27.10.2020

WORKING DOCUMENT

on Inputs of the Special Committee on Beating Cancer (BECA) to influence the future Europe’s Beating Cancer Plan

Special Committee on Beating Cancer

Rapporteur: Véronique Trillet-Lenoir
This document aims to share some inputs of the Special Committee on Beating Cancer (BECA) to influence the future Europe’s Beating Cancer Plan.

1. CONTEXT

Cancer is a critical public health issue, one of the first causes of death in most European countries, which leads to the deaths of 1.4 million people each year in Europe, including 6000 children. Nearly 4 million people develop cancer every year and more than 12 million cancer survivors face the difficult return to a “normal life”.

Cancer patients need to be at the centre when dealing with all stages of the disease. Cancer is responsible for intense suffering of patients and their families, and it is a clear concern for governments, which are confronted with the growing economic burden of this disease and its related treatments on national health and social systems, budgets, productivity and growth of the economy.

Although there has been a slight decrease in mortality rates thanks to steps forward in screening campaigns and treatments, the number of cases diagnosed is increasing, notably due to longer life expectancies, and to better detection via screening. However, these increasing trends are not fully explained by a growing and ageing population as there is a complex interplay of multiple risk factors in the causes and mechanisms of cancer. According to the International Agency for Research on Cancer (IARC), new cancer cases are projected to increase from 3.9 million in 2018 to 4.7 million by 2040, with the highest rates predicted in the elderly population. There is evidence of gender differentiation in different cancer types.

There are significant disparities in terms of incidence, access to diagnosis, treatment and mortality from one country to another, and from one region to another in a given country. The 5-year survival rate from cancer is roughly 54% (80% for children), but these figures vary from 38 to 64% from one country to another, and there is as much as a 20% difference in children's survival rates among European countries. Inequalities and disparities are also identified between gender, social classes, demographic and ethnic groups (including marginalized groups), and with respect to the age of patients.

The current health crisis of COVID19 has affected cancer at all stages of the disease and poses an ongoing challenge for patients, researchers and medical professionals.

2. METHODS

In order to reduce the incidence of cancer, to help patients live a longer and better life, and to pursue a reduction in health inequalities, Europe’s Beating Cancer Plan could follow this specific methodology:

- to catalogue, publish and analyse current legislative and financial instruments on
cancer and the opportunities for Europe’s Beating Cancer Plan to build upon these and/or other successful European initiatives developed by the cancer community itself (e.g. by European and international level healthcare professional and patient organisations);

- to determine general and specific objectives and estimate their respective strengths, weaknesses, opportunities and threats;

- to identify and compare the various actions already taken by Member States in establishing their National Cancer Control Plans and impact assessments of these plans;

- to propose a list of measures for actions, revised or new legislation, incentives, guidelines and recommendations;

- to clarify which measures fall under European legislative competences, and which can be achieved either through recommendations to Member States or by voluntary measures;

- to define the competent authorities (European, national, regional, local) required for the implementation of the different measures;

- to indicate the most recently available scientific data underpinning the proposed measures, as well as data currently lacking that should be addressed in the context of Europe’s Beating Cancer Plan, the EU Cancer Mission and the EU4Health programme;

- to consider for each measure the potential implications for the different public and private stakeholders, including various patient associations, European learned institutions, social partners, Non-Governmental Organizations involved in the cancer field and medical companies;

- to assess the feasibility and estimate the required financial resources for the different measures;

- to define measurable and reproducible impact indicators accordingly.

3. POSSIBLE DOMAINS OF ACTIONS - For a coordinated and effective fight against cancer

   a. Areas of action

      i. Global prevention
More than 40% of all cancers are preventable through coordinated actions on individual, social, environmental and commercial health determinants. The European Code Against Cancer is an initiative of the European Commission developed by the IARC to inform people about actions they can take for themselves or their families to reduce their risk of cancer. Successful cancer prevention requires these individual actions to be supported by governmental policies and actions.

