



European Cancer  
Patient Coalition



# White Paper on Socio-economic ableism and Disparities induced by Cancer

*A Review of the 2019 **ECPC Survey** Results  
and Policy Recommendations*

Apostolidis, K  
Bajorek, Z  
de Miro d'Ajeta, R  
de Lorenzo, F  
Myloneros, T  
Wilson, S

May 2023



# Table of Contents

<b>Executive Summary</b> .....	<b>i</b>
<b>Acknowledgements</b> .....	<b>ii</b>
<b>Introduction</b> .....	<b>3</b>
<b>Background</b> .....	<b>4</b>
Contextualizing disability .....	6
Disability and cancer .....	8
Cross-border quality of care and social rights equality .....	9
<b>Aim of the survey</b> .....	<b>11</b>
<b>Methodology</b> .....	<b>12</b>
<b>Results</b> .....	<b>12</b>
Cancer disability and benefits for patients and carers .....	12
Cancer patients and carers in education or employment .....	13
Self-employed workers .....	13
Cancer and pension rights .....	13
Financial discrimination against cancer patients and survivors .....	13
Examples of best practice .....	13
<b>Recommendations</b> .....	<b>13</b>
<b>References</b> .....	<b>17</b>



## Introduction

It has been more than thirty years since it was widely discussed and accepted by health policy makers, that to tackle the major diseases and their impact on people, we need to look further than just the narrow spectrum of health care services and medical treatment. The Dahlgren-Whitehead rainbow model [1] illustrated in a simple manner that human activities and the way we organize our societies, determine our health far more than personal behaviour and lifestyle.

That approach encouraged policy makers to think beyond health sector and develop multisectoral policies that would end up improving health, well-being and the overall quality of life, such as environmental and urban planning policies. One of these sectors, that preceded health systems, is welfare and social insurance; a mechanism that protected people from the risk and impact of ill-health and greatly supported the development of the 20<sup>th</sup> century.

This model also proved to be substantial in recognizing how social inequalities affect health [2]. Socioeconomic inequities indicate the existence of health inequities, meaning that some people not only do have greater risk of getting sick because of the conditions they live in, but also because of structural inequities that can be eliminated with effective policies. Sir Professor Michael Marmot captured the very essence of that notion by starting his seminal book “The Health Gap: The Challenge of an Unequal World” [3] with the phrase “*Why treat people and send them back to the conditions that made them sick?*”.

Non-communicable diseases (NCDs) are the main driver of burden of disease and of loss of quality life in Europe, with cancer being the second cause of death after cardiovascular diseases. It is estimated that in 2020 approximately 2.7 million people in the European Union were diagnosed with cancer, and another 1.3 million people lost their lives to it [4]. However, lives lost to cancer in the EU are set to increase by more than 24% by 2035 making it the leading cause of death in the EU [5]. Considering that cancer does not only affect the lives of the patients but also of their families, friends and carers, the impact is expected to be broader and most importantly uncharted.

Recently the EU has embarked on a multifaceted fight against cancer and renewed its commitment, for the first time since the early 1990s. Europe’s Beating Cancer Plan [6] reflects that commitment by mobilising the collective power of the EU to tackle major challenges across the cancer care spectrum. More specifically, the Plan aims to tackle the entire disease pathway based on four key action areas: prevention; early detection; diagnosis and treatment; and quality of life of cancer patients and survivors.

This is where the European Cancer Patient Coalition’s present report comes in. The ECPC as a trusted partner of EU institutions is standing at the core of Europe’s Beating Cancer Plan collective powers, by ensuring the voice of cancer patients in Europe is heard and represented in all relevant policymaking decisions in the European Union [7]. The results of a survey performed in 2019 looking

into the social and financial support that Member States provide to cancer patients, survivors and their caregivers, can significantly help the fourth pillar which focuses on improving the quality of life of cancer patients and survivors.

Europe's Beating Cancer Plan might be focusing initially on what research, innovation, digitalisation and new technologies has to offer, however, ECPC identifies that eliminating social inequities, strengthening the welfare state and promoting whole-of-government approaches that improve living and working conditions of patients and caregivers are key to minimizing the incidence and social burden of cancer.

## Background

According to updated evidence by the European Cancer Inequalities Registry<sup>1</sup>, wide social inequalities in cancer incidence and survival exist both between (Figure 1) and within European countries (Figure 2). In order to understand the social and economic impact of cancer on individuals and families it is necessary to consider a range of social policy areas including eligibility to welfare support, protection in employment, and access to financial services. The European Cancer Patient Coalition continues to lead an EU-level campaign towards greater equality and equity in social determinants related to cancer, especially in the working environment that affect also cancer care.

**Social groups that experience discrimination, exclusion and marginalization, face greater risk in cancer inequities, both in terms of incidence and impact.** Overall socioeconomic and racial/ethnic inequalities in cancer incidence, survival and mortality have been documented since decades ago [8]–[10]. It is far more likely for people that already experience inequities in health care access to also receive poor quality care, that significantly increases the risks of long-term effects, disability and impairment.

