The Economist Intelligence Unit

A report by The Economist Intelligence Unit

THE ROAD TO A BETTER NORMAL:
Breast cancer patients and survivors in the EU workforce

Sponsored by:

Pfizer Oncology

CONTENTS

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ABOUT THE RESEARCH

The road to a better normal: Breast cancer patients and survivors in the EU workforce is an Economist Intelligence Unit report, sponsored by Pfizer. It investigates the challenges involved in the return to employment for a growing number of breast cancer patients and survivors of working age. In particular, it examines the growing number of women in this situation who wish to work, the barriers to doing so, and how key stakeholders could help.

The findings of this briefing paper are based on extensive desk research and interviews with a range of healthcare experts. As part of the research, EIU Healthcare—an Economist Intelligence Unit company specialising in evidence-based healthcare—conducted focused, systematic searches of relevant medical and other databases. The report also benefited from the guidance of an international advisory board of experts in the field. None of the members of this board or any of the other interviewees received financial support or expense reimbursement from the sponsor.

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- Kathi Apostolidis, vice president, European Cancer Patient Coalition
- Liz Atkinson, chair, Patient Support Working Group of the Association of European Cancer Leagues; and head of Care Services, Cancer Focus Northern Ireland
- Pascale Breton, director of consulting, Groupe Prévia
- Liz Egan, lead, Working through Cancer Programme, Macmillan Cancer Support
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- Bo Rix, head, Documentation and Development & Patient Support and Community Activities, Danish Cancer Society
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- Barbara Wilson, founder, Working With Cancer
- Jacci Woodcock, campaign founder, Dying to Work

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EXECUTIVE SUMMARY

Healthcare systems in Europe have slowly transformed breast cancer from a fatal condition into a (frequently chronic) disease. This transformation, while greatly welcome, has brought in its wake a growing societal challenge. An increasing number of female breast cancer patients and survivors of working age are capable of returning to employment and wish to do so.[1] Not all of them succeed, however, and not simply for medical reasons. Breast cancer creates psychological and economic stress for the women directly involved, but it also impacts society as a whole. For cancer overall, one academic study put the combined cost to Europe of sick leave, underemployment and unemployment caused by cancer at €9.4bn (US$11.1bn) annually. Although detailed data are not available, breast cancer, the most common female form of the disease in Europe, inevitably exacts a notable part of that toll. This large human and economic cost looks set to increase as more cancer patients live longer, creating pressing societal challenges that a range of relevant actors will need to address.

This Economist Intelligence Unit study, sponsored by Pfizer, has drawn on the insights of a high-level advisory board, seven interviews with relevant experts and an extensive programme of desk research to look at this issue, the impediments to greater labour force participation by breast cancer patients and survivors, and how key stakeholders can improve the situation. Its key findings include:

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 last 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. For 40-somethings, this figure is 81.4%. These are, though, the same ages during which breast cancer risk rises substantially. This is a particular issue in the European Union, which has nine of the ten highest crude incidence rates of the disease in the world. Moreover, incidence, both crude and age-adjusted, has been rising on the continent. Crude mortality rates, in contrast, have been stable. Not all the women affected are of working age, but many are. Figures from one British study project that by 2020, around 3% of females aged 45-64 will be breast cancer survivors.

The rate at which breast cancer patients and survivors return to work is highly uneven, suggesting substantial room for improvement. Surveys of those of employment age diagnosed with cancer indicate that most place a high importance on returning to work, typically because of the psychological benefits it brings, such as a sense of returning to a normal life. Nevertheless, success is highly variable. National return-to-work rates for breast cancer patients and survivors who were in a job at the time of diagnosis range from 43% in the Netherlands to 82% in France. Moreover, among those who try to stay in the workforce, the unemployment rate for breast cancer survivors is more than double that of healthy control populations (35.6% versus 15.2%). Impediments clearly exist to returning to work, and as the number of chronic breast cancer patients and

[1] Although male breast cancer does occur, it is very rare, with an age adjusted incidence of less than 1 per 100,000 in most of Europe and no clear sign of increase or decrease (Diana Ly *et al.*, "An International Comparison of Male and Female Breast Cancer Incidence Rates", *International Journal of Cancer*, 2012). This study therefore deals exclusively with female breast cancer.

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survivors increases, the effect of such barriers, unless addressed, will keep ever more women out of the workforce.

Breast cancer and treatment side effects make returning to work harder, but they are far from the only issues. Breast cancer itself is physically challenging, and treatment side effects, while unavoidable in many cases, can compound difficulties for those trying to return to the workplace: lymphedema, for example, arising from the removal of lymph nodes by surgery, can cause substantial upper-body pain, and chemotherapy is associated with declines in cognitive function. 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.

In the near future, the most progress is likely to come from key stakeholders beginning to address the issue and communicating about it with patients and survivors. Cancer survivorship—let alone its relationship to employment—is an emerging area for which firm evidence on interventions is spotty. Available evidence and expert views point to several stakeholders who could act in important ways to ease a return to work.

- *Healthcare professionals*: Too often medical personnel are reluctant to discuss employment issues or use return to work as an outcome of treatment. Gaining a better understanding of how cancer care impacts work, and discussing these issues directly with patients, would represent a substantial cultural change for healthcare professionals. Currently, the lack of communication on this topic is impeding many women who wish to return to work.

- *Employers*: One of the clearest messages from existing data is that employer actions and attitudes are central to a successful return to work for cancer patients and survivors. Research indicates that most employers are actually well-disposed towards their employees who develop breast cancer, but that they rarely consider the issue until one of their staff is directly affected. Thinking through the issues ahead of time would prevent the need for an ad hoc, perhaps ill-considered, response. Given the differences in how people experience cancer and its aftermath, policies should not be one-size-fits-all. Instead, employers should have mechanisms to initiate and maintain communication with employees with breast cancer to tailor their response to individual situations. Employers also need to be prepared to communicate with other employees whose work load may increase temporarily to cover for a colleague with cancer. Otherwise, resentment is likely to build in the workplace.

- *Governments*: Government policies, regulations and guidance on cancer and employment are widely lacking in Europe, and where they do exist, they are often the result of the application of rules and tools created for other purposes. Those governments without a relevant policy should, like employers and healthcare

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professionals, think these issues through. Those with existing regulations and programmes should examine adapting relevant policies to the specific needs of breast cancer patients—for example, by instituting a phased return to work or temporary disability status. Governments must also avoid being too prescriptive, instead creating fair ground rules and an environment that is conducive to helping employees and employers to work out individualised return-to-work strategies.

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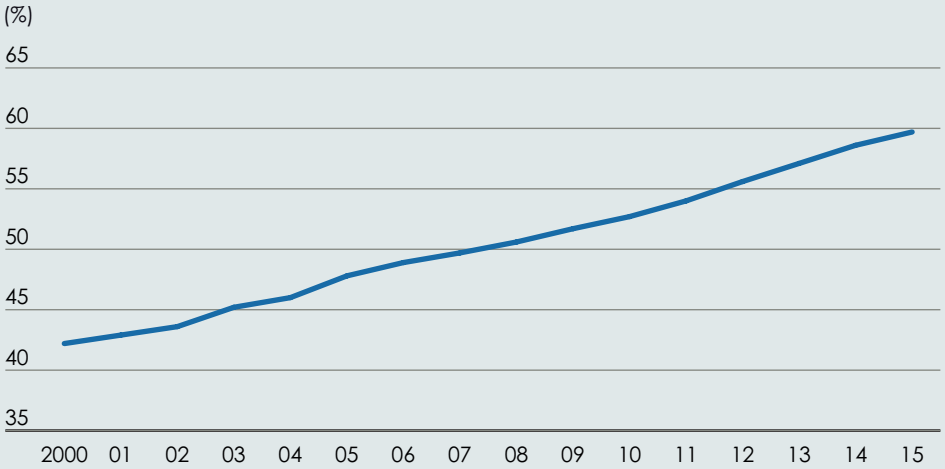
I. THE GROWING CHALLENGE

Two trends meet

When disparate trends intersect, previously unappreciated issues can quickly emerge. The challenges around the employment of breast cancer patients and survivors in Europe are one such case.

Chart 1

European Union female labour force participation rate, ages 50-64, 2000-15



Source: eurostat.

The first relevant factor here is the rise in the labour-force participation rate among women in the second half of the traditional working lifespan. In the 28 member states of the EU the workforce participation rate among women aged 50-64 rose by over one-third in 2002-15, to 59.6%. Among females in their 40s, workforce participation rates were already higher in 2002 (75.9%), but they too have gone up slowly to reach 81.4% in 2015. In short, most European women aged between 40 and 65 are either in, or looking for, employment. (Chart 1)

During this same time of life, however, the risk of female breast cancer goes from relatively low to becoming an important health consideration. This is particularly marked in the EU countries, where the overall crude incidence rate in 2012—the latest year for which there are good, international data available—was 139.5 per 100,000 women.[2] Incidence varies widely across member states and is lower in southern and eastern countries (Romania has the lowest rate at 81.5 per 100,000 women) and greater in the EU's west and north, with Belgium's 188 per 100,000 women topping the EU and the world. Overall, nine of the top ten national crude incidence rates for the disease are found in the EU.[3]

[2] This study uses the unadjusted "crude" rate of incidence because this reflects the actual proportion of the population affected by cancer. Age-standardised figures are more commonly used elsewhere because they allow international comparisons between younger populations and older ones, as is the case in most European countries.