Many significant health inequalities exist within the EU in regards to cancer prevention. Prevention policy must be enshrined in a framework of social justice in order to account for the inequalities vulnerable and low-income populations face in terms of preventable risk factors.

**Tobacco use**, in particular cigarette smoking, is the main risk factor for cancer death in Europe. Various measures to fight against smoking appear heterogeneous and inconsistently implemented. Overall, the WHO Europe region is the global area with the highest tobacco consumption, with major discrepancies between Member States, as the proportion of smokers varies by a factor of up to 5 from one country to another.

**Harmful alcohol consumption**, whether or not in combination with tobacco-smoking, provokes a significant increase in many different types of cancers. Overall, the level of alcohol consumption is high and varies from 10 to 12 litres per person per year among EU countries.

Cancer is the first cause of work-related death in Europe. **Exposure at work** accounts for 8% of cancer, according to a 2018 ETUI report, and is responsible for up to 150 500 cancer cases each year. The elimination of carcinogens and mutagens and the reduction of workers’ exposure in production processes will decrease the number of occupational cancers. The fraction of cancers attributable to occupation is often underestimated, owing to the very long exposure time period required for cancer to be clinically detectable, and thus to be declared as an occupational disease by the public health authorities.

Promising advances have been made regarding the prevention of cancers related to infectious diseases, in particular national **vaccination** programmes in the fight against human papilloma virus (HPV) that can induce uterine cervix cancer in women and an increased number of anogenital and oropharyngeal cancers in both sexes. The majority of Member States have introduced vaccination campaigns but not all have organized programmes, and the targeted populations vary. Major discrepancies appear in the level of vaccination coverage between Member States, from less than 30% to more than 70% (the required level for population effectiveness). Vaccination against Hepatitis B is recommended by IARC for newborns.

An individual’s cancer risk can also be reduced by adopting **healthy nutritional habits** from their dietary intake (high intake of fruits and vegetables, grain and pulses; low intake of sugar, saturated fatty acids, sugary drinks and processed meat; reduction of red meat) and keeping a
healthy body weight. The Farm to Fork strategy will contribute in this regard.

Regular adapted physical activity is helpful in the prevention, and reduction of recurrences, of some cancers.

Radiation from the sun contains invisible ultraviolet (UV) radiation which can lead to skin cancer. Exposure to radioactive substances is a known risk factor for cancers and attention should also be paid to other environmental radioactive agents such as radon.

The detection of a genetic predisposition to breast and colorectal cancers is possible and may help with prevention, early detection or even prophylactic measures.

Environmental pollution in the air, food, water and soil, and exposure to chemicals including dangerous and carcinogenic substances are risk factors for cancer. Improved implementation of existing EU environmental legislation, better research on the correlation between the environmental factors and cancer, as well as commitments under the implementation of the European Green Deal with its zero pollution ambition for a toxic-free environment will contribute to cancer prevention in Europe via the reduction of these risk factors. There is not yet a reliable measurement of the health impact of such policies in Europe.

Tobacco and alcohol, poor nutrition, high body mass index and sedentary lifestyles are also risk factors common to other chronic diseases.

Health promotion requires specific attention to vulnerable populations in order to avoid any type of discrimination towards cancer patients, especially during times of economic, social or public health crises.

ii. Screening and early detection

Lack of information, non-adherence to, and non-provision of cancer screening detection processes frequently lead to delays in cancer diagnoses.

In 2003, the Council issued a set of recommendations on the establishment of cancer screening programmes in EU Member States. Recommendations include a shared commitment to implement systematic population-based national (or regional) screening programmes for breast cancer, colorectal cancer and uterine cervix cancer. Their implementation is far from complete and significant inequalities remain in terms of access to quality-assured cancer screening. Only 18 Member States have national or regional population-based screening programmes for these tumours. Development and implementation of these programmes also differs between countries.
Early detection is a key factor for beating cancer. Big differences exist in the length of time for diagnosis as well as in the process of follow-up after successful treatment. New innovative
imaging screening strategies and early blood detection technologies are currently being evaluated in many types of cancers.

iii. Equal access to patient-oriented treatments

Cancer treatment and care involve a very wide range of treatment modalities.

