DIPARTIMENTO DI GIURISPRUDENZA

Cattedra di Tutela Internazionale dei Diritti Umani

THE RIGHT TO BE FORGOTTEN FOR CANCER SURVIVORS

RELATORE

Chiar.mo Prof.

Pietro Pustorino

CANDIDATO

Giulio Giovannini

Matr. 158563

CORRELATORE

Chiar.mo Prof.

Roberto Virzo

Anno Accademico

2022/2023

Cancer Survivors Should Not Pay Twice

Françoise Meunier

Table of Contents

List of Abbreviations

WHO	World Health Organization
ICCPR	International Covenant on Civil and Political Rights
UDHR	Universal Declaration of Human Rights
UNCTAD	United Nations Conference on Trade and Development
SGD’s	Sustainable Development Goals
ICESCR	International Covenant on Economic, Social and Cultural Rights
CESCR	Committee on Economic, Social and Cultural Rights
CRC	Convention on the Right of the Child
RTBF	Right To Be Forgotten
EU	European Union
HRC	UN Human Rights Committee
CFEU	Charter of Fundamental Rights of the European Union
GDPR	EU General Data Protected Regulation
ECHR	European Convention on Human Rights
ECJ	European Court of Justice
TFEU	Treaty on the Functioning of the European Union
GRA	AREAS Reference Grid
KCE	Belgian Health Care Knowledge Centre
Wmk	Medical Examinations Act
UAVG	GDPR Implementation Act

Introduction

According to data from the World Health Organization (WHO) for 2020, there are 19 292 789 new instances of cancer worldwide, and the number is rising.[1] For both sexes, there are around 9 958 133 cancer fatalities.[2] These figures comprise the total of region-specific countries.[3] Statistics include both industrialized and developing nations, where there are fewer diagnoses due to inadequate scientific research and preventative efforts.[4] The incidence rate is higher but there are fewer fatalities in regions such as Europe, North America, and Oceania. There are over 32 million survivors in the world and this estimated number is expected to grow thanks to the increase of life expectancy after more efficient treatments and cancer screening.[5] In Europe, 5% of the population is estimated to be alive after a cancer diagnosis[6], and in countries such as Italy, the number of cancer survivors is around 1 million.[7] Cancer stands as the second leading cause of death globally, yet continuous advancements in the scientific field are anticipated to curtail mortality rates and elevate survivorship figures. International and regional organizations are constantly coming together for the fight against cancer, ensuring the best practices to increase the survival rate. However, the journey of a cancer patient comes with many consequences. It is within this context that the significance of this thesis unfolds. As elucidated further, the trajectory of cancer involves myriad repercussions throughout the treatment continuum. Cancer patients engage in prolonged battles, often spanning years, in their struggle for life. The international community, and notably individual states, persist in making strides in the battle against cancer. Nevertheless, there is a noticeable lack of understanding and

---

[1] '*Cancer Today*' <http://gco.iarc.fr/today/home> accessed 10 August 2023.

[2] ibid.

[3] ibid.

[4] ibid.

[5] '*Overview of Cancer Survivorship Care for Primary Care and Oncology Providers*' <https://www.medilib.ir/uptodate/show/16613> accessed 6 August 2023.

[6] ESMO, '*Complete Cancer Prevalence in Europe in 2020 Reveals an Increased Proportion of Cancer Survivors Beyond 5 Years from Diagnosis*' <https://www.esmo.org/oncology-news/complete-cancer-prevalence-in-europe-in-2020-reveals-an-increased-proportion-of-cancer-survivors-beyond-5-years-from-diagnosis> accessed 3 January 2024.

[7] lucia, '*Rinascita: tornare alla vita dopo la malattia*' (*LILT Milano Monza Brianza*, 15 January 2024) <https://www.legatumori.mi.it/resta-informato-post/tumori/progetto-rinascita/> accessed 28 January 2024.

discourse concerning the post-treatment lives that cancer patients aspire to lead. Therefore, the choice of this thesis lies on the increasing importance of ensuring that after treatment, patients can fully enjoy the life they fought for without encumbrances or discriminatory impediments.

The continual surge in the number of cancer survivors has underscored the imperative to reintegrate them into society. Cancer treatments encompass a spectrum of long-term and short-term challenges, spanning both physical and psychological dimensions. Regrettably, these issues are compounded by discrimination in various domains, including the workplace, financial services, and the adoption process, perpetuated by the lingering stigma associated with cancer. Despite cancer survivors successfully completing their treatments and remaining free from disease recurrence for extended periods, they persistently contend with the label of being deemed individuals at risk. The focal concern at hand revolves around the dual burdens faced by cancer survivors. In addition to navigating significant obstacles and hardships in the journey to reclaim a normal life, they subsequently encounter heightened difficulties in securing employment, obtaining mortgages, procuring insurance, and pursuing adoption. This thesis also aims to provide light on the prejudice, stigma and discrimination experienced by cancer survivors and any potential human rights abuses associated with it.

The legal acknowledgment of cancer survivors, a topic to be explored in this thesis, is inadequately covered in international, European, and national human rights laws. Cancer survivors lack proper identification, receive no legal acknowledgment, and are left grappling with the aftermath of rebuilding their lives. The challenge of insufficient recognition and the discrimination encountered by cancer survivors as they reintegrate into normal life is the problem that the concept of the Right To be Forgotten aims to address. The establishment of a well-defined and consistent legal framework at the international or regional level is essential to confront and acknowledge the discriminations experienced. This framework is crucial for the effective implementation of the Right to Be Forgotten (RTBF) in a coherent manner through national legislation.

The objective of this thesis is to address a fundamental question regarding the extent of efforts needed, at the international, regional and national level, to combat discrimination against cancer survivors. The specific inquiry is framed as follows: "*To what extent does international and European human rights law ensure the Right To Be Forgotten for cancer survivors, and how is it implemented through national legislations*?" The legal focus of this thesis involves an initial examination of the international and European human rights laws pertinent to the analysed discrimination encountered by cancer survivors, particularly delving into the protection afforded by the Right to Be Forgotten. Following this scrutiny, it becomes crucial to assess and draw comparisons on the implementation of RTBF in national legislations in alignment with European directives. This research also reserves the right and scope to advise a specific interpretation of “cancer survivors”, which not only serves for the purpose of this thesis, but also as a definition that helps the identification of this category and its recognition for a concrete legal application.

This emerging concern has gained significance, with limited resources available for comprehensive study. The research methodology will combine empirical analysis of the discriminations, safeguarded rights, and potential violations experienced by cancer survivors, alongside a legal examination of national legislations implementing the Right To Be Forgotten. To address this issue, the methodology adopts a progressive approach to comprehend the identified problem.

Scientific data from diverse sources, including literature, medical journals, and reputable websites, will be utilized to delineate and contextualize the problem, contributing to the formulation of terms used in the research. For legal recognition, an assessment of international declarations, action plans, and resolutions will be undertaken, situating cancer and its treatment within the global context. Defining the term "cancer survivors" will involve evaluating doctors' perspectives, personal experiences, scientific studies, and surveys, utilizing an evaluative and quantitative research methodology to contextualize cancer, explore its legal recognition, and define the term "cancer survivor."

To analyse various forms of discrimination faced by cancer survivors, the methodology will employ evaluative and qualitative research techniques, including literature reviews, case studies, and interviews with relevant stakeholders such as doctors and nurses. Literature reviews will provide a comprehensive summary of existing research on prejudice against cancer survivors, while case studies and surveys will offer real-life examples illustrating the challenges confronted by survivors in diverse settings. Interviews with cancer patients and those addressing discrimination will provide firsthand narratives and perspectives. To assess potential unguaranteed rights for cancer survivors, statutory interpretations and doctrinal research will be conducted, interpreting international, regional, and national legal rules, principles, and statutes to comprehend the intent, and meaning of laws and advocate for the protection of cancer survivors in analysed discriminations.

A normative research methodology will be employed to review the RTBF concept, initially as a general concept in international and EU law. This will involve literature analyses and legal sources, assessing international instruments like the International Covenant on Civil and Political Rights (ICCPR) and the General Data Protection Regulation (GDPR). General comments and guidelines will be evaluated to demonstrate the international connection and ensure its application. Utilizing a comparative approach with the EU framework and case law, such as Google v. Spain, will reinforce interpretations of international human rights law. Another comparative and normative approach will be essential to establish national recognition of the RTBF, using France as a leading example and other states for comparison. National normative sources and doctrine on such laws will be analysed and explained for comparison purposes. These methodological approaches are imperative for answering the research question, identifying relevant human rights violations, and illustrating the necessity of a comprehensive legal framework ensuring the RTBF for cancer survivors.

The necessity of employing a blend of diverse methodological approaches and sources stemmed from the limited existing literature in this domain. Legal resources were constrained to the interpretation of Conventions and national legislations. Doctrine and jurisprudence, however, were accessible solely for international conventions and international and European case law. Despite the paucity of legal resources, the research drew extensively from medical journals, stakeholders' publications, surveys, and studies. These non-legal sources played a crucial role in comprehending the discrimination faced by cancer survivors. The limited resources afforded a greater degree of interpretive flexibility in exploring the intricacies of the thesis while maintaining a robust and coherent foundation.

To address the posed inquiry, the thesis will be segmented into four chapters, each sequentially dissecting distinct facets of the matter. The inaugural chapter endeavours to contextualize the thesis subject, cancer and survivors, adopting a dual lens of scientific and legal perspectives. Scientific data will be employed to apprehend the escalating significance of cancer survivors, delineating the trajectory of their increasing numbers and the ensuing imperative to safeguard a broader spectrum of rights. The legal framework acknowledging cancer and its afflicted individuals will undergo scrutiny to furnish a historical backdrop elucidating the international orchestration of the fight against cancer by entities like the World Health Organization (WHO). Delving into patients' rights, the chapter aims to portray the legal considerations they receive and, conversely, the dearth of efforts directed towards their seamless reintegration into society, thereby presenting a comprehensive depiction of their entitlements. A consolidated interpretation of the term "cancer survivor" is proffered, informed by diverse medical viewpoints. The ensuing deliberations culminate in a definitive term adopted for the research, substantiated by the alignment with varying national legislations.

The second chapter concentrates on a comprehensive analysis of the discriminations faced by cancer survivors, examining the stigma intricately associated with this ailment and the potential infringements upon their rights, imposing a dual burden upon them. Individual scrutiny will be dedicated to distinct forms of discrimination, commencing with the scrutiny of workplace discriminations. Here, the pervasive stigma, misconceptions, and repercussions stemming from a cancer history, notably periods of unemployment in one's professional trajectory, often manifest in discriminatory practices during job acquisition or reintegration into prior roles. Delving into the apprehensions surrounding information disclosure and the subsequent repercussions on a cancer survivor entering the workforce will be explored, elucidating the psychological challenges entailed in societal reintegration. Proceeding to the examination of the right to work, a meticulous analysis will be undertaken employing pertinent articles from human rights conventions and general comments. The aim is to discern and interpret the application of this right for cancer survivors, ensuring their protection under such a right. If such protection is found lacking, exploration into the necessary implementation mechanisms will ensue. The subsequent facet under examination is the restricted access to financial services, encompassing bank loans, mortgages, and insurances. Utilizing studies and firsthand interviews, the adverse outcomes of compelled disclosure of cancer history will be underscored. Frequently, insurance policies and banks impose exorbitant premiums or withhold financial services based on an erroneous medical perception of the implications of being a cancer survivor. Following this, financial service rights for cancer survivors will be meticulously examined and expounded upon through the interpretation of international declarations, specifically addressing the right to housing and adequate living conditions. The assessment will commence at the international level before delving into the European realm, juxtaposed against consumer protection policies featuring non-discrimination principles. Concluding this chapter, the challenges encountered by cancer survivors in the adoption process will be expounded. Scrutiny will be directed towards adoption family requirements mandating the disclosure of medical information, contending the lack of correlation with the child's best interest. The discourse will be substantiated through an interpretative lens, invoking conventions and general comments as guiding principles.

The third chapter of this thesis is dedicated to an in-depth examination of the evolution, comprehension, and application of the Right to Be Forgotten (RTBF). Over time, the RTBF has undergone a transformative evolution, encompassing various dimensions of the right to privacy and the right to erasure. Originating from the French "*droit à l'oubli*" and the Italian "diritto all'oblio" specifically related to criminal records, these terms can be translated as the right to forget, often colloquially referred to as the right to oblivion.[8] This conceptual framework pertains

---

[8] Ignacio Nicolás Cofone and McGill University (eds), *The Right to Be Forgotten: A Canadian and Comparative Perspective* (Routledge, Taylor & Francis Group 2020), p.2.

to the objective of expunging court decisions and criminal records after a stipulated period. However, this right to forget is yet to be fully acknowledged for cancer survivors, establishing a paradox wherein cancer survivors seemingly possess fewer rights than individuals with a criminal record. The interconnection between the right to privacy and the RTBF will be harnessed to substantiate the application of human rights principles to cancer survivors. The doctrinal and jurisprudential analysis will be systematically delineated, exploring the application of the RTBF in both international and European legal frameworks. This exploration will elucidate how Conventions, policies, and case law have recognized and ensured the RTBF. Having established the contextual groundwork for the RTBF, this chapter will serve as the foundation for comprehending its application to cancer survivors. The ensuing examination will shed light on how the European Union aims to safeguard this right, proposing the formulation of national legislations by member states. This nuanced analysis is imperative for understanding the significance, evolution, and multilateral application, including that of cancer survivors, of the RTBF.

The concluding chapter, the fourth and final segment of this thesis, is dedicated to an exhaustive analysis and legal comparison of the implementation of the Right to Be Forgotten (RTBF) for cancer survivors across six distinct European countries: France, Belgium, Netherlands, Portugal, Spain, and Italy. The benchmark for this comparative study is France's pioneering model, being the first country to comprehensively implement the RTBF for cancer survivors. A detailed legal analysis and commentary on the French model will serve as the foundational framework for scrutinizing the corresponding legislations of the other nations under consideration. Whenever feasible, a thorough examination and contextualization of each law will be undertaken. The areas of scrutiny and comparison will revolve around the scope of application delineated by each legislation, elucidating the extent to which these laws can safeguard rights. Delving into defining time limits for the application of this right, a critical factor in delineating the term "cancer survivors" and its application, will be a focal point. The manner in which each country applies and ensures the human rights principles embedded in their constitutions and provided by the European Convention on Human Rights (ECHR) will be assessed. Strengths and weaknesses inherent in each legislation will be deliberated upon, underscoring the imperative of continued advocacy for the protection of the rights of cancer survivors. Critical differences among the various legislations will be systematically analysed and commented upon, culminating in the final conclusion, where the potential of an international-regional legal framework will be highlighted. This framework aims to foster a more cohesive application and enforcement of the RTBF for cancer survivors.

This thesis represents an innovative and groundbreaking exploration of the rights of cancer survivors, with a specific focus on their definition and identification, a fundamental aspect of their protection. By scrutinizing various discriminations and the associated rights, it aims to provide insights into the essential elements that need to be ensured to establish a comprehensive framework guaranteeing their protection. Recognizing the broad application of the right to oblivion for cancer survivors is pivotal in enabling them to fully enjoy the life they fought for. The comparative analysis of different legislations provides an understanding of the ongoing improvements in each country's approach and underscores the need for continued efforts to control and regulate this burgeoning issue effectively.

In addition to shedding attention on a pressing topic, this thesis hopes to empower cancer patients and survivors by educating them about their rights in advance. A further objective is to promote greater discourse on this subject, enabling other individuals to offer feedback and contribute to the initial investigation and evaluation of cancer survivors' right to be forgotten.

Chapter 1. Cancer and its legal recognition

1.1 Scientific definition and legal recognition of cancer

30 trillion cells make up the basic units of the human body.[9] Through the process of cell division, our system grows and forms new cells.[10] When these cells become old or damaged, they die, and the newly born cells can take their place.[11] Cancer occurs when some of these cells start to grow uncontrollably. These cells go beyond their usual genetic information, invading adjoining parts and finally causing metastasis, which is the major cause of death from cancer and occurs when the malignant cells spread to other organs.[12] One in five people in the world gets cancer during their lifetime.[13] There are over 100 various illnesses that fall under the category of cancer.[14] Each type need a specific treatment and has different side effects according to the stage of its identification.[15] The most common treatments are chemotherapy, radiotherapy, and surgery.[16] However, sometimes these treatments have an impact on the patients' lives even years after the treatments.

Cancer is an illness that affects the physical, emotional, family, financial and working life of patients.[17] The heavy treatments that patients have to undergo are multiple according to the type of cancer. The most common side effects during the treatments are pain, fatigue, anemia, nausea and vomiting, and problems with the

---

[9] '*What Is Cancer*?' (*Cancer.Net,* 1 August 2012) <https://www.cancer.net/navigating-cancer-care/cancer-basics/what-cancer> accessed 5 August 2023.

[10] '*What Is Cancer? - NCI*' (17 September 2007) <https://www.cancer.gov/about-cancer/understanding/what-is-cancer> accessed 5 August 2023.

[11] ibid.

[12] '*Cancer'* <https://www.who.int/health-topics/cancer> accessed 5 August 2023.

[13] '*Cancer Topics – IARC*' <https://www.iarc.who.int/cancer-topics/> accessed 6 August 2023.

[14] '*What Is Cancer?*' (n 9).

[15] '*Cancer'* <https://www.who.int/news-room/fact-sheets/detail/cancer> accessed 6 August 2023.

[16] Department of Health & Human Services, '*Cancer'* <http://www.betterhealth.vic.gov.au/health/conditionsandtreatments/cancer> accessed 6 August 2023.

[17] PharmD Lea Ann Hansen, '*Challenges Patients Face in Cancer Care: Implications for the Healthcare Team*' <https://www.theoncologypharmacist.com/top-issues/issue-archive/14797-top-14797> accessed August 2023.

skin, hair, and nails.[18] On the other hand, some patients can experience long term effects that can last even forever. To mention just few of them, we can find menopause, infertility, endocrine system problems, lung or heart problems and digestion problems.[19] Furthermore, there are consequences, such as the amputation of a limb due to a sarcoma, that constitute a life impairment. All these issues both throughout the therapies and the fear of encountering long-term effects, have a significant impact on patients' psychological well-being and re-integration in society. The late and lasting emotional, social, and medical challenges result in long lasting disabilities.[20]

In the United States (US), 40% of cancer survivors have activity limitations and involvement restrictions due to the long-term effects of cancer.[21] However, the idea, discussion and identification of cancer survivors as disable are largely absent from clinical and cancer health studies.[22] A wide range of long-term physical, sensory, cognitive, and emotional impacts are experienced by survivors; these symptoms combined limit their ability to engage in self-care, employment, leisure, and social responsibilities.[23] In order to facilitate the transition of cancer survivors into life after treatment, cancer care professionals ought to adopt anti-ableist practises and have candid conversations regarding the long-term effects of cancer.[24] The analysis of the consequences of cancer treatment, with the possibility of permanent or temporary disabilities, is necessary in the framework of the definition of cancer survivors and their rights. In fact, as will be further discussed, the problem arises when identifying the subject as falling under disabilities acts, under cancer survivor rights, or both.

---

[18] '*Side Effects of Cancer Treatment*' (Yale Medicine) <https://www.yalemedicine.org/conditions/side-effects-cancer-treatment> accessed 6 August 2023.

[19] '*Long-Term Side Effects of Cancer Treatment*' (*Cancer.Net*, 14 October 2010) <https://www.cancer.net/survivorship/long-term-side-effects-cancer-treatment> accessed 6 August 2023.

[20] '*Cancer Survivorship*' (*The Cancer Atlas*) <http://canceratlas.cancer.org/rky> accessed 6 August 2023.

[21] Susan Magasi and others, '*Cancer Survivors' Disability Experiences and Identities: A Qualitative Exploration to Advance Cancer Equity*' (2022) 19 International Journal of Environmental Research and Public Health 3112.

[22] ibid.

[23] ibid.

[24] ibid.

The number of cancer survivors has increased because of scientific advancement. The progress in prevention, early detection and cancer treatment contributed to significant increase in the number of cancer survivors.[25] A person is regarded as a cancer survivor from the moment of diagnosis till the end of their life.[26] There are many kinds of survivors, including individuals who have cancer and those who don't.[27] Instead of serving as a label that may or may not connect with individuals, this phrase is intended to describe a group of people who have a history of cancer.[28] However, for the purpose of this research this definition will be further analysed in the chapter.

Considering the demographic changes, the wealth, facilities of countries worldwide, the age-standardized death rate has decreased by 15% since 1990.[29] The continuous improvements in research in the field, the spread of awareness of periodic screening according to genetic history and age led to early detection of cancers and an increase in survival rate.[30] States and international organizations understood the importance of collaboration in this field to continue to decrease the second leading cause of death in the world.

1.2 Cancer and its legal recognition

Cancer is classified in the group of noncommunicable diseases. These are diseases that are not spread through infection or other people[31] and are also known as chronic

---

[25] '*Cancer Survivors*' (*WCRF International*) <https://www.wcrf.org/diet-activity-and-cancer/global-cancer-update-programme/cancer-survivors/> accessed 6 August 2023.

[26] 'Office of Cancer Survivorship | Division of Cancer Control and Population Sciences (DCCPS)' <https://cancercontrol.cancer.gov/ocs> accessed 6 August 2023.

[27] ibid.

[28] ibid.

[29] Max Roser and Hannah Ritchie, '*Cancer'* [2015] Our World in Data <https://ourworldindata.org/cancer> accessed 7 August 2023.

[30] 'Cancer' (n 15).

[31] 'Non-Communicable Diseases | IFRC' <https://www.ifrc.org/our-work/health-and-care/community-health/non-communicable-diseases> accessed 18 October 2023.

diseases.[32] Amongst these diseases, we also find cardiovascular diseases, diabetes, and chronic respiratory diseases, which account for 41 million deaths per year, translating to 41% of all deaths worldwide.[33]

The WHO, in 2013, launched the Global Action Plan for the Prevention and Control of Noncommunicable Diseases (NDCs) 2013-2020.[34] The goal, as defined in the overview, is to reduce the preventable and avoidable burden of morbidity, mortality, and disability due to noncommunicable diseases through multisectoral collaboration and cooperation at national, regional and global levels. The aim is that populations reach the highest attainable standards of health and productivity at every age, and these diseases are no longer a barrier to well-being or socioeconomic development.[35] It establishes nine overarching principles and a set of voluntary global targets.

The action plan contributed to the launch of the World Cancer Declaration by the Union for International Cancer Control (UICC), a non-governmental organization aiming to reduce the global cancer burden and promote greater equity.[36] The World Cancer Declaration reflects the UICC's goal by calling governments, UN agencies, civil society, the relevant private sector, and other key stakeholders with a shared vision to build collaborative partnerships addressing the global cancer burden, promoting greater equity in the access to cancer services, and integrating cancer control into the global health and development agenda.[37] The declaration lays forth nine objectives that must be met by 2025 to decrease the number of cancer-related fatalities that occur prematurely, enhance the quality of life, and increase cancer survival rates. The aims include priorities for cancer prevention, early detection, diagnosis, treatment, and care in order to accomplish this mortality reduction in

---

[32] 'Non-Communicable Diseases' <https://www.who.int/news-room/fact-sheets/detail/noncommunicable-diseases> accessed 18 October 2023.

[33] ibid.

[34] World Health Organization, Global Action Plan for the Prevention and Control of Noncommunicable Diseases 2013-2020 (World Health Organization 2013) <https://apps.who.int/iris/handle/10665/94384> accessed 7 August 2023.

[35] ibid., p. 3.

[36] 'About UICC | UICC' <https://www.uicc.org/who-we-are/about-uicc> accessed 20 October 2023.

[37] '*World Cancer Declaration | UICC*' <https://www.uicc.org/what-we-do/driving-global-impact/targeted-commitments/world-cancer-declaration> accessed 20 October 2023.

every nation. They align with the global ambition of a 25% reduction in premature death from NCDs by 2025.[38]

The World Health Assembly, in 2017, passed the Resolution Cancer Prevention and Control in the Context of an Integrated approach (WHA70.12)[39]. The Resolution urges international organizations, such as the WHO, and governments to expedite plans to achieve the targets included in the Global Action Plan for the Prevention and Control of Noncommunicable Disease (NCDs) 2013-2020 and the 2030 UN Agenda for Sustainable Development to reduce premature mortality from cancer.[40]

The Resolution recognizes that cancer is a growing public health concern and a leading cause of death, with projections showing that by 2030, there would be 21.6 million new cases of cancer annually, up from 14.1 million in 2012.[41] The Resolution properly prioritizes Member States' actions towards several measures. It urges Member States to implement and integrate cancer prevention and control plans in respect of the commitments defined by the Global Action Plan, the United Nations General Assembly resolutions 66/2 (2011)[42] and 68/300 (2014). Furthermore, it urges the collection of data on the incident and mortality of cancer for all age groups by cancer type, including measurements of inequalities.[43] Moreover, it urges the collaboration to strengthen, where appropriate, regional and subregional partnerships and networks in order to create centres of excellence for the management of certain cancers, which is crucial for countries to assess the cancer survival rate and establish a regional network.[44] It urges the promotion of cancer survivors' follow-up, including the need for rehabilitation, relations to work, psychological services considering the chronic nature and long-term effects of

---

[38] ibid.

[39] World Health Assembly, 70. (2017). Cancer prevention and control in the context of an integrated approach. World Health Organization. https://apps.who.int/iris/handle/10665/275676.

[40] *Note:* the SDG Target 3.4 goal is to reduce, by 2030, to one third premature mortality from non-communicable diseases through prevention and treatment and promote mental health and well-being (Accessible at https://sdgs.un.org/goals/goal3).

[41] 'Resolution on the Seventieth World Health Assembly, WHO, WHA70.12, Agenda Item 15.6, 31 May 2017.'

[42] 'UN General Assembly Resolution, Political Declaration of the High-Level Meeting of the General Assembly on the Prevention and Control of Non-Communicable Diseases, A/66/L.1, 16 September 2011.'

[43] 'Resolution on the Seventieth World Health Assembly, WHO, WHA70.12, Agenda Item 15.6, 31 May 2017.' (n 41)., para. 1(1), (5).

[44] ibid., para. 1(11).

cancer, providing an initial definition of cancer survivor.[45] Furthermore, the Resolution requests the Director-General to ensure collaboration between Member States, nongovernmental organization, Non-State Actors and private sector entities to achieve and to improve the quality of life of cancer patients, suggesting periodic public health- and policy-oriented world report on cancer.[46] The Resolution, by reflecting on the General Assembly Resolution 66/2 (2011), highlights once again the role of the WHO and the International Agency for Research on Cancer (IARC), in drafting world reports on cancer, collaborating with relevant stakeholders, including cancer survivors.

This brief explanation is useful to have a better understanding of what cancer is, how it affects people, its possible long-term effects that could impair survivors' quality of life, its current incidence in the world's population, how it is accounted for worldwide as the second leading cause of mortality, and most importantly how at the international level, the importance of implementing a global regime to improve cancer survivors' lives is understood, both during and after they have ended their treatment. This is, in fact, demonstrated by both the cancer and control Resolutions and the aim of SDG 3.4. The Sustainable Development Goals (SDGs), adopted by all UN Member States in 2015, offer a common template for enduring peace and prosperity for both people and the environment. Its core tenets are the seventeen Sustainable Development Goals (SDGs), which represent a pressing need for global cooperation and action from both developed and developing nations. In this regard, SDG 3.4 requires, by 2030, a reduction by one third in premature mortality from non-communicable diseases through prevention and treatment and promotion of mental health and well-being.[47] This goal underscores the relevance of cancer survivorship as a problem that needs to be tackled through the collaboration of Member States, relevant stakeholders, and cancer survivors themselves.

---

[45] World Health Assembly, 70. (2017). Cancer prevention and control in the context of an integrated approach. World Health Organization. https://apps.who.int/iris/handle/10665/275676, paras. 1(16), (17) and (18).

[46] ibid., paras. 2.(4) and (7)

[47] 'Goal 3 | Department of Economic and Social Affairs' <https://sdgs.un.org/goals/goal3#targets_and_indicators> accessed 18 October 2023.

With the UN Resolutions and the SDG on noncommunicable disease cancer has been identified and categorized. Their main goal is to prevent and decrease the mortality from cancer. A positive aspect is the call for collaboration amongst countries at an international and regional level to collect relevant data. By doing so there will be more scientific knowledge on the fight against cancer. These data will also be relevant when discussing the Right To Be Forgotten solutions (see Chapter 3). However, for the interest of this thesis, there is scarce mention of the life after cancer and the identification/definition of cancer survivor. Only the UN Resolution A/66/L.1 and the WHA70.12, with more emphasis, stress the importance of rehabilitation for cancer survivors. Furthermore, a definition of cancer survivors can only be depicted from the WHA70.12 in paragraph 2(16) when "to anticipate and promote cancer survivor follow-up, late effect management and tertiary prevention, with the active involvement of survivors and their relatives". In the international legal sphere, there are poor definitions and considerations for life after cancer. With big plans to reduce mortality, the number of cancer survivors will inevitably grow, and with it their necessity for legal rights and protection. Why can States not prevent this event?

The necessity for global collaboration in the exchange of data and understating of cancer survivor's issues, while involving them in the solution of related problems, has been of growing importance. This brief description helps to picture with clear data and numbers the mortality rate of cancer but also the important improvements in science, which will potentially lead to higher number of cancer survivors. It is also important to know and understand all the burdens that cancer patients must bear during their treatments and the idea of possible irreversible consequences that might change their life perspectives. Cancer patients must be protected throughout their entire life since their diagnosis, the moment they can be considered survivors and onwards. Survivors' issues unfortunately do not stop just with problems associated with the disease and treatments. Financial, work, social, mental, and physical issues are a price that survivors often must deal with even years after the end of their treatment.

1.3 Cancer patients' legal status

Cancer patients throughout their treatment journey experience a variety of issues. Starting from the mental difficulties in accepting their disease to the effects of the treatment. It is important here to firstly understand their rights during their healing process.

Once diagnosed with cancer, patients have a series of rights that arise from international, regional and national legislation. Some of these rights are inalienable and customary human rights, such as the right to health. Others are more specific, such as the right to information and national social welfare. This section will conduct an analysis of cancer patients' rights under International Conventions by using articles and comments. Subsequently, it will describe the European Cancer Plan and how these two sources of law must be implemented by the respective Member States.

1.3.1 Cancer patients' rights under international law.

In searching for an international protection policy for cancer patients the only specific sources and definitions are from the above-mentioned UN Resolutions and SDGs. At the international level, there are not specified rights for cancer patients. The focus is mainly on the prevention and control of noncommunicable diseases, hence cancer, and the reduction of mortality. However, there is a clear lack of protection in defining cancer patients' rights throughout their journey. Nevertheless, some of these rights can be deduced and extrapolated from human rights Conventions and analysed individually.

An illness as cancer keeps patients from going to work, attending family responsibilities and full participation in daily social life. The right to health is a fundamental and customary international human right. "*The right to the enjoyment of the highest attainable standard of physical and mental health*" was first articulated in the WHO Constitution in 1946, implying a precise set of legislative requirements for states to provide suitable circumstances for everyone to enjoy health without discrimination.[48] The preamble defines health as "*a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity*".[49] It further states that "*the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction*".[50] From this definition it can be seen how cancer patients' health can be regarded from the moment of their diagnosis until their full reintegration into society, encompassing their need to come back to a normal life.

Furthermore, the right to health is acknowledged in various international instruments. The 1948 Universal Declaration of Human Rights (UDHR) in its Article 25 affirms that "*Everyone has the right to a standard of living adequate for the health of himself and of his family, including food, clothing, housing and medical care and necessary social services*".[51] The International Covenant on Economic, Social and Cultural Rights in its Article 12 provides for an extensive and comprehensive definition of the right to health in international human rights law. In 12(1) of the Covenant, States parties recognize "the right of everyone to the enjoyment of the highest attainable standard of physical and mental health",[52] while article 12(2) enumerates, by way of illustration, a number of "steps to be taken by the States parties ... to achieve the full realization of this right".[53] Article 12 has broadened the scope and inclusion of new categories in discussion about the right to health. The rise in cancer cases presents new challenges when addressing the right to health, requiring consideration when interpreting Article 12.[54] In fact, international instruments impose an immediate obligation on States to realize the

---

[48] '*Human Rights*' <https://www.who.int/news-room/fact-sheets/detail/human-rights-and-health> accessed 20 October 2023.

