



Republic of San Marino

San Marino Bioethics Committee

***THE RIGHT TO BE FORGOTTEN
FOR CANCER SURVIVORS***

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TABLE OF CONTENTS

PRESENTATION	3
INTRODUCTION	4
“CANCER SURVIVOR” STATUS	6
EUROPEAN CONTEXT IN THE FIGHT AGAINST MALIGNANT NEOPLASMS	8
DEVELOPMENT OF A SOCIAL CULTURE OF CANCER SURVIVORS	10
PSYCHO-SOCIAL ASPECTS OF THE “SURVIVOR SYNDROME”	12
THE RIGHTS OF SURVIVORS AND CAREGIVERS	14
THE RIGHT TO BE FORGOTTEN FOR CANCER SURVIVORS	17
VULNERABILITY OF CANCER SURVIVORS	19
INSURANCE PROTECTION OF PERSONS CURED OF AN ONCOLOGICAL DISEASE	22
CONCLUSIONS	24
RECOMMENDATIONS	25

PRESENTATION

San Marino Bioethics Committee (CSB), which has always been attentive to little-debated topics in the bioethical sphere, has decided to devote a document to an issue that is still unexplored in the civil community and in the legal context, namely the exclusion of persons cured of cancer from participation in some social services. The stigma of “cancer patient” *de facto* constitutes a social discrimination, which persists throughout life even in those who have faced and overcome the disease.

The severe discomfort experienced by these persons has led patients' associations to request that, after the remission of the disease, they are granted the so-called “right to be forgotten for cancer survivors”, namely the possibility of accessing some specific services, including financial and insurance services, without having to provide information on their health history.

Until now, this request has received little response in the legal sphere, even less in the bioethical sphere; however, last year the European Parliament passed a Resolution in which it explicitly called on Member States to initiate a regulatory process to guarantee this right, following the example of what has happened in a (still small) number of countries.

Therefore, a new course is being taken in Europe to ensure equity of access to some services even for those citizens excluded on the basis of an unacceptable health stigma.

In this context, the CSB considered it most appropriate to offer a bioethical reflection that could raise public awareness on this subject, in order to trigger a cultural process that would promote the implementation of the principles of equity and justice for persons cured of cancer and, at the same time, provide institutions with a bio-legal advice for any legislative action.

Indeed, this document highlights the importance of developing a social culture of cancer survivors, from a point of view that is not only bioethical and bio-legal, but also clinical and psychological, offering original reflections on the insurance protection of cured people.

CSB's attention to the rights of persons made vulnerable by a disease also extends to caregivers; the latter must indeed always be taken into account in both theoretical reflections and social policies, not only because their support cannot be replaced, but also due to the possible vulnerability linked to the psychological, financial and professional consequences of their daily commitment.

I am particularly proud to present this work, which is unique in the bioethical and scientific areas; indeed, there is no literature on this subject to date, as can be seen from the absence of a concluding chapter devoted to bibliography.

For the drafting of this text, the CSB collaborated with Dr Roberto Ercolani, as an external expert psychologist.

This document was approved at the meeting of 18 October 2023 by all members: Borgia, Cantelli Forti, Carinci, Garofalo, Hrelia, Raschi, Santori, Selva, Strollo, Tagliabracchi. Mr. Griffo, Ms. Guttmann and Mr. Iwanejko were absent.

Luisa M. Borgia
CSB President

INTRODUCTION

Equal access to care is a fundamental human right, widely recognised in international law.

In bioethics, it is based on the **principle of justice**.

Nevertheless, after recovering from a serious disease, most persons suffer from the stigma related to such disease; therefore, it is very difficult for them to achieve full recognition of the rights previously enjoyed, including equal access to all sectors of society.

This discrimination, hitherto underestimated or ignored even by bioethics, affects to an alarming degree those who have faced and overcome an oncological disease.

For the latter persons, the WHO has coined the term “cancer survivors”, i.e., those who, after having gone through the necessary diagnostic and therapeutic process, are in a condition of complete remission; this means that they are cured of the disease, based on all investigations aimed at identifying the persistence of even the slightest risk of recurrence or relapse.

Such persons have *de facto* achieved full restoration of their functional health (physical, developmental and psychosocial), to the extent that they have a life expectancy equal to that of the general population¹.

In this sense, the scientifically recognised timing of different forms of cancer for the purpose of reducing the risk of recurrence cannot be ignored. For example, in the case of thyroid cancer, the 5-year limit is currently considered reliable, but this is extended to 10 years for colon cancer and melanoma, 15 years for bladder or kidney cancer, non-Hodgkin lymphoma (large B-cell or follicular lymphoma, myeloma and leukaemia) and 20 years for breast and prostate cancer².

Whereas in the early days of oncology, persons with malignant tumours of all kinds were almost invariably doomed to a painful and short-term fatal course of the disease, the situation has changed dramatically in the current state of scientific knowledge.

Thanks to the ever-increasing dissemination of early detection tools included in large-scale public or private screening programmes, coupled with a higher effectiveness of targeted therapies and supportive care, cancer survival rates are growing significantly, and they currently exceed an estimate of 12 million persons (of which 300,000 minors) per year in Europe alone.

However, “cancer survivors” experience complications related to the disease or to the various more or less invasive treatments they have undergone, such as “demolishing surgery” at various levels, increasingly targeted radiotherapy - but still damaging some healthy tissues -, debilitating chemotherapy, effective immunotherapy that has in any case predictable side effects, including, for example, autoimmune hypothyroidism, and indirect pharmacotherapy (for example, corticosteroid therapy, posing the risk of reduced muscle mass and resurgence of diabetes).

¹ WORLD HEALTH ORGANIZATION, *Cancer Control: Knowledge into Action - Diagnosis and treatment WHO Guide for Effective Programmes*, World Health Organization, Switzerland, 2008

² AIOM FOUNDATION, [Right to be forgotten for cancer survivors](#)

The CSB believes that ignoring this condition would mean trivialising a disease that, although having transformed over the years in terms of *quoad vitam* prognosis and thus losing many of its past anxiogenic characteristics, still requires timely, personalised and holistic oncological rehabilitation aimed at the total recovery of functional and psychological deficits linked to the therapy and full reintegration into social, working and family life.

