

# Rehabilitation and return to work after cancer — instruments and practices

European Risk Observatory  
Executive summary

Authors:

Inge Braspenning, Sietske Taminga, Monique Frings-Dresen, Monique Leensen and Angela de Boer, Coronel Institute of Occupational Health, Academic Medical Centre, Amsterdam Public Health research institute, Amsterdam, the Netherlands

Christina Tikka and Jos Verbeek, Finnish Institute of Occupational Health, Finland

Fehmidah Munir and Sally Hemming, Loughborough University, United Kingdom

Ziv Amir and Liz Smith, School of Health Sciences, University of Salford, United Kingdom

Linda Sharp and Anna Haste, Institute of Health and Society, Newcastle University, United Kingdom

Project management:

Marine Cavet and Elke Schneider, European Agency for Safety and Health at Work (EU-OSHA)

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The ‘Rehabilitation and return to work after cancer — instruments and practices’ project provides an insight into the issues surrounding rehabilitation and return to work (RTW) after a cancer diagnosis and the problems encountered by workers affected by cancer and their employers. Furthermore, the report presents recommendations for instruments, practices, policies and interventions to successfully support the RTW of workers affected by cancer.

Each year, an estimated 3.4 million new cases of cancer are diagnosed in Europe. About half of the people diagnosed with cancer are of working age. Although cancer occurrence differs from one region to another in Europe, the most frequent forms of cancer are breast, colorectal, prostate and lung cancer. These types of cancer were estimated to account for over half of the overall burden of cancer in Europe in 2012.

The impact of cancer on a person’s daily life is immediate and striking. The diagnosis usually results in long periods of sickness absence because of medical treatments and functional restrictions. Although, in general, cancer management has improved over the past three decades and the overall number of people who survive cancer is increasing, many cancer survivors still face long-term symptoms and impairments after their treatment ends, such as fatigue.

These symptoms and impairments can affect the work ability of cancer survivors, making it more difficult to remain in or re-enter the job market. Research shows that most cancer survivors are able to remain in or return to work, but that overall the risk of unemployment among cancer survivors is 1.4 times higher than among people who have never been diagnosed with cancer.

Optimising the rehabilitation and RTW of workers affected by cancer is therefore important to both improve the well-being of this vulnerable group and reduce the societal and financial impacts of cancer on European enterprises and society at large.

Instruments, practices, policies and interventions aimed at the promotion of rehabilitation and RTW are clearly important.

This ‘Rehabilitation and return to work after cancer — instruments and practices’ project reports on the emerging issue of rehabilitation and RTW after cancer and provides national examples of successful instruments, practices, policies and interventions to prevent long-term sickness absences and unemployment.

The project is divided into the following main tasks:

- a literature review on rehabilitation and RTW after a cancer diagnosis;
- detailed descriptions of instruments, practices, policies and interventions to support rehabilitation and RTW after a cancer diagnosis;
- company case studies;
- qualitative research with experts and intermediaries;
- support for the EU-OSHA stakeholder seminar.

## Rehabilitation and RTW after a cancer diagnosis

### *Health and safety implications for workers affected by cancer*

Workers affected by cancer report various effects of cancer and its treatment on their health, including mental, cognitive and physical symptoms. The most frequently reported symptom is a diminished level of energy, described as fatigue or exhaustion, and emotional strain due to the ongoing battle with the illness. Other implications of cancer and its treatment that are reported to have an effect on occupational safety and health (OSH) are diminished mental health, including depression and anxiety, diminished physical functioning and symptoms such as pain and diminished cognitive capacities, including attention and memory problems.

The explicit occupational implications are diminished work productivity, work ability impairments and reduced functioning at work. This means that, due to one or more of these implications, workers treated for cancer are likely to have to take sick leave because their work capacity is diminished and they can no longer carry out their usual tasks. These implications can occur early in the treatment process or can last years after diagnosis, when they are especially problematic. For example, workers with cancer can be hindered by fatigue or cognitive problems several years after diagnosis and treatment.

### ***Costs for workers, employers and society***

The RTW of cancer survivors is economically important. Not returning to work during or after treatment leads to a financial loss for the worker, the employer and society. Adapting the work environment may enable RTW. This may come with costs for the company and the worker but, in the long run, these may be less than the costs of long-term sick leave.

