DEMOS

THE COST OF BREAST CANCER MODELLING THE ECONOMIC IMPACT TO THE UK

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Supported by

BREAST CANCER NOW The research & support charity

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Any errors remain the authors' responsibility.

Lucy Bush Jennifer Misak Sara Macdonald January 2024

FOREWORD DELYTH MORGAN

Breast cancer remains one of the UK's biggest health challenges. And its impact continues to be far-reaching and long-lasting.

For 50 years we've been supporting those living with breast cancer through the physical and emotional impact it has on their lives, and the lives of those closest to them. And investing in groundbreaking research to discover ways to dramatically lessen that impact.

In that time so much information and data has been collected about breast cancer, which has helped to fuel huge progress in prevention, treatment and survival. But if we want to reach our vision of making sure that by 2050, everyone who develops breast cancer lives and is supported to live well, we still have huge progress to make.

At a time of enormous pressure on our health system and our economy, it's vital that we understand the full impact breast cancer is having.

Now, for the first time ever, our report in partnership with Demos, lays bare the scale of the economic and wellbeing costs we face in tackling breast cancer. Giving a clear picture of the financial burden breast cancer is having on the NHS, our society and those affected by it.

The direct economic costs – including screening and treating patients on the NHS – are significant at an estimated f2.6 to f2.8 billion. But that's only a fraction of the story. Our report also reveals the true human cost of this devastating disease.

We know that when someone is diagnosed and treated for breast cancer, their wellbeing can suffer and their quality of life can deteriorate. And that has an impact on their close family and friends too. In 2024, we estimate the wellbeing costs associated with breast cancer will stand at a staggering £17.5bn. That's around six times higher than the estimated economic cost and shows the major, and often unrecognised, impact breast cancer has on people, families and communities across the UK.



While the costs uncovered in this report are alarming, they can act as a catalyst for change. For the first time, we have a detailed picture of how changes in policy could have a direct impact on the cost of breast cancer. From increasing screening rates and introducing more clinical nurse specialists to helping more people return to work following their diagnosis. Transforming the experience for people diagnosed with the disease and making substantial savings for the UK economy.

We can't afford to become complacent. Too many lives are at stake. Today, 98% of women diagnosed with stage 1 breast cancer survive for five years or more. That's progress to be celebrated. But that figure drops to around 26% for women first diagnosed with stage 4, when the cancer has spread to another part of the body and become incurable.

The job isn't done.

I hope this report acts as a reminder and wake-up call that the challenges created by breast cancer haven't disappeared.

Delyth Morgan, Chief Executive, Breast Cancer Now

BREAST CANCER NOW The research & support charity

EXECUTIVE SUMMARY



of breast cancer each year in the UK.

This is the first study in which the wellbeing costs associated with breast cancer have been calculated.

In 2024 this stands at £17.5 billion in the UK.

> This means that by 2034, if nothing is done to prevent the impact of the disease, the estimated yearly cost to the economy will have risen to...

£3.6 illion.

cancer to the UK economy

is estimated to be

£2.6-£2.8

At Demos, we advocate for a more **preventative approach to healthcare.** In the case of breast cancer this would cover interventions to reduce incidence, as well as those that reduce the harm, or early death, caused by the disease.

Our economic model shows that higher levels of screening, more cancer nurse specialists and **better help for people returning to work** would be the highest impact interventions.

These interventions are not radically new ideas - they all exist in some form in our current system. What our analysis shows is that we simply need to be doing more of them.

Preventative measures may come with a price tag, but we have been able to show the impact that targeted investment can have on reducing the overall economic and wellbeing burden.

1 Gunn, T. Risk of dying from early invasive breast cancer down by around two-thirds in the last 20 years. 13 June 2023. https://news. cancerresearchuk.org/2023/06/13/breast-cancer-mortality-down-66-percent-since-the-1990s/

INTRODUCTION

The recent story of breast cancer treatment gives us much to be positive about. Survival rates have improved dramatically - a combination of both improvements in treatment and early diagnosis. Risk of death from breast cancer was just over 1 in 7 in the 1990s to 1 in 20 now.²

But the challenge that breast cancer poses certainly isn't over. There remain around 55,000 new cases of breast cancer every year in the UK, resulting in over 11,000 deaths. Breast cancer is the fourth most common cause of cancer death in the UK, accounting for 7% of all cancer deaths in 2017-2019. Among women in the UK, breast cancer is the second most common cause of cancer death and accounts for 15% of all female cancer deaths.

It is estimated that almost a quarter (23%) of breast cancer cases in the UK are preventable.³ That's because breast cancer can be related to lifestyle factors, such as being overweight, alcohol consumption and physical inactivity. There are clearly great opportunities in the prevention space to tackle the incidence of breast cancer through public health interventions and support.

This project is part of Demos' work on public service reform and within this, our advocacy for a more preventative approach to health care. To make the case for funding preventative approaches and demonstrate the benefit, we need to understand the full costs of diseases such as breast cancer. Economic modelling and analysis can be extremely powerful in making those arguments. In this, our strategic aims have aligned with those of Breast Cancer Now (BCN), the UK's largest charity focussed solely on breast cancer funding and support for those living with the disease. BCN uses data to determine where the greatest need is in the healthcare system. They had identified some significant gaps in the current evidence base namely, the amount of money that breast cancer is costing to the UK economy each year, the size and value of the psychological impact

of breast cancer and the relative cost savings associated with a selection of potential interventions. This project was borne of a shared recognition between Demos and BCN of the value of such economic modelling.

This piece of work is the first of its kind to evaluate with rigour and depth the true economic costs to the UK economy of breast cancer. It is also the first of its kind to calculate the most significant wellbeing costs associated with the impact of the disease on patients and relatives.

The case we have been making at Demos for more investment in preventative public services is all about shifting our public spending upstream. For us, this is about preventing problems before they happen and reducing human suffering and unsustainable costs to the public purse further down the line. Our definition of prevention would cover interventions to reduce the incidence of breast cancer, as well as those that reduce early death and the impact of the disease, which are typically referred to as secondary and tertiary prevention respectively in the healthcare space. We believe a more effective, evidence-led approach to preventing and treating breast cancer and supporting people through their illness is one critical part of rethinking how healthcare might be better delivered. Shifting towards a more preventative model of healthcare overall is vital as we face a rising tide of demand for healthcare that fire-fighting alone will not stem. It is central to our argument that a preventative approach to public service design will reduce the strain on the public purse at the same time as creating a stronger and more resilient population.

In this report we show that adopting preventative measures can reduce the cost of breast cancer to the economy and individuals. But this does not always bring costs down in a simple way. Some measures that can be shown to prevent early death for example, may increase the cost in places, while

² Gunn, T. Risk of dying from early invasive breast cancer down by around two-thirds in the last 20 years. 13 June 2023. https://news. cancerresearchuk.org/2023/06/13/breast-cancer-mortality-down-66-percent-since-the-1990s/

³ Brown KF, Rumgay H, Dunlop C, et al. The fraction of cancer attributable to known risk factors in England, Wales, Scotland, Northern Ireland, and the UK overall in 2015(link is external). British Journal of Cancer.

driving it down in others.