“CANCER SURVIVOR” STATUS

In this context, “cancer survivors” can be identified as a new social group whose specific interests - hitherto socially scotomised due to an unconscious fear of a disease considered as inexorable, and therefore misunderstood and even ignored - must be protected and promoted, similarly to what is still often the case for persons with disabilities.

Although with difficulty, the latter persons have now obtained the protection of their rights and the promotion of their well-being thanks to national and international legal instruments³. However, this is not the case for cancer survivors, who are not legally recognised as a disadvantaged group with special needs, therefore, some EU countries are moving in this direction to implement special programmes aimed at their complete reintegration⁴.

This phenomenon is already relevant as such, but even more so for adults who have experienced cancer in childhood and have then been judged cured and “out of risk”; indeed, such persons often have various kinds of disability as a consequence of the therapies undergone and, even more often, an underlying malaise, which has become chronic over time, and which cannot be adequately defined and is difficult to objectify and quantify.

The stigma of inability to sustain a work pace compatible with today's hyper-efficiency persists on all of them and, as a result, there are considerable difficulties in finding or keeping a stable and rewarding job or in obtaining deserved career advancement.

Moreover, for cancer survivors it is particularly complex, if not impossible, to access some specific financial, banking or insurance services (a phenomenon referred to as “financial toxicity”), or to initiate the necessary procedures for adopting a child.

What has been described above shows that persons who have struggled to overcome a disease - hitherto considered fatal - are *de facto* classified as part of a separate group of persons destined for certain death and reduced to persons deprived of the rights guaranteed to all other citizens, since they are considered to be perpetually “at risk”.

Therefore, “*long-survivors*” suffer a perpetual stigma despite the fact that science has proven the effectiveness of new diagnostic and therapeutic processes, thanks to which today the treatment of 35% of cases is successful in the long run, with an increasingly high expected cure rate over time.

In this regard, the Irish Cancer Society conducted a study on the condition of cancer patients, showing that 75% of them, although cured of cancer, are excluded from insurance benefits⁵.

This phenomenon still creates unequal treatment between persons, in blatant violation of the principle

³ The main documents protecting the rights of persons with disabilities include: UN GENERAL ASSEMBLY, [Convention on the Rights of Persons with Disabilities](#), Resolution/Adopted by the UN General Assembly on 24 January 2007; EUROPEAN UNION, [Charter of Fundamental Rights of the European Union](#), 2012.

⁴ For an in-depth examination of the bioethical significance of the right to be forgotten for cancer survivors, also in the European context, see L. BORGIA: *I diritti umani oltre la malattia: i sopravvissuti al cancro e il diritto all'oblio oncologico*. Online legal archive (issn 2282 2828), vol. II, no. 2 2023.

⁵ NATIONAL CANCER REGISTRY IRELAND (NCRI). 2021. *Cancer in Ireland 1994-2019: Annual Report of the National Cancer Registry*. 2021 Annual Report.

of justice in achieving equal treatment; indeed, it restricts access of many persons cured of cancer to expensive specific treatments, thus forcing them to live with various forms of disability that prevent “survivors” from resuming a viable productive life.

Therefore, a vicious circle is triggered whereby the lack of social recognition of recovery and the denial of the right to be forgotten for cancer survivors entails that such persons undergo a progressive process of ghettoisation and forced passivity, due to the granting of various forms of social security support and other support provided by welfare entities⁶.

Such a condition, although created for commendable assistance purposes, entails considerable costs for society, without guaranteeing due respect for the real needs of patients; indeed, in Italy, scientific societies and patients' associations have for years been advocating the interests of persons cured of cancer, above all in terms of quality of life⁷.

⁶ M. LAWLER, F. MEUNIER, *Don't make cancer survivors pay twice-the right for them to be "forgotten" should be law everywhere*, in *British Medical Journal*. 2022 Sep 21;378:o2197. doi: 10.1136/bmj.o2197. PMID: 36130783.

⁷ AIOM, AIRO, SIMG, CIPOMO, SIUrO, SUCO, AIRTUM, SIPO, ANISC, FAVO, *Consensus Conference Dalla pratica del “follow up” alla cultura di “survivorship care”*. Rome, 10-11 September 2015: http://media.aiom.it/userfiles/files/doc/documenti_scientifici/2015_Documento_di_consenso_def.pdf

EUROPEAN CONTEXT IN THE FIGHT AGAINST MALIGNANT NEOPLASMS

The introductory report on the spread of oncological diseases across Europe clearly confirmed the fear expressed by specialists in this field since the outbreak of the SARS-CoV-2 pandemic, based on an apparent initial decrease in cases due to the difficulty of effective contact over time, immediately followed by a rapid increase in cases due to a lack of active surveillance.

This condition *de facto* prevented the implementation of the **principles of beneficence/non-maleficence and of justice**; indeed, a considerable number of cancer patients were unable to reach specialised centres and were forced to ignore the disease due to a misunderstood overestimation of the risk of infection compared to the oncological risk.

Therefore, it has been confirmed that the pandemic has markedly worsened cancer treatment, interrupting the virtuous chain of activities aimed at prevention, treatment and control over time of the disease, which had previously been very active. Moreover, the pandemic prompted the European authorities to draw up the “Europe’s Beating Cancer Plan”⁸, aimed at guaranteeing access to treatment even in crisis situations with concrete Community actions to guide health professionals in the optimal management of the entire course of the disease, from prevention to treatment and subsequent support of the patient to best deal with the problems of everyday life “after cancer”.

In particular, the “EU4Health Programme”⁹ will provide Member States with significant financial support of EUR 4 billion to ensure prevention, early detection, diagnosis, treatment and improvement of the quality of life of cancer patients and survivors, which are the pillars of a structured process that is expected to produce great results.

To this very end, the “European Cancer Information System”¹⁰ is already monitoring the incidence of cancer in Europe from 2021 onwards. New crucial indicators have been included, among which some related to childhood cancers and others capable of capturing more specific elements of individual countries, in the hope of simplifying the analysis of possible correlations between disease, socio-economic and environmental data as much as possible¹¹.

In the plan just described, due emphasis is given to respecting the fundamental determining factors of cancer patients’ health; particular attention is paid to socio-economic status, gender, profession and education, with a specific reference to the need for equal access to cancer prevention and treatment and to combating discrimination against vulnerable persons within the oncological category, including the elderly, persons with disabilities and minorities of all kinds.