[49] UN General Assembly, Entry into force of the constitution of the World Health Organization, 17 November 1947, A/RES/131.

[50] ibid.

[51] United Nations General Assembly. The Universal Declaration of Human Rights (UDHR). New York: United Nations General Assembly, 1948.

[52] UN General Assembly, International Covenant on Civil and Political Rights, 16 December 1966, United Nations.

[53] 'UN Committee on Economic, Social and Cultural Rights (CESCR), General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant), 11 August 2000, E/C.12/2000/4, para. 2.'

[54] ibid., para. 10.

right to health and to take all reasonable actions towards that end, given the means at their disposal.[55]

As evident, health is recognized as a fundamental right crucial for exercising other human rights, as established in the International Bill of Rights. These rights include human dignity, life, non-discrimination, equality, and privacy. The highest attainable standard of health encompasses the right to live a life with dignity, a right maintained by cancer patients throughout their journey. The right to health also comprises rights that are legally enforceable in numerous national jurisdictions, such as the right to non-discrimination in relation to health facilities, goods and health services.[56] The right to health for cancer patients is therefore protected under international law and is at the base of the enjoyment of other human rights. Human rights are interdependent, meaning that if cancer patients cannot enjoy their right to health, it could impair their right to work or education, and vice versa.[57]

Indeed, the right to health comprises elements of *availability, accessibility, acceptability and quality*. These elements are interrelated and crucial at all levels. Hence, cancer patients have the right to have the availability of functioning public health and health-care facilities, have access without discrimination within the jurisdiction of State Parties. The interconnected right to non-discrimination plays a crucial role in defining the role, identity, and place of cancer patients throughout their treatment journey. In fact, the non-discrimination and equality are fundamental human rights principles and essential elements of the right to health.

International institutions have not provided a tangible framework specifically designed for cancer patients. While they do enjoy their right to health, it is not fully addressed. Implementing the broad guidelines provided by the Conventions is left to regional and national legislation. The general comment 14 gives a decent understanding of the interpretation of Article 12 ICCPR endorsing for the first-time

---

[55] 'UN Office of the High Commissioner for Human Rights (OHCHR), Fact Sheet No. 31, The Right to Health, June 2008, No. 31, p. 5.'

[56] 'UN Committee on Economic, Social and Cultural Rights (CESCR), General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant), 11 August 2000, E/C.12/2000/4.' (n 53)., para. 1.

[57] 'UN Office of the High Commissioner for Human Rights (OHCHR), Fact Sheet No. 31, The Right to Health, June 2008, No. 31, p. 6.'

cancer patients. A better description of cancer patients' rights is given at the European level.

1.3.2 Cancer patients' rights under EU law

Despite the lack of clear protection of cancer patients' rights under international human rights, at a regional level the discussion is more advanced.

The right to health is a fundamental right that is protected and guaranteed by the European Union. It is included in Article 35 of the Charter of Fundamental Rights of the European Union (CFR), which establishes that "*Everyone has the right of access to preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices. A high level of human health protection shall be ensured in the definition and implementation of all Union policies and activities.*"[58] The article expresses two rights; to have access to preventive health care and to benefit from medical treatment, and one cross-cutting principle to ensure a high level of human health protection.[59] The right to preventive health care, as ensured by Articles 20 and 21 CFR, must be understood as the right to equal access, aiming at the prevention of the disease. Consequently, patient's treatment of the disease is covered by the right to benefit from medical treatment.[60] These rights are enjoyed by all citizens but are limited depending on the State laws and practices. Furthermore, the Union's ties with third nations under Article 208 TFEU, its strategy for development cooperation, must not infringe upon the rights outlined in Article 35 CFR.[61] The wording of the second sentence is akin

---

[58] European Union, Charter of Fundamental Rights of the European Union, 26 October 2012, 2012/C 326/02, Art. 35.

[59] Tobias Lock, '2195 Article 35 CFR' in Manuel Kellerbauer, Marcus Klamert and Jonathan Tomkin (eds), *The EU Treaties and the Charter of Fundamental Rights: A Commentary* (Oxford University Press 2019) <https://doi.org/10.1093/oso/9780198759393.003.557> accessed 20 October 2023.

[60] ibid.

[61] ibid.

to Article 168(1) TFEU's mainstreaming obligation, which incorporates the precautionary principle.[62]

The European Social Charter, signed in 1961 and revised in 1966, has made a significant contribution to the definition and application of the right to health, particularly in its Articles 11 and 13.[63] In these articles, the Charter requires that States have the right facilities to promote good health, requiring access to health care without discrimination and ensure the effective exercise of the right to medical assistance. Furthermore, the Charter asserts "*Everyone has the right to benefit from any measures enabling him to enjoy the highest possible standard of health attainable*"[64], aligning with the health requirements set by the WHO. The main issue that arises is the reliability on international guidelines at the European level for the implementation of the right to health.

Starting from the European Cancer Patient's Bill of Rights, the European Code of Cance Practice (The Code), the European Beating Cancer Plan and the European Charter of Patients' Rights (ECPR), cancer patients enjoy more favourable and defined rights.

The initial recognition of the need for regional protection of patients' rights comes from the WHO with the establishment of the Declaration of the Promotion of Patient's Rights in Europe. It displayed the human rights and values in health care, the importance of information and consent, the need for a secure protection of privacy and confidentiality, the equal access to treatment and application of such rights without discrimination. The European Charter of Patients' Rights reflects the WHO requirements. In 2002 organizations from 15 EU countries, established the European Charter of Patients' Rights, listing 14 fundamental patients' rights (and 3 Rights of Active Citizenship), which each EU country must protect and guarantee.[65] Based on Article 35 of the European Union Charter of Fundamental Rights, each of

---

[62] *Case C-477/14, Pillbox 38, EU:C:2016:324, para. 116.*

[63] 'Article 35 - Health Care' (*European Union Agency for Fundamental Rights*, 25 April 2015) 35 <http://fra.europa.eu/en/eu-charter/article/35-health-care> accessed 24 October 2023.

[64] Council of Europe, European Social Charter (Revised), 3 May 1996, ETS 163, Part I para. 11.

[65] Make Next, 'THE EUROPEAN CHARTER OF PATIENTS' RIGHTS' (*Active Citizenship Network*, 22 August 2022) <https://www.activecitizenship.net/charter-of-rights.html> accessed 24 October 2023.

these rights is essential when it comes to health care and European citizenship. Regarding patient rights, the national health systems of the EU Member States all exhibit quite distinct realities. Certain systems could include charters for the rights of patients, legislation, rules governing administration, service charters, organisations like Ombudspersons, processes like ADR, etc. Some might not possess any of these. In any case, the current Charter can serve as a means to harmonise health systems, prioritizing the rights of citizens and patients, and strengthening the protection of these rights in various national and international settings. This is crucial, particularly in light of the EU's free movement of people and the expansion plan.[66]

The disparities among European countries regarding access to cancer care, optimal treatment, information, supporting for cancer survivorship, and long-term follow up have been acknowledged by a group of oncology leaders who have formed a partnership with cancer patients and their representatives.[67] The European Cancer Concord (ECC) is a patient-centred project created to provide European citizens with the best possible cancer treatment and research. Its guiding principles aim to strengthen and preserve the rights of each cancer patient/survivor.[68] More than 20 European and pan-European cancer patient advocacy organizations have become active partners in ECC, representing over 1,000 national organizations and millions of cancer patients and survivors in Europe.[69]

The ECC successfully developed a patient charter known as the "European Cancer Patient's Bill of Rights," which would guarantee equal access to the best possible care for all Europeans with cancer, in order to give concrete advantages to cancer patients throughout the continent. The Bill of Rights is composed of three patient-centred principles named Articles. Article 1 determines "*The right of every European citizen to receive the most accurate information and to be proactively involved in his/her care.*"[70] It includes the right to privacy, with the level of

---

[66] ibid.

[67] Mark Lawler and others, '*A Catalyst for Change: The European Cancer Patient's Bill of Rights*' (2014) 19 The Oncologist 217, p. 217.

[68] '*Meetings: European Cancer Concord* | Society for Translational Oncology' <https://sto-online.org/meetings-european> accessed 20 October 2023.

[69] ibid.

[70] Lawler and others (n 55), p.220.

confidentiality of their data to be decided by the patient. It also includes information on cancer survivorship and support services addressing post-treatment issues. Article 2 requires "*The right of every European citizen to optimal and timely access to appropriate specialized care, underpinned by research and innovation.*"[71] It requests that all European patients should have access to appropriate psychosocial support at all stages of their cancer journey, to deal with the impact of screening, diagnosis, treatment, quality of life and survivorship. Article 3 establishes "*The right of every European citizen to receive care in health systems that ensure improved outcomes, patient rehabilitation, best quality of life and affordable health care.*"[72] It stipulates that patients should receive care in a health system underpinned by National Cancer Control Programs (NCCPs), organized according to national guidelines. These systems should be regularly reviews by external experts, including patient representatives, to ensure conformity with European guidelines and international best practice.[73] It also calls for the need to address the key issues of long-term follow-up and patient survivorship to ensure best quality of-life and personal fulfilment with active re-integration and participation in society and the workplace. In fact, NCCPs should create a cancer centre multidisciplinary network that captures all aspects of cancer care, research, and innovation, from diagnosis through treatment and rehabilitation, including patient survivorship and end-of-life care.[74] This third element has to be guided by an all-encompassing, holistic strategy that takes into account the whole cancer care continuum.

The work of the ECC promotes optimal cancer care and research, reducing loss of productive life-years, enabling active survivorship and rehabilitation, and increasing health care innovation, thus leveraging wider benefits for European citizens and societies.[75]

In conclusion, recognizing the legal status and rights of cancer survivors is pivotal. While international frameworks provide a foundation, regional initiatives like the European Cancer Patient's Bill of Rights play a crucial role in ensuring concrete

---

[71] ibid., p. 221.
[72] ibid., p. 222.
[73] ibid.
[74] ibid., p. 219.
[75] ibid., p. 221.

and tailored rights for cancer patients. This not only contributes to the well-being of individuals but also fosters a more cohesive and equitable approach to cancer care across regions, emphasizing the importance of active survivorship and societal reintegration. Addressing the legal status and recognition of cancer survivors is crucial for upholding their rights, promoting equality, fostering societal understanding, and creating a supportive environment for active survivorship. Legal frameworks provide a foundation for ensuring that individuals who have overcome cancer can lead fulfilling lives with dignity, free from discrimination, and with access to necessary support services.

1.4 Cancer survivor definition

Cancer treatment is a journey that can last for several years after diagnosis. It is here that many debates have started regarding the moment, if possible, when a patient can be defined out of risk and if such being identified as a survivor. Despite lacking a unanimous definition, the term ‘cancer survivor’ is used by clinical institutions, political organizations, various people, and academic bodies.[76] There are different schools of thoughts that identify the term either according from the moment of complete remission or regardless of any phase of the journey.

The concept of “survivorship” was first articulated by Fitzhugh Mullan, an American physician diagnosed with cancer in the 1980s. In his “Season of Survival: Reflection of a Physician with Cancer”, he explained how the cancer journey was not a matter of cure or death but of survival, which all patients pass through as they struggle with their illness. Accordingly, survival is a useful concept because is a generic idea that applies with everyone diagnosed with cancer, regardless of the course of their illness, which can go for more or less than five/ten years. Thus, survival begins at the point of the diagnosis because that is the moment when

---

[76] Chiara Marzorati, Silvia Riva and Gabriella Pravettoni, ‘*Who Is a Cancer Survivor? A Systematic Review of Published Definitions*’ (2017) 32 Journal of Cancer Education 228, p. 228.

patients have to start the fight against cancer and adjust their immediate and long-term future. However, once reflected with his experience and having talked with other cancer patients he realized that it was not a definition that accurately characterized the experience. Indeed, he suggested that, due to the vagaries and phases of the journey, he suggested two separate courses: one for those who are cured and one for those who are not. From here, he both developed and explained the seasons of survival. The first season, denominated acute survival, begins with the diagnosis, which is dominated by diagnostic and therapeutic efforts to stem the illness.[77] This includes the part where treatment occurs, which can be medical, surgical and radiologic. The second season, denominated extended survival, begins when the patient has ended the basic, rigorous course of treatment and enters a phase of remission. Here the patient has periodic examinations, consolidation or intermittent therapy. The acute phase is over, and the season of extended survival has begun.[78] This phase is also characterized by the fear of recurrence in a patient where it is relatively higher. The third and final season is permanent survival, a term not commonly found in literature, but Mullan equates it with the word 'cured'. It is the moment when the extended survival phase evolves into a period when the activity of the disease or the likelihood of its recurrence is sufficiently small that the cancer can now be considered permanently arrested. In this phase Mullan considers them as actual survivors. Mullan explains how every survivor is indelibly affected, physically and emotionally, by the journey. Therefore, Mullan argued that the simple idea of treatment did not adequately represent the long-term effects of cancer and defined survivorship as a distinct phenomenon with particular difficulties for those who had survived the disease.

The National Coalition for Cancer Survivorship (NCCS), where Fitzhugh Mullan was amongst the founders, coined and approved the term "cancer survivor" in order to guarantee that resources and efforts were focused on this newly formed demographic and to push for high-quality treatment for the increasing number of persons who are living past a cancer diagnosis. At their first meeting, early members

---

[77] Fitzhugh Mullan, '*Seasons of Survival: Reflections of a Physician with Cancer*' (1985) 313 New England Journal of Medicine 270, p. 271.
[78] ibid, p. 272.

of the NCCS agreed to use the term ‘survivor’ instead of ‘cancer victim’ or ‘cancer patient’ to define individuals who were disease-free following treatment for a minimum of 5 years.[79] However, the United States National Cancer Institute (NCI) and the NCCS agreed on a different and recognized cancer survivor definition. According to them, an individual is considered a cancer survivor from the time of diagnosis and for the balance of life.[80] The Institute interprets this term including those living with cancer and those free of cancer, without making distinctions. Their goal is to include anyone who has received a cancer diagnosis, regardless of the label that may or may not resonate with individuals. Therefore, this definition includes all phases of the cancer journey. There is no distinction or differentiation according to the phase of the therapy or remission. This definition was developed and used in the US for advocacy reasons and to promote research and care of this growing population.[81]

Noreen M. Aziz and Julia H. Rowland considered and expanded the NCCS and Mullan definitions. They take into consideration the philosophical definition of cancer survivor given by the NCCS and the seasons defined by Mullan. They then outlined the meaning of cancer research, encompassing the identification, examination, prevention and control of adverse outcomes related to cancer diagnosis and treatment; providing a knowledge base regarding optimal follow-up care, surveillance of cancer survivors and optimize health after cancer treatment.[82] They stated that the late and long-term consequences of cancer, which refer to the impacts of primary therapy on the health and well-being of survivors, need to be considered in any evaluation of survivorship. Late effects are unidentified toxicities that remain hidden or sub-clinical after the completion of initial cancer treatment, and they can manifest months to years afterward. Indeed, they suggested that the term “long-term cancer survivor”, which also embodies the concept of permanent

---

[79] NF Khan and others, ‘*Interpretation and Acceptance of the Term “Cancer Survivor”: A United Kingdom-Based Qualitative Study: Identity as a Cancer Survivor*’ (2012) 21 European Journal of Cancer Care 177.

[80] ‘Definitions | Division of Cancer Control and Population Sciences (DCCPS)’ <https://cancercontrol.cancer.gov/ocs/definitions> accessed 30 October 2023.

[81] Nada F Khan, Peter W Rose and Julie Evans, ‘*Defining Cancer Survivorship: A More Transparent Approach Is Needed*’ (2012) 6 Journal of Cancer Survivorship 33.

[82] N Aziz and J Rowland, ‘*Trends and Advances in Cancer Survivorship Research: Challenge and Opportunity*’ (2003) 13 Seminars in Radiation Oncology 248, p. 249.

survival described by Mullan, is more appropriate when dealing with individuals who are 5 or more years beyond the diagnosis of their primary disease.

Whereas in the USA this definition and terminology has become part of the discussion of living past cancer, it has been used differently outside of the USA.[83] However, in the UK and Europe, where the NCCS does not operate, the term 'cancer survivor' has been increasingly adopted by researchers and policymakers independently of its advocacy roots, raising concerns about how the word is being used and 'misused'.[84] The newly established National Cancer Survivorship Initiative (NCSI), which is a partnership between the UK government's Department of Health and the charity Macmillan Cancer Support, uses a broad definition of 'those who are undergoing primary treatment, those who are in remission following treatment, those who are cured and those with active or advanced disease'.[85] The reason for this definition is the survivorship agenda, aiming to support individuals throughout the entire journey and beyond. This shows once again how the interpretation of such definition is different in different national health care systems and the different scope of each research.

Another example is given by the choice of the "European Guide on Quality Improvement in Comprehensive Cancer Control" to define cancer survivorship as anyone with a diagnosis of cancer and who is still alive, including patients having completed primary therapy and who are free of disease as well as those patients living with recurrent and/or advanced disease". This definition is chosen because the rehabilitation, although the process is not specific, is defined as "a process aimed at enabling them (people with disabilities) to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels." In fact, cancer may be seen as a chronic illness with patients enduring physical and psychological symptoms years after treatment.[86]

---

[83] Khan, Rose and Evans (n 81).

[84] Khan and others (n 76), p. 178.

[85] 'Department of Health, Macmillan Cancer Support, NHS Improvement. National Cancer Survivorship Initiative: Vision. London: Department of Health, Crown Copyright; 2010.'

[86] Tit Albreht, Régine Kiasuwa and Marc Van den Bulcke, '*European Guide on Quality Improvement in Comprehensive Cancer Control*', 2017, p. 137.

The breakpoint is the time in which a person becomes a survivor. Some use the end of active treatment as an arbitrary cutoff. Others define and focus survivorship research and policy using a 5-year postdiagnosis cutoff, despite cancer being a disease with significant prognostic heterogeneity based on tumour location and stage at diagnosis, among other criteria. In Europe, unlike the USA, the field of cancer survivorship has taken a different approach. The term “cancer survivor” is used to define those cancer patients who remain tumour-free for at least five years after diagnosis.[87] However, most policymakers now use this term to identify individuals who have been without any signs of cancer for five to ten years after the conclusion of the treatments. The application of the term cancer survivors depends on the type of cancer, the prognosis, and the age at which the diagnosis was given.

To correctly use the term ‘cured’, as Mullan referred to the last season, a specific amount of time must pass after the cancer diagnosis. During this time, the patient's risk of dying from the disease should not be higher than that of the general population with similar sex and age. Put differently, a patient with cancer may be considered "cured" only if their life expectancy equals that of the general population with similar sex and age.[88] It is common for oncologists and general physicians to avoid using the phrase "cured." As a result, some cancer patients may worry excessively and ineffectively due to a profound sense of uncertainty about their future. In contrast, the term "cured" may help individuals cope more effectively with the psychological and medical aftermath of their illness. After hearing from their oncologists that they are cured of their cancer and have finished treatment and follow-up, patients in various cultures, including Italian culture, may be more receptive to accepting and adhering to comprehensive intervention programmes that aim to restore and maintain overall well-being through modifying potentially harmful lifestyle choices and heeding screening recommendations for all cancers and other common diseases. It is by using the Mullan’s definition of cured and the

---

[87] ‘National Insittutes of Health, National Cancer Institue; 2004. President’s Cancer Panel, 2003–2004 Annual Report: Living beyond Cancer: A European Dialogue. NIH Publication No. P996.’

[88] P Tralongo and others, ‘*Use of the Word “Cured” for Cancer Patients—Implications for Patients and Physicians: The Siracusa Charter*’ (2015) 22 Current Oncology e38.

long-term cancer survivor that a common ground for the definition of cancer survivor can be reached.

A globally recognised definition of cancer survivorship should be developed, according to some researchers, in response to these divergent views. This is because the absence of a formal definition affects when patients receive survivorship-specific treatment.[89] Individual risk assessment and management should be conducted for patients to determine when to offer these treatments. The optimal time to offer these services will likely depend on the type, stage, and individual preferences for cancer follow-up, as well as the chosen treatment. The ability to provide services should be based on these unique qualities rather than being constrained by the absence of a consensus definition of what it means to be a cancer survivor.[90]

Therefore, due to the vague definition of the term cancer survivor and the varied use conducted in accordance with the different scopes of application, this thesis tries to contribute to a conclusion that could be appropriately use for this research. Departing from the initial idea of Mullan's season of permanent survival and the recent uses by oncologists, the term cancer survivor must be directed to those individuals who, depending on the cancer and prognosis, have had no signs of cancer for a period of 5 years from the end of treatment if diagnosed before the age of 21 and 10 years from the end of treatment if diagnosed after the age the age of 21 years old. The goal of targeting this specific category is to further emphasize that these long-term survivors have completed their reinsertion into society and can finally be perceived as individuals out of risk. With this identification can survivors are able to not be defined by their cancer. For the purpose of this research, when addressing cancer survivors throughout this thesis it will be referring to this definition.

---

[89] Khan and others (n 79).

[90] ibid.

Chapter 2. Possible discriminations faced by cancer survivors

2.1 Cancer survivors pay twice

Despite all the adversities that cancer survivors experience throughout their treatment and follow-up journey, they continue to face issues after they have been considered out of risk. These problems are not related to the effects of the treatments or the disease but arise from discriminations suffered because of the survivor status. The aim of cancer survivors, once their treatments are done, is to return to their daily life. However, restrictions lay upon them even after enduring all the distress of the treatments, imposing a double burden.

In many countries cancer survivors face barriers that restrict their ability to live productive lives and reintegrate in society.[91] The main problems that cancer survivors face, are the ability to access to banks loans and mortgages, obtain insurances such as health care insurance and life insurance, finding a job or reinsertion in the workplace (including the public sector).[92] Amidst the difficulties faced by cancer survivors in different countries, we also find penalization in adopting a child or obtaining the medical certificate needed to drive a vehicle or engage in competitive sports.[93] These types of discriminations are the result of a stigmatization of cancer. There are misconceptions and stereotypes associated with cancer that led to discrimination, for example in the workplace. Cancer survivors are often required to declare their cancer even when it should not be used as an assessment criterion. In this section, we will analyse the different problems and related stigmas faced by cancer survivors. In displaying the various discrimination, the related human rights violation will be analysed, while a further analysis and contextualization with the right to be forgotten will be conducted in Chapter 3.

---

[91] Mark Lawler and Françoise Meunier, '*Don't Make Cancer Survivors Pay Twice—the Right for Them to Be "Forgotten" Should Be Law Everywhere*' [2022] BMJ o2197, p. 1.

[92] Paola Quarello and others, 'Get up, Stand up: Alongside Adolescents and Young Adults with Cancer for Their Right to Be Forgotten' (2022) 108 Tumori Journal 402, p. 403.

[93] Ibid., p. 404.

2.2 Cancer survivors and the workplace

Cancer survivors must adapt to the consequences of cancer. Due to their impairments and new needs, they eventually change their job perspectives. They encounter difficulties in returning to work freely and under the right conditions at their disposals. An additional challenge arises when disclosing a past medical cancer history becomes a basis for discrimination in the workplace, stemming from misconceptions associated with cancer to the fear of the possible consequences of revealing or not revealing their cancer history. What needs to be more recognized and ensured is a comprehensive response to assist individuals in coping with stigmatization, misunderstanding and lifetime challenges when accessing to jobs.[94]

Many survivors have reported unfavourable developments in their careers, stemming from the employer's misperception of possible relapse and their need to identify new career goals.[95] Survivors are concerned about the stigmatization associated with the disease, often leading to guilt issues.[96] They live with the fear of recurrence even if such risk is inexistent, which together with the stigmatization upon them makes them believe that they could be a burden for the employer. When applying for a job that suits their needs, they are uncertain if they should disclose or not their history of cancer, because they do not want to be perceived as incapable of performing something that they are very much able to do.[97] Survivors feel the guilt of being a potential economic risk for future employers in case of recurrence.[98] This is often due to the persistent societal misconception of cancer as a death sentence, a perception that can no longer be sustained thanks to the constant scientific improvements in this field. Moreover, they are often living with the pressure from employers to return to work and perform at the levels achieved before the treatments.[99] This is a restrain that could lead to the termination of the contract

---

[94] Lifang Liu and others, '*Cancer in Europe: Death Sentence or Life Sentence?*' (2016) 65 European Journal of Cancer 150, p. 150.

[95] Isabella Braun and others, '*Changes, Challenges and Support in Work, Education and Finances of Adolescent and Young Adult (AYA) Cancer Survivors: A Qualitative Study*' (2023) 64 European Journal of Oncology Nursing 102329, p. 7.

[96] ibid.

[97] ibid.

[98] ibid.

[99] ibid., p. 9.

and further economic and mental problems for the individual. When in search for an occupation survivors have experienced discrimination due to their medical past and needs.[100] In some cases, survivors are forced to accept only part-time positions because of their rehabilitation programmes and possible medical visits throughout the years.[101] When a cancer survivor is trying to get back to his life, all these issues together with the stigma associated with cancer, amount to a decrease in importance of work in life for them.[102] This does not affect only the individual and the people around them, but also the society as a whole. In fact, the failure to achieve equal opportunities for the reinsertion of survivors into the job market leads to an increase in unemployment.[103] This implies that a higher number of people will need to use more welfare resources and hospital services, resulting in increased costs for health services.[104] Therefore, the need to disclose the information about their clinical history and stigma upon cancer survivor situation leads to discrimination towards them in the employment sector.

Legally, employers cannot ask about an applicant medical history. However, a problem arises when there is a need to disclose the reasons for work-related absences in the curriculum vitae.[105] Cancer survivors sometimes need to self-disclose their cancer history to justify potential absences due to check-ups or treatments effects. They fear to disclose health related information because they are afraid of possible recruitment repercussions. However, when survivors decide to self-disclose, they are less likely to receive a response to their application.[106] It would be easy to simply not disclose such information, however honesty and good working relationship are very important in the workplace. Not disclosing such information could cause future discrimination when advancing for career or contract renewals.

---

[100] ibid.
[101] ibid.
[102] ibid.
[103] Liu and others (n 32).
[104] ibid.
[105] Carolyn Rabin, '*Cancer-Related Self-Disclosure in the Workplace/School by Adolescent and Young Adult Cancer Survivors*' (2020) 9 Journal of Adolescent and Young Adult Oncology 528, p. 528.
[106] ibid., p. 529.

A study from Ghent University, Belgium, conducted a vignette experiment to study the discrimination against cancer survivors. They studied how recruiters' hiring decisions and perceptions were affected by fictitious job candidates with cancer experiences, in relation to the various types of stigmas identified in the literature. This study is also supported by a previous research conducted by the Journal of Economic Behaviour & Organization, which proved that in the United States cancer survivorship is a source of hiring discrimination.[107] This study theorises that perceived organisational costs, which are imperfectly signalled by health-related periods of non-employment, could underlie such discrimination.[108]

The Ghent University study distinguished candidates with periods of non-employment in their careers, including those who had experienced cancer. They found that employment opportunities were lower for candidates with a history of cancer, compared to candidates without such a gap. This penalty is especially based on the belief that these applicants are more likely to take sick days and incur additional expenses.[109] Employers who utilise a candidate's cancer history as a criterion for employment constitute discrimination. This study shows how discrimination and stigmatization remains a barrier for cancer survivors' re-employment. The study found that cancer survivorship harms candidates' hiring probabilities, compared to candidates who were continuously employed. The researchers urge lawmakers to incorporate health-related reasons for discrimination into labour market audits, which have hitherto concentrated on diversity in terms of race or gender.[110] In fact, employers using their understanding of cancer survival when making employment decisions engage in discrimination. But as the study data also suggests, there may be fewer job prospects if there are unexplained gaps (and consequent assumptions of skill loss). The study highlights how difficult it is for cancer survivors to disclose their status when they are ready to re-enter the

---

[107] Sheryll Namingit, William Blankenau and Benjamin Schwab, '*Sick and Tell: A Field Experiment Analyzing the Effects of an Illness-Related Employment Gap on the Callback Rate*' (2021) 185 Journal of Economic Behavior & Organization 865.

[108] ibid.

[109] Philippe Sterkens, Adelina Sharipova and Stijn Baert, '*Disclosing the "Big C": What Does Cancer Survivorship Signal to Employers?*' [2023] The European Journal of Health Economics <https://link.springer.com/10.1007/s10198-023-01618-2> accessed 6 November 2023.

[110] ibid.

workforce. While the study clearly shows that unexplained periods of unemployment might result in even severe labour market penalties, it also found that reporting a history of cancer remained a source of health-based stigmatisation. In fact, revealing one's cancer survivor status also helps to dispel stereotypes that are often connected to unemployment (such as the expectation of skill loss). In a similar vein, individuals who decide to conceal their cancer history from potential employers should be prepared for unfavourable assumptions about the loss of skills brought on by unemployment. Because of this, reintegration specialists, like employment coaches, may be very important members of the multidisciplinary teams that monitor the lives of cancer survivors.

Cancer survivors’ choice to disclose their past history is affected by many factors, from explaining the unemployment gap, the fear of recurrence, guilt, the stigma associated with cancer, to the dread of being mistreated or being seen differently. All these reasons hamper the possibility for cancer survivors to re-enter into society and live the life they fought. Without the fundamental right to work without discrimination, individuals find it challenging to attain dignity and a place in the world. Without a job is difficult to find a purpose and create a future for them and their families. As suggested by the study, policymakers have the potential to ensure sure that every cancer survivor has access to all the necessary information, is in the appropriate environment, and has the right to make a conscious decision on whether or not disclose such information.

2.2.1 The right to work for cancer survivors

As highlighted in General Comment n.18, the right to work is a universal and inalienable human right that forms an integral part of human dignity.[111] Article 6 of the International Covenant on Economic, Social and Cultural Rights (ICESCR),

---

[111] ‘UN Committee on Economic, Social and Cultural Rights (CESCR), General Comment No. 18: The Right to Work (Art. 6 of the Covenant), 6 February 2006, E/C.12/GC/18’, para. 1.

recognises the right to work for all individuals, enabling them to live in dignity.[112] Article 6 ICESCR encompasses the right for everyone to earn a living through freely chosen and accepted work, with the Member States taking all appropriate steps to achieve the full realization of this right.[113] The essence of these objectives is also emphasised in Article 23 of the Universal Declaration of Human Rights (UDHR), which additionally advocates for favourable working conditions and protection against unemployment.[114]

The right to work, as recognized in the ICESCR, comprises the right not to be unfairly deprived of employment, which is the basis for the discrimination faced by cancer survivors due to their past medical history. This fundamental right is crucial for the personal development, social integration, and economic inclusion of cancer survivors.[115] The Committee on Economic, Social and Cultural Rights (CESCR) has emphasized the importance of accessibility to the labour market. As outlined in Article 2(2) and 3 ICESCR, no discrimination in access to and maintenance of employment is allowed based on health status or physical and mental disability, with the objective of preserving the right to work on the basis of equality.[116] The Human Rights Council Resolution 31/15 (2016), recognizes the significance of ensuring equality and non-discrimination in access to work to address social prejudices and disadvantages that may exist in the labour market, undermining equality and dignity.[117]

The right to work for cancer survivors and the prohibition of discrimination based on their previous health status are therefore ensured in this Convention. As highlighted by the CESCR and the UN Assembly, of fundamental importance is the cooperation at the international level among UN agencies, programmes, and funds, particularly the International Labour Organization (ILO), at the regional and national levels in supporting the efforts of States to promote full and productive

---

[112] UN General Assembly, International Covenant on Economic, Social and Cultural Rights (ICESCR), 16 December 1966, United Nations, Treaty Series, vol. 993, Art. 6.

[113] ibid.

[114] United Nations General Assembly. The Universal Declaration of Human Rights (UDHR). New York: United Nations General Assembly, 1948.