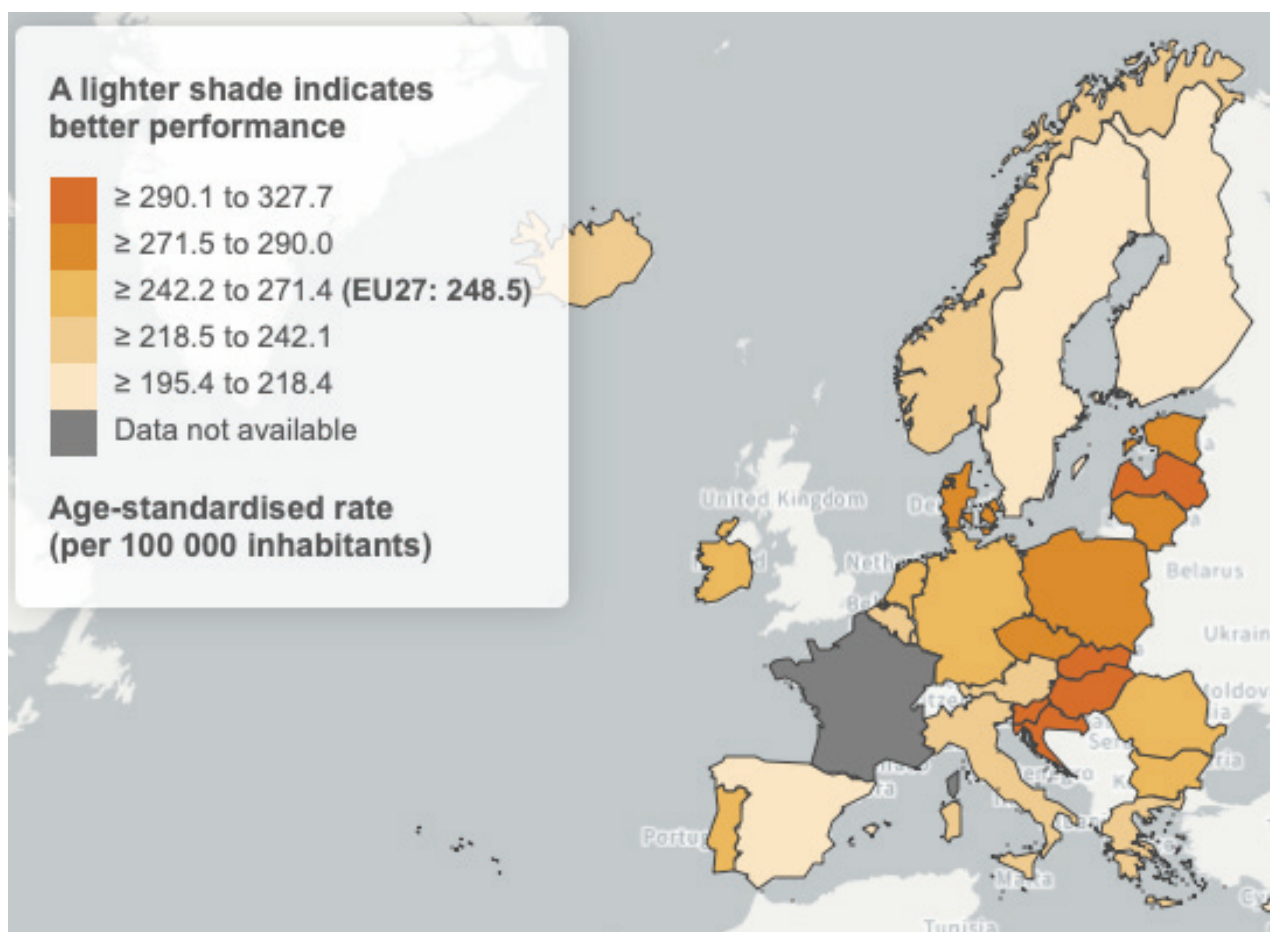


Figure 1. Death rate of malignant neoplasms (2019) by country, ECIS

1 <https://cancer-inequalities.jrc.ec.europa.eu>

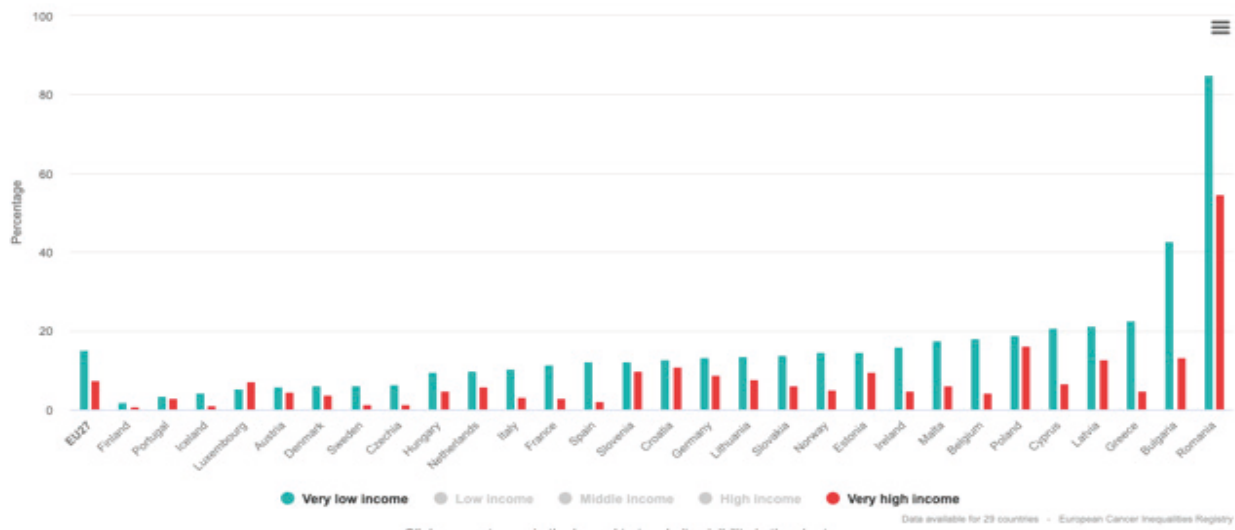


Figure 2. Women that self-reported to have never had breast examination by X-ray (2019) by country and income, ECIS

**Cancer outcomes are very much linked to a range of factors and socioeconomic determinants including health care quality, health system capacity, funding, governance, inclusion policies and political commitment.** Cancer survival rates, which are a core indicator of the quality of cancer care, vary substantially between countries and social groups. It is evident that there are not only disparities between high- and low-income economies [11], [12], but also between countries with seemingly similar health systems [13] and between different population groups within countries [14] depending on local social determinants, access to health and social care and financial protection.

**It has been evidenced that Financial Toxicity, originating from lost income, care expenses, etc. results in an important, yet understudied actual threat to patient and family quality of life after diagnosis and poorer outcome of treatments. Financial toxicity is a major determinant of health and relates to the financial hardship that cancer patients and their carers can have related both to the cost of treatment, but also to the financial burden on other aspects of their life, either direct or indirect** (out-of-pocket payment for care, payment for non-clinical costs related to access in care, loss of income, etc.). Cancer is typified by treatment plans which are burdensome and exact a heavy toll on all aspects of quality of life - including physical functioning and emotional well-being -with protracted recovery times in some cases. Financial toxicity results in a substantially understudied threat for the patient’s health and quality of life, as well as their close social circle and carers [15].