From a bioethical point of view, what has just been described relates to respect for the **principle of justice**. This principle is at the basis of the European project to develop further adequate screening

⁸ EUROPEAN COMMISSION, [Europe’s Beating Cancer Plan. Communication from the Commission to the European Parliament and the Council](#), 2021.

⁹ EUROPEAN COMMISSION, [EU4Health programme 2021-2027 – a vision for a healthier European Union](#).

¹⁰ The European Cancer Information System (ECIS) will become an integral part of the Cancer Knowledge Centre: <https://ecis.jrc.ec.europa.eu/>.

¹¹ For example, with data from the human biomonitoring programme for the EU (HBM4EU) (<https://www.hbm4eu.eu/>) or environmental data available through the Information Platform for Chemical Monitoring (<https://ipchem.jrc.ec.europa.eu/>).

programmes and personalised medicine based on genomics, as well as to implement high quality care standards that are uniform in all Member States, through the creation of a network among national cancer centres and in terms of access to essential drugs and technological innovation.

In this regard, a “European pharmaceutical strategy”¹² based on the reform of the general pharmaceutical legislation will be implemented to facilitate access to the various products, ensuring better economic conditions and a significant strengthening of the supply chains in the increasingly frequent occurrence of drug shortage; moreover, thanks to the implementation of the “EU regulation on clinical trials on medicinal products for human use”¹³, a coordinated and simplified system for the assessment, conduct and monitoring of clinical trials in the EU will be established.

¹² COMMUNICATION FROM THE COMMISSION TO THE EUROPEAN PARLIAMENT, THE COUNCIL, THE EUROPEAN ECONOMIC AND SOCIAL COMMITTEE AND THE COMMITTEE OF THE REGIONS, [Pharmaceutical Strategy for Europe COM/2020/761 final](#).

In the context of equal access to care in the EU, worth mentioning is also the recent Recommendation of the Committee of Ministers on access to medicinal products and medical equipment in a situation of shortage: [Equitable access to medicinal products and medical equipment in a situation of shortage](#), Recommendation CM/Rec(2023)1 of the Committee of Ministers to member States Adopted by the Committee of Ministers on 1 February 2023 at the 1455th meeting of the Ministers' Deputies.

¹³ [Regulation \(EU\) No 536/2014 of the European Parliament and of the Council of 16 April 2014 on clinical trials on medicinal products for human use, and repealing Directive 2001/20/EC](#)

DEVELOPMENT OF A SOCIAL CULTURE OF CANCER SURVIVORS

From a bioethical point of view, in relation to the principles of beneficence and justice, particularly relevant is the commitment of the above-mentioned European plan to combat all forms of welfare, social and professional discrimination in order to improve the quality of life of cancer patients, cancer survivors and their families.

Indeed, according to what has been reported by oncologists and by patients' associations, the related clinical and bioethical aspects are particularly burdensome and require the concrete dissemination of the so-called "survivorship care" culture; without renouncing the commitment to containing expenditure and combating the waste arising above all from the costs of follow-up visits and examinations - currently estimated to be about ten times higher than those actually needed - such culture is aimed above all at making medical and surgical interventions as minimally invasive as possible, with a view to maximising respect for patients' quality of life in the psychophysical sphere and social reintegration in the short and long term¹⁴.

The doctor-patient relationship, which supports the acceptance of the disease, is based on frequent check-ups, and the excessive prescription of tests also reflects the doctor's need to appease the patient's anxiety with the expected, though not entirely certain, reassurance offered by negative results of various tests.

Surgery, radiotherapy and debilitating drug therapies may induce long-term toxicity and loss or reduction of fertility, reduce resistance to possible relapse, and induce various kinds of comorbidity, which, in turn, may give rise to interpretative doubts about various symptoms or signs.

This leads to a request for further investigations or the repetition of those that have given rise to doubts, determining in some doctors a sort of "prescription bulimia", which worsens the patient's anxiety in a negative spiral of altered coenesthesia of uncertainty of the future; this causes a consequent chronic distress, i.e., the opposite of that life quality improvement hoped-for by the European plan described above.

Such a context contributes to generating a greater and more persistent need for good health in the patient than in the general population, also, if not exclusively, due to the destructive effects of the treatments undergone.

In the light of what has just been described, the CSB believes that a new cultural approach is needed to overturn the concept of "ableism", whereby a disease is a disadvantaged condition compared to that of good health and segregates the sufferer in a context characterised by the greatest possible commitment of resources in the acute phase, and then justifies total public disengagement after recovery.

In order to pursue the **bioethical principle of non-maleficence**, it is appropriate to adopt - where clinically justified - minimally invasive interventions in an attempt to contribute to making the subsequent course of the disease less painful for the patient and less costly - with the same foreseeable

¹⁴ CONSENSUS CONFERENCE [Dalla pratica del "follow up" alla cultura di "survivorship care"](#). Rome, 10-11 September 2015.

results - for the national healthcare system.

Precisely by virtue of this bioethical principle, an attitude of “abandonment” of the patient because of a misunderstood sense of “total overcoming of the problem” will not be justified under any circumstances.

Indeed, the oncological team will be required to carry out periodic clinical surveillance and will have to provide facilitated access and priority codes in the event of suspected relapse of disease or new oncological disease in compliance with specific guidelines; this is also aimed at carrying out clinical studies and collecting data useful for improving knowledge in this field, on the basis of scientifically valid procedures suitable for disseminating a serious and productive approach as much as possible.

According to the **principle of beneficence**, such oncological surveillance should be encouraged in a context of specific counselling and educational and psychotherapeutic processes aimed at maximum lifestyle improvement for primary and secondary prevention.

To this end, the doctor should ensure effective and empathic patient-centred communication aimed at mitigating the anxious uncertainty and distress related to the fear of recurrence.

Therefore, a person cured of an oncological disease should enjoy a specific and constant interdisciplinary care and rehabilitation programme agreed between the “main” specialist, indirect specialists and the primary health physician, in order to achieve the patient's full reintegration into emotional and social life.