[115] ‘CESCR, General Comment No. 18, (n 176), para. 4.

[116] ibid., para. 12(b)(i).

[117] UN Human Rights Council, The right to work: resolution adopted by the Human Rights Council, 19 April 2016, A/HRC/RES/31/15, para 5.

employment, decent work for all, and the full realization of the right to work.[118] It is through this type of process that the right to work can be fully recognized and ensured for cancer survivors, establishing a coherent and unified legal framework.

What needs to be more recognized and ensured is the necessity for a comprehensive response to assist individuals in coping with stigmatization, misunderstanding and lifetime challenges when accessing jobs.[119] The category of cancer survivors can be partially reproduced in the wording of the non-discrimination principle enshrined in Article 2 UNDHR and in Article 2(2) ICESCR, especially in the phrase "other status". This is further emphasized by the Human Rights Council resolution 28/15 (2015), which state that "*States should undertake to guarantee that the right to work is to be exercised without discrimination of any kind as to race, colour… or other status.*"[120] It is only through the General comment of the CESCR that the "health status" is specified.

Moreover, the Charter of Fundamental Rights of the European Union (CFREU) provides for free access to work and the right to working conditions with respect to health, safety, and dignity.[121] The reinforcement of the rights of EU citizens to freely engage in work, choose, and accept occupation is established in Article 15 CFREU. Such freedom has to be pursued in line with the prohibition of discrimination of any kind, as suggested under Article 21 CFREU, while respecting the dignity of workers through fair and just working conditions, as protected under Article 31 CEFREU. The right to work is also protected under the European Social Charter, which devotes attention to related rights such as the protection of health, the provision of social security, social and medical assistance and the provision of social welfare services.[122] On the other hand, the European Convention on Human Rights (ECHR) does not explicitly protect social rights such as the right to work. Nevertheless, the European Court of Human Rights (ECtHR) partially protects aspects of this right. An example is given by the Campagnano v Italy judgment where the Court

---

[118] ibid., para. 24.

[119] Lifang Liu and others (n 32), p. 150.

[120] UN Human Rights Council, The right to work: resolution adopted by the Human Rights Council, 2 June 2015, A/HRC/RES/28/15.

[121] European Union, Charter of Fundamental Rights of the European Union, 26 October 2012, 2012/C 326/02, Arts. 15, 21, 31.

[122] Council of Europe, European Social Charter (Revised), 3 May 1996, ETS 163.

introduced the idea that private life protected under Article 8 includes the possibility to seek employment and the right not to be arbitrarily deprived of employment opportunities.[123] Significantly, albeit frequently indirect, protection of employer interests is offered by the ECHR. The European Court of Human Rights has made significant progress in integrating elements of the right to work, relying on an evolutive and purposeful approach to interpretation and drawing on other documents such as the ESC and ILO material. Employment rights are protected by the provisions of Article 6 of the Convention on Civil Rights and Article 14 of the Convention on Non-Discrimination where they fall under the definition of a "civil right" or the "ambit" of a Convention right.[124] This shows how the right to work includes different elements, encompassing the right to an opportunity to earn a livelihood and specifically the right to seek employment and freely choose an occupation. More importantly, there is a “core obligation” of non-discrimination that demands particular consideration regarding members of disadvantaged groups. In our case, cancer survivors might have to change their job perspective and when freely applying for a job that suits their needs, they are often discriminated against for their cancer history. As analysed, there are tools for the protection of the rights of cancer survivors in freely entering the job market. Depriving cancer survivors of such a right not only amounts to a violation of such right but also their right to enjoy their private life with dignity and provide for their family with dignity.

The point of discussion that can arise from the difficulties faced by cancer survivors in the employment field is how they could be handled. Cancer survivors do not have recognition as a distinct group, however, they fall under the umbrella of non-communicable diseases, as defined by SDG 3.4. In this regard, Human Rights Council Resolution 31/15 (2016) welcomes the adoption by the General Assembly of the 2030 Agenda for Sustainable Development, focusing on promoting sustained, inclusive, and sustainable economic growth, full and productive employment and decent work for all, including its targets.[125] Therefore, it includes target 3.4 for

---

[123] ‘O’Connell, Rory, The Right to Work in the European Convention on Human Rights (March 7, 2012). European Human Rights Law Review, No. 2, 2012.’

[124] ibid.

[125] UN Human Rights Council, The right to work: resolution adopted by the Human Rights Council, 19 April 2016, A/HRC/RES/31/15, para. 16.

people with non-communicable disease. A broad interpretation of such paragraph must be made to find a glimmer of protection and development for the recognition of cancer survivors.

According to some national systems, cancer survivors are recognized either as protected patients and/or as disabled people, defined by the degree of impairment and the time period of their treatments. However, they do not have a specific classification in international treaties or conventions. Little is ensured in the reintegration of cancer survivors into society and the employment sector. Ensuring the right to work for all people is a rightful sign of equality. However, treating everyone the same can sometimes lead to inequalities.[126] Cancer survivors constitute a rising category that needs to be protected. In the United States the acknowledgment that supervisors and co-workers have misconceptions about the ability and capacities of cancer survivors led to declare cancer-based discrimination illegal.[127] In fact four federal laws provide different job protections to cancer survivors: the Americans with Disabilities Act (ADA),[128] the Federal Rehabilitation Act,[129] the Family and Medical Leave Act (FMLA),[130] and the Employee Retirement and Income Security Act (ERISA).[131] The ADA prohibits discrimination against individuals who have a history of cancer.[132] Employers cannot ask about the health history of applicants, they can only inquire if the applicant can perform the duties of the job.[133] These federal laws establish for a legal framework that protects not only cancer survivors from discrimination by the employers and in the workplace in general but also by other stakeholders involved, such as family and caregivers.[134] This is an example on how the category of cancer survivors is and should be recognized. Basic international human right Conventions only establish the right to work and non-discrimination, specifying only a few protected

---

[126] Sandra Fredman, *Discrimination Law* (2nd ed, OUP Oxford 2011), p. 2.

[127] B Hoffman, '*Cancer Survivors at Work: A Generation of Progress*' (2005) 55 CA: A Cancer Journal for Clinicians 271, p. 274.

[128] Americans with Disabilities Act of 1990. 42 U.S.C. 2000:12101-12213.

[129] Federal Rehabilitation Act. 29 U.S.C. 2000; 701-796.

[130] Family and Medical Leave Act. 29 U.S.C. 2000;2611-2654.

[131] Employment Retirement and Income Security Act. 29 U.S.C. 2000;1001-1191.

[132] Hoffman (n 185), p. 275.

[133] ibid., p. 275.

[134] ibid., pp. 275-279.

categories. An international framework that allows States to implement guidelines in their national cancer plans guidelines to address the return to work must be called for deeper research.[135]

Having established the importance of such a right, the question that comes to mind is how to implement and ensure this right for cancer survivors. A partial answer can be found in the Right to Be Forgotten (RTBF) laws in Europe that will be further discussed in the following chapters. Here it is important to stress the confusion in international, regional and national legislations regarding the protection and implementation of such right for cancer survivors. It is clear that working for the economy of each country is crucial, but more importantly, it is essential for the dignity of an individual. Internationally and regionally the right to work requests non-discrimination and emphasizes the need to ensure that disadvantaged groups are taken into account when drafting policies. The problem that arises is the recognition of cancer survivors as a specific group that could be more easily recognized. Once again it emphasizes the importance of a definition for such a category. A definition is needed for the inclusion and identification when implementing policies in their favour. On the other hand, the commitment in achieving the SDG's by 2030 can be a launching pad for more consideration for such a growing issue worldwide.

2.3 Financial burdens of cancer survivors: bank loans, mortgages and insurances

One of the main challenges that cancer survivors must confront is the financial burden associated with cancer. Many survivors have encountered difficulties in securing bank loans and mortgages due to the requirement of disclosing their cancer history. Insurance companies, when assessing applications for loans, mortgages, life or health insurance, categorize cancer survivors as high-risk customers, imposing

---

[135] Davies and others (n 62), p. 18.

high premiums that are challenging to manage or even outright denying insurance. These types of discriminations are often based on data that are not supported by any medical or scientific relevance.

The increasing awareness of the need to ensure adequate standards of living for cancer survivors has brought to light many unregulated discriminations. Taking personal loans or home loans to secure a better living condition is a common practice in many countries worldwide. Within the EU-27 IN 2020 almost 27% of the population were owner-occupants with mortgages, and 44 homeowners with outstanding mortgages.[136] In the UK, 28% of the population owned a house through a mortgage or a loan in 2020,[137] while in the United States 42% of households had mortgages.[138] This significant proportion of the population on different continents demonstrates how people value the need to own a house to improve their quality of life, enabling them to create a household and raise a family. However, in countries like France and the Netherlands, reports indicate that cancer survivors encounter difficulties in obtaining home loans or mortgages,[139] thus impeding their right to achieve the standard of living they deserve. A history of cancer often results in denials of bank loans or the requirement to obtain life insurances to secure necessary credit.[140] It is not uncommon for insurance companies, influenced by misleading and outdated perceptions of risks associated with cancer survivors, to offer contracts only at the cost of high premiums or with the condition of an Exclusion from Warranty clause.[141] Insurance companies and bankers, adopting a precautionary approach, often rely on misleading and outdated data to assess the risks associated with cancer.[142] By excluding cancer survivors from obtaining life

---

[136] 'Europe: Owner Occupiers with and without Mortgage 2021' (*Statista*) <https://www.statista.com/statistics/957803/homeowners-with-and-without-an-outstanding-mortgage-in-eu-28-per-country/> accessed 15 July 2023.

[137] 'UK Mortgage Statistics 2023 - Mortgage Facts and Stats Report' (*Uswitch*) <https://www.uswitch.com/mortgages/mortgage-statistics/> accessed 15 September 2023.

[138] 'Average American Debt' (*Ramsey Solutions*) <https://www.ramseysolutions.com/debt/average-american-debt> accessed 15 July 2023.

[139] Agnès Dumas, Florent De Vathaire and Gilles Vassal, 'Access to Loan-Related Insurance for French Cancer Survivors' (2016) 17 The Lancet Oncology 1354.

[140] Grazia Scocca and Françoise Meunier, '*A Right to Be Forgotten for Cancer Survivors: A Legal Development Expected to Reflect the Medical Progress in the Fight against Cancer*' (2020) 25 Journal of Cancer Policy 100246, p. 2.

[141] ibid.

[142] ibid.

insurance, mortgage insurance, property ownership becomes difficult or almost impossible in some countries, leading to a sense of double payment for survivors striving to return to a normal life.[143]

Marianne Massart's testimony, given in an interview with Françoise Meunier on the 'Ending of Discrimination of Cancer Survivors' channel, illustrates how the requirement to disclose cancer history poses a problem for cancer survivors, regardless of the severity of their cancer or their financial situation.[144] Marianne Massart was diagnosed in 2008 with brain cancer, a condition successfully treated.[145] Several years later, she and her husband, decided to purchase a house in France and sought a loan from the bank.[146] As part of the loan process, the bank strongly recommended insurance as collateral, leading them to approach an insurance company.[147] The insurance company presented a comprehensive questionary that included inquiries about diagnoses of serious diseases and whether the person was undergoing radiological exams such as MRI's scans. Due to the regular check-ups that cancer survivors must undergo annually, Marianne had to answer positively.[148] Despite six years passing since the diagnosis, the couple faced an unpleasant conversation with the insurance company, resulting in the denial of their insurance request.[149] Marianne reported a similar discriminatory experience in Luxembourg when attempting to purchase a house three years later, a total of nine years after the initial diagnosis.[150] Again, they received the same recommendation for loan insurance and encountered an identical questionnaire.[151] This situation compelled Marianne Massart to seek financial assistance from her family and

---

[143] Grazia Scocca and Françoise Meunier, '*Towards an EU Legislation on the Right to Be Forgotten to Access to Financial Services for Cancer Survivors*' (2022) 162 European Journal of Cancer 133, p. 134.

[144] *Marianne Massart, Cancer Survivor Testimony* (Directed by Ending Discrimination Against Cancer Survivors, 2023) <https://www.youtube.com/watch?v=3DEGktuUUu4> accessed 16 May 2023.

[145] ibid., minute: 00:40.

[146] ibid., minute: 02:55.

[147] ibid., minute: 03:07.

[148] ibid., minute: 03:23.

[149] ibid., minute: 04:11.

[150] ibid., minute: 04:59.

[151] ibid., minute: 05:15.

husband to gather additional funds, persuading the bank to grant the loan. Unfortunately, this led to long-term debt payments to her family and husband.[152]

Moreover, insurance companies require cancer survivors to disclose their medical history, including their diagnosis, to make their assessments.[153] Based on the information collected both from the questionary and available data, insurers may increase insurance premiums by up to 300% or reject the application.[154] The obstacles that cancer survivors face prevent them from obtaining not only health or life insurance but also simple insurances, such as travel insurance, typically provided to people with similar health.[155] This type of discrimination exacerbates the challenges for cancer survivors to enjoy basic standards of living and increases the socio-economic burden upon them even years after successfully completing their treatments.[156] There is a lack of uniform criteria applied by private actors, contributing to the expansion of a fragmented assessment practices that are self-regulated by insurance companies, lacking transparency and monitoring control.[157] In fact, many cancer survivors have tried for years to obtain life insurance and felt they have been accused of something they had not done.[158] Sir Peter Jonas, who, in the 45 years since he was diagnosed with Hodgkin's disease, has successively been the Director of several orchestras worldwide, declared that he has been refused health insurance anywhere in the world. He urged insurance companies and employers to acknowledge the reality of cancer survivors.[159]

Young survivors are also a category that could be highly affected by the discrimination suffered when accessing insurances for loan and mortgages. Survivors who have been treated at a young age will still have to disclose such information, even if their cancer occurred in the early stages of their life and they have been healthy for decades. For patients receiving treatment at a young age, with

---

[152] ibid., minute: 05:28.

[153] 'Andrew Davies, Csaba L. Dégi, Matti Aapro et al., "*Free from Cancer: Achieving Quality of Life for All Cancer Patients and Survivors*", European Cancer Organisation, 19 November 2020, 1-28', p. 19.

[154] ibid.

[155] ibid.

[156] ibid.

[157] Scocca and Meunier (2022), (n 52), p. 134.

[158] Liu and others (n 32), p. 151.

[159] ibid.

their entire life ahead of them when treatment is over, access to insurance for loans and mortgages is crucial since it can enhance their material living circumstances and social well-being. However, no research has been done on the challenges adult survivors of childhood or teenage cancer encounter when attempting to get loans. A French study was conducted on this matter and was also supported by the French State. The aim was to report the hardship experienced by cancer survivors via the data collected through a questionnaire given to 1920 survivors treated before the age of 18. The question of whether they had encountered any difficulties, defined as rejection, increased premiums, or exclusions, was posed to survivors who had attempted to apply for loans. This study showed that even for survivors who did not have any health issues, disclosing childhood cancer to an insurer 30 years after diagnosis caused problems in obtaining insurance when applying for a personal loan or a house loan. Moreover, insurance accessibility declined when socioeconomic factors including age, gender, education level, and family status were taken into account.[160]

The issues associated with income loss brought on by obstacles to returning to work are sometimes made worse by refusal of insurance or bank loans.[161] The cumulative effects of these barriers create further psychological issues for cancer survivors in returning to a normal life.[162] The difficulty may be amplified for people who have family obligations, affecting the social well-being of spouses and kids.[163] The discrimination against cancer survivors in accessing financial services amounts to a violation of the right for an adequate standard of living. Moreover, their requirement to disclose their information to access financial services deprives them from their right to privacy while violating consumer protection policies.

---

[160] Agnès Dumas and others, '*The Right to Be Forgotten: A Change in Access to Insurance and Loans after Childhood Cancer?*' (2017) 11 Journal of Cancer Survivorship 431.

[161] Liu and others (n 32), p. 151.

[162] ibid.

[163] ibid.

2.3.1 Financial services rights for cancer survivors

Everyone has the right to an adequate standard of living for themselves and their family, including adequate housing and continuous improvement of living conditions.[164] The right to an adequate living condition and the right to housing is provided in Article 11(1) ICESCR, Article 25 UDHR and also in Article 31 ESC.[165] The discrimination faced by cancer survivors in accessing adequate housing is in contrast with Article 2(2) ICESCR. Such violation is evident when applying for financial services that are necessary to acquire a house. These financial services involve mortgages and insurances that, as will be seen, are regulated under the umbrella of consumer protection, which furthers the difficulties for cancer survivors and call for a legal framework for cancer survivors.

In accessing financial services, the right not to disclose personal medical information, must be established. The right to privacy is a fundamental human right, that must be ensured in the protection of consumers. It is through consumer protection policies that the right to be forgotten can be deduced and applied for cancer survivors.

2.3.1.1 Financial services at the International Level

At the international level, the United Nations Conference on Trade and Development (UNCTAD) in 2016 provided Guidelines for consumer protection.[166] The objective of the guidelines is to take into account the interests and needs of consumers in all Member States, to assist countries in achieving or maintaining adequate protection for their consumers, to encourage high levels of ethical conduct for those engaged in the distribution of services to consumers, to assist countries in

---

[164] ICESCR, Art. 11.

[165] United Nations General Assembly. The Universal Declaration of Human Rights (UDHR). New York: United Nations General Assembly, 1948.

[166] 'United Nations Guidelines for Consumer Protection, United Nations Conference on Trade and Development (UNCTAD), New York and Geneva, 2016, UNCTAD/DITC/CPLP/MISC/2016/1.'

curbing abusive business practices by all enterprises at the national and international levels that adversely impact consumers, and to further international cooperation in the field of consumer protection.[167] Its scope of application applies to consumers, generally referred to as natural person, regardless of nationality, acting primarily for personal, family or household purposes.[168] It aims to invite Member States to develop, strengthen or maintain a strong consumer protection policy in accordance with the economic, social and environmental circumstances of the country and the needs of its population, while bearing in mind the costs and benefits of such measures.[169] The guidelines aim to meet and protect the economic interests of vulnerable and disadvantaged consumers, by allowing them access to essential services, which are essential to obtain an equitable standard of life.[170] UNCTAD specifies how all enterprises should obey the relevant laws and regulations of the countries in which they do business and conform to the appropriate provisions of international standards for consumer protection to which the competent authorities of the country in question have agreed.[171] As a matter of fact, amongst the good business practices displayed by UNCTAD, it is specified the right to privacy: "*Businesses should protect consumers' privacy through a combination of appropriate control, security, transparency and consent mechanisms relating to the collection and use of their personal data*".[172] Member States are in fact invited to establish consumer protection policies that encourage consumer privacy and data security.[173] Therefore, the privacy of cancer survivors can only be secured by businesses if they follow established legal frameworks that allow them to understand what mechanisms they have to follow in gathering the lawful information to provide the requested financial service. It is here that the right to be forgotten for cancer survivors needs to establish guidelines for businesses to follow.

---

[167] ibid., para. 1.
[168] ibid., paras. 2-3.
[169] ibid., para. 4.
[170] ibid., para. 5.
[171] ibid., para. 9.
[172] ibid., para. 11(d).
[173] ibid., para. 14(h).

According to the principle of commercial behaviour, businesses should not subject consumers to illegal, unethical, discriminatory or deceptive practices.[174] Businesses and their authorized agents should have due regard for the interests of consumers and responsibility for upholding consumer protection as an objective.[175] In providing financial services, Member States shall encourage and establish financial consumer protection regulatory and enforcement policies, appropriate controls and insurance mechanisms.[176] Member States in adopting measures to reinforce and integrate consumer protection polices shall consider international standards and guidelines and adapt them to their economic circumstances.[177] UNCTAD specifies the need for international cooperation, where Member States in a regional and sub-regional context should develop mechanisms for information exchange, cooperate in the implementation and enforcement of consumer protection policies through consumer protection enforcement agencies.[178]

The UNCTAD Guidelines highlight the importance and the connection between the right to privacy and the right to adequate consumer protection in financial services. Member States through regional cooperation and the implementation at national level of consumer protection policies must protect their privacy in the access of such services. This perfectly applies to the RTBF. By adhering to international standards and principles of business practices, Member States must ensure the RTBF, which helps in combat discrimination for cancer survivors in accessing of financial services. It is only by following international guidelines, which in the field of the RTBF must be revised and implemented, that a substantial impact can be achieved at the regional and subsequently at the national level.

---

[174] ibid., para. 11(b).
[175] ibid., para. 11(b).
[176] ibid., para. 66.
[177] ibid., paras. 67-68.
[178] ibid., para. 79.

2.3.1.2 Financial Services at EU and national level

At the Regional level, an example of the right to privacy and the RTBF in consumer protection is provided by Directive 2014/17/EU on credit agreements for consumers relating to residential immovable property.[179] Article 18 of the Directive establishes an obligation to assess the creditworthiness of the consumer. This business rule entails an obligation to conduct a thorough assessment based on established, documented and maintained information, taking into account relevant factors to verify the consumer's prospect of meeting obligations under the credit agreement.[180] Moreover, Article 20 states that "*the assessment of creditworthiness shall be carried out on the basis of information on the consumer's income and expenses and other financial and economic circumstances which is necessary, sufficient and proportionate.*"[181] This implies that the practices to assess creditworthiness and the criteria to assess the risk lie with the applicant. In case in where the applicant does not disclose all the relevant information required by the insurance company, such as not disclosing their medical history when requested, the contract is considered null and void.[182] This jeopardise cancer survivors chances of obtaining mortgages and insurances, leading to discriminations that once again contradict '*everyone's right to a standard of living adequate for the health and well-being of himself and of his family,… or other lack of livelihood in circumstances beyond his control*' established in Article 25 UDHR.[183] The return to a normal life must be ensured without being penalised.[184]

Cancer survivors face unfair treatment when seeking financial services, prompting a discussion about the jurisdiction of the European Union and the necessity to promote harmonization of laws among Member States on the subject.[185] With the

---

[179] Directive 2014/17/EU of the European Parliament and of the Council of 4 February 2014 on credit agreements for consumers relating to residential immovable property and amending Directives 2008/48/EC and 2013/36/EU and Regulation (EU) No 1093/2010 Text with EEA relevance.

[180] ibid., Art. 18.

[181] ibid., Art. 20.

[182] ibid., Arts. 18(4) & 20.

[183] United Nations General Assembly. The Universal Declaration of Human Rights (UDHR). New York: United Nations General Assembly, 1948.

[184] Scocca and Meunier (2022), (n 52), p. 134.

[185] Scocca and Meunier (2022), (n 52), p. 135.

entry into force of the Charter of Fundamental Rights of the European Union (CFEU), the human rights dimension of consumer protection has deepened in the Single Market, especially in the field of Retail Financial Services, including access to mortgage loans and insurance services.[186] Article 38 of the CFEU establishes that *"Union policies shall ensure a high level of consumer protection."*[187] The proper and functional operation of the single market is guaranteed by an adequate consumer protection strategy, aiming to uphold consumers' rights in their dealings with businesses and to provide better safeguards for customers who are at risk.[188]

Article 4.2 letter (f) and Articles 12, 114 and 169 of the Treaty on the Functioning of the European Union (TFEU) establish that *"In order to promote the interests of consumers and to ensure a high level of consumer protection, the Union shall contribute to protecting the health, safety and economic interests of consumers, as well as to promoting their right to information, education and to organise themselves in order to safeguard their interests."*[189] Therefore the willingness to improve consumer protection aligns with the purpose of cancer survivors' rights which should be furthered implemented at the EU and international level. Protection for consumer services can also help decrease the fragmentation of national practices in creditworthiness assessment and ensure equivalent access to credit for cancer survivors.[190]

The human health protection envisaged in Article 35 CFUE, read together with Article 168 TFUE, establishes a high level of human health protection in the definition and implementation of all Union policies and activities. This calls for a joint effort among all Member States to cooperate in improving health and financial services. Furthermore, it provides for a common legal framework that could facilitate the sharing of data and enhance consumer rights. Moreover, in the definition of all these polices, Article 10 TFUE establishes that *"in defining and*

---

[186] ibid.

[187] European Union, Charter of Fundamental Rights of the European Union, 26 October 2012, 2012/C 326/02.

[188] Mária Dzúrová, '*Consumer Legal Protection in the EU*' (2020) 83 SHS Web of Conferences 01013, p. 1.

[189] European Union, Consolidated version of the Treaty on the Functioning of the European Union, 26 October 2012, OJ L. 326/47-326/390; 26.10.2012.

[190] Scocca and Meunier (2022), (n 52), p. 135.

implementing its policies and activities, the Union shall aim to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation."[191] This guarantees the right for cancer survivors not to be discriminated against in financial services and common commercial polices provided within EU Member States, calling for the implementation of a legal framework. The EU has the right to intervene in order to advance social inclusion, equality, the fight against discrimination, and the best possible standard of living and health for EU members.[192] A legal framework can therefore be used to increase the applicability of the non-discrimination principle provided by EU and International bodies, decreasing the adverse impact on cancer survivor's financial services.

2.4 Cancer survivors' hardship in adoption procedures

One of the many effects of cancer treatment is the risk of infertility.[193] In fact, infertility rates are between 42% to 66% among male childhood cancer survivors and from 11% to 26% among female childhood cancer survivors, with higher rates among those who received alkylating agents and/or pelvic radiation.[194] Cancer patients are afraid of the low chances of getting pregnant, possible miscarriage or not achieving a successful pregnancy outcome.[195] Despite only 5-10% of cancers being inherited,[196] many cancer survivors are concerned that their condition could have an adverse impact on the children conceived after the diagnosis, placing them

---

[191] European Union, Consolidated version of the Treaty on the Functioning of the European Union, 26 October 2012, OJ L. 326/47-326/390; 26.10.2012.

[192] Scocca and Meunier (2022), (n 52), p. 135.

[193] 'Overview of Cancer Survivorship Care for Primary Care and Oncology Providers' (n 5).

[194] Vicky Lehmann and others, '*Gonadal Functioning and Perceptions of Infertility Risk Among Adult Survivors of Childhood Cancer: A Report From the St Jude Lifetime Cohort Study*' (2019) 37 Journal of Clinical Oncology 893, p. 893.

[195] 'Overview of Cancer Survivorship Care for Primary Care and Oncology Providers' (n 5).

[196] 'If You Have Cancer, Will Your Children Get It? | Penn Medicine' (*Penn Medicine - Abramson Cancer Center*) <https://www.pennmedicine.org/cancer/about/focus-on-cancer/2015/august/if-you-have-cancer-will-your-kids-have-it-too> accessed 20 May 2023.

at risk of malignancy or congenital anomalies.[197] For these reasons, the alternative option that cancer survivors often choose to become parents and create a family is through adoption. Among the many challenges that cancer survivors face during and after treatment there is difficulty and discrimination when accessing and concluding adoption procedures. Despite the adoption procedure being complex and requiring time and money for their seekers, there are more barriers that cancer survivors must face, especially due to the requirement to disclose their health history. This hampers cancer survivors right to found a family without discrimination.

Oncology healthcare, healthcare providers and cancer organizations are not fully aware of the requirements, barriers and resources needed by cancer survivors when seeking adoption.[198] Cancer patients lack clear access to adoption information and face discrimination in both domestic and international adoption processes.[199] Each state has its adoption laws, which are complex and rigorous even for individuals without a stigmatized medical condition, mandating that adoption must be conducted through authorized agencies.[200] Each agency, however, has its own additional requirements that prospective parents must meet. The first step is usually a home study, followed by eligibility defined by factors such as age, probationary placement periods, background checks, home visits, individual evaluations and health requirements.[201] The list of requirements is detailed to ensure maximum protection for the child. Adoption agencies have full discretion in evaluating the health conditions of adoptive parents, following specific procedures and legal documents to assess the health status and perspectives of future parents.[202] However, cancer survivors are not explicitly included in any legal documentation or legislation, leaving their destiny as adoptive parents to the decision and discretion

---

[197] 'Overview of Cancer Survivorship Care for Primary Care and Oncology Providers' (n 5).

[198] Gwendolyn P Quinn and others, '*Adoption and Cancer Survivors: Findings from a Learning Activity for Oncology Nurses: Adoption and Cancer Survivors*' (2015) 121 Cancer 2993, p. 2996.

[199] Shauna L Gardino, Andrew E Russell and Teresa K Woodruff, '*Adoption After Cancer: Adoption Agency Attitudes and Perspectives on the Potential to Parent Post-Cancer*' in Teresa K Woodruff and others (eds), *Oncofertility*, vol 156 (Springer US 2010), <http://link.springer.com/10.1007/978-1-4419-6518-9_11> accessed 20 May 2023, p. 153.

[200] ibid., p. 156.

[201] ibid., p. 154.

[202] ibid., p. 157.

of adoptive agencies.[203] The process that cancer survivors have to follow is not clearly described by adoption agencies.[204]

Adoption agencies require a medical history and a physician's letter from all prospective adopting parents to be shared with the birth mother.[205] It is challenging for an adoption agency to accurately interpret the medical history of a cancer survivor, especially because no physician can guarantee that a patient is fully cured, even 5 to 10 years after the diagnosis.[206] The 'open adoption' approach, which involves disclosing all information, including a cancer history, could be wrongly perceived as a threat to the birth mother. This misperception could impact her decision to place her child for adoption.[207]

Another reported challenge occurs when dealing with international adoption agencies.[208] Most agencies do not have a complete ban but impose stricter regulations regarding the medical and history documents of cancer survivors.[209] Others either prohibit adoption by cancer survivors or only allow them to adopt children with special needs.[210]

While there is no law or legislation explicitly prohibiting cancer survivors from adopting a child, the prejudice against these parents leads agencies to refrain from allowing such adoptions. A person with a completely clean medical history, when compared to a cancer survivor, despite the 5-10 years elapsed since the diagnosis, often receive preferential treatment from adoption agencies.[211] This situation might give the appearance of market-driven decisions in the adoption process rather than outright discrimination. However, the assessment based on cancer survivorship, as previously discussed, lacks medical relevance, and is solely rooted in stigma and prejudice. The best interest of a child should not be determined by the regressed medical history of an individual who has undergone all the necessary treatments.

---

[203] ibid.
[204] ibid.
[205] Quinn and others (n 77), p. 2996.
[206] ibid.
[207] ibid., p. 2997.
[208] ibid.
[209] ibid.
[210] ibid.
[211] Gardino, Russell and Woodruff (n 78), p. 162.

For cancer survivors, the illness is not terminal, and they face a long life ahead that allows them to have and raise a family. Moreover, the lack of information that adoption agencies have on cancer survivorship and cancer diagnosis in general contradicts their professed values of openness and friendliness.[212] Despite wanting to be recognized as cancer-friendly, they often lack awareness of how many parents have had cancer and have not established any policies regarding adoption by cancer survivors.[213] This leads to discrimination and bias decisions during the assessment and decision-making process. Furthermore, cancer survivors frequently find themselves lost in the adoption process, and the lack of information on how to share their medical history creates mental and emotional distress.[214] There is evidence that cancer survivors face *de facto* discrimination during the adoption process, denying them their right to family. It is crucial to analyse how the status of being cancer survivor status is ensured and protected in the adoption process.

2.4.1 Adoption rights for cancer survivors

The UDHR provides, in Article 16 paragraph four, that "*family is the natural and fundamental group unit of society and is entitled to protection by society and the State.*"[215] It further establishes that there must be no limitation to have the right to found a family.[216] Article 21 of the Convention on the Right of the Child (CRC) attributes as a primary objective the interests of the child when States Party permit an adoption system.[217] Moreover in its first paragraph stresses that State Parties shall ensure that the '*adoption of a child is authorized only by competent authorities who determine, in accordance with applicable law and procedures and on the basis*

---

[212] ibid., p. 163.
[213] ibid., p. 163.
[214] ibid., p. 164.
[215] United Nations General Assembly. The Universal Declaration of Human Rights (UDHR). New York: United Nations General Assembly, 1948.
[216] ibid., Art. 16(1).
[217] UN General Assembly resolution 44/25, Convention on the Rights of the Child, 20 November 1989, United Nations.

of all pertinent and reliable information, that the adoption is permissible'.[218] These competent authorities, namely adoption agencies, must comply with applicable national law, yet they do not always consider the full interest of a child when discriminating cancer survivor parents.