**Suboptimal health coverage can push cancer patients and their relatives closer to poverty** [16]. Not only that, but impoverishment increases the risk of relapse, multimorbidity, disability or even death. That means that any effort to address the burden of cancer must be aligned by a comprehensive social support package, in order not to make the treatment futile. In that manner, if the spectrum of cancer care does not include the social and financial protection aspects, it might as well create a negative loop of diseases and hardship and increase the impact of cancer-induced disability among both patients and survivors [17].



## Contextualizing disability

**There are approximately one billion people with disabilities globally.** Despite the fact that disability affects roughly 15 % of the global population, it is often overlooked both in health policy and in research on health access [18].

**There are quite a few definitions of disability across agencies, academic fields, health and social organizations, national systems and international frameworks.** Only in the USA in 2003, there were no fewer than 67 federal statutory definitions of disability [19]. Definitions that determine eligibility for services and supports tend towards minimizing the number of beneficiaries due to cost and increasing aging population. Other services and organizations that aim to protect the rights of patients and people are rightly so more focused on antidiscriminatory approaches.

**Definition differences mostly reflect the evolution of the society's perspective and understanding of disability and its relation to health.** This means that mechanisms and legal framework will always be steps behind the actual needs of the people with actual disabilities. In that sense, national governments and stakeholders have to be constantly inclusive in order to succeed flexibility to adapt towards strengthening social and health coverage.

**Lack of comparability in defining disability has been a key obstacle in developing both a solid body of evidence on the health disparities, as well health and social policies** [19]. A recent study on disability, work absenteeism, sickness benefits, and cancer in selected European OECD Countries [20], concluded alarmingly that there are significant signs of falling societal responsibility toward the citizens experience different kinds of incapacity or impaired working ability and independence.

**According to the 2011 World Report on Disability** [21], **disability is the umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors).** Disability is not only related to a person's health condition or impairment, but results from the interaction with a range of contextual factors including the range of welfare state coverage, cultural background, societal attitudes, access to infrastructure, discriminatory policies, age, and gender. Experiencing disability is largely affected by the normalization of ableist attitudes and social structures [19]. Ableism is stereotyping, prejudice, discrimination, and social oppression of people with disabilities [22]. These limitations, which interact with personal and contextual factors of the environment, result in disability. Consequently, disability is mainly identified in the interaction between individual and structural factors [23], [24].

**Disability as the outcome of multiple and dynamic interactions is related to the eco-social approach, which considers that population health is much shaped by the interaction of factors at the micro- and macro-level** [25]. Linking different determinants of health factors such as age, gender, and disability status with environmental influences, not only can offer a useful analytical tool

to examine the complexities of physical and social vulnerabilities, but it is considered a “one-way street” policy if we want to invest in equality and sustainability.

**Based on the above, the International Classification of Functioning, Disability, and Health (ICF)<sup>2</sup>, conceptualises disability as emerging at the intersections of contextual and personal factors, and health conditions.** Disability results from the interaction of having a condition-based limitation and experiencing barriers in the environment. As described above ([Introduction](#)) the environment includes not only the physical environment, but also social factors like culture, attitudes, economics, and policies that shape our life experiences [1]. The ICF model is the most accepted model of disability in public health but its adoption has been slow because it is based on a model of social participation, and not on the medical model that is still predominant in the health systems.

## Disability and cancer

**The ICF is a useful tool to understand how long-term effects contribute to significant disability among cancer survivors.** The ICF recognizes the dynamic interplay between health conditions (such as cancer and its treatments) with bodily symptoms and side effects (such as pain, fatigue, and mental functions), which in turn contribute to more distal outcomes such as activity limitations and participation restrictions. The ICF offers a broad lens to understand disability, as it acknowledges both the need for curative and rehabilitative approaches to prevent and treat disease and dysfunction, while addressing the equally important goal of maximizing participation in meaningful life activities.

**Disability rates vary by cancer type, cancer stage, and treatment protocol, which makes it even more difficult to assess the situation.** For example, in survivors of breast cancers, sarcomas (especially when the treatment protocol includes amputation) and head and neck cancers (especially when the treatment protocol includes neck dissection), common long-term negative effects include pain, fatigue, disturbed sleep, psychosocial distress, anxiety, depression and altered body image [26].

When it comes to cancer and disability there are two distinctive cases:

**(a) When a disability precedes the diagnosis of cancer (Figure 3):** In this case, usually disabled people face inequities in accessing cancer care. Not only do people with disabilities experience disparities in health access and outcomes, but their needs and experiences also remain invisible [19]. There is a growing body of evidence on disparities in cancer service utilization for people with disabilities, predominantly screening and diagnostic services, limited information is available on cancer incidence [27]. For instance, research has consistently been documenting that women with disabilities receive lower rates of clinical preventive services such as mammograms, and receive differential treatment of detected cancers [28], [29].

**In this first case, three pathways of embodiment of discrimination in relation to accessing cancer services have been identified [30].**

---

2 <https://icd.who.int/dev11/l-icf/en>

- **Normativity expectations** where several of the interactions with healthcare services shared by the participants point to aggressions towards their dignity and right to receive appropriate care, by having their disability-related needs ignored.
- **Lack of disability awareness**, by healthcare professionals.
- **Discontinuity of care**, where people living with cancer often experience a lack of coordination between the different clinicians involved in their care. Disabled people are especially exposed to this discontinuity of care, because they are often observed by one team for their impairment and by a separate one when something new emerges, such as cancer.

**(b) When a disability follows the diagnosis and usually is a direct or indirect result of cancer (Figure 4).** In the second case, we are looking into how cancer can be the cause of any kind of disability or impairment. The current report is focusing on this case, by reviewing the results of a survey investigating inequities in disability assessment and benefits for cancer patients and survivors.