By identifying the true economic costs, we have been able to show with this piece of work the impact that targeted investment can subsequently have on bringing down those costs. Preventative measures come with a cost - our analysis shows that increasing screening rates, providing support to breast cancer survivors to return to work and training up cancer nurse specialists would not be cheap. But even so, the ultimate cost savings - both hard economic costs and wellbeing costs too - far outweigh the initial investments.

METHODOLOGY

INTRODUCING THE ECONOMIC ANALYSIS

We have created a model that estimates the economic costs to the UK economy of breast cancer now and up until 2034, as compared to a world without breast cancer. The figures we have calculated represent actual amounts of money in the UK economy that may be spent, saved, gained or lost depending on the policy environment.

The model uses Cancer Research UK incidence projections and annual breast cancer registry data from 2019 (to avoid the Covid19 data issues) on the number of newly diagnosed patients. These figures have been used to calculate the likely number of cases in the UK every year up to 2034. So for instance, in 2019 there were 56,343 new cases of breast cancer diagnosed. In 2034 the increase in breast cancer incidence is expected to have increased by 14.8% and so the likely number of breast cancer cases that year is calculated as being 64,708.

We have used a 'Cost of Incidence' approach in the model. Therefore, the costs presented for 2024 are the lifetime costs associated with those breast cancer patients diagnosed in 2024. The predicted incidence rates are then used to calculate the size of the main areas of cost over time. **These costs identified in our research and fed into the model are:**

- NHS costs i.e. screening and treatment costs
- Societal costs i.e. costs of informal care and productivity loss (from illness and early mortality) from carers and patients
- Individual costs i.e out of pocket expenses and loss of labour income whilst sick

It is worth noting that the economic costs in our model are conservative central estimates. For example, we have used the mid-range of survival rates and costs. Assumptions in areas such as productivity loss are at the lower end of the ranges.

We also consider the costs associated with the loss of unpaid work, though as this is less robust it is not included in the final totals (it is included in the Technical Annex for completeness). The costs to DWP of benefits paid to patients and carers is also estimated but as they are economic transfers they are not included in the total costings. The economic costs in 2034 are calculated by taking the latest year we have full data for, 2019, and using a combination of incidence data and existing research projecting the increase in costs to 2034. The costs mainly fall to the NHS and the wider UK economy through loss of labour productivity with both patients and carers costs included.

INTRODUCING THE WELLBEING ANALYSIS

We have also estimated the wellbeing cost of breast cancer. This gives a monetary value to the reduced quality of life a patient has when they are diagnosed and subsequently experience treatment, illness, and/ or an early death from breast cancer. The wellbeing costs also include some of the wider psychological impacts on partners, children and carers, but it has not been possible to provide a monetary estimate for all of the impacts, on patients nor on others. Wellbeing costs are not reflective of an actual value in GDP or national income, but represent an established way to understand and value non-market impacts on people's lives. It is a useful tool to be able to compare and consider the wellbeing impacts of breast cancer and the possible policy options which might alleviate some of this wellbeing loss.

It shows that these additional wellbeing impacts are likely to be considerable and if only the 'market' impacts are included in an estimate of the costs of breast cancer, it greatly underestimates the full impacts on patients, their friends and families.

Wellbeing costs included in this model are made up of:

- Reduced quality of life from a patients' illness
- Patients' early death / mortality
- Wellbeing losses to informal carers

- Wellbeing losses to partners (including widows)
- Anxiety in children

We used Quality Adjusted Life Years (QALY) measures for cancer patients and children and WELLBYs (Life Satisfaction on a 0-10 scale) for carers and partners.

Both economic costs and wellbeing costs have been calculated using the methodology from the HMT Greenbook and supplementary guidance.⁴ This means that the calculations are consistent with those used for policy analysis across the UK government.

BRINGING TOGETHER THE ECONOMIC AND WELLBEING COSTS IN THE MODEL

The model includes both economic and wellbeing costs run from the same data for incidence, survival rates, additional deaths and projections. By having both the economic costs and the wellbeing costs calculated, and on a consistent basis, we can see the scale of the two. The design of the model also means we can present a totality of the costs associated with breast cancer, but also change variables and run scenarios to illustrate different economic and wellbeing costs. This enables us to see the cost impact of potential policy changes where we can estimate the impact of the policy change in terms of incidence rates, survival rates, stage diagnosis profile, costs of treatments etc.

The main drivers of the costs are incidence rates, stage distribution, survival rates, the costs associated with patients' care and the impacts on wellbeing. Policies which affect these factors will change variables in the model to result in different costs. For example, an increase in screening rates increases the incidence of breast cancer but also shifts the stage diagnoses profile as more patients are diagnosed earlier, and ultimately reduces the number of deaths. So whilst there are increases in costs from more patients there are cost savings, over the baseline of lower screening rates, from the stage profile shift and fewer deaths.

^{4 &}lt;u>The Green Book: appraisal and evaluation in central government - GOV.UK</u>, <u>Green Book supplementary guidance: wellbeing - GOV.UK</u>. This is the guidance which is used for policy analysis across the UK government, for officials to assess how the social benefits to society compare to the social costs to society when a new policy or change is proposed.

SECTION 1 THE COSTS OF BREAST CANCER

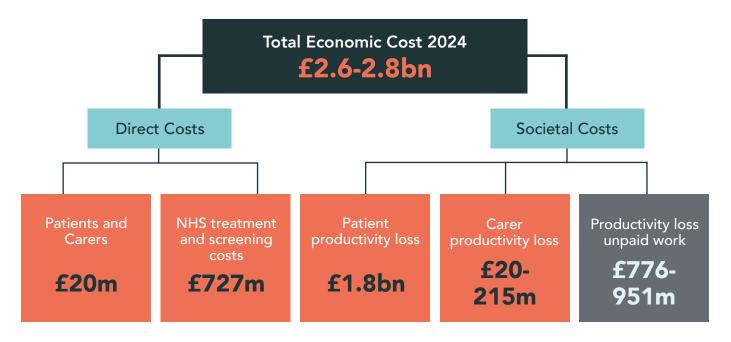
ECONOMIC COSTS

Our economic modelling reveals that in 2024 the total cost of breast cancer to the UK economy is estimated to be £2.6-2.8bn. This is around 0.1% of UK gross output. This means that by 2034, if nothing is done to prevent the impact of the disease, the estimated yearly cost to the economy will have risen to £3.6bn.

