

# Cancer, costs and the care gap

The escalating impact of cancer in the workplace and what employers are doing about it



### Introduction

# Cancer isn't waiting. Neither are employers.

We can define the cancer care gap as the distance between supply and demand; between the care required by those living with and beyond cancer, and looking after someone with cancer, and what can be provided by public and private services. This gap is currently extensive and also rapidly expanding, and it has real, costly implications – not just for individuals, but for their employers.

The number of under-50s being diagnosed with cancer has increased 80% in the last 30 years<sup>1</sup>. The number of cancer survivors is set to double between 2008 and 2030<sup>2</sup>. And, while there have been huge improvements in treatment, leading to improved survival rates, a growing cohort of people are living with side-effects of cancer and its treatment. The impact of these combined forces is more people living and working with cancer, with significant healthcare needs, than ever before. This is the demand.

Now to supply. Soaring numbers of survivors, plus significant challenges in the three main pathways to rehabilitation suggest the need for a new model.

### Consultant-led care

The current consultant shortfall – 15% and set to rise to 25% by  $2027^3$  – means that consultant support beyond treatment is rare.

### Community care

Macmillan states that 'There may be a lack of Allied Health Professionals available to provide services, or those who do exist may not be trained in cancer specific rehabilitation needs<sup>44</sup>.

### • Primary care

GPs may feel ill-equipped to provide adequate support (a study found that 71% don't feel confident managing the complex side-effects of cancer treatment<sup>5</sup>). We commissioned this research because, although we as cancer specialists understand the size and impact of the cancer care gap, we wanted to know whether employers see it too. This research shows that they very clearly do. That cancer rates in the workforce are escalating is obvious to them; as is the discrepancy between supply and demand, and its associated costs. What surprised us is the extent to which the businesses surveyed unanimously feel it's a problem, and their agreement that the charitable sector alone cannot bridge the gap.

Historically, the NHS and private medical insurers have taken responsibility for delivering good quality cancer care, however, in recent years this has become harder to access. Unprecedented delays to every stage of the cancer lifecycle have resulted in long waiting times, and have as yet failed to be addressed by the Government as part of their long-awaited cancer plan for England. Additionally, healthcare insurers are not yet managing cancer as the chronic condition it now is, resulting in a lack of quality follow-up care.

It is clear that no white knight is coming. Employers must care for their own and innovation is required for them to do that (and do it well). They know this. The research revealed that more than 3 in 5 have considered seeking, or have sought, external advice or guidance on how to effectively support employees with cancer. That's encouraging. But if we are to get ahead of cancer, we must do it quickly, cleverly and together. The time is right for innovation. A new clinical pathway that works in collaboration with primary care, community care and private healthcare, to provide the specialist cancer support that's needed, is crucial to addressing the gap and giving people living with and beyond cancer access to the care that they deserve.

### Kelly McCabe

Co-founder and CEO, Perci Health

### **Morgan Fitzsimons**

Co-founder and CXO, Perci Health



# What we measured

Across May and June 2023, Perci partnered with Censuswide to survey more than 500 UK employers about their experiences of cancer in the workplace.

### What kinds of companies were surveyed?

The organisations surveyed operate in a broad range of industries, from architecture, engineering and building, through to the arts, education, finance, healthcare and IT. They ranged from sole traders to companies of more than 500 employees, and from a turnover of less than £100,000 to more than £500,000,000.

### Who was surveyed within the organisations involved?

The individuals within each company who responded to the survey were senior decision-makers, director level or higher.



### What we learned

# Four key insights from employers about cancer in the workplace

- 1. An increasing number of employees are affected by cancer
- 2. The financial impact of cancer is a major concern for employers
- 3. Employers are noticing gaps in care
- 4. Employers do not believe that charities are the solution to these gaps in care

1.

# An increasing number of employees are affected by cancer



# **The research found that** more than half of employers (54%) have recently noticed an increase in employees affected by cancer within their workforce, while a fifth (20%) have noticed a significant increase.

**Q.** To what extent, if at all, have you noticed an increase in the number of employees affected by cancer within your workforce in recent years? (either directly or indirectly)



If you've noticed an increase in employees either living with or beyond cancer, or caring for someone with cancer, you're not alone. The research makes it clear that employers are increasingly noticing the impact of cancer on their workforce. In fact, only 1 in 16 (6%) of those surveyed said they've noticed a decrease in the number of employees affected by cancer.