[3] Figures from the International Agency for Research on Cancer (IARC), "Estimated Cancer Incidence, Mortality and Prevalence Worldwide in 2012", online database. Available at: globocan.iarc.fr/Pages/online.aspx

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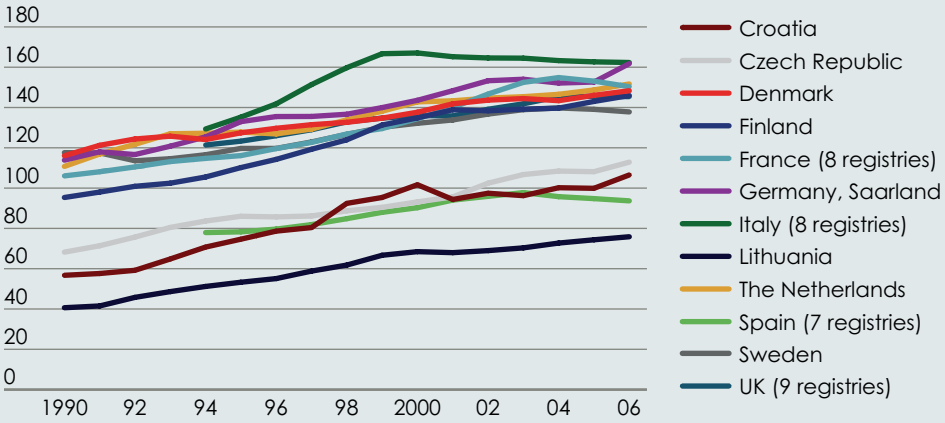
But even where the incidence rate is lower in Europe, breast cancer remains a prominent public health issue. In 2012 it was the most common cancer among women in every European state and accounted for 30% of all female cases on the continent—including 38% of those among women of working age. In both cases this is considerably more than double the number of the next leading cancer among women, colorectal (12.7%).[4]

Chart 2

Breast cancer - Crude incidence rate - Ages 0-85+ - Selected European countries -1990-2006
(rate per 100,000)



Source: International Agency for Research on Cancer (IARC).

Worse still, this incidence is rising. Registry data from the Cancer Incidence in Five Continents (C15) series by the International Agency for Research on Cancer (IARC)—the only robust time series available—shows the general trend (Chart 2). Part of this reflects demographic ageing, which leads to a greater proportion of the population being at higher risk of developing the disease. The age-adjusted figures, however, also show a steady, if less pronounced, increase across much of Europe.[5]

Fortunately, trends in the EU's breast cancer mortality figures differ markedly from those of incidence. Rather than increasing, the crude rate of breast cancer mortality in Europe has stayed stable since the 1990s, with IARC estimates putting it at 35.3 per 100,000 women in 2012. This actually represents substantial progress, given the growing incidence. Indeed, according to the Global Burden of Disease figures from the World Health Organisation (WHO), age-adjusted mortality, which takes into account the ageing of the European population, has dropped by just over one-fifth since 1990, although the extent to which widespread screening and better treatment, or both, are responsible remains hotly debated.

Diverging incidence and mortality figures mean that, across the EU, the number of women who currently have, or have survived, breast cancer rises by several hundred

[4] IARC, "Estimated Cancer Incidence, Mortality and Prevalence Worldwide in 2012"; J Ferlay *et al.*, "Cancer incidence and mortality patterns in Europe: Estimates for 40 countries in 2012", *European Journal of Cancer*, 2013.

[5] There are likely to be many contributors to the rise in breast cancer incidence in Europe, but while some are widely accepted, others remain controversial or uncertain. The same is true of declining mortality rates, where the impact of screening remains a topic of hot debate. For background on these issues, which are beyond the scope of this study, see The Economist Intelligence Unit, *Breast cancer in Asia*, 2016.

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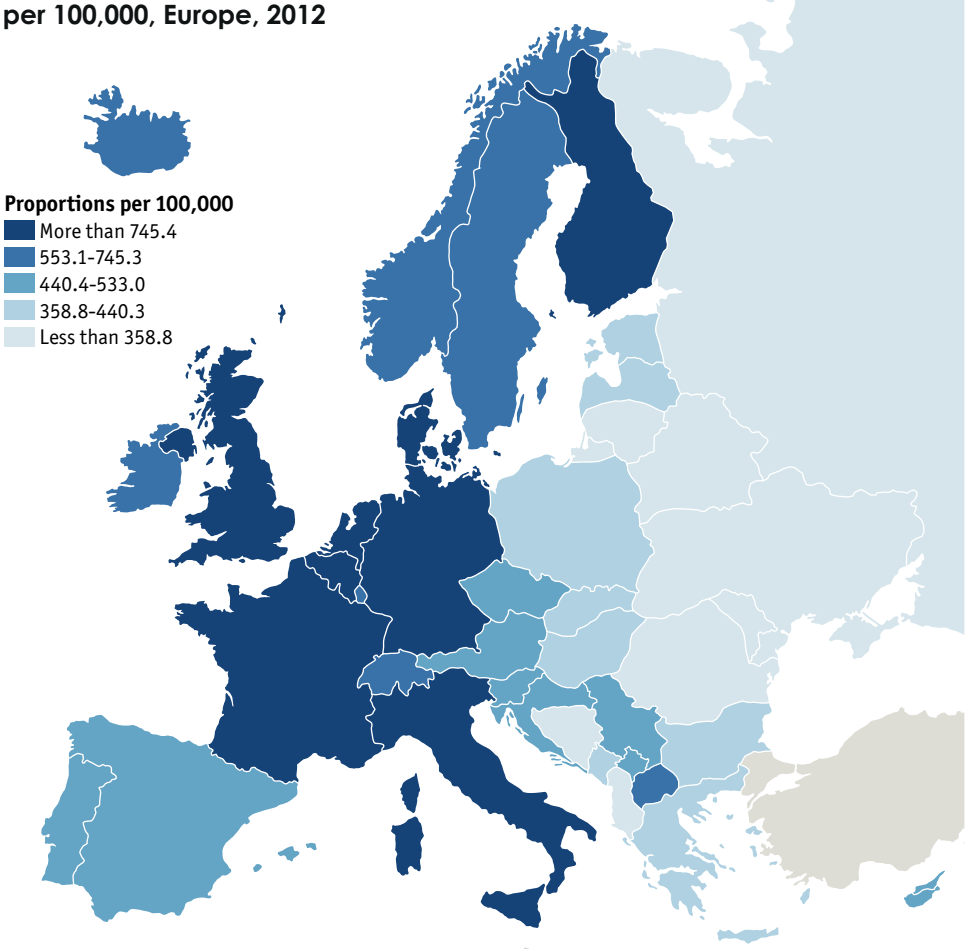
thousand annually. By 2012 over 1.4m women had been diagnosed with the disease in the preceding five years, although the prevalence per 100,000 differs between eastern and western Europe. (Map 1).

Map 1

Estimated 5-year prevalence of breast cancer in women, proportions per 100,000, Europe, 2012



Sources: World Health organisation; International Agency for Research on Cancer; European Union.

However, the five-year prevalence figure—the most commonly available prevalence statistic—markedly understates the actual number of survivors. The UK, for example, has the elevated, rising incidence figures typical for its part of Europe. Figures from a 2008 study indicate that by then the total number of breast cancer survivors was triple that of those who had been diagnosed in the preceding five years.[6] These longer-lived survivors, and in some cases metastatic patients, matter to our topic: according to recent Dutch research, the impact of the disease on employment prospects lasts at least a decade.[7]

A substantial number of these patients and survivors are of working age. Figures from another UK study indicate that by 2020, 3% of females aged 45-64 will be breast cancer survivors.[8] Unlike in the past, when treatment outcomes were less favourable, many

[6] Jacob Maddams *et al.*, "Cancer prevalence in the United Kingdom: estimates for 2008", *British Journal of Cancer*, 2009.

[7] C Paalman *et al.*, "Employment and social benefits up to 10 years after breast cancer diagnosis: a population-based study", *British Journal of Cancer*, 2016.

[8] Jacob Maddams *et al.*, "Projections of cancer prevalence in the United Kingdom, 2010–2040", *British Journal of Cancer*, 2012.