To provide some comparators:

- In research published in 2020⁵, the estimated cost of bowel cancer to the UK was £1.74 billion in 2018.
- In 2023, the cost of kidney disease in the UK is estimated to be £7bn.⁶
- In 2023, the cost of asthma in the UK is estimated to be £6 billion and the cost of COPD to be £9 billion.⁷

The diagram below shows how this total figure is broken down across different areas:



5 IHE Report 2020:6 (digestivecancers.eu)

6 Kidney disease: A UK public health emergency - Kidney Research UK

7 Investing in breath: Measuring the economic cost of asthma and COPD in the UK and identifying ways to reduce it through better diagnosis and care Technical Report (2023)

Productivity Loss from Patients

Productivity losses from illness and early death (£1.8bn in 2024) make up the majority of the economic costs. This represents all the time taken off work when someone becomes ill with breast cancer and undergoes treatment and aftercare. This is calculated using research which provides assumptions on the duration of absence from the labour market (sick-leave), the proportion of patients who return to work and the proportion who return part-time.

It also includes all the years of productive economic life that are lost when someone of working-age dies early due to breast cancer. This is calculated using the specific survival rates by age and stage of diagnosis for each patient and aggregated, compared to the life expectancy they would have had.

Productivity Loss from Informal Carers

There are also small costs borne to society from informal carers being out of the labour market and providing care. These costs are calculated using two methods to give a range:

- 'Value of care method' is a conservative estimate apportioning a shadow wage rate for the assumed hours of care a carer is providing.
- Labour market loss is also calculated using the wage carers would have acquired in their regular work - this aligns with the amount of time the patient is out of the labour market and is a higher estimate.

NHS Diagnosis and Treatment Costs

These costs include all existing screening, diagnostic, therapeutic and support services provided through the NHS. As discussed in the Technical Annex there are several studies which provide estimates for these and a range of costs is available. We have used conservative estimates here from Hall, PS (2015) updated to 2019 prices of £11,061 on average for 15 months of care. This reflects hospital-based care and we may be under-estimating by not having included formal care such as that provided in care homes through Local Authorities - though no estimates broken down by disease exist for this.

Screening costs come from the UK nations for the year in question and are scaled up by the future incidence projections for years after data is available.

We are likely to be including some element of overdiagnosis (where breast cancer wouldn't have caused an issue in the patient's lifetime) but the estimates reflect the costs of the treatment, regardless of if it was extra to what was necessary. Similarly the model will not correct for under-diagnosis but there are only costs in the model where there is identified incidence. Neither under nor over-diagnosis in the UK are particularly well estimated, this could be considered if research led to better estimates.

The Burden of Economic Costs

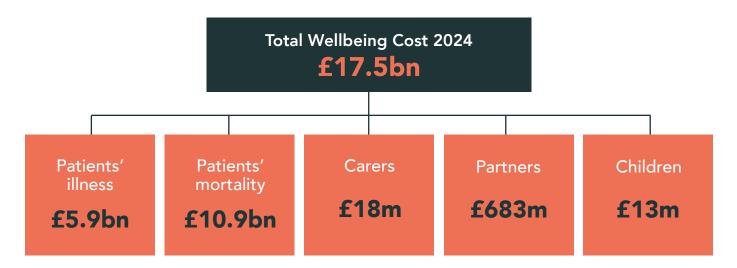
What these calculations clearly show is that society largely bears these costs (and of course it would be even larger if unpaid work was included). We can see that direct costs borne by the NHS (£727m in 2024) are significant but actually account for only a quarter of the total figure. We can also see here that there are very few, if any costs assumed to fall on employers as the economy replaces workers when sick employees, and their informal carers, are absent. Whilst there might be some frictional costs associated with this disruption in the workplace – recruitment and training costs for instance - overall these are minimal.

Wellbeing costs

The diagnosis and treatment of cancer has a number of wide-ranging and long term impacts on the wellbeing and quality of life of those diagnosed, and on others. Our calculations reveal that the total figure put on the wellbeing costs associated with breast cancer stand at £17.5bn in 2024.

This figure is not a cash value which is spent, but rather a representation of the human costs, calculated in a consistent way with the costs to the economy estimated above. It represents the loss of wellbeing experienced by breast cancer patients and those close to them. It is around six times higher than the estimated economic cost, demonstrating the significant - and often unrecognised - impact that the disease has on the UK population.

The diagram below shows how this total figure is broken down across different areas:



The wellbeing costs attributed to patients' illness and patients' mortality have been calculated with higher levels of confidence, although of course there are assumptions and averages included in these figures. The costs attributed to the wellbeing loss of informal carers, partners and children of those with breast cancer are calculated with lower levels of confidence and in most cases should be considered an underestimate (more details on this below). In any case they should be indicative and comparable.

Patients' illness

The wellbeing costs attributed to patients' illness and early mortality has been estimated at £16.8bn⁸ in 2024.

Of this, the human costs of experiencing illness and poor health related to breast cancer stands at £5.9bn.

This cost is a calculation based on the percentage reduction in a person's quality of life from the point of breast cancer diagnosis, through to either the end of treatment or end of life.⁹ It is comprised of the average impact on mobility, self-care, usual activities, pain/discomfort and anxiety/depression in each stage of breast cancer¹⁰ and multiplied by the incidence in the population. Including only these impacts is likely an underestimate of the full psychological impacts of breast cancer, which are discussed below under the 'non-monetised impacts' on patients.

The figure assumes some loss of wellness (e.g. illness or disability) for the remainder of the person's life, with the greatest impact for up to 8 years after the initial diagnosis and a smaller impact for the following years. It is worth noting that this 8-year dip in wellbeing may be an overestimate for some patients, e.g. those who observe little to no impacts once their breast cancer is controlled or treatment has finished. For others, however, it may be an underestimate, as there are cases where people continue to experience the impacts for many years. But overall, the drop in impacts at 8 years, with continued, smaller impacts for the remaining years, is considered a reasonable assumption.

Non-monetised impacts of patients' illness

These monetised impacts mask the depth of emotions and psychological impacts which are associated with breast cancer. The model and these figures don't include:

 The differentiated states with deeper levels of psychological distress which are masked by averages;

⁸ A high estimate for this total loss of Quality Adjusted Life Years is £25.4bn, based on Global Burden of Disease (2019) estimates of the total Disability Adjusted Life Years in 2019. This takes a different approach to estimation, since it is based on the adjusted years of life lost in 2019, rather than the adjusted years of life lost from diagnosis in a certain year, but could be considered a high upper-end estimate.
9 To calculate the percentage reduction in a person's quality of life from different injuries, disability weights were used. Stouthard et al (1997) was chosen (reference recommended in the UK Green Book manual for policy appraisal) since this source is differentiated by stage of breast cancer, enabling a match with the incidence numbers. We also draw from GBD (2019) for estimates of impacts when patients are in a 'controlled phase'.