How can an individual declared 'cancer free' be deemed inadmissible in adopting a child just because of their successful fight against cancer? This is a question that remains unanswered and should be examined in conjunction with Article 2 of the same Convention. In fact, the first paragraph of Article 2 states that there must be no discrimination against the child of any kind. Non-discrimination is an absolute right and is not subject to any conditions or qualification.[219] The principle of non-discrimination mandates equal treatment of children in the adoption process, which is crucial in combating discriminatory practices against certain groups of children.[220] Yet discrimination persists towards prospective parents when being assessed on unequal terms amongst other candidates. Article 3(1) of the CRC also establishes the best interest of the child in adoption processes, which is an overarching principle of children's rights.[221] By denying adoption to parents whi are cancer survivors, based on no scientific evidence and solely on misconceptions, the best interest of the child is not upheld. This reveals an imbalance between the non-discrimination principle of the child, its best interest and the discrimination faced by cancer survivors in their right to establish a family.

The ECHR provides for the right to family in its Article 12 by establishing "*the right to found a family shall be guaranteed in accordance with the national laws governing the exercise of these rights*".[222] For cancer survivors in Europe, the Convention on the Adoption of Children establishes requirements that can hinder their possibility to found a family if a proper right to not disclose past irrelevant

---

[218] ibid., Art. 21(1).

[219] Ziba Vaghri and others (eds), *Monitoring State Compliance with the UN Convention on the Rights of the Child: An Analysis of Attributes*, vol 25 (Springer International Publishing 2022), <https://link.springer.com/10.1007/978-3-030-84647-3> accessed 21 May 2023, p. 17.

[220] ibid., p. 173.

[221] 'Committee on the Rights of the Children, GE.13-44189, General Comment No. 14 (2013) on the Right of the Child to Have His or Her Best Interests Taken as a Primary Consideration (Art. 3, Para. 1)', para. 1 and 6(b).

[222] 'Council of Europe, European Convention for the Protection of Human Rights and Fundamental Freedoms, as Amended by Protocols Nos. 11 and 14, 4 November 1950, ETS 5.'

health information is not ensured. Recognizing in Article 4 the best interest of the child, Article 10 sets preliminary enquiries concerning the adopter. To grant the adoption, the competent authority shall consider, as far as possible, the health of the adopter in particularly their ability to bring up the child or any limitations imposed by law.[223] As the Convention stands, competent authorities are required to investigate the health of the adopter. Nevertheless, this requirement is contingent on the adopter's capability in raising a child. Cancer survivors with no signs of disease are perfectly capable of raising a child and have no health conditions that could impair their ability to do so. Their requirement to disclose this information could inevitably lead to both discrimination and injustice when considered for adoption procedures. It is for this reason that their right to not disclose such information becomes crucial when applying for adoption procedures. While it is true that it is a case-by-case decision and might not always be taken into consideration, this information will be disclosed to the mother or the child, who, as seen above, might be reluctant to give a child in adoption to a cancer survivor. This decision could be based on stigma and a wrong perception of the situation.

2.5 Conclusions

In analysing the issues faced by cancer survivors years after their diagnosis, it is evident how they are paying twice: first for the disease and secondly for the types of discrimination they suffer. Medical developments in the fight against cancer are not being met with the right legal protection for cancer survivors. The discriminatory practices mentioned above clearly violate inalienable human rights, such as the right to life, the right to work, the right to an adequate standard of living for individuals and their families, and the right to found a family. By requiring a

---

[223] Council of Europe, European Convention on the Adoption of Children (Revised) (2008) CETS 202, Arts. 4, 10(a)(e).

medical history that has no medical relevance, cancer survivors are being defined by their cancer, while simultaneously denying them access to a normal life.

There is still a misconception and stigmatization associated with both the words ‘cancer’ and ‘cancer survivor’. Their definition gives rise to legal placement problems. Where and how can they be placed if the definition encompasses the entire life of an individual since its diagnosis? Are they to be regarded as disabled people and therefore protected by the Convention on the Rights of Persons with Disabilities[224], or should their rights be addressed by various Conventions according to individual problems? The lack of clarification of their status creates uncertainties regarding their protection under international human right laws. SDG 3.4 speaks about non-communicable diseases but only regarding the decrease of mortality attributed to them. Nothing in relation to the life that cancer survivors fight for is addressed. There is little understanding in the legal field compared to the vast interconnection of data at the medical level, where doctors and scientists exchange information to improve the life expectancy of cancer patients. How can cancer survivors fight for months or years for a life in a world that is not capable of addressing them? The discrimination is a double price that they face. Most States, in their constitutions, provide for the basics right of economic and employment equality to obtain the necessary resources for the establishment of a family and personal dignity. However, how can this be achieved if a cancer survivor faces discrimination when applying for a job that should provide for the necessary financial resources to buy a house, only to be rejected due to the discrimination that occurs when asking for a mortgage? A house is the primary need for a couple when trying to raise a family. This family is often hard to establish when cancer survivors face discrimination in adoption processes, which is the most used solution due to the infertility caused by cancer treatments.

International human right law ensures inalienable rights for people, such as the right to life, the right to health, the right to employment, and adequate standard of living for individuals and their family. However, what is missing is a clear identification

---

[224] UN General Assembly, Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106.

of the category of cancer survivors and how their rights can be deduced and applied. Despite the lack of an international human rights law's interest in the rising issue of cancer survivors, in Europe has recently recognised and implemented measures to address the issue. The solution for the above-mentioned problem has been found through the right to be forgotten for cancer survivors. In the next chapter, the full extent of the right to be forgotten will be analysed, from its early understandings to its application for cancer survivors.

Chapter 3. The evolution, understanding and application of the right to be forgotten.

This chapter will first be based on a historical analysis. Second, it will explore its application in international, European, and domestic law using cases such as the Google v. Spain case. Third, after displaying its current legal relevance, the objective will be to connect it to the right to be forgotten for cancer survivors. One of the discovered problems is that it is challenging to establish this connection with the different types of discrimination, especially in adoption procedures and the workplace. The goal is to give legal relevance to a concept that can be applied for the benefit of cancer survivors.

3.1 The development of the Right To Be Forgotten and its legal recognition

The RTBF has expanded in meanings since its early understanding. Initially, the RTBF was perceived as a concept based on the belief that after a certain amount of time, an individual's past should not be regarded.[225] With the surge of technology, the arrival of newspapers on the world wide web, the high availability of data and social media, obtaining information on a person have become easier than ever before. The concept of being forgotten has expanded to the right for a person to prevent the media from revealing true facts about their personal life to the public when there is no public interest that prevails.[226] Its meaning then went further in respect to personal data, which involves the right to access, control and erase data held by others.[227] Therefore, the meaning and application of this concept fluctuates

---

[225] 'Right to Be Forgotten: Explained' <http://www.varonis.com/blog/right-to-be-forgotten> accessed 23 July 2023.

[226] Franz Werro (ed), *The Right To Be Forgotten: A Comparative Study of the Emergent Right's Evolution and Application in Europe, the Americas, and Asia*, vol 40 (Springer International Publishing 2020), <https://link.springer.com/10.1007/978-3-030-33512-0> accessed 23 september 2023, p. 1.

[227] ibid.

around the right to privacy, human dignity, private and family life, which are interconnected because dignity underlines the rationale behind the recognition of human rights. The general right to privacy in fact can be recognized as "a fundamental human right that has been defined as the presumption that individuals should have an area of autonomous development, interaction and liberty, a 'private sphere' with or without interaction with others and free from state intervention and free from excessive unsolicited intervention by other uninvited individuals."[228] This complex notion of privacy comes with the fundamental right to be left alone or the right to obscurity, where the legal system, especially international law, bears the obligation of safeguarding individuals and their privacy against governmental and private involvement.

In practical terms, the right to be forgotten is now used as a protection against the media which would otherwise have the right to publish and keep individuals' information in their platforms.[229] In fact, it is conceived today as the right to erasure or delisting of an individual personal data.[230] However, the right to privacy of a person might compete with the right to freedom of speech and information of others.[231] In this context the application of the right to be forgotten makes a clear demarcation on the importance of the public interest at stake, which must be absent.

The evolution of the right to be forgotten is clearly applicable to cancer survivors. They have the right to keep their information confidential when it is no longer of any medical relevance. It is a right that must be guaranteed for their personal development and reinsertion in society once there are considered survivors. The interference by both private and public entities in requesting to disclose past medical events amounts to a deprivation of their dignity as humans. They shall have the right to forbid access and not be in the position to answer question regarding

---

[228] 'Martin Scheinin, "*Report of the Special Rapporteur on the Promotion and Protection of Human Rights and Fundamental Freedoms While Countering Terrorism*", UN Human Rights Council, (October 28, 2009): A-HRC-13-37.'

[229] Werro (n 226)., p. 2.

[230] Mart Susi (ed), *Human Rights, Digital Society and the Law: A Research Companion* (1st edn, Routledge 2019), <https://www.taylorfrancis.com/books/9781351025379> accessed 10 October 2023, p. 198.

[231] Werro (n 223), p. 2.

their past oncological history that could impair their enjoyment of the right to work, housing and family.

3.2 RTBF in international law

Initially the right to privacy derived from the principle that everyone shall have full protection of their personal and property freedom.[232] The changes in society subsequently demanded a redefinition and extensive application of the protection of privacy. In principle, the law only provided a remedy for physical interference with life and property. However, the scope of these legal rights broadened, with the right to life being perceived as the right to enjoy life, which establishes the right to be let alone.[233] The continuous development and understanding of these rights let to today's international legal framework. The initial collocation in international human right law of the right to privacy, which protects the right to respect private and family life, is given in Article 12 of the UDHR. It aims to ensure that none is subject to interference or attacks on their privacy.[234] It is common to argue that privacy serves as a "gateway" right, supporting other rights both online and offline, such as the freedom of expression and assembly, equality, and non-discrimination. Nonetheless, privacy is a value unto itself, vital to the preservation of human dignity and the growth of human personality, two central tenets of the UDHR. It gives us the power to defend our lives against unjustified intervention and to choose how we wish to engage with the outside world. By establishing boundaries, privacy enables us to control who has access to our information.[235] In certain situations, such as when jail officials check cells for contraband, someone's right to privacy might be impaired. Privacy violations must, however, be proportionate to the advantages to

---

[232] 'Harvard Law Review, Vol. 4, No. 5. (Dec. 15, 1890)', pp. 193-220.

[233] ibid.

[234] United Nations General Assembly. The Universal Declaration of Human Rights (UDHR). New York: United Nations General Assembly, 1948.

[235] 'Universal Declaration of Human Rights at 70: 30 Articles on 30 Articles - Article 12' (*OHCHR*) <https://www.ohchr.org/en/press-releases/2018/11/universal-declaration-human-rights-70-30-articles-30-articles-article-12> accessed 16 November 2023.

society. For instance, in 2000 the European Court of Human Rights decided that the secret service's compilation of a dossier against a Romanian citizen, which included information (some of it fraudulent) going back 60 years, was not "necessary in a democratic society."[236] Therefore, the right for cancer survivors to be let alone and enjoy their life after such a turbulent experience is in line with their right to privacy and the unnecessary advantage to society.

Another important definition of the right to privacy, which reasserts the UDHR and shows its development, is found in Article 17 of the International Covenant on Civil and Political Rights (ICCPR).[237] Both these Articles position the right to privacy as a fundamental human right under international law, allowing individuals to obscure or hide elements of their life and protect personal and family life.[238] Article 17 ICCPR establishes the right to privacy by stating that "*No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful attacks on his honour and reputation*".[239] It further recognizes protection under the law against such interference or attacks.[240] The CCPR General Comment No. 16, adopted by the UN Human Rights Committee (HRC), clarified the definition and application of Article 17 ICCPR.[241] The HRC describes how this right must be guaranteed against all such interferences and discriminations whether they emanate from State authorities or from natural or legal persons.[242] This means that no attack towards cancer survivors shall interfere with their right to privacy, hence not disclosing past medical history, to state authorities, natural or legal persons in the workplace, adoption processes personnel or financial service. The HRC defines the meaning of the words "unlawful" and "arbitrary interference", where the former means that no interference can take place except in

---

[236] ibid 70.

[237] UN General Assembly, International Covenant on Civil and Political Rights (ICCPR), 16 December 1966, United Nations.

[238] Kristian P Humble, '*International Law, Surveillance and the Protection of Privacy*' (2021) 25 The International Journal of Human Rights 1, p. 1.

[239] ICCPR, Art. 17(1).

[240] UN General Assembly, International Covenant on Civil and Political Rights, 16 December 1966, United Nations., Art. 17(2).

[241] 'UN Human Rights Committee (HRC), CCPR General Comment No. 16: Article 17 (Right to Privacy), The Right to Respect of Privacy, Family, Home and Correspondence, and Protection of Honour and Reputation, 8 April 1988', para. 10.

[242] ibid., para. 1.

cases envisaged by the law, and the latter extends to interference provided for under the law.[243] This means that it is primarily through national legislation and subsequent implementation that the protection of the right to privacy can be achieved.[244] Moreover, the Committee lays the groundwork for upholding the RTBF at the international level, establishing the requirement for public authorities, legal and natural persons, to hold information to an individual's private life only when it is essential in the interests of society.[245]

The requirement of the public interest is at the base of the delimitation with the contrasting right of information. In fact, this distinction is once again highlighted in the EU approach towards the right to privacy as demonstrate in the Google v. Spain Case. Therefore, his concept has to be red together with Article 8 of the Charter of Fundamental Rights of the European Union (CFEU), where the protection of personal data is understood as a fundamental right for individuals,[246] giving an initial placement in the international legal sphere of the RTBF.

Here is where the RTBF must be used to protect cancer survivors from the requirement to disclose their medical history. By implementing and regulating regionally and nationally the RTBF for cancer survivors, their right to privacy can be ensured. The guiding statement of the HRC that the gathering and holding of information must be regulated by the law[247] has been followed in a number of European Court of Human Rights (ECtHR) decisions.[248] An example is given in the S and Marper v the UK[249] decision where it provided that the *"protection of personal data is of fundamental importance to a person's enjoyment of his or her right to respect for private and family life, as guaranteed by Article 8 of the Convention."*[250] It also further specified and extended the reach of the decision by

---

[243] ibid., paras. 3-4.
[244] ibid., para. 2.
[245] ibid.
[246] European Union, Charter of Fundamental Rights of the European Union, 26 October 2012, 2012/C 326/02.
[247] CCPR General Comment No. 16 (n 108).
[248] Humble (n 105), p. 4.
[249] *S and Marper v UK, ECHR, Appl No 30542/04, (2008).*
[250] ibid., para. 103.

including the need to ensure domestically that the storage and use of personal data are lawful.

The right to privacy includes information that is not public yet unless required by the law, while the RTBF is the right to erase information that is of public domain. However, the RTBF for cancer survivors can be misleading in the interpretation of its wording. What it entails is the right not to disclose cancer information, therefore, not to publicize, unless required by the law. The law itself must regulate when and how such information can be requested and when it cannot be the basis of an assessment. The right to privacy and the right to be forgotten are intertwined when applied to cancer survivors, because it is not in the interest of the public to have such an information, which encompasses the right to hide personal life data.

3.3 RTBF in EU law

In Europe, a first milestone for the protection of the private sphere of individuals was enhanced by the CoE Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data of 28 January 1981, no. 108, and amended by the Protocol of 10 October 2018.[251] The objective of this Convention is to protect and secure fundamental freedoms and rights such as the right to privacy, in the territory of each Member State, "*with regard to automatic processing of personal data relating to him ("data protection")*."[252] The first step laid down by the Council has been to secure and protect automatic data processing and collection with respect to individuals right to privacy. According to the Convention, personal information must be obtained, gathered, and used with the subject's consent or in accordance with the law, provided that the legislation complies with standard requirements for clarity and predictability, adequately balancing the interests of the general public and the individual. From this perspective, what counts is, on the one

---

[251] Council of Europe, Convention for the Protection of Individuals with Regard to the Automatic Processing of Individual Data, 28 January 1981, ETS 108.

[252] ibid., Art. 1.

hand, the type and content of the personal data collected, which cannot contain the person's sensitive information unless there are special legal conditions. On the other hand, the use of this data must be directly related to the reasons for which they were collected from the individuals or to the broad objectives specified by law, in any case, in line with the proportionality principle.[253] Here, the application of the right to privacy for cancer survivors is better defined, requiring that certain information can be used and collected only when required by the law and not to impair the enjoyment of life of cancer survivors.

A further step towards the improvement and implementation of the right to privacy has been given by the EU General Data Protected Regulation (GDPR). The scope of the Regulation is to protect the processing and use of personal data, meaning that businesses must preserve the personal information of EU citizens and cannot use it or disclose it to third parties without their permission.[254] These businesses do not have to be placed and process the data within the EU territory. The territorial application of the Regulation, "*applies to the processing of personal data by a controller not established in the Union, but in a place where Member State law applies by virtue of public international law*".[255] In Article 17 of the GDPR the RTBF is identified and regulated. It is defined as the right of an individual to have their personal data no longer processed once the relevant purposes have been fulfilled, which is in line with the right to privacy discussed above.[256] Therefore, the goal of RTBF is to give people a legal remedy to ensure that everyone has always a true representation of their personal identity.[257] Such legal claim suggests that under certain circumstances information in the public domain should be erased since its circulation is no longer required or changed to reflect factual developments.[258] In this context we still find the opposite interest of someone to receive information. In fact, the European framework, and the general

---

[253] Pietro Pustorino and Guido Raimondi, *Introduction to International Human Rights Law* (Asser Press 2023), p. 177.
[254] EU General Data Protection Regulation (GDPR) (n 7), Art. 2.
[255] ibid., Art. 3.
[256] ibid.
[257] Marco Bassini and Oreste Pollicino, '*Reconciling Right to Be Forgotten and Freedom of Information in the Digital Age. Past and Future of Personal Data Protection in the European Union*' (1 January 2014) 641, p. 642.
[258] ibid.

understanding of the RTBF do not treat the right to be forgotten as an absolute one but instead as subjected to the condition that certain objectives are not considered of general interest. This is resonated in two other Articles of the GDPR. Article 6 together with Article 11 establishes that personal data shall be considered lawfully processed only when it is necessary for the performance of a task carried out in the public interest and for no longer than the purpose for which the data was collected.[259] The RTBF here fully represents the requirement of restricting the right to privacy only when required by the law, which in this case must be in line with the public interest.

In fact, the right to the protection of personal data is strictly linked with the right to be forgotten in regard to individuals' information. In this context, the RTBF consists of the right to have information about past events that no longer fit the person's current profile. This includes personal data that the person did not initially consent to being processed or later withdrew consent for, as well as data that was collected but is no longer needed for the public or private purposes for which it was obtained.[260]

All these developments on the RTBF led to a wider catalogue of rights. Firstly, the right of access allows the interested party to acquire every detail and verify the existence of their personal data.[261] Secondly, the right to rectification, which allows the owner to correct inaccurate data without delay, usually one month, or the integration of incomplete data.[262] Thirdly, the right to object to the exercise of further processing of personal data and lastly the right of the interested party not to subject to a decision based only on automated treatment that could produce legal effects against them.[263] These rights and many others complete the picture of how a person data shall be handled. Therefore, only when the data is necessary to carry out tasks for the public interest can it legally be processed. In any other case, an

---

[259] EU General Data Protection Regulation (GDPR), (n 7).

[260] Pustorino and Raimondi (n 253).

[261] EU General Data Protection Regulation (GDPR): Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation), OJ 2016 L 119/1., Art. 15.

[262] ibid., Arts. 16 & 19.

[263] ibid., Arts. 21 & 22.

individual has the right to be forgotten. Therefore, States shall weight and consider the right to privacy and reputation of the individual with the conflicting right to information of the general public. A conflict that could arise from of events that could even be compromising for an individual, such as past criminal convictions. These considerations include the identity of the person who is thought to be the victim of the violation, the pertinent facts, including when they happened, the method of information dissemination, and the effects on individuals of learning about past events.[264] In applying these criteria the European Court of Human Rights (ECtHR) has established a balance between the right to respect private and family life contained in Article 8 and the right to freedom of expression contained Article 10 of the European Convention on Human Rights (ECHR).[265] On several occasions, the Court has tried to balance these conflicting rights. In the case of Matalas v. Greece,[266] the Court determined that remarks found in confidential documents meant for private distribution and known to a limited group of individuals could damage the reputation of the individual targeted as well as her professional and social circles. As a result, the Court concluded that the allegations were severe enough to violate someone's rights under Article 8 and looked into whether the domestic authorities had fairly balanced the applicant's right to free speech under Article 10 with the recipient's right to respect for her reputation under Article 8.[267]

On the other hand, the ECtHR in the M.L. and W.W. v. Germany case confirmed the need to balance the line between the protection granted in Article 8 and the freedom of expression of radios and editors, together with the right of the public to access information, both guaranteed by Article 10 of the Convention.[268] The applicants were two half-brothers convicted in the 90s for having murdered a popular actor in Germany. After having served the sentence, they were finally released on probation, respectively, in 2007 and 2008. In 2007, the applicants

---

[264] Pustorino and Raimondi (n 253).

[265] 'Council of Europe, European Convention for the Protection of Human Rights and Fundamental Freedoms, as Amended by Protocols Nos. 11 and 14, 4 November 1950, ETS 5.' (n 222).

[266] *Matalas v Greece, App no 1864/18, ECtHR judgment, 25 March 2021*.

[267] 'Council of Europe, European Court of Human Rights, Guide on Article 8 of the European Convention on Human Rights, Right to Respect for Private and Family Life, Home and Correspondence, 31 August 2022, para. 87.'

[268] *ML and WW v Germany, App no 60798/10 and 65599/10, ECtHR judgment, 28 June 2018, para. 89.*

realised that information related to their criminal proceedings were still available on the internet, especially on web archives belonging to the German radio and newspapers *Deutschlandradio*, *Der Spiegel* and *Mannheimer Mor gen*. For this reason, they brought proceedings before national courts, claiming that the maintenance and availability of such reportages on the web jeopardised their imminent reintegration in society and amounted to a new stigmatisation 15 years after the committed crime and after having served the sentence in full, without being supported by a genuine interest of the public in their case after a long time. After two successful instances, the applicants were finally defeated before the Federal Court of Justice, which quashed the judgments of the Court of Appeal in all three proceedings, based on the freedom of the press and the connected right of the public to be informed. Bringing the case to the ECtHR, the claimants complained that the existence and maintenance of the articles on the internet was a violation of their right to privacy and, in particular, that national courts did not properly consider that such information was permanently available on the internet through search engines. The Court reaffirmed the notion of private life, stating that it includes the protection of personal data and information, which individuals can legitimately expect not to be used by third parties without consent.[269] Conversely, the Court recognized the interest and right of the public to be informed about a well-known criminal proceeding, while recognizing the interest and right of the Applicants to be forgotten for their reintegration in society. However, the Court emphasized that interferences and anonymisation imposed on the press has to be carefully evaluated, as it might have the unintended consequence of deterring journalists from carrying out their duties in a proper and unrestricted manner.[270] Based on these factors and the significant public interest in the ML and WW case, the Court determined that the news pieces continued to contribute to a topic of broad interest even after the passage of time. Although the ECtHR noted that data are permanently available online, it also observed that the case at hand limited access to the data. The items were only accessible through payment and weren't shown in the news sections, which further limited access. This implied that access to such information was

---

[269] ibid., paras. 86-88.

[270] ibid., para. 105.

limited to those who genuinely wanted to learn the news. For these reasons, the Court upheld the assertion that the publications in question had little bearing on the plaintiffs' personal lives. [271] In balancing these conflicting rights, the Council has successfully specified the needs of convicts for their reintegration in society in commenting the M.L. and W.W. v. Germany case in regard to the application of Article 8.[272] Notably, a criminal conviction does not deny the convicted individual of their right to be forgotten, especially if their sentence has run its course. Even while a person may gain a certain reputation during a trial, over time the public's interest in the offence and, thus, the person's renown, may wane. In order to facilitate their reintegration back into society, those who have been convicted of a crime would want not to be reminded of their actions once a specific amount of time has passed. This can be particularly the case once a guilty individual is at last freed.[273]

Another case in which the ECtHR balanced the right to privacy of an individual with the right to freedom of expression of another has been the *von Hannover v. Germany* case.[274] The plaintiff in the case of von Hannover v. Germany was the eldest daughter of Prince Rainier III of Monaco. She alleged that various media outlets had taken photographs of her in locations where she believed she had a reasonable expectation of privacy. She argued that the media's dissemination of candid photos featuring her and her family in these places amounted to a violation of her privacy rights as per Article 8 of the European Convention on Human Rights.[275] The German courts, considering the Princess's status as a semi-public figure, concluded that her right to privacy was inherently diminished due to her social standing. They authorized the publication of these images, citing the principles of press freedom and expression. Contending that the German courts had inadequately safeguarded her privacy rights from media intrusion, thereby breaching their positive obligations under the constitution and the European Human

---

[271] ibid., paras. 112-116.

[272] ibid.

[273] 'Council of Europe, European Court of Human Rights, Guide on Article 8 of the European Convention on Human Rights, Right to Respect for Private and Family Life, Home and Correspondence, 31 August 2022, para. 187.' (n 264).

[274] *von Hannover v Germany, App no, 59320/00, 24 June 2004, EMLR 21.*

[275] ibid., paras. 1-9

Rights Convention, the Princess took legal action against the state of Germany before the European Court of Human Rights.[276]

The European Court of Human Rights (ECtHR) overturned the ruling of the German courts. Despite the Princess being considered a semi-public figure, the ECtHR emphasized that the notion of private life encompasses aspects related to personal identity, such as one's name or image. The Court clarified that "private life" extends to both physical and psychological integrity, interpreting Article 8 to safeguard the unimpeded development of an individual's personality in their interactions with others. Consequently, the ECtHR determined that there exists a sphere of interaction with others, even in a public setting, that may be considered part of one's "private life."[277]

In reaching its conclusion, the Court underscored the need to strike a balance between the freedom of expression guaranteed by Article 10 of the Convention and the protection of private life.[278] The court found that “the decisive factor in balancing the protection of private life against freedom of expression should lie in the contribution that the published photos and articles make to a debate of general interest.”[279] This underscores the European approach, where constitutional rights not only shield individuals from State transgressions but also compel the State to implement adequate and affirmative measures to ensure protection against infringements by other individuals. The von Hannover decision thus effectively scrutinizes a claim of privacy rights violation through the lens of individual rights, rather than confining the right to privacy to its public law dimension. Respecting an individual's private life, autonomy, and dignity sets boundaries on what can be made public, especially when the information has become non-newsworthy over time.

These concepts have been confirmed in the most characteristic law case involving the right to be forgotten by the European Court of Justice (ECJ) in the Google v. Spain case, showing its wide range of application in practice. The Google v. Spain

---

[276] ibid., paras. 18-42.
[277] ibid., para. 50.
[278] ibid., para. 58.
[279] ibid., para, 76.

case involved the request from a Spanish national to erase from Google search engine personal information regarding two property auction notices for the recovery of social security debts that he had owed 16 years earlier.[280] The ECJ in giving its decision regarding the applicability of Article 12(b) and Article 14(a) of the Directive 95/46 (right of access), current GDPR, established that the plaintiff had the right to not have his name linked to the information in question without causing him prejudice.[281] The Court, according to Article 7 and 8 of the Charter of Fundamental Rights of the European Union (right to object), furthered established that the data subject may request that the information in question no longer be made available to the general public.[282] Despite the lack of a specific legislation for the RTBF, the Court was able to balance the freedom to information and the RTBF while deducing for the first time the right to oblivion from the Directive 95/46. The Court furthered stressed the concept that the RTBF can be limited only when the interest in information is at stake, while the economic interest of the service provider cannot prevail. This decision helped for the implementation of the new EU GDPR in establishing the right to erasure and elevate this concept in the fundamental justification of the right to human dignity and self-determination.

Therefore, the RTBF can be traced to the right of someone's privacy, which then entails more ramifications of such right. In fact, an individual's request to be forgotten is an expression of someone's privacy.[283] The right of an individual to have their information not disclosed is a necessary tool to fully enjoy dignitary privacy. Therefore, it cannot be seen only as the right to delete information or to preclude their diffusion. The legal developments expanded its application regarding personal freedom, self-realization, and dignity.[284] The right to privacy can also be perceived as the right to personal self-determination.[285]

---

[280] *Google Spain*, Google Spain SL and Google Incorporated v Agencia Española de Protección de Datos ('AEPD') and Costeja González, Judgment, reference for a preliminary ruling, Case C-131/12, ECLI:EU:C:2014:317, ILEC 060 (CJEU 2014), 13th May 2014, Court of Justice of the European Union [CJEU]; European Court of Justice [ECJ]; European Court of Justice (Grand Chamber), para. 14.
[281] ibid., para. 99.
[282] ibid., para. 99.
[283] Werro (n 223), p. 11.
[284] ibid., p. 18.
[285] ibid.

The two privacy principles that originate from these case laws, European Union (EU) law, akin to the legislation in many countries, are data privacy and dignitary privacy. The former, which is safeguarded by the fair information practices outlined in the Directive, govern the handling of personal information, ensuring, among other considerations, that such data is utilized solely for the explicitly stated purposes for which it was legally collected. Operating under an instrumental logic, data privacy aims to empower individuals with "control" over their personal data, and it doesn't necessitate the demonstration of harm to establish violations. The latter can be found in Article 7 of the Charter of Fundamental Rights of the European Union, which safeguards individuals' dignity by regulating inappropriate communications that pose a threat to degrade, humiliate, or mortify them. Dignitary privacy operates under a normative logic, aiming to forestall harm to one's personality resulting from breaches of civility rules. Internationally, courts uphold dignitary privacy by weighing the potential harm a communication may inflict on an individual's personality against legitimate public interests in the communication.[286] In applying these concepts, dignitary privacy aligns with the purpose of the privacy that cancer survivors seek. By keeping their information confidential their dignity is protected, and they are not forced to pay twice.

3.4 RTBF application to cancer survivors

The increasing significance of the right for individuals to freely exercise control over the disposition, access, and utilization of their information is evident. Instances of data leaks and the public exposure of personal details underscore the relevance of this right. Frequently, information may become public either through events covered by newspapers or through an individual's voluntary decision to disclose

---

[286] 'Data Privacy and Dignitary Privacy: Google Spain, the Right To Be Forgotten, and the Construction of the Public Sphere | Duke Law Journal' <https://dlj.law.duke.edu/article/data-privacy-and-dignitary-privacy-post-vol67-iss5/> accessed 1 December 2023.

certain facts about themselves. As elucidated earlier, this contrasts with the rights to privacy, information, being informed, and freedom of expression.

The juxtaposition of the right to privacy and the right to information has prompted considerations regarding convicted criminals who seek the expungement of information no longer of public interest. Following the completion of their sentences, these individuals possess the right to be forgotten, facilitating their full reintegration into society after undergoing rehabilitation. The significance lies in the recognition that they should not be perpetually judged for past actions for which they have already atoned.

The European Court of Human Rights (ECtHR) has emphasized the paramount importance of the public interest as the sole impediment to the right to be forgotten. However, this perspective raises questions when applied to cancer survivors.[287] While individuals with a criminal history, upon completing their sentences, have the right to be forgotten, cancer survivors, despite being clinically deemed out of the risk of relapse, are compelled to disclose their medical history. This discernible disparity in treatment gives rise to the discriminatory concerns discussed in Chapter 2.

Cancer survivors should be afforded the opportunity to realize their full potential in life, unencumbered by unnecessary disclosure of their past medical history. In this regard, the European Parliament has commendably laid the groundwork for a legal framework facilitating the implementation of the right to be forgotten for cancer survivors.

In June 2020 the European Parliament approved the creation of the Special Committee on Beating Cancer (BECA).[288] After conducting public hearings involving eminent experts, facilitating a dialogue with national parliaments and international organizations, such as the WHO, and undertaking a public

---

[287] 'Cécile de Terwangne, '*The Right to Be Forgotten and the Informational Autonomy in the Digital Environment*', 2013, European Commission, Joint Research Centre Institute for the Protection and Security of the Citizen.'