Little is reported about the costs of cancer for workers, employers or society and, within the little that is reported, there are no consistent results. No reports exist on the costs to companies of workers being diagnosed with cancer. The total economic loss to the European Union (EU) due to lost working days as a result of cancer was estimated to be EUR 9.5 billion in 2009, but this is not all related to unsuccessful RTW.

### ***Work-related and occupational cancer***

The development of cancer may be caused by work and its environment. Occupational cancer can be defined as cancer that is mainly caused by exposure at work, whereas work-related cancer is considered multifactorial and exposure at work plays a smaller role, among other factors, than in occupational cancer.

No studies were found that focus on the RTW of workers with occupational or work-related cancer. This could mean either that RTW is not a problem that needs examining separately in these types of cancer or that the problem simply has not been studied. As most occupational cancers have long latency and occur after working life, or the prognosis is too severe, it could be that RTW is not a desired outcome. For other work-related cancers, exposure to carcinogens at work may go unnoticed and thus the RTW issues are no different from those of other non-work-related cancers.

During the EU-OSHA stakeholder seminar, the European Commission underlined the importance of the tertiary prevention of occupational diseases and outlined the difference between work-related and occupational diseases. The importance of performing risk assessments was also highlighted. Due to the long latency and sensitivity of work-related cancer, risk assessments are needed to allow working conditions to be adjusted in time. Furthermore, in the case of work-related cancer, it is important to talk about the risks (risk communication), so that both the employer and the worker are informed of the risks that RTW poses to health.

### ***Small and medium-sized enterprises (SMEs)***

The size of a company seems to have an impact on cancer survivors' possibilities for returning to work. Companies with fewer than 250 workers (SMEs) lack information and resources for RTW strategies or programmes, and support and education for such enterprises are needed. These problems seem to be especially apparent in small enterprises (fewer than 50 workers) and micro enterprises (fewer than 10 workers).

It has been reported that the RTW of cancer survivors seems to be more problematic for the self-employed and those working in small enterprises. This is because being off work for treatment and necessary rest is more difficult in small companies, as such companies have limited access to occupational health services and they lack experience in the management of sickness absence.

During the EU-OSHA seminar, stakeholders indicated the importance of making straightforward recommendations to stakeholders in companies.

Recommendations for how cancer and RTW issues can be integrated into more general RTW programmes are especially important. For SMEs, this is vital because they most likely need intermediaries or consultants to supply these programmes. In addition, grouping SMEs for OSH information/assistance is valuable because SMEs could learn from each other and together it is easier to access this kind of help from occupational health services.

However, stakeholders also saw the small size of SMEs as an advantage, as such companies provide a more family-like atmosphere, which may create a more supportive environment for workers with cancer returning to work. However, very little has been reported in the literature and the conclusions are weak due to the small evidence base.

## **Instruments, practices, policies and interventions to support rehabilitation and RTW after a cancer diagnosis**

The terms instruments, practices, policies and interventions in this report are understood broadly and include both very active approaches of support, such as training, and less active approaches, such as information provided over the phone, online or on paper.

A limited number of scientific studies have evaluated the effect of interventions to help cancer survivors return to work. Results from the scientific literature show that only multidisciplinary interventions that combine vocational counselling with patient counselling and physical training have increased RTW rates, although only to a small extent.

In the scientific and grey literature, and through contacting experts, a total of 78 instruments, practices, policies and interventions addressing rehabilitation and RTW were found. These examples were collected from 13 EU countries, the USA and Australia. Some interventions were described as workplace accommodations and these were mostly meant to accommodate fatigue and provide more flexibility in working times or a reduction in working time, which could also take the form of paid leave for healthcare appointments. Interventions included proposals for adjustments to workload, modifications to duties, the provision of assistance and changes in personnel.

An extensive number of psycho-educational interventions, such as advising cancer survivors by telephone or providing information on a dedicated website, were also found to be used in practice. Available interventions include information and training on cancer and RTW issues, rehabilitation services, guidelines and workplace accommodations.

For employers, support interventions can help them to construct RTW plans for employees with cancer, create ideas for workplace accommodations to facilitate RTW and improve communication with the employee and co-workers; they can also provide factual information about the diagnosis and treatment of cancer.