¹⁰ I.e. the measurement of a Quality Adjusted Life Year (QALY) using EQ-5D, the measure which is used to inform health treatment decisions. Central disability weight values are taken throughout and compared to the norm for the average population, who have existing injuries, illnesses and conditions.

• The wellbeing impacts which are not included in the current measurement of quality of life, the Quality Adjusted Life Year (QALY).

In this model, it was only possible to monetise the average impacts on quality of life for each stage of breast cancer. In reality, there will be intermediate 'states' which are likely to result in a differentiated level of wellbeing. The experience of breast cancer is a journey and psychological experience will change over time with some parts exerting greater psychological toll than others, such as receiving diagnosis, telling others about it, anticipating and waiting for tests, test results. Treatment decisions and treatment can resurface anxiety and existential concerns that may never go away even years after treatment.

Beyond these fluctuations, there are likely to be wider psychological impacts which are not captured through the measurement of quality of life which is currently used in the UK. As described above, the questionnaire used to assess the QALYs, used for the monetised quality of life impacts,¹¹ asks individuals about their mobility, self-care, usual activities, pain/ discomfort and anxiety/depression. Although impacts in these dimensions will be relevant for cancer patients, there are likely to be further impacts on wellbeing, which are not captured by this scale. For example, Brazier et al's (2022)¹² review to inform the development of a holistic measure for health and wellbeing suggested that control, identity and social connections could also usefully be measured. Specifically for cancer patients, wider quality of life scales include assessments of body image, sexuality, family wellbeing, quality of close friend relations, quality of medical interactions, spirituality, levels of positive mood and energy level: impacts which may only be partially captured by the quality of life scale and the associated monetisation.

Specifically, the impact of breast cancer on social connectedness is likely to be a type of loneliness called existential loneliness where you feel separate from other people around you and is very often associated with a health condition or diagnosis. This is a relatively small but growing area of loneliness research but is important because feeling close to others matters to both having a positive self perception and feeling cheerful, the core components of mental wellbeing. Some of the impact of this type of loneliness can be mitigated by connecting with people in a similar situation although often, for geographical and other reasons, this will often take place online. The impacts of both treatment and the time it takes can impact on more well studied areas of social isolation and social and emotional loneliness because you are less able to spend time with people doing the things you enjoy.

Body image and appearance have a bigger impact on subjective wellbeing than might be expected because of the very high impact of social comparisons on wellbeing.

Feeling that you have the freedom to choose what you do in your life has an impact on your wellbeing;¹³ it can impact your life satisfaction, positive mood and protects against depression. This control or autonomy can be affected, and its loss mitigated, through breast cancer testing, diagnosis, treatment and recovery as well as the quality of the interactions around these.

Loss of life

The wellbeing cost of early mortality associated with breast cancer is estimated to be £10.9bn in 2024.

This figure is calculated by according a monetary value to a 'year of life' and multiplying that by the number of years of life 'unlived' by those who die from breast cancer. Survival rate data for England,¹⁴ for each stage and age, is used to estimate the number of breast cancer mortalities each year. This is then used to estimate the total number of years of lost life. For example, when someone dies at age 50, it is estimated that 32.9 years are lost.¹⁵ Each year lost, compared to the average life expectancy, is valued with the current UK government 'value of a statistical life year', which equals £70,000. This value is used in a broad range of policy areas, including environmental, transport, and health economics.¹⁶

The £10.9bn figure refers to 160,000 years of lost life.

The impacts on those who are diagnosed with breast cancer are, as expected, the most significant wellbeing impacts which can be monetised. Yet it is not only the patients themselves who suffer from

11 EQ-5D

14 Representing 85% of cases

¹² https://www.valueinhealthjournal.com/article/S1098-3015(22)00083-3/fulltext

¹³ Steckermeier, L.C. The Value of Autonomy for the Good Life. An Empirical Investigation of Autonomy and Life Satisfaction in Europe. Soc Indic Res 154, 693–723 (2021). https://doi.org/10.1007/s11205-020-02565-8

¹⁵ This is done by taking the median age for each age band, e.g. age 50 years for the 45–54 years age group. For the 15-44 age group, age 40 is taken and the age norm of 35-44, since the greater proportion of diagnoses is within the 35-44 age band. For 75-99, age 80 is taken. 16 This value is not lost productivity, which is calculated in the economic costs above, but rather a proxy valuation of the human costs for a year of life lost. This valuation of the human costs of a year of life lost is also distinct from the value which is used by NICE to take decisions about drug treatments.

a diagnosis and the resulting illness and treatment. Partners and children of the affected patient are also taken on a troubling journey of uncertainties and anxieties, often with significant changes to their lives. The figures in the following sub-headings present an indication of what these wider human impacts may be equivalent to in monetary terms, when following UK government methodologies to value these consistently.

Informal Carers

The total cost associated with loss of life satisfaction amongst carers of people with breast cancer stands at ± 43 m, with a range of $\pm 33-54$ m.¹⁷

This is calculated with some uncertainty and is likely to be an underestimate since it assumes that carers are caring for only one year, whereas in reality many may do so for longer than that. It is also an 'average' figure, which does not reflect differences in the amount of time per week the person spends caring¹⁸ or take into account gender differences (e.g. MacDonald and Powdthavee, 2018, find that females are more adversely affected by informal caregiving than men).¹⁹

There are at least 6.5 million informal carers in the UK, the majority of whom are women. Carers UK's *State of Caring* 2018 report identified that 8 out of 10 carers faced social isolation, 72% had suffered mental ill health as a result of caring, and almost two-thirds of carers (64%) focused on the care needs of the person they care for over their own needs. Most research indicates that caring is associated with poorer physical and mental health (Smith, et al., 2014; Powdthavee, et al., 2018, Schulz, et al., 2020; Ervin, et al., 2022). Carers can feel burdened and sometimes resentful of their role, isolated from others and experiencing increased loneliness and lower happiness.²⁰ Carers also report unexpected

changes and a sense of being permanently on call which result in more constant levels of stress and anxiety.²¹ Unpaid caregiving can lead to a scarcity of time and challenges balancing the time required for caregiving and other work and family commitments.²²

Partners

The total cost of the loss of life satisfaction amongst partners of those with breast cancer stands at £638m in 2024, with a range of £495 - 793m.²³

This is a combined figure, covering both the 'spillover' effect in loss of mental wellbeing from the patient to their partner and impact of widowhood. We have been careful not to double-count partners and carers and have based this figure on partners who are assumed not to be carers.

Wellbeing evidence in Australia has shown that when the mental health of an individual improves, there is a 'spillover' of 15% to the partner (Frijters and Mervin, 2014).²⁴ The wellbeing impact on partners assumes that this spillover effect also holds in the UK and that there is a degree of spillover when wellbeing *drops* rather than improves.²⁵ In our calculations, the spillover effect is estimated as a drop in partner Life Satisfaction that varies according to the stage of cancer the patient is at.²⁶

It should be noted, these are estimations based on rough assumptions and proxies. They are estimated purely to give an idea of the scale of effect rather than provide reliable evidence of the observed impacts on wellbeing. However, this is likely to be a conservative estimate, since there is no evidence of the duration of any spillover impacts in life satisfaction terms and the impacts on partners may continue for longer than one year, up to the years of duration of the illness.