However, in this context the aforementioned team should be oriented to empowerment and should try to avoid activities or attitudes that may ghettoise patients within their disease, thus becoming an obstacle to the patients’ right to be forgotten.

The CSB considers that the real challenge will be to maintain as high a level of attention as possible to broad-spectrum preventive activity for relapses and possible adaptation reactions (a concept now accepted for many other diseases with targeted screening and checks according to age, family predisposition, etc.), without any discrimination based on the specific disease, thanks to the statutory protection of privacy in terms of health data.

This would strike a balance between protecting the rights of cancer survivors to be forgotten for the purpose of job retraining and maximum insurance coverage.

PSYCHO-SOCIAL ASPECTS OF THE “SURVIVOR SYNDROME”

In this reflection on the many aspects of the right to be forgotten for cancer survivors, the CSB also wishes to highlight an often underestimated element, which concerns the damage resulting from the so-called “survivor syndrome”: this refers to a permanent uneasiness related to the “shame of having defeated death”, which is an apparent contradiction in terms that does not allow the victims to distance themselves from a past characterised by disease, due to a feeling of guilt for being - or having been - a burden to their loved ones. If this feeling, which is deep and rooted in the unconscious, comes to the surface of consciousness, it is often hidden from others out of shame and, in this way, risks suffocating those who experience it; these persons are therefore imprisoned in a Post Traumatic Stress Disorder that manifests itself with a strong sense of guilt for having survived, unlike other persons encountered in the course of treatment who died, despite having the same or similar disease. Even if they rationally know that they have no responsibility, the interested persons tend to think that they could and should have done something different, or that, by their own behaviour, they may have, in some way, interfered with the care of others.

Indeed, in the course of psychological support, there is a clear indication to share one's cancer experience as a therapeutic act (an indication often misinterpreted as disclosure on social networks). As a matter of fact, talking about one's disease is tantamount to being able to address the problem through the experience shared with others and facilitating the understanding of the existence of a valid treatment strategy.

However, it is necessary to put in place strategies to reduce the risk of discrimination arising from the improper sharing of health data; this is necessary to prevent the loss of the beneficial effects of a possible law on the right to be forgotten in everyday life, due to the failure to adequately raise everyone's awareness of the need to respect privacy, which is violated by data subjects themselves because of their need to share such data. Talking about the disease with persons who live through the same tragedy, who are involved in the care or who are part of the family and friendship support, is very different from sharing it with persons who are only curious or motivated by less noble aims.

The CSB believes that the process to achieve the statutory right to be forgotten for cancer survivors must be supported by a deep cultural change in citizens, through careful sharing - rather than mere disclosure - that minimises, and possibly eliminates, the risk that the population may fall back into the old taboos linked to the disease as a stigma.

This can only happen through a constant and widespread educational activity, starting from schools.

Indeed, today's contradictory social environment tends to conceal diseases that are considered taboos just as it shares every detail of private life online, imprudently publishing personal and sensitive information on social media.

Such behaviour allows artificial intelligence algorithms to reconstruct everyone's medical history and to provide disease-related data to possible interested private institutions, by sharing secrets about previous childhood cancers, with serious family repercussions.

Finally, the risk of discrimination also affects the very personal sphere of parenthood: having been a

cancer patient may indeed change the judgement of suitability for adoption and thus heavily alter a family life project. A cancer patient is therefore forced to suffer double discrimination: the first as a result of the disease and the second because of the permanence of the stigma even after recovery.

It is necessary to reflect on the reasons that most often underlie the application for adoption by those who cannot have children, represented by the hope of starting a family and, at the same time, of offering affection and a dignified future to a child in difficulty. To deny this possibility is therefore a serious limitation of the future quality of life of both the prospective parents and the child to be adopted. However, in this regard, it is crucial first and foremost to protect children from possible psychological and socio-economic damage resulting from rash or self-centred decisions of the adults concerned. This certainly requires a careful assessment of the risks and benefits of adoption, taking into account, among other things, the life expectancy of the parent. This latter element is extremely important, and for this reason, a maximum age difference between the adopter and the adopted child is universally established in order to ensure a sufficient length of time for the expected cohabitation and the necessary support for the child¹⁵.

In this regard, the CSB considers that persons who, at the end of a statistically defined period from the end of the disease according to the type of cancer, are classified as former patients, should enjoy the same adoption right as apparently healthy persons, since they statistically share the same probability of disease.

¹⁵ Article 62 of Law no. 49/1986 of the Republic of San Marino requires that adoptive parents must be at least 18 years and no more than 45 years older than the adopted child.

THE RIGHTS OF SURVIVORS AND CAREGIVERS

Europe envisages the digitisation and centralisation of data on cancer patients and the issuance of a smart card from which healthcare professionals can trace the medical history of cancer patients. This enables them to keep track of the treatment performed at the various follow-up stages and to identify and monitor the most common difficulties faced by survivors due to poor management of the long-term effects of treatment, low levels of coordination within healthcare staff, lack of communication with such staff or insufficient rehabilitation programmes.

Indeed, all the above can cause varying degrees of emotional distress in persons previously suffering from cancer and can make cancer recurrence or metastatic disease more likely.

Moreover, in the social sphere, the most frequent emotional distress stems from the difficulties encountered in returning to work even after many years of the diagnosis and even after recovery.

For this reason, the process for cancer patients should include from the outset an assessment of the working conditions and possible adaptation upon return to work in order to implement measures facilitating social integration and professional reintegration¹⁶. Special attention should be paid to autonomous work, for which any disease of excessive duration would lead to complete exclusion from the market; this element has never been fully addressed in any socio-political agenda. The reason for this can be found in a paradoxical attitude, a source of serious and progressive social isolation, whereby autonomous workers are not considered entitled to claim the same rights as dependent workers by virtue of a tacit, presumed and misleading equalisation of the terms “autonomous” and “self-sufficient”.

The European Commission, through the “European Social Fund Plus”, will intensify support to Member States for the promotion of retraining and skills development programmes to help cancer survivors re-enter the labour market¹⁷.

In addition, a European study on the return to work of cancer survivors¹⁸ was launched; it is aimed at recognising the most relevant obstacles to full reintegration and the problems requiring particularly urgent action, in order to precisely indicate the activities effectively implemented by the political institutions of individual countries.

