

## SPECIAL ARTICLE

# Freedom from the stigma of oncologic disease: legislative and ethical aspects of the right to be forgotten in oncology

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## ABSTRACT

Cancer diagnosis, treatment, and prevention advances have significantly improved European outcomes, but the stigma surrounding cancer survivorship remains challenging. Discrimination against cancer survivors has a negative impact on their quality of life, autonomy, and financial stability. While some European countries have implemented legislation recognizing the “right to be forgotten” for cancer survivors, Italy has no such protective measures. This leaves cancer survivors in Italy susceptible to discrimination based on their medical history. Both the European Union Cancer Plan and the European Parliament resolution stress the importance of safeguarding the rights of cancer survivors and preventing discrimination. Although implementation of legislation at the European level may take time, it is essential that national legislatures, including Italy’s, act quickly. This article explores the issue of discrimination against cancer survivors in Europe, focusing on the specific case of Italy. It examines existing legislative solutions and assesses their effectiveness in addressing discrimination. It also discusses the ethical considerations associated with the “right to be forgotten” in oncology, emphasizing its role in promoting equality and safeguarding the privacy of cancer survivors.

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KEY WORDS: Patient rights; Cancer survivors; Social discrimination.

Advancements in early detection, treatment, and prevention methods over the past few decades have positively impacted cancer outcomes in Europe, with the five-year survival rate for all cancers combined currently standing at around 60%, according to the European Cancer Information System (ECIS).<sup>1</sup> However, survival rates vary widely depending on the type of cancer, with some having much higher survival rates, such as breast cancer, with a rate of 85% or higher. Others, like lung cancer, have much lower survival rates of around 15%. Pediatric patients have shown encouraging survival rates, with four out of five children still alive five years after

diagnosis. In Italy, early detection has resulted in a high survival rate of 92% and 87% after five years for prostate and breast cancer, respectively, according to 2020 data. Furthermore, at least one in four cured individuals have a life expectancy equal to that of someone who has never had cancer, leading to a steady growth in the population of cancer survivors, which is increasing at a rate of 3% per year. There are currently 20 million cancer survivors in Europe, with 7 million (35%) of them being long-term survivors diagnosed at least 10 years ago without relapse or recurrence since then.<sup>2, 3</sup>

Even after recovering from cancer, people may

still face discrimination due to the stigma associated with being a cancer patient. This discrimination can negatively impact their quality of life, dignity, and autonomy, lasting decades. Accessing financial and banking services can be challenging, as individuals are often required to disclose past medical conditions, including cancer, which can result in being classified as “at risk” clients and facing additional costs or even being denied access to such services. These services include health insurance, loans, mortgages, and travel insurance.

According to a recent survey by the Irish Cancer Society,<sup>4</sup> cancer survivors face difficulties in accessing financial services, with a higher number of refusals and perceived unfair treatment compared to the general population (almost half of the respondents experiencing problems). Cancer survivors’ experiences of discrimination can extend to other areas, such as parenting, where their previous cancer diagnosis may influence suitability judgments for adoption. This kind of discrimination, in addition to the burden of the disease itself, can lead to a “double condemnation” for cancer survivors: first by the disease itself and second by the lingering stigma even after recovery.

In recent years, many European countries, including Belgium, the Netherlands, Luxembourg, France, Romania, and Portugal, have enacted laws recognizing a “right to be forgotten” (RTBF). The primary objective of these regulations is to establish time limits, after which financial institutions and others may no longer require information about the medical history of individuals who have been treated for cancer. Unfortunately, Italy lacks such legislation, so discrimination against cancer survivors based on their medical history remains possible.<sup>5</sup>

The main focus of this article will be to examine and scrutinize the current situation concerning discrimination against former cancer patients in Europe and Italy. Our analysis will encompass an evaluation of the existing legislative solutions and a critical assessment of the potential for further improvement in this area.

### The legal framework of the right to be forgotten in Europe

Although the significant problem of oncological forgetting has been known for many years,

regulatory intervention by individual European member countries is relatively recent. France became the pioneer country to pass a law in 2016 granting the “right to be forgotten” to cancer survivors. This law empowers long-term survivors who have been cancer-free for 10 years after diagnosis as adults or 5 years as children to prevent financial institutions from accessing their medical history.