That more and more employees are and will be affected by cancer in the future is likely unsurprising. One in two of the population will now receive a cancer diagnosis in their lifetime, while close to half of those will be of working age<sup>6</sup>. What is less well known is that, fearing discrimination, as many as 50% of employees will choose not to tell their employer about their cancer diagnosis<sup>7</sup>. Meanwhile, those caring for someone with cancer can take up to two years to identify with the term 'carer', and also conceal this status at work. Although cancer is something most of us have been touched by, we're not necessarily comfortable talking about it. This is a challenge for employers as they need to tackle taboos in order to support their workforce effectively.

Morgan Fitzsimons, Co-Founder and CXO, Perci Health

So while it's clear that the cancer cohort in the workforce is increasing, to the extent that employers are now noticing the change, it's worth considering how many more employees are living and working alongside the impact of cancer, and remaining invisible to both the research and their employers. Cancer in the workplace is likely to be even more prevalent than we know, making effective support even more essential.

# The financial impact of cancer is a major concern for employers



**The research found that** almost 7 in 10 (69%) employers surveyed are concerned about the potential financial impact cancer could have on organisational costs; more than a quarter (27%) are very concerned. This concern is felt twice as much by those who have noticed a significant increase in the number of employees affected by cancer.

**Q.** How concerned are you, if at all, about the potential financial impact that cancer could have on your organisation's healthcare costs?



In the US, the costs associated with cancer have outstripped costs for musculoskeletal conditions (the previous frontrunner), cardiovascular disease and diabetes for the first time.<sup>8</sup> In fact, it's not unusual for cancer costs to exceed 10% of healthcare budgets.<sup>9</sup> UK health trends tend to follow the pattern of the US, so we can expect to see our own costs begin to mirror this. The incidence of cancer in the population is increasing, but the reasons behind the rise in costs are more complex than that. Many of us still consider cancer to be a disease of old age, as well as one with a high death rate. Neither is true any longer. Death rates from cancer have dropped by 33% since 1991<sup>10</sup> and continue to decline by around 1.5% each year<sup>11</sup>, due largely to effective prevention and screening, and innovations in treatment. Cancer is rapidly becoming a disease that an increasing number of people not just survive, but live and – crucially – work with. The number of people living with cancer who are of working age in the UK currently stands at around 900,000 and is estimated to reach 1.15 million by 2030<sup>12</sup>. Cancer – and the costs associated with it – is now increasingly a workplace concern.

This is reflected in the fact that data from leading insurers indicates that cancer is the single biggest contributor to claims, yet many PMIs do not yet recognise it as a long-term condition. This means that once treatment ends, access to vital support for long-term side-effect management and secondary conditions, including cancerspecific physiotherapy, onco-psychology and dietetics, isn't usually covered. Combine insurance challenges with a healthcare crisis, such as the UK is currently experiencing, and the devastating impact Covid-19 has had on cancer care within the NHS and charity-led support services, and the result is a significant gap in treatment and support - one that employers are increasingly picking up the tab for.

Employers are absolutely right to be concerned about the financial impact of cancer in the workplace and we cannot see the current upwards trend in this reversing.

Kelly McCabe, Co-Founder and CEO, Perci Health





# Employers are noticing gaps in care



Too many people living with and beyond cancer, and their carers, find themselves unable to access the healthcare they need and deserve. This variation in access to rehabilitation and long-term support for people after cancer treatment drives health inequalities and contributes to the cancer care gap. The employers we surveyed have noticed care gaps across the entire cancer lifecycle, from prevention, diagnosis and rehabilitation, to treatment and return to work, and also in support for carers.

### Support for carers

**The research found that** more than 7 in 10 employers (73%) think there is a gap in support for those caring for someone with cancer; a third (33%) say there is a significant gap.



**Q.** To what extent, if at all, do you think there is a gap in care for employees who are carers?

In 2016, the number of cancer carers in the UK exceeded 1.4 million<sup>13</sup>, however the true number is thought to be much higher. For this, often invisible, group – a high proportion of which are women – the pressures of caring while juggling a job are substantial, with physical, psychological and financial implications.

Pre-pandemic, 84% of all carers across the UK said that caring had a negative impact on their health. Post-pandemic, 91% of carers felt their levels of stress and anxiety had increased. Around 77% reported worsened mental health, while 67% reported worsened physical health<sup>14</sup>. Furthermore, 75% of carers worry about continuing to juggle work and care, and 65% have sacrificed opportunities at work because of caring<sup>15</sup>.

