

I have cancer but I want to work. Working rights of cancer patients.

An initiative of the ABC Global Alliance

7 November 2018, European Parliament, Brussels, Belgium

MEETING REPORT

European politicians and policymakers were called on to implement consistent and flexible policies to enable cancer patients and cancer survivors to return to work, at an event at the European Parliament in Brussels organised by the ABC Global Alliance, the multistakeholder organisation for tackling the many issues faced by people with advanced breast cancer.

The meeting heard from a range of speakers about the increasing number of cancer survivors and in particular about those with advanced and metastatic breast cancer, as one of Europe's most prevalent cancers; how employers should be helping people return to work or keeping their jobs; current legislation at European and national level; and various projects and resources that are informing policy and patient advocacy.

Lieve Wierinck, a Belgium MEP, and a cancer survivor, opened the meeting by emphasising that cancer has impact in the personal, social and working relationships of people, and that it is part of the big picture of addressing the cancer burden in Europe by providing more options for patients. It is crucial to address disparities and harmonise standards for all Europeans she said. Many people want to continue working for financial security and to have a helpful distraction from their illness, and they should expect flexible support from their employers, as the effects of cancer treatment such as pain and fatigue can differ at various times.

Wierinck told attendees that she was diagnosed with colorectal cancer and had 6 months of chemotherapy. Quality of life is strongly impacted by cancer and she said she was happy to go to work for the distraction of focusing on something else. It made her life richer, and she said it is important to enable people to live a normal life.

Scale of the issue

Fatima Cardoso, a medical oncologist in Portugal and chair of the ABC Global Alliance, described the global and European burdens of cancer, to put breast cancer into context. Citing latest figures from Globocan, she showed that cancer is the leading cause of premature death in developed countries (i.e. in those aged below 70), and how it is rising up the rank of cause in Africa and other parts of the developing world. By 2020, there will be more than 13 million deaths a year from cancer and in about a decade, one in two people will get cancer in their lifetime.

Globally, breast cancer is by far the most common in terms of incidence, followed by prostate cancer, but lung cancer is the biggest cause of cancer mortality, particularly among men, although the delay in women taking up smoking means their lung cancer incidence is rising.

Today, 1 in 8 to 10 women will have breast cancer in their lifetime, and the number of annual deaths will rise to more than 800,000 globally by 2030, about 43% more than the 560,000 deaths or so recorded in 2015. In Europe, there is a breast cancer diagnosis every 2.5 minutes and a death every 6.5 minutes. Cardoso explained that about a third of those diagnosed with early stage breast cancer will later relapse with a recurrence, and an important point that was made several times at the meeting is that cancer registries do not record the occurrence of recurrence. For this reason, the actual number of patients living with advanced cancer is currently unknown. This makes it harder to convince policymakers about measures that need to be taken in areas such as workplace provision. Indeed, the meeting heard that an MEP, Deirdre Clune, has been pushing for EU funds for a pilot project to gather data on the employment status of people with metastatic cancer, with a focus on breast cancer patients, to assist in designing better policies and service provision.

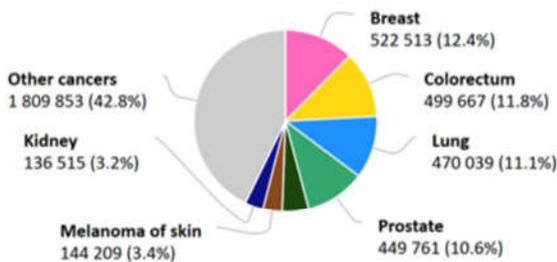
Cardoso further explained that ABC refers to both metastatic breast cancer, which has spread to distant sites and is incurable and inoperable, and to locally advanced breast cancers, which is very advanced locally but not

yet spread to distant sites. The 5-year survival rate for metastatic breast cancer has not improved much in recent years, and stands at a median of about 26%, with advances mainly in a specific subtype of the disease called HER2 positive. The median survival of ABC patients is still only about 3 years – a disturbingly low figure that should concern everyone.

A number of people are first diagnosed with advanced breast cancer, about 10-15% in the developed world but at a much higher rate, 50-80%, in developing countries. A rough estimate of those currently living with metastatic breast cancer globally is 2.2 million, said Cardoso, which is about a third of the near 7 million 5-year prevalence of breast cancer overall; in Europe the 5-year prevalence of breast cancer is over 2 million, so those at metastatic stage could number as many as 700,000.