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patients and survivors will now be able to— and wish to—participate in the labour force. As Pascale Breton, director of consulting at Groupe Prévia, a French company which helps organisations with return-to-employment issues, notes: "Twenty years ago most cancer patients were not returning to work; it is unlikely today that a young person, especially, would not." Survey data back her up: a poll by Macmillan Cancer Support, a UK charity, found that of those diagnosed with any cancer, 68% considered continuing employment to be "very important", and a further 17% "fairly important".[9] Bo Rix, head of Documentation and Development & Patient Support and Community Activities at the Danish Cancer Society, adds that return to work "is now turning into a bigger issue because people with cancer survive longer. It is becoming a chronic disease, which changes the focus to rehabilitation."

Can everyone who wants to return to work?

The data on how many breast cancer patients and survivors actually return to employment after receiving treatment (or keep working through it) remain patchy. Nevertheless, existing research already reveals that "big differences exist across countries in Europe", according to Taina Taskila, a research fellow in the Health and Society Research Group at the University of Greenwich in London. (Table 1)

Table 1
Return to work rates for breast cancer patients and survivors from selected European studies[10]

Country	Year	
Netherlands	2008	43% (one year after diagnosis)
Sweden	2012	57% (18 months after diagnosis)
Germany	2012	59% (one year after rehabilitation)
France	2012	82% (36 months after diagnosis)
United Kingdom	2007	82% (18 months after diagnosis – mixed group of female cancer survivors but biggest component had breast cancer)

Interpreting what this means is not straightforward. For some women, the experience of cancer will be so life-changing that their interest in spending time in paid employment declines.[11] Others will take the opportunity to leave unpleasant jobs. Barbara Wilson, founder of Working With Cancer, a UK consultancy providing coaching and training to people affected by cancer, believes that resuming employment can play an important part in an individual's return to well-being, but she also sees little benefit from going back if work is "awful and grim". Indeed, recent research has found that job dissatisfaction before diagnosis correlates with not working after breast cancer.[12]

[9] Macmillan Cancer Support, "1 in 5 people who return to work after cancer face discrimination". Press release, November 7th 2016.

[10] Data taken from Tania Islam *et al.*, "Factors associated with return to work of breast cancer survivors: a systematic review", *BMC Public Health*, 2014; Oliver Rick *et al.*, "Reintegrating Cancer Patients Into the Workplace", *Deutsches Ärzteblatt International*, 2012; and Sophie Quinton Fantoni *et al.*, "Factors Related to Return to Work by Women with Breast Cancer in Northern France", *Journal of Occupational Rehabilitation*, 2010.

[11] Maggi Banning, "Employment and breast cancer: a meta-ethnography", *European Journal of Cancer Care*, 2011.

[12] Eskil Heinesen *et al.*, "Return to work after cancer and pre-cancer job dissatisfaction", Rockwool Foundation Research Unit, Study Paper No. 108, 2016.

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As noted above, however, these women are the exception, as most breast cancer patients and survivors want to resume working. In some cases, this wish reflects constraints: self-employment or lack of access to health insurance increase the likelihood of women working through, or returning quickly after, breast cancer treatment.[13] In the majority of cases, though, those resuming work are primarily after its psychological benefits. Liz Egan, who leads the Working through Cancer Programme at Macmillan, reports that her organisation's survey of cancer survivors has found that "while there are issues around financial security, the number one reason people want to go back to work is to return to normality. It represents getting one's life back." Ms Wilson agrees. Not being able to work, "and the feelings of isolation and rejection by society it gives rise to, can be devastating. Work is often about self-esteem and identity."[14] The psychological benefits may yield physical ones: an American study found a link among breast cancer patients and survivors between at least some employment and self-reported health status.[15]

However, not all those who wish to return to work succeed. Setting aside those who leave the labour force entirely in frustration, according to a large meta-analysis the unemployment rate for breast cancer survivors is more than double that of healthy control populations (35.6% versus 15.2%).[16] Moreover, even when caught at a very early stage, breast cancer has a negative impact on employment.[17] This human toll also exacts economic costs. A 2013 study calculated that sick leave, as well as under- or unemployment caused by cancer, cost Europe €9.4bn (US$11.1bn) per year.[18] With breast cancer responsible for such a large share of cancer in women of working age, it is likely to be driving a substantial proportion of this cost.

Overall, this is "a big, growing issue that will increase as more people survive and live longer with cancer", according to Ms Egan. Awareness of the problems around returning to work for cancer survivors is rising, adds Liz Atkinson, chair of the Patient Support Working Group of the Association of European Cancer Leagues, but she notes that in most European countries "no employment protection at all" exists for cancer patients and survivors. Other key stakeholders are equally unfocused over the long term. Ms Wilson describes a recent comment from a senior HR executive at a law firm—"We did cancer last year; this year we are doing mental health"—as not unusual. Nor is it an issue that will inevitably solve itself over time: a Dutch study showed that the rate of return to full-time work declined in the Netherlands between 2002 and 2008.[19]

With this as background, we turn next to the impediments to greater labour-force participation by breast cancer patients and survivors, as well as what key stakeholders might do to improve the situation.

[13] Linda Sharp and Aileen Timmons, "Social welfare and legal constraints associated with work among breast and prostate cancer survivors: experiences from Ireland", *Journal of Cancer Survivorship*, 2011; Cathy Bradley *et al.*, "Does employer-provided health insurance constrain labor supply adjustments to health shocks? New evidence on women diagnosed with breast cancer", *Journal of Health Economics*, 2013.

[14] See also Mary Wells *et al.*, "Supporting 'work-related goals' rather than 'return to work' after cancer? A systematic review and meta-synthesis of 25 qualitative studies", *Psycho-Oncology*, 2013; DM Rasmussen and B Elverdam, "The meaning of work and working life after cancer: an interview study", *Psychooncology*, 2008.

[15] Allegra Timperi *et al.*, "Employment Status and Quality of Life in Recently Diagnosed Breast Cancer Survivors," *Psychooncology*, 2013.

[16] AGM de Boer *et al.*, "Cancer Survivors and Unemployment: A Meta-analysis and Meta-regression", *JAMA*, 2009.

[17] Sonja Eaker *et al.*, "Breast Cancer, Sickness Absence, Income and Marital Status. A Study on Life Situation 1 Year Prior Diagnosis Compared to 3 and 5 Years after Diagnosis", *PloS One*, 2011.

[18] Ramon Luengo-Fernandez *et al.*, "Economic burden of cancer across the European Union: a population-based cost analysis", *Lancet Oncology*, 2013.

[19] Corné Roelen *et al.*, "Trends in return to work of breast cancer survivors", *Breast Cancer Research and Treatment*, July 2011.

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II. BARRIERS TO UNDERSTANDING AND TO EMPLOYMENT

Working with little light

Any discussion of employment by breast cancer patients and survivors must acknowledge the basic state of current knowledge. Indeed, survivorship itself remains relatively unexplored territory. Dr Rix explains, for example, that "most people know that if you are treated for breast cancer, you will likely survive, but few know about the late effects. Treating them is a whole new area, and even many doctors do not know the side effects." Kathi Apostolidis, vice president of the European Cancer Patient Coalition, adds that when it comes specifically to employment, for most relevant questions "in reality, from what I have seen, we do not have the data".

In particular, although understanding is growing as to what correlates with higher return-to-work rates, how to act on this knowledge is less clear. A recent review of relevant medical intervention studies found only a handful of even moderate quality.[20] As for other stakeholders, notes Dr Taskila, "we are starting to realise that employers play an important role in return to work, but we don't really know exactly how, and I have not come across any research on what government policies work here."

Another complication is that much of the existing research around employment involves cancer in general, and as Ms Breton notes, "it can be difficult to isolate breast cancer specifically." The differences between cancers sometimes matter: existing evidence indicates that breast cancer treatment, and therefore time away from employment, tends to last longer than for many other cancers. Similarly, unemployment rates are slightly—but to a statistically significant degree—higher among women with breast cancer than among those who experience other forms of the disease.[21] Nevertheless, general studies of links between cancer and employment typically include a large number of breast cancer participants. Moreover, experts interviewed for this study did not cite any substantial differences facing breast cancer patients or survivors in the workplace. Relying on general research is therefore a reasonable, if imperfect, course.

The broader implication of existing data on breast cancer and employment, though, remains: while the nature of the problem is coming into better focus as patients are living longer, in some areas it is still unclear, and what to do about it often has to rely more on common sense than robust evidence.

Barriers to returning to work

The difficulties that breast cancer—and indeed all cancer—patients and survivors face in getting back into employment are complex. To begin with, context matters greatly as the disease exacerbates existing issues. For example, recent unemployment or even

[20] AGM de Boer *et al.*, "Interventions to enhance return-to-work for cancer patients", *Cochrane Database of Systematic Reviews*, 2015.

[21] Régine Kiasuwa Mbengi *et al.*, "Barriers and opportunities for return-to-work of cancer survivors: time for action—rapid review and expert consultation", *Systematic Reviews*, 2016; AGM de Boer *et al.*, "Cancer Survivors and Unemployment: A Meta-analysis and Meta-regression".