20 What Works Centre for Wellbeing (2019). When we sing it sounds like there are more of us: Findings from the first cohort of the Carer's Music Fund. CMF Insight document series. Spirit of 2012

21 Bowes, A., Dawson, A., & Ashworth, R. (2020). Time for care: Exploring time use by carers of older people. Ageing & Society, 40(8), 1735-1758. doi:10.1017/S0144686X19000205

22 The caregiving stress process model (Pearlin, et al., 1990) and time-scarcity models (Strazdins, et al., 2011) propose several mechanisms through which unpaid caregiving can impact mental health.

23 The range represents the low and high WELLBY value in 2019 prices, of £10-16k (£13k central estimate)

24 https://www.sciencedirect.com/science/article/abs/pii/S0277953614001063

 $15\% \times 0.28 = 0.04$ drop in Life Satisfaction for partners of cancer patients in stages 1 and 2 and 15% of 1.08 = 0.16 drop in LS for partners of cancer patients in stages 3 and 4.

¹⁷ The range represents the low and high WELLBY value in 2019 prices, of £10-16k (£13k central estimate)

¹⁸ In general, studies suggest that negative effects on health and quality of life are worse for those caring for 20 or more hours per week or co-resident care (Legg, et al., 2013).

¹⁹ This can be explained largely by the fact that, compared to male caregivers, female caregivers are significantly more likely to be primary caregivers; provide more intensive and complex care; have difficulty with care provision and balancing caregiving with other family and employment responsibilities; have relatively little formal caregiving support; (in comparison, males are more likely to split their time between full-time employment and caregiving and, hence, are more likely to obtain formal and informal assistance with caregiving). Females suffer from poorer emotional health secondary to caregiving (see Table 7's results). As such, it should probably come as no surprise that we find a stronger statistically significantly negative effect of informal caring for women than for men (e.g., Pinquart and Sorensen, 2003).
20 What Works Centre for Wellbeing (2019). When we sing it sounds like there are more of us: Findings from the first cohort of the Carer's

²⁵ This approach requires a figure of the Life Satisfaction impact of cancer, which is not available. A very rough proxy estimation has been used, taking an idea from the drop in life satisfaction of 1.08 associated with moving from healthy to poor physical health (self rated)#. This is likely to be a fitting proxy for stage 3 and 4 cancer, but potentially an overestimate for stages 1 and 2. For stages 1 and 2, the drop is estimated as 25% of this impact, mirroring the relative scale of drop in QALY value for these stages.

In the case of death, Lucas et al. (2003) found that the person's partner typically exhibits sharp declines in life satisfaction in the year surrounding spousal loss (-0.86 Life Satisfaction points on a 0-10 scale), with evidence suggesting that life satisfaction takes up to eight years to return back to pre-loss levels. Based on findings in the paper, this has been incorporated in the model (an increase of 0.1 points per year). These are of course averages: evidence shows that some people never return to prewidowhood levels. Others return to their 'baseline' or pre-widowhood levels earlier than this average.

Children

The monetised wellbeing cost of the impact on children of breast cancer patients stands at £13m. This calculation is based on a number of assumptions, where further evidence could improve the analysis. It estimates the impact of the parents' illness but does not include the impact of their early death by breast cancer because the data to enable this is not available.

Evidence²⁷ suggests that children of breast cancer patients are impacted when their caregiver has a diagnosis of breast cancer on both mental wellbeing and behaviour. To take a conservative estimate, we can assume that impacts may be strongest for children of school age, in particular secondary school age. Using figures that allow us to estimate the age and number of children affected,²⁸ we take a conservative assumption that 15% of women diagnosed with breast cancer have children of a relevant age for evidenced psychological impacts.

We have used available evidence on levels of distress amongst children with a parent who has received a breast cancer diagnosis²⁹ to conservatively estimate that around 40% of children are impacted by anxiety and this holds for one year after diagnosis. Since this is to be averaged over a full year, we apply the disability weight associated with mild anxiety which is 0.03 (GBD, 2019). This may be a conservative assumption. Although all children are likely to be impacted by this diagnosis, we have only included the proportion reporting 'high' and 'severe' levels of distress. In addition, impacts are assumed for one year, yet there could be longer term impacts. $^{\rm 30}$

In the case of death of a mother, there is strong evidence of the wellbeing impact which bereavement has on children, including wider, long lasting impacts.³¹ However, a lack of sufficient evidence in the format required for monetisation means that these impacts have not been monetised in the model. Further evidence could improve this analysis and enable these impacts to be monetised in wellbeing terms.

²⁷ For example Breast Cancer Research Centre-WA, https://bcrc-wa.com.au/offspring-study-on-effects-of-a-cancer-diagnosis-on-children/ and a systematic review Annemieke Visser, Gea A. Huizinga, Winette T.A. van der Graaf, Harald J. Hoekstra, Josette E.H.M. Hoekstra-Weebers, <u>The impact of parental cancer on children and the family: a review of the literature</u>, Cancer Treatment Reviews, Volume 30, Issue 8, 2004, Pages 683-694. Key findings of the study included: 31% of the offspring reported high distress; 10% displayed severe distress, requiring immediate intervention; highest distress for offspring is soon after diagnosis; Female offspring have higher rates of distress than male. 28 See Technical Annex

²⁹ Evidence from Australia has shown that 31% of the offspring reported high distress; 10% displayed severe distress and that the highest distress for offspring is soon after diagnosis, https://bcrc-wa.com.au/offspring-study-on-effects-of-a-cancer-diagnosis-on-children/

³⁰ For example, the impact of mother's mental illness on their children is known to be associated with lower wellbeing in childhood and later life, Clark, Andrew, Flèche, Sarah, Layard, Richard, Powdthavee, Nattavudh and Ward, George. The Origins of Happiness: The Science of Well-Being over the Life Course, Princeton: Princeton University Press, 2018. https://doi.org/10.1515/9781400889129

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SECTION 2 SCENARIO TESTING AND MODELLING POLICY IMPACTS

We ran a number of scenarios through the model to see how different policy interventions might impact on economic and wellbeing costs. Of course we were especially interested in those that reduce those costs, as well as those that have an impact on reducing morbidity and mortality rates (even if there is a higher associated cost). **The three scenarios we ran with the greatest impact on costs are:**

- Increasing screening.
- Providing more cancer nurse specialists.
- Supporting people to return to work during and after being ill with breast cancer.