Support for carers has traditionally fallen to charities, who typically offer amazing advice and community support, yet carers juggling a job also need a deeper level of help specific to the workplace, including changes to working hours or patterns, financial support and skilled management. Employers who are willing and able to provide this kind of assistance are those who will see this particular care gap begin to close.

### Prevention, diagnosis and rehabilitation

**The research found that** almost 7 in 10 employers say there is a gap in support for prevention (68%), a gap in support around diagnosis (68%) and a gap in support around recovery and rehabilitation (68%).

### **Prevention**

Q. To what extent, if at all, do you think there is a gap in care for employees with regards to cancer prevention?



Only 5–10% of cancer diagnoses are linked to family history, with most cancers developing as a result of a combination of risk factors, such as getting older and lifestyle. Currently, around 4 in 10 cancer cases are caused by preventable risk factors including smoking and obesity<sup>16</sup>. Scientific research from the World Cancer Research Fund (WCRF) has shown that what you eat and drink, how much you weigh, and how physically active you are, can all make a difference.

### -11

It's important to state that no lifestyle can completely eliminate the risk of developing cancer, but by making healthy choices, it can be significantly lowered.

Nichola Williams, Consultant Dietitian, Perci Health

It follows that support around cancer prevention – which can take the form of evidence-based diet and lifestyle advice, and also information about screening programmes – has the potential to reduce the impact of cancer in the workforce as well as costs to employers, yet there is a clear gap in provision.

### **Diagnosis**

Q. To what extent, if at all, do you think there is a gap in care for employees at the point of cancer diagnosis?



A cancer diagnosis is a huge shock, not only to individuals experiencing it but also to their families, and people will have many questions. This is when NHS or private healthcare support is most prolific for the person impacted by cancer. Treatment teams deliver excellent care and are on hand to provide emotional and psychological support during this time, yet employers still perceive a care gap at this stage in the cancer lifecycle. Why is this?

One reason may be the lack of support for those at diagnosis that specifically relates to the workplace. The majority of people with cancer who were employed when diagnosed say it was important for them to continue to work after diagnosis yet support to help them do this often isn't in place<sup>17</sup>. There may be anxieties about financial and job security that members of their treatment team can't assist with. This is where dedicated support from cancer nurse specialists, occupational therapists and other professionals can help.

### - / /

The huge benefit of working with an occupational therapist is that it's holistic; we look at your 'occupation' in the broadest sense – your work and your life outside work – and all the elements that need to be in balance to help you remain in work if you want to.

Anna Howells, Occupational Therapist, Perci Health



It's also possible that employers perceive the very noticeable care gap experienced by those whose loved ones are diagnosed with cancer. A cancer diagnosis is not only a major event for the person diagnosed, but also for their family – frequently the default caregivers. In fact, some studies report that the impact on family members can be even greater than that on patients.<sup>18</sup>

### **Recovery and rehabilitation**

Q. To what extent, if at all, do you think there is a gap in care for employees requiring cancer recovery and rehabilitation?



The side-effects from cancer treatment can range from mild to severe and, in some cases, can continue for years after treatment ends. These might include fatigue, difficulty with aspects of day-to-day living, changes to physical appearance, general health and wellbeing, pain and neuromusculoskeletal disorders. Those living beyond cancer are at risk for anxiety, depression and PTSD, and may experience challenges with relationships and finances.

Whether physical, psychological or practical, these side-effects are all barriers to transitioning back to work, and working productively when returned. They also typically arrive at a time when there is a palpable down shift in support from an individual's treatment team. The specialist support many individuals need is often not available on the NHS, not covered by PMI or delayed by long waiting lists – hence, the care gap employers perceive here. This, despite the fact that four in five people who accessed vocational rehabilitation (VR) support for cancer have stayed in work or returned to work<sup>19</sup>.

## -"

Physical exercise helps to maximise response to treatment, minimise the impact of sideeffects, and reduce the risk of cancer returning.

Kat Tunnicliffe, Specialist Cancer Physiotherapist, Perci Health

### Treatment

# **The research found that** almost two thirds (65%) of employers say there is a gap in care around treatment for employees with cancer.

80 70 60 65% 50 40 36% 30 29% 20 23% 10 12% 0 Net: significant Significant gap Not sure A slight gap No gap or slight gap

Q. To what extent, if at all, do you think there is a gap in care for employees having cancer treatment?

Delays for NHS treatment have reached critical levels. Cancer is of particular concern due to its increasing prevalence and current failure to meet targets set by the government. These targets state that 85% of patients with confirmed cancer should start treatment within 62 days of an urgent GP referral. In November 2023, this target was being missed for 34% of patients<sup>20</sup>.