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working under a short-term or easy-to-terminate contract before diagnosis correlates with being out of a job in the years after cancer.[22]

Moreover, despite improved survival rates, breast cancer, its common aftereffects such as lymphedema and the nature of treatment take a substantial physical and emotional toll on patients. Upper-body pain, fatigue and depression are common side effects. For some, inevitably, these will be debilitating. For most, they cause ongoing problems: a recent Danish study found that even after five years, breast cancer survivors on average reported significantly poorer work ability than did members of a control group.[23] Adding to the complexity, recovery is not linear, with survivors' emotional and physical states seeing both advances and declines for some time. As Dr Rix explains: "You might feel fine after treatment, but then have lymphedema to deal with months or years later." Not surprisingly, feelings of uncertainty and vulnerability colour many women's consideration of resuming work.[24]

Such physical and mental challenges, however, are not simply manifestations of the direct effects of breast cancer and its care and treatment. As the above-noted Danish study found, survivors reporting impaired work ability in the years after diagnosis were generally also those who reported low levels of help and support from job supervisors. Ms Atkinson notes that surveys referenced by the European Cancer League show such a combination to be common: "People lose their confidence, have ongoing side effects of the treatment, and then feel employers don't understand."

Return-to-work rates thus depend on a wide range of interacting factors rather than a single cause. These can be divided as follows:[25]

The impact of the disease itself: Higher ongoing levels of pain, fatigue and depression are consistent with lower success in returning to, or staying in, work.

The impact of treatment and its side effects: Care and treatment of breast cancer have improved greatly in recent years, otherwise the issue of return to work would be less pressing. Nevertheless, they are far from perfect. For example, chemotherapy in particular, but also radiotherapy—both, in practice, still often though not inevitably parts of breast cancer treatment regimens—are associated with lower return-to-work rates and longer time off for those who receive them. To some extent, they exacerbate problems arising from cancer, such as tiredness, but they can also cause their own issues, which reduce the ability to work. Chemotherapy, for example, frequently reduces cognitive function—a side-effect of what is popularly called "chemo-brain"—which presents its own challenges.

The nature of work: Studies in numerous countries have found that those in manual, low-skilled jobs return to employment at a lower rate. Once more, part of this correlation is likely to result from overlap with other issues. Upper-body pain and fatigue may impede a desk job, but they make strenuous manual labour nearly impossible. The attributes of such work, though, also add their own complications to the mix: the typically lower wages of blue-collar jobs make returning less enticing.

[22] Kathrine Carlsen *et al.*, "Unemployment among breast cancer survivors", *Scandinavian Journal of Public Health*, 2014; Institut National du Cancer, *La vie deux ans après un diagnostic de cancer - de l'annonce à l'après cancer, collection études et enquêtes*, 2014; Thomas Barnay *et al.*, "The Effects of Breast Cancer on Individual Labour Market Outcomes: An Evaluation from an Administrative Panel", Travail, Emploi et Politiques Publiques Working Paper, 2016-05.

[23] Kathrine Carlsen *et al.*, "Self-reported work ability in long-term breast cancer survivors: A population-based questionnaire study in Denmark", *Acta Oncologica*, 2013. See also Beate Hauglann *et al.*, "A cohort study of permanently reduced work ability in breast cancer patients", *Journal of Cancer Survivorship*, 2012; and studies cited in Gill Hubbard *et al.*, "Case management vocational rehabilitation for women with breast cancer after surgery: a feasibility study incorporating a pilot randomised controlled trial", *Trials*, 2013.

[24] Corine Tiedtke *et al.*, "Survived but feeling vulnerable and insecure: a qualitative study of the mental preparation for RTW after breast cancer treatment", *BMC Public Health*, 2012.

[25] The rest of this section summarises findings from the following: Joanne Park and Mamdouh Shubair, "Returning to Work After Breast Cancer: A Critical Review", *International Journal of Disability Management*, 2013; Tania Islam *et al.*, "Factors associated with return to work of breast cancer survivors: a systematic review"; Régine Mbengi *et al.*, "Barriers and opportunities for return-to-work of cancer survivors: time for action – rapid review and expert consultation", *Systematic Reviews*, 2016; and Institut National du Cancer, *La vie deux ans après un diagnostic de cancer - de l'annonce à l'après cancer, collection études et enquêtes*, 2014.

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The nature of the workplace: As one literature review notes: "Almost all the articles [on return to work after breast cancer] have identified that positive and active support from employers and colleagues are the key facilitators."[26] Dr Taskila agrees: "Line managers' support is crucial, and also colleagues can offer support."

Sociodemographic situation: Certain other characteristics correlate with different employment outcomes for patients and survivors. Older individuals, who are therefore closer to retirement age, are less likely to resume employment. Those with higher levels of education return to work more frequently. Single, divorced and widowed women also do so more often, although in some cases this probably reflects financial necessity.

These factors kick in at different stages of the return-to-work process, with the physical and psychological aspects acting as initial barriers, while the workplace issues affect those who have overcome them.[27]

They also combine to affect specific populations especially strongly. In particular, low levels of education often limit employment choices to low-skilled or manual work and in turn reduce earning capacity. In Ms Breton's words: "It's pretty obvious that there is a big difference between the blue-collar population and the managerial population, with the former the most vulnerable to losing employment after cancer." In contrast, a study in the Paris region found a rate of return of 92% after two years among a group of women, most of whom were salaried office workers or professionals in large firms with extensive occupational health provision.[28] That said, return to work is never easy: in France, La Ligue contre le cancer says that the typical users of its legal advice services around employment are salaried breast cancer patients and survivors in the Paris region.[29]

Getting more women who wish to do so back into the workforce is clearly a multifaceted challenge. A good place to start is to look at which actors are best placed to modify which issues. This will be considered in the rest of this study.

[26] Tania Islam *et al.*, "Factors associated with return to work of breast cancer survivors: a systematic review".

[27] Sietske Tamminga, "Breast cancer survivors' views of factors that influence the return-to-work process – a qualitative study". *Scandinavian Journal of Work, Environment, and Health*, 2012

[28] M Sevellec *et al.*, "Répercussions du cancer sur la vie professionnelle des salariés en Île-de-France", in *Situations De Travail Et Trajectoires Professionnelles Des Actifs Atteints De Cancer*, Institut National de Cancer, 2012.

[29] *Observatoire Sociétal Des Cancers Rapport 2013*, 2013.

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III. WHERE CHANGE IS NEEDED

A. Medical personnel

Doctors and nurses inevitably affect how quickly, or even if, breast cancer patients and survivors return to work. As discussed earlier, the choice of therapy itself can create barriers. In many cases, the specifics of the cancer do much to dictate the particular treatment. Even here, though, options may be available. For example, survival rates for women with early-stage breast cancer are the same for breast-conserving surgery—so-called lumpectomies—and radical mastectomies.[30] The latter are also associated with a lower rate than the former of returning to work and a longer time away from employment.[31] Improvements in care over time are likely to increase these options: a new European study indicates that a genetic test may be able to identify some 46% of early-stage patients who could safely avoid chemotherapy.[32]

More generally, notes a recent review, "due to the vast combination of treatment options, associated symptoms, and comorbidities, [return to work] outcomes can vary drastically".[33] Unfortunately, in selecting among those options, "a big challenge has been that health systems do not see work as a clinical outcome of care," notes Ms Egan of Macmillan Cancer Support. Doing so would be consistent with patient views of what recovery looks like and lead to choices that could reduce, where possible, barriers to resuming employment.

This, though, adds Ms Egan, would represent a "substantial, long-term cultural change". Ms Atkinson reports that surveys conducted by the Association of European Cancer Leagues reveal a common issue among patients, namely "a lack of awareness from medical staff about employment. Consultants often approach it negatively, saying 'Don't worry about work', or 'You won't be able to go to work'. They frequently advise people to change jobs or reduce hours, but without understanding what that means [for the patient's life]." Ms Wilson adds that general practitioners often simply do not know the impact of treatment on employment, so tend to shy away from the topic. Similarly, a Belgian study found that "once treatment has finished, treating physicians want to stimulate patients' [return to work], but they reported having a lack of knowledge on RTW [return to work] procedures and possibilities. In addition, they often feel ill-equipped to advise on work-related issues..."[34]

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. Similarly, a small Dutch study found that opposition from health professionals was a barrier to returning to work, but a positive attitude by clinicians facilitated it. Indeed, simple encouragement can have substantial effects. One of the few studies of effective medical interventions in this

[30] Allison W Kurian *et al.*, "Use of and Mortality After Bilateral Mastectomy Compared With Other Surgical Treatments for Breast Cancer in California, 1998-2011", *JAMA*, 2014.

[31] Sonja Eaker, "Breast Cancer, Sickness Absence, Income and Marital Status. A Study on Life Situation 1 Year Prior Diagnosis Compared to 3 and 5 Years after Diagnosis"; Régine Mbengi *et al.*, "Barriers and opportunities for return-to-work of cancer survivors: time for action – rapid review and expert consultation"; Joanne Park and Mamdouh Shubair, "Returning to Work After Breast Cancer: A Critical Review".