Since this anti-discriminatory law allows cancer survivors to lead healthier and more productive lives without financial toxicity, five European countries (Belgium, Luxembourg, the Netherlands, Portugal, and Romania) have also enforced similar laws.<sup>6</sup>

In European countries that have adhered to oncological forgetting, regulations have been introduced limiting the period during which information about an individual’s medical history can be requested when applying for insurance policies or loan/mortgage contracts. Generally, this period cannot exceed 10 years after the person’s recovery. In contrast, Belgium law does not provide a right for cancer patients not to disclose certain information about their past. Still, it merely emphasizes the right not to be discriminated against based on past medical history. This way, Belgian legislation appears weaker than other European countries.

In Luxembourg, a government-insurance company agreement has been in effect since October 29, 2019, despite the absence of a formal law. The Netherlands passed a decree-law on November 2, 2020, that grants the “right to oncological forgetting,” while Portugal recently enacted Law No. 75 on November 18, 2021, which enhances access to credit and insurance contracts for individuals who have overcome or reduced their health risks or disabilities, while prohibiting discriminatory practices. Additionally, the legislation in France and the Netherlands includes provisions that shorten the time limit for exercising the right to oncological oblivion to five years from the end of treatment if the cancer diagnosis was made before age 18 and 21, respectively. Furthermore, some of these regulations specify certain types of cancer with a favorable prognosis, for which reduced timeframes are established to exercise this right.<sup>5</sup> In February 2022,

France even strengthened its law by limiting the long-term survivor definition to five years post-diagnosis.<sup>7</sup>

In Ireland, there is no legislation regarding the right to be forgotten for cancer patients. However, the Irish Cancer Society,<sup>4</sup> performed a study, and it found that people who have had cancer, including patients and their partners, often struggle to get financial products or services due to their past diagnosis. Insurance companies were the primary source of difficulty, with almost half of the respondents experiencing problems. With these data, a campaign was led, resulting in recognition of the right to be forgotten as an essential issue by the Cross Party Parliamentary Group on Cancer. Activists are hopeful that this issue will be legislated and become law by 2023.<sup>8</sup>

As for the problem of oncological forgetting at the level no longer of individual states but of European institutions, it is particularly felt because, in the name of equality of all European citizens, it turns out to be unacceptable any form of discrimination, even concerning one's clinical past. Therefore, European institutions have begun to move in this direction. To achieve this goal, amendments to existing legislation and adopting a dedicated European framework may be necessary.

The Beating Cancer Plan is a comprehensive strategy launched by the European Union (EU) in February 2021 to tackle cancer across Europe. It urges member states to take action to prevent cancer and improve the quality of life for cancer patients, survivors, and their families and caregivers. The plan aims to reduce the burden of cancer by promoting prevention, improving diagnosis and treatment, and enhancing the quality of life for cancer patients and survivors. Among the goals of the Beating Cancer Plan is present Supporting the quality of life of cancer patients and survivors: the plan aims to reduce the impact of cancer on people's lives by providing better support for physical, psychological, and social needs. This goal involves enhancing treatment and diagnosis pathways and promoting a life "free from discrimination and unfair obstacles," such as difficulties in accessing financial services. Thus, the plan is not only limited to ensuring that Europeans have the best possible cancer

care and reducing the cancer burden in the EU by 15% by 2030 but also aims to give equal opportunities to cancer survivors compared to the general population.<sup>9</sup>

Following the strategy of the beating cancer plan, the EU's mission (Horizon Europe research and innovation program for 2021-2027) dedicated to the fight against cancer also puts "Quality of life for patients and their families" on the same level in its four objectives with understanding cancer, prevention, and optimizing diagnostics and treatments.<sup>10</sup>

The "right to be forgotten" also affects many people in Spain, with an estimated 2.2 million individuals impacted.<sup>11</sup> The Spanish Association against Cancer (AECC) emphasizes that job loss and challenges in reentering the workforce are common issues cancer survivors face. According to their data, 21% of individuals who have overcome cancer had to cease working due to the disease, and 14% had to seek new employment opportunities.<sup>12</sup>

To address this issue, the Spanish government, under the leadership of Prime Minister Pedro Sanchez, plans to introduce legislation that guarantees the "right to be forgotten" in the context of oncology in June 2023.<sup>13</sup> The proposed law aims to grant a new right to individuals who have completed cancer treatment without relapse for a minimum of five years before entering into a contract. It will invalidate contractual clauses that discriminate or exclude based on a person's cancer history when contracting products or services. The objective is to prevent insurers from imposing more burdensome conditions on individuals with a history of cancer. This legislation will involve amendments to existing consumer protection and insurance contract laws. It will establish, for the first time, the right for individuals not to disclose their previous cancer diagnosis when applying for insurance related to mortgages.