SCENARIO: SCREENING

By increasing the screening uptake from 2019 rates to 80% we would see a net cost saving in both the economic and wellbeing costs. Economic savings are in the range of £96m to £111m in 2034 and wellbeing cost savings have been calculated at £1.2bn, also in 2034.

This cost saving ultimately comes from re-profiling of the stage at diagnosis i.e. through increasing screening rates diagnosis picks up more cases in earlier stages. Interestingly with this scenario, increasing the incidence rates does initially increase associated costs - because there are simply more people being diagnosed and receiving treatment. However, as we have seen, that investment pays off. More people being diagnosed at stage 1 and fewer at stages 2 and 3 means the costs of increased patient numbers are mitigated by the cost savings from fewer late diagnoses.

NB. The cost savings differ by UK nation because from the 2019 rates some areas were closer to 80% than others, e.g. to get to 80% requires a 104% increase in screening in Northern Ireland compared to 116% in Wales.

SCENARIO: CANCER NURSE SPECIALISTS

We assume the baseline contains, as currently, very few cancer nurse specialists and in the scenario, everyone diagnosed is able to access one. A cancer nurse specialist provides support and information to cancer patients and their families and are specifically trained in psychological support.³²

We used research from Sweden³³ where there is data to show the impact of having specialist psychology-

³² https://www.imperial.nhs.uk/our-services/cancer-services/psycho-oncology

³³ Arving et al (2014) https://pubmed.ncbi.nlm.nih.gov/24115469/

trained nurses in place that are akin to cancer nurse specialists. The study shows an improvement in measured quality of life for patients and a reduction in total healthcare costs, in spite of the initial investment. We use this reduction in costs in the economic costs to reduce the NHS costs in the same ratio as the study and in the wellbeing costs to adjust the coefficient that improves wellbeing in line with the study.

Running this through our model shows that providing cancer nurse specialists would, despite the initial costs, actually be a saving to the NHS of over £118m in 2034. The savings are even more in wellbeing terms - £312m in 2034. The investment costs would cover training fees and increased salaries for the specialist grade. But the savings would be greater. These would result from lowered treatment costs related to, for example, a reduced requirement for follow-up appointments. This may be through a better understanding of the condition and treatment, but it could also be related to the importance of psychological support. Specifically for breast cancer, a study has shown that patients with anxiety and depression more often requested additional investigations to routine follow-up visits than nondistressed patients.³⁴ Studies have proposed that unmet needs for psychosocial support can lead to an increased utilisation of healthcare resources.³⁵

There is also some research indicating that specialist nurses improve survival rates but this is not included in our calculations as this is still under investigation. If it is the case, then an even further decrease in economic and wellbeing costs would result.

There are further scenarios which have not been possible to quantify due to the lack of data available, but have the potential to reduce aspects of the economic and/or wellbeing costs of breast cancer. For example, support courses have been shown to measurably improve patient quality of life,³⁶ which would reduce the wellbeing costs for patients.

For children and wider family members, early stage studies suggest that family orientated interventions could help mitigate impacts for children of mothers with breast cancer.^{37,38}

SCENARIO: SUPPORTING PEOPLE TO RETURN TO WORK

The specific scenario tested was to understand what the impact would be if we could:

- Halve the number of sick days taken by those with breast cancer
- Help 50% of those who currently only return to work on a part-time basis, back into full-time work
- Help 50% of patients who currently don't return to work at all, back into the workplace

This was the scenario that would have the biggest economic impact if policies were enacted to create such impacts. If we assume a scenario where there are improvements to labour market outcomes and patients return to the labour market both at a quicker rate and at a higher rate, then we see improvements to the individual and society which mean cost saving of £328 to £411m in 2034.

These economic savings relate entirely to savings from reduced productivity losses from illness and reduced caring requirements (NB. the wellbeing savings could be not calculated for this). It is a large benefit to society and individuals which could be funded in part by tax payer / employer contribution through government programmes to improve return-to-work rates or it could also reflect improved employer sickness absence practices.

As the estimates attribute no cost to employers, this may be a hidden cost saving which employers would benefit from in part. While we do not have estimates for any reduction in frictional costs in the model (recruitment etc) it would follow that there could be some.

³⁴ de Bock GH, Bonnema J, Zwaan RE, et al. Patient's needs and preferences in routine follow-up after treatment for breast cancer. Br J Cancer 2004; 90(6): 1144–1150.

³⁵ de Boer AG, Wijker W, de Haes HC. Predictors of health care utilization in the chronically ill: a review of the literature. Health Policy 1997; 42(2): 101–115; Oleske DM, Cobleigh MA, Phillips M, Nachman KL. Determination of factors associated with hospitalization in breast cancer survivors. Oncol Nurs Forum 2004; 31(6): 1081–1088; Keyzer-Dekker CM, Van Esch L, Schreurs WH, et al. Health care utilization one year following the diagnosis benign breast disease or breast cancer. Breast 2012. From Arving et al (2014).

³⁶ The 2017 evaluation of BCN's moving forward course (Frontline, 2017) demonstrated a difference of 0.04 EQ-5D scores in pre- and post- figures. We have taken a decision at this stage not to quantify and monetise this specific impact since the course content and format has changed significantly since 2017, to improve the offer for patients.

³⁷ https://pubmed.ncbi.nlm.nih.gov/23760766/ John K, Becker K, Mattejat F. Impact of family-oriented rehabilitation and prevention: an inpatient program for mothers with breast cancer and their children. Psychooncology. 2013 Dec;22(12):2684-92. doi: 10.1002/pon.3329. Epub 2013 Jun 13. PMID: 23760766.

³⁸ https://onlinelibrary.wiley.com/doi/abs/10.1111/ecc.12432 Supporting children facing a parent's cancer diagnosis: a systematic review of children's psychosocial needs and existing interventions

TECHNICAL APPENDIX A

FURTHER DETAIL ON CALCULATING THE WELLBEING COSTS

Choice of measure(s) for wellbeing impacts

There are many different measures to assess the wellbeing and quality of life of cancer patients, survivors, carers and family members (see e.g. Perry et al 2007; Chen et al, 2010 for cancer patients). Some of these measures are better than others at capturing the full impacts, including the psychological impacts. However, because the focus of this part of the work is on monetisation, we need to choose a measure which may not be perfect for capturing all the impacts nor completely specific for the UK, but can be monetised in a consistent manner with wider appraisal in the UK government. The Green Book Supplementary Guidance on Wellbeing (2021) states that, "where direct evidence on QALY/DALY impacts is available, this approach is recommended for appraisal. Using SWB values in addition would pose a significant risk of double counting". For this reason, we are using Disability Adjusted Life Years (DALY)/ Quality Adjusted Life Years (QALY) measures for cancer patients and Life Satisfaction (on a 0-10 scale) for carers, partners and children, multiplied by the value of a QALY and the value of a WELLBY³⁹ which are used for government appraisal in the UK. Where changes in Life Satisfaction are stated in this paper, these are always Life Satisfaction on a 0-10 scale, unless described otherwise.