THE BURDEN OF CANCER IN EUROPE: in 2018

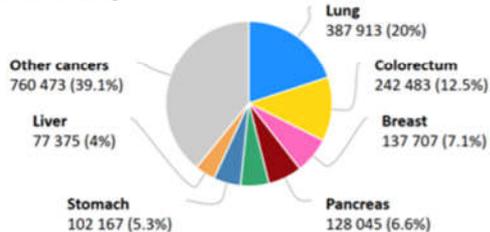
Incidence/New Cases



GLOBOCAN 2018 data

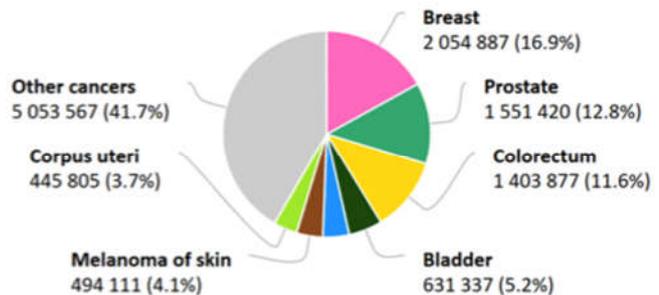
Total : 4 229 662

Mortality



Total : 1 943 478

5-year Prevalence



Total : 12 132 287

She introduced the charter of the ABC Global Alliance, which among its 10 goals calls for doubling of median survival, increasing access to multidisciplinary care, improving communications and information, and reducing stigma. Last but by no means least among the goals is “help patients with ABC continue to work by implementing legislation that protects their rights to work and ensure flexible and accommodating workplace environments”, which given the rising incidence of breast cancer will mean more women (and some men) having to negotiate workplace arrangements (which of course also applies to those with other advanced cancers).

Working with employers and employees

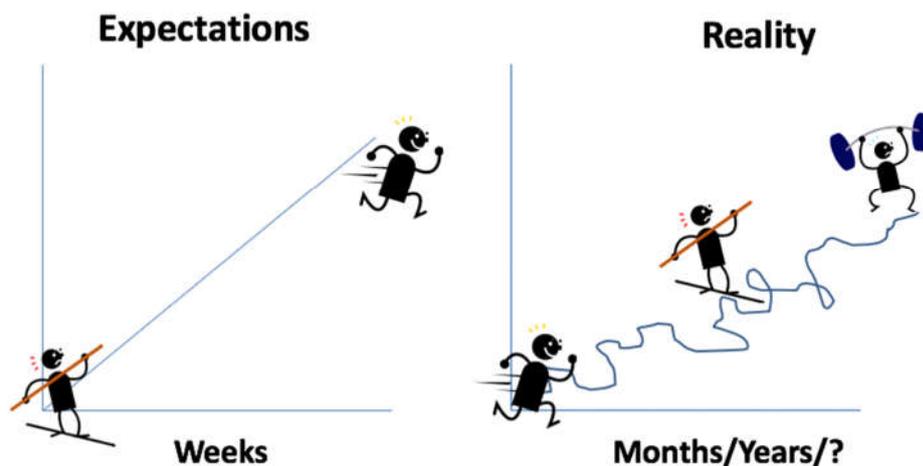
Barbara Wilson, founder of Working With Cancer, advises organisations and people on how to manage work during and after cancer treatment. She is a breast cancer survivor who had a senior position in a large company and experienced obstacles on returning to work, and had three key messages for the meeting:

- It is possible for most people with cancer, even those who are terminally ill, to continue to work (and she gave the recent example of a senior British civil servant who worked until a month of dying from lung cancer)
- Information must be given to employers and employees on what to expect during and after cancer treatment and how to manage at work. This means regular communication about the side-effects of treatment and having the flexibility to make adjustments for a gradual and successful return to work
- There must be a consistent EU-wide framework that supports all people with cancer who face discrimination in the workplace. Wilson said that the UK Equality Act 2010, while not fully taken onboard by every employer, does a lot to protect cancer survivors against discrimination at work and to support their return to work, through for example, the requirement for employers to make reasonable workplace adjustments.