In this context, the CSB intends to emphasise the importance of guaranteeing the various assistance services in terms of rehabilitation and follow-up, without any impact at school in the case of minors or in the work place for adults who, due to reduced working hours, could suffer repercussions on their current income and future old-age pension, all amplified by gender inequalities.

The CSB also wishes to emphasise the need to guarantee specific forms of protection not only for patients and survivors, but also for caregivers who, burdened with their heavy responsibility to provide assistance, also have to bear the heavy economic consequences of the disease, including the expenses that patients and their families have to bear for travel and for rehabilitation and treatment

¹⁶ [Cancer Control Joint Action \(CanCon\)](https://cancercontrol.eu/archived/uploads/images/Guide/042017/CanCon_Guide_7_Survivorship_LR.pdf):

https://cancercontrol.eu/archived/uploads/images/Guide/042017/CanCon_Guide_7_Survivorship_LR.pdf.

¹⁷ <https://ec.europa.eu/european-social-fund-plus/it/cose-lfse>

¹⁸ This study is reported in the Europe’s Beating Cancer Plan, indicated in footnote 8.

programmes, coupled with reduced income due to continued absence from work.

This becomes all the more socially unjust because it discriminates against those who cannot resort to loans adequate to overcome the risk of insolvency and exposes patients and caregivers to a debilitating physical and mental overload; the latter increases their susceptibility to the various intercurrent diseases, in a vicious circle that is difficult to break, except with the due support of the society in which they are physically included but by which they are often ignored.

In this context, the EU Directive on work-life balance for parents and carers¹⁹ is rightly aimed at promoting - where necessary - carers' leave and flexible working hours in all Member States.

Therefore, the CSB believes that, alongside successful treatment, the key to restoring a true sense of normality in cancer survivors is social and professional reintegration, in accordance with the **bioethical principle of autonomy**.

The envisaged inclusion of cancer patients and survivors among persons with disabilities could provide additional support in the area of employment, under the "Strategy for the Rights of Persons with Disabilities 2021-2030"²⁰.

Another aspect that is economically and psychologically relevant to life quality is the frequent need for cancer survivors who have long healed to deal with insurance conditions that are unjustifiably prohibitive²¹.

Indeed, access to certain financial and banking services is provided only after declaring current or past diseases.

In this context, those who admit to having overcome cancer are considered "risk customers"²².

The risk calculation criteria applied by private financial stakeholders are mostly self-regulated, i.e. lacking specificity and uniformity.

Indeed, in the absence of up-to-date information on the continuous therapeutic progress made, in case of a serious, complex and relapse-prone disease such as cancer, they rely on data or models that are often obsolete and remain focused on the utmost defence of the principle of profitability of the financial institution.

All this contributes to generating a fragmentary, non-transparent and therefore poorly verifiable method of assessment, the outcome of which is often disappointing, i.e. characterised by a considerable increase in costs for the applicant or even a flat refusal of the requested service.

¹⁹ [Directive \(EU\) 2019/1158 of the European Parliament and of the Council of 20 June 2019 on work-life balance for parents and carers and repealing Council Directive 2010/18/EU](#)

²⁰ EUROPEAN COMMISSION, [Strategy for the Rights of Persons with Disabilities 2021-2030](#)

²¹ Patients' organisations refer in this regard to a "right to be forgotten", which should not, however, be confused with the same terminology used in the context of the [General Data Protection Regulation](#).

²² Article 18 of the [Directive 2014/17/EU of 4 February 2014 on credit agreements for consumers relating to residential immovable property](#) (Mortgage Credit Directive or "MCD") provides that, before concluding a credit agreement, the creditor makes a thorough assessment of the consumer's creditworthiness. That assessment shall take appropriate account of factors relevant to verifying the prospect of the consumer to meet his obligations under the credit agreement. Similarly, Article 20, paragraph 1 provides that the assessment of creditworthiness shall be carried out on the basis of necessary, sufficient and proportionate information on the consumer's income and expenses and other financial and economic circumstances.

What has just been described is in complete contrast to **at least two fundamental principles of bioethics**: that of **justice**, as equality of all with respect to essential rights, and that of **non-maleficence**. Indeed, in some countries, exclusion from life insurance and other financial instruments poses almost insurmountable obstacles and sometimes absolute impediments to the purchase of property for many former cancer patients; cancer survivors experience this as a “doubling of the punishment” by society, which, after patients have overcome a tragedy that is in itself difficult to accept, denies them the possibility of a gradual return to normal life.

In this context, the Europe’s Beating Cancer Plan will attempt to provide the European Commission with appropriate tools to assess as objectively as possible the practices related to financial services, including insurance services, with the aim of guaranteeing cancer survivors in long-term remission the same rights as apparently healthy people, while respecting the **bioethical principle of equity**.

To this end, the Commission will agree with companies on a code of conduct that combines their profit-making purposes with the progress made in cancer treatment; in this way, the assessment of eligibility for access to credit, insurance related to any credit or loan contracts and other financial services will include only the information that is strictly necessary and, in any case, proportionate to the amount to be disbursed.

THE RIGHT TO BE FORGOTTEN FOR CANCER SURVIVORS

The CSB believes that, in the light of what has been said so far, bioethics must urge society to reflect on the fundamental principles violated by a world immersed in the dream of eternal and widespread well-being, as unattainable as it is anaesthetising.

The **principles of justice**, of **non-maleficence** and, more broadly, of **autonomy** understood as the possibility of deciding how to invest one's physical, mental and economic resources, should be guaranteed to all citizens - and all the more so to those who have had to devote a large part of such resources to survival - through specific actions.

Therefore, the CSB hopes that in the Republic of San Marino a legislative gap can be filled in favour of cancer patients thanks to regulations recognising a “right to be forgotten” (RTBF)²³, similar to what has happened in some European countries²⁴.

At the time of drawing up this document, the Italian Chamber of Deputies unanimously approved a Unified Text²⁵, which will have to be examined by the Senate of the Republic before becoming State Law.

The text consists of five articles to eliminate unequal treatment in access to banking, financial and insurance services, adoption, access to insolvency procedures, employment and vocational training.