### ***Description of good practice examples***

The following seven innovative good practice examples were identified from five Member States:

- Cross-organisational working in Macmillan Cancer Support's 'Working Through Cancer' programme (the UK): the programme provides support to different stakeholders — people with cancer and their carers, health and social care professionals and employers — in helping people with cancer to remain in and/or return to work and in influencing government policy and service commissioners. The programme provides a range of information resources, training materials and guidance for employers; information and helpline employment advice for employees affected by cancer and carers, with specific advice for the self-employed; and resources for health and social care professionals.
- Municipality-based occupational rehabilitation programme (Denmark): the programme involves different stakeholders, namely the hospital (nurses), the employer, a job consultant and the employee. One of the innovative elements of this intervention is the timing and early onset of

the occupational rehabilitation. The job consultant acts as an intermediary between the employer and employee.

- In-hospital rehabilitation intervention (the Netherlands): this intervention involves an oncological nurse, an occupational health physician (OHP), a supervisor and the employee. This hospital-based intervention opts for early intervention, as most cancer patients otherwise have no contact with their supervisor or OHP during the early phases of their cancer treatment.
- Work reintegration agency Rentree (Belgium): the agency involves different stakeholders and, from among these, the worker chooses the ones that he or she would like to be involved in his/her personal RTW process. Therefore, the programme is tailored to the user.
- Work reintegration agency Re-turn (the Netherlands): the agency covers issues regarding work, home, family, relationships and the physical and mental effects of treatment and RTW. Re-turn also involves different stakeholders.
- Work reintegration agency oPuce (the Netherlands): the agency provides help to unemployed cancer patients. Working together with large companies and many other stakeholders, including the worker, results in new job opportunities for unemployed cancer survivors.
- Booklet of the Irish Congress of Trade Unions (Ireland): the aim of this booklet is to break down the stigma associated with cancer and RTW, to encourage good conversations between employers and employees, and to provide assistance to unions that represent members diagnosed with breast cancer who are returning to work.

Overall, it seems that RTW is influenced by the institutional context of a country, especially the length of paid sick leave. In addition, early intervention or paying attention to RTW early in the illness process appears to be important in every programme.

Working together with different stakeholders, including the worker and his/her family, the employer, healthcare professionals and occupational rehabilitation experts, seems important in all good practice examples and has a positive impact on the RTW process.

## Policies and interventions in companies to support RTW after a diagnosis of cancer

Employers are key stakeholders in the RTW process because they are in a position to create good working conditions, reduce discrimination and stigmatisation, help minimise the economic impact of a cancer diagnosis, and ensure workers' well-being. Furthermore, employers must have a positive attitude and a good understanding.

We collected examples of enterprises that have implemented interventions for managing the RTW of employees diagnosed with cancer. As far as possible, they represent different types of cancer, cover a variety of workplace sizes, activity sectors and locations, and include medium-sized companies, lower socioeconomic groups and both genders, i.e. a variety of professions:

- A large conglomerate with multiple companies (the Netherlands) has a programme in place that includes a 'Tailored Sport Plan' aimed at sports, rehabilitation and RTW.
- A medium-sized enterprise (the Netherlands) provides an external sports, rehabilitation and RTW programme for its employees diagnosed with cancer.
- A company (the UK) has a programme in place that includes numerous modules of support, information, absence management policy and sick pay, as well as the involvement of a general practitioner.
- A department store (the Netherlands) provides the work reintegration agency Re-turn's programme for its employees diagnosed with cancer.
- A hospital (Belgium) offers a programme aimed at promoting communication between different stakeholders (the employer, an OHP, the human resources (HR) director, the HR assistant and the division manager) on the RTW of employees with a long-term illness. Supervisors are trained in communicating with employees about RTW after a long period of sickness.

- A banking organisation (the Netherlands) provides its employees that have been diagnosed with cancer with information via an intranet and trains supervisors in communicating with employees about RTW after cancer.
- An independent not-for-profit healthcare provider (Ireland) liaises with its members of staff regarding RTW on an ongoing basis during and after treatment for cancer.
- A manufacturing company (Belgium) applies a 'relocation policy' within the company, i.e. workers are given a temporary job with adjusted tasks before they return to their original job.
- A banking organisation (Belgium) has a unique policy regarding communication with employees with a long-term illness.

### ***Experiences of stakeholders in companies***

We interviewed different stakeholders about a worker's RTW process in their company, e.g. workers, employers, OHPs and representatives of trade unions.