Work, she said, is an important part of one’s identity. It fulfils the need for social structure and provides financial stability, a sense of normality and of purpose. But treatment and medication can cause fatigue, cognitive dysfunction, pain and other symptoms, and the path to getting better is not smooth; there are good days and weeks, but also bad times, and getting back to “normal” is often not possible. Fundamentally it is about establishing a “new normal”, which might take months and sometimes years to achieve; and some things never entirely disappear, particularly the fear of recurrence. Cancer is life changing – physically and emotionally – it would be wrong to think otherwise.

Wilson said a key issue, therefore, in returning to work is the uncertainty of managing periods of illness and that the generic sickness policies of many employers do not take this into account.

The impact of side effects



She made several other points – that this is not about making people return to work but about giving people choices; that the information given to patients on side-effects is often of poor quality; that more could be done to provide individuals with self-management tools and strategies; that employers and health professionals should do more to engage with each individual’s full support network to aid their recovery; and that it should always be remembered that recovery is both physical and psychological – too often the latter is ignored.

Wilson gave an example of Kathryn, who was off work for 18 months during extended treatment (with complications) for breast cancer. When she did return, her job and her team had changed and there was little managerial contact. After coaching with Kathryn and briefing her manager on equality legislation and the nature of cancer, Kathryn's return to work was successful, with her line manager saying that what had been really helpful was to have a benchmark on what is "normal" in terms of the adjustments needed and the time it takes to return to work successfully.

Employment/return to work issues facing people with ABC

Karen Benn, head of policy and public affairs at Europa Donna, the European Breast Cancer Coalition, gave a detailed account of EU and national legislation, and also presented the results of a Europa Donna survey of people with breast cancer about their experiences and support in their countries for employment and return to work. She started by reiterating how important work can be – how the stimulation of work and the dignity of being an active member of society can contribute to quality of life; people do not want to feel they are a societal burden and by continuing to work they can make a contribution. However, it is commonplace for people to experience stigma and discrimination and they can even be forced out of work.

The EU's Employment Equality Framework Directive 2000 is the legislative framework that should protect people with both early and advanced cancer from discrimination. This Directive prohibits discrimination on the grounds of disability, sexual orientation, religion or age, and cancer can be considered to be a disability, said Benn. But it is an EU Directive and not an EU Regulation, and while it must go onto the statute of the EU member states, each country has the flexibility to define what constitutes disability, and therefore whether or not cancer fits their definition. The Directive requires employers to make "reasonable accommodation" for the working environment for all employees on the one hand, but, on the other hand it must not cause the employer "disproportionate burden". Who defines this, asked Benn.

Some countries, such as the Nordic countries, Netherlands, Ireland, France, Belgium and the UK do give cancer patients the ability to register as disabled and therefore to benefit from this legislation for their working rights, among other things. In Italy and France, for example, people can also register as disabled for a certain period of time and then "unregister" themselves – as not everyone wants to be defined as disabled for the rest of their lives. However, in many European countries, formal protection is either non-existent or the situation is legally ambiguous, and there is no data on how many cancer patients return to work or how easy they find it to do so.

There are also big disparities in how countries help people to return to work after long-term illness – here the Scandinavian countries are good, said Benn, offering every cancer survivor a return to work plan. She said that there is an opportunity for national cancer plans to address employment as part of survivorship; this is already happening in the UK and France, and has been proposed in the European multistakeholder reports which resulted from the EU joint action projects, the European Partnership for Action Against Cancer (EPAAC) and its successor, Cancer Control Joint Action (CanCon).

Europa Donna's survey, which was completed at a training course for metastatic patient advocates, found that a majority of the 35 countries represented at the course do indeed have disability discrimination legislation that protects cancer patients, and some countries also have other legislation which protect people living with cancer from discrimination. A majority also said there is information on social security and welfare, and on leave of absence and return to work, and on working part time, although the latter is mostly dependent on the employer. Representatives also reported that pressure from employers and colleagues discourages return to work, and there is stigma and lack of awareness of living and working with cancer.

Europa Donna members said that existing regulations/legislation are insufficient, as employers still discriminate against people with cancer, especially those with advanced disease, and there is pressure to resign, or people are fired. They highlighted lack of visibility and need for awareness, saying that it should be part of the regular advocacy agenda, and needs a dedicated legal framework.

There is some movement at EU level. A report from the European Parliament, on pathways for the reintegration of workers recovering from injury and illness, now includes amendments on cancer. In May 2018,

a group of MEPs led by Rory Palmer (UK) launched the European *Dying to Work campaign*, which aims to protect terminally ill workers from dismissal; as it stands, there are no specific protections for terminally ill employees. The campaign, which originated in the UK, “notes with concern the cases of the unfair dismissal or treatment of terminally ill employees. We are calling for the introduction of EU legislation to the safeguard of the rights of employees by identifying terminal illness as a protected characteristic.”

