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## How do social security schemes and labor market policies support the return-to-work of cancer survivors? A review article



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#### ABSTRACT

Objective: About 40% of new cancer diagnoses are detected among working age individuals. Cancer diagnosis and treatment have high impact on the work ability of workers and represent a real challenge for the healthcare and social security systems but also for employers and the labour market. This review aims at investigating the legal frameworks set up in EU Member States that support the retention and integration of workers with disability. Furthermore, we look at these initiatives or measures to see whether they fit the specific needs of workers with cancer.

Methods: We searched the PubMed database combining 4 key words: cancer, labour market, labour law and disability insurance or disability benefits. A total of 1.185 articles were found of which 10 were used for this review. In addition, grey literature, reports from the European Commission, the OECD and the WHO were searched and included in the material used for this review.

Results: Few peer reviewed articles discuss the impact of labor market law on the (re)integration of cancer survivors. Most measures and initiatives support workers with chronic diseases but present important limits when considering workers with cancer. Collaboration and coordination among health providers, social workers and employment decision makers is the mostly required and effective.

Conclusion: More research efforts should be made to systematically assess the impact of labor market and employment measures and initiatives on the (re)integration of workers with chronic diseases, with specific attention for workers with cancer. Legal frameworks need to be rethought for a better balance between productivity and equity, inclusion and social justice.

#### 1. Background

The basic objectives of return-to-work policies are to ensure the quality of life of workers by maintaining them professionally active while supporting employers to cope with ill-workers needs and their own performance needs. This seemingly straightforward objective in fact turns out to be complicated due to the different domain and level of competences involved.

While the treatments and the management of its effects are the prerogatives of healthcare providers, the assessment of the ability to work and the underlying recovering time and social benefits are organised through the social security schemes. On the other hand, the rights and duties of both employees and employers depend on the labour market and employment laws.

According to the country history and welfare system in place, these spheres of competencies are shared by different authorities having different agendas and priorities. The resulting return-to-work pathway is at crossroads of these three areas (healthcare, social security and employment) in addition of importantly relying on the self-perceived health status and ability to work of the ill-worker.

Cancer-related work disability

In 2012, the WHO estimated the worldwide 5-year prevalence of cancer survivors in the EU-28 to 7 157 000 people (Globocan 2012). Among them, children who will need to be educated despite potentially be suffering from learning disabilities or bone and muscle problems; but also adults who need to care for their children and or remain active on the labour market; and elderlies who have to struggle with multimorbidity and poor quality of life.

In this paper, we will focus on adult cancer survivors who still present minimum working abilities and their (re)integration on the

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labour market.

Cancer is a long-term illness that can cause temporary and/or permanent disabilities but does not always obtain an official recognition as a disability or the access to disability benefits. Currently, cancer is often regarded as a chronic disease because of the potentially recurrent spells of treatment or relapses and the accompanying inability to work.

However, the cancer diagnosis and its inextricable link with the vital prognosis make it specific, with singular medico-social requirements. The announcement of the cancer diagnosis may provoke important psychosocial distress in patients and family.

Cancer treatments have an intensive and acute phase (repeated in case of non-response or relapse) with short-term and side effects. The most common reported effects are fatigue, pain and psychosocial distress. Unlike most chronic diseases, cancer treatment also implies long-term and late effects that can appear several months or years after the end of the treatment, such as neuropathy and neurocognitive deficits, cardiopathy, fertility issues, dysfunction of digestive or respiratory systems, etc. [1].

As the number of new cancer diagnosis increase and that cancer mortality rates decrease, decisions-makers in charge of organizing cancer control policies will need to pay more attention to cancer survivors, and notably those representing the working force, to ensure the sustainability of healthcare and social security systems.

In this paper, we first explore the different measures and initiatives in the EU-28 which aim at facilitating the labour market retention and integration of people with disabilities. Secondly, we discuss the extent to which these policies are adequate and benefit also to cancer survivors.

