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## A European Cancer Survivors' Right to be Forgotten?

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**By Hannah van Kolschooten and Mirko Faccioli**

There are currently **over 12 million** cancer survivors in Europe. Due to improving cancer screening methods and medical treatment, this number is expected to grow every year. Former cancer patients often face multiple forms of discrimination throughout their lives. Many commercial companies make long-term cancer survivors “**pay twice**” – while having similar life expectancies as their peers, they are denied access to key services because of their former cancer status.

To combat this unfair practice, some European countries are establishing a “cancer survivors’ right to be forgotten,” also referred to as the “oncological right to be forgotten.” **Italy’s** parliament just passed a law to establish the right. **Patients’ rights organizations** and EU institutions are pushing for a “*European cancer survivors’ right to be forgotten*.” This post outlines the purpose of such a right and flags potential challenges in its adoption.

### 1. Discrimination Against Former Cancer Patients

Recovered cancer patients experience discrimination in various areas of life due to their diagnosis. Long after recovering from cancer, ex-cancer patients are requested to report their former medical condition to commercial companies, for example to life insurance companies or funeral insurance companies. These companies are allowed to take into consideration medical history to determine the risks of providing services. Due to **difficulties** in assessing the actual risks, companies often take a precautionary “one-size-fits-all approach” and refuse insurance to cancer survivors or ask for significantly higher premiums. This approach does not reflect the **medical progress** in cancer treatment methods.

As a result, a cancer diagnosis leads to differential access to financial services such as insurance, loans, and mortgages. To illustrate, even after 5+ years in remission, **50% of cancer patients in the Netherlands** were refused coverage by life insurance companies in 2019. In response to this unfair treatment of former cancer patients, there are **increased calls for legislation** all over Europe.

### 2. Outline of a Cancer Survivors’ Right to be Forgotten

In the EU cancer committee report, the right to be forgotten for cancer survivors is described as “the possibility to take up mortgages, loans or life insurance by cancer survivors without being penalized by their disease.” This right is now explicitly recognized in **8 out of 27 Member States** (Belgium, **France**, **Ireland**, Luxembourg, the Netherlands, Portugal, Romania, and Spain). **Italy** is expected to pass a law to establish the right before the end of 2024. The number of years it takes “to be forgotten,” however, varies per Member State, ranging from five to ten years. While some countries have a ban to request information after a certain amount of years for *all* types of cancer, **Belgium**, for example, has adopted an additional document with “reduced time limits” to access the right to be forgotten for specific cancer pathologies. This list is updated every two years, in accordance with the available scientific data on medical progress.

### 3. Difficulties in Ensuring a European Cancer Survivors’ Right to be Forgotten

In 2022, the European Parliament adopted a **resolution** on Europe’s cancer strategy and called for a right to be forgotten for all European cancer patients by 2025 at the latest: “all Member States should guarantee the right to be forgotten to all European patients 10 years after the end of their treatment, and up to five years after the end of treatment for patients whose diagnosis was made before the age of 18.”

However, a uniform EU “Cancer Survivors’ Right to be Forgotten” may be difficult to implement in practice. First, in spite of what its title suggests, the right is not directly protected under existing legislation such as the EU General Data Protection Framework (GDPR), as the GDPR contains **exceptions** for these situations. Importantly, the **Treaty on the Functioning of the EU** limits the EU’s

involvement in the organization of health care and related policies, which makes it complicated to adopt EU regulations in this field. At the same time, the EU does play a role in **consumer protection** policies and anti-discrimination laws. The GDPR also requires health data processing to be proportionate – and requesting cancer history after 10 years in remission may in fact constitute a **disproportionate measure**.

Nonetheless, in any case, finding consensus on a uniform interpretation of a European “cancer survivors’ right to be forgotten” will be a complex task. It is, however, likely that EU Member States will inspire each other to also adopt the right, encouraged by the active campaigning of patients’ rights organizations.

The European Commission does take other measures to protect former cancer patients against financial discrimination. First, the Commission is planning to develop a **code of conduct** in collaboration with financial service providers, to ensure that medical developments in cancer treatments are reflected in their practices, and to avoid **fragmented national practices**. The plan is to **finalize** the code by early 2024. On top of this, the new **EU Proposal on consumer credits** stipulates that cancer data should not be used when conducting a creditworthiness assessment. These measures may limit financial discrimination faced by ex-cancer patients.

#### 4. Conclusions and the Way Forward

Equipping cancer survivors with an effective right to be forgotten is essential in picking up life after recovery. With rapidly advancing prospects for ex-patients because of advancing medical science, the number of recovered cancer patients in Europe will only grow. The risk assessment of financial companies should reflect this change. On top of this, with the increased availability of personal data (i.e., via social media), and the growing use of automated decision-making for insurance applications, a strong right for patients is only getting more important. Let’s hope that Italy’s new law will inspire other EU Member States to adopt a similar right to empower cancer survivors.

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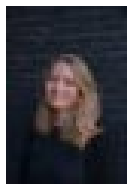
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