Also in 2018, MEP Deirdre Clune (Ireland) proposed a pilot project to the European Commission on collecting data on the number of people with metastatic cancer in the workplace, using breast cancer as a model; however, this project has not yet been funded. The aim of the project is to assist in designing better policies and service provision.

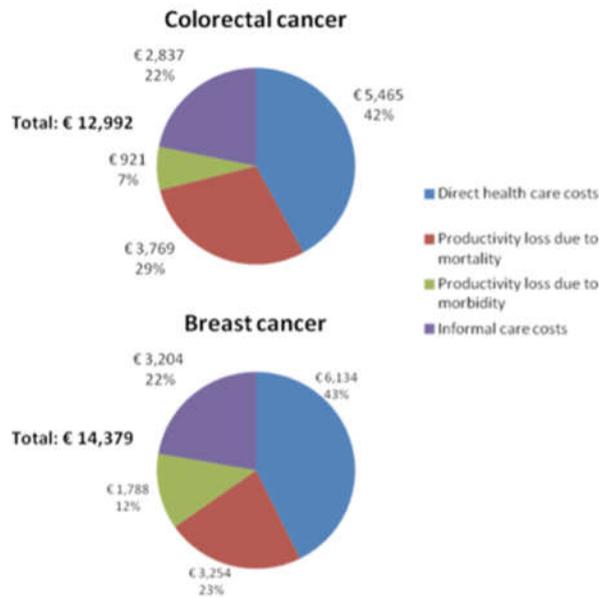
Benn said that a positive step is that the European Network of Cancer Registries (ENCR), which focuses on finding ways to integrate data from Europe’s cancer registries, is now being run at the European Commission’s Joint Research Centre. This may lead to solutions on how to collect data on metastatic recurrences in breast and other cancers.

EU-OSHA, the European Agency for Safety and Health at Work, has also recently produced a report, and advice for employers, on reintegrating workers with cancer in the workplace; and Eurofound, the EU agency for the Foundation for the Improvement of Living and Working Conditions, produces data on cancer in the workplace. EPF, the European Patients’ Forum, has also focused on patients’ rights in the workplace and protecting those living with chronic illness from workplace discrimination.

Costs and value in cancer care

Richard Sullivan, professor of cancer and global health at King’s College, London, provided high level context about health systems in Europe. He told attendees that there are big threats to achieving equitable care for breast cancer and other diseases – social inequalities, which are rising in Europe, and the impact of technology such as new drugs and imaging, which must be subject to guidelines and also have a healthcare workforce that can deliver appropriate care. Otherwise care will become ever more expensive, he said, noting that breast cancer and colorectal cancer, due to their incidence, are the two cancers that particularly determine economic burden and whether policy response can control costs.

Economic impact is framed by direct healthcare costs and informal costs, balanced against productivity losses – and the figures are substantial. In Europe, total costs for breast cancer are over €14 billion, made up of 43% healthcare, 22% informal care, and 35% productivity lost to mortality and morbidity. It was highlighted later in the meeting that productivity loss of people unable to work is one of the biggest concerns for employers, although these figures also show the sheer cost that advanced cancer has on societies as people are lost to the disease, and Sullivan noted that metastatic cancer is substantially more expensive to care for than early stage disease.



Economic impact framed by:

Direct expenditure and informal costs

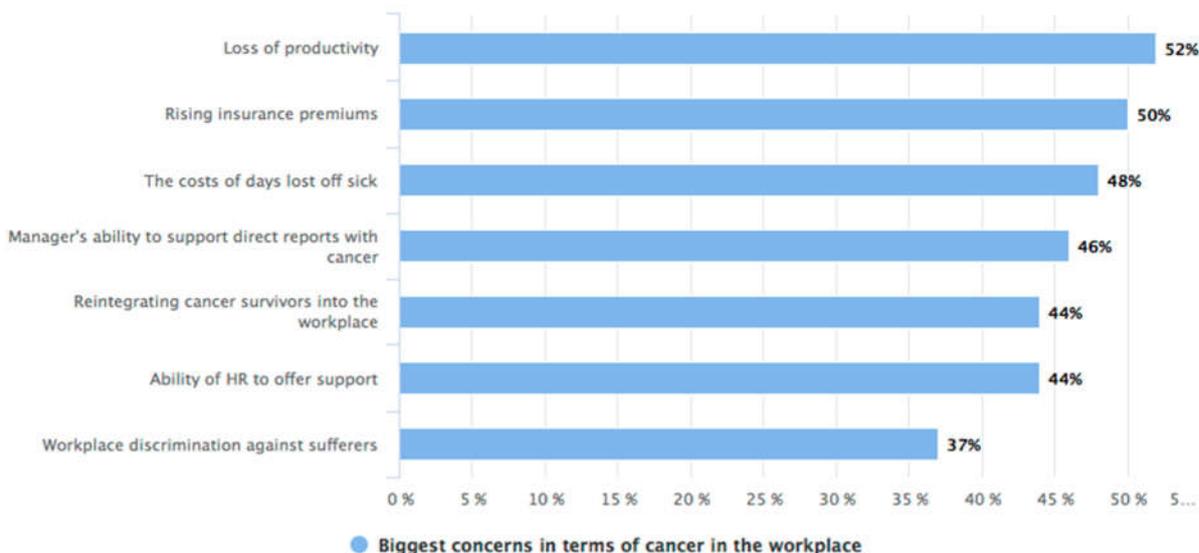
balanced against

Productivity losses

He went on to discuss price and value models, asking how do we achieve better outcomes while ensuring affordability and equity, and indeed whether universal health coverage for breast cancer is achievable. He outlined several reasons why there are major challenges for establishing cost effectiveness measures and making value judgements on new healthcare technologies, and said that what really matters is the total healthcare expenditure of countries and the protection given to patients. We need much greater value from all cancer technologies and systems, said Sullivan, and this requires buy-in from the professional community, patient organisations and research funders.

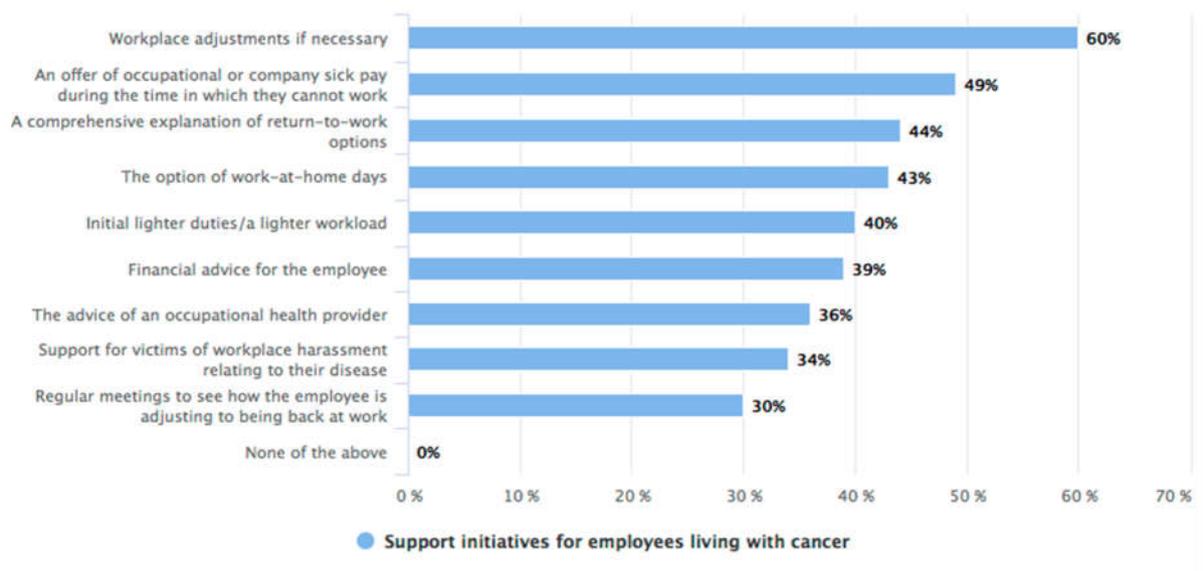
Reports and projects

The productivity angle was picked up in the next segment of the meeting, which focused on reports. The first, *Cancer in the Workplace*, published by the Economist Intelligence Unit in collaboration with Bristol-Myers Squibb in 2016, assessed the challenges that cancer poses for employers and reported that loss in productivity of cancer survivors who were unable to return to paid work in the UK was £5.3 billion in 2010. In a survey, productivity loss was ranked highest among the concerns of employers, followed by rising insurance premiums and the cost of days off sick. Notably, high among the concerns was the ability of managers to support employees with cancer.