**Evidence from a research investigating the relationship between disability and four common types of cancer (colorectal, prostate, ovarian, and non-Hodgkin's lymphoma) suggest that persons with disability may constitute a high-risk population, with higher cancer incidence [31].** Considering the fact that in some countries, like the UK, cancer diagnosis is considered a disability no matter if there are symptoms present [32] and disability increases barriers in access to care, we can conclude that both people with disabilities and people with cancer do have something in common. They often experience structural disadvantages in the form of marginalization, stigma, impoverishment because of their health status, higher rates of unemployment or informal employment and exclusion from their basic human, social and health rights [21]. When these two are combined the results are devastating for the persons, their families and the social cohesion.

**However, the connection of cancer to disability on a long-term basis is largely absent from health policy and health equity agendas.** Even though according to contemporary and legal definitions cancer survivors are considered to be people with disabilities, it has been found that approximately 40 % of cancer survivors experience long-term effects of the disease, which led to severe activity limitations and participation restrictions [33]. Cancer survivors display multiple approaches in addressing disability identity issues, like rejecting, othering, acknowledging, and affirming.

## Cross-border quality of care and social rights equality

**At the core of the European Union is the concept of four types of freedom of movement: free movement of goods, services, people and capital.** Among the challenges of realizing that concept is pertaining an appropriate quality of health and social care services across countries and that the movement of people is not constrained by their health or any disparities in employment rights including health benefits. Whereas many of the elements required to deliver high-quality health care are subject to European standards, such as the licensing of pharmaceuticals and certain technical

aspects of health technology, there is still much to be done to ensure that a health and social care service or social benefits are not preventing people from moving in the region [34].

**In 2011 the European Parliament and the European Council issued the Directive 2011/24/EU on the application of patients' rights in cross-border healthcare [35] which moves away from promoting trade in services towards promoting citizens' rights.** The main scope of the Directive was to facilitate access to safe and high-quality healthcare in another Member State and to ensure patient mobility in accordance with the case law of the Court of Justice of the European Union. However, the Directive did not create any new patient entitlements, only clarified existing ones including the right of EU citizens to receive reimbursable health care in another EU country as long as the type of treatment and costs involved would normally be covered in their own national health jurisdiction [35]. The second goal of the 'Directive' was to promote cooperation on healthcare between Member States for the benefit of EU citizens, regarding access to medicines, cost-sharing, innovative and/or experimental treatment and health technology assessment.

**Cross-border equality in social rights, benefits and quality of care has become a prominent issue in the European Union.** The increasing mobility of people, either deliberately or forced by circumstances, has increased also the amount of people seeking jobs and requiring medical care in different national contexts. More often now people move across borders even with the sole purpose of seeking care that is either non-existent in their country (i.e., innovative cancer therapy) or of better quality. For example, initiatives to eliminate barriers in access to rare cancer treatment consider that persons from all EU Member States should have equal access; consequently, for the treatment to have the same quality and efficiency, a high-level social support should apply.

---

*The Joint Action on Rare Cancers (JARC) [36] is aimed to integrate and maximize efforts of the European Commission and EU Member States to advance quality of care and research on rare cancers. Accordingly, JARC is shaping its efforts around the European Reference Networks (ERNs)<sup>3</sup> three of which are specifically devoted to rare cancers and have been conceived by the EU Commission as a means to provide "highly specialised healthcare for rare or low-prevalence complex diseases". Furthermore, the JARC produced ten recommendations instrumental to the policy agenda on rare cancers in the European Union for the years to come, the "Rare Cancers Agenda 2030" [37]. It is rather evident that EU is moving forward unifying approaches to cancer, therefore it's only a matter of time for actions towards addressing cancer-induced disabilities to follow.*

---

**The concept of quality in health systems is understood in diverse ways, therefore there is no consensus on how precisely to define quality of care.** In general, quality of care is the degree to which health services for individuals and populations increase the likelihood of desired health outcomes

---

3 [https://health.ec.europa.eu/european-reference-networks\\_en](https://health.ec.europa.eu/european-reference-networks_en)

and are consistent with current professional knowledge [38], [39]. The concept of quality of care is also described according to a set of dimensions. These are *effectiveness, efficiency, access, safety, equity, appropriateness, timeliness, acceptability, satisfaction, patient responsiveness* or *patient-centeredness*, and *continuity of care*.

**Patient safety is considered a core element rather than just a dimension of quality of care.** Safety relates to the reduction of risk, including minimizing and eliminating the risk of disability. This can be done at three levels: the clinical, the organizational and the national. Policies to minimize and eliminate risk of disability due to a disease should be aligned with a broader set of policies, outside the narrow set of clinical interventions. The added vulnerability of patients who work, reside and/or receive care outside their country of residence, where they are unfamiliar with the system or they have less entitlements than in their country, requires that particular attention is paid to not undermine the rights of European citizenship.

## Aim of the survey

In 2015, the European Cancer Patient Coalition (ECPC) published the Position Paper titled “Challenging the Europe of Disparities in Cancer - A Framework for Improved Survival and Better Quality of Life for European Cancer Patients” [40]. In 2017, consultation with ECPC members led to a project presented at the 2018 AGM for mapping the legal framework provisions for illness, pension and employment for cancer patients and their carers in all EU Member States. In 2019, the ECPC conducted a survey on the socio-economic burdens of cancer with the aim to trace a complete frame of social disparities in Europe; indicate issues and suggest remedies; and point out and highlight eventually existing best practices. The survey had a large field of interest, covering different aspects of socio-economic difficulties of people affected by cancer: patients, relatives and formal or informal carers.

The scope and hope of the survey and its results are to support EU and its Member States formulate a better picture of social disparities that exist in Europe, provide concrete examples of best and worst practices, draw attention and raise questions, draft answers and suggest policies in order to achieve real change in securing social rights across the European Union for all people affected by cancer: those undergoing acute treatment, the survivors and those with advanced and metastatic cancers, including people who care for them – their carers. The ECPC members believe, supported by the already mentioned scientific findings on financial toxicity, that socio-economical rehabilitation is not only a necessary part of the treatment and a fundamental right of the persons affected by cancer, but also a prerequisite of social cohesion and healthy and sustainable development.

## Methodology

The survey questionnaire was divided in five sections:

- (a) After diagnosis, steps to certification or assessment of a disability conditions.
- (b) Difficulties for employed patients and/or carers.
- (c) Difficulties for self-employed patients and/or carers.
- (d) Pension prejudice for patients and/or carers.
- (e) Insurance, Loans, Mortgages and other discriminations.