Prime Minister Sanchez has engaged in discussions with various cancer associations, expressing the government's commitment to advancing this law. The announcement has been welcomed by the AECC, who regard it as a significant step forward regarding social protection for cancer patients. In summary, introducing this law in

Spain aims to provide increased protection and support for individuals who have triumphed over cancer, addressing their specific needs and promoting social inclusion.

The European Parliament adopted a resolution on February 16, 2022, entitled “Strengthening Europe in the fight against cancer – Towards a comprehensive and coordinated strategy.” Among the points in this resolution, it also highlighted the need for legislation on the “right to be forgotten” in oncology.<sup>14</sup>

The resolution recognizes the need for insurers and banks to refrain from using the medical history of cancer survivors in their decision-making processes. It further calls for national legislation to safeguard the rights of cancer survivors against discriminatory practices by financial service providers. The European Commission intends to collaborate with businesses to create a code of conduct to ensure that improved cancer treatments are reflected in the practices of financial service providers. The resolution also commends the “right to be forgotten” provisions in France, Belgium, Luxembourg and the Netherlands for cancer survivors and recommends that all European patients should have the right to be forgotten ten years after the end of their treatment or up to five years after the end of treatment if they were diagnosed before the age of 18. The document urges the establishment of common standards for the right to be forgotten under the consumer protection policy of the Treaty on the Functioning of the European Union to remedy the fragmented national practices that limit cancer survivors’ access to creditworthiness assessment and financial services. Finally, the document proposes integrating the right to be forgotten for cancer survivors into relevant EU legislation to prevent discrimination and improve access to financial services.

It is important to note that future European legislation may take a long time to be enacted and subsequently implemented by member states. Additionally, it should be noted that the documents adopted by institutions thus far are not legally binding on member states. As a result, given the current regulatory vacuum at the European level, national legislatures must take prompt action. The European Union has urged

all member countries to implement “right to be forgotten” measures by 2025.

### **The overview of the oncological right to be forgotten in Italy**

More than 3,600,000 people in Italy diagnosed with cancer are not recognized as having the right to oncological forgetting.<sup>15</sup> The AIOM Foundation (Italian Medical Oncology Association) initiated its campaign in 2021 to promote acknowledging the right to be forgotten. The campaign’s objective was to advocate for relevant legal frameworks safeguarding individuals who have undergone cancer.<sup>16</sup> A proposed bill was introduced to the Senate on 28th February 2022, acknowledging the entitlement of those impacted by oncological ailments to non-discriminatory treatment concerning the adoption of minors or access to banking and insurance services.<sup>17</sup>

The proposed bill, titled “Provisions on equal treatment of persons who have been affected by oncological diseases,” consists of five articles and aims to ensure non-discrimination for individuals affected by oncological conditions. The constitutional basis for this right is identified in Articles 2, 3, and 32 of the Constitution. Article 3 emphasizes equal social dignity and the duty of the Republic to remove economic and social obstacles that impede the full development of individuals.

The bill also recognizes additional normative sources, such as Articles 7, 8, 21, 35, and 38 of the Charter of Fundamental Rights of the European Union and Article 8 of the European Convention for the Protection of Human Rights and Fundamental Freedoms.

The key innovations introduced by the bill are outlined in Articles 2 to 5. Article 2 states that no health information regarding past oncological conditions should be requested from consumers if ten years have passed since active treatment without relapse or five years if the disease was diagnosed before age twenty-one. Furthermore, after these periods, the previously provided information should not be used to assess the consumer’s risk and solvency. Article 3 amends the Law of 4th May 1983, No. 184, related to the adoption and custody of minors, to include the

same time limits of 10 and 5 years. This means that information about past oncological illnesses should no longer be requested or considered during the evaluation of adoption applications. Lastly, Article 4 establishes a “Council for the Equal Treatment of Persons affected by oncological diseases.” This council will have various functions, including recommending to the Ministry of Health, every two years, a list of pathologies for which treatment terms and requirements may deviate from the general ones of 5 years for neoplasms diagnosed before the age of 21 and 10 years for others.

