant specialists, involves informal carers as long as they wish to and are supported, includes psychosocial support,^{ix} careful use of complementary medicines, and systems that are in place for data collection and sharing. Facilitate coordination between Member States in order for them to establish Comprehensive Cancer Care Networks (CCCNs)^x which is the optimal way of offering multidisciplinary and integrated cancer care according to the CanCon Guide recommendations^{xi,xii}. CCCNs should as a minimum digitally interconnect and integrate precursor and co-morbid conditions and diseases such as obesity.
3. Provide guidance to Member States to ensure both healthcare professionals (HCP) and informal carers^{xiii,xiv} can bridge knowledge gaps by being trained to identify and manage comorbid conditions. Properly trained HCPs, such as nurses, play a key role in prevention by educating patients and their families on healthy living and disease management if they receive the proper support. Informed citizens as a consequence make better choices, are

more likely to seek timely and appropriate medical attention and can better manage their condition, leading to improved health outcomes in the long term as well as decreased health expenditure.

4. Address the privacy concerns with cross-border data sharing by ensuring that the European Health Data Space is the preferred place for sharing data, in compliance with GDPR and forthcoming guidelines.
5. Dedicate funding to research on comorbidities to fill existing gaps in research and better understand disease interactions within EU's Horizon Europe (2021-2027) research programme.
6. Commission a survey by Eurostat on Survivorship in order to better understand the follow-up needs of those affected by cancer (e.g. personalised follow-up, late effect management and tertiary prevention).

Annex I – List of Initiative members

Leader



The European Cancer Patient Coalition (ECPC) represents 450 member organisations supporting all types of cancer patients in 46 countries.

Members



EASO is a federation of professional membership associations from 34 countries, with a network of over 130 specialist Collaborating Centres for Obesity Management across the region.



The EAU represents the leading authority within Europe on urological practice, research and education counting over 16,000 medical professionals in its ranks.



The European Brain Council (EBC) is a network of key players with the ultimate goal of improving the lives of the estimated 179 million Europeans living with brain conditions, mental and neurological alike.



EUROCARERS is the European network representing informal carers and their organisations, irrespective of their age or the particular health and care need of the person they are caring for.



The European Federation of Neurological Associations (EFNA) is an umbrella group representing pan-European neurology patient groups.



Representing more than one million nurses over 36 National Nurses Associations at European Level, the European Federation of Nurses (EFN) is the independent voice of the nursing profession.



The European Society of Cardiology is a medical society uniting more than 100.000 healthcare professionals across all cardiology subspecialties.



The European Specialist Nurses Organisation (ESNO) facilitates and provide an effective framework for communication and co-operation between its specialist nurse members.



The European Thrombosis and Haemostasis Alliance (ETHA) is an alliance of 25 national European thrombosis and haemostasis associations.



The International Society on Thrombosis and Haemostasis (ISTH) is a global membership organisation of specialists in the field of blood coagulation and its disorders, such as thrombosis and haemophilia.



Thrombosis Ireland is The Irish Patient Voice representing Thrombosis Patients, families & Carer's including the 1 in 5 Cancer Patients who experience Cancer-associated Thrombosis.



Thrombosis UK unites the NHS, healthcare providers and individuals to work to improve prevention of venous thromboembolism (VTE) and the management and care of unavoidable VTE events.

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Annex II – References

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- ^v [US] National Cancer Institute. Depression (PDQ®)—Health Professional Version.
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- ^{xi} Albrecht, Tit, Régine Kiasuwa & Marc Van den Bulcke (2017): *European Guide on Quality Improvement in Comprehensive Cancer Control*. Ljubljana: National Institute of Public Health; Brussels: Scientific Institute of Public Health.
- ^{xii} Albrecht, Tit et al. (2015): *European Guide for Quality National Cancer Control Programmes*. Ljubljana: National Institute of Public Health.
- ^{xiii} Eurocarers Cancer Carer toolkit (2019): <https://www.eurocarers-cancer-toolkit.eu/introduction/> [Accessed 25.02.2020].
- ^{xiv} ECPC & Eurocarers (2018): White Paper on Cancer Carers: Finding the right societal response to give people with cancer and their carers a proper quality of life. ECPC White Papers