

TIME TO ACCELERATE: THE RIGHT TO BE FORGOTTEN

A position paper of the European Cancer Organisation

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Cancer is no longer a death sentence. The latest scientific research and data indicate that there are more than 20 million cancer survivors in Europe¹, with 3.5 million new diagnoses yearly. However, a survivor's journey is often disrupted by various forms of discrimination. This is a particular problem when attempting to (re)integrate into the workplace and when trying to access financial services such as loans, mortgages, and life or travel insurance. Such discrimination is unacceptable and must be called out and countered at a European level. A key approach is to ensure that the 'Right to be Forgotten'² is embedded across Europe, so that a cancer patient when cured does not have to reveal their previous cancer diagnosis³. This principle should be enshrined in European law.

With this in mind, under the fourth pillar (survivorship) of Europe's Beating Cancer Plan, the European Commission is currently seeking to develop a Code of Conduct on fair access of cancer survivors to financial services, which is set to be published in March of this year. Stakeholders have been invited to contribute to roundtable discussions with the Code authors to provide their perspective and experience, towards the final text of the Code.

¹ 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

² <https://endingdiscrimination-cancersurvivors.eu/>

³ Lawler M, Meunier F. [Don't make cancer survivors pay twice-the right for them to be "forgotten" should be law everywhere](#). *BMJ*. 2022 Sep 21;378:o2197. doi: 10.1136/bmj.o2197. PMID: 36130783



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What follows are some key points, reflections, and concerns from the European cancer community, with the aim of informing the best possible drafting of a European Code of Conduct on fair access of cancer survivors to financial services.

This initiative to achieve a **common approach** by the EU financial service sector towards fair provision of services to cancer survivors is broadly welcomed, yet several points of contention must be addressed, to achieve a sufficient text that serves the needs of cancer survivors.

I. Citizen rights should be protected in legislation, not voluntary codes

Across Europe, a growing number of countries are recognising the need to protect cancer survivors by introducing national legislation against financial services. Notable leaders in these efforts include France⁴, Belgium⁵, the Netherlands⁶, Portugal⁷, Romania⁸, Italy⁹, Spain¹⁰ and Cyprus. This is further bolstered by the recent adoption of the Directive on Consumer Credit in September 2023¹¹, which requires that a cancer diagnosis should not be taken into consideration after a relevant period following the end of medical treatment.

⁴ <https://www.gouvernement.fr/actualite/droit-a-loubli-etendu-pour-les-anciens-malades-de-cancer#:~:text=Dor%C3%A9navant%2C%20le%20droit%20%C3%A0%20,un%20risque%20aggrav%C3%A9%20de%20sant%C3%A9>.

⁵ https://www.ejustice.just.fgov.be/cgi_loi/change_lg.pl?language=fr&la=F&cn=2019052603&table_name=loi

⁶ <https://zoek.officielebekendmakingen.nl/stb-2020-453.html>

⁷ <https://www.parlamento.pt/ActividadeParlamentar/Paginas/DetalheIniciativa.aspx?BID=110342>

⁸ https://www.cdep.ro/pls/proiecte/upl_pck2015.proiect?idp=20059&fbclid=IwAR32oJB8ffZrG00UGjRIHZaNRVxSwRM6lvuWF3EpcG7myUH_vpOH3MRI9z0

⁹ <https://www.normattiva.it/uri-res/N2Ls?urn:nir:stato:legge:2023;193>.

¹⁰ <https://www.boe.es/buscar/act.php?id=BOE-A-2023-15135>

¹¹ https://www.europarl.europa.eu/meetdocs/2014_2019/plmrep/COMMITTEES/IMCO/AG/2023/05-22/1277771EN.pdf



In this sense, the establishment of a voluntary code of conduct for financial service providers is a weaker response to the issue of discrimination than the present trend for securing protection for citizens through legislation.

While a Code of Conduct can set out useful parameters for the harmonisation of approach by countries and the financial service sector towards the Right to be Forgotten, in no way should it be considered a substitution towards securing legal and harmonised protection for European citizens. Therefore, we propose that the Right to Be Forgotten should be transcribed into European legislation.

II. Five years following the end of active treatment should be the European standard for the Right to be Forgotten

The European cancer community calls clearly, and with a united voice, for the standard application of a Right to be Forgotten as applying from five years following the end of an individual's active cancer treatment. This is the legal standard pioneered by the French legal *Droit à l'oubli*. Five-year survival is also the international standard for measuring survival for cancer.

France's innovative approach has enabled cancer survivors to reclaim control over their personal narratives, fostering an environment that promotes improved mental well-being and reintegration of cancer survivors into society. France's model should serve as an inspiration for other Member States, encouraging the adoption of similar measures to ensure the protection and enhancement of individuals' quality of life after overcoming such challenging health experiences.

Any Code of Conduct that suggests a longer survival period would be extremely difficult for the European cancer community to support as it does not reflect the needs of cancer survivors.

III. The Code of Conduct should be the first step towards ending discrimination against cancer survivors in the EU

Cancer survivors can face many forms of discrimination, including but not limited to, social stigmatisation, job loss, and workplace discrimination. However, the development of a consensus and expert-formed European Code of Conduct on fair access of cancer survivors to financial services can provide a clear basis on which a pan-European goal for ending one form of discrimination against cancer survivors could be based.

The next European Commission 2024–2029, as it implements the next stages of Europe’s Beating Cancer Plan, should state a clear goal of encouraging every EU Member State to implement a legal Right to be Forgotten, taking the Code of Conduct as the consensus basis for the regulatory parameters.