Surgery is a key component of cancer treatment and contributes significantly to improved cancer survival in Europe. Surgery has the potential to cure most solid tumours and therefore remains the primary treatment option in cancer. Yet only 25% of patients worldwide are receiving safe, timely, affordable, and high-quality surgical care.

Radiation therapy is essential in more than half of all cases of cancer and has a clear curative impact in many cancer types. However, studies suggest that at least one in four people needing radiation therapy does not receive it. Across Europe, there is a 6 to 7-fold variation in the access to radiation therapy equipment and a 3 to 5-fold variation in available personnel and workload.

Most recent advances in the field of cancer treatment are related to the availability of innovative new drugs thanks to better knowledge of cancer molecular mechanisms. The total expenditure for cancer-related drugs in the EU is around €13 billion per year.

The strengthening of the European Medicines Market could guarantee equal access to affordable treatments and innovations, reduce the risk of shortages of medicines, allow shared evaluation of medical devices and medicines, increase the transparency on price-fixing procedures, overcome the high prices of innovative treatments and improve cancer treatments and best practices in adults and children. Shortages particularly affect cancer medicines and some patients are forced to stop their treatment.

Age-specific care taking into account specific needs is not yet available whenever needed. The growing use of targeted therapies requires common molecular diagnostic techniques. EU patients still face challenges in accessing healthcare. The best quality care in cancer relies on rapid access to the finest skills and tools in terms of diagnosis without delay, optimal and tailored treatment, follow-up and quality of life at every stage of the disease. Every patient in Europe, wherever she or he may live, and regardless of the social background, expects to be given the same chances to beat cancer and benefit from adequate coordination between all health, medical and non-medical professionals, specialists and general practitioners from both the private and public sectors, as well as recent advances in outpatient treatments, maximizing the potential of digital health, and optimal supportive care, including palliative care during the end-of-life stage.

The EU has a role in many areas related to patient access to specialized multidisciplinary and multiprofessional cancer teams, including through professional qualification recognition.
legislation, legislation pertaining to workforce conditions and safety, as well as workforce planning and classification activity.

According to OECI (Organization of European Cancer Institutes), there are approximately 280 to 300 cancer centres in the EU. Only 80 to 100 of those are in a recognised accreditation programme to fulfil the requirements for the “comprehensive cancer centres” label. However, only 34 so far have been designated as “Comprehensive Cancer Centres” (CCCs).

While 49% EU nationals feel well informed about healthcare reimbursement in their own country, 17% feel the same about another EU country and only 10% are aware of the availability of cross border healthcare.

iv. **Strong support to patients and caregivers (including family caregivers)**

Cancer patients often suffer “double punishment” in their daily lives. They face various problems such as physical trauma, mental health and difficulties in returning to school, work or leisure, **and work-life balance**. They also often lack medical, psychological, social and financial support, as do their families and caregivers during treatment. Additionally, individuals with occupational cancer can suffer especially from the lack of recognition of their work-related disease. Caregivers do not have a recognized legal status in all Member States.

The mobilization of various healthcare specialists, support from patient associations and advocacies are helpful. Children, adolescents and young adults may require specific assistance, notably regarding, treatment to restore fertility. Rehabilitation, including restoration of esthetic integrity, is a key issue to support cancer related quality of life. Too many insurers and banks indeterminately take into account the medical history of people who were affected by cancer. Four Member States have implemented the “right to be forgotten” after cancer cure.

b. **Possible action tools**

i. **Holistic research and innovation**

Horizon Europe’s Cancer Mission has published its inspiring report in the context of the Europe’s Beating Cancer Plan. As stated in the recommendations of the European Academy of Cancer Sciences - and reiterated in the declaration of the Trio Presidency of the European Union (EU) - to reduce the enormous cancer burden requires a joint program covering the whole cancer research/care continuum as well as the establishment of interconnected high-quality infrastructures.