The content of the programmes and the people involved in the programmes differed. Multidisciplinary programmes involving several stakeholders from both inside and outside the company were most common. Some programmes included psychosocial support and others offered exercise programmes; some multidisciplinary programmes combined physical support with social support through collaboration in mini-teams and some programmes included the support of only an OHP. We also found that about half of the companies implementing successful programmes had put in place their own RTW programmes and measures, while the other half collaborated with external agencies and programmes to facilitate successful RTW. Not all of the programmes focused solely on workers diagnosed with cancer; some were intended for a wider range of workers with other (serious) illnesses.

The extent to which companies provided support to the worker varied. Most workers felt supported by their supervisors but, in a few cases, external programmes or the OHP had to intervene to establish adequate support from the workplace.

In addition, the communication of the possibilities of engaging in the programmes, initiatives and policies was different, depending on the size of the company. In smaller companies, the communication lines seemed to be shorter and therefore the worker was likely to be informed sooner. The uptake of the programmes provided depended on the situation of the worker, including the severity of the medical diagnosis and personal preferences.

The views of employers differed regarding budgeting for additional help for workers diagnosed with cancer. Most employers had no financial incentives to begin the RTW process for workers diagnosed with cancer, but considered it part of good employment practice. Employers who themselves needed to pay for the long-term absence of employees did, however, indicate that financial motivation might be an incentive to put more effort into RTW.

The most successful programmes were those that were multidisciplinary — including psychosocial and physical aspects — and flexible (tailored to the worker's situation), and those that involved good communication, knowledge of cancer-specific RTW processes and information being made available on the company intranet.

The project organisation within the companies was very diverse and no conclusion can be drawn regarding the most effective form of project organisation. Some programmes were actual policies within the companies, while others were organised by external agencies; some had teams within the company that organised the project and others had no project organisation at all.

As regards transferability, all the interviewees considered that their programme would be transferable if companies were willing to support and finance the programmes. However, for small companies, this might be more difficult due to costs and flexibility needs.

## Barriers to and facilitators of the successful implementation of instruments, practices, policies and interventions for the RTW of employees diagnosed with cancer

Most employers and HR personnel considered that legislation was highly important for (successfully) implementing programmes. Due to differences in legislation, the incentives and possibilities of an employer to provide workers with programmes were different among the countries. The majority of stakeholders indicated that communication with the worker diagnosed with cancer throughout the sickness period was an important facilitator of a successful programme. Furthermore, communication between the stakeholders (HR, the employer, the supervisor and actors from external agencies) was also essential for facilitating the programmes.

Some facilitators provided knowledge to HR personnel and supervisors on cancer and work via, for instance, workshops. Finally, a positive company policy and attitude towards workers with a serious illness returning to work was a prerequisite for successful RTW.

A barrier to the implementation of the RTW programmes seemed to be the inability of some companies to provide the worker with the required work adjustments. This was the case when, for instance, the company had only a specific type of (hard) work. Another barrier was that physical and psychosocial care were often not covered in the treatment phase.

To further explore the barriers to and facilitators of the successful implementation of the policies, systems, programmes and instruments in the field of rehabilitation and RTW of workers diagnosed with cancer in various countries and companies, we arranged focus group sessions in four countries: Belgium, Ireland, the Netherlands and the UK. The stakeholders, experts and intermediaries in the focus groups came from different backgrounds. In addition, the results of the project were presented and discussed in a one-day EU-OSHA stakeholder seminar in October 2017.

On a macro-system level (societal context, culture and politics), one barrier to successfully implementing RTW programmes was the lack of clarity as to who was responsible for supporting workers in their RTW. It should therefore always be made clear to employers, workers and other stakeholders who is responsible for the RTW of workers diagnosed with cancer. In addition, the cultural stigma of a cancer diagnosis and the (cultural) misconceptions about the possibilities of working after a cancer diagnosis were considered important barriers to implementing RTW programmes. It is hence necessary to address these misconceptions and remove the stigma that is associated with the diagnosis of cancer on a societal level. The participants of the seminar discussed how important it would be for physicians to consider 'work' as a health outcome for the future. Increasing the importance of work could start by including 'participation in work' as a health outcome for physicians in research and practice.

