

Press Release

Making sure that Europe's 'Beating Cancer Plan' works for patients

04 February 2021

The European Patients' Forum (EPF) welcomes the publication of the European Commission's "**Europe's Beating Cancer Plan**". EPF is an umbrella organisation of patient organisations across Europe and across disease-areas. Our 75 members include disease-specific patient groups active at EU level and national coalitions of patients. Within EPF's membership, many members represent cancer patients directly or indirectly.

Cancer is the second leading cause of death and disability in the EU - it carries with it a huge societal and personal burden due to premature deaths, loss of productivity and the costs associated with its treatment and care. Cancer is known for frequently intersecting with other chronic diseases, increasing the complexity, burden and cost of possible treatments for patients. Besides, certain chronic diseases share risk factors cancer or even predispose patients to certain types of cancer.

To better tackle these complexities, the Cancer Plan will need to build synergies with other ongoing initiatives (e.g., the Horizon Europe's Cancer Mission, and the European Partnership for Health Innovation). This is vital to avoid duplication and waste of resources. It will require a "Health in All Policies" approach, recognising the role of non-health sectors as determinants of patients' health. In our view, an effective Cancer Plan may lead to benefits for other chronic diseases, including a better understanding of the links between diseases, improving quality of care, a holistic patient-centred approach, survivorship issues, non-discrimination, and redressing health inequalities.

EPF's view on the Cancer Plan

In our response to the public consultation in May 2020, we highlighted several priorities from a patient perspective that we wished to see as part of the Cancer Plan. These can be read in full [here](#)).

EPF welcomes its comprehensive approach that aims to tackle the entire continuum from prevention, early detection and diagnosis to treatment, and quality of life of cancer patients as well as survivorship issues. We welcome the recognition of financial discrimination faced by cancer survivors, such as in insurance. The Plan also puts forward positive actions to tackle some environmental determinants of cancer.

However, we regret that some patients' priorities are not included in the Plan and would like to see stronger actions in the following areas:

1. Fully implementing access to a holistic range of services

- Screening is well covered in the Cancer Plan with flagship initiatives aiming to widen access to screening. However, there are no clear actions to tackle the access barriers experienced by patients with regard to diagnosis^[1] whilst the impact of the proposed measures remains to be seen. As they will be implemented in cooperation with the Member States, it is key that these engage with patients' organisations at national level.
- The Cancer Plan mentions examine practices in financial and insurance services from the point of view of fairness towards cancer survivors in long term remission, but it does not make an explicit reference on reducing barriers to healthcare, which include reviewing coverage policies, reimbursement, user-charges and co-payments – a problem in many countries. Thus, EPF calls for evidence-based policies to reduce access to these barriers.
- One tool to redress inequities in access to treatment would be using the Cross-Border Healthcare Directive and Regulation to enable patients to access treatments that are not available in their own country. We also believe it is important to identify ways to enable patients' access to clinical trials across borders – participating in clinical trials is of supreme importance and the only treatment option for certain cancer patients.^[2]
- Survivorship actions comprise a series of voluntary initiatives. Cancer survivors are patients with a chronic condition, whose medical, social and other needs need to be taken into account. We welcome the attention to this area, but it will be important to develop and implement these actions in collaboration with patient groups representing cancer patients and survivors.

2. Tackling health inequalities and a strategy on health literacy

- The Cancer Plan foresees the creation of a Cancer Inequalities Registry to map trends in key cancer data identifying inequalities between Member States and regions. However, if these inequalities are not addressed with concrete actions these are unlikely to be reduced.
- The proposed actions can contribute to tackling barriers concerning access to cancer treatment, including therapies, medicines, and other care. However, their success will depend to a large extent on effective synergies with the EU Pharmaceutical Strategy. To facilitate access to effective treatments, it is vital to implement the EU framework on Health Technology Assessment and consider joint procurement strategies.^[3]
- Health literacy is mentioned only in the context of cancer prevention. However, it is also a vital strategy to empower patients in the context of diagnosis and choice of treatment options, as well as supporting self-management and coping. Health literacy is also an important strategy to reduce health inequalities. EPF therefore calls for a comprehensive strategy and action plan on health literacy to be developed, which should extend beyond the health sector to also include other sectors, e.g., education.^[4]

3. Research and innovation for and with patients

- Through the Cancer Mission, which is part of the upcoming research programme Horizon Europe, the Cancer Plan foresees financing research and innovation on the area of cancer. For these to bring concrete added value, EU-funded research consortiums must ensure that patients are included and compensated as full partners, and engage with them in a process of co-creation from the very start.

4. **Better use health data to inform policy-making**

- The Cancer Plan emphasises the need for better collecting and using health data – to tackle inequalities, survivorship, advance research, etc. – all while benefiting from the upcoming European Health Data Space. While all these are welcomed, we stress the importance of including patients as partners in particular when it comes to (re) using their health data for research purposes, and in data governance.^[5]

5. **Meaningful involvement of patients and patients' organisations at all levels of the health system, and in the effective co-design of health policies**

- The Cancer Plan outlines a few instances in which patients and their organisations will be consulted or engaged with. Patient involvement should in our view be the cornerstone of the Cancer Plan implementation, to ensure that it addresses the needs and expectations of its end-users. This should include patient organisations' formal representation on the Implementation Board, not only through the EU Health Policy Platform.
- Our organisations are in a key positioned as a bridge between patients and policy-makers, with significant expertise on how to involve grass-roots communities. Involvement of patient organisations should be built in at the European and national level to ensure the Plan is fit-for-purpose and useful for European patients.

Conclusion

EPF welcomes the Cancer Plan, presented today by the European Commission, but at the same time, it strengthens its commitment to making it work for patients with cancer and/or other chronic diseases. For the Cancer Plan to succeed and live up to the high expectations that society and the patient community have placed on it, it should be co-implemented with its end-users to ensure that their views and needs are considered and met.

To fulfil the latter purpose, EPF remains at the full disposal of the EU institutions, its membership, and other interested stakeholders to co-implement the Cancer Plan, making sure that it addresses patient's needs.

[1] Please see EPF (2017) "Patients' perceptions of quality in healthcare", <https://www.eu-patient.eu/globalassets/policy/quality-of-care/quality-survey-report.pdf> ; EPF (2016) Survey on Access to healthcare, https://www.eu-patient.eu/globalassets/policy/access/final-access-survey-report_16-dec.pdf

[2] <https://www.youthcancereurope.org/2020/10/new-paper-cross-border-access-to-clinical-trials-in-the-eu/>

[3] Please see EPF's 2020 position paper on the value and pricing of innovative medicines, <https://www.eu-patient.eu/globalassets/library/position-papers--briefings/position-paper---pricing---finalversion.pdf> and our response to the EU Pharmaceutical strategy, <https://www.eu-patient.eu/globalassets/policy/access/epf-pharma-strategy-final.pdf>

[4] See WHO (2013) Health literacy. The solid facts. <https://apps.who.int/iris/bitstream/handle/10665/128703/e96854.pdf>

[5] See also EPF's responses to the EU Data Strategy and statement on artificial intelligence: <https://www.eu-patient.eu/news/latest-epf-news/2020/epf-data-strategy-and-ai-white-paper-consultation/>