#### 2. Material and methods

Three searches have been conducted on PubMed. The first search used *Cancer (and) employment law* as key words. It resulted in 27 results, of which 14 were retained after a careful title screening. Three of these 14 articles were effectively used, based on the reading of the abstracts.

The same selection strategy was performed on the 702 results obtained from the use of *cancer* (and) labour law, with 10 articles retained after titles screening and 1 finally used for this review; and on the 223 resulting papers from the search using *cancer* (and) disability insurance, of which 20 were selected based in their titles and 6 retained after reading the abstracts.

The political and legal dimension of the issue required also a screening of the grey literature, especially reports, communication and recommendations of the EU Commission<sup>1</sup> and Parliament. The OECD, ILO and WHO websites were also screened.

The list of articles and the major reports used to write this review are reported here below:

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(PubMed) cancer survivors (and) employment law 27 results; 14 retained after title screening and 3 used

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(PubMed) cancer (and) disability insurance; 223 results; 20 selected after titles screening and 6 used after abstracts screening

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European Parliament's Employment and Social Affairs Committee (EMPL)

<sup>&</sup>lt;sup>1</sup> http://ec.europa.eu/social/main.jsp?langId=en&catId=22.

European Commission European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe COMMUNICATION FROM THE COMMISSION TO THE EUROPEAN PARLIAMENT, THE COUNCIL. THE EUROPEAN ECONOMIC AND SOCIAL COMMITTEE AND THE COMMITTEE OF THE REGIONS European Commission, DG Sick pay and sickness benefit Employment, Social Affairs schemes in the European Union. and Inclusion Background report for the Social Protection Committee's. In-Depth Review on sickness benefits (2016) European Commission, DG Disbaility and Labour Market **Employment, Social Affairs** Integration. Analytical Paper. and Inclusion Ágota Scharle and Márton Csillag, Budapest Institute European Commission, DG Promoting new measures for the Employment, Social Affairs protection of women workers and Inclusion with oncological conditions by means of social dialogue and company-level collective bargaining World Health Organization WHO global disability action (WHO) plan 2014-2021 Organization of Economic Sickness, Disability and Work: Cooperation and Breaking the Barriers. A Development (OECD) Synthesis of Findings across OECD Countries Published on November 24, 2010 United Nations (UN) Convention on the Rights of Persons with Disabilities International Labour C159 - Vocational Rehabilitation Organisation (ILO) and Employment (Disabled Persons) Convention, 1983 (No. 159) Convention concerning Vocational Rehabilitation and Employment (Disabled Persons)

#### 3. Results

The 10 peer review articles that were selected for this review are mainly focusing on reporting individual (or small cohort of cancer patients) experiences with return-to-work and discuss the associated observed limits without bringing it at the system level.

On the other hand, most reports, communication and recommendations from the large international institutions present legal and ethical aspects on the labor market (re)integration of -mainly-people with disabilities, with scarce cancer-related specificities.

The junction of both types of results allows us to have an enlightened thought and discussion on the fitness of labour and employment-related political measures and legal frameworks with the need of cancer survivors.

## 3.1. EU and international institutions attempts to promote the (re) employment of ill-workers

The measures that support people with disabilities in resuming work mainly depend on national or regional healthcare, social security and employment policies. Even though the European institutions have limited prerogatives of providing binding frameworks in these areas, one can notice the multiplication of EU attempts to encourage Member States at paying attention to the issue (Box 1) [2]. A prominent example is the paragraph 35 of the European Parliament resolution of 10 April 2008 on combating cancer in the enlarged European Union which states that the EU "Calls on the Commission to draw up a charter for the protection of cancer patients and chronically sick people in the workplace with a view to requiring companies to enable patients to continue in employment during their treatment and to return to their normal professional activities".