[32] Fatima Cardoso *et al.*, "70-Gene Signature as an Aid to Treatment Decisions in Early-Stage Breast Cancer", *New England Journal of Medicine*, 2016.

[33] Joanne Park and Mamdouh Shubair, "Returning to Work After Breast Cancer: A Critical Review".

[34] Corine Tiedtke *et al.*, "Supporting Return-to-Work in the Face of Legislation: Stakeholders' Experiences with Return-to-Work After Breast Cancer in Belgium", *Journal of Occupational Rehabilitation*, 2012.

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field—which took place as far back as the 1970s—involved counselling of mastectomy patients by a specialist nurse, which included advice on resuming employment. Although this did not reduce physical discomfort, it did improve return-to-work rates markedly (75%, compared with a control group's 54%).[35]

Accordingly, Ms Egan believes, a major gap in healthcare provision at the moment is that "very few are having the conversation [around patients' questions about the impact of their disease on employment] within healthcare systems. This stems from health professionals not seeing it as their role or duty. We don't expect clinicians to be experts on work, but they should, at a minimum, have conversations about it, use their clinical knowledge to support individuals or signpost people onto support. To ignore the problem is not the solution." The key, she believes, is "shifting the perspectives [of clinicians] to understand that work is important for people's health and recovery."

B. Employers

The nature of employer attitudes and workplace environments are among the strongest correlates of return to work for breast cancer patients and survivors.

What, then, are the concrete steps employers should take to be supportive? Unfortunately, in many ways, this is still a work in progress. Indeed, the perceptions, attitudes and experiences of employers, as well as the constraints facing them, have received very little attention even by the standards of this understudied field.[36]

Nor is it easy to generalise, given that much of what employers can or are required to do depends greatly on context, notes Dr Taskila. "In all the Scandinavian countries there are national occupational health services for all employees, which is not the case in the UK. Similarly, the situation varies for people in large companies who have access to occupational care, but people who are self-employed or work in small businesses may not have access to such services."

Nevertheless, several points have general applicability.

First, given the growing number of chronic cancer patients and survivors of all kinds in the European population, at the very least businesses must decide whether they are committed to keeping on those employees. This is currently far from given. Ms Apostolidis of the European Cancer Patient Coalition notes that, in practice, "in much of Eastern Europe a cancer diagnosis can mean immediate dismissal. Patients try to hide as much [about their condition] as they can to stay on the job." She adds that in southern Europe current high levels of unemployment in certain countries also make problems for cancer patients and survivors all too common: "In Greece and Spain it is easy to find a replacement for an employee who develops cancer, and new hires do not negotiate very hard about their salaries."

Even in countries where this does not occur, employers understandably see a need to balance the overall good of the company with that of an employee with cancer. Good

[35] Anna Mazurkiewicz, "Kobiety z rakiem piersi i ich powrót do pracy", *Oncology in Clinical Practice*, 2009; Sietske Tamminga, "Breast cancer survivors' views of factors that influence the return-to-work process – a qualitative study"; P Maguire *et al*, "The effect of counselling on physical disability and social recovery after mastectomy", *Clinical Oncology*, 1983.

[36] Corine Tiedtke *et al*., "Return to Work Following Breast Cancer Treatment: The Employers' Side", *Journal of Occupational Rehabilitation*, 2014.

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business arguments exist, however, to bolster the case for being supportive. As discussed below, in several European countries, albeit a minority, cancer patients and survivors enjoy certain legal protections in the workplace. Moreover, although studies are lacking in this area, presumably treating employees well increases staff loyalty.

Finally, replacements are also not always easy to find, and even when they are, the process can be costly. Research is lacking on the economic benefits of programmes to support employees affected by cancer. More generally, though, a recent study by Oxford Economics, a global advisory firm, found that, on average in the UK, replacing an employee costs over £30,000 (US$38,800), with more than £25,000 of that resulting from lower productivity until the new employee reaches the required performance level.[37] Even in lower-paying industries such as retail, getting a new employee up to speed costs roughly £20,000—no small consideration in balancing the inevitable costs of supporting an existing worker. Good estimates of the latter are not available, and the actual figure almost certainly varies widely depending on the individual. As Dr Taskila notes, though: "There is good evidence that only a very small minority of returning survivors need extensive support."

More surprising is how unimportant economic arguments may be. Several experts interviewed for this study note how often companies with which they deal wish to do well by their employees with cancer because it is the right thing to do. Indeed, much research—a majority of which comes from western Europe and North America—indicates that a large proportion of employers are already generally well-intentioned.[38] And one Spanish study from before the financial crisis found that none of the 80 women interviewed reported any discrimination at work after revealing they had breast cancer.[39]

What should these well-intentioned companies be doing?

First, given the growing number of survivors from breast and other cancers, they need to prepare for the increasing possibility that their own employees will be affected. This begins with giving the issue sufficient attention. As Ms Breton explains: "Many managers don't consider it a priority if they don't have anyone in the organisation with cancer, and so won't be able to do anything if it happens." Worse still, in some countries the fear commonly generated by the disease, and even the social taboos around it, make executives less likely to address the topic.

As a result, many businesses have failed to develop the necessary knowledge or put in place the policies that are needed to react when an employee is affected. British research has found that even when line managers—who in practice do much HR management in large firms—and other executives are well disposed and supportive, most have a more negative attitude about the contribution returned employees will be able to make than the employees themselves. Another study found that nearly half of occupational health professionals were not certain they had the knowledge to address questions of cancer in their workplace.[40] Ms Egan adds that, in particular,

[37] Oxford Economics, *The Cost of Brain Drain*, 2014.

[38] Joanne Park and Mamdouh Shubair, "Returning to Work After Breast Cancer: A Critical Review".

[39] R Molina Villaverde, "Employment in a cohort of breast cancer patients", *Occupational Medicine*, 2008.

[40] Ziv Amir *et al.*, "Return to Work After Cancer in the UK: Attitudes and Experiences of Line Managers", *Journal of Occupational Rehabilitation*, 2010; Beth Grunfeld *et al.*, "Cancer survivors' and employers' perceptions of working following cancer treatment", *Occupational Medicine*, 2010; Ziv Amir *et al.*, "Cancer survivorship and return to work: UK occupational physician experience", *Occupational Medicine*, 2009.

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misunderstanding about the long-term challenges facing cancer patients and survivors can cause difficulties, and initial support often decreases over time. In general, Dr Taskila says, "it is not necessarily that employers do not have a will to help. Often they don't really know how." As a result, notes Ms Atkinson, relevant "training is essential". Ms Breton agrees: "Employers need to train and inform managers, human resources and the rest of the workforce about the difficulties cancer patients may experience when returning to work. Give them key behavioural and communication tips."

Policies also need to be in place so that the organisational response to a diagnosis is not simply ad hoc. The Danish Cancer Society and Macmillan in the UK have published useful guides to help employers with the basics.[41] Such documents, and a better understanding of the implications of cancer, are necessary to provide background information on which to base policies, but nothing can provide an easy set of rules to follow.

These do not exist for two reasons. First, different approaches might work better depending on national context: one Scandinavian study found that Finnish companies provided more support through occupational health services and Norwegian ones more through supervisors, but that the net result was the same.[42]

More important, 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".[43] The most effective response, says Ms Egan, is to put in place policies that are not prescriptive, but which create a framework to allow flexibility to respond to people's individual circumstances.

This, in turn, requires extensive communication. Dialogue should begin as early as possible, ideally including a specific meeting—involving the employer, the employee and other relevant participants—soon after the diagnosis to discuss its employment implications. Communication should then continue in structured and unstructured ways, as desired by the employee, throughout the course of treatment. This will allow employers to tailor their actions in a host of areas where those with cancer frequently have a range of wishes. These include issues of social support (such as the extent of ongoing contact that the affected employee would find helpful during treatment); what accommodation the employee may need or wish on returning to work (such as extra time away for ongoing treatment, adjusted job duties to take account of changes in physical strength, or as little difference as possible from before); and how to shape a realistic return-to-work plan so that expectations are clear to all. As Ms Apostolidis notes: "Frank communication is important for building trust on both sides and allowing a smooth transition from work, to sickness leave, to work."

Ongoing communication also allows arrangements for individual employees to take into account the dynamic situation involved in time off and return to employment. Those

[41] Danish Cancer Society, *When an employee develops cancer*, 2002; Macmillan Cancer Support, *A Guide for Employers*, 2010.

[42] Sævar Gudbergsson *et al.*, "Received and needed social support at the workplace in Norwegian and Finnish stage 1 breast cancer survivors", *Acta Oncologica*, 2009.

[43] Corine Tiedtke *et al.*, "Return to Work Following Breast Cancer Treatment: The Employers' Side".