OVERVIEW TABLE

INPUTS, ASSUMPTIONS, SOURCES AND CALCULATIONS

INPUTS	IMPACT	SOURCES	CALCULATIONS AND NOTES
Quality of Life impact on people diagnosed with Breast Cancer: Central estimate	Various, by stage	Disability weights referenced in the Green Book Guidance for UK appraisal, Stouthard et al (1997) Additional disability weights for controlled phase from GBD (2019) ⁴⁰	Reduction in quality of life compared to general population applied to number of patients and number of years in this condition, multiplied by value of a statistical life year (consistent with valuation in the UK) Number of years of lost life multiplied by value of a statistical life year and discounted

39 1 point change in Life Satisfaction on a 0-10 scale: £13k in 2019 prices

40 Due to the lack of detailed figures on mastectomy in the UK and to take a conservative estimate, the figure for "controlled phase of breast cancer without mastectomy" was used.

INPUTS	ІМРАСТ	SOURCES	CALCULATIONS AND NOTES
Quality of Life impact on people diagnosed with Breast Cancer: High estimate		GBD (2019) - total number of DALYs from illness and death	
Yearly Life satisfaction impact on carers	0.22 ⁴¹ WELLBYs	Assumption, based on estimates of the life satisfaction impact on informal carers: MacDonald and Powdthavee (2018)	Translated from 1-7 scale to 0-10 scale and multiplied by number of informal carers to obtain WELLBYs Multiplied by value of a WELLBY and discounted
Life satisfaction impact on partners following diagnosis	15% spillover 1.08 drop in WELLBYs	Assumption, based on spillover effect (Mervin and Frijters, 2014) and LS impact of drop in self-assessed health (Frijters et al, 2014), moving from healthy to poor self rated health.	 15% of 1.08 for partners of patients in Stages 3 and 4 Assume proportionate difference in WELLBYs as with QALYs 15% x 0.28 drop in Life Satisfaction for partners of cancer patients in stages 1 and 2 Multiplied by value of a WELLBY and discounted
Life satisfaction impact on partners in case of death	0.86 WELLBYs, reducing 0.1 points per year ⁴²	Assumption, based on impact of spousal loss: Lucas et al (2003)	The number of deaths associated with diagnosis in given year were estimated, across the following 40+ years. Multiplied by average number of partners and WELLBY impact across the following 8 years. The impact of widowhood was calculated in present value terms, to estimate the total 'widowhood' wellbeing impacts of those with a diagnosis in this year. ⁴³

⁴¹ Converting from a 7 point scale to the 11 point scale required for monetisation. Using the estimate of "caring for other member who had an accident within last year and can still do daily activities". This is considered as the best proxy for the impact on carers of 'average' breast cancer sufferers. Coefficients which do not break the group into those who can and can't do daily activities are statistically significant and larger. This chosen coefficient is not statistically significant, but smaller in scale and by the description considered a better match for the situation. This coefficient was chosen by Parsekar et al (2021) in their assessment of the potential wellbeing impacts on carers of cancer patients 42 Lucas' linear model indicated that people report a 0.935 point drop in satisfaction during the 1st year of widowhood and then increase at a linear rate of 0.101 points per year. Again, however, the standard deviation of this slope is very large (0.175), illustrating that there is a great deal of variability in the rate at which people change. In fact, people whose within-subject slope is just slightly greater than one half of one standard deviation below the mean are predicted not to adapt to widowhood. Thus, not everyone experiences adaptation; many respondents report stable or even decreasing levels of satisfaction for many years following the loss of a spouse. On the other hand, there are many individuals (those who have slopes that are higher than average) who return to baseline much more quickly than the average slope would suggest.

INPUTS	IMPACT	SOURCES	CALCULATIONS AND NOTES
Number of partners impacted	61.3% of cancer patients, based on average number of people in a partnership or cohabiting (50.6% plus 13.1%)	ONS release "Families and households in the UK: 2020" and 2022 ⁴⁴ popn estimates by marital status and living arrangements ⁴⁵	Assess average number of partners per cancer stage. Assume that informal carers are primarily the partners of cancer patients in the 'higher' stages. Calculate how many affected partners are in addition to informal carers, for each stage. ⁴⁶
Quality of Life impact on children following diagnosis	0.03 QALY loss	Assumption, based on disability Weight of 'Mild Anxiety' from GBD (2019)	Multiplied by number of children impacted, applied for 1 year Multiplied by value of QALY and discounted for future years
Number of children impacted	1.92 mean number of children	ONS release for mean number of children ⁴⁷ Assumptions for number of children in school age Assumptions based on evidence from Australia ⁴⁸ for proportion of children suffering severe and high distress	Incidence numbers x 15% x mean number of children ⁴⁹ x 40% of children
Discount rate	1.5%	HMT Green Book	Applied across QALY and WELLBY impacts
Value of a WELLBY	£13,000 in 2019 prices ⁵⁰	HMT Green Book Supplementary Guidance ⁵¹	Multiplied across WELLBY impacts, with range of £10,000- £16,000
Value of a Statistical Life Year	£70,000 in 2019 prices	HMT Green Book	Multiplied across QALY impacts
Scenarios			
Quality of Life Impact of having access to a cancer nurse specialist	Improvement of 0.045 QALYs over 2 years	Assumption, based on Arving et al (2014)'s study in Sweden. ⁵²	Applied as a reduction in QALY impacts (described above) for 2 years

44 https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/families/bulletins/familiesandhouseholds/2022

45 Population estimates by marital status and living arrangements, England and Wales - Office for National Statistics (ons.gov.uk)

46 We estimate the numbers based on the average number of people in a partnership or cohabiting (61.3%) (Population estimates by marital status and living arrangements, England and Wales - Office for National Statistics (ons.gov.uk), assess average number of partners per cancer stage, assume that 50% of informal carers are partners and that informal carers are primarily the partners of cancer patients in the 'higher' stages, calculate how many affected partners are in addition to informal carers, for each stage.

47 https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/conceptionandfertilityrates/bulletins/ childbearingforwomenbornindifferentyearsenglandandwales/2020

48 For example Breast Cancer Research Centre-WA, https://bcrc-wa.com.au/offspring-study-on-effects-of-a-cancer-diagnosis-on-children/ 49 Women in England and Wales born in 1975 who completed their childbearing years in 2020, had on average 1.92 children (Childbearing for women born in different years, England and Wales - Office for National Statistics (ons.gov.uk)). Standardised mean age of mother at childbirth is 30.9 in 2021 (Births in England and Wales: summary tables - Office for National Statistics (ons.gov.uk)) and was 29.1 in 2005, 28.5 in 2000. This means that a proportion of patients in the age ranges 15-44, 45-54 and part of 55-64 could be of a relevant age: we assume half of the group to 54. Since the rough proportion of breast cancer cases in the age groups up to 54 is 30%, we assume that this holds for 15% of the group. 50 2019 prices used for value of a WELLBY and value of a Statistical Life Year to maintain consistency with economic costs, see appendix B

50 2017 prices used for value of a WELEBT and value of a Statistical Life fear to maintain consiste
 51 https://www.gov.uk/government/publications/green-book-supplementary-guidance-wellbeing

52 This study only applied to patients undergoing adjuvant therapy. We have assumed that this may also hold for breast cancer patients in general, since the majority of women with breast cancer in stages I, II, or III are treated with some form of surgery.