The report also surveyed employees and, encouragingly, when asked whether they feel confident that their employer would support them during the period of illness and up to 1 year thereafter, around 75% of respondents said that they would be fairly confident or very confident. This figure is higher among respondents in large companies. However, in the Q&A session later at the Brussels meeting, it was mentioned that in a survey in the Netherlands, it was small, family owned businesses that offered the most support, ahead of larger companies and the public sector.

Cancer in the Workplace also identified some innovative strategies, such as offering paid leave to caregivers and pooling unused annual leave for use by employees affected by cancer, and reinforced messages presented earlier at the Brussels meeting, such as training for managers so they are prepared for dealing with employees with serious illnesses, and better information on company guidelines and policies for serious illnesses. Among support initiatives, workplace adjustments were found to be relatively common in companies (60% of respondents).



Another project presented at Brussels was *A Policy Roadmap on Addressing Metastatic Breast Cancer*, which is raising awareness on clinical, economic and societal burden of metastatic breast cancer. Its recommendations include:

- Provide wider support systems and decision-making tools for metastatic breast cancer patients for coping with their diagnosis, handling their disease, managing their treatment's side-effects, and organising their lives to allow for minimal disruption
- The European Commission should use the European Pillar of Social Rights as a policy framework to initiate adequate measures to ensure member states provide patients and informal carers with employment regulations that sufficiently protect their work-life balance
- Increase recognition of the role of informal carers and formalise their rights and access to available support systems.

The roadmap is sponsored by pharmaceutical company Lilly, and the meeting heard from the company's Marjo Haka Kemppinen on these and other main recommendations, plus a brief look at the company's involvement with Oncology@Work, a multistakeholder initiative in Germany that is addressing issues such as return to work for cancer patients.

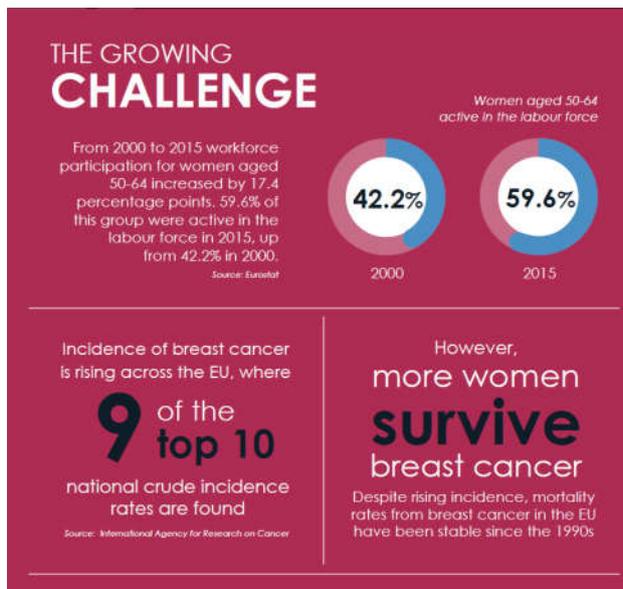
Next up was Donatella Decise from Novartis, who updated attendees on the company's Here & Now campaign for advanced breast cancer patients, which has evolved into My Time, Our Time. In 2019, said Decise, the campaign will conduct a similar survey to the one that launched Here & Now, to see what has changed for patients and carers in terms of the real-life impact of advanced breast cancer. In 2013, 40% of women in Europe with advanced breast cancer who were surveyed were working and of those, 25% worked full-time;

50% of patients had to make some change to their employment status, with the most common changes relating to a reduced working life.