[288] 'EP Special Committee on Beating Cancer Holds Constitutive Meeting | News | European Parliament' (23 September 2020) <https://www.europarl.europa.eu/news/en/press-room/20200918IPR87431/ep-special-committee-on-beating-cancer-holds-constitutive-meeting> accessed 3 December 2023.

consultation, the European Parliament Committee on Environment, Public Health and Food Safety (BECA) officially approved its conclusive report on December 9, 2021. The report, titled 'Strengthening Europe in the Fight Against Cancer – Towards a Comprehensive and Coordinated Strategy,' represents the culmination of these comprehensive efforts. The primary recommendations of the report encompass heightened European Union (EU) intervention to mitigate the principal risk factors associated with cancer, the expansion of screening programs, initiation of an EU platform dedicated to national screening centres, facilitation of cancer patients' access to cross-border healthcare and participation in clinical trials, and the establishment of European multi-centre clinical trials. Additionally, the report endorses the extension of joint procurement procedures for the management of shortages in cancer medicines. Furthermore, it advocates for the acknowledgment of cancer survivors' 'right to be forgotten' as a safeguard against discrimination and an enhancement of their access to financial services.[289]

The European Parliament had regard to the UN Sustainable Development Goals, in particular SDG 3, whose importance has been stressed in Chapter 1 for tackling and recognizing cancer survivors. Moreover, the Parliament had regard to the mentioned European Code Against Cancer and the European Code of Cancer Practice. In recognizing their importance in drafting the report, it also highlights the rising need for more than 12 million cancer survivors and their families to return back to their normal life. The Parliament emphasizes the inequality of EU citizens after recovery or when in remission in their ability to return to work, to be financially independent and to return to a harmonious familial, social and emotional life.

Within the 'Areas of Action' delineated for cancer prevention across all European policies, there is an encouragement for both the European Commission and the Member States to actively pursue the United Nations Sustainable Development Goals (SDGs). Specifically, emphasis is placed on SDGs addressing communicable diseases with the overarching objective of fostering preventive measures against cancers, stressing the importance of including the SDGs.

---

[289] Laurence Amand-Eeckhout, ‘Strengthening Europe in the Fight against Cancer’.

The adopted text centres on enhancing the assistance provided to individuals affected by cancer, including patients, survivors, and caregivers. It underscores the imperative that cancer patients should not endure a 'double punishment' in their day-to-day existence. The text urges the adoption of an anti-discrimination directive and advocates for the equitable and impartial enforcement of directives pertaining to financial services, including but not limited to the Consumer Credit Directive.[290] This entails ensuring that cancer patients and survivors are not subject to any form of discriminatory treatment in the application of such directives. The Consumer Credit Directive (CCD) 2008/48/EC was adopted in 2008.[291] The subject matter of the Directive is to "*harmonise certain aspects of the laws, regulations and administrative provisions of the Member States concerning agreements covering credit for consumers*".[292] This directive establishes the foundation for upholding fundamental rights and adhering to the principles enshrined, notably, in the Charter of Fundamental Rights of the European Union. Specifically, the directive aims to guarantee the comprehensive adherence to regulations concerning the safeguarding of personal data, the right to property, non-discrimination, protection of family and professional life, and consumer protection as outlined in the Charter of Fundamental Rights of the European Union. The European Parliament successfully addresses the need to ensure the implementation of the directive and its application for the case at stake. Only by implementing and ensuring the application of non-discriminatory data access, as pointed out in Article 9, creditors will not hamper the possibility of cancer survivor to obtain financial services. On October 30, 2023, a Directive of the European Parliament has been published with the goal to "*lay down a common framework for harmonisation of certain aspects of the laws, regulations and administrative provisions of the Member States concerning credit agreements for consumers*".[293] In doing so, the Directive acknowledges that many cancer

---

[290] European Parliament, P9_TA (2022)0038, Strengthening Europe in the fight against cancer European Parliament resolution of 16 February 2022 on strengthening Europe in the fight against cancer – towards a comprehensive and coordinated strategy, (2020/2267(INI)), para. 110.

[291] Directive 2008/48/EC of the European Parliament and of the Council of 23 April 2008 on credit agreements for consumers and repealing Council Directive 87/102/EEC 2008.

[292] ibid., Art. 1.

[293] 'Directive (EU) 2023/2225 of the European Parliament and of the Council of 18 October 2023 on Credit Agreements for Consumers and Repealing Directive 2008/48/EC, PE/22/2023/REV/1, Art. 1.'

survivors encounter discriminatory practices when attempting to avail themselves of financial services. Despite having undergone successful treatment for an extended duration, spanning potentially several decades, they often confront exorbitant insurance premiums. To ensure equitable access for consumers who have triumphed over cancer, Member States are urged to mandate that insurance policies refrain from relying on personal data pertaining to the consumers' diagnoses of oncological diseases beyond a specified period following the conclusion of their medical treatment. This stipulated timeframe, as determined by individual Member States, should not exceed 15 years from the cessation of the consumer's medical treatment.[294] In this regard the Directive successfully addressed the mentioned need to implement Article 9. In fact, the evaluation of creditworthiness must be grounded in information pertaining to the financial and economic standing of the consumer. Such information should be deemed necessary and proportionate, aligning with the principles of data minimization as delineated in Regulation (EU) 2016/679. It should be relevant, comprehensive, and accurate, encompassing essential details such as the consumer's income, expenses, prevailing obligations, including living expenses within the consumer's household, and financial liabilities. The data, however, should exclude special categories of personal information specified in Article 9(1) of Regulation (EU) 2016/679, including health data such as information related to cancer, and should not incorporate details obtained from social networks.[295]

Moreover, the European Parliament is urging Member States to acknowledge the long-term effects (physical or mental disabilities) and instances of social discrimination, particularly in the workplace, experienced by individuals following cancer. It recognizes that cancer constitutes a financially burdensome ailment, extending beyond the scope of cancer treatments. The Parliament calls on Member States to enhance the reintegration of cancer survivors into social activities and the labour market. This includes providing assistance for transitioning into new professional roles in situations where sequelae impede their ability to continue in

---

[294] ibid, para. 48.
[295] ibid.

the same job. Furthermore, there is a directive to facilitate the return of paediatric cancer survivors to school or higher education.[296]

As a result of the discrimination suffered by cancer survivors and the aforementioned considerations, in paragraph 125, the European Parliament requests the implementation of the Right To Be Forgotten for cancer survivors by all Member States by 2025. The European Parliament maintains the position that insurers and banks should refrain from considering the medical history of individuals who have experienced cancer. Advocating for the enactment of national legislation to prohibit discrimination against cancer survivors compared to other consumers, it takes note of the Commission's intention to engage with businesses in formulating a code of conduct. This ensures alignment between advancements in cancer treatments, the improved effectiveness of such treatments and the business practices of financial service providers. Concurrently, it supports the promotion of advancements witnessed in France, Belgium, Luxembourg, and the Netherlands, where cancer survivors benefit from the 'right to be forgotten.' It calls for a stipulation that by the year 2025, all Member States must guarantee the right to be forgotten for all European patients. This should commence 10 years post the conclusion of their treatment and extend up to five years after the conclusion of treatment for patients diagnosed before reaching the age of 18. Urges the establishment of uniform standards for the right to be forgotten under the relevant provisions of the consumer protection policy within the Treaty on the Functioning of the European Union. This aims to rectify the existing fragmented national practices in creditworthiness assessment and ensure equitable access to credit for cancer survivors. Furthermore, advocates for the integration of the right to be forgotten for cancer survivors into pertinent EU legislation to prevent discrimination and enhance cancer survivors' access to financial services.[297]

The text underscores the importance of protecting the rights and interests of individuals who have experienced cancer, particularly in the context of financial

---

[296] European Parliament, P9_TA (2022)0038, Strengthening Europe in the fight against cancer European Parliament resolution of 16 February 2022 on strengthening Europe in the fight against cancer – towards a comprehensive and coordinated strategy, (2020/2267(INI)), paras. 111 and 120.
[297] ibid., para. 125.

services. It advocates for legal measures at both national and EU levels to prevent discrimination against cancer survivors, emphasizing the need for a 'right to be forgotten' mechanism. The call for uniform standards across Member States and the engagement with businesses to align practices with advancements in cancer treatments reflect a commitment to ensuring fair treatment and equal access to financial services for individuals with a history of cancer. Overall, the text highlights a comprehensive approach to addressing the challenges faced by cancer survivors in various aspects of their lives, especially in the realm of financial services and creditworthiness assessment.

Chapter 4. The Right To Be Forgotten for Cancer Survivors

After identifying the discriminatory challenges faced by cancer survivors even 5 to 10 years post the successful completion of their treatment and thoroughly examining the legal implications and application of the Right to Be Forgotten, it is imperative to assess the efforts undertaken by States and the European Union to mitigate discrimination against cancer survivors while aligning with international human rights law.

The RTBF for cancer survivors essentially entails their entitlement not to disclose their cancer status after a specified period, ranging from 5 to 10 years, contingent upon the type of cancer and the age at diagnosis.[298]

The implementation of the RTBF was initiated in France in 2016. Consequently, several other European countries have initiated and completed the implementation process, aligning with the European Parliament resolution that advocates for the RTBF' implementation across all Member States by the year 2025.[299]

4.1 France as the leading example on the RTBF

The drafters of the RTBF in France recognised the significant societal issue surrounding access to credit. This issue becomes particularly acute when considering individuals seeking loans who, due to life's uncertainties, find themselves exposed to health risks exacerbated by illness or disability. In many cases, the procurement of borrower insurance becomes a requisite condition for loan approval. The process to reduce discrimination in accessing credit for loans or

---

[298] Quarello and others (n 30), p. 404.

[299] European Parliament, P9_TA (2022)0038, Strengthening Europe in the fight against cancer European Parliament resolution of 16 February 2022 on strengthening Europe in the fight against cancer – towards a comprehensive and coordinated strategy, (2020/2267(INI)), para. 125.

insurances in France can be tracked back to 1991.[300] The initial agreement between public authorities and professional insurers, although only partially met, aimed to adjust the processing of medical data for life insurances and mortgages.[301] In 2001, a second convention, known as the Belorgey Convention, was convened to incorporate additional stakeholders, including professionals, consumer associations, and associations representing patients or disabled people.[302] This convention extended the coverage to include more pathologies and established a code of good conduct. The need for enhanced legal entitlements led to the convening of the ARES Convention in 2006. This Convention, addressing guarantees against invalidity alongside death benefits, established a framework for limiting supplementary insurance premiums. It reinforced stipulations within the scrutiny of loan applications and introduced both a Study and Research Committee and a Mediation Commission.[303] Following preceding enhancements, an initial amendment in 2011 paved the way for subsequent changes. In 2015, a significant amendment was enacted, instituting the Right to Be Forgotten.[304] The continuous evolution in this field saw two additional amendments, first in 2019 and then in 2020, further strengthening the RTBF and introducing the AREAS Reference Grid (GRA).[305] Consequently, individuals with a history of cancer, once specific time limits expire, are relieved from the obligation to disclose their prior cancer diagnosis when seeking an insurance contract. This exemption shields them from exclusionary measures or elevated premium rates.[306] Moreover, the GRA specifies cancerous pathologies and other conditions, including chronic ailments, for which insurance providers are obligated to extend coverage without resorting to discriminatory practices.[307] The grid undergoes periodic updates to align with advancements in medical knowledge and available health data.[308]

---

[300] 'Les Textes de Référence' <https://www.aeras-infos.fr/sites/aeras/accueil/la-convention-aeras/les-textes-de-reference.html> accessed 26 July 2023.

[301] ibid.

[302] ibid.

[303] ibid.

[304] ibid.

[305] ibid.

[306] ibid.

[307] ibid.

[308] ibid.

Upon the incorporation of the Right to Be Forgotten (RTBF) within the ARES Convention, enacted in the Law on the modernization of the National Health System (Law no. 2016-41, 26 January 2016), France introduced Article 190, now denoted as Article L1141-5, stipulating the Right To Be Forgotten tailored for individuals who have survived cancer.[309] The rule states that "*the national agreement mentioned in Article 1141-2 of the Public Health Code,*[310] *determines the terms and deadlines beyond which people who have suffered from a cancerous pathology cannot, as a result, see themselves apply a rate increase or an exclusion of guarantees for their insurance contracts whose purpose is to guarantee the reimbursement of a loan covered by the said agreement. The agreement also provides for time limits beyond which no medical information relating to cancerous pathologies can be collected by the insurers in this context".*[311] This paragraph of Article L1141-5 establishes crucial provisions safeguarding individuals who have experienced cancerous pathologies within the framework of insurance contracts aimed at guaranteeing loan reimbursements. The Article mandates that the national convention referenced in Article L. 1141-2 prescribes specific terms and temporal limitations under which individuals with a history of cancer cannot face heightened premiums or be subjected to exclusions in guarantees for their insurance contracts. Furthermore, the agreement outlined in this provision delineates explicit deadlines beyond which insurers are prohibited from collecting any medical information pertaining to cancerous pathologies within the context of these insurance contracts. The primary objective is to ensure fair treatment and protection for those who have overcome cancer in the realm of insurance agreements related to loan reimbursement.

This provision must be integrated with the standards of the ARES Convention and especially the GRA, along with the norms of the French Public Health Code (as L.

---

[309] European Cancer Patient Coalition, '*Factsheet on the Right to Be Forgotten in the EU National Legislations, Legal Background and Current Status from France, Belgium, Luxembourg and the Netherlands*', p. 1 <https://ecpc.org/wp-content/uploads/2020/12/Factsheet-National-Legal-framework-on-the-right-to-be-forgotten_UpdatedDEC2020-1.pdf>.

[310] 'Article L1141-2 - Public Health Code - Légifrance' <https://www.legifrance.gouv.fr/codes/article_lc/LEGIARTI000027645844> accessed 26 September 2023.

[311] Légifrance - Publications officielles - Journal officiel - JORF n° 0022 du 27/01/2016, LOI no 2016-41 du 26 janvier 2016 de modernisation de notre système de santé, Art. 190.

1141-2). The ARES Convention plays a significant role as it aims to facilitate access to insurance and loans for people who could face discrimination based on their diseases. It ensures that financial institutions and credit institutions fully consider guarantees as an alternative to insurance while specifying the correct processes for notifying applicants, reviewing their applications, and managing disputes.[312] On the other hand, the role of the GRA has been stressed in the second paragraph of Article L1141-5 in stating that "*On the basis of the proposals established and made public by the National Cancer institute mentioned in the article L. 1415-2, the list of pathologies and the deadlines… are set in accordance with a reference grid, defined by said convention, making it possible to set, for each of the pathologies, the deadlines beyond which no increase in prices or exclusion of guarantee will be applied or no medical information will be collected for the pathologies concerned*."[313] The constant update of the GRA provides for reliable information that insurance companies must follow when considering the application of a subject that falls into the protected categories. Of remarkable importance is the establishment of a Monitoring and Proposal Committee, composed of 23 members and structured as follows:

i. six members appointed by professionals, lenders and insurers;
ii. six members appointed by associations representing patients or disabled people and consumer associations;
iii. four representatives of the ministers responsible for the economy and health;
iv. five qualified members appointed by the ministers responsible for the economy, health and solidarity;
v. two experts from the Prudential Control and Resolution Authority, including one in charge of customer protection.[314]

---

[312] European Cancer Patient Coalition (n 142), p. 2.
[313] 'Section 2: Risques Aggravés (Articles L1141-2 à L1141-6) - Légifrance' 2, Art. L1141-5.
[314] 'The Monitoring and Proposals Committee' <https://www.aeras-infos.fr/sites/aeras/accueil/la-convention-aeras/les-instances/la-commission-de-suivi-et-de-pro.html> accessed 26 May 2023.

The Monitoring Committee is responsible for overseeing the accurate implementation of the stipulations within the Convention and ensuring adherence to the commitments made by the involved parties. It systematically examines matters that may pose challenges unresolved by the Agreement, engages in deliberations regarding potential enhancements, and possesses the authority to commence specific inquiries to vigilantly monitor the execution of the Agreement.[315] It monitors the progress made in the field of borrower insurance and it sets the work program after consulting the Commission for Studies and Research (CER) for cancer pathologies, the working group on the "right to be forgotten" and reference grid for pathologies, and approves updates to the GRA.[316] In addition to this organism, a Committee for Studies and Researches has been created, entrusted with gathering and analysing the information on mortality and disability brought on by the major diseases.[317] Moreover, a Mediation Committee has been established to investigate each of the loan applicants' specific grievances.[318] To execute the insurer need to provide information, France issued a new decree (Decree 2017-147) at the beginning of 2017. According to the legislation, the insurer must provide applicants for credit payback insurance with an "information document on the right to be forgotten" together with the standard risk disclosure form.[319]

The AERAS Reference Grid (GRA) enumerates the pathologies, including cancerous and chronic conditions, facilitating eligibility for borrower insurance under standard or analogous terms. The GRA specifies:

i. The attributes of the pathologies and the prescribed timelines beyond which no pricing augmentation (surcharge) or guarantee exclusion will be enforced for individuals who have experienced these specific conditions.

---

[315] ibid.
[316] ibid.
[317] European Cancer Patient Coalition (n 142), p. 2.
[318] ibid.
[319] ibid.

ii. The maximum additional premium rates applicable by insurers for certain pathologies, barring individuals afflicted by them from accessing borrower insurance at standard rates.

The GRA provisions come into effect under the following three conditions:

i. Insurance contracts encompass professional loans for the acquisition of premises and/or equipment, as well as real estate loans.
ii. Applicable to real estate loan transactions where the insured portion does not exceed €420,000 (excluding bridging loans) for the acquisition of a Principal residence. For other instances of real estate loans and professional loans, it applies to contracts with a cumulative outstanding amount not exceeding €420,000.
iii. Insurance contracts must conclude before the borrower's 71st birthday.

The GRA, currently effective as of September 2023, is subject to periodic updates in tandem with therapeutic advancements and available epidemiological data.[320]

The law of February 28, 2022, for fairer, simpler and more transparent access to the borrower insurance market, in light of an insurance contract, established that "*no information relating to the state of health nor any medical examination of the insured person may be requested by the insurer*".[321] The removal of a medical questionnaire for subscribing to borrower insurance is set under two conditions:

> *i. "The insured portion of the cumulative outstanding credit contracts does not exceed 200,000 euros per insured person.*
>
> *ii. The repayment deadline for the loan taken out is before the sixtieth birthday of the insured."*[322]

---

[320] 'The "Right to Be Forgotten" and the AERAS Reference Grid' <https://www.aeras-infos.fr/sites/aeras/accueil/aeras-en-pratique/les-points-cles/le-droit-a-loubli-et-la-grille-d.html> accessed 18 December 2023.

[321] LAW no. 2022-270 of February 28, 2022, for fairer, simpler and more transparent access to the borrower insurance market, Section 10.

[322] ibid.

This provision became effective on June 1, 2022, for newly established contracts, and for contracts already underway prior to this date, it applies from September 1, 2022. Consequently, individuals meeting these dual conditions are not obligated to furnish any information pertaining to their health status or undergo any medical assessments. This exemption from a medical questionnaire is exclusively applicable to real estate loans extended to consumers for the procurement of residential properties and for properties utilized for both residential and professional purposes.[323] For loans not conforming to the aforementioned criteria, the "right to be forgotten" affords individuals who have experienced cancer or viral hepatitis C the exemption from declaring such medical history. This mechanism is applicable when the following two conditions are satisfied:

i. Insurance contracts encompass designated or specific consumer loans, professional loans for the acquisition of premises and/or equipment, and real estate loans.

ii. The insurance contracts must reach termination prior to the borrower's 71st birthday.[324]

Initially, no medical information could be collected by the insurer if 10 years had passed after the end of treatment for those cancerous pathologies occurred before 21 years of age and 5 years after the end of treatment for those occurred before 18 years of age.[325] In September 2020, and in line with the ARES Convention Amendment, the 5-year requirement was increased to patients that were diagnosed after 21 years of age. Currently, Article L1141-5 (modified by LAW n°2022-270 of February 28, 2022, art. 9) provides that "*In all cases, the period beyond which no medical information relating to cancerous pathologies and viral hepatitis C can be collected by insurers cannot exceed five years from the end of the therapeutic protocol.*"[326] This implies that individuals who have survived cancer possess the

---

[323] 'The "Right to Be Forgotten" and the AERAS Reference Grid' (n 320).

[324] ibid.

[325] Légifrance - Publications officielles - Journal officiel - JORF n° 0022 du 27/01/2016, LOI no 2016-41 du 26 janvier 2016 de modernisation de notre système de santé.

[326] 'Article L1141-5 - Public Health Code - Légifrance' <https://www.legifrance.gouv.fr/codes/article_lc/LEGIARTI000045272010> accessed 11 December 2023.

entitlement, following the designated period, to abstain from disclosing their prior history of cancer when pursuing a borrower insurance contract or applying for a loan. If someone meets these mentioned medical conditions, they do not have to declare their history of cancerous disease or viral hepatitis C and they benefit from insurance without any additional premium or exclusion of cover relating to this history. Cancer survivors are not required to provide any information relating to the cancerous diseases or viral hepatitis C as part of their search for loan insurance. However, if they do provide such information by mistake, the insurer's medical department will not take it into account in its risk assessment. Additional medical conditions, risk factors, ongoing states of incapacity, disability, or work inability, irrespective of their connection to the condition falling under the "right to be forgotten," must be disclosed to the insurer as per the health questionnaire. Such information may warrant a tailored decision or pricing accordingly. The ramifications of cancer disease or those arising from treatments, including potential side effects are not encompassed by the provisions of the "right to be forgotten" and, therefore, must be disclosed to the insurer.

France is the example to follow when creating a legal framework for cancer survivors and non-communicable diseases. It did not only recognize and define the right to be forgotten but also ensured its implementation with the creation of the three bodies to monitor the Convention. As the monitoring progressed, they went in further implementation of the RTBF with new important Amendments, such as by increasing the threshold to 21 years old. Furthermore, cooperation and data exchange are allowing a continuous update of the GRA, enhancing insurance companies to have complete knowledge on the different types of diseases.

In conclusion, France has demonstrated a commitment to addressing discrimination in accessing credit and insurance, with a timeline dating back to 1991. The legislative journey reflects adaptability to societal needs. The legislation encompasses various conventions and amendments, such as the Belorgey Convention, ARES Convention, and subsequent amendments, creating a comprehensive legal framework. The incorporation of the RTBF within the ARES Convention showcases a clear recognition of the rights of cancer survivors. The specified conditions and timelines for rate increases or exclusions provide clarity and protection. However, some provisions, like the removal of a medical questionnaire, apply only under specific conditions (e.g., loan amount and repayment deadline), potentially leaving certain borrowers without the same benefits. The elaborate structure involving committees and authorities may lead to administrative challenges and delays in decision-making. France should consider streamlining the legal framework to enhance clarity and ease of understanding for all stakeholders, ensuring efficient implementation. It could evaluate the possibility of extending the benefits, such as the removal of a medical questionnaire, to a broader range of loans, promoting inclusivity. France's legal framework reflects a commendable effort to protect the rights of individuals seeking loans, especially cancer survivors. While the legislation has strengths, continuous improvement and adaptation to changing societal needs are crucial for ensuring fair and accessible credit practices. Streamlining and expanding the application of certain provisions could contribute to a more effective and inclusive legal framework.

4.2 Other states following France model

As of 2024, six Member States within the European Union have enacted legislative measures to address and mitigate financial discrimination against individuals who have survived cancer. France, as the pioneer in this domain, promulgated legislation concerning the Right to be Forgotten for cancer survivors in January 2016. Subsequently, Belgium followed suit in March 2018. From January 2021 onwards, the Netherlands implemented the 'clean-slate policy,' incorporating the Right to be Forgotten. Portuguese policymakers embraced this legal framework in January

2022. The most recent additions to this cohort of EU countries adopting the law include Spain, in July 2023, and Italy in December 2023.[327]

This section will concentrate on scrutinizing the legal frameworks adopted by various European countries that have emulated France's initiative in instituting the Right to be Forgotten for cancer survivors, with a meticulous examination of their divergences. Such examination is instrumental in proposing a cohesive framework that could be universally applied on both the international and regional legal fronts.

4.2.1 Belgium’s legislation

In Belgium, in 2020, a law entered into force, “*Loi relative aux assurance, C − 2014/11239, 4 Avril 2014*”, promulgated in 2019 modifying the Insurance Regulation and reforming Article 61.[328] The provisions are relevant to insurance agreements pertaining to both mortgage and professional loans. Section “*Ibis*” of Article 61 introduced the RTBF. In 2022 the Subsection of such Article was furthered implemented, defining the applicability of the provisions in Article 61/1, such as insurance contracts, mortgage credit, professional credit and work insurance contracts.[329] Article 61/2 on the other hand, establishes that cancer survivors who have successfully ended cancer treatment with no recurrence for more than 8 years are not obligated to disclose their medical history.[330] These provisions impose a prohibition on insurance companies considering prior cancer pathologies after a lapse of 10 years following the successful completion of treatment and the absence of a relapse during the same period. A successful treatment is defined as the duration

---

[327] ‘OVERVIEW OF LEGISLATION AT THE NATIONAL LEVEL’ (*Ending discrimination against cancer survivors*) <https://endingdiscrimination-cancersurvivors.eu/national-level/> accessed 30 December 2023.

[328] ibid, p. 3.

[329] ‘LOI - WET’ <http://www.ejustice.just.fgov.be/cgi_loi/loi_a1.pl?language=fr&la=F&cn=2014040423&table_name=loi&&caller=list&F&fromtab=loi&tri=dd+AS+RANK&rech=1&numero=1&sql=(text+contains+(%27%27))#LNK0033> accessed 30 December 2023.

[330] ibid.

subsequent to the conclusion of active treatment and the non-occurrence of a new manifestation of the pathology.[331] Such period of time is reduced to 5 years if the interested person was under the age of 21 when the cancerous pathology was diagnosed.[332] On 27 October 2022, the Belgian Parliament passed a law (Law no. C − 2022/34022) with the aim of expanding the Law of 4 April on the right to be forgotten in the context of insurance. With this law, the waiting period for cancer survivors to be "forgotten" was immediately reduced to eight years and will be further decreased to five years starting from 1 January 2025. Therefore, by 2025 both periods will be of five years.[333] However, there is no reference to a monetary ceiling in the amount covered by insurance companies.

Moreover, based on scientific data, the King of Belgium, on the proposal of the Belgian Health Care Knowledge Centre (KCE) may determine, in a reference grid, certain types of cancer conditions for which the time period can vary according to age categories and/or types of cancerous condition.[334] In fact, in May 2019, in accordance with Article 61/3, the regulatory framework was enacted through the adoption of a reference table (Document No. C − 2019/12990). Similar to the French reference grid, this table specifies a shortened duration for the application of the Right to be Forgotten concerning specific cancer diseases. Every two years, the Belgian Health Care Knowledge Centre (KCE) evaluates the reference table based on medical advancements and available scientific data pertaining to the referenced pathologies. After the period mentioned in the reference grid, the insurance company is prohibited from taking these conditions into account when determining the current state of health.[335] The reference grid specifies a certain number of chronic illnesses for which, where applicable, in accordance with certain procedures, the insurance undertaking may not charge an additional premium, provide for an exclusion or refuse to conclude the contract because of this condition.[336] Every two years, the *Centre Fédéral d'Expertise des Soins de Santé* or

---

[331] 'OVERVIEW OF LEGISLATION AT THE NATIONAL LEVEL' (n 327).
[332] 'LOI - WET' (n 329).
[333] ibid.
[334] ibid., Art. 61/3.
[335] ibid., Art. 61/3.
[336] ibid., Art. 61/4.

KCE evaluates the reference grid in the light of medical progress and available scientific data relating to the pathologies referred to in Articles 61/3 and 61/4.[337] The Belgian monitoring office of pricing (*Bureau du suivi de la tarification*) is responsible for handling disputes related to the implementation of the relevant provisions.

In April 2022, KCE conducted an initial assessment focused on early-stage breast cancer. Following a meticulous analysis of survival curves for this cancer type, KCE researchers have proposed adjustments to shorten the waiting period, potentially impacting approximately half of women with breast cancer. [338]

Starting from February 2022, the Belgian association of insurers, Assuralia, adopted a code of conduct extending the application of the Right to be Forgotten to guarantee income disability insurance for individuals cured of cancer. Guaranteed income (or incapacity for work) insurance, as defined in Article 201, §1, 2 of the Law of 4 April 2014 on insurance, provides full or partial compensation for the reduction or loss of professional income due to the incapacity for work of the insured person. This code is obligatory for all insurance companies that are members of Assuralia, making Belgium the first EU country to implement such a code of conduct.[339]

In June 2023, Belgium took an additional step regarding breast cancer survivors when the Minister of Health and Social Affairs and the Minister of Economy and Employment advocated for an expedited Right to be Forgotten for breast cancer survivors. Specifically, for individuals with breast cancer in situ, where the tumour is confined to its original tissue, the waiting period will be entirely eliminated. For those with early-stage breast cancer that has spread to other tissues but is still small or diagnosed early, the waiting time will be reduced to just 1 year.[340]

---

[337] ibid., Art. 61/5.

[338] 'OVERVIEW OF LEGISLATION AT THE NATIONAL LEVEL' (n 327).

[339] ibid.

[340] ibid.

4.2.2 Netherland’s legislation

In November 2020, the Netherlands, passed a Decree regulating insurance inspections of ex-cancer patients for the purpose of purchasing life insurance and funeral insurance.[341]

This decision is grounded in the provisions of Article 14, third paragraph of the Medical Examinations Act (Wmk). The Wmk, in effect since January 1, 1998, governs the legal status of individuals undergoing medical examinations in the context of civil-law employment relationships, or for pension, life, or disability insurance purposes. Inquiries regarding an individual's health status constitute a medical examination under the purview of this Act. Consequently, the Wmk serves as an appropriate legal framework for the realization of the envisioned arrangement for former cancer patients.[342]

Article 3 first paragraph, of the Wmk broadly stipulates that no questions or investigations may be conducted that would disproportionately infringe upon the personal privacy of the examinee.[343] Article 14 third paragraph, of the Wmk establishes the authority to establish further regulations in this regard through an order in council. The current decision aligns with the general rule in Article 3, first paragraph of the Wmk by specifying that, after a certain duration, inquiries about a person's past occurrence of cancer, which has not recurred for an extended period, may no longer be made. With the passage of time, posing such questions is deemed unwarranted, considering the socially responsible equilibrium between ensuring accessibility to insurance for former cancer patients and the imperative of a judicious risk assessment.[344] Interrogating individuals about such medical history,

---

[341] Besluit van 2 november 2020, houdende regels voor verzekeringskeuringen van ex-kankerpatiënten ten behoeve van het afsluiten van overlijdensrisicoverzekeringen en uitvaartverzekeringen (Besluit verzekeringskeuringen ex-kankerpatiënten) 453, Jaargang 2020, Staatsblad van het Koninkrijk der Nederlanden.

[342] Ministerie van Financiën, ‘*Besluit van 2 november 2020, houdende regels voor verzekeringskeuringen van ex-kankerpatiënten ten behoeve van het afsluiten van overlijdensrisicoverzekeringen en uitvaartverzekeringen* (Besluit verzekeringskeuringen ex-kankerpatiënten)’ (*artikel 14, derde lid, van de Wet op de medische keuringen*, 17 November 2020) <https://zoek.officielebekendmakingen.nl/stb-2020-453.html> accessed 9 January 2024.

[343] ibid.