One in five employees who have been impacted by delays say their work has been affected. Around 40% have had to make changes to the tasks they do, 20% have reduced their working hours while they wait for treatment, and 10% have been forced to go on long-term sick leave<sup>21</sup>. It goes without saying that the financial burden of these delays lies with employers, who would benefit significantly from a closure in this particular care gap.

-11-

It's estimated that the current NHS backlog will take years to clear, leaving huge numbers of employees struggling to cope with ill health or pain, as well as the anxiety experienced as a result of the uncertainty and delays.

Kelly McCabe, CEO and Founder, Perci Health



### **Return to work**

# **The research found that** 7 in 10 employers (70%) say there is a gap in care with regards to supporting those impacted by cancer to return to work.

Q. To what extent, if at all, do you think there is a gap in care for employees around return to work?



85% of people with cancer who were employed when diagnosed say it was important for them to continue work after diagnosis, yet 57% lack the support they need to do so.<sup>22</sup> The reality is that many will need to take time off work during treatment and recovery. A study on breast cancer found that the average absence was six months<sup>23</sup> but it is not uncommon for individuals to take a year or more off work.

When returning to work after cancer treatment, an employee cannot simply pick up where they left off. By law, employers must make reasonable adjustments to support the return, which may include a phased return, reduced hours or job sharing, and/or adaptations to the working environment. However, employees may struggle with several factors that require more specialist support. These include physical side-effects from cancer treatment, poor mental health and financial concerns.

### - [ [

I liken going back to work after cancer to returning after maternity leave: my life was very different after having children and my life is very different now after cancer. I have this extra element to me, that I'm not sure people will ever understand unless they've been through it too.

Helen, TV executive and Perci member



# Employers do not believe that charities are the solution to these gaps in care



**The research found that** more than three quarters (76%) of employers surveyed agree there is an overreliance on support from charities for employees with cancer due to lack of support in other areas; over a third (36%) strongly agree.

**Q.** To what extent do you agree or disagree that there is an overreliance on support from charities for employees with cancer due to a lack of support in other areas?



There is a clear correlation between employers believing gaps in care for employees with cancer are present across the cancer lifecycle, and the perception that there is an overreliance on charities. This is unsurprising as we know that gaps in care mean that charities are increasingly needing to plug them. However, even the largest charity isn't a healthcare provider.

Charities simply don't have the resources to provide the healthcare required for the complex

side-effects and needs of the growing population of people living with and beyond cancer, and their carers. They do an incredible job of providing trusted and safe information for employees and employers, and can even offer some financial and professional support, but they cannot be expected to provide scalable and clinically effective healthcare for this population, and perhaps this is why those surveyed felt that charities shouldn't be relied on to deliver the care required.

# **Take action**

What can employers do to reduce the impact of cancer on their workforce?

# 1. Seek guidance around supporting employees impacted by cancer

The research tells us that more than 3 in 5 (**64**%) employers have considered seeking or sought external advice or guidance on how to effectively support employees with cancer.

As cancer rates increase exponentially and have an increasing impact on the workforce, learning that employers are proactively engaging in conversations about cancer and seeking guidance around support, is highly encouraging. What's more encouraging still is that those who have consulted with external experts or resources, are most likely to say they are confident in providing support and resources (96%) and feel prepared to handle and support employees impacted by cancer (93%).

The message is clear: when it comes to supporting employees impacted by cancer, seeking external advice works.

# 2. Invest in healthcare benefits that support employees impacted by cancer

The research tells us that more than 4 in 5 employers (**81%**) are looking at, or would be open to looking at, providing healthcare benefits for employees impacted by cancer.

That employers are considering investing in healthcare benefits that support employees living with and beyond cancer, and their carers, is a huge step towards closing the care gaps perceived by the employers we surveyed.

Clarity around exactly what is offered by PMI, EAPs and risk insurers is essential here. To effectively support employees as well as protect employers from rising costs associated with cancer, benefits should span the entire cancer lifecycle, from prevention, diagnosis and treatment, to recovery and rehabilitation, return to work, and support for carers.

# **About Perci**

Perci is the UK's first virtual cancer survivorship clinic. Founded in 2020 with leading oncologists, we provide gold-standard cancer care supporting prevention, treatment, recovery and caregivers, all on one easy platform.

We connect the dots by working collaboratively with line managers, occupational health teams, oncologists, GPs and case managers to deliver end-to-end support across the cancer lifecycle.