In 2008, the Employment and Social Affairs Committee of the European Parliament requested a study to "gain an understanding of the barriers but also of the facilitators enhancing reintegration outcomes for chronically sick and absent workers" [3]. In the conclusions, authors provided nine policy recommendations that relate either to a greater psychosocial and vocational rehabilitation support for workers or to the revision of the legal disability frameworks to avoid discrimination, and finally to implement actions according to an integrated approach.

Worldwide, the oldest initiative is probably the Vocational Rehabilitation and Employment (Disabled Persons) Convention of 1983 of the International Labour Organization. In its second article, the convention states that "Each Member shall, in accordance with national conditions, practice and possibilities, formulate, implement and periodically review a national policy on vocational rehabilitation and employment of disabled persons". At present, 83 (/187 members) countries have ratified the Convention.

#### Box 1

The list of the main documents from the EU institutions that support the implementation of a supportive legal, social or economic protection framework for the return to work of cancer survivors.

- the Charter of Paris (4 February 2000), which was signed at the New Millennium World Cancer Summit;

(Entry into force: 20 Jun 1985)

- the European Charter of Patients' Rights, which was drafted by Active Citizenship Network and 12 citizens' organizations (including the Belgian Federation against cancer) at the conference on The Future Patient (Brussels, 14–15 November 2002);
- the Joint Declaration on the Rights of People with Cancer (Oslo, 29 June 2002), and the European Guidelines for the Rights of People with Oncological Conditions, (Athens, 16 April 2005), which were approved at the general meeting of the European Associations against Cancer, ECL. (31 countries):
- the 2005 European Framework for of protection for sick workers, drafted, once again, by ECL;
- the European Parliament Resolution on breast cancer (5 June 2003);
- the 2007 Manifesto on Preventing Cervical Carcinoma in Europe, promoted by the European Association against Cervical Cancer, and supported by the International Association and the European Organization against Cancer;
- the European Parliament Resolution (25 October 2006), focusing on women workers with breast cancer;
- the European Parliament Resolution against cancer in the enlarged European Union (10 April 2008).

**Table 1**List of initiatives related to work reintegration after sick leave in EU member states (type and year enacted).

	Economic incentives (year of the reform)	Revalidation or re-integration measures (year of the reform)	Evaluation (year of the evaluation)
Norway The Netherlands	2002: new calculation of the benefits 2006: experience-rating for insurance fees for employers	2002: the Gatekeeper Protocol	2013 and 2014 2016
The Netherlands	2006: (faster) degressive benefits	2002. He Gulekeeper Frotocol	2010
Denmark		2009: Mandatory rehab during sick leave	2015
The United Kingdom		2003: the pathway to work programme and enlarged in 2005	2007 and 2013
Hungary		2009: personalized and comprehensive support	2016
Austria		2013:Fit2Work programme	2015
Italy		2003: part-time return to work	
Estonia	2016: new work ability assessment	-	

In 2010, the OECD considered the issue of the employment of disabled people and published the report entitled "Sickness, Disability and Work: Breaking the Barriers" [4]. This report clearly demonstrates the high risk for disabled people and their family to fell into poverty, mainly because of a limited access to the labour market. The main underlying recommendations concern the involvement and coordination of all actors (healthcare providers, employers, workers, authorities). It also suggests the provision of incentives to promote job retention and hiring of people with disabilities and call for more systematic evaluation of local programmes to support the evidence-based practice and policy developments.

#### 3.2. EU member states initiatives to facilitate the employment of ill-workers

Within EU Member States, very few specific legislation are protecting cancer survivors and those in force are mainly related to the avoidance of occupational exposure to carcinogens. Most initiatives target general workers with disabilities (mainly chronic or musculoskeletal problems).

While reviewing the initiatives in that direction, we do observe two perspectives in the actions taken to (re)integrate disabled-workers on the labour market. First those initiatives that relate to the level of wages and social benefits (reported as 'financial incentives' directed to employees or employers) and second, those which focus on the employability of the ill-worker [5]. In the EU-28, Nordic countries (Denmark, Sweden and Finland), the Netherlands, the United Kingdom, Austria and Spain are found as the pioneers in the implementation of reintegration strategies [4–6]. The Table 1 summarizes the initiatives described below.

