# Protecting cancer survivors across Europe from financial discrimination: The right to be forgotten

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Mark Lawler and Françoise Meunier highlight the financial discrimination that many cancer survivors face despite being cured of their disease and propose a data-informed legal solution so that cancer patients are not punished for a previous cancer diagnosis

## The financial toxicity of being a cancer survivor

Imagine the scenario – the doctor says you have cancer. You face one of the biggest challenges of your life. But you are one of the lucky ones. Your cancer responds to the treatment. Five years post-treatment, the doctor says that you are cured. You have beaten cancer. But there is a sting in the tail: When you go to get a mortgage for that little cottage by the sea that you always wanted, you find that you have to reveal your previous cancer diagnosis (even though you are now cured) and that this will have a negative impact on you getting a mortgage, securing house and life insurance.

The story above is an imaginary situation, but unfortunately, the financial discrimination that it highlights is all too real. Despite the fact that nearly 20 million Europeans are living beyond cancer, <sup>(1)</sup> our data regrettably show that the cancer stigma lives on through a particularly unjust form of financial discrimination. Despite the robust scientific evidence of a 'cure' that we and others have revealed through an evidence-based approach, <sup>(2-5)</sup> cancer survivors across Europe routinely experience significant discrimination in accessing a variety of financial products and services, including health and travel insurance, loans and mortgages. <sup>(2-6)</sup> A survey by the Irish Cancer Society, Ireland's largest cancer charity, revealed that a third of cancer survivors experienced significant difficulties in accessing appropriate products with insurance companies, while nearly a quarter of cancer survivors were unable to get even a quote for the financial services that were on offer to the general public, simply because they once had cancer. <sup>(7)</sup>

# Protecting the cancer survivor – the Right to be Forgotten

Recognising the financial discrimination that cancer survivors face, Dr Françoise Meunier, inspired by France's legislation on the 'Right to be Forgotten,' has been advocating for a past cancer diagnosis to be disregarded for cancer survivors at the EU level. This approach ensures that cancer survivors can get access to the financial services and products that they need. To that end, Dr Meunier founded the European Initiative on Ending Discrimination against Cancer Survivors to push for similar legal provisions to be adopted in all European Member States.

In January 2016, France became the first country in the world to bring into law the Right to be Forgotten, <sup>(8)</sup> thus ensuring that long-term cancer survivors accessing financial services would no longer be discriminated against due to a previous cancer diagnosis. As of September 2024, a further seven European countries have followed France's lead (Belgium (March 2018), The Netherlands (January 2021), Portugal (January 2022), Romania

(July 2022), Spain (July 2023), Cyprus (November 2023) and Italy (<u>December 2023</u>)). Other European countries have not gone as far, adopting either agreements between government and insurers (Luxembourg) or self-regulatory codes of conduct by the financial/insurance industries (Ireland, Denmark, Greece, and Finland). That still leaves 40 countries in the WHO European region that have no protections in place for financial discrimination against cancer survivors.

## Embedding an evidence-informed solution into national law

Ensuring all cancer survivors are protected requires legislation at a national level, supported by a European legal framework so that all European cancer survivors are protected in a similar way, no matter where they live. Implementing the Right to be Forgotten Europe-wide has been emphasised through a position paper by the <u>European Cancer Organisation</u>, <u>Europe's largest multi-professional cancer organisation</u>.

National legislation is also valuable, especially while no European provisions are in place. In February 2022, the European Parliament called on Member States to implement national legislation, <sup>(9)</sup> but while some countries have responded positively and enacted legislation as described above, a significant majority of EU countries (70%) have been somewhat reticent. For the last year, the European Commission has been consulting with stakeholders on the potential to develop a Europe-wide Code of Conduct, as foreseen by Europe's Beating Cancer Plan. The financial institutions, however, have been championing a time limit that may be as much as 10 to 15 years for the Right to be Forgotten to apply. For the cancer community, this timeline is unacceptable, again reflecting the absolute need to have a legal imperative to ensure the Right to be Forgotten safeguards cancer survivors from financial discrimination in a way that enables their speedy return to 'normal life'. As such, both cancer patients and cancer professionals favour the evidence-informed five-year limit.

So, what has been the impact of the Right to be Forgotten where it has been introduced into law? Looking at France, which now has more than eight years of experience following implementation, there is no evidence to suggest any significant financial impact on insurance companies. <sup>(10)</sup> The evidence presented in our recent paper, <sup>(3)</sup> published in The Lancet Oncology, clearly demonstrates that a five-year limit after the end of treatment and in the absence of relapse represents the most appropriate time frame after which the Right to be Forgotten should apply.

# Stopping the discrimination – acting on the evidence

The data are unequivocal. When a cancer professional indicates that you are cured and the significant body of evidence from international benchmarking agrees, then by what authority can financial institutions claim that you are not? Our evidence of financial toxicity for cancer survivors is undeniable. Our estimates are probably conservative – the financial burden may be even more pronounced. It is unacceptable that significant numbers of cancer survivors continue to be discriminated against financially and have a previous cancer diagnosis hanging over their heads. While the current cost of living crisis is hard for everyone, it is so much worse for cancer survivors, with the additional financial burden making daily life even more challenging. We must embed legislation across Europe to protect our cancer survivors who are living beyond their cancer as a matter of urgency.

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#### Stakeholder Details

- Article Tags
- Cancer Research
- Finance
- Publication Tags
- OAG 044 October 2024
- Stakeholder Tags
- SH Patrick G Johnston Centre for Cancer Research

**Primary Contributor** 

Mark Lawler
Queen's University Belfast, UK

Additional Contributor(s)

Françoise Meunier

European Initiative on Ending Discrimination against Cancer Survivors

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