

Patient Advisory Committee of the European Cancer Organisation Rue de la Science 41 1040 Brussels, Belgium

20 February 2025

Dear Commissioners Albuquerque and Várhelyi,

On behalf of the **Patient Advisory Committee of the European Cancer Organisation**, we extend our heartfelt congratulations on your recent appointments. We also look forward to enlisting **your support in fulfilling the promise of Europe's Beating Cancer Plan** in combatting financial discrimination against cancer survivors.

Even though cancer is no longer a death sentence, many survivors continue to face discrimination throughout their treatment and post-treatment journeys. All members of the European Cancer Organisation Patient Advisory Committee are united in our resolve: Europe's 20 million cancer survivors¹ must be protected from facing unfair discrimination as a result of their past cancer diagnosis.

One area of particular concern is how cancer survivors are often treated by financial service providers. Survivors seeking loans, mortgages, or insurance policies are frequently denied access solely due to a past cancer diagnosis, **no matter how long ago that diagnosis was received and regardless of achieving a complete remission**. Some studies have suggested up to **25% of those living beyond their cancer may be having more difficulty accessing appropriate financial services and face discrimination**². This is patently unacceptable, and we urge be countered at the European level, in the context of the ongoing implementation of Europe's Beating Cancer Plan.

The "Right to be Forgotten" refers to the **rights of cancer survivors to resume a "normal" lifestyle without encountering discrimination based on their past cancer diagnosis, after they have been declared cured**³. It is our considered view that an individual's former cancer diagnosis should no longer be relevant to a financial service application **five years after the end of active treatment**⁴.

As of today, nine EU member states have now made the important move to provide a binding legal framework to establish a right to be forgotten, with more countries giving this active consideration. However, twelve member states currently do not have any form of protection against this inequity. We ask for your support to ensure that the 'Right to be Forgotten' is embedded across Europe and enshrined in European legislation.

There are many ways to address this issue. From August 2023 to May 2024, the European Cancer Organisation and other partners have been involved in the numerous roundtable negotiations for the development of a Code of Conduct on Fair Access of Cancer Survivor to Financial Services (HADEA/2022/OP/0019), chaired by DG SANTE and DG FISMA. Although agreement between partners on such a Code during this time was not achieved, the medical evidence, exchanges, relationships and advances made during these nine months should not be lost. Instead, they should inspire fresh binding initiatives during the 2024-2029 Commission period.

Additionally, the revision of the Consumer Credit Directive in 2021 [2021/0171(COD)] introduced a framework requiring Member States to ensure that personal data concerning consumers'

Lawler M, De Lorenzo F, Lagergren P, Mennini FS, Narbutas S, Scocca G, Meunier F; European Academy of Cancer Sciences. Challenges and solutions to embed cancer survivorship research and innovation within the EU Cancer Mission. Mol Oncol. 2021; 15:1750-1758. doi: 10.1002/1878-0261.13022 . PMID: 34053182

Ending financial discrimination for cancer survivors: embedding the Right to be Forgotten in legislation across Europe - K3
https://endingdiscrimination-cancersurvivors.eu/financial-discrimination-against-cancer-survivors/

^{4 &#}x27;Any intervention or therapy, including the use of surgery, radiation therapy, hormone therapy, targeted therapy, chemotherapy, biological agents, immunotherapy, bone marrow transplant, cell or gene therapy, clinical trials for cancer treatments, any combination of these treatments or other evidence-based medical approaches, depending on the type and stage of cancer. These therapies may have been employed in both the localised (adjuvant and neoadjuvant) settings and advanced setting. The term excludes any form of preventative or rehabilitative therapy, medicine intended to reduce recurrence risk or progression following complete remission or monitor the former cancer patient.'



diagnoses of oncological diseases are not used for insurance policies related to credit agreements after a period determined by each Member State, not exceeding 15 years following the end of medical treatment. The upcoming revision of the Mortgage Credit Directive (2014/17/EU) **should strive to introduce a five-year protection period after the end of active treatment**. France, Spain, and Belgium (as of January 2025) allow a person's medical history to be forgotten after five years and should serve as a model for all European countries.

This form of discrimination can only be overcome with your support. We hereby ask that the cooperation between DG SANTE and DG FISMA to address this topic, initiated during the term of the last European Commission, be re-established under your joint authority and instruction.

We remain at your disposal for further discussions, through an online or in-person meeting.

We are very much looking forward to hearing from you and exploring ways to collaborate on this major issue.

Yours sincerely,



Rue de la Science 41 1040 Brussels, Belgium +32 2 775 02 00 info@europeancancer.org