#### 3.2.1. Economic measures: the financial incentives

Until the beginning of the 21st Century, the inclusion in the labour market of people with disabilities has for a long time not been considered as a priority and was even reported as a taboo when coming to cancer survivors [7]. The financial crisis of 2007 led to the scarcity of resources, austerity and forced governments to engage drastic savings. Social protection systems were consequently challenged and most EU countries started to look for decreasing expenditures on social security, including disability benefits. This has mainly led to the revision of the access and the level of disability benefits, based on the idea that a decrease in social benefits tends to motivate recipients to return-to-work.

In Norway and in the Netherlands, the calculation and the level of disability benefits have been revised (and reduced). In both cases, first results of evaluation have shown positive impact on return-to-work, especially among young workers, i.e. below 45 years old [8–10].

In Austria, companies have to employ at least one disabled worker per 25 employees, on pain of a fine<sup>2</sup> and in Sweden, employers can be entitled to retrieve up to 80% of the wage of their disabled workers [11].

In the Netherlands, where workers have to be since at least two years on sick leave before applying for disability benefits, since 1996, employers are obliged to provide wages during these two years. In 1998, the Dutch government introduced the "experience-rated system". Employers therefore cover the costs of disability (up to ten years, except for small companies) according to their past experience of employees receiving disability [12].

In Italy, the Legislative Decree no. 276/2003 grants people with cancer the right to work part-time instead of full-time and return to their full-time employment later on. However, this measure did not produce tangible results, mainly because the weak correlation of working time measures with social security and assistance benefits, and with incentive schemes promoting reemployment. They inevitably involve adaptation of the work environment on the part of the employer that is not offset by the reduction of the sick worker's salary because of fewer hours worked.

#### 3.2.2. Vocational rehabilitation measures

The United Kingdom introduced the "Pathways to Work programme" through pilots in 2003 which were expanded in 2005 and finally introduced in Great Britain in June 2011 [13]. The programme target social benefit recipients and enroll them eight weeks after having entered a benefit claim. They receive several support sessions with advisers focusing on their ability to work, planning actions for their return to work (including discussion on job opportunities). Encouraging results but to be taken with cautious of an evaluation conducted in 2007 [14] present higher rates of employment among participants compared to the others.

Regarding mental disorders, an international initiative funded by the European Commission (DG Health and Consumers) called EQOLISE [15] was run in six European Member States. The initiative was based on the principle of the "Individual Placement Support" (IPS) which provides direct training on the job, instead of general vocational rehabilitation. The evaluation of this randomized control study [16] reported better employment outcomes for workers who benefit from the IPS, as well as a more interesting cost-effectiveness balance.

#### 3.3. Cancer-related boundaries and specificities

As exemplified in the previous, very few initiatives are diseasespecific, with mental health as the only exception.

However, it has been reported that workers with chronic diseases are the victim of prejudices and stereotypes related to their disease, and have to cope with forms of work organization that penalize them as based on extremely rigid criteria, among others workplace presence, fitness for work and productivity [17].

Cancer-related stigmas are well known and start with the relation to death [18]. Despite the outstanding improvement in cancer treatments and survival, cancer remains associated with death. This stigma is even more problematic and discriminative when coming to extended health insurance and private disability insurance which can be denied to cancer survivors because of a past diagnosis of breast cancer [19].

 $<sup>^2</sup>$  English description of the Act on the official ILO website:  $http://ilo.org/dyn/natlex/natlex4.detail?p_lang = en&p_isn = 42258&p_count = 96232&p_classification = 08.01&p_classcount = 1625.$ 

Cancer survivors also fear the image that their coworkers have of them because of their physical changes (hair loss, weight loss) but also because some would think and argue that they are responsible to have develop cancer, through non-adequate behaviors [20].