Lastly, Vincent Clay from Pfizer presented another report from the Economist Intelligence Unit, *The road to a better normal: Breast cancer patients and survivors in the EU workforce*. It notes:

- Societal and medical trends in Europe are intersecting to increase the number of breast cancer patients and survivors who are likely to want to work. In the past 15 years the proportion of European women aged 50-64 in employment has risen steadily, so that now a majority (59.6%) of that group are active in the labour force
- The rate at which breast cancer patients and survivors return to work is highly uneven, suggesting substantial room for improvement. National return-to-work rates for breast cancer patients and survivors who were in a job at the time of diagnosis ranged from 43% in the Netherlands to 82% in France
- Breast cancer and treatment side-effects make returning to work harder, but they are far from the only issues. Important non-medical barriers also impede a return to work, including lack of employer

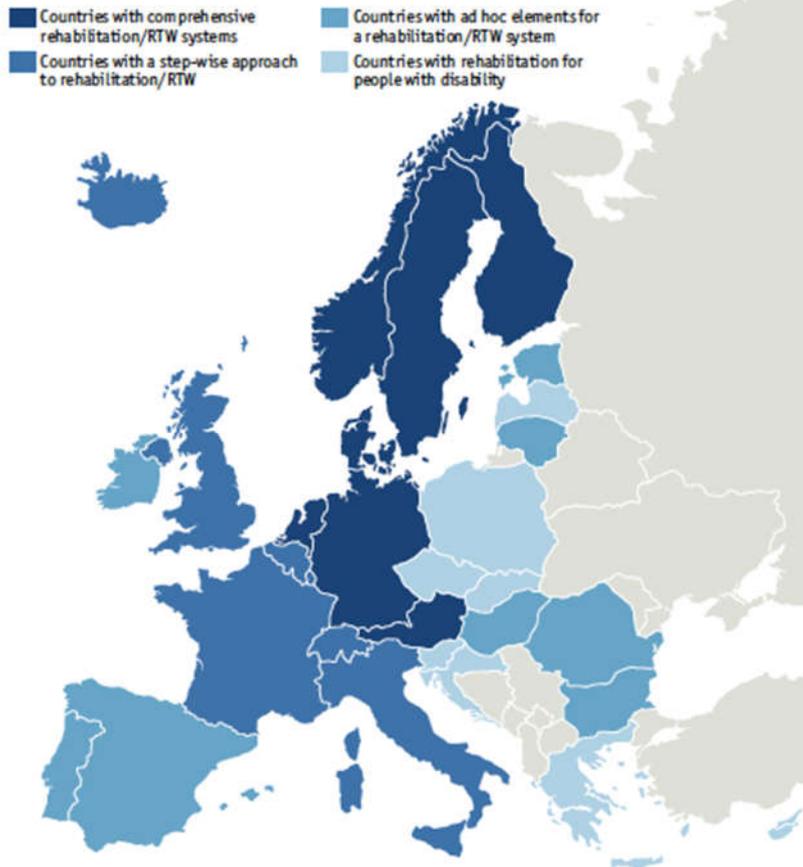
or colleague support, the extent to which work is physically demanding, and the level of education of the women involved. Such factors overlap to make specific populations vulnerable, particularly working-class women.



The report discusses change needed in three groups – healthcare professionals, employers and government, and includes the following points:

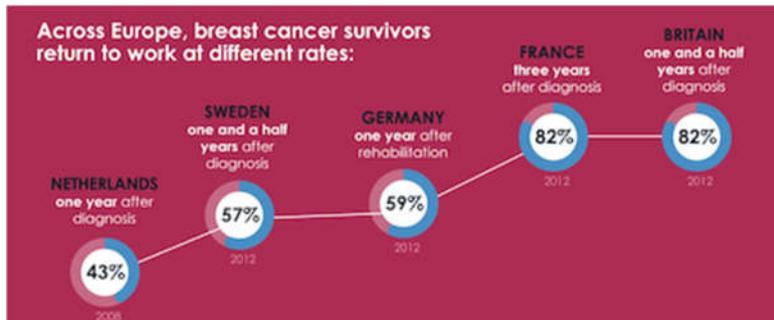
- Given that patients often feel uncertain and vulnerable about returning to work, uninformed neutrality towards or advice against resuming employment are likely to dissuade women. In a report based on a series of interviews in Poland with breast cancer survivors, for example, one theme was the experience of women who initially wished to return to work but did not do so on advice from their oncologists
- There is a wide variety in the experience and needs of breast cancer patients and survivors. This can pose substantial challenges for process-driven organisations. One study of Belgian employers found that the “unpredictability of the course of the illness ... was a difficult concept for employers to get to grips with”
- The report is blunt in stating that legislation and policy shaping the environment for the return to work of chronic breast cancer patients and survivors is in many European countries either completely lacking or has been designed with other needs in mind.

Approaches of EU member states to rehabilitation and return to work



Sources: European Agency for Safety and Health at Work.