[344] ibid.

if persisted, would thus represent an undue intrusion into the personal privacy of former cancer patients. Should an insurer persist in posing such questions, Article 11 of the Wmk empowers the examinee to refuse cooperation. In practical terms, this implies that a former cancer patient is not obliged to furnish information about their medical history concerning this disease if requested by a life insurance company or funeral insurer in contravention of this decision. Any disputes arising from such situations can be brought before the Financial Services Complaints Institute by the applicant.[345]

When an individual applies for term life insurance or funeral insurance, an insurer may already possess information regarding the client's past cancer treatment, as the client may have previously disclosed this information while obtaining a prior insurance policy. Alternatively, a prospective insured person might provide this information for the first time in an insurance application just before the enactment of this decision.[346] In such scenarios, it is stipulated by Article 30, third paragraph, part b, of the GDPR Implementation Act (UAVG) that the insurer is prohibited from incorporating this data into its decision on a new insurance application or modifications to an existing insurance policy. Furthermore, the data must not be utilized for determining premium rates.[347] The use of health data is permissible under the UAVG only when it is deemed "necessary" for the insurer's assessment of the risk to be insured. This necessity is absent in the situations outlined in this decision. Additionally, the principle of purpose limitation (Article 5, first paragraph, part b, GDPR) precludes insurers offering health insurance from utilizing the medical data they possess in that capacity when evaluating risks associated with other insurance policies, excluding health insurance.[348]

The Decree entered into force on 1st January 2021. In Article 2 of the Decree establishes that there is a need of no recurrence of cancer for a period of 10 years from the end of treatments and 5 years if the examinee was under 21 years of age

---

[345] ibid.
[346] ibid.
[347] ibid.
[348] ibid.

when the cancer was diagnosed.[349] The regulation is applicable to funeral insurance plans that are signed or completed before the age of 61 for the individual whose life the policy refers to, as well as life insurance policies for applicants under the age of 71. This article establishes a fixed time frame for inquiring about cancer history. Following a period of 10 years (or 5 years for individuals diagnosed before age 21) from the day of complete remission, where disease activity is no longer detectable, former cancer patients are exempt from questions regarding their disease history, especially if the cancer has not recurred during that period. This exemption is based on the care provider's assessment, relying on existing protocols for diagnosis, control, and treatment. The absence of disease activity is confirmed through various means, such as imaging or laboratory research conducted within the applicable protocol, excluding non-protocol actions. The article explicitly states that posing questions about cancer history beyond the specified period disproportionately infringes on the personal privacy of the former cancer patient, aligning with the general standard of Article 3, first paragraph, Wmk. In cases where the exact moment of complete remission is not evident in the medical file, a substantiated estimate can be made based on available information. Insurers are urged to communicate clearly when questions about cancer history no longer apply. However, insurers still retain the right, when issuing term life or funeral insurance policies, to consider other relevant aspects, such as lifestyle, existing complaints, and diseases, without making general assumptions solely based on past cancer history.

Article 3 provides for shorter deadlines to apply when the type of cancer has a lower recurrence probability according to medical data and the agreements reached under Article 9 of the Medical Examination Act (Wet op de medische keuringen, thereinafter Wmk) between representatives of patients’ organizations and insurers regarding the limits to be applied with respect to specific forms of cancer.[350] For certain types of cancer, statistical data indicate a substantial reduction in the

---

[349] Besluit van 2 november 2020, houdende regels voor verzekeringskeuringen van ex-kankerpatiënten ten behoeve van het afsluiten van overlijdensrisicoverzekeringen en uitvaartverzekeringen (Besluit verzekeringskeuringen ex-kankerpatiënten) 453, Jaargang 2020, Staatsblad van het Koninkrijk der Nederlanden., Art. 2.

[350] ibid., Art. 3.

likelihood of cancer recurrence within a relatively brief timeframe. Additionally, advancements in treatment methods contribute to the dynamic nature of recurrence probabilities for specific cancer types. The ten-year absolute horizon (five years for young individuals) stipulated in Article 2 is deliberately broad, encompassing all cancer forms. This inclusive approach considers cancers with extended recurrence risks or insufficient statistical information to determine a shorter period within the specified timeframe. It is crucial to clarify that the general horizon in Article 2 should not impede the adoption of shorter periods for specific cancers, during which no further questions may be posed in examinations. Therefore, Article 3 explicitly allows for the application of shorter periods if there is consensus between representative patient organizations and insurers. In such cases, the shorter term replaces the general ten-year period in Article 2 for the specified cancer type. Part (a) emphasizes the role of universally accepted medical insights and actuarial data in deciding whether a shorter period is appropriate for a specific cancer type. Even with shorter terms, striking a balance between ensuring access to insurance and enabling insurers to conduct thorough risk assessments is paramount.[351] When determining a period shorter than ten years, potential complications arising from treatment during the abbreviated term may impact the life expectancy of former cancer patients, influencing the prudential assessment of the risk. Designated shorter deadlines by representative organizations will be compiled into a list, which must be publicly disclosed and effectively communicated to prospective insured individuals.

The limit for the life insurance is set at € 294,803 and is adjusted every three years by ministerial regulation to the consumer price index.[352] The Explanatory note of the Decree specifies that if an insurer asks questions regarding a person’s cancer history, according to Article 11 of the Wmk the examiner has the right to refuse to cooperate.[353] This means that a cancer survivor has the right to not disclose any related medical information if asked when applying to a life insurance company or

---

[351] Financiën (n 342).

[352] Ministerie van Binnenlandse Zaken en Koninkrijksrelaties, ‘*Wet op de medische keuringen*’, <https://wetten.overheid.nl/BWBR0008819/2023-01-01> accessed 31 May 2023, Art. 5(2).

[353] Besluit van 2 november 2020, Staatsblad van het Koninkrijk der Nederlanden (n 164), Explanatory note 9.3.

funeral insurance company. Moreover, the applicant can submit any disputes about this to the Financial Services Complaints Institute.[354]

In the event that the insurance company possesses prior knowledge of its client's history of cancer treatment, it is prohibited from incorporating this information into its determination concerning a new insurance policy application or modifications to an existing insurance policy. Additionally, such data may not be utilized in the calculation of premium rates.[355]

An additional exception pertains to the application of abbreviated timeframes after which an applicant cannot be inquired about their history of a specific cancer type. This exception applies to forms of cancer for which, in accordance with widely accepted medical insights, actuarial, and statistical data, the probability of recurrence after a brief period is sufficiently negligible that the insurer's prudential interest no longer justifies inquiring about that specific form of cancer. Agreements have been established between representative organizations of patients and insurers to delineate the applicable time limits in relation to said form of cancer.[356]

Notably, within the explanatory note, the Decree recognizes the challenges faced by cancer survivors who are compelled to recurrently disclose their historical medical records related to cancer. It underscores the adversities encountered in securing insurance, often accompanied by exorbitant premiums. The Decree underscores the potential impediment to the prospects of cancer survivors seeking to rebuild their lives post overcoming a severe illness. It emphasizes the undesired re-engagement with their past illness when seeking insurance, contrary to their aspirations to move beyond such medical history. The Decree conducts a comprehensive analysis of the conflicting interests between insurance entities and cancer survivors, particularly in light of the discriminatory implications that such practices may impose. It acknowledges the legitimate necessity for insurance companies to pose medical queries to comprehensively evaluate applicants and tailor suitable policies accordingly. These inquiries, however, may delve into

---

[354] ibid.
[355] ‘OVERVIEW OF LEGISLATION AT THE NATIONAL LEVEL’, Netherlands (n 326).
[356] ibid.

sensitive or confrontational aspects for the prospective insured individual, thereby impacting their personal privacy. In principle, this pertains to inquiries about a person's current or past history of cancer. Conversely, the Decree contends that there exists a point at which the continued inclusion of the risk of cancer recurrence in the risk assessment is no longer justifiable. Once an individual, previously afflicted by cancer, has remained cancer-free for an extended period and the statistical likelihood of cancer recurrence is exceedingly minimal, the interests of the former cancer patient should prevail over the insurer's interest in soliciting queries pertaining to their historical illness as a former cancer patient. This perspective is grounded not only in the individual interests of former cancer patients but also recognizes the broader societal significance of ensuring equitable access to insurance.[357] Such consideration also reflects the mentioned ECtHR decisions, such as Google v. Spain, in determining the lack of public interest and the right to erase personal information.

The legislation, rooted in the Medical Examinations Act (Wmk), emphasizes the protection of individuals' privacy, particularly those with a history of cancer. The prohibition on intrusive inquiries aligns with Article 3, first paragraph, of the Wmk, preventing disproportionate infringements on personal privacy. The Decree provides clear and specific guidelines, outlining the timeframes after which inquiries about past cancer history are deemed unwarranted. This clarity enhances legal certainty for both insurers and former cancer patients. The incorporation of provisions from the GDPR Implementation Act (UAVG) ensures alignment with broader data protection regulations, reinforcing the legal foundation of the legislation. Article 11 of the Wmk grants former cancer patients the right to refuse cooperation in case of unwarranted inquiries. The option to escalate disputes to the Financial Services Complaints Institute adds a layer of accountability.

The legislation recognizes and addresses the challenges faced by cancer survivors, including the potential discrimination they may encounter when seeking insurance. This acknowledgment reflects a commitment to social responsibility. The

---

[357] Financiën (n 342).

legislation strikes a balance between the interests of insurers in assessing risks and the rights of former cancer patients to move beyond their medical history. This is crucial for ensuring fair and equitable access to insurance.

The interaction between multiple legal acts, such as the Wmk and UAVG, might pose challenges in interpretation and implementation, potentially leading to legal complexities. While the legislation emphasizes the importance of clear communication by insurers regarding the inapplicability of cancer history questions, the effectiveness of this communication depends on insurers' compliance.

Consideration could be given to simplifying the legal framework to enhance accessibility and understanding for both insurers and former cancer patients. Implementing mechanisms for ongoing oversight and periodic review of the legislation's effectiveness could ensure continued protection of privacy rights. Initiatives to raise public awareness about the legislation, its implications, and the rights of former cancer patients could enhance its impact. Periodic reviews could include comparisons with international standards and practices to identify opportunities for improvement and alignment with global privacy protection norms. Actively involving patient representatives in the ongoing development and review of the legislation ensures that the interests of former cancer patients are adequately represented.

In summary, the Netherlands Decree demonstrates a commitment to balancing the interests of insurers and the privacy rights of former cancer patients. While it has clear strengths, there is room for simplification, enhanced oversight, and improved public awareness to maximize its effectiveness. Periodic reviews and international benchmarking can contribute to continuous refinement in line with evolving legal and ethical standards.

4.2.3 Portugal's legislation

Over 17 years ago, the Portuguese Parliament unanimously passed legislation resulting from initiatives by multiple political parties, including Centro Democrático Social (CDS), Partido Socialista (PS), Partido Ecologista (PEV), Bloco de Esquerda (BE), and Partido Comunista Português (PCP).[358] This legislation, officially known as Law 46/2006 of 28 August, was designed to prohibit and penalize discrimination based on disability and the presence of an exacerbated health risk.[359] Recognizing various forms of discriminatory practices, Article 4(c) of the aforementioned law specifically acknowledged instances such as "the denial or imposition of conditions related to the sale, rental, or subleasing of real estate, as well as access to bank credit for housing acquisition, and the rejection or penalization in the execution of insurance contracts."

Article 13 of the Constitution of the Portuguese Republic recognises that "all citizens have the same social dignity and are equal before the law".[360] However, this constitutional precept is, however, constructed daily by the laws, institutions and practices we adopt or fail to adopt, and serious and unfair discrimination still persists for various groups in our population.

Among these groups are people with an aggravated health risk and also those who, having overcome their illness, are affected by certain discriminatory contractual practices. These practices are particularly evident in access to credit, especially mortgages, and insurance contracts, with significant implications for personal development and the realisation of rights such as the right to housing for these citizens.

---

[358] Projeto de Lei n.º 691/XIV/2.ª Reforça a proteção da pessoa segurada, proibindo práticas discriminatórias, melhorando o acesso ao crédito e contratos de seguros por pessoas que tenham superado riscos agravados de saúde, consagrando o "direito ao esquecimento" 2021.

[359] 'DetalheIniciativa' <http://www.parlamento.pt:80/ActividadeParlamentar/Paginas/DetalheIniciativa.aspx?BID=110342> accessed 17 February 2024.

[360] 'Constituição da República Portuguesa' <http://www.parlamento.pt:80/Legislacao/Paginas/ConstituicaoRepublicaPortuguesa.aspx> accessed 22 January 2024.

Portuguese legislators take France's pioneering provisions as a leading example. They draw inspiration from the reference grid adopted by France and acknowledge the broadening spectrum of pathologies whose therapy is proven to significantly and durably limit their effects. The Portuguese law proposition considers the initial France prohibition to collect information about the medical condition that caused the aggravated health risk from the 10th year after completing the therapeutic protocols for that pathology or, in the case of young people, from the 5th year, and the age limit for the right to be forgotten for paediatric cancer was extended from 18 to 21 years by Law 2019-180.

With the Law 691/XIV/2.ª, the Parliamentary Group of the Socialist Party intends to establish in Portugal the right to be forgotten by people who have overcome situations of aggravated health risk in accessing credit and insurance contracts. Replicating the French model, they propose not only a mandatory and general rule on the right to be forgotten, but also the development of rules to facilitate access to credit for these citizens through an agreement with the financial and insurance sector or, in the absence of an agreement, by decree-law, always with the opinion of the National Data Protection Commission.[361]

On 11 November 2021 the Portuguese Parliament passed the Lei 75/2021 "*Reinforces access to credit and insurance contracts for people who have overcome or mitigated situations of aggravated health risk or disability, prohibiting discriminatory practices and enshrining the right to be forgotten, amending Law 46/2006 of 28 August and the legal framework for insurance contracts*".[362] Article 1 expands the scope of application of the right to be forgotten to those "*people who have overcome or mitigated situations of aggravated health or disability risk, improving their access to credit and insurance contracts*".[363]

---

[361] 'OVERVIEW OF LEGISLATION AT THE NATIONAL LEVEL' (n 327).

[362] 'Diploma Aprovado' <http://www.parlamento.pt:80/ActividadeParlamentar/Paginas/DetalheDiplomaAprovado.aspx?BID=23295> accessed 21 January 2024.

[363] Diário da República, 'Lei n.º 75/2021' (*Diário da República*) <https://diariodarepublica.pt/dr/detalhe/lei/75-2021-174480833> accessed 22 January 2024.

Paragraph c) of article 3 of Law no. 46/2006 defines "people with an aggravated health risk" as those people suffering from any pathology that determines an irreversible, long-term, evolving, potentially disabling organic or functional alteration, with no prospect of complete remission and which alters the sufferer's quality of life on a physical, mental, emotional, social and economic level and is a potential cause of early invalidity or a significant reduction in life expectancy.[364] Accordingly, Article 2 of Law no. 75/2021 defines the application of Article 1 to those who have overcome a situation of aggravated health risk, thanks to a therapeutical protocol that has proven to be able to significantly and lastingly limiting its effects.[365] It defines those who have overcome a situation of disability, which are protected when "*proven to have been in a situation of disability equal to or greater than 60% and who have recovered their psychological, intellectual, physiological or anatomical structures or functions, reducing their disability below that threshold*". The law also applies to those people who have mitigated situations of aggravated health or disability risk, and therefore "*people who are undergoing treatments proven to be capable of significantly and lastingly limiting the effects of their situation of aggravated health or disability risk*". Furthermore, within the purview of the legal framework, the term "consumers" encompasses individuals involved in credit agreements pertaining to residential properties and credit arrangements, aligning with the directives outlined in 2014/17/EU and 2008/48/EC.[366]

The ambit of application and the definitions articulated in the initial two articles of the legislation endorsed by the Portuguese Parliament exemplify the expansive reach of the right to be forgotten. This extends beyond the realm of cancer survivors or individuals with non-communicable diseases, encompassing all instances of exacerbated health conditions that might face discriminatory practices in the context of credit access or insurance. This legislative approach signifies a progressive stride towards inclusivity, non-discrimination, and equality, presenting

---

[364] 'Lei n.º 46/2006 | DR' <https://diariodarepublica.pt/dr/detalhe/lei/46-2006-540797> accessed 22 January 2024.

[365] República (n 352), Art. 2.

[366] ibid.

an innovative paradigm not hitherto explored by scrutinized jurisdictions. This perspective facilitates the non-disclosure of additional health conditions or disabilities upon meeting specified criteria, provided such conditions do not impede work progression or hinder access to credit and insurance.

Article 3 enshrines the Right to be Forgotten for individuals who have surmounted or alleviated situations involving heightened health risk or disability, as consumers, in the context of procuring housing credit and consumer credit, as well as when entering into mandatory or elective insurance contracts linked to said credit. The statute safeguards this demographic from encountering augmented insurance premiums and/or the exclusion of guarantees within insurance contracts. Importantly, credit institutions or insurers are barred from collecting or processing any health information pertaining to the medical condition giving rise to the exacerbated health risk or disability in a pre-contractual setting.[367]

The Law provides for uninterrupted periods, after which no health information relating to a situation of aggravated health risk or disability may be collected by credit institutions or insurers in a pre-contractual context:

i. 10 years since the end of the therapeutic protocol, in the case of aggravated health risk or disability overcome;

ii. Five years since the end of the therapeutic protocol, if the pathology overcome occurred before the age of 21;

iii. Two years since the commencement of a continued and effective therapeutic protocol, in the case of aggravated health risk or mitigated disability.[368]

Additional specifics regarding the legal provision require elucidation, particularly concerning the reference table. An agreement shall outline the protocol for formulating the grid, specifying the terms and deadlines corresponding to each pathology or disability, in accordance with advancements in therapeutics, scientific data, and an understanding of the health, credit, or insurance risk associated with

---

[367] ibid., Art.3.
[368] ibid.

each condition. The reference table is subject to biennial updates and must be made accessible to the public.[369]

The inclusion of the right to be forgotten is a pivotal strength, safeguarding individuals from intrusive inquiries into their health history after a specified period, promoting their privacy rights. The legislation aligns with constitutional principles, recognizing the equal social dignity of all citizens and working towards eliminating unfair discrimination, especially for those with health-related challenges. In conclusion, the Portuguese legislative framework, particularly Law 75/2021, marks a progressive and innovative step in the realm of combating discrimination based on health conditions and disabilities. While celebrating its strengths, such as constitutional alignment, inspiration from successful models, and an expansive reach, there is a need for ongoing vigilance. Clarifications are necessary to address emerging challenges and ensure the law's effective and equitable implementation. The Portuguese approach, inspired by the French model, establishes a positive precedent and encourages ongoing scrutiny, refinement, and potential emulation by other jurisdictions facing similar challanges.

4.2.4 Spanish legislation

On June 28, 2023, following a Council of Ministers session on June 27, Spain enacted the right to be forgotten through Royal Decree-Law 5/2023.[370]

---

[369] 'OVERVIEW OF LEGISLATION AT THE NATIONAL LEVEL' (n 327).

[370] 'BOE-A-2023-15135 Real Decreto-Ley 5/2023, de 28 de Junio, *Por El Que Se Adoptan y Prorrogan Determinadas Medidas de Respuesta a Las Consecuencias Económicas y Sociales de La Guerra de Ucrania, de Apoyo a La Reconstrucción de La Isla de La Palma y a Otras Situaciones de Vulnerabilidad; de Transposición de Directivas de La Unión Europea En Materia de Modificaciones Estructurales de Sociedades Mercantiles y Conciliación de La Vida Familiar y La Vida Profesional de Los Progenitores y Los Cuidadores; y de Ejecución y Cumplimiento Del Derecho de La Unión Europea.*' <https://www.boe.es/buscar/act.php?id=BOE-A-2023-15135&p=20231228&tn=1> accessed 10 January 2024.

Chapter II introduces measures to enforce the right to be forgotten in the acquisition of insurance and banking products for individuals with oncological pathologies. This enforcement applies once a specified period has elapsed since the completion of treatment without relapse. Pursuant to this objective, it is decreed that clauses excluding a party based on a history of cancer are null and void. Furthermore, discrimination in insurance procurement for individuals who have experienced an oncological pathology is prohibited once five years have passed since the completion of radical treatment without subsequent relapse.[371]

Furthermore, for life insurance applications, there is no obligation to disclose a history of cancer after the aforementioned period has elapsed. Additionally, such oncological history cannot be considered for these purposes.[372] This aligns with the European Parliament Resolution of February 16, 2022, on strengthening Europe in the fight against cancer.

The urgency for provisions related to the right to be forgotten in oncological contexts stems from the Non-Law Proposition approved by the Health and Consumer Commission of the Congress of Deputies on March 29. This proposition urges the Government to promptly implement regulatory measures in compliance with the European Parliament Resolution of February 16, 2022. This resolutions mandates member states to legislatively establish the right to oncological oblivion within a maximum of ten years after overcoming cancer and, for individuals who overcame it as minors, five years of attaining majority.

The reform of the consolidated text of the General Law for the Defense of Consumers and Users, as approved by Royal Legislative Decree 1/2007 on November 16, and Law 50/1980 on October 8, concerning Insurance Contracts, is the only viable measure to adhere to the directives of the Congress of Deputies and meet the expectations of the European Parliament.[373] The proposed regulatory modifications are urgently needed to address the situation, requiring immediate

---

[371] ibid.

[372] ibid.

[373] Real Decreto Legislativo 1/2007, de 16 de noviembre, *por el que se aprueba el texto refundido de la Ley General para la Defensa de los Consumidores y Usuarios y otras leyes complementarias*, BOE-A-2007-20555.

regulatory action within a shorter timeframe than that stipulated by ordinary legislative processes or emergency parliamentary procedures for law processing.

In the Spanish context, the Right to be Forgotten is introduced through Article 209 of the Decree, which amends Article 10 of Law 50/1980, dated October 8, concerning Insurance Contracts.[374] This provision constitutes the Fifth Additional Provision, which specifically addresses the prohibition of discrimination based on HIV/AIDS, cancer, or other health conditions. Article 209 establishes that "*policyholder of life insurance is not obliged to declare whether he or the insured has suffered from cancer once five years have passed since the completion of the radical treatment without subsequent relapse. Once the stated period has elapsed, the insurer may not consider the existence of an oncological history for the purposes of contracting the insurance, and any discrimination or restriction on contracting for this reason is prohibited.*"[375]

This law, known as the Fifth Additional Provision, addresses non-discrimination based on HIV/AIDS, a history of cancer, or other health conditions. The provision outlines three key points.

The first paragraph establishes a fundamental prohibition against discrimination targeting individuals with HIV/AIDS or other health conditions. It explicitly delineates prohibited actions, such as denial of access to contracting, deviation from standard contracting procedures, or imposition of more stringent conditions. Notably, any such discriminatory actions are only permissible if objectively documented and grounded in justified, proportionate, and reasonable causes. This requirement emphasizes the necessity for legal and factual justification, ensuring fairness and preventing arbitrary discrimination.[376]

The second paragraph reinforces the non-discrimination principle, extending protection to individuals who have suffered from an oncological pathology. The provision expressly forbids denial of access to contracting, deviation from standard contracting procedures, imposition of more burdensome conditions, or any other

---

[374] Ley 50/1980, de 8 de octubre, de Contrato de Seguro.

[375] 'BOE-A-2023-15135 Real Decreto-Ley 5/2023, de 28 de Junio,' (n 370)., Art. 209.

[376] ibid., Art. 209, Fifth provision.

form of discrimination against such individuals. The critical aspect here is the establishment of a five-year timeframe since the completion of radical treatment without subsequent relapse, signalling a balance between the protection of individuals with a history of oncological pathologies and the insurer's legitimate concerns.[377]

The third paragraph grants the Government authority, through a royal decree, to modify the timelines outlined in the preceding section and in the final paragraph of Article 10. This provision acknowledges the dynamic nature of scientific evidence and allows for adjustments to be made based on evolving knowledge. The use of a royal decree underscores the significance of this decision-making power and provides a mechanism for adapting the legal framework in response to advancements in medical understanding and treatment protocols for specific oncological pathologies.[378]

On the other hand, Article 210, modifies the consolidated text of the General Law for the Defence of Consumers and Users and other complementary laws, approved by Royal Legislative Decree 1/2007, of November 16.

The single additional provision of the consolidated text in its first paragraph, establishes the nullity of clauses, stipulations, conditions, or agreements that result in the exclusion of a party due to HIV/AIDS or other health conditions. The provision reflects a clear legislative intent to prohibit discriminatory practices in contractual relationships based on health status. The inclusion of the term "void" underscores the absolute nature of this prohibition, and any attempt to waive these protections by the party with HIV/AIDS or other health conditions is also expressly declared void. This underscores the legislature's commitment to preventing any compromise of the rights enshrined in this provision.[379]

The second paragraph extends the prohibition of exclusionary clauses to individuals with a history of cancer. The specified nullification comes into effect five years after the completion of radical treatment without subsequent relapse. Additionally,

---

[377] ibid.

[378] ibid.

[379] ibid., Art. 210.

the paragraph imposes a prohibition on soliciting oncological information from consumers when entering into a consumer contract, reinforcing the protection of individuals with a cancer history against unwarranted scrutiny. The voidance of waivers in these situations further emphasizes the importance of upholding these protective measures.[380]

The third paragraph confers authority upon the Government to modify the established timelines within the provision through a royal decree. This provision recognizes the dynamic nature of scientific evidence and medical understanding, allowing for timely adjustments to be made. The inclusion of "oncological pathologies" acknowledges the diverse nature of cancer and permits tailored responses to emerging scientific insights. This provision ensures that the legal framework remains adaptable and responsive to evolving medical knowledge, underscoring the legislature's commitment to staying aligned with advancements in the field of oncology.[381]

Both additional provisions share a common objective of prohibiting discrimination. They explicitly address non-discrimination based on specific health conditions, such as HIV/AIDS, other health conditions, and a history of cancer. However, Article 210 uses the term "other health conditions" without specific enumeration.

In both additional provisions, the government is granted authority through a royal decree to modify certain aspects of the regulations. This reflects a recognition of the need for adaptability based on evolving scientific evidence.

Both provisions explicitly declare the voidance of any waivers attempted by the party affected by the health conditions. This emphasizes the non-negotiable nature of the protections afforded by these provisions.

Article 210 explicitly addresses consumer contracts, irrespective of the sector. It includes a prohibition on soliciting oncological information from consumers and the nullification of clauses related to cancer history in such contracts. The Fifth additional provision does not explicitly mention consumer contracts.

---

[380] ibid.
[381] ibid.

The legal basis for the two laws is different. The Fifth additional provision is a standalone provision, whereas Article 210 modifies the Consolidated Text of the General Law for the Defense of Consumers and Users and other complementary laws.

The legislation establishes a robust non-discrimination principle, explicitly prohibiting discrimination based on health conditions such as HIV/AIDS, cancer, and other health conditions. This comprehensive approach ensures a broad protection against arbitrary discrimination.

The legislation prioritizes privacy protection for individuals with a history of cancer, particularly in the context of insurance applications. The right to be forgotten is recognized, allowing individuals to withhold disclosure of a cancer history after a specified period, enhancing personal privacy.

The legislation aligns with the European Parliament Resolution of February 16, 2022, showcasing Spain's commitment to harmonizing its legal framework with broader European directives related to the fight against cancer and the right to be forgotten. This alignment enhances consistency and cooperation at the international level. The legislation demonstrates a capacity for urgent and responsive legislative action. The use of a Royal Decree-Law and emergency procedures highlights the legislature's agility in addressing pressing issues, especially those related to public health and consumer rights. Granting the Government authority, through a royal decree, to modify timelines based on evolving scientific evidence reflects a forward-looking approach. This provision ensures that the legal framework remains adaptable to emerging knowledge in the field of oncology.

The legislation uses the term "other health conditions" without specific enumeration, potentially leading to ambiguity. A more precise definition of covered health conditions could enhance clarity and ensure that the legislation addresses a comprehensive range of health-related issues. The provision granting the Government authority to modify timelines through a royal decree may introduce a degree of regulatory uncertainty. The absence of specific criteria for such modifications may lead to ambiguity regarding the circumstances under which adjustments will be made, potentially causing confusion among stakeholders. While the Royal Decree-Law addresses the procurement of insurance and banking products, it does not explicitly mention other consumer sectors. Expanding the scope to include all consumer sectors could ensure consistent protection across various industries. The legislation lacks explicit details on enforcement mechanisms and penalties for non-compliance. Clear provisions outlining the consequences for discriminatory practices could enhance the effectiveness of the legislation and serve as a deterrent.

In conclusion, the Spanish legislation exhibits a proactive and rights-oriented approach, addressing discrimination based on health conditions while safeguarding individual privacy. The legislative reforms align with European directives, respond to urgent matters through emergency legislative procedures, and provide a framework adaptable to evolving scientific insights. The nuanced balance between individual rights and societal considerations reflects a commitment to a fair and responsive legal framework. While the analysed legislation demonstrates notable strengths in its non-discrimination principles, privacy protection, and alignment with European directives, there are areas for improvement, expanding the scope, addressing potential regulatory uncertainty, and enhancing enforcement mechanisms.

4.2.5 Italian legislation

The Right To Be Forgotten, *diritto all'oblio oncologico*, was unanimously approved in the Italian Senate on the 5th of December 2023, following approval by the Chamber of Deputies at the beginning of August. The legislative intent is aimed at safeguarding the dignity and entitlements of individuals who have undergone cancer treatment, successfully conquered the ailment, and aims to prevent instances of discrimination and inequitable treatment, particularly in the context of access to financial and insurance services.[382]

To preclude any manifestation of bias or disparate treatment, this legislation establishes provisions concerning equal treatment, non-discrimination, and the assurance of the right to be forgotten for individuals who have been cured of cancer ailments. This legal framework serves as a testament to a significant milestone, underscoring the contemporary era where individuals afflicted by cancer should not be marginalized within society or their respective communities.

The recent enactment, titled 'Legal Provisions Ensuring Equal Treatment, Non-Discrimination, and the Right to be Forgotten for Individuals Recovered from Oncological Pathologies,' emerged from the amalgamation of various propositions deliberated upon extensively over several months.[383] The esteemed Maria Elena Boschi and Patrizia Marrocco were the inaugural signatories. Commemorating the balloting outcome within Palazzo Madama are individuals who diligently contributed to aligning Italian legislation with the guidelines of the European Plan Against Cancer and the expectations of numerous former patients.[384]

A "law of civilization" extends its purview to encompass medical oncologists as well. Francesco Perrone, the President of AIOM (Italian Medical Oncology Association), highlighted the progressive facets of legislation that transcend the confines of financial institutions, extending its influence into offices, factories, and various workplaces. Perrone explained that the law's protective ambit extends beyond interactions with banks and insurance entities, encompassing realms such as competitive scenarios where physical fitness is a requisite, as well as adoption proceedings. This underscores the legislation's advanced nature, surpassing

---

[382] 'Il diritto all'oblio oncologico è legge' (*Fondazione Umberto Veronesi*) <https://www.fondazioneveronesi.it/magazine/articoli/oncologia/il-diritto-alloblio-oncologico-e-legge> accessed 28 January 2024.

[383] ibid.

[384] 'Il diritto all'oblio oncologico è legge' (*Fondazione Umberto Veronesi*) <https://www.fondazioneveronesi.it/magazine/articoli/oncologia/il-diritto-alloblio-oncologico-e-legge> accessed 3 January 2024.

comparable laws enacted in other jurisdictions that have addressed this subject matter.[385]

Article 1 outlines the object, purpose and definition of this law, which aims to exclude any form of prejudice or unequal treatment of individuals cured of oncological pathologies. Its purpose is to guarantee equal treatment, prevent discrimination, and ensure the right to oblivion for those who have overcome such pathologies. This legislative intervention is grounded in constitutional principles, EU regulations and international provisions.[386]

Article 1 refers to Articles 2, 3 and 32 of the Italian Constitution.[387] Article 2 guarantees inviolable human rights, while Article 3 ensures equality before the law without distinction.[388] Article 32 emphasises the protection of health as a fundamental right and interest of the community.[389] The law also aligns with Articles 7, 8, 21, 35 and 38 of the Charter of Fundamental Rights of the European Union, which establishes fundamental principles and rights of Union citizens. Additionally, Article 8 of the Convention for the Protection of Human Rights and Fundamental Freedoms is referenced, highlighting its connection with international regulations.[390] The law refers to this convention, signed in 1950 and enforced in Italy in 1955. The second paragraph of the law introduces the clear definition of the 'oncological right to be forgotten'. This right empowers individuals cured of oncological diseases not to provide information or be investigated about their previous medical condition, as specified by law. This provision aims to protect the privacy and dignity of those who have overcome an oncological disease.