The facilitators for implementing successful programmes were the legal possibilities of offering part-time work and incentives for the employer to support RTW, both of which are given as recommendations for legislation. An important factor that hampers RTW is privacy legislation, which hinders open communication. This is nevertheless the statutory right of patients. As the privacy rights of patients are of the utmost importance and are constitutional, stakeholders working in RTW programmes should be trained in how to accomplish open communication without the disclosure of the diagnosis.

To implement successful RTW programmes, society needs better knowledge regarding side effects and regarding RTW opportunities and limitations. The EU and/or national government could play a role in providing this information. Although the findings of this project could be applicable to all Member States, national-level differences should be taken into account in the process of implementing successful RTW programmes in other countries.

On a meso-system level (company, healthcare, legislative and insurance system), the structural implementation of an RTW programme or RTW policy within a company is an important facilitator of its success. Consequently, it is recommended that companies willing to implement RTW programmes make the implementation a structural part of their policies throughout the company. In addition, it is crucial to train supervisors, HR personnel and case managers in cancer and work aspects such as long-term side effects, in communication with the worker with cancer and in the elements of the RTW programme.



At the workplace level, it is essential that colleagues are involved in the RTW process. The importance of practical tools was stressed during the seminar: spreading knowledge to HR personnel and supervisors on cancer and work via, for instance, workshops, would be of added value. EU-OSHA could possibly take a role in promoting best practices on how sharing information at the workplace level could be achieved: this was discussed during the seminar. Barriers to the implementation of RTW included a lack of time, financial difficulties, a lack of knowledge and insufficient skills at the workplace to support the RTW of the worker with cancer. Consequently, for the implementation of the programmes to be successful, companies should allocate enough time and finances and provide training on the knowledge and skills required. Effective, successful programmes must also be multidisciplinary, timely and tailor made. Furthermore, successful programmes should target not only RTW but also remaining in work once a worker has returned. When companies consider an RTW programme, these aspects should be incorporated into it.

Finally, for successful programmes, it is of the utmost importance that the OHP has access to and can support both the worker and the employer early in the diagnosis and treatment process. Furthermore, practical information is needed regarding, for example, reasonable accommodation within the organisation. Hence, it is essential that companies involve an OHP as soon as the diagnosis has been disclosed. Significant barriers to the implementation of programmes are the failure to address work immediately from the start of the treatment and the fact that attending physicians are too protective regarding RTW or have a negative view of it. Ideally, physicians should be educated during their medical training on the effects of a disease on a worker's involvement in work, the importance of work for the quality of a patient's life and the effect of RTW advice from an attending physician. The participants of the seminar discussed that it is important for physicians to be trained to address RTW issues. The health insurer should play a role in this by funding time for healthcare professionals to do this.

For SMEs, it is considered very difficult to implement RTW programmes because it is harder for them to accommodate work modifications and provide gradual RTW, as they have less flexibility. The seminar participants discussed how information and resources for RTW strategies or programmes are lacking in SMEs, and how support and education are needed. The larger a company is, the more likely it is to have the resources to support and keep an employee with reduced work ability at work or on long-term sick leave. SMEs should therefore receive help in making work requirements more flexible or in aligning themselves with other companies that are more flexible.

On the micro-system level of the worker, it was concluded that early intervention or paying attention to RTW early in the illness process is essential. Communication with the worker diagnosed with cancer throughout the sickness period is another important facilitator of a successful programme. The worker should remain in contact with the workplace during his/her sick leave, especially in the early phases of diagnosis and treatment. Successful implementation is further facilitated by the worker being highly motivated to return to work, taking responsibility for him- or herself and realising that he or she has to plan RTW. These aspects should therefore be part of a successful RTW programme. Furthermore, there is a need for tailor-made programmes for workers diagnosed with cancer; tailoring the programme to suit the worker's preferences could complement the use of a framework for the RTW of workers diagnosed with cancer.

Issues regarding work-related cancer were not mentioned in the focus groups. It was considered as an inappropriate environment for employers or other stakeholders to discuss the RTW of workers with work-related cancer mostly because of legal issues (e.g. the possibility that employers might be legally liable for not preventing work-related cancer). These legal issues regarding work-related cancer for employers might also have been the reason why the subject was not spontaneously mentioned during the focus groups.

To make RTW programmes more successful, there is a further need for RTW policies for cancer and for legislation for self-employed workers affected by cancer.