Respondents were individuals from ECPC network of national representatives. They were asked to answer each question according to their real-life experience or direct professional knowledge. Some responses therefore may not provide a complete picture of that country depending on the knowledge base of the respondent. However, they responses are pretty indicative of the situation and steers the focus on the necessity of further thorough research on the subject.

## Results

### Cancer disability and benefits for patients and carers

Respondents from 27 countries confirmed that a procedure for assessment of a disability status is required from cancer patients. In at least 8 member states, however, the procedure is conditioned by the employment status of the patient. It has to be pointed out that a distinction between working disability (both general or job-specific) and disability as an impairment of the health condition of the person can lead to inequalities. There is no Europe-wide classification of disability caused by cancer. Wherever disability assessment can determine access to any facilitation, cancer-induced disabilities have peculiarities that must be considered: a patient's condition is changing rapidly in time, due to surgery or side effects of medical treatments, differing a lot from other disabilities, which are more likely permanent or time lasting. The duration of disability assessment procedures varies a lot in different countries, in a range from few weeks to a couple of years. Cancer patients, more than other disabled persons, dramatically need speeding up the procedure, otherwise any facilitation might be cancelled or minimized by the delay in decision making. As a best practise, in Italy the Law provides for accelerated procedure in cancer cases (namely, 15 days).

In most EU countries the assessment of a total disability or partial inability status entitles the person to social benefits such as economic allowances, tax reductions, paid sick leave. Fewer countries (less than half) allow benefits to the caregiver of a disabled person. A few more country reports indicate legal provisions in favour of parents or other caregivers for children. Respondents from 4 countries (Cyprus, Greece, Latvia, Luxembourg) stated that caregivers have no entitlement to social benefits depending to the disability of family member cancer patients.

### Cancer patients and carers in education or employment

Thanks to medicine progress, most of cancer patients may have a life expectancy equal to the general population. Any means of preserving their occupation should be considered a fundamental part of rehabilitation and, on the other hand, this is a critical issue for the sustainability of welfare systems. Adult cancer patients employed in public or in private education are allowed paid sick leave in most EU countries, for an extent of time which varies a lot, ranging from a minimum of few weeks in Denmark, to a maximum of 2 years in Switzerland. Further inequalities depend on being employed in the public or private sector. Only in 17 countries, employees are protected from unfair dismissal. In a minority of countries caregivers can be entitled to paid leave. In this case the best practise is in Italy, where a caregiver for a seriously handicapped family member (a cancer patient being considered as such when under high impact therapy or terminal) is allowed 3 days per month of paid leave plus two years in his life. In most countries an employed cancer patient can obtain reasonable adjustment of his working conditions, which include part-time, exemption from night or heavy work, smart working, protection against change of location, but respondents from Hungary, Latvia and Slovakia could not find a reference of similar protections. A lower level of protection and benefits exist in some countries in favour of caregivers.



It is crucial that employers be encouraged and assisted in employing cancer survivors. In most EU countries there is no legally established incentives for employers to employ cancer patients and survivors.

## Self-employed workers

Even though the EU Social Pillar compels member states to abolish inequalities between employed and self-employed workers, in most countries the self-employed face a severe discrimination in case of illness afflicting their work-capacity, due to a lack of public insurance or indemnity provisions.

The assumption that self-employment is synonymous with 'self-sufficiency' leads to the lack of community support and in most cases assistance is depending upon private insurance. Those without private insurance (or lacking sufficient contributions to government schemes where these exist) are left to fend for themselves. There are few examples of the self-employed being entitled to state support in the form of paid sick leave.

Self-employed individuals are more financially vulnerable than employed people when they are diagnosed with a serious condition. As a consequence, some may be forced to continue working when they are not fit enough to do so or rely on disability benefits. The responses also show vastly divergent systems in place across Europe and make it difficult to recommend specific policy interventions in this area. The lack of benefit provisions is even worse in the case of self-employed caregivers. Overall, self-employed patients and caregivers families appear to be more at risk of financial difficulties than those who work.

## Cancer and pension rights

On the basis of the survey responses it is apparent that half of EU countries do not make provision for pension contributions that are missed as a result of illness, unless paid sick leave includes contribution. In Croatia, it was noted that survivors are only entitled to benefits if the cancer had resulted in incapacity to work.

Fewer than half of the countries represented in the survey reported entitlement to pension benefits in compensation of the time spent out of work caring. In Estonia there is only entitlement if the cancer patient is a child. Finland reported that a carer is only entitled to benefits of this type after a care agreement has been concluded. The level of compensation provided can be dependent on the type of care required.

Of the countries that responded positively in their answer to the question that some type of entitlement to pension credits is available for carers, half stated that a disability assessment was necessary to qualify.

In Romania a carer can classify for disability benefits, and financial support, but the cancer patients must be classified as having a particular degree of disability in order for the social welfare measure to apply. Similarly, in Belgium and Estonia the disability needs to be certified. In Norway, the requirement for an assessment depends on the level of care to be provided.

In Finland, it was highlighted that different municipalities have different processes.

## Financial discrimination against cancer patients and survivors

The social rehabilitation not just of a Cancer patient, but even of a Cancer survivor is jeopardized by the stigma of a presumed shorter life expectancy than the general population. Even if there is contrasting evidence and uncertainty in scientific literature on the subject, insurance companies, banks and employers incline to discriminate the Cancer people.

In a number of countries (e.g. Finland, Greece, Hungary, Ireland, Lithuania, Norway, Portugal, Romania, Slovenia and Sweden) policies are dependent on the individual terms and conditions of the insurance company.

In the UK survivors can subscribe for health insurance, but there may be restriction and exclusions, or the policy may be more expensive than the average claim, and insurers can still decline a claim. In Belgium people are entitled to a private health insurance, meaning an insurance company can't refuse insurance, when they apply. However private insurers can exclude an existing condition from coverage.