The Italian text intends to remove, in accordance with Article 3 of the Italian Constitution, the obstacles

²³ G. SCOCCA, F. MEUNIERB, *A right to be forgotten for cancer survivors: A legal development expected to reflect the medical progress in the fight against cancer*, in *Journal of Cancer Policy* 25 (2020) 100246.

²⁴ These are currently France (2016), Portugal, Belgium (2019), the Netherlands (2020), Romania and Luxembourg (2019). In Belgium, for example, persons who have been declared cured of cancer for at least ten years exercise their “right to be forgotten” when applying for insurance for outstanding balances and this facilitates the process of becoming property owners thanks to the granting of a mortgage loan. The same law reduces the above-mentioned period for certain types of cancer, limits the possibility of refusing insurance and reduces the additional premium ceiling for specific diseases as part of a policy ensuring broader protection of the chronically ill. In France and the Netherlands, the time-limit for the beginning of the right to be forgotten is five years after the end of treatment when cancer occurs before the age of 18 or 21; moreover, additional specific reductions of this time-limit are envisaged for a number of exceptions, which are regularly updated according to therapeutic progress in this field. Among other things, in France it is no longer necessary to fill out a medical questionnaire for loans of up to EUR 200,000 repayable by the age of 60; moreover, a national study has been launched to create an objective database for the real period of clinical monitoring needed after different types of cancer (on this topic, see: ELF ASSOGBA, A. DUMAS, A-S WORONOFF, C. MOLLÉVI, C. COUTANT, S. LADOIRE, I. DESMOULINS, TS DABAKUYO-YONLI; FRENCH NETWORK OF CANCER REGISTRIES (FRANCIM)). *Cross-sectional nationwide mixed-methods population-based study of living conditions, and identification of sexual and fertility profiles among young women after breast cancer in France: the Candy study protocol*. *British Medical Journal* 2022;12:e056834. doi:10.1136/bmjopen-2021-056834). Pending a scientifically valid answer, France is following the choice of other countries, in which the period of clinical monitoring regularly carried out after the end of treatment coincides with the maximum time-limit for the collection of information by insurance companies (see <https://ecpc.org/policy/the-right-to-be-forgotten/>).

²⁵ Chamber of Deputies, *“Provisions for the prevention of discrimination and the protection of the rights of people who have been affected by oncological diseases”*, text approved on 3 August 2023. In Italy, these activities are also part of the new National Oncology Plan 2023-2027 (MINISTRY OF HEALTH, *National Oncology Plan: planning and policy document for cancer prevention and control 2023-2027*, approved in the State-Regions Conference on 26 January 2023) to make the process for cancer patients more effective, efficient and appropriate, in order to empower people and at the same time contain health and social costs of cancer therapies thanks to greater integration between prevention, early diagnosis and care.

that limit the equality of persons cured of cancer, incorporating the European Parliament Resolution²⁶, which requests that "by 2025, at the latest, all Member States should guarantee the right to be forgotten to all European patients 10 years after the end of their treatment, and up to five years after the end of treatment for patients whose diagnosis was made before the age of 18".

These European requests aim at avoiding fragmentation of national practices, thus ensuring equal access to credit for cancer survivors, in line with the protection of personal health data expressed by the Council of Europe in two Recommendations of the Committee of Ministers:

- I. Recommendation (2016)8²⁷ on the processing of personal data for insurance purposes, which identifies the conditions justifying the processing of health-related personal data by insurers and prohibits, unless expressly authorised by law, to request predictive data related to genetic tests;
- II. Recommendation (2019)2²⁸ on rights and fundamental freedoms, in particular the right to privacy and to protection of personal data, which lays down special conditions for the processing of health-related data and reiterates the prohibition on disclosing such data to insurance companies and employers.

²⁶ [European Parliament Resolution of 16 February 2022 on strengthening Europe in the fight against cancer — towards a comprehensive and coordinated strategy](#) (2020/2267(INI)),

²⁷ Recommendation [CM/Rec\(2016\)8](#) of the Committee of Ministers to the member States on the processing of personal health-related data for insurance purposes, including data resulting from genetic tests (Adopted by the Committee of Ministers on 26 October 2016 at the 1269th meeting of the Ministers' Deputies).

²⁸ Recommendation [CM/Rec \(2019\)2](#) of the Committee of Ministers to the member States on Protection of Health-Related Data (Adopted by the Committee of Ministers on 27 March 2019 at the 1342nd meeting of the Ministers' Deputies)

VULNERABILITY OF CANCER SURVIVORS

The CSB believes that a change in the current cultural paradigm in favour of cancer survivors is paramount.

To achieve this, it is necessary to protect cancer survivors not only through immediate action, but also by means of a structured system of “pedagogical” initiatives that avoid the recurrence of punitive attitudes, even unintentional ones, in daily life.

A useful way of doing this is to grant such persons a specific status of vulnerability linked to the ethics of care - extensively justified by literature²⁹ - within which the right to be forgotten is also included.

The ethics of care is an approach based on moral assumptions and interests that place the care relationship between doctor and patient at the centre; such moral assumptions and interests also emphasise the importance of the informal aspects of health care and of the networks of relationships based on the concepts of caring, responsibility, competence and responsiveness implemented by the entire society, all of which support the quality of life of cancer survivors^{30,31}, including in relation to gender experiences in informal assistance and care relationships within and outside the oncological context.

What has just been described will be necessary in order to learn to reflect on the emotions associated with chronic and serious diseases, which are too often ignored due to atavistic fears and thus de facto relegated to the deepest silence by the culture of rejection³².

Precisely in relation to gender experiences, the CSB notes the paradoxical condition whereby the tendency to carry out generalised population screening may be one of the factors of vulnerability.

Indeed, without prejudice to the undoubted generic benefits of all screening actions, attention should be paid, for example, to the emotional imbalances associated with prostate cancer due to the related high risk perceived of losing sexual potency or, in women, the screening for breast cancer.