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living with and through breast cancer do not simply fail or succeed in resuming their old workplace activities. One recent study found that "survivors used multiple adjustments and drew upon both formal and informal tactics to minimize or prevent cancer- or treatment-related effects from negatively affecting job performance".[44] These include everything, from participating less in non-work activity at the workplace in order to save strength to modifying their work environment. The potential exists for a partnership between employer and employee to maximise the effect of these coping strategies.

Finally, keeping other employees onside is key to maintaining workplace support over the long term. According to Ms Egan, it is "critical to make sure, if the employee with cancer consents, that colleagues are both informed and supported to manage workloads while the employee is off sick. Often managers fail to remember that the team may also need support while their colleague is going through their cancer treatment."

Not every company will be able to provide equally comprehensive support. In particular, notes Ms Breton, "even if you are very willing to support your employee, you can face terrible problems in a small company," which my simply lack the resources to absorb the long-term absence of a key employee. Nevertheless, understanding the issues around cancer in the workplace ahead of time, as well as keeping up communication with those who have developed the disease and the colleagues who are indirectly affected, will allow a greater understanding of what options may exist.

C. Government

Like clinicians and employers, European governments on the whole have given relatively little consideration to the issues around breast cancer and employment. Further generalisation is difficult because "there are no common policies across Europe but a huge variation", according to Ms Atkinson.

In practice, national regulation in this field arises not from thought-out policies but largely depends on how general rules in certain relevant fields happen to apply to patients and survivors of breast or other types of cancer. One form this takes is the overlap of human rights and disability regulation with employment law. All EU member states have translated into national law the 2000 EU Directive on Employment Equality, which covers disability in the workplace. In a 2006 ruling, however, the European Court of Justice found that illness did not always equate with disability, meaning that cancer was not necessarily covered by these rules. At the national level, on the other hand, a number of countries—including the Netherlands (in 2003), Ireland (2005) and the United Kingdom (2010)—have over the years specifically given cancer patients the same rights as those with disabilities. In Italy, meanwhile, the Biagi Law of 2003 gives workers with cancer the right to move to part-time employment and return to full-time work when they are ready to do so. Nevertheless, in many European countries formal protection is either non-existent or the situation is legally ambiguous.[45]

[44] Joanne Sandberg, "Strategies Used by Breast Cancer Survivors to Address Work-Related Limitations During and After Treatment", *Women's Health Issues*, 2014.

[45] Peter McIntyre, "Protection of employment rights: still work in progress", *Cancer World*, 2008.

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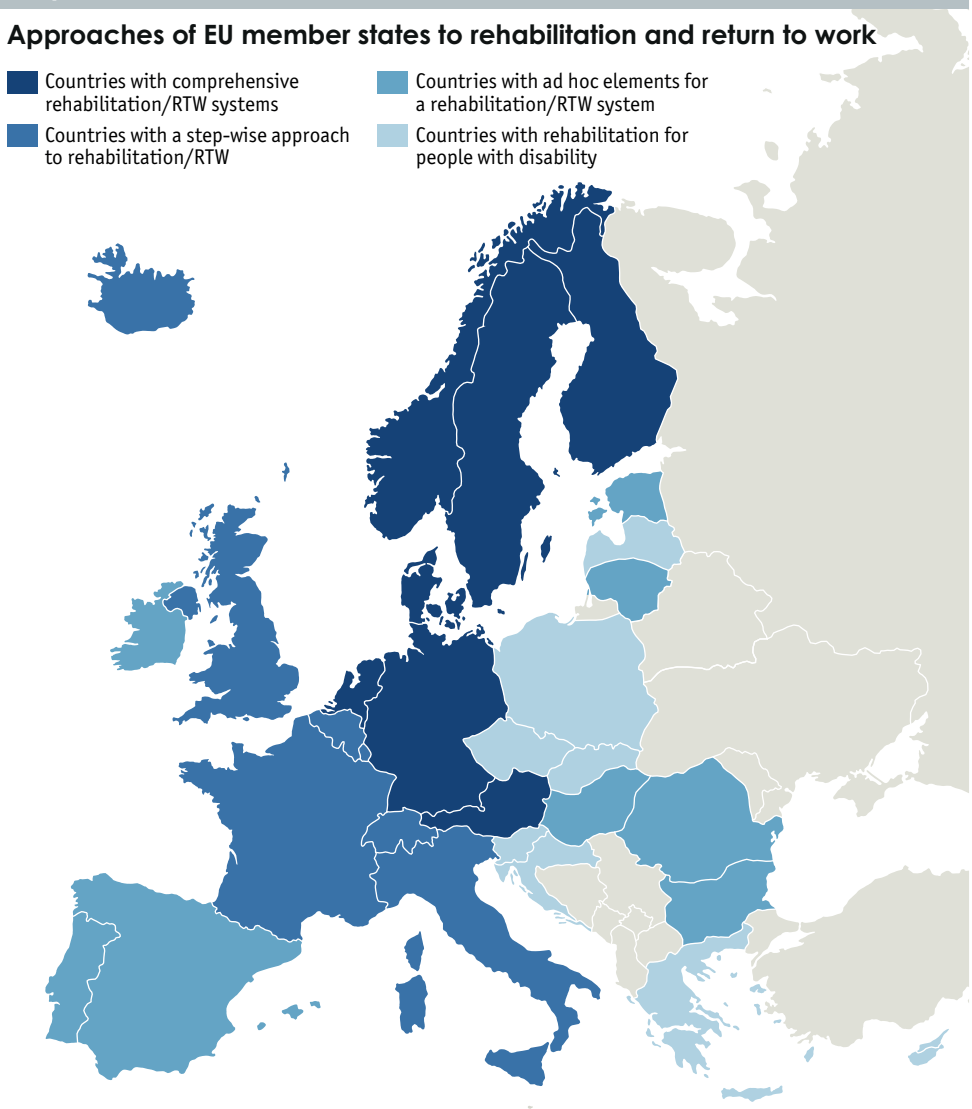
Map 2

Approaches of EU member states to rehabilitation and return to work



Sources: European Agency for Safety and Health at Work.

Another highly relevant area of regulation is that specifically setting out required processes and stakeholder responsibilities around return to work after long-term illness. As a map drawn from a recent EU review of policy in this area shows, though, here too there are vast disparities across Europe. (Map 2)

Conditions go from integrated social, employment and healthcare-system efforts to only modest rehabilitation programmes for those who have a disability. These groupings give the impression of greater similarities in practice than is actually the case. Among the most advanced collection of countries, for example, in Norway and Sweden national agencies co-ordinate return-to-work efforts, in Denmark this is the responsibility of the municipalities, and in Germany pension plans play a major role.[46]

[46] European Agency for Safety and Health at Work, *Rehabilitation and return to work: Analysis report on EU and Member States policies, strategies and programmes*, 2016.

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Moreover, the balance between rehabilitation and return to work is not always helpful. Although Belgium falls into the second-best category in the EU review, a separate study of the practical effect of its return-to-work legislation—one of the few such pieces of research done anywhere—found that by emphasising the survivor's role as patient and disabled person, but not as employee, Flemish law did little to encourage resumption of employment.[47]

Nevertheless, because return-to-work systems and requirements include everyone with a long-term illness, where they are strong, they can greatly benefit cancer patients. For example, Dr Taskila explains, "in Scandinavian countries, every breast cancer survivor has access to an individually tailored return-to-work plan."

Lastly, beyond human rights and return-to-work laws, national cancer control plans (NCCPs) have begun to address employment as part of survivorship. France's plan, for example, has a specific goal to minimise the career interruptions which patients undergo as a result of the disease. England's 2015-20 strategy recommends that supporting return to work should be a key focus. More generally, the European Guide for Quality National Cancer Control Programmes, which arose out of the EU-funded European Partnership for Action Against Cancer, recommends that NCCP survivorship provision should include the ability to return to work as a goal.[48]

This variety of laws and policies brings some advantages. Anchoring rules relevant to breast cancer and employment within broader regulations can avoid the creation of unwieldy new bureaucratic and regulatory structures. Moreover, these different kinds of policies certainly have the potential to benefit the individuals—and companies—affected by the disease. One Swedish study suggested that the country's general rules against dismissal on the basis of illness might explain the lack of difference it found in the unemployment rate of breast cancer survivors and a control group.[49] Legal requirements for reasonable accommodation by employers can also shape the workplace in a way that correlates with improved return-to-work rates.[50]

That said, even well-meaning policies—including longer-lasting or earlier disability pensions—have also been implicated in breast cancer patients and survivors delaying employment resumption or not returning at all.[51] More generally, research carried out in the Netherlands found that the specific way in which Dutch employers are mandated to apply return-to-work rules for employees creates distrust between the two parties.[52] Clearly there is room for improvement, but a lack of research makes it hard to say anything concrete about which specific arrangements are most effective to promote a return to work after breast cancer. Experts interviewed for this study, however, point to several common weaknesses in Europe, most of which seem to arise from the ad hoc, patchwork nature of these policies.