## Conclusion

Surviving cancer can limit one's work ability for various reasons. The implications of cancer and its treatment can affect all aspects of human health and well-being, including physical, mental and cognitive

symptoms. These implications can be either short or long term. When returning to work, survivors may face difficulties in balancing work and treatment demands, including negative attitudes or behaviours among their colleagues and employers. All of this may lead to a reassessment of work and life goals, and thus may hinder RTW.

With the rising number of cancer survivors, effective interventions are needed to enable RTW and to reduce the costs to individuals, companies and society at large. The only scientific evidence for RTW having been improved is in comparison between multidisciplinary interventions and usual care. These interventions include physiotherapy, occupational therapy, speech therapy, vocational rehabilitation and psychology in relation to RTW (delivery of, for example, education, counselling and training).

We found 78 good practice examples of rehabilitation or RTW support through instruments, practices, policies and interventions for people diagnosed with cancer. Subsequently, seven good practice examples from five Member States (Belgium, Denmark, Ireland, the Netherlands and the UK) demonstrated that working together with different stakeholders — including the workers and their family, the employer, healthcare professionals and occupational rehabilitation experts — was important in having a positive impact on the RTW process. In addition, early intervention or paying attention to RTW early in the treatment phase also appeared to be important in every programme.

We interviewed stakeholders from companies that had a variety of programmes, initiatives and policies in place to support the RTW of workers diagnosed with cancer. The content of the programmes and the people involved in the programmes differed. Multidisciplinary programmes involving several stakeholders from both inside and outside the company were the most common. The facilitators of successful execution of the programmes were legislation encouraging RTW, communication between stakeholders, knowledge of cancer and work and of RTW processes, and positive attitudes towards workers returning to work after a serious illness. The perceived barriers to successful implementation were an inability to implement work adjustments and insurance issues. Overall, the stakeholders were enthusiastic about their programmes, initiatives and policies and believed that these could be transferred to other companies.

The experts and intermediaries in the focus groups indicated a range of barriers to and facilitators of the successful implementation of policies, systems, programmes and instruments in the field of rehabilitation and RTW for workers diagnosed with cancer in their various countries and within their companies. Furthermore, they discussed the requirements for and obstacles to implementing programmes and initiatives for rehabilitation and RTW after cancer. Important barriers were the lack of clarity regarding who is responsible for supporting workers in their RTW, the cultural stigma of a cancer diagnosis, issues around disclosure and privacy, a lack of involvement of OHPs or experts, the inability to provide work accommodations and failures to address RTW issues in the healthcare setting. Success factors for organisations included structural implementation of the RTW programme or RTW policy, communication between all stakeholders and supportive legislation.

In the EU-OSHA seminar for stakeholders, the importance of making straightforward recommendations to stakeholders in companies was discussed. Recommendations for how cancer and RTW issues should be integrated into more general RTW programmes are especially important. For SMEs, this is vital because they most likely need intermediaries or consultants to supply these programmes. During the EU-OSHA stakeholder seminar, the European Commission further underlined the importance of the tertiary prevention of occupational diseases. The participants of the seminar also discussed how important it would be for physicians to consider ‘work’ as a health outcome for the future. Increasing the importance of work could start by including ‘participation in work’ as a health outcome for physicians in research and practice.

In conclusion, a range of RTW instruments, practices, policies and interventions exist for workers with cancer, and these are considered essential for improving the work outcomes of those diagnosed with cancer. To develop effective, efficient RTW interventions, the facilitators for executing successful programmes seem to be legislation that encourages RTW, communication between stakeholders, knowledge of cancer and work and of RTW processes, and positive attitudes towards workers returning to work after a serious illness.

**The European Agency for Safety and Health at Work (EU-OSHA)** contributes to making Europe a safer, healthier and more productive place to work. The Agency researches, develops, and distributes reliable, balanced, and impartial safety and health information and organises pan-European awareness raising campaigns. Set up by the European Union in 1994 and based in Bilbao, Spain, the Agency brings together representatives from the European Commission, Member State governments, employers' and workers' organisations, as well as leading experts in each of the EU Member States and beyond.

**European Agency for Safety and Health at Work**

Santiago de Compostela 12, 5th floor  
48003 Bilbao, Spain  
Tel. +34 944358400  
Fax +34 944358401  
E-mail: [information@osha.europa.eu](mailto:information@osha.europa.eu)

<http://osha.europa.eu>



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