There are ethically questionable but completely ignored aspects in this area: the minimisation of the biological risk involved in diagnostic procedures (exposure to a low but nevertheless cumulative overload of ionising radiation) and the anxiety of the person waiting for a diagnosis - worsened by the

²⁹ On the relationship between vulnerability and the ethics of care see, among others: L. BENAROYO, *Responsibility and vulnerability: The resources of Emmanuel Levinas' thought for the ethics of care*. *Teoria*. (2023) RIVISTA DI FILOSOFIA, 43(1), 11–23. [HTTPS://DOI.ORG/10.4454/TEORIA.V43I1.170](https://doi.org/10.4454/TEORIA.V43I1.170); C. BOTRUGNO, *Information and Communication Technologies in Healthcare: A New Geography of Right to Health*, in "Rivista di filosofia del diritto, Journal of Legal Philosophy" 1/2021, pp. 163-188, doi: 10.4477/100643; L. CANDIOTTO ET AL., *Essere chiamati dalla sofferenza. Etica della cura appassionata e vocazione vulnerabile*. *Esperienze filosofiche/Filosofie della medicina e forme della cura*, 2015, 1: 39-51; D. RUGGIU, *Soggetto vulnerabile, innovazione tecnologica ed etica della cura*, in *Ars interpretandi, Rivista di ermeneutica giuridica* 2/2019, pp. 133-154, doi: 10.7382/95815; MG BERNARDINI ET AL., *Vulnerabilità: etica, politica, diritto*. (2018) Methexis. IF Press. ISBN 978-88-6788-135-2; S. BROTTTO, *Etica della cura. Una introduzione*, Orthotes, Naples 2013.

³⁰ M. DE VRIES, CJW LEGET, *Ethical dilemmas in elderly cancer patients: a perspective from the ethics of care*. *Journal of Clinical Oncology* 2018 Jul 20;36(21):2216-2222

³¹ ST AUNAN, GC WALLGREN, S. HANSEN, *The value of information and support; Experiences among patients with prostate cancer*. *Journal of Clinical Nursing* 2021;30:1653–1664

³² K. KENNY, A. BROOM, E. KIRBY, JL OLIFFE, D. WYLD, Z. LWIN, *Reciprocity, Autonomy, and Vulnerability in Men's Experiences of Informal Cancer Care*, *Qualitative Health Research* 2020, Vol. 30(4) 491–503

inherent error rate of the method used.

In the light of the above, it is necessary to take into account the biological, psychological and social characteristics of the person being screened, as well as the personal, social, political, economic or environmental circumstances in which the diagnosis is made and which may *de facto* worsen the “pathogenic vulnerability”.

The latter stems from the fact that an imbalance of power could easily arise between groups or persons already involved in morally dysfunctional relationships, including those dominated by abuse, or could trigger reactions capable of making socially weak persons even more vulnerable, thus radicalising certain unjust social or political manifestations or bringing about new conditions of vulnerability.

This position, apparently opposed to the undisputed current attitude of prevention at all costs, is supported by those who would like to avoid that activities originally animated by altruistic aims could generate harm in socially weak women, who, as such, are easy prey to their dysfunctional entourage, or in other women who are particularly apprehensive and could get caught in the net of a series of invasive and extensive, aggressively preventive interventions, despite presenting a low-grade malignant cancer³³.

However, beyond that, the vulnerability of cancer survivors remains. It represents a silent condition that can dramatically emerge at certain moments in life, often linked to apparent recrudescence of the disease, sometimes reawakened by age-related transition phases or particular social events.

The vulnerability of cancer survivors is often associated with a capacity for resilience that allows them to attribute meaning to the conflicting experiences and emotions lived in the impending risk of dying; this requires a radical differentiation between superfluous and essential aspects and a reworking of one's goals to adapt to an uncertain future or chronic disease³⁴.

Another source of vulnerability is the continuous alternation of treatment phases that are not entirely predictable, as they are strongly influenced by oncological progress.

This phenomenon is already being studied by a number of researchers involved in the design, implementation and verification of effective targeted interventions aimed at improving the quality of care in a clinical process that is increasingly characterised by chronic disease and by the aforementioned changes in interventions³⁵.

Indeed, not all therapeutic activities are necessarily a positive moment: some, in particular, can undermine the patient's motivation to fight against the disease and are themselves sources of vulnerability; this is due to the heavy side effects that can suddenly worsen the quality of life and cause significant economic losses, because of a sudden drop in work productivity and, sometimes, of the

³³ DA ROGERS, *Analysing the ethics of breast cancer overdiagnosis: a pathogenic vulnerability*. *Medicine, Health Care and Philosophy* (2019) 22:129-140

³⁴ N. MICHAEL, X. SYMONS, GL MENDZ, D. KISSANE, *Vulnerability and Resilience: Phenomenological Analysis of Cancer Patients Value Directives*. *Journal of Pain and Symptom Management*. 2022;64:438–448.

³⁵ K. SAURO, A. MAINI, M. MACHAN, D. LORENZETTI, S. CHANDARANA, J. DORT, *Are there opportunities to improve care as patients transition through the cancer care continuum? A scoping review protocol*. *British Medical Journal Open* 2021;11:e043374. doi:10.1136/bmjopen-2020-043374

additional costs linked to hospitalisation in private facilities or the purchase of drugs on one's own.

Quality of life is a key factor at any stage of life.

Older cancer patients perceive their natural ageing process more negatively than younger patients. This phenomenon has also been proposed as an indicator of vulnerability as it appears to have a long-term negative impact on physical health³⁶.

Young survivors, on the other hand, face different problems, represented mainly by doubts about fertility even more than by long-term insurance difficulties³⁷; for this reason, current treatment protocols try to preserve gonadal function as much as possible. However, almost inevitably cancer survivors will have to resort, upon request, to assisted reproduction, whose methods are not always fully supported by evidence-based protocols but often reflect experimental approaches, which are therefore not subject to insurance coverage. This entails very high costs that represent an insurmountable barrier for many of the patients and families concerned; on the other hand, applying for adoption - already complex in itself - entails a high risk of being denied this possibility by self-referential protocols, which are not superseded by specific regulations such as the one on the right to be forgotten³⁸.

³⁶ S. SCHROYEN, P. MISSOTTEN, G. JERUSALEM, M. VAN DEN AKKER, F. BUNTINX, F. ADAM, *Association between self-perception of aging, view of cancer and health of older patients in oncology: a one-year longitudinal study*. BMC Cancer (2017) 17:614 DOI 10.1186/s12885-017-3607-8

³⁷ A. DUMAS, R. ALLODJI, B. FRESNEAU, D. VALTEAU-COUANET, C. EL-FAYECH, H. PACQUEMENT, A. LAPRIE, TD NGUYEN, P-Y BONDIAU, I. DIALLO, C. GUIBOUT, C. RUBINO, N. HADDY, O. OBERLIN, G. VASSAL, F. DE VATHAIRE, *The right to be forgotten: a change in access to insurance and loans after childhood cancer?* Journal of Cancer Survivorship 2017;11:431-7.