As to Life insurance, patients have limited or no access to life insurance across Europe and cover is frequently restricted or subject to special terms and conditions. Cancer survivors' access to life insurance policies is restricted and those surviving cancer may find themselves subject to cover limitations and higher premiums. In Belgium there is a compensation fund which applies when people have to pay excessive premiums because of medical reasons, with potential to support cancer survivors. In Lithuania it was reported that insurance companies may decline access altogether. In Estonia it was noted that being a cancer survivor is seen as a liability and an individual is a high risk: an individual's prognosis is a deciding factor.

Cancer survivors access to long-term loans and mortgages is very restricted in some European countries; access is said to be non-discriminatory in fewer than half: Belgium, Croatia, Cyprus, Czech Republic, Denmark, Hungary, Norway, Romania, Slovenia, Sweden. In Croatia, it was reported that the denial to provide a loan would be considered under the discrimination act.

In Italy, a long term loan may be obtainable subject to the condition that the lessee obtains a life insurance, which return to the above mentioned issue.

Lease agreements are similarly affected.

Under the name of "Right to be forgotten" few EU countries (France, Belgium, The Netherlands, Luxembourg) have recently (some, after the survey was made) introduced statutory provision preventing that policies or loan contracts require a Cancer survivor to declare this personal condition, after 5 or 10 year after the end of treatment (shorter delays for some specific cancers) in order to prevent any discrimination. Examples of best practice and recommendations

**Cancer diagnosis should immediately set the person eligible for temporary benefits until the assessment is completed.** Mental distress and time for diagnostic exams alone require for employment benefits, paid sick-leave of minimum 90 calendar days or until assessment is completed and non-clinical costs related to cancer care. Moreover, this would strengthen treatment at early stage of cancer and also motivate social services to pace up the assessment and compensation procedures.

**In continuation to the above, it is necessary to minimize waiting times to be assessed for disability benefits and assessment criteria that recognise the specific challenges of patients with cancer and of those who care for them.** Not only the quick assessment has immediate impact to the course of the treatment, but it is important for the patient to not experience any kind of psychosocial distress especially related to structural barriers and disparities. Social and financial benefits are crucial to the outcome of the disease directly and indirectly to the quality of life. Best practice to this purpose is in Italy, where the disability level assessment procedures must be completed within 15 days from the diagnosis certification.

**Cancer diagnosis should enhance employees' rights, protect their health and ensure smooth transition between disease stages, especially for women who historically have been facing social discriminations in the working environment.** According to the Article 168 of the Treaty on the Functioning of the European Union [41], EU action on health issues aims to improve public health, prevent diseases and threats to health. That includes de facto protecting employees from conditions that may lead to worsening health or causing impairment. These rights mean a cancer patient or survivor can have more power to negotiate for changes in their workplace or working conditions, that do not reduce their income and protect also their health.

**Harmonisation of disability, functionality and impairment framework across European Member States with respect to employment rights of patients and their carers, and effective enforcement of legislation protecting cancer patients from unfair dismissal.** Even if definitions vary, the EU needs to adopt a general guideline on what is considered as disability and protect the rights of the patients in an equal manner across the region

**Cancer patients or survivors in higher education and/or research, should be eligible of health and social benefits, regardless of income, and considered in a full employment relationship with their institution in terms of negotiation flexibility.** People involved in education and research, belong to one of the most productive population groups and are a significant asset for the sustainability and equity of our societies. Any risk related to the impact of diseases and specifically cancer, should be eliminated. Thus, not only students and researchers should be protected and supported, but the rule of law when it comes examinations, deadlines and fee payments should be flexible according to the needs of the person.

**Adopt mechanisms and models to support cancer survivors financially, socially and mentally.** Cancer survival might be considered the end of a personal and difficult journey by most, it is however the beginning of a complex set of interconnected elements between health protection against recurrence, social reintegration (right to be forgotten) and dealing with PTSD. There are models developed by research [42], that can help policymakers, practitioners and researchers to understand and address the complex relationships between elements acting at different levels of health services and systems that are thought to contribute to variation in survival.

**Compensate for periods of ill-health resulting in gaps in pension contributions either due to illness or caring for a family member.** Financial support for the period where loss of income occurs due to

the disease is the cornerstone of the welfare state in Europe since the 19<sup>th</sup> century. When cancer is related to exposure through the working environment this compensation should be higher; this would also enhance protective measures and prevention from the employers.

**Eliminate insurance, loan and mortgage discriminations against cancer patients and survivors through a set of legal framework and directives.** Not allowing a person access to financial support due to health status is violating basic social rights. Even more so when doing so while under treatment, when most probably there is loss of income.

Develop culture of quality training programmes for health professionals **concerning the rights and social rehabilitation of cancer patients and family carers.** Widespread cultural change especially in the health system and health workforce will gradually enforce cultural change in the society when it comes to the elimination of ableism and social support as crucial component. Eliminating cancer-related disparities might be a global public health priority, but it should be also a whole-of-government global social policy priority, focusing on the human and social rights aspect.

**Acknowledging and addressing structural ableism is important because pervasive experiences of ableism are associated with poorer health and well-being.** The impact of real and anticipated stigma has also been shown to decrease health and help-seeking behaviours and overall quality of life. Real and anticipated stigma around disability was identified as one reason that participants eschewed a disability identity.

**Disability among cancer survivors should be approached considering two different aspects:**

- (a) The heterogeneity of the disability experience.** There is significant diversity in the nature and severity of individual impairments and their impact on people's lived experience. The disabling long-term effects tend to be both under-diagnosed and difficult to treat. Cancer survivors often feel unprepared and unsupported when dealing with long-term disabling symptoms and their impact on social roles and participation. Stigma and structural ableism is internalized in patients, providers and processes, resulting in severe health inequities for cancer survivors [26].
- (b) The lack of a common definition of the term 'disability'.** In spite of the profoundly pervasive physical, cognitive, and psychosocial long-term effects, only half of cancer patients identify themselves as a person with a disability or even avoid the label of disability as a result of external and internalized negative biases against disability. Acknowledging one's disability status may help increase self-worth, self-efficacy and access to available health and community-based services as well as social supports [43].