ADDITIONAL NOTES ON CALCULATIONS:

Illness and mortality calculations

- There is a natural level of uncertainty in these estimates, because these stages of cancer and its treatment impacts individuals differently, depending on age, existing conditions, among others. Within the 4 Breast Cancer Stages, there are a number of intermediate 'states' which are likely to result in a differentiated level of wellbeing. For example, the state of wellbeing while waiting for the results of a scan, the wellbeing during different stages of treatment, the different experiences of care and support at different points in time, wellbeing during the transition at the end of hospital-based treatment.⁵³ However, since data and consistent wellbeing evidence is not available across each of these states, this has not been possible to differentiate and an average has been taken.
- We assume that the calculated disability weights of the cancer stages described in Stouthard et al (1997) apply for 8 years, after which the impact drops and the disability weights of a 'controlled phase' from GBD (2019) apply. The lower disability weight is applied for the rest of a patient's life.⁵⁴ This may be an overestimate for some patients, who observe little to no impacts once their breast cancer is controlled, it may be an underestimate for others, who continue to experience impacts for many years. The drop in impacts at 8 years, with continued, smaller impacts for the remaining years, is considered a reasonable assumption.
- A high estimate has been taken directly from the Global Burden of Disease Disability Adjusted Life Years estimates for 2019. This is a different calculation, since it is an estimate of the Quality of Life Years lost due to breast cancer in 2019, i.e. in the year itself, rather than the full lifetime cost of those diagnosed in 2019. However, this figure for 2019 will include the later QALY impacts of those who have been diagnosed in the previous years. This figure may be an overestimate, where survival rates have improved. It is taken as a high estimate.

All impacts on wider family members

- Across the piece, these monetised estimates are exploratory. Although they follow the Green Book methodology for UK government appraisal, the evidence underpinning the figures is in many places based on assumptions. Better evidence on e.g. the wellbeing impacts on partners and children during the illness of a loved one, as well as evidence of the bereavement impact on children, could help improve the confidence in this analysis.
- Although the impacts on wider family members are clear, we need to exercise caution with the monetised figures, to avoid 'double counting'. According to government methodology papers, the value of the statistical life year, i.e. the monetised impact of a patient's illness and death incorporates "losses to society as well as losses that are borne by the victims themselves, their friends and relatives."55 This could either be interpreted that the value of a QALY incorporates these impacts on friends and relatives: when the value of a QALY is used, the value on others is considered to be included. Another interpretation would be that the psychological distress that the potential impact on loved ones/ dependants brings to the individual is distinct and additional to the affect on others (e.g. a mother feeling bad about the prospect of being unwell and unable to help her kids is separate from the impact that her kids experience). We include an assessment of what these values may be, if they were to be included, with caution that there could be an element of double counting.

- 53 See Breast Cancer Care Moving Forwards Evaluation (Frontline, 2017)
- 54 A recent study has suggested that patients observe impacts from breast cancer up to 14 years after diagnosis
- 55 WebTag guidance, TAG Unit A4.1 Social Impact Appraisal

TECHNICAL APPENDIX B

Methodology of the Incidence-based Economic Cost Model

A baseline year (2019) is established through using breast cancer incidence data from each UK nation, broken down by stage and age.

All costs are driven by the volume of patients diagnosed at various stages of breast cancer in each year. Incidence costs are defined as the costs of delivering care to a homogeneous cohort of patients fixed in the year of their diagnosis and followed up for a number of years. In every year following the diagnosis, incidence costs include only patients who survive the previous year, mortality data being used.

For subsequent forecast years several different forecast assumptions are used – the Cancer Research UK projection[1] will be the base case though others can be used e.g. ONS population projections, which mean incidence changes only by the demographic composition of the population over time. We have modelled the identified economic costs where data is available. Where it is not, robust assumptions are evidence-based and use the latest research. The model enables variables to be altered to show the impacts of different assumptions and sensitivity analysis will test the analysis for robustness.

DATA ACQUISITION AND SELECTION

The cost model uses the most recent academic research and government data on which to base modelling and provide robust estimates. The methodology follows HM Treasury Green Book⁵⁶ and The Aqua Book⁵⁷ standards for analysis and modelling.

An overview of the inputs, sources, calculations and outputs is set out in the table below:

INPUTS	SOURCES	VARIABLES	CALCULATIONS	OUTPUTS
Numbers of people diagnosed with breast cancer annually	Incidence data	By UK nation, stage 1-4 at diagnosis.	Use English age and stage data for other nations to split out, apply projection delta for years 2019-2034	Forecast of the numbers of breast cancer patients to 2034, by age and stage for all UK nations.

56 The Green Book (2022) - GOV.UK (www.gov.uk)

57 The Aqua Book: guidance on producing quality analysis for government - GOV.UK (www.gov.uk)

INPUTS	SOURCES	VARIABLES	CALCULATIONS	OUTPUTS
Survival rates	NHS digital data/ cancer registry			Forecast number of additional deaths, used to calculate economic cost of productivity loss and wellbeing costs of early mortality. Provides end points for costs incurred during illness.
Costs of treatments and services over lifetime for breast cancer	Several sources from research and literature - see below.	Broken down by stage of diagnosis	Applied to forecast incidence numbers, using the range of costs available	Forecast costs of treatments and NHS care over the lifetime.
Numbers of informal carers annually / per patient	Family Resources Survey/General Household survey	By age, occupation	Used for calculating costs of carers' lost labour - we assume that every stage 3&4 patient has 1 carer.	Intermediary output for other calculations on cost of informal care.
Labour Market data on breast cancer patients and their carers – including employment rates, wages	LFS, ASHE Research estimates–DWP systematic review 2019	By age, gender, other characteristics	Multiplying the wages, lost hours and employment rates	To establish the loss, and cost, of labour market participation to the individual and their informal carer(s).
Employer impacts and productivity effects	Data on loss of hours and wages	By age, gender, other characteristics	Using the loss to the individual and informal carers calculated above to pro-rata for employers costs and loss of productivity through spill-overs.	Employer and wider productivity costs
Costs of DWP benefits (transfer)	DWP data sources – Feb 2023 (next out May 23) Benefit expenditure. Forecasts where available.	By gender