Article 1 of this Act reflects a significant legislative commitment to promoting equality, non-discrimination, and the right to be forgotten for individuals healed from oncological conditions. Its constitutional basis, alignment with EU legislation,

---

[385] ibid.

[386] ‘LEGGE 7 Dicembre 2023, n. 193 - Normattiva’ <https://www.normattiva.it/uri-res/N2Ls?urn:nir:stato:legge:2023;193.> accessed 31 January 2024.

[387] ‘Gazzetta Ufficiale’ <https://www.gazzettaufficiale.it/eli/id/2023/12/18/23G00206/sg> accessed 17 February 2024.

[388] Costituzione della Repubblica Italiana, n. 298, entrata in vigore il 1 gennaio 1948. 1947.

[389] ibid.

[390] European Union, Charter of Fundamental Rights of the European Union, 26 October 2012, 2012/C 326/02.

and reference to international principles highlight its broad scope and commitment to human rights. The clear definition of the 'oncological right to be forgotten' provides operational guidance for its implementation, emphasising the protection of privacy and dignity of the individuals concerned.[391]

Article 2 regulates access to banking, financial, investment, and insurance services. The first paragraph prohibits the request for information on the state of health related to oncological pathologies dating back more than ten years from the date of the request, reduced by half if the pathology arose before the age of 21, during the conclusion or renewal of contracts in these sectors.[392] This period ensures the right to oncological oblivion and prohibits the acquisition of such information from sources other than the contractor. Additionally, it prevents the use of this information to determine contractual conditions. The legislator's decision to include cases of contractual stipulations between private parties allows for an extensive application of the subsection in various cases, such as the rental of real estate. The second paragraph requires banks, credit institutions, insurance companies, and financial and insurance intermediaries to provide appropriate information on the law and the right to be forgotten during all stages of accessing services, including pre-contractual negotiations. This information must be expressly mentioned in the forms or documents prepared and used for the purpose of concluding or renewing the aforementioned contracts.

Paragraph 3 stipulates that no limits, additional costs, charges, or different treatment of the contractor compared to the general contractor under existing legislation shall be applied to the contractor. This provision impedes insurance companies or financial providers to impose additional premiums due to the disclosure of past health history.[393]

---

[391] LEGGE 7 dicembre 2023, n. 193. '*Disposizioni per la prevenzione delle discriminazioni e la tutela dei diritti delle persone che sono state affette da malattie oncologiche*', (23G00206), entrata in vigore del provvedimento: 02/01/2024.

[392] ibid.

[393] ibid.

Paragraph 4 explicitly prohibits financial institutions from requiring medical examinations or health assessments for the conclusion of contracts relating to oncological conditions.[394]

Paragraph 5 stipulates that previously provided health information, because it is not covered and thus protected by the regulation, may not be used for risk or solvency assessment after the specified period of ten or five years, as applicable. Additionally, the contractor must submit a certification within a specified period, and the information must be deleted within 30 days of receipt.[395]

Paragraph 6 states that the violation of the preceding provisions renders in the nullity of the contractual clauses deviating from the expressed principles null but does not invalidate the entire contract. Nullity is detectable *ex officio* and benefits the contractor.[396]

Paragraph 7 requires the Interministerial Committee for Credit and Savings and the Insurance Supervision Institute to establish implementation modalities for paragraph 1 within six months of the law's entry into force, after consulting the "*Garante*" for the protection of personal data. This may include the preparation of forms and templates.[397]

Article 2 aims to protect the privacy and rights of individuals recovering from oncological diseases during financial and insurance transactions. This approach ensures equal treatment by restricting the request and use of health information, promoting the right to be forgotten regarding oncology, and establishing sanctions for violations. Consultation with the Data Protection Supervisor and the establishment of implementing regulations demonstrate a commitment to effective enforcement.[398]

Article 3 is innovative in sense that it provides for the application of the right to be forgotten in adoption matters.[399]

---

[394] ibid.
[395] ibid.
[396] ibid.
[397] ibid.
[398] ibid., Art. 2.
[399] ibid.

Letter a) of the first paragraph amends Law no. 184/1983[400] regarding adoption, specifically Articles 22, 29-bis, and 57. Article 22, paragraph 4, allows the Court to conduct investigations into the ability of applicants to care for a minor, their personal and economic situation, the health, the family environment, and reasons for wishing to adopt the minor.[401] A new provision is introduced in Article 22, Paragraph 4, establishing that investigations into the health of applicants cannot include information on previous oncological pathologies if more than ten years have passed since the conclusion of active treatment without relapses, or more than five years if the pathology arose before the age of twenty-one years.[402] This amendment aims to protect privacy and the right to oncological oblivion during adoption procedures.

Furthermore, in the first Paragraph, letter b) introduces a provision to Article 29-bis, Paragraph 4 c), mandating compliance with the regulation outlined in Article 22, Paragraph 4, second sentence, regarding international adoption.[403] This means that the health status of applicants, especially concerning oncological pathologies, cannot be considered during international adoption proceedings.

Subsequently, in Paragraph one, letter c), a reference to Article 22, Paragraph 4, second sentence, is added to Article 57, third Paragraph, letter a). This ensures that health assessments adhere to the updated provisions of Article 22, Paragraph 4, thereby maintaining consistency in the evaluation of the adoption circumstances throughout the process.

The second Paragraph authorizes the Minister of Health, in consultation with the Minister of Justice and after consulting the Commission for International Adoptions, to establish the implementation methods for the provisions introduced in the first Paragraph. This may include defining practical procedures, assessment protocols, and standards to be followed when applying the new provisions.[404]

---

[400] LEGGE 4 maggio 1983, n. 184, '*Diritto del minore ad una famiglia*'.

[401] LEGGE 7 dicembre 2023, n. 193. '*Disposizioni per la prevenzione delle discriminazioni e la tutela dei diritti delle persone che sono state affette da malattie oncologiche*', (23G00206), entrata in vigore del provvedimento: 02/01/2024, Art. 3.

[402] ibid.

[403] ibid.

[404] ibid.

The accompanying notes provide the complete text of Articles 22, 29-bis, and 57 of Law no. 184/1983 and emphasise the significance of Article 22, Paragraph 4, second sentence, regarding health assessments of applicants. These provisions clearly delineate the guidelines for managing applicant health information, particularly regarding oncological pathologies and the right to be forgotten after a specified period. Effective communication and coordination among juvenile courts, social welfare services, and the Commission for International Adoptions are underscored as essential for the proper conduct of adoption procedures.

Article 4 addresses "Access to competitive and selective procedures, employment and vocational training".[405] Paragraph 1 establishes that candidates participating in competitive and selective procedures, whether public or private, cannot be subjected to psycho-physical or health inspections. Specifically, it is prohibited to solicit information regarding candidates' health status related to oncological pathologies that have been resolved for more than ten years without recurrence. The prohibition period is halved if the disease occurred before the age of 21. These provisions aim to prevent discrimination against candidates based on past oncological pathologies, fostering equal opportunities in both public and private selection processes.

Paragraph 2 states that within six months of the law's enactment, a decree from the Minister of Labour and Social Policies, in coordination with the Minister of Health, may initiate active policies to promote equal employment opportunities for individuals affected by oncological pathologies. These policies may involve cancer patient organizations registered in the Single National Register of the Third Sector in their development.[406] The aim is to ensure employment integration, stability, and advancement, including career and enhancements, within the limits of existing legislation and resources.

The notes provide the complete text of Article 41 of Legislative Decree 117/2017[407], known as the Third Sector Code. This article delineates associative networks within

---

[405] ibid., Art. 4.
[406] ibid.
[407] DECRETO LEGISLATIVO 3 luglio 2017, n. 117, *Codice del Terzo settore.*

the Third Sector, outlining their establishment, operations, and functions. Associative networks coordinate, protect, represent, and promote associated entities within the Third Sector. The article also outlines criteria for registration in the Single National Register of the Third Sector and the conditions for accessing the Fund's resources. Overall, the legislation aims to ensure transparency, representativeness, and integrity within the Third Sector entities.

Article 4 serves as a cornerstone in protecting individual rights and fostering a more equitable professional environment. By addressing discrimination, especially concerning health challenges like oncological pathologies, it aligns with broader societal aspirations for fairness and equal opportunities.

Meanwhile, article 5 introduces transitional and final provisions, offering detailed instructions for the Law's implementation. Notably, the second paragraph requires the Minister of Health to define, within three months of the law's enactment, a list of oncological pathologies warranting shorter deadlines than those established in other Articles of the Law. [408] Until this decree is issued, the timelines outlined in the law will remain in effect, providing initial flexibility to address specific diseases more efficiently.

The third paragraph underscores the retroactive nature of the provision, mandating compliance with its principles for banking, financial, and insurance contracts established into after its enactment. This includes ongoing proceedings and open competitions, with any conflicting contractual clauses or administrative acts deemed null and void, benefiting the contracting individual. This retroactivity ensures consistent application of the new regulations across all relevant transactions.

In the fourth paragraph, oversight of the Law's implementation falls under the purview of the "*Garante per la protezione dei dati personali*".[409] This underlines

---

[408] LEGGE 7 dicembre 2023, n. 193. '*Disposizioni per la prevenzione delle discriminazioni e la tutela dei diritti delle persone che sono state affette da malattie oncologiche*', (23G00206), entrata in vigore del provvedimento: 02/01/2024, Art. 5.

[409] ibid.

the significance of upholding privacy and data protection in line with the law’s provisions.

Paragraph five emphasizes fiscal responsibility, stipulating that no additional financial burdens on public resources should arise from the law's implementation. Administrations must adhere to the law's mandates within existing human, instrumental, and financial resources, ensuring its financial sustainability.

In conclusion, Article 5 5 serves as a comprehensive framework for the effective implementation of the law on the right to be forgotten, addressing procedural matters, retroactivity, and supervision.

The law comprehensively addresses various aspects, including equal treatment and non-discrimination, extending its protection to areas like employment and adoption. This ensures a broad and inclusive approach. Its foundation in constitutional principles, alignment with EU regulations, and adherence to international standards ensure a robust legal framework that upholds fundamental rights. Clear definitions, particularly regarding the right to be forgotten for cancer survivors, enhance the law's applicability and underscore its focus on privacy and dignity for individuals overcoming cancer. The involvement of medical oncologists and collaboration with relevant authorities, such as the Minister of Health and the Minister of Justice, ensures a holistic approach that considers diverse perspectives and societal impacts beyond financial and insurance sectors. Retroactivity provisions ensure that existing contracts and ongoing processes align with the newly established principles. This retroactive approach enhances consistency and prevents the perpetuation of discriminatory practices. Entrusting the "*Garante per la protezione dei dati personali*" with data protection supervision further reinforces the law's commitment to safeguarding privacy rights in line with its provisions.

While the law outlines comprehensive provisions, the practical implementation may pose challenges. Ensuring widespread awareness and understanding of the law among relevant stakeholders, including financial institutions, employers, and the public, will be crucial. The law relies on existing resources for implementation, which might limit the scope of its effectiveness. Adequate resources, both human and financial, are essential for enforcing the law successfully.

The analysed law on the Right To Be Forgotten for cancer survivors represents a significant advancement in protecting the rights and dignity of individuals who have overcome oncological pathologies. Its comprehensive coverage, alignment with constitutional and international standards, clear definitions, interdisciplinary approach, retroactive application, and supervision by data protection authorities are commendable aspects. However, challenges in implementation may arise, emphasizing the need for effective dissemination of information and resource allocation. The law's importance extends beyond individual rights, contributing to a more equitable and inclusive society by addressing discrimination in various sectors, from employment to financial services. Despite these challenges, the law's importance goes beyond individual rights. By addressing discrimination in various sectors, including employment and financial services, it contributes to a more equitable and inclusive society. Therefore, while acknowledging potential implementation challenges, the law represents a significant step forward in promoting justice and fairness for cancer survivors.

Conclusion

This thesis introduces novel perspectives supporting the implementation of the Right to Be Forgotten (RTBF) for cancer survivors. By examining various forms of discrimination and establishing their close alignment with principles and norms of international law, it uncovers fresh connections that fortify the protection of cancer survivors' rights. The analysis successfully demonstrates how the rights of cancer survivors find assurance in international Conventions, such as the Universal Declaration of Human Rights (UDHR) and the International Covenant on Civil and Political Rights (ICCPR). This protection extends firstly at a regional level through the Charter of Fundamental Rights of the European Union (CFEU) and then at the national level via legislations of the RTBF. Emphasizing the RTBF's intersection with consumer protection provides cancer survivors access to their right to privacy. Each chapter calls for a more defined placement of cancer survivors in the realm of international human rights, advocating for an internationally recognized definition and collaboration among international organizations to develop a cohesive legal framework.

Chapter 1 has explored the multifaceted nature of cancer and its profound impact on the lives of individuals diagnosed with the disease, both during and after treatment. The chapter has illuminated the legal recognition of cancer as a growing public health concern and the need for robust legal frameworks to support cancer survivors. It has discussed the current incidence of cancer globally, recognizing it as the second leading cause of mortality and delved into the criticality of international cooperation in establishing a global regime to combat cancer's far-reaching effects. Reflecting on the juridical context, it is apparent that international resolutions such as the UN General Assembly Resolution A/66/L.1 and the World Health Assembly Resolution WHA70.12 have made strides in acknowledging the necessity for comprehensive cancer care. These include the rehabilitation and quality of life improvements for cancer survivors as well as data collection to bolster scientific knowledge in the fight against cancer. However, the thesis has identified limitations within these frameworks, including a scarcity of attention to post-treatment life and a lack of clear definitions and considerations for "cancer survivor."

Recommendations moving forward include an urgent call for more detailed and specific legal recognition of the rights and status of cancer survivors. There must be a concerted effort to harmonize health systems, ensuring equitable access to care and adherence to the rights outlined in international, regional, and national legislation. The inclusion of cancer survivors and their families in policy discussions is crucial to tailor effective health interventions and legal protections. The Chapter also identifies the necessity for continual advancements in medical research, particularly in understanding the long-term effects of cancer treatment. This understanding is fundamental for the development of legal protections that are adaptive and responsive to the evolving needs of cancer survivors. The impact of cancer extends beyond the individual, affecting social, financial, and mental well-being. As such, the protection of cancer patients must be considered a lifelong commitment, beginning from diagnosis and extending through survivorship, hence when they can be considered survivors. Legal frameworks must recognize and adapt to this reality, ensuring the provision of rights and protections that encompass the entirety of a cancer patient's journey.

It is imperative that the international community unites in its efforts to not only fight cancer but also to advocate for the rights and well-being of those who live in the aftermath of the disease. The world must recognize that the battle against cancer does not end with remission. Survivorship carries its own set of challenges that require legal acknowledgment and protection. As we make strides in medical treatment and survivorship numbers grow, it is the legal and moral obligation of societies to evolve and provide a framework that supports survivors through the complex landscape of life post-cancer. The journey of a cancer survivor is one of resilience and courage, and it is our collective responsibility to ensure that their rights, dignity, and quality of life are upheld at every stage.

Chapter 2 delves deeply into the intricate challenges encountered by cancer survivors as they strive to reintegrate into society, particularly in crucial areas such as employment, family life, access to financial services, and participation in adoption procedures. Through a rigorous examination of legal safeguards, the chapter assesses the extent to which international, European, and national laws effectively uphold the rights of cancer survivors. The analysis uncovers a troubling disparity between the theoretical protections afforded by these legal frameworks and the practical hurdles faced by survivors in their everyday lives. Despite certain provisions offering partial protection, the chapter concludes that substantial gaps persist, leaving many cancer survivors vulnerable and underserved by existing legal mechanisms.

International instruments such as the International Covenant on Economic, Social and Cultural Rights (ICESCR) articulate the right to work. However, their implementation lacks specificity concerning cancer survivors. European law provides additional protections through instruments like the European Social Charter and the rulings of the European Court of Human Rights (ECtHR). These legal tools offer a broader interpretation of rights, like the right to private life, which can indirectly benefit cancer survivors seeking employment. At the national level, the situation is heterogeneous with variations in the acknowledgment of cancer survivors as a specific category needing protection. For instance, some national systems recognize them under the umbrella of disabled persons, depending on the treatment period and degree of impairment. Despite these recognitions, there is a lack of a unified international or European standard specifically addressing the rights of cancer survivors, resulting in inconsistent application and protection across jurisdictions. Policymakers and stakeholders must advocate for an international framework that comprehensively protects the rights of cancer survivors, ensuring their full reintegration into the job market and society at large. Reintegrating into society, particularly through employment, is paramount. Without a job, individuals cannot maintain a dignified life, which includes buying a house, supporting their family, and ensuring the best interests of a potential adopted child. Therefore, if these rights are not fully safeguarded, it creates a vicious cycle of disadvantage. This would involve a collective effort to recognize the unique circumstances of cancer survivors and proactively remove barriers in areas such as employment, financial services, insurance, and adoption.

The chapter has rigorously explored discriminative practices impacting cancer survivors' access to financial services such as bank loans, mortgages, and insurances. Despite frameworks advocating for non-discrimination and the right to an adequate standard of living, survivors consistently face undue hardships due to longstanding prejudices and a lack of harmonized, enforceable regulations specific to their circumstances. While the right to non-discrimination is recognized under instruments such as the Universal Declaration of Human Rights and the Charter of Fundamental Rights of the European Union, a substantial gap remains in practical protection for cancer survivors' rights. This gap is exacerbated by the financial sector’s reliance on outdated risk assessments, which fail to consider current medical advancements and the long-term prognosis of cancer survivors. The limitations of current legal frameworks are apparent in the insufficient integration of survivors' rights into the financial services industry. At the international level, the UN Guidelines for Consumer Protection provide a basis for consumer rights but lack enforceability. The European Union has made progress in recognizing the non-discrimination principle and the right to privacy through consumer protection policies. However, the absence of uniform criteria and the self-regulated nature of insurance companies call for a more robust legal framework to safeguard the rights of cancer survivors effectively. At the national level, various countries have enacted legislation such as the Right to Be Forgotten (RTBF) in Europe, offering some respite to cancer survivors. Nevertheless, such initiatives are not universally adopted and fail to comprehensively protect the rights of cancer survivors across all jurisdictions.

The analysis reveals a complex interplay of health, legal, and societal factors contributing to a significant burden for cancer survivors in adoption procedures. This thesis has demonstrated that while cancer survivors have, in principle, the same adoption rights as non-cancer individuals, they often face additional scrutiny and potential discrimination due to their medical history. This is particularly evident when considering the discretion granted to adoption agencies in assessing the health and suitability of prospective adoptive parents, lacking clear legal guidelines to protect the interests of cancer survivors. While international, European, and national legal frameworks provide some protections, they may not explicitly extend to cancer survivors. Human rights instruments such as the European Convention on Human Rights (ECHR) and the United Nations Convention on the Rights of Persons with Disabilities (CRPD) articulate broad non-discrimination principles, but the lack of explicit recognition of cancer survivors leaves room for inconsistent application. The non-binding nature of some documents and discretion at the national level result in non-uniform protection. Summarizing the conclusions obtained, cancer survivors encounter additional hurdles in adoption processes, not adequately addressed by current legal protections. The stigma surrounding cancer and fear of recurrence can influence the adoption agencies' decisions, leading to unfair treatment and infringement on the right to family. Additionally, the absence of a clear definition and understanding of cancer survivor further complicates the pursuit of equitable treatment. Reflecting on the juridical context, the hardship in adoption procedures faced by cancer survivors calls for a more nuanced and informed approach by legal systems. Adoption agencies need guidance on fairly assessing the eligibility of cancer survivors without prejudice. Robust application of the right to non-discrimination, privacy, and the right to found a family in international human rights law is necessary to prevent unfair disadvantages for cancer survivors.

Legal protections for cancer survivors are not comprehensive or consistently applied across different legal systems. There is an opportunity for the international community to create cohesive policies and legal standards that fully protect the rights of cancer survivors. There is an opportunity for the international community to create cohesive policies and legal standards that fully protect the rights of cancer survivors. The limitations of the current legal protections highlight the need for specific legislation or guidance that explicitly recognizes the unique situation of cancer survivors. Future developments could include the formalization of definitions and protections within international treaties and the creation of binding national laws addressing the rights of cancer survivors in the analysed contexts. There is an opportunity for international collaboration in the formation of a universal legal framework that specifically addresses the rights of cancer survivors. The growing recognition of the need for social inclusion of disadvantaged groups and the advancements in medical understanding of cancer survivorship provide a solid foundation for legal evolution. Engagement with stakeholders, including survivor advocacy groups, financial service providers, and legal experts, is crucial for driving these developments forward. The establishment of explicit protections and legal recognition is imperative to ensure cancer survivors lead dignified lives with equitable access to financial services. The responsibility lies with the international community, European institutions, and national governments to bridge the gap between medical advancements and legal protections for cancer survivors. Empirical research should support policy-making, and ongoing medical advancements should be integrated into financial risk assessments to avoid discrimination.

The chapter reaffirms the imperative for legal systems at all levels to evolve and adapt in response to the specific needs of cancer survivors. The overarching goal should be to ensure that cancer survivors are not defined by their past medical history but by their present and future contributions to society. Legal reform, informed by medical insights and survivor experiences, is necessary to protected and uphold the rights of cancer survivors. Enforceable regulations and guidelines aligned with modern medical understanding and the social realities of cancer survivors are needed to address the disparities between policy and practice. Targeted legal reform is essential to ensure the rights of cancer survivors to an adequate standard of living, privacy, and non-discrimination are truly upheld. Recommendations call for a unified effort by international bodies, the European Union, and national governments to bridge the gap between legal provisions and the lived experiences of cancer survivors, enabling them to participate fully and equitably in all aspects of economic life.

Chapter 3 has meticulously examined the nuances and intricacies surrounding the Right to be Forgotten (RTBF) for cancer survivors, against the backdrop of international, European, and national legal frameworks. The discussion establishes that while strides have been made towards the protection of cancer survivors' rights, the juridical context remains uneven and requires further harmonization and reinforcement. The RTBF has gained legal recognition and is now a pivotal element of data protection law, rooted in the concept of personal dignity and the evolution of privacy rights. The RTBF champions the notion that an individual's past, especially concerning medical history like cancer, should not be a perpetual source of discrimination or disadvantage, particularly in areas such as creditworthiness assessment and access to financial services. At the international level, the RTBF aligns with the right to privacy under the International Covenant on Civil and Political Rights and the interpretations provided by the UN Human Rights Committee. European law, through the GDPR, explicitly enshrines the RTBF, reflecting a commitment to data protection and personal autonomy. Nationally, the application of the RTBF is varied, with some countries like France, Belgium, Luxembourg, and the Netherlands advancing towards stronger protections for cancer survivors. Cancer survivors' rights are increasingly recognized, but legal protections remain fragmented. The RTBF has been affirmed by the GDPR in Europe, providing a framework for erasure of outdated or irrelevant information. This has been reinforced by pivotal cases such as Google v. Spain, which underscore the necessity of balancing public interest with individual rights to privacy and data protection. Hence, this chapter has effectively examined the progression of the right to be forgotten and its appropriate utilization for safeguarding the privacy of cancer survivors. This privacy aspect is also reinforced by national laws concerning the implementation of the right to be forgotten, as demonstrated in the last chapter. Therefore, the broad scope and development of the right to be forgotten can indeed be extended to benefit cancer survivors. Despite legal advancements, the juridical context is marked by heterogeneity across nations, reflecting varied interpretations and applications of the RTBF. Limitations stem from the tension between the right to information and the protection of privacy, as well as from discrepancies in national legislations concerning the enforcement of the RTBF for cancer survivors.

Promote the adoption of uniform standards across all Member States to ensure consistent application of the Right to be Forgotten (RTBF), mitigating the current fragmentation. Encourage national legislatures to enact specific provisions safeguarding cancer survivors against discrimination, particularly in employment, insurance, and financial services. Strengthen international cooperation to develop common guidelines that respect cancer survivors' RTBF. Increase public awareness and professional education on the importance of RTBF for cancer survivors to foster a more supportive societal and business environment. Implement mechanisms to monitor the effectiveness of the RTBF and the non-discrimination provisions for cancer survivors, facilitating periodic reviews and updates in response to technological and medical advancements.

The future of RTBF for cancer survivors must be marked by a unified legal doctrine that transcends borders and sectors, ensuring that these individuals can integrate into society with dignity, free from the shadows of their past medical conditions. Only through concerted legal efforts, policy-making, and societal engagement can we guarantee a just and equitable future where the right to be forgotten becomes a universally upheld right, providing cancer survivors with the respect and opportunities they rightfully deserve.

Chapter 4 presents a comprehensive analysis of the Right to be Forgotten (RTBF) for cancer survivors within various European legal frameworks. It underscores the commitment among EU Member States to address and mitigate financial discrimination against individuals who have overcome cancer. The chapter delves into the legal complexities and practical applications of the RTBF, highlighting the pioneering legislation in France. This legislation has been subsequently emulated by other countries, including Belgium, the Netherlands, Spain, Portugal and Italy.

The French model has set a significant precedent, with the ARES Convention and subsequent amendments forming a robust legal framework that has inspired other states. This comprehensive approach not only defines but actively enforces the right to be forgotten, ensuring that cancer survivors are not discriminated against when seeking insurance and financial services. It balances the interests of insurers in risk assessment and the privacy rights of former cancer patients. However, the complexity of legal interactions and the need for clearer communication and enforcement mechanisms are identified as areas for improvement. France's comprehensive approach encompasses the ARES Convention, the GRA, and multiple amendments, setting a robust precedent by addressing the needs of cancer survivors to access financial services without the burden of their past illnesses weighing on their prospects. The inclusion of stipulations within Article L1141-5, which prevents increased rates or exclusions of guarantee based on a past cancer diagnosis after a specified period, demonstrates a commendable effort towards equity. Moreover, the formation of monitoring bodies such as the Monitoring and Proposal Committee and the various conventions and amendments included in France's legal framework reflect an adaptable and rigorous system aimed at mitigating financial discrimination. Despite these advances, there remain areas for improvement. The legislation's complexity and the intricate administrative structures pose challenges in terms of clarity and efficiency. There is also a need to consider extending the benefits of the RTBF to encompass a broader range of loans to enhance inclusivity. It should be observed that this legislation only addresses financial discrimination and does not encompass the other areas of discrimination examined, such as employment and adoption. Additionally, the variations in legislative adoption timelines and scope among EU Member States indicate a need for a more unified approach to ensure consistent protection for cancer survivors across the EU.

Belgium's legislation, following France's lead, has shown progress by adopting a code of conduct for insurers, thereby extending the RTBF to disability insurance, and conducting assessments to potentially shortening waiting periods for early-stage breast cancer survivors. This progressive stance is indicative of a broader trend towards more inclusive insurance policies. The Belgian law, with its meticulous crafting and implementation, has established clear guidelines for insurance companies, dictating that cancer survivors who have been free of the disease for more than 8 years (to be reduced to 5 years by 2025) are not required to disclose their medical history when seeking insurance. This policy is instrumental in protecting the rights of cancer survivors, ensuring they are not unfairly penalized for their past medical conditions and can access financial services on equal footing. A crucial component of the Belgian legislation is the establishment of the reference grid by the Belgian Health Care Knowledge Centre (KCE), that is subject to biennial review. This allows the RTBF framework to remain responsive to medical advancements and ensures that the legislation is grounded in the latest scientific understanding of cancer prognoses. The adoption of a code of conduct by Assuralia further extends these protections to cover income disability insurance, marking

Belgium as a trailblazer in this regard. However, there are limitations to the current legislative framework. The absence of a monetary ceiling could potentially leave room for ambiguity regarding the extent of coverage provided by insurance companies. Moreover, the legislation does not yet address all types of chronic illnesses, which could be considered for inclusion in future amendments to create a more comprehensive RTBF policy. Future developments should focus on expanding the scope of the RTBF to include a wider range of medical conditions beyond cancer, while also considering the integration of a cap on insurance premiums to prevent exorbitant costs. Furthermore, continuous monitoring and evaluation of the reference grid are essential to ensure that the waiting periods for RTBF remain aligned with the state of medical knowledge and the actual risk profile.

Netherland’s legislation specifically addresses the concerns of cancer survivors facing potential discrimination when applying for life and funeral insurance. The legislation's strength lies in its clear and specific guidelines that establish a time limit beyond which inquiries into an individual’s past cancer history are no longer warranted. This time limit, set at ten years since the end of treatment (or five years for those diagnosed before the age of 21), is anchored on the principle of minimizing unnecessary infringements on personal privacy as articulated in Article 3 of the Wmk. Additionally, the right granted by Article 11 of the Wmk for an examinee to refuse cooperation with unwarranted inquiries serves as a robust protection mechanism for cancer survivors. While the legislation does take into account the interests of insurers to conduct risk assessments, it tempers these needs with the societal imperative of providing equitable access to insurance for former cancer patients. The integration with the GDPR Implementation Act (UAVG) further solidifies the legal framework for the protection of personal data, ensuring alignment with broader data protection regulations. However, the legislation is not without its limitations. The intricate interplay between various legal acts may present complexities that could result in interpretational and implementation challenges. On the one hand, the discussion extends only to funeral insurance, neglecting to encompass employment and adoption, thus limiting the broader application of the Right to Be Forgotten. On the other hand, the Dutch legislation has laid down a significant foundation in the quest to balance the rights of cancer survivors with the practical considerations of the insurance industry. The protections afforded by the Wmk and subsequent Decree demonstrate a laudable commitment to upholding the dignity and privacy of former cancer patients, thereby contributing to their full reintegration into society without the lingering shadow of discrimination. The Netherlands' approach offers a commendable model for other jurisdictions grappling with the same issue, paving the way toward greater social responsibility and inclusivity in insurance practices.

Portugal’s legislative response presents a commendable approach towards non-discrimination and the protection of privacy rights in the realm of credit access and insurance. Law 75/2021, in conjunction with Law 46/2006, marks a substantial advancement in establishing a "right to be forgotten" that echoes the ethos of social dignity and equality enshrined in the Constitution of the Portuguese Republic. The legislation effectively protects cancer survivors by disallowing the collection and processing of health information related to their past condition after specified periods. This move significantly mitigates the risk of augmented insurance premiums or exclusion from guarantees within insurance contracts, facilitating a fairer playing field for those who have previously battled with serious health issues. However, despite its strengths, the legal framework possesses certain limitations that merit attention. The practical application of the law requires continuous monitoring and potential clarification, particularly in relation to the reference table that is central to the operationalization of the right to be forgotten. There is a need for explicit guidelines that would enable a clear, predictable application of the law for individuals and institutions alike. However, once again, this legislation fails to provide for a comprehensive extension to address other forms of discrimination experienced by cancer survivors. Looking towards future developments, it would be prudent to consider periodic reviews of the law to ensure its alignment with advancements in medical treatments and evolving societal values. Moreover, fostering greater public awareness of these rights is essential to ensure that the intended beneficiaries can fully avail themselves of the protections offered. The Portuguese approach not only fortifies the legal rights of cancer survivors but also reaffirms the broader commitment to human dignity and equality before the law, principles that are foundational to any progressive legal system.

Spanish Royal Decree-Law 5/2023 firmly establishes non-discrimination principles by rendering null and void any contractual clauses that exclude individuals based on a history of cancer. This legislation protects cancer survivors by ensuring they are not obligated to disclose their cancer history in life insurance applications after five years post-radical treatment without relapse. Such measures exhibit Spain's commitment to upholding the rights of cancer survivors, thus providing them with a degree of security and dignity as they reintegrate into social and economic life.

The legal framework shows a rights-oriented approach, recognizing the right to be forgotten and preventing discrimination based on health conditions. However, the legislation has certain limitations. Firstly, it lacks specificity in defining "other health conditions," potentially leading to ambiguity. Secondly, it does not offer explicit details about enforcement mechanisms and penalties for non-compliance, which may affect the robustness of the protections.