Cancer care must be intentionally anti-ableist. There is a need for frank discussions about the long-term disabling impact of cancer as well as the implementation of interventions to promote meaningful social participation amongst cancer survivors [26]

**ECPC has also been recommending repeatedly that carers are entitled to appropriate health insurance to help prevent and alleviate the mental, psychological and physical burden they**

**experience.** The members have highlighted that ‘providing monetary compensation for carers is essential in valuing their contribution to society, reducing financial toxicity of carers and improving the sustainability of long-term care’. The survey observations indicate that many countries fail to provide this and seemingly undervalue the carer role.

**Disability assessment is largely linked to the capacity to work or attaining a job in quite a few countries. This is problematic in at least two ways and it should be changed.** First, it creates barriers in access to assessment for excluded, marginalized and other persons that do not belong in the working body of the population (children, unemployed, refugees, informal workers,+ etc). Second, it de facto discriminates the population in regard to their health and social rights, depending on their working ability, which is a significantly outdated approach. Overall, the aim should be to not even include a question whether disability assessment depends on the employment status. This issue would merit further research. The quality of assessment should not be affected by work status. On the other hand, if a person is in work, all options for helping them retain their job should be explored.

## References

- [1] G. Dahlgren and M. Whitehead, "Policies and strategies to promote social equity in health. Background document to WHO – Strategy paper for Europe," *Inst. Futur. Stud.*, no. September 1991, p. 69, 1991.
- [2] G. Dahlgren and M. Whitehead, "The Dahlgren-Whitehead model of health determinants: 30 years on and still chasing rainbows," *Public Health*, vol. 199, pp. 20–24, Oct. 2021, doi: 10.1016/j.puhe.2021.08.009.
- [3] M. Marmot, "The health gap: the challenge of an unequal world," *Lancet*, vol. 386, no. 10011, pp. 2442–2444, 2015, doi: 10.1093/ije/dyx163.
- [4] ECIS - European Cancer Information System, "Cancer burden statistics and trends across Europe," 2020. <https://ecis.jrc.ec.europa.eu/index.php> (accessed Apr. 20, 2022).
- [5] International Agency for Research on Cancer, "Cancer Tomorrow," 2023. <https://gco.iarc.fr/tomorrow/en/> (accessed Jan. 22, 2023).
- [6] EU and European Commission, "Europe's Beating Cancer Plan - Communication from the Commission to the European Parliament and the Council," *COM(2021) 44 Final*, 2021, [Online]. Available: [https://health.ec.europa.eu/system/files/2022-02/eu\\_cancer-plan\\_en\\_0.pdf](https://health.ec.europa.eu/system/files/2022-02/eu_cancer-plan_en_0.pdf).
- [7] European Cancer Patient Coalition, "Policy and Societal Issues," 2023. <https://ecpc.org/policy/> (accessed Jan. 22, 2023).
- [8] N. Krieger, "Defining and investigating social disparities in cancer: Critical issues," *Cancer Causes Control*, vol. 16, no. 1, pp. 5–14, 2005, doi: 10.1007/s10552-004-1251-5.
- [9] M. Kogevinas, N. Pearce, M. Susser, and P. Boffetta, "Social inequalities and cancer: a summary by the editors.," in *IARC Scientific Publications*, 1997.
- [10] H. P. Freeman, "Poverty, Culture, and Social Injustice: Determinants of Cancer Disparities," *CA. Cancer J. Clin.*, 2004, doi: 10.3322/canjclin.54.2.72.
- [11] C. Allemani *et al.*, "Global surveillance of trends in cancer survival 2000-14 (CONCORD-3): analysis of individual records for 37 513 025 patients diagnosed with one of 18 cancers from 322 population-based registries in 71 countries," *Lancet (London, England)*, vol. 391, no. 10125, pp. 1023–1075, Mar. 2018, doi: 10.1016/S0140-6736(17)33326-3.
- [12] A. R. Hosseinpoor *et al.*, "Socioeconomic inequality in the prevalence of noncommunicable diseases in low- and middle-income countries: Results from the World Health Survey," *BMC Public Health*, vol. 12, no. 1, 2012, doi: 10.1186/1471-2458-12-474.
- [13] M. Arnold *et al.*, "Progress in cancer survival, mortality, and incidence in seven high-income countries 1995–2014 (ICBP SURVMARK-2): a population-based study," *Lancet Oncol.*, 2019, doi: 10.1016/S1470-2045(19)30456-5.
- [14] A. Kampouras *et al.*, "Child Morbidity and Disease Burden in Refugee Camps in Mainland Greece," *Children*, vol. 6, no. 3, p. 46, Mar. 2019, doi: 10.3390/children6030046.
- [15] F. Perrone *et al.*, "The association of financial difficulties with clinical outcomes in cancer patients: Secondary analysis of 16 academic prospective clinical trials conducted in Italy," *Ann. Oncol.*, 2016, doi: 10.1093/annonc/mdw433.
- [16] S. Thomson, J. Cylus, and T. Evetovits, "Can people afford to pay for health care? New evidence on financial protection in Europe," Copenhagen, 2019. [Online]. Available: <https://apps.who.int/iris/bitstream/handle/10665/311654/9789289054058-eng.pdf>.
- [17] L. W. Niessen *et al.*, "Tackling socioeconomic inequalities and non-communicable diseases in low-income and middle-income countries under the Sustainable Development agenda," *The Lancet*. 2018, doi: 10.1016/S0140-6736(18)30482-3.
- [18] H. Kuper and P. Heydt, "The Missing Billion Report," *WHO Publ.*, 2019, [Online]. Available: <https://www.themissingbillion.org/the-report-2>.
- [19] G. L. Krahn, D. K. Walker, and R. Correa-De-Araujo, "Persons with disabilities as an unrecognized health disparity population," *Am. J. Public Health*, vol. 105, pp. S198–S206, 2015, doi: 10.2105/AJPH.2014.302182.
- [20] M. Jakovljevic, C. Malmose-Stapelfeldt, O. Milovanovic, N. Rancic, and D. Bokonjic, "Disability, work absenteeism, sickness benefits, and cancer in selected European OECD Countries-forecasts to 2020," *Front. Public Heal.*, 2017, doi: 10.3389/FPUBH.2017.00023.
- [21] WHO, "World Report on Disability," Geneva, 2011. doi: 10.1111/j.1741-1130.2011.00320.x.
- [22] K. R. Bogart and D. S. Dunn, "Ableism Special Issue Introduction," *J. Soc. Issues*, 2019, doi: 10.1111/josi.12354.
- [23] D. Marks, "Dimensions of Oppression: Theorising the embodied subject," *Disabil. Soc.*, 1999, doi: 10.1080/09687599925975.