Moreover, importantly and unlike most chronic diseases or people with permanent impairments, cancer survivors are at risk to face late effects, several months or years after the treatment ended [1]. This reality is destabilizing for the worker, its line manager and colleagues. One could seem to have completely recovered and several weeks after his return present disabling symptoms, such as extreme fatigue, digestive and/or respiratory complications.

Some research even found that among working women, self-reported discrimination seems to be endogenous to job loss [21]. Within cancer survivors, differences in employment rates are also found according to gender and the type of occupation. For example, farmers and laborers are less likely to be employed after their diagnosis than individuals with other occupations. In general, low-income individuals appear the most likely to lose their job later on. These results highlights the reinforced vulnerability in the workplace for workers whose job requires an important amount of physical efforts and who are surviving cancer [21].

Two categories deserve therefore specific attention. First, the self-employed people who bear earlier financial burden and pressure to resume work despite their recovery needs putting at risk the effectiveness of the treatment [22]. Besides self-employed, those survivors unemployed at the moment of diagnosis are also especially vulnerable because their cancer history add to their difficulty of finding a new job [23].

#### 4. Discussion

Most initiatives and measures are financial and put more burden on either employers or workers or sometimes, on both of them. However, these financial incentives present limits and are not always adequate with the practical needs. Moreover, in the case of workers with cancer, studies have shown that the return-to-work represents more than only financial resources. It also means complete recovery, recover self-esteem, social contacts, return to "normal" life, etc. [24,25].

Besides financial measures, a reallocation of public subsidies should follow. They should not be used to fund passive policies that lead to inactivity but to promote incentives favouring workers' retraining and return to work [17]. Even if return-to-work has been suggested as an indicator of rehabilitation success [26], vocational rehabilitation remains too rarely offered to cancer patients [27].

Three important aspects seem to be underlying the success of the reviewed measures and initiatives. First, the pragmatism which prescribes that incentives should be accompanied by very practical support for employers and workers such as it was the case in Denmark, where the Danish Cancer Society published in 2002 a brochure at the attention of managers and caregivers entitled "When an Employee Develops Cancer" [28].

Second, it has to be person and work-centered. Indeed, a better and objective assessment of work ability is needed [29]. Studies reveals that worker noted that, for example, the forms used to assess their ability to work ignore several important factors such as the fluctuations in condition and late effects which are unpredictable [30]. One needs to conduct evaluations targeted on each person and that consider one's ability to work, occupation and tasks, type of contract and working time, work environment and relationship with colleagues and supervisors [17].

Thirdly, the elimination of discriminant practices is essential as well as more attention on those who are the most at risk, such as self-employed, low income and unemployed workers who get cancer. The implementation of non-discriminant policies need to be monitored and accompanied by sanctions to ensure their implementation. Indeed, when the occupied job allows for the adjustment of working-time and/

or the arrangement of the workstation and ergonomics are technically feasible but not provided, cancer survivors may rightfully feel discriminated [31].

Health professionals, as well as survivors themselves, must take action on three fronts to combat cancer-based discrimination: public and professional education, individual and group advocacy, and appropriate use of legal remedies [32].

#### 5. Conclusion

The objective of this review was to identify the main measures and initiatives implemented to support the (re)integration of people with disabilities on the labour market; and discuss into which extent they are adequate and can benefit to cancer survivors.

We found out that, in general, in order to ensure the provision of a supportive and equitable legal framework for ill-workers, important shifts in the policy making process and the way to apprehend the work ability are required. Initiatives should find the right balance between compensation and integration, avoiding passivity of workers, employers and social workers.

Barely any cancer-specific measures can be found. Reasons are mainly ethical because governments cannot take the risk to create inequalities among diseases. When coming to workers with cancer, more attention needs to be given to break the stigma and to better inform and prepare the co-workers.

Industrial relations systems are now called to handle the transformations, either in formal and notional terms, of concepts such as "workplace presence", "work performance", "fulfillment of contractual obligations" and to strike a new balance between productivity and equity, inclusion and social justice.