First, the existence of any relevant regulation or policy of substance is, in practice, largely limited to countries in the north and north-west of the continent. Ms Atkinson notes that

[47] Corine Tiedtke *et al*., "Supporting Return-to-Work in the Face of Legislation: Stakeholders' Experiences with Return-to-Work after Breast Cancer in Belgium".

[48] Tit Albreht *et al*. (eds), *European Guide for Quality National Cancer Control Programmes*, 2015.

[49] Sonja Eaker *et al*., "Breast Cancer, Sickness Absence, Income and Marital Status. A Study on Life Situation 1 Year Prior Diagnosis Compared to 3 and 5 Years after Diagnosis".

[50] Joanne Park and Mamdouh Shubair, "Returning to Work After Breast Cancer: A Critical Review".

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"in general, there seems to be little policy in this area, and in a lot of European countries no legal protection at all" for cancer patients and survivors in the workplace.

Next, because these rules were designed with other issues in mind—especially in the case of disability rights and return-to-work regulations—they will often need to be retrofitted to take into account the specifics of breast cancer survivorship. For example, Dr Taskila points out that European unemployment and disability benefit systems, many of which were developed in the 1990s, frequently no longer address current needs because they tend to see people as either working or not working. "Many times you hear survivors saying they would love to go back to work but can't do so full time," since if they do so, they would lose too much of their benefits. "There should be more flexibility," she adds, noting that several Scandinavian countries now have systems that allow part-time sick leave. A study of people with musculoskeletal disorders found that this sped up return to work, although no data exist for those who develop cancer.[53]

Similarly, disability status—and the accompanying disability pensions—are treated as a one-way street in many countries. Indeed, at the European level part of the definition of disability is its enduring nature. This is not consistent with the experience of the large majority of patients and survivors whose breast cancer does not metastasise. Frequently, these women are incapable of working in the middle of treatment but gain strength over time. Such a permanent status is more than inaccurate: it can be psychologically damaging. Ms Breton explains: "Imagine emotionally what it means for a breast cancer patient not only to face cancer but also to think from now on she is disabled." Instead, she thinks one of the advantages for cancer survivors in France is the existence of temporary disability status, which lasts from one to five years and gives the holder the type of job support available to the disabled, including employment quotas, without having to accept a permanent change of status.

The lack of direct focus on cancer and employment also frequently leads to a lack of cohesion in the government and the policy activities that do exist. Ms Breton notes that although the French NCCP has for over a decade included a commitment to reduce disruption to employment among survivors, "there are lots of individual initiatives, but a lack of co-ordination and no coherence."

Similarly in England, Ms Egan argues that efforts to raise the profile of cancer-related employment issues "are disjointed, with cancer-care strategies not linked into wider government employment policies. There is quite a long journey to go on to ensure that happens." Moreover, a lack of co-ordination across government can undermine the impact of existing policy. While employees with cancer enjoy protection in the UK under the 2010 Equality Act and the Disability Discrimination Act 1996 in Northern Ireland, cuts in legal advice services, as well as the introduction of substantial employment tribunal fees, can impede the effectiveness of protections offered by this legislation, adds Ms Egan. More striking is the situation in Italy, where the impact of laws designed to help cancer patients and survivors is weakened by a lack of coherent information provided

[51] Tania Islam *et al.*, "Factors associated with return to work of breast cancer survivors: a systematic review".

[52] Nicole Hoefsmit *et al.*, "Work resumption at the price of distrust: a qualitative study on return to work legislation in the Netherlands", *BMC Public Health*, 2013.

[53] Daniela Andrén and Mikael Svensso, "Part-Time Sick Leave as a Treatment Method for Individuals with Musculoskeletal Disorders", *Journal of Occupational Rehabilitation*, 2012.

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to patients and contradictions in the way in which individual government agencies approach the issue.

Experts interviewed for this study believe that the solution here is to ensure that some agency has overall responsibility for the issue of cancer and employment. "Work and health issues, including on cancer and employment, require leadership and joined-up action from across government departments," Ms Egan says. Otherwise the issue of employment can get lost amid the many pressing concerns in delivering effective national cancer strategies.

The same problems that affect national policy also beset EU policy. As noted earlier, EU legislation currently has little direct impact on issues of cancer and employment. Efforts to improve the situation go back at least a decade, but as Ms Apostolidis notes, "things in EU policy move slowly." She adds that currently discussions are ongoing within the Directorate-General for Employment about the extent to which it can co-operate and co-ordinate with the Directorate-General for Health on this issue.

Policy around breast cancer and employment across Europe, then, remains a patchwork not always well-suited to purpose. As the number of chronic cancer patients and survivors in the workforce grows, however, governments are likely to come under pressure to focus more on it. In doing so, how can they contribute in the best possible way?

Dr Rix warns that, like employers, policymakers cannot look for one-size-fits-all solutions but need to keep the diversity of individual cancer experiences in mind. He cites Danish sickness leave rules designed to get cancer survivors back into work, which in some cases had the effect of forcing women with breast cancer to resume work before they were ready. The rules have since been modified because of complaints, and women with breast cancer can now have longer sickness leave depending on treatment and needs.

At the European level, detailed, continent-wide regulations would be even more problematic, given the greater distance of the EU institutions from the individual level and the wide variety of national practice in areas such as occupational health. Ms Atkinson believes that the EU should instead provide a set of guidelines and best practice. Ultimately, the goal of regulation needs to be to create a helpful, supportive environment, with fair ground rules for patients and employers to create employment arrangements on a case-by-case basis.

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CONCLUSION

European societies are facing a problem resulting from healthcare progress. Medical, diagnostic, treatment and health-system advances have made breast cancer to a large extent a chronic disease. As a result, increasing numbers of women of working age are not only surviving it, they are also willing and able to be part of the workforce. A majority succeed, but the return to work is typically so difficult that too many give up.

To date, this new challenge is often overlooked by stakeholders who will play crucial roles if it is to be addressed effectively. While hard data on the impact of specific interventions are lacking, this study finds repeatedly that simply engaging with the issue is an important, and necessary, first step.

- Clinicians: Healthcare professionals are frequently unaware of the issues around employment and breast cancer or are uncomfortable talking about them. As working has become a realistic possibility for patients and survivors, doctors and nurses—including those involved in occupational health—should begin to discuss these questions with their patients as part of a growing focus on the challenges and opportunities of cancer survivorship.

- Employers: Most employers have also not begun to address how to deal with employees who develop cancer. Rather than waiting for someone to become ill and responding in an ad hoc way, they should think ahead in order to have appropriate policies and, where applicable, programmes in place. These should emphasise communication with an eye to shaping responses tailored to individual situations.

- Governments: 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. Policymakers should therefore also engage with the issue, retrofitting relevant disability and return-to-work legislation or putting effective policies in place. As part of an increasing focus on survivorship, NCCPs should also include employment issues.

Perhaps most important of all, all three of these stakeholder groups need to engage not just with this issue but with the affected women themselves. Breast cancer patients and survivors are already coming back to work in large numbers and are making their own formal and informal adjustments to ensure that employment becomes a viable option. Each will have her own specific needs. Creating an environment in which they work in partnership with medical professionals and employers to enhance what they can do on their return to work will be the most likely way to provide a long-term solution to this social challenge and pave the way to a better normal.

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BREAST CANCER PATIENTS AND SURVIVORS IN THE EU WORKFORCE

BRITAIN[1]: TIME TO MOVE BEYOND A STRONG LAW

This report is part of a series of profiles focusing on the main employment-related issues affecting female breast cancer patients and survivors in selected EU countries[2].

Key data (UK figures)	
Crude breast cancer incidence rate per 100,000:	164.5 (2012, IARC)
Breast cancer prevalence (five-year) per 100,000:	755.1 (2012, IARC)
Labour force participation rate—general:	77.6% (2015, OECD)
Labour force participation rate—women aged 40-64:	72.7% (2015, EIU calculations from OECD data)
Unemployment rate—general:	5.7% (2015, OECD)
Unemployment rate—women aged 40-64:	3.6% (2015, EIU calculations from OECD data)

Britain had Europe's, and the world's, fifth-highest crude breast cancer incidence rate in 2012, at 164.5 per 100,000,[3] although this is only slightly above the average rate for western Europe (161.3 per 100,000), the region with the highest such incidence in the world. As a result, the UK has a substantial five-year prevalence of breast cancer patients and survivors in the population (755.1 per 100,000), or just over 200,000 women.

This five-year figure, although easy to use in international comparisons, greatly understates the true extent of survivorship: according to data from one UK study, in 2008 the total number of breast cancer patients and survivors in the country was about three times that of those diagnosed only within the last five years.[4] Looking ahead, the prevalence of survivors appears set to rise. Another British study projected that by 2020, 3% of women aged 45-64 will be battling, or have fought, breast cancer.[5]

Many of these same women will be employed, or want to be. British labour force participation rates for females aged 40-64 have risen more slowly than in most of Europe recently, going up from 68.9% to 72.7% between 2005 and 2015. However, the more recent figure is still comfortably above the average in the EU (68.6%) and is not far from the participation rate for all Britons of traditional working age (77.6%).