- [24] T. Shakespeare, *Disability rights and wrongs revisited, second edition*. 2013.
- [25] N. Krieger, "Methods for the scientific study of discrimination and health: An ecosocial approach," *Am. J. Public Health*, 2012, doi: 10.2105/AJPH.2011.300544.
- [26] S. Magasi, H. K. Marshall, C. Winters, and D. Victorson, "Cancer Survivors' Disability Experiences and Identities: A Qualitative Exploration to Advance the Cancer Equity," *Int. J. Environ. Res. Public Health*, vol. 19, no. 5, 2022, doi: 10.3390/ijerph19053112.
- [27] D. Sakellariou and E. S. Rotarou, "Cancer disparities for people with disabilities: Bridging the gap," *JNCCN J. Natl. Compr. Cancer Netw.*, vol. 18, no. 8, pp. 1144–1146, 2020, doi: 10.6004/jnccn.2020.7614.
- [28] S. L. Parish and A. W. Saville, "Women with cognitive limitations living in the community: Evidence of disability-based disparities in health care," *Mental Retardation*. 2006, doi: 10.1352/0047-6765(2006)44[249:WWCLLI]2.0.CO;2.
- [29] E. P. McCarthy *et al.*, "Disparities in breast cancer treatment and survival for women with disabilities," *Ann. Intern. Med.*, 2006, doi: 10.7326/0003-4819-145-9-200611070-00005.
- [30] D. Sakellariou *et al.*, "Pathways of disability-based discrimination in cancer care," *Crit. Public Health*, vol. 30, no. 5, pp. 533–543, 2020, doi: 10.1080/09581596.2019.1648762.
- [31] L. I. Iezzoni, S. R. Rao, N. D. Agaronnik, and A. El-Jawahri, "Cross-sectional analysis of the associations between four common cancers and disability," *JNCCN J. Natl. Compr. Cancer Netw.*, vol. 18, no. 8, pp. 1031–1044, 2020, doi: 10.6004/jnccn.2020.7551.
- [32] H. of Lords Select Committee on the Equality Act, "The Equality Act 2010: the impact on disabled people," *London Station. Off.*, 2016.
- [33] K. D. Stein, K. L. Syrjala, and M. A. Andrykowski, "Physical and psychological long-term and late effects of cancer," *Cancer*. 2008, doi: 10.1002/cncr.23448.
- [34] WHO, *Cross-border Health Care in the European Union. Mapping and analysing practices and policies*. 2011.
- [35] European Parliament and European Council, "Directive 2011/24/EU: The application of patients' rights regarding cross-border healthcare," *Off. J. Eur. Union*, 2011.
- [36] European Commission, "Joint Action on Rare Cancers [JARC] [724161]," 2016. [https://webgate.ec.europa.eu/chafea\\_pdb/health/projects/724161/summary](https://webgate.ec.europa.eu/chafea_pdb/health/projects/724161/summary) (accessed Jan. 25, 2023).
- [37] Rare Cancers Europe, *Rare Cancer Agenda 2030*. Youcanprint, 2020.
- [38] Lohr K.N., *Institute os Medicine. Medicare: a strategy for quality assurance*. 1990.
- [39] H. Legido-Quigley, I. A. Glinos, K. Walshe, B. van Beek, C. Cucic, and M. McKee, "Quality and safety," in *Cross-border Health Care in the European Union. Mapping and analysing practices and policies*, M. Wismar, W. Palm, J. Figueras, K. Ernst, and E. van Ginneken, Eds. 2011.
- [40] M. Lawler *et al.*, "Challenging the Europe of Disparities In Cancer - A Framework for Improved Survival and Better Quality of Life for European Cancer Patients," Brussels, 2015. Accessed: Jan. 25, 2023. [Online]. Available: <https://ecpc.org/wp-content/uploads/2019/08/ECPC-White-Paper-Europe-of-disparities-EN-3.pdf>.
- [41] European Union, "Treaty on European Union and the Treaty on the Functioning of the European Union (Official Journal C 326 , 26/10/2012 P. 0001 - 0390)," *Off. J. C 326 , 26/10/2012 P. 0001 - 0390*, 2012.
- [42] M. Morris, S. Landon, I. Reguilon, J. Butler, M. McKee, and E. Nolte, "Understanding the link between health systems and cancer survival: A novel methodological approach using a system-level conceptual model," *J. Cancer Policy*, vol. 25, no. June, p. 100233, 2020, doi: 10.1016/j.jcpc.2020.100233.
- [43] M. R. Nario-Redmond, J. G. Noel, and E. Fern, "Redefining Disability, Re-imagining the Self: Disability Identification Predicts Self-esteem and Strategic Responses to Stigma," *Self Identity*, 2013, doi: 10.1080/15298868.2012.681118.
- [44] Lillini · De Lorenzo · Baili · Iannelli · Del Campo · Pero · Traclò · Sproviero · Sant · Perrone Out-of-pocket costs sustained in the last 12 months by cancer patients: an Italian survey-based study on individual expenses between 2017 and 2018 - The European Journal of Health Economics <https://doi.org/10.1007/s10198-022-01544-9>
- [45] Riva, Efficace, Di Maio, Bryce, Del Campo, De Lorenzo, Frontini, Giannarelli, Gitto, Iannelli, Jommi, Montesarchio, Traclò, Vaccaro, Arenare, Canzanella, Gimigliano, Romano, Savio, Sparavigna, Piccirillo, Guizzaro, Gallo, Perrone A qualitative analysis and development of a conceptual model assessing financial toxicity in cancer Support Care Cancer 29, 3219–3233 (2021). <https://doi.org/10.1007/s00520-020-05840-z> patients accessing the universal healthcare system



European Cancer  
Patient Coalition

06, Avenue des Arts  
1210 Brussels  
Belgium  
info@ecpc.org  
[www.ecpc.org](http://www.ecpc.org)