Across Europe, breast cancer survivors return to work at different rates:



Q&A

The presentations covered a lot of ground, but attendees still found important points to make in the closing Q&A session:

- There are substantial numbers of self-employed women who do not have a formal workplace to return to, and face financial difficulties in particular. Younger women with breast cancer are likely to be most affected. Richard Sullivan said the only answer is to have mandatory insurance – voluntary schemes do not work
- The public sector should lead by example, but government employers are often the worst at supporting return to work
- People’s privacy must be respected – not all want their employers to know they have cancer, or how advanced it is. But employers cannot make adaptations if they do not have information. This also has implications for data collection, as some people will not be counted
- Organisations may respond better to incentives to adopt flexible policies rather than penalties. However, penalties have been given to companies, such as in the UK, where they have refused to make adjustments
- Fatima Cardoso suggested that legislation protecting the right to return to work part time or with flexible hours, coupled with financial support and/or tax exemption for employers who apply that legislation, could be a solution to protect both employees and employers
- Lieve Wierinck, in closing remarks, emphasised that financial support is crucial to enabling flexibility for employers that find it hard to support unpredictable patterns of absence for cancer patients. Replacement income from welfare that switches in on days when an employee cannot work would help solve this.

Resources

European Parliament report on pathways for the reintegration of workers recovering from injury and illness into quality employment

<http://www.europarl.europa.eu/sides/getDoc.do?type=REPORT&reference=A8-2018-0208&language=EN>

European Parliament: Getting back to work after a long sickness or injury (video)

<http://www.europarl.europa.eu/news/en/headlines/society/20180830STO11344/getting-back-to-work-after-a-long-sickness-or-injury-video>

European Pillar of Social Rights

https://ec.europa.eu/commission/priorities/deeper-and-fairer-economic-and-monetary-union/european-pillar-social-rights_en

European Pillar of Social Rights – work-life balance

<http://ec.europa.eu/social/main.jsp?catId=1311&langId=en#navItem-relatedNews>

European Agency for Safety and Health at Work (EU-OSHA). Rehabilitation and return to work after cancer – instruments and practices.

<https://osha.europa.eu/en/tools-and-publications/publications/rehabilitation-and-return-work-after-cancer-instruments-and/view>

Association of European Cancer Leagues, return to work for employers

https://www.europecancerleagues.org/wp-content/uploads/Return-to-Work-presentation-for-employers_2018.pdf

European Patients Forum. Equal treatment for patients in education and employment

http://www.eu-patient.eu/globalassets/policy/anti-discrimination/epf-position-paper_equal-treatment-in-education-and-employment.pdf

Eurofound – European Foundation for the Improvement of Living and Working Conditions

<https://www.eurofound.europa.eu>

Dying to Work – European campaign

<https://www.dyingtoworkeu.org>

Dying to Work – UK

<https://www.dyingtowork.co.uk>

European School of Oncology

<https://www.eso.net>

ABC Global Alliance

<https://www.abcgloballiance.org>

ABC5 – International Consensus Conference for Advanced Breast Cancer

<http://www.abc-lisbon.org>

Working With Cancer – (founder Barbara Wilson)

<https://www.workingwithcancer.co.uk>

Interview with Lieve Wierinck

<https://www.workingwithcancer.co.uk/wp-content/uploads/2018/07/Lieve-Wierinck-Discusses-Transforming-Breast-Cancer-Together-with-Barbara-Wilson-July-2018.pdf>

Cancer in the workplace. Economist Intelligence Unit.

<http://cancersurvivorship.eiu.com/briefing-paper>

Metastatic Breast Cancer Policy Roadmap

<https://lillypad.eu/entry.php?e=3336>

My Time Our Time/Here & Now – Novartis

<https://www.wearehereandnow.com/my-time-our-time>

<https://www.wearehereandnow.com>

The road to a better normal: Breast cancer patients and survivors in the EU workforce

<https://www.workingwithcancer.co.uk/wp-content/uploads/2017/11/EIU-Reports.pdf>

Europa Donna – metastatic breast cancer

<https://mbc.europadonna.org/>

Global Status of Advanced/Metastatic Breast Cancer 2005-2015. Decade Report

https://www.abcgloballiance.org/pdf/Decade-Report_Full-Report_Final.pdf

Macmillan. Work and cancer

<https://www.macmillan.org.uk/about-us/what-we-do/how-we-work/work-and-cancer>