Moreover, matters relating to employment for cancer survivors in England are often seen through the prism of the country's stark employment gap for all of those living with disability. In 2013, among those of working age with any disability, only 53% were employed, while for their healthy peers the equivalent figure was 85%.[6]As discussed below, this issue is on the political agenda, even if the specific concerns of cancer patients and survivors make up only a part of the broader discussion.

[1] This article focuses on England and not the United Kingdom as a whole because key elements of health, social policy and even human rights legislation vary between the constituent nations of the UK. This article nevertheless uses UK-wide data where these are the most accessible. As England contains 84% of the British population, the UK figures are unlikely to vary greatly from those of England.

[2] Although male breast cancer does occur, it is very rare, with an age-adjusted incidence of less than 1 per 100,000 in most of Europe and no clear sign of increase or decrease (Diana Ly *et al.*, "An International Comparison of Male and Female Breast Cancer Incidence Rates", *International Journal of Cancer*, 2012). This study therefore deals exclusively with female breast cancer.

[3] Unless otherwise stated, incidence, mortality and prevalence data are estimates by the International Agency for Research on Cancer (IARC) of the situation in 2012, the latest internationally comparable figures available.

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BREAST CANCER PATIENTS AND SURVIVORS IN THE EU WORKFORCE
BRITAIN[1]: TIME TO MOVE BEYOND A STRONG LAW

For England, and Britain in general, there are fewer data available than for some other European countries on the extent of the difficulties faced by breast cancer survivors when seeking to return to work. What information there is available suggests that the problem in England is similar to that in much of the EU. One study of individuals employed at the time of their cancer diagnosis—nearly half of whom had breast cancer—found that 82% returned to work.[7] As elsewhere, workplace conditions, in particular relations with managers and colleagues, seemed to be a key factor in a successful resumption of employment.[8] This is an important point, since 18% of cancer survivors who returned to their jobs in the UK complained of workplace discrimination.[9]

Although these challenges are similar to those experienced by breast cancer patients and survivors elsewhere in Europe, the specific tools available to help English patients return to work are quite different from those on the continent.

On the one hand, the Equality Act of 2010, which subsumed and expanded on the Disability Discrimination Act of 2005, specifically equates a cancer diagnosis with a disability. As a result, the law has for over a decade banned employers from treating those with cancer differently than others with a disability in all areas of employment, including recruitment, terms, conditions and benefits, opportunities for promotion and training, and dismissal. It also leaves employers open to penalties in the event of proven harassment and victimisation of cancer patients or survivors. Finally, the law requires reasonable accommodation in the workplace for the needs of employees who are cancer patients or survivors. The Act's protection is not temporary: any ill-treatment because of a previous cancer diagnosis, even if the employee no longer shows signs of the disease, is covered.

According to Barbara Wilson, who founded Working with Cancer, a UK consultancy, the existence of the Equality Act changes the nature of the conversation between employer and employee. "If cancer survivors know that they have rights and employers have responsibilities, it makes it easier to ask for accommodation. It gives them the confidence to get the adjustments they need," she explains.

There are, however, weaknesses with this legislation. In Ms Wilson's experience, "relatively few employees diagnosed with cancer know that they are protected by the law forever." Moreover, although in practice many British managers are sympathetic towards their employees with cancer,[10] ultimately, in the event of a dispute, enforcement of the law relies on an individual's ability to take a case to an employment tribunal. Liz Egan, lead of the Working through Cancer Programme at Macmillan Cancer Support, a UK charity, believes that, because of the law, "many employers are taking steps not to discriminate and to make reasonable accommodations for staff with cancer."

[4] Jacob Maddams *et al.*, "Cancer prevalence in the United Kingdom: estimates for 2008", *British Journal of Cancer,* 2009.

[5] Jacob Maddams *et al.*, "Projections of cancer prevalence in the United Kingdom, 2010–2040", *British Journal of Cancer,* 2012.

[6] Tyna Taskila *et al., Returning to Work: Cancer survivors and the Health and Work Assessment and Advisory Service,* 2013.

[7] Ziv Amir *et al.*, "Return to paid work after cancer: a British experience", *Journal of Cancer Survivorship,* 2007.

[8] Ziv Amir *et al.*, "Cancer survivors' views of work 3 years post diagnosis: a UK perspective", *European Journal of Oncology Nursing,* 2008.

[9] "One-fifth of cancer patients face work discrimination", *BBC News,* November 7th 2016. Available at: http://www.bbc.co.uk/news/health-37861712.

[10] Ziv Amir *et al.*, "Return to Work After Cancer in the UK: Attitudes and Experiences of Line Managers", *Journal of Occupational Rehabilitation,* 2011.

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However, she says that the law's effectiveness has been weakened because "not many people would have the motivation or are physically able to take a case to a tribunal whilst going through or recovering from cancer treatment. Hefty tribunal fees and legal costs are additional deterrents. In fact, enforcing those rights is pretty hard." Indeed, she counsels that these tribunals should be a last resort and that ongoing communication and reasonable adjustments "are key to enable job retention for staff with cancer."

While cancer patients and survivors in England have clearer legal rights than their peers in many other European countries, they lack some key regulations and institutions which are used in other European states to ease the transition back to work. For example, although the Fit for Work scheme (discussed below) encourages employers and employees to consider a phased return to work where appropriate, no provision exists in the benefit system for a partial, staged return to work during recovery from cancer, as is the case in Belgium or Finland. Instead, the long-term illness and disability benefit in the UK is the employment and support allowance, which kicks in once the employer's sick-pay obligation ends 28 weeks after an employee goes on sick leave. This allows 16 hours of work per week at most, and maximum earnings of £115.50 (US$150) per week.

More generally, state actors play a limited role in helping women prepare for a return to work. The Learning and Work Institute, a UK think-tank dedicated to full employment, found that fewer than 10% of disabled individuals as a whole in Britain receive any formal employment support.[11] Charities such as Macmillan, which has produced information leaflets and runs awareness campaigns for employees on their rights at work, try to fill the gap.[12] Nevertheless, the need remains substantial.

In practice, reintegration is the responsibility of businesses and line managers. These, however, often operate without the benefit of expertise or guidelines. Occupational health is of limited assistance. In a 2011 survey only 38% of workers reported having access to occupational health services of any kind, and the best estimate is that just 13% of employees are in organisations with an occupational physician.[13] Making matters worse, where such facilities exist, "there is poor understanding about cancer and its work impacts in occupational health," says Ms Egan. Meanwhile, 73% of firms have no formal policy covering what to do when an employee develops cancer.[14] In practice, however sympathetic they are towards those with cancer, managers would benefit greatly from further training and information.[15] Non-governmental organisations (NGOs) and consultancies also try to fill this void with guidebooks, kits and training programmes, but there is only so much they can do.

[11] "Government aims to halve disability employment gap in UK", Guardian, October 31st 2016.

[12] Macmillan Cancer Support, "Your Rights at Work When You're Affected by Cancer", 2013.

[13] All Party Parliamentary Group on Occupational Safety and Health, *Occupational medical workforce crisis: The need for action to keep the UK workforce healthy*, 2016.

[14] Tyna Taskila *et al.*, *Returning to Work: Cancer survivors and the Health and Work Assessment and Advisory Service*, 2013.

[15] Ziv Amir *et al.*, "Return to Work After Cancer in the UK: Attitudes and Experiences of Line Managers", *Journal of Occupational Rehabilitation*, 2011.

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The government, however, has been taking steps in the right direction. In 2015 it created the voluntary Fit for Work scheme. Any employer or general practitioner can refer an employee who has been off work for more than four weeks to this service, provided the individual in question agrees. The employee then has a consultation with an occupational health specialist. Together they create a return-to-work plan, and the specialist can also refer the employee to other services where appropriate. Fit for Work should bring some improvement for cancer patients and survivors. Its success, however, will depend on how well its occupational health experts understand the specific issues created by the disease and its treatment.

Another sign of change is last year's Green Paper—a preliminary report designed to stimulate discussion—in which the government set the goal of cutting the disability gap in employment by 50%, a policy of relevance to cancer patients and survivors given their status under UK law.[16] Meanwhile, England's 2015 Cancer Plan includes a recommendation that "NHS [National Health Service] England should work with partners to ensure that supporting people with cancer to return to work is a key focus".[17]

Ms Egan believes that the Green Paper and cancer strategy "are positive steps. The next challenge is to ensure that these recommendations are implemented. There is quite a long journey to go on to ensure that happens."

Overall, English breast cancer patients and survivors seeking to stay in or return to work have some of the clearest legal protections in Europe. Now the government needs to find better practical ways to help their transition back to work.

Note: *This country report was sponsored by Pfizer. None of the interviewees received financial support or expense reimbursement from the sponsor.*

[16] *Work, health and disability green paper: improving lives*, 2016.

[17] *Achieving World-Class Cancer Outcomes: A Strategy for England 2015-2020*, 2015.

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