To enhance the effectiveness of the legislation, it is recommended that the scope of the law expands to include all consumer sectors. The legislation should specify a more comprehensive list of "other health conditions" to avoid ambiguity. A clear enforcement mechanisms and penalties for non-compliance should be established. The Government should ensure transparency in exercising its authority to modify legal timelines, with specific criteria set forth for such modifications.

Italy’s legislation is a robust framework designed to safeguard cancer survivors against discrimination, particularly in the realms of financial services, employment, and adoption processes. Italy's legislation aligns with constitutional values, EU guidelines, and international human rights standards, showcasing the country's dedication to upholding the dignity and privacy of individuals who have overcome cancer. An analysis of the legislation reveals its comprehensive coverage, the clear definition of the RTBF, the interdisciplinary approach involving both the medical community and relevant ministerial authorities, and its retroactive application to ensure the continuity of principles in existing contracts and processes. Effective dissemination of information to all stakeholders, including financial institutions, employers, and the general public, is crucial. Moreover, the law's reliance on existing resources for its execution could limit its effectiveness, highlighting the need for adequate resource allocation for the enforcement of the law's provisions. In the juridical context, the legislation stands as a significant milestone, advancing the discourse on the rights of cancer survivors and setting a benchmark for other nations. It serves as an acknowledgment of the evolving societal landscape where the long-term impacts of cancer survival are recognized and addressed in legal terms. Future developments might include the establishment of more robust mechanisms for monitoring compliance, the provision of additional resources to ensure comprehensive enforcement, and potential amendments to address any shortcomings that may arise during the law's application. The law is not merely a set of provisions, it is a declaration of the values that the Italian society strives to uphold. As such, it must be nurtured and its implementation vigilantly overseen to ensure that the rights it enshrines are fully realized, thus paving the way for a future where the right to be forgotten is an inalienable part of cancer survivorship. Italy’s approach must serve as an example for future applications. It is the legislation with the wider scope of application including not only financial services but also adoption processes and public competitive applications.

Each nation's legislation differs in the specifics of its application, the duration after which the RTBF takes effect, and the types of insurance or financial services it encompasses. These variances reflect different societal, legal, and health care contexts, demonstrating the importance of tailoring the RTBF to national circumstances while adhering to overarching human rights principles. The limitations of the current legislative landscape include the potential for administrative complexities, the necessity for clearer definitions and enforcement mechanisms, and the need for harmonization across national borders. The juridical context underscores the delicate balance between protecting individuals' rights and addressing the operational concerns of the insurance and financial sectors.

For future developments, it is recommended that EU Member States consider establishing a coherent, unified legal framework for RTBF that aligns with international human rights standards and reflects the most effective elements of national legislations. Continuous improvement, including periodic review and international benchmarking, is essential to adapt to advances in medicine and societal changes.

The RTBF is a transformative legal tool that upholds the dignity and privacy of cancer survivors, facilitating their reintegration into society without the shadow of their medical history. The proactive and rights-oriented approach taken by the Member States discussed herein serves as a commendable model for other jurisdictions. The collaborative efforts in establishing an international legal framework will undoubtedly contribute to a more equitable and inclusive global society, ensuring that the victories of cancer survivors extend beyond their health into all spheres of life.

The culmination of the research, delving into the international framework with arguments drawn from the EU and its Member State example, has yielded insights into the main research question. The overall assurance of the Right to Be Forgotten (RTBF) at the international level is found to be lacking. The existence of such a right is not clearly established, and its recognition can only be inferred from the arguments presented throughout the thesis. The study identified pertinent human rights violations linked to cancer survivors, emphasizing the absence of a distinct categorization for this group. Consequently, this thesis advocates for immediate intervention by International Institutions in addressing this emergent yet deeply entrenched problem.

Notably, the thesis underscores that the RTBF for cancer survivors is conspicuously absent from UN and relevant international organization plans, illustrating the near non-existent protection of this right. In contrast, the EU's efforts have been commendable. The directive demanding Member States to implement financial services rights for cancer survivors has shed light on the issue, prompting many countries to take steps in this direction. However, this implementation is limited to financial services and has not extended to other areas of discrimination addressed in the thesis, such as the workplace and adoption processes. Italy stands out as the sole EU member ensuring a law encompassing the RTBF in adoption procedures. Consequently, it can be asserted that the RTBF for cancer survivors is only partially ensured at all levels. This study reiterates the need for comprehensive protection of cancer survivors' right not to disclose their information when medically irrelevant.

The thesis proposes that Member States and/or patient unions should submit recommendations to the United Nations, urging the formulation of proper guidelines or ideally, a Convention specifically identifying the category of cancer survivors. An all-encompassing convention covering all phases of cancer, from prevention to reintegration into normal life, is advocated. The call is for swift international cooperation to enhance databases and knowledge for addressing every aspect of cancer collectively.

Moreover, further research is deemed essential to gain a deeper understanding of the extent and types of discriminations faced by cancer survivors. Despite the growing importance of these issues, only a handful of studies have examined the tangible problems that cancer survivors may encounter post-diagnosis and treatment, including the socio-economic impacts of survival. There is a paucity of knowledge and assessment concerning workplace discrimination. The voices of cancer survivors, expressed through their representatives and hospital coalitions, must be heard. Engaging all stakeholders is imperative for developing an effective legal framework. Additional research is required for the implementation of UNCTAD's guidelines for consumer services protection. National and regional assessments are essential to identify areas for improvement. The RTBF for cancer survivors needs further development in the international and regional human rights environment, aligning with SDG 3.4. A broader solution, encompassing other non-communicable diseases, could be the establishment of a legal framework offering comprehensive protection for this category. This would extend the scope of the RTBF to all individuals who should not be identified solely based on their medical condition.

Bibliography

1. Primary sources

1.1 Legal instruments

1.1.1 International legal instruments

- 'Article 35 - Health Care' (European Union Agency for Fundamental Rights, 25 April 2015) <http://fra.europa.eu/en/eu-charter/article/35-health-care> accessed 24 October 2023
- 'Committee on the Rights of the Children, GE.13-44189, General Comment No. 14 (2013) on the Right of the Child to Have His or Her Best Interests Taken as a Primary Consideration (Art. 3, Para. 1).'
- 'Goal 3 | Department of Economic and Social Affairs' <https://sdgs.un.org/goals/goal3#targets_and_indicators> accessed 18 October 2023
- 'Resolution on the Seventieth World Health Assembly, WHO, WHA70.12, Agenda Item 15.6, 31 May 2017.'
- 'UN Committee on Economic, Social and Cultural Rights (CESCR), General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant), 11 August 2000, E/C.12/2000/4.'
- 'UN Committee on Economic, Social and Cultural Rights (CESCR), General Comment No. 18: The Right to Work (Art. 6 of the Covenant), 6 February 2006, E/C.12/GC/18.'
- 'UN General Assembly Resolution, Political Declaration of the High-Level Meeting of the General Assembly on the Prevention and Control of Non-Communicable Diseases, A/66/L.1, 19 September 2011.'
- 'UN Human Rights Committee (HRC), CCPR General Comment No. 16: Article 17 (Right to Privacy), The Right to Respect of Privacy, Family, Home and Correspondence, and Protection of Honour and Reputation, 8 April 1988.'

- ‘UN Office of the High Commissioner for Human Rights (OHCHR), Fact Sheet No. 31, The Right to Health, June 2008, No. 31, Available at: Https://Www.Refworld.Org/Docid/48625a742.Html.’
- ‘United Nations Guidelines for Consumer Protection, United Nations Conference on Trade and Development (UNCTAD), New York and Geneva, 2016, UNCTAD/DITC/CPLP/MISC/2016/1.’
- ‘Universal Declaration of Human Rights at 70: 30 Articles on 30 Articles - Article 12’ (OHCHR) <https://www.ohchr.org/en/press-releases/2018/11/universal-declaration-human-rights-70-30-articles-30-articles-article-12>.
- UN General Assembly, Convention on the Rights of Persons with Disabilities: resolution / adopted by the General Assembly, 24 January 2007, A/RES/61/106.
- UN General Assembly, Entry into force of the constitution of the World Health Organization, 17 November 1947, A/RES/131.
- UN General Assembly, International Covenant on Civil and Political Rights, 16 December 1966, United Nations.
- UN General Assembly, International Covenant on Economic, Social and Cultural Rights, 16 December 1966, United Nations, Treaty Series, vol. 993.
- UN General Assembly resolution 44/25, Convention on the Rights of the Child, 20 November 1989, United Nations.
- UN Human Rights Council, The right to work: resolution adopted by the Human Rights Council, 2 June 2015, A/HRC/RES/28/15.
- UN Human Rights Council, The right to work: resolution adopted by the Human Rights Council, 19 April 2016, A/HRC/RES/31/15.
- United Nations General Assembly. The Universal Declaration of Human Rights (UDHR). New York: United Nations General Assembly, 1948.
- World Health Assembly, 70. (2017). Cancer prevention and control in the context of an integrated approach. World Health Organization. https://apps.who.int/iris/handle/10665/275676.

1.1.2 European legal instruments

- European Union, Charter of Fundamental Rights of the European Union, 26 October 2012, 2012/C 326/02.

- ‘Council of Europe, European Convention for the Protection of Human Rights and Fundamental Freedoms, as Amended by Protocols Nos. 11 and 14, 4 November 1950, ETS 5.’

- ‘Council of Europe, European Court of Human Rights, Guide on Article 8 of the European Convention on Human Rights, Right to Respect for Private and Family Life, Home and Correspondence, 31 August 2022.’
- Council of Europe, Convention for the Protection of Individuals with Regard to the Automatic Processing of Individual Data, 28 January 1981, ETS 108.
- Council of Europe, European Convention on the Adoption of Children (Revised) (2008) CETS 202.
- Council of Europe, European Social Charter (Revised), 3 May 1996, ETS 163.
- Directive 2008/48/EC of the European Parliament and of the Council of 23 April 2008 on credit agreements for consumers and repealing Council Directive 87/102/EEC 2008.
- Directive 2014/17/EU of the European Parliament and of the Council of 4 February 2014 on credit agreements for consumers relating to residential immovable property and amending Directives 2008/48/EC and 2013/36/EU and Regulation (EU) No 1093/2010 Text with EEA relevance.
- EU General Data Protection Regulation (GDPR): Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation), OJ 2016 L 119/1.
- ‘Directive (EU) 2023/2225 of the European Parliament and of the Council of 18 October 2023 on Credit Agreements for Consumers and Repealing Directive 2008/48/EC, PE/22/2023/REV/1.’

- European Parliament, P9_TA (2022)0038, Strengthening Europe in the fight against cancer European Parliament resolution of 16 February 2022 on strengthening Europe in the fight against cancer – towards a comprehensive and coordinated strategy, (2020/2267(INI)).
- European Union, Charter of Fundamental Rights of the European Union, 26 October 2012, 2012/C 326/02.
- European Union, Consolidated version of the Treaty on the Functioning of the European Union, 26 October 2012, OJ L. 326/47-326/390; 26.10.2012.
- ‘EP Special Committee on Beating Cancer Holds Constitutive Meeting | News | European Parliament’ (23 September 2020) <https://www.europarl.europa.eu/news/en/press-room/20200918IPR87431/ep-special-committee-on-beating-cancer-holds-constitutive-meeting> accessed 3 December 2023.

1.1.3 Domestic legal instruments

- Americans with Disabilities Act of 1990. 42 U.S.C. 2000:12101-12213.
- ‘Article L1141-2 - Public Health Code - Légifrance’ <https://www.legifrance.gouv.fr/codes/article_lc/LEGIARTI000027645844> accessed 26 September 2023.
- ‘Article L1141-5 - Public Health Code - Légifrance’ <https://www.legifrance.gouv.fr/codes/article_lc/LEGIARTI000045272010> accessed 11 December 2023.
- Besluit van 2 november 2020, houdende regels voor verzekeringskeuringen van ex-kankerpatiënten ten behoeve van het afsluiten van overlijdensrisicoverzekeringen en uitvaartverzekeringen (Besluit verzekeringskeuringen ex-kankerpatiënten) 453, Jaargang 2020, Staatsblad van het Koninkrijk der Nederlanden.
- ‘BOE-A-2023-15135 Real Decreto-Ley 5/2023, de 28 de Junio, Por El Que Se Adoptan y Prorrogan Determinadas Medidas de Respuesta a Las Consecuencias Económicas y Sociales de La Guerra de Ucrania, de Apoyo a La Reconstrucción de La Isla de La Palma y a Otras Situaciones de Vulnerabilidad; de Transposición de Directivas de La Unión Europea En

Materia de Modificaciones Estructurales de Sociedades Mercantiles y Conciliación de La Vida Familiar y La Vida Profesional de Los Progenitores y Los Cuidadores; y de Ejecución y Cumplimiento Del Derecho de La Unión Europea.' <https://www.boe.es/buscar/act.php?id=BOE-A-2023-15135&p=20231228&tn=1> accessed 24 January 2024.

- 'Constituição da República Portuguesa' <http://www.parlamento.pt:80/Legislacao/Paginas/ConstituicaoRepublicaPortuguesa.aspx> accessed 22 January 2024.
- Costituzione della Repubblica Italiana, n. 298, entrata in vigore il 1 gennaio 1948. 1947
- 'Diploma Aprovado' <http://www.parlamento.pt:80/ActividadeParlamentar/Paginas/DetalheDiplomaAprovado.aspx?BID=23295> accessed 21 January 2024.
- Employment Retirement and Income Security Act. 29 U.S.C. 2000;1001-1191.
- Family and Medical Leave Act. 29 U.S.C. 2000;2611-2654.
- Federal Rehabilitation Act. 29 U.S.C. 2000; 701-796.
- Financiën M van, 'Besluit van 2 november 2020, houdende regels voor verzekeringskeuringen van ex-kankerpatiënten ten behoeve van het afsluiten van overlijdensrisicoverzekeringen en uitvaartverzekeringen (Besluit verzekeringskeuringen ex-kankerpatiënten)' (artikel 14, derde lid, van de Wet op de medische keuringen, 17 November 2020) <https://zoek.officielebekendmakingen.nl/stb-2020-453.html> accessed 9 January 2024.
- Koninkrijksrelaties M van BZ en, 'Wet op de medische keuringen' <https://wetten.overheid.nl/BWBR0008819/2023-01-01> accessed 31 May 2023.
- LAW no. 2022-270 of February 28, 2022, for fairer, simpler and more transparent access to the borrower insurance market (1).

- Légifrance - Publications officielles - Journal officiel - JORF n° 0022 du 27/01/2016, LOI no 2016-41 du 26 janvier 2016 de modernisation de notre système de santé.
- 'LEGGE 7 Dicembre 2023, n. 193 - Normattiva' <https://www.normattiva.it/uri-res/N2Ls?urn:nir:stato:legge:2023;193.> accessed 31 January 2024.
- 'Lei n.o 46/2006 | DR' <https://diariodarepublica.pt/dr/detalhe/lei/46-2006-540797>.
- 'Les Textes de Référence' <https://www.aeras-infos.fr/sites/aeras/accueil/la-convention-aeras/les-textes-de-reference.html>.
- 'LOI - WET' <http://www.ejustice.just.fgov.be/cgi_loi/loi_a1.pl?language=fr&la=F&cn=2014040423&table_name=loi&&caller=list&F&fromtab=loi&tri=dd+AS+RANK&rech=1&numero=1&sql=(text+contains+(%27%27))#LNK0033> accessed 30 May 2023.
- Next M, 'THE EUROPEAN CHARTER OF PATIENTS' RIGHTS' (Active Citizenship Network, 22 August 2022) <https://www.activecitizenship.net/charter-of-rights.html> accessed 24 October 2023.
- Projeto de Lei n.º 691/XIV/2.ª Reforça a proteção da pessoa segurada, proibindo práticas discriminatórias, melhorando o acesso ao crédito e contratos de seguros por pessoas que tenham superado riscos agravados de saúde, consagrando o "direito ao esquecimento" 2021
- Real Decreto Legislativo 1/2007, de 16 de noviembre, por el que se aprueba el texto refundido de la Ley General para la Defensa de los Consumidores y Usuarios y otras leyes complementarias, BOE-A-2007-20555.
- República D da, 'Lei n.o 75/2021' (Diário da República) <https://diariodarepublica.pt/dr/detalhe/lei/75-2021-174480833> accessed 22 January 2024.

- ‘Section 2: Risques Aggravés (Articles L1141-2 à L1141-6) - Légifrance’ <https://www.legifrance.gouv.fr/codes/id/LEGIARTI000027645844/2023-12-11/#LEGIARTI000027645844> accessed 18 December 2023.
- ‘The Monitoring and Proposals Committee’ <https://www.aeras-infos.fr/sites/aeras/accueil/la-convention-aeras/les-instances/la-commission-de-suivi-et-de-pro.html> accessed 26 May 2023.
- ‘The “Right to Be Forgotten” and the AERAS Reference Grid’ <https://www.aeras-infos.fr/sites/aeras/accueil/aeras-en-pratique/les-points-cles/le-droit-a-loubli-et-la-grille-d.html> accessed 18 December 2023.

1.2 Case law

- Case C-477/14, Pillbox 38, EU:C:2016:324.
- Google Spain, Google Spain SL and Google Incorporated v Agencia Española de Protección de Datos (‘AEPD’) and Costeja González, Judgment, reference for a preliminary ruling, Case C-131/12, ECLI:EU:C:2014:317, ILEC 060 (CJEU 2014), 13th May 2014, Court of Justice of the European Union [CJEU]; European Court of Justice [ECJ]; European Court of Justice (Grand Chamber).
- Matalas v Greece, App no 1864/18, ECtHR judgment, 25 March 2021.
- ML and WW v Germany, App no 60798/10 and 65599/10, ECtHR judgment, 28 June 2018.
- S and Marper v UK, ECHR, Appl No 30542/04, (2008).
- von Hannover v Germany, App no, 59320/00, 24 June 2004, EMLR 21.

2. Secondary sources

2.1 Books

- Bassini M and Pollicino O, ‘*Reconciling Right to Be Forgotten and Freedom of Information in the Digital Age. Past and Future of Personal Data Protection in the European Union*’ (1 January 2014) 641.

- Cofone IN and McGill University (eds), *The Right to Be Forgotten: A Canadian and Comparative Perspective* (Routledge, Taylor & Francis Group 2020).
- Fredman S, *Discrimination Law* (2nd ed, OUP Oxford 2011).
- Gardino SL, Russell AE and Woodruff TK, '*Adoption After Cancer: Adoption Agency Attitudes and Perspectives on the Potential to Parent Post-Cancer*' in Teresa K Woodruff and others (eds), Oncofertility, vol 156 (Springer US 2010).
- '*Harvard Law Review*, Vol. 4, No. 5. (Dec. 15, 1890), Pp. 193-220'.
- Lock T, '2195 Article 35 CFR' in Manuel Kellerbauer, Marcus Klamert and Jonathan Tomkin (eds), *The EU Treaties and the Charter of Fundamental Rights: A Commentary* (Oxford University Press 2019) <https://doi.org/10.1093/oso/9780198759393.003.557> accessed 20 October 2023.
- 'O'Connell, Rory, *The Right to Work in the European Convention on Human Rights* (March 7, 2012). European Human Rights Law Review, No. 2, 2012.'
- Pustorino P and Raimondi G, I*ntroduction to International Human Rights Law* (Asser Press 2023).
- Susi M (ed), Human Rights, Digital Society and the Law: A Research Companion (1st edn, Routledge 2019).
- Vaghri Z and others (eds), *Monitoring State Compliance with the UN Convention on the Rights of the Child*: An Analysis of Attributes, vol 25 (Springer International Publishing 2022).
- Werro F (ed), *The Right To Be Forgotten: A Comparative Study of the Emergent Right's Evolution and Application in Europe, the Americas, and Asia*, vol 40 (Springer International Publishing 2020).

2.2 Articles and related

- 'Andrew Davies, Csaba L. Dégi, Matti Aapro et al., "*Free from Cancer: Achieving Quality of Life for All Cancer Patients and Survivors*", European Cancer Organisation, 19 November 2020, 1-28.'

- Aziz N and Rowland J, ‘*Trends and Advances in Cancer Survivorship Research: Challenge and Opportunity*’ (2003) 13 Seminars in Radiation Oncology 248.
- Braun I and others, ‘*Changes, Challenges and Support in Work, Education and Finances of Adolescent and Young Adult (AYA) Cancer Survivors: A Qualitative Study*’ (2023) 64 European Journal of Oncology Nursing 102329.
- ‘*Data Privacy and Dignitary Privacy: Google Spain, the Right To Be Forgotten, and the Construction of the Public Spher*e | Duke Law Journal’ <https://dlj.law.duke.edu/article/data-privacy-and-dignitary-privacy-post-vol67-iss5/> accessed 1 December 2023.
- ‘Department of Health, Macmillan Cancer Support, NHS Improvement. *National Cancer Survivorship Initiative*: Vision. London: Department of Health, Crown Copyright; 2010.’
- Dumas A and others, ‘*The Right to Be Forgotten: A Change in Access to Insurance and Loans after Childhood Cancer*?’ (2017) 11 Journal of Cancer Survivorship 431.
- Dumas A, De Vathaire F and Vassal G, ‘*Access to Loan-Related Insurance for French Cancer Survivors*’ (2016) 17 The Lancet Oncology 1354.
- Dzúrová M, ‘Consumer Legal Protection in the EU’ (2020) 83 SHS Web of Conferences 01013.
- Hoffman B, ‘*Cancer Survivors at Work: A Generation of Progress*’ (2005) 55 CA: A Cancer Journal for Clinicians 271.
- Humble KP, ‘*International Law, Surveillance and the Protection of Privacy*’ (2021) 25 The International Journal of Human Rights 1.
- Khan NF and others, ‘*Interpretation and Acceptance of the Term “Cancer Survivor*”: A United Kingdom-Based Qualitative Study: Identity as a Cancer Survivor’ (2012) 21 European Journal of Cancer Care 177.
- Khan NF, Rose PW and Evans J, ‘*Defining Cancer Survivorship: A More Transparent Approach Is Needed*’ (2012) 6 Journal of Cancer Survivorship 33.

- Lawler M and others, '*A Catalyst for Change: The European Cancer Patient's Bill of Rights*' (2014) 19 The Oncologist 217.
- Lawler M and Meunier F, '*Don't Make Cancer Survivors Pay Twice—the Right for Them to Be "Forgotten" Should Be Law Everywhere*' [2022] BMJ o2197.
- Lehmann V and others, '*Gonadal Functioning and Perceptions of Infertility Risk Among Adult Survivors of Childhood Cancer: A Report From the St Jude Lifetime Cohort Study*' (2019) 37 Journal of Clinical Oncology 893.
- Liu L and others, '*Cancer in Europe: Death Sentence or Life Sentence*?' (2016) 65 European Journal of Cancer 150.
- Magasi S and others, '*Cancer Survivors' Disability Experiences and Identities: A Qualitative Exploration to Advance Cancer Equity*' (2022) 19 International Journal of Environmental Research and Public Health 3112.
- Marzorati C, Riva S and Pravettoni G, '*Who Is a Cancer Survivor? A Systematic Review of Published Definitions*' (2017) 32 Journal of Cancer Education 228.
- Mullan F, '*Seasons of Survival: Reflections of a Physician with Cancer*' (1985) 313 New England Journal of Medicine 270.
- Namingit S, Blankenau W and Schwab B, '*Sick and Tell: A Field Experiment Analyzing the Effects of an Illness-Related Employment Gap on the Callback Rate*' (2021) 185 Journal of Economic Behavior & Organization 865.
- 'National Insittutes of Health, National Cancer Institue; 2004. President's Cancer Panel, 2003–2004 Annual Report: Living beyond Cancer: A European Dialogue. NIH Publication No. P996.'
- Quarello P and others, '*Get up, Stand up: Alongside Adolescents and Young Adults with Cancer for Their Right to Be Forgotten*' (2022) 108 Tumori Journal 402.
- Quinn GP and others, '*Adoption and Cancer Survivors: Findings from a Learning Activity for Oncology Nurses: Adoption and Cancer Survivors*' (2015) 121 Cancer 2993.

- Rabin C, '*Cancer-Related Self-Disclosure in the Workplace/School by Adolescent and Young Adult Cancer Survivors*' (2020) 9 Journal of Adolescent and Young Adult Oncology 528.
- Scocca G and Meunier F, '*A Right to Be Forgotten for Cancer Survivors: A Legal Development Expected to Reflect the Medical Progress in the Fight against Cancer*' (2020) 25 Journal of Cancer Policy 100246.
- '*Towards an EU Legislation on the Right to Be Forgotten to Access to Financial Services for Cancer Survivors*' (2022) 162 European Journal of Cancer 133.
- Sterkens P, Sharipova A and Baert S, '*Disclosing the "Big C": What Does Cancer Survivorship Signal to Employers*?' [2023] The European Journal of Health Economics <https://link.springer.com/10.1007/s10198-023-01618-2> accessed 6 November 2023.
- Tralongo P and others, 'U*se of the Word "Cured" for Cancer Patients—Implications for Patients and Physicians: The Siracusa Charter*' (2015) 22 Current Oncology e38.

2.3 Websites

- 'About UICC | UICC' <https://www.uicc.org/who-we-are/about-uicc> accessed 20 October 2023.
- 'Average American Debt' (Ramsey Solutions) <https://www.ramseysolutions.com/debt/average-american-debt> accessed 15 July 2023.
- 'Cancer' <https://www.who.int/health-topics/cancer> accessed 5 May 2023.
- 'Cancer' <https://www.who.int/news-room/fact-sheets/detail/cancer> accessed 6 May 2023.
- 'Cancer Survivors' (WCRF International) <https://www.wcrf.org/diet-activity-and-cancer/global-cancer-update-programme/cancer-survivors/> accessed 6 May 2023.
- 'Cancer Survivorship' (The Cancer Atlas) <http://canceratlas.cancer.org/rky> accessed 6 May 2023.

- ‘Cancer Today’ <http://gco.iarc.fr/today/home> accessed 10 May 2023.
- ‘Cancer Topics – IARC’ <https://www.iarc.who.int/cancer-topics/> accessed 6 May 2023.
- ‘Definitions | Division of Cancer Control and Population Sciences (DCCPS)’ <https://cancercontrol.cancer.gov/ocs/definitions> accessed 30 October 2023.
- ESMO, ‘Complete Cancer Prevalence in Europe in 2020 Reveals an Increased Proportion of Cancer Survivors Beyond 5 Years from Diagnosis’ <https://www.esmo.org/oncology-news/complete-cancer-prevalence-in-europe-in-2020-reveals-an-increased-proportion-of-cancer-survivors-beyond-5-years-from-diagnosis> accessed 3 February 2024.
- ‘Europe: Owner Occupiers with and without Mortgage 2021’ (Statista) <https://www.statista.com/statistics/957803/homeowners-with-and-without-an-outstanding-mortgage-in-eu-28-per-country/> accessed 15 July 2023.
- ‘Human Rights’ <https://www.who.int/news-room/fact-sheets/detail/human-rights-and-health> accessed 20 October 2023.
- ‘If You Have Cancer, Will Your Children Get It? | Penn Medicine’ (Penn Medicine - Abramson Cancer Center) <https://www.pennmedicine.org/cancer/about/focus-on-cancer/2015/august/if-you-have-cancer-will-your-kids-have-it-too> accessed 20 July 2023.
- ‘Il diritto all’oblio oncologico è legge’ (Fondazione Umberto Veronesi) <https://www.fondazioneveronesi.it/magazine/articoli/oncologia/il-diritto-alloblio-oncologico-e-legge> accessed 28 January 2024.
- Lea Ann Hansen P, ‘Challenges Patients Face in Cancer Care: Implications for the Healthcare Team’ <https://www.theoncologypharmacist.com/top-issues/issue-archive/14797-top-14797> accessed 6 May 2023.
- ‘Long-Term Side Effects of Cancer Treatment’ (Cancer.Net, 14 October 2010) <https://www.cancer.net/survivorship/long-term-side-effects-cancer-treatment> accessed 6 May 2023.

- lucia, ‘Rinascita: tornare alla vita dopo la malattia’ (LILT Milano Monza Brianza, 15 January 2024) <https://www.legatumori.mi.it/resta-informato-post/tumori/progetto-rinascita/> accessed 3 February 2024.
- ‘Meetings: European Cancer Concord | Society for Translational Oncology’ <https://sto-online.org/meetings-european> accessed 20 October 2023.
- ‘Non-Communicable Diseases’ <https://www.who.int/news-room/fact-sheets/detail/noncommunicable-diseases> accessed 18 October 2023.
- ‘Non-Communicable Diseases | IFRC’ <https://www.ifrc.org/our-work/health-and-care/community-health/non-communicable-diseases> accessed 18 October 2023.
- ‘Office of Cancer Survivorship | Division of Cancer Control and Population Sciences (DCCPS)’ <https://cancercontrol.cancer.gov/ocs> accessed 6 August 2023.
- ‘Overview of Cancer Survivorship Care for Primary Care and Oncology Providers’ <https://www.medilib.ir/uptodate/show/16613> accessed 6 August 2023.
- ‘Right to Be Forgotten: Explained’ <http://www.varonis.com/blog/right-to-be-forgotten> accessed 23 July 2023.
- Roser M and Ritchie H, ‘Cancer’ [2015] Our World in Data <https://ourworldindata.org/cancer> accessed 7 May 2023.
- Services D of H& H, ‘Cancer’ <http://www.betterhealth.vic.gov.au/health/conditionsandtreatments/cancer> accessed 26 September 2023.
- ‘Side Effects of Cancer Treatment’ (Yale Medicine) <https://www.yalemedicine.org/conditions/side-effects-cancer-treatment> accessed 16 June 2023.
- ‘UK Mortgage Statistics 2023 - Mortgage Facts and Stats Report’ (Uswitch) <https://www.uswitch.com/mortgages/mortgage-statistics/> accessed 15 September 2023.
- ‘What Is Cancer?’ (Cancer.Net, 1 August 2012) <https://www.cancer.net/navigating-cancer-care/cancer-basics/what-cancer> accessed 13 June 2023.

- ‘What Is Cancer? - NCI’ (17 September 2007) <https://www.cancer.gov/about-cancer/understanding/what-is-cancer> accessed 13 June 2023.

2.4 Reports and related

- ‘Cécile de Terwangne, The Right to Be Forgotten and the Informational Autonomy in the Digital Environment, 2013, European Commission, Joint Research Centre Institute for the Protection and Security of the Citizen.’

- European Cancer Patient Coalition, ‘Factsheet on the Right to Be Forgotten in the EU National Legislations, Legal Background and Current Status from France, Belgium, Luxembourg and the Netherlands’ <https://ecpc.org/wp-content/uploads/2020/12/Factsheet-National-Legal-framework-on-the-right-to-be-forgotten_UpdatedDEC2020-1.pdf>.

- Laurence Amand-Eeckhout, ‘Strengthening Europe in the Fight against Cancer’.
- ‘Martin Scheinin, “Report of the Special Rapporteur on the Promotion and Protection of Human Rights and Fundamental Freedoms While Countering Terrorism”, UN Human Rights Council, (October 28, 2009): A-HRC-13-37.’
- ‘OVERVIEW OF LEGISLATION AT THE NATIONAL LEVEL’ (Ending discrimination against cancer survivors) <https://endingdiscrimination-cancersurvivors.eu/national-level/> accessed 30 December 2023.
- Tit Albreht, Régine Kiasuwa and Marc Van den Bulcke, ‘European Guide on Quality Improvement in Comprehensive Cancer Control’.
- ‘World Cancer Declaration | UICC’ <https://www.uicc.org/what-we-do/driving-global-impact/targeted-commitments/world-cancer-declaration> accessed 20 October 2023.
- World Health Organization, Global Action Plan for the Prevention and Control of Noncommunicable Diseases 2013-2020 (World Health Organization 2013) <https://apps.who.int/iris/handle/10665/94384> accessed 7 May 2023.

2.5 Miscellaneous

- Marianne Massart, Cancer Survivor Testimony (Directed by Ending Discrimination Against Cancer Survivors, 2023) <https://www.youtube.com/watch?v=3DEGktuUUu4> accessed 16 May 2023.