Valid and useful findings rely on independent, adequately financed and cross-sector multidisciplinary and highly cooperative cancer research, “from bench to bedside”, that is from
the laboratory to applied studies involving patients. The unmet expectations of European patients may be addressed through fundamental, translational, clinical or interventional studies. Better knowledge of cancer biology requires the implementation of genomics and bioinformatics infrastructures. In this regard, there is a huge potential for the use of Artificial Intelligence as a transformative technology in the diagnosis and treatment of cancers in the coming years.

Clinical research may evaluate the feasibility, efficacy and cost-effectiveness of non-treatment related interventions such as studies on health determinants both before, during and after the disease or on quality of life. Non-profit, clinical trials, including academic trials, may improve treatment strategies. Early phase 1 trials on new drugs are a valuable means to improve access to innovative new treatments, such as personalised therapy and precision oncology, in adults, children. Access to promising clinical trials is often not guaranteed because of age-related requirements or geographical origin.

Human and social sciences may be required, in particular those addressing health inequalities throughout the different stages of cancers. Research programmes could be developed to identify effective cancer prevention strategies and methods to provide up-to-date knowledge to the EU and the Member States.

Patient groups are increasingly involved in the elaboration of clinical trials. Some Member States offer the possibility of patient-reported outcomes (PROMs). Communication portals to allow patients access to available clinical trials already exist or are being developed in many European countries.

ii. Shared knowledge

Shared expertise

The 24 European Reference Networks (ERNs) aim to connect healthcare professionals around Europe with expertise on rare diseases which allows them to discuss patients’ records and provide the best diagnostic and treatment options in these complex situations. Two of them are currently dedicated to rare cancers.

Shared data

Cancer registries are a very important source of objective cancer data to evaluate cancer burden and help design cancer control plans. The European Network of Cancer Registries (ENCR) currently gathers 178 individual registries across Europe, including non-EU countries, but it appears that registration is hampered by significant disparities in their quality and coverage.
Independent collection, sharing and analysis of anonymized clinical and biological “big data” is crucial to better understand cancer mechanisms, cancer determinants, cancer predispositions, and treatment resistances. Some countries have already set up national databases. An optimal critical mass is needed to ensure efficiency, independence and competitiveness of data sharing.

The experts of the Mission Board for Cancer have proposed 2 different types of platforms:

- a European Initiative to Understand Cancer (UNCAN), a European platform that would integrate patient data, samples and biomarkers, shedding light on how tumours start, develop and spread.
- a European digital centre for cancer patients to create a standardised and interoperable virtual (patient-controlled) health data network, a global knowledge centre on cancer prevention, health promotion, diagnosis, treatment and supportive care. Also a contact point to provide guidance and support to survivors and to feed into oncology research.

Generating more real-world data is important in order to provide evidence of how treatments are actually used in clinical practice.

**Shared training**

Some common training programmes for health professionals are developed in close connection with European learned institutions. Preventive measures may also be useful to prevent the burnout of cancer care professionals. Interdisciplinary and multidisciplinary health workforce education has shown efficiency.

The potential of genomic medicine and use of artificial intelligence makes it necessary to specialise in medical training and to extend specialised profiles within medical activity.

Educating and training of patients and family caregivers enhances empowerment and health (digital) literacy, known factors that improve quality of life.

**Shared communication**

Adequate and updated guidelines for health professionals, as well as clear and validated information to citizens are key for public education and the fight against misinformation. They are already available in some Member States, but not all.

The European institutions do not currently provide for any structure dedicated to the coordination of such networking tools on expertise, training and communication.