Coordination is the key to operate the shift [33]. Employment, health and social security decision makers have to work together to define and build a coherent return-to-work pathway. Health professionals such as specialists, occupational physicians and general practitioners also have to closely collaborate for the coordination of their work would ensure that the worker is well informed about his condition and working abilities and that he is physically and mentally ready to resume work. To ensure objectivity of their work, a detailed and condition and work-tailored assessment needs to be performed and results have to be transmitted to all professionals in charge of the (re)integration of the worker.

The case of Norway stands out as noteworthy. There, the public employment service works together with the national institute of social security to simplify and coordinate the services provided, and to ensure close interaction between active and passive employment policies, for example when granting work incentives and disabilities benefits [17].

Likewise important is envisaging innovative and individually-targeted welfare policies, and measures promoting new definitions for "productivity" and "workplace presence" helping reconcile patients' and employers' needs. There is an increasing awareness of the need for wide-ranging and innovative changes when considering the relationship between work and chronic diseases. Indeed, public institutions adopt a narrow-minded approach to regulate the issue, for instance by considering rights, obligations, sanctions, and the provision of care and assistance as separate elements. Yet a comprehensive strategy is needed that considers sick workers' human dimension while laying down inclusion policy.

Research efforts need to be engaged to support decision makers and to highlight the specific needs underlying the different conditions.

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# <u>Update</u>

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# Erratum regarding missing Declaration of Competing Interest statements in previously published articles

Declaration of Competing Interest statements were not included in published version of the following articles that appeared in previous issues of Journal of Cancer Policy. Hence, the authors of the below articles were contacted after publication to request a Declaration of Interest statement:

- 1 "How do social security schemes and labor market policies support the return-to-work of cancer survivors? A review article" [Journal of Cancer Policy, Volume 15, Part B, May 2018, Pages 128–133] 10.1016/j.jcpo.2018.02.008
- 2 "Are essential medicines available, reliable and affordable in low-middle income countries?" [Journal Title, Volume 19, March 2019, 100180] 10.1016/j.jcpo.2018.12.001
- 3 "Teleoncology in sub-Saharan Africa: A literature review" [Journal of Cancer Policy, Volume 17, September 2018, Pages 9–14] 10.1016/j.jcpo.2018.07.002
- 4 "Impact of organized colorectal cancer screening programs on screening uptake and screening inequalities: A study of systematic-and patient-reliant programs in Canada" [Journal of Cancer Policy, Volume 24, June 2020, 100229] 10.1016/j.jcpo.2020.100229

- 5 "Lessons learnt from the medical and psychosocial evaluation of childhood acute lymphoblastic leukemia (ALL) survivors enrolled in EORTC Children Leukemia Group Trials between 1971 and 1998 and future perspectives for long-term outcome research" [Journal of Cancer Policy, Year; Volume 15, Part B, May 2018, Pages 82–86] 10.1016/j.jcpo.2018.02.006
- 6 "Efficiency and productivity of cancer care in Europe" [Journal of Cancer Policy, Volume 21, September 2019, 100194] 10.1016/j. jcpo.2019.100194
- 7 "Improving European policy to support cancer survivors" [Journal of Cancer Policy, Volume 15, Part B, May 2018, Pages 72–75] 10.1016/j.jcpo.2018.01.004
- 8 "From here to 2025: Personalised medicine and healthcare for an immediate future" [Journal of Cancer Policy, Year; Volume 16, June 2018, Pages 6–21] 10.1016/j.jcpo.2017.12.008
- 9 "A unique research infrastructure from the European Organisation for Research and Treatment of Cancer (EORTC) to optimize long-term follow up of patients-the YOU (Your Outcome Update) protocol: Rationale, scope, design and research opportunities" [Journal of Cancer Policy, Year; Volume 15, Part B, May 2018, Pages 118–121] 10.1016/j.jcpo.2018.03.001