Our groundbreaking virtual cancer clinic connects your people to the UK's largest community of cancer experts, including NHS-trained cancer nurses, registered dieticians, psychologists, physiotherapists, menopause practitioners and more.

We provide quick and easy access to personalised, evidence-based care designed to achieve optimal outcomes and lower costs, empowering everyone impacted by cancer to live and work to their full potential.

## 48 hours

Average time for a virtual appointment on the Perci platform

# About Censuswide

Censuswide specialises in robust, high-quality market research for the global communications industry. Offering both quantitative and qualitative methodology, their quick turnaround surveys deliver accurate results in line with clients' brand message and trusted by media. Censuswide is a member of Esomar – a global association and voice of the data, research and insights industry – and complies with the MRS code of conduct based on the Esomar principles.



# References

<sup>1</sup>Guardian, September 2023, <u>https://www.theguardian.com/society/2023/sep/05/cancer-cases-in-under-50s-worldwide-up-nearly-80-</u> in-three-decades-study-finds

<sup>2</sup>Macmillan Cancer Support, 2012, <u>https://www.macmillan.org.uk/\_images/people-living-with-cancer\_tcm9-283689.pdf</u>

<sup>3</sup>Royal College of Radiologists, 2022, <u>https://www.rcr.ac.uk/news-policy/policy-reports-initiatives/state-of-the-wait/</u>

<sup>4</sup>Macmillan, 2015, <u>https://www.macmillan.org.uk/\_images/allied-health-professionals\_tcm9-283173.pdf</u>

<sup>5</sup>Walter et al., Oct 2015, <u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4617271/</u>

<sup>6</sup>ONS, 2019, <u>https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/datasets/</u> <u>cancersurvivalratescancersurvivalinenglandadultsdiagnosed</u>

<sup>7</sup>Publicis Group, 2023

<sup>8</sup>Business Group on Health, 2023, <u>https://www.businessgrouphealth.org/en/resources/2023%20large%20employers%20health%20</u> <u>care%20strategy%20survey%20intro</u>

<sup>9</sup>Business Group on Health, 2023, <u>https://www.businessgrouphealth.org/en/resources/2023%20large%20employers%20health%20</u> <u>care%20strategy%20survey%20intro</u>

<sup>10</sup>American Cancer Society, 2023, <u>https://www.cancer.org/research/cancer-facts-statistics/all-cancer-facts-figures/2023-cancer-facts-figures.html</u>

<sup>11</sup>Rebecca L Siegel et al., 2023, <u>https://pubmed.ncbi.nlm.nih.gov/36633525</u>

<sup>12</sup>Be.Macmillan, accessed March 2024, <u>https://be.macmillan.org.uk/be/s-1068-work-and-cancer.aspx</u>

<sup>13</sup>Macmillan, 2016, <u>https://www.macmillan.org.uk/\_images/cancer-carers-in-the-uk\_tcm9-298126.pdf</u>

<sup>14</sup>Carers UK, 2022, <u>https://www.carersuk.org/reports/state-of-caring-2022-report/</u>

<sup>15</sup>Carers UK, 2022, <u>https://www.carersuk.org/reports/state-of-caring-2022-report/</u>

<sup>16</sup>'Cancer in the UK Overview 2023,' Cancer Research UK, 2023, <u>https://www.cancerresearchuk.org/sites/default/files/cancer\_in\_the\_uk\_report-overview-03.pdf</u>

<sup>17</sup>Macmillan 2017, <u>https://www.macmillan.org.uk/\_images/people-of-working-age-with-cancer\_tcm9-282791.pdf</u>

<sup>18</sup>Girgis et al., 2012, <u>https://ascopubs.org/doi/10.1200/JOP.2012.000690</u>

<sup>19</sup>The Association of British Insurers, 2023, <u>https://www.abi.org.uk/globalassets/files/publications/public/health/abi-closing-the-</u> evidence-gap---how-insurance-supports-good-health-and-productivity.pdf

<sup>20</sup>Cancer Research UK, 2024, <u>https://news.cancerresearchuk.org/2024/02/08/cancer-waiting-times-latest-updates-and-analysis/</u>

<sup>21</sup>Broadstone, 2022, <u>https://www.broadstone.co.uk/resource-library/</u>

<sup>22</sup>Macmillan, 2017, <u>https://www.macmillan.org.uk/\_images/people-of-working-age-with-cancer\_tcm9-282791.pdf</u>

<sup>23</sup>Mélanie Drolet et al., 2005, <u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1216317/</u>