In summary, the proposed bill aims to ensure equal treatment for individuals affected by oncological diseases by setting time limits on the collection and use of health information, amending adoption laws, and establishing a council to address the equal treatment of such individuals.<sup>18</sup>

However, in 2023, during the latest Assembly, the National Economic and Labor Council (CNEL) approved a legislative proposal to eliminate obstacles that prevent those who have overcome cancer from exercising their rights freely and equally. The proposal is similar to the bill already put forward in the Senate and seeks to implement various articles, including those in the Constitution (Articles 2, 3 and 32), Charter of Fundamental Rights of the European Union (Articles 7, 8, 21, 35, and 38), the European Plan against Cancer (COM (2021) 44 final) and European Convention for the Protection of Human Rights and Fundamental Freedoms (Article 8). Additionally, the proposal aligns with GDPR regulations that state that personal data related to past oncological conditions can be banned from processing after ten years since the last active treatment, in the absence of relapse, or five years if the condition occurred before the age of 21.<sup>7</sup>

### Ethical considerations on the right to be forgotten in oncology

As previously mentioned, the right to cancer oblivion is an essential ethical principle that ensures equality for cancer patients compared to the healthy population. Currently, receiving a cancer diagnosis leads to stigma and societal judgment for the affected individual. From a moral and eth-

ical standpoint, it is unacceptable that even after a successful recovery, a cancer patient carries a sense of “guilt” that cannot be attributed to their actions. This situation causes frustration and erodes trust in society and its institutions. Therefore, these institutions must take urgent action to rectify this unfortunate state of affairs.

Unfortunately, cancer incidence is increasing, primarily due to population aging and changes in lifestyle and the environment. Failing to address this issue promptly will result in a devastating consequence: a more significant population subjected to discrimination and victimization. Institutions must recognize the urgency of the matter and swiftly provide a solution. By granting the right to cancer oblivion, we can promote inclusivity, empathy, and a society that supports all individuals’ well-being and equal treatment, irrespective of their medical history.

The Veronesi Foundation’s ethics committee,<sup>19</sup> a strong advocate for the right to oncological oblivion, raises significant concerns regarding the bill, emphasizing the urgency of its implementation. However, the committee believes that further considerations are necessary to ensure the effectiveness of the proposed measures.

One crucial aspect highlighted by the committee is the need for a clear definition of cancer pathology. Different types of cancer have varying healing timelines and “disease-free periods”.<sup>20</sup> If the regulatory measure oversimplifies these timelines by imposing global limits, it could inadvertently harm individuals with less aggressive cancer forms with shorter healing times. Therefore, the committee suggests the inclusion of disease-specific time intervals to strike a balance and provide appropriate care for different cancer forms. The existing Council for the Equal Treatment of Persons Who Have Been Affected by Oncological Diseases lacks provisions in this regard and should be complemented by a constant program of reviewing scientific evidence from literature and conducting epidemiological studies. The committee proposes including a scientific committee alongside the Council to address this concern.

Additionally, the committee contemplates identifying other potential areas of discrimination, particularly in employment. It suggests ex-

panding the information campaigns outlined in the bill to encompass pediatric oncology-related discrimination. Moreover, the target audience of such campaigns should extend beyond the “consumers” of financial services to include all individuals who have received an oncological diagnosis during childhood or those seeking to pursue adoption. These information campaigns would educate potential victims of discrimination on the implications of sharing sensitive data about their disease through online platforms. By addressing these points, the committee aims to enhance the comprehensiveness and effectiveness of the proposed bill, ensuring that it provides adequate protection and support for individuals affected by cancer.

### Conclusions

The patients affected by cancer and the scientific community are united in their efforts to globally promote the importance of standing up for their rights, including the right to be forgotten. Cancer survivors should not have to continuously fight discrimination for years after recovery. They should be free to tell their story and choose what aspects of their life to share with the public. The legislative measures protect them from financial toxicity and discrimination. In addition, insurers companies will be minimally affected by this legal framework, which will have significant implications for patients.

However, each country must take action to ensure the 20 million Europeans who have survived cancer are not punished twice for their diagnosis. The right to be forgotten must be enshrined in European law to end this injustice and allow individuals affected by cancer equal access to services without discrimination.

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#### *Conflicts of interest*

The authors certify that there is no conflict of interest with any financial organization regarding the material discussed in the manuscript.

#### *Authors' contributions*

Conceptualization: Paolo Bailo and Giovanna Ricci. Methodology: Paolo Bailo and Filippo Gibelli. Writing original draft preparation: Paolo Bailo and Filippo Gibelli. Writing, review, and editing: Paolo Bailo, Filippo Gibelli and Anna M. Caraffa. Supervision: Anna M. Caraffa and Giovanna Ricci. All authors have read and agreed to the published version of the manuscript.

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