³⁸ KC BURNS, H. HOEFGEN, A. STRINE, R. DASGUPTA, *Fertility preservation options in pediatric and adolescent patients with cancer*. Cancer 2018;124:1867-76

INSURANCE PROTECTION OF PERSONS CURED OF AN ONCOLOGICAL DISEASE

In many national legislations, during the period from diagnosis to treatment and possible recovery, persons suffering from various kinds of cancer in different organs are temporarily recognised as entitled to benefits similar to those of persons with disabilities.

Indeed, they receive a pension, have access to employment benefits (part time, possibility of smart working during the coronavirus pandemic, etc.), are exempted from co-payments on prescribed drugs and enjoy certain tax breaks. Therefore, in this sense, they can be considered to be disabled during the period of the disease, as this causes functional limitations which, in combination with various kinds of barriers, obstacles and discrimination, prevent full and effective participation in social life on an equal footing with other citizens. The issue of insurance is related to the social and cultural stigma that affects such persons.

The UN Convention on the Rights of Persons with Disabilities provides for the prevention of discrimination also in the field of insurance. Indeed, when taking out insurance policies, it is common practice to consider persons with any kind of functional limitations as being at greater risk of a reduced life expectancy or exposed to health complications specific to the underlying disease. The approach just described increases the cost of insurance premiums and may even lead to a refusal to take out a policy. For this reason, Article 25 (Health) of the UN Convention reads that «States Parties shall (...) e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner.

This issue then shifts from the clinical description of the disease or functional limitation, summarised in a diagnosis, to the topic of being a person, with all personal characteristics.

In the United States of America, the approach of precision medicine and precision psychiatry³⁹ has recently been proposed, according to which, starting from diagnosis, the health status of persons affected by a disease or functional limitations is addressed in a more precise manner. This approach is intended to prevent that a diagnosis only involves the health description of the person, by going instead into the actual functioning. The above methodology could be applied to anyone who has a disability or has had cancer and recovered from it, assessing the real impact of the health condition when taking out insurance. From this perspective, it is not merely functional limitation or age that will affect life expectancy and health status, but the lifestyle maintained up to that moment.

This issue has been underlined by some research activities, which have shown that the insurance system penalises and discriminates against persons with disabilities, particularly those of an intellectual and relational nature, and their families, and anyone in a particular condition of dependence because they suffer from multiple disabilities.

Even in Italy, some insurance companies have started to make adjustments in the taking out of certain policies. Other countries, such as the United States of America, have paid attention to this matter. The

³⁹ NATIONAL RESEARCH COUNCIL – Committee on framework for developing a new taxonomy of disease. *Toward precision medicine: building a knowledge network for biomedical research and new taxonomy of disease*. Washington (DC): National Academies press (US); 2011. FERNANDES et al., *The new field of "precision psychiatry"*. BMC Medicine 2017.

Italian law called “Dopo di noi” (After us), which is in favour of those who no longer have parental care, increases the deductible limits of insurance policies for persons with complex disabilities.

Therefore, in addition to the necessary right to be forgotten, due consideration should also be given to positive measures such as those just described, which are capable of eliminating discrimination based on prejudice and supporting the full citizenship of such persons in terms of equal opportunities.

CONCLUSIONS

The CSB believes that the legal status of vulnerable persons is fundamental to enhancing the psychosocial coping capacities of cancer survivors, through the design of specific care interventions and the development of inclusive and non-discriminatory programmes, thus fully implementing the European guidelines aimed at harmonising such behaviours among all the participating countries⁴⁰.

These interventions will be more incisive and effective if they are based on the continuous progress of medical care, through an open dialogue between scientists and decision-makers; beyond the need to identify stable general criteria for the recognition of the right to be forgotten for cancer survivors, such dialogue should enable the rapid updating of “legal” cure times for the different types of neoplasia⁴¹, in a new cultural and social view of disease, which guarantees full respect for the fundamental rights of cancer patients and the bioethical principles of beneficence, non-maleficence, autonomy and justice understood as equal access to treatment.

⁴⁰ OPINION OF THE ETHICS COMMITTEE OF THE UMBERTO VERONESI FOUNDATION, *Dignity and justice beyond disease*. 2022.

⁴¹ The usefulness of providing research lines in this regard has been demonstrated by a recent report by the *Belgian Health Care Knowledge Centre* (KCE): <https://annualreport.kce.be/2021/en/right-to-be-forgotten-programme/>

RECOMMENDATIONS

Aware of the profound bioethical significance of the need to undertake a cultural process that avoids the stigmatisation of persons cured of cancer and promotes the implementation of the principles of equity and justice, the CSB makes the following recommendations:

- that the various institutions, starting with schools, can take information and educational actions regarding a conscious use of social media and the importance of not providing one's own health data to such media, so as not to unintentionally contribute to encouraging possible forms of discrimination and stigmatisation relating to one's own diseases or those suffered by the loved ones;
- that the implementation of operational plans to ensure access to cancer prevention and treatment even in times of crisis be strengthened;
- that institutions promote and support the conduct of clinical trials marked by a culture of evidence-based clinical diagnostic and therapeutic appropriateness in a context of continuous advancement of scientific knowledge in the specific field of reference;
- that the systematic collection of information on cancer patients is implemented through the establishment and continuous updating of the cancer register;
- that it is possible to delete information on the web concerning the health conditions of persons who have been diagnosed with cancer or other diseases from which they have been cured on the basis of certificates from competent professionals or institutions;
- that the presence of disability/impairment and life expectancy are included in a comprehensive, personalised and accurate assessment of the health condition of a person applying for an insurance policy, by considering not only the consequences of the diagnosis, but also other factors, such as lifestyle and general health conditions, in order to overcome cultural and social discrimination and stigma;
- that research on the actual health conditions of persons suffering from diseases or functional limitations is encouraged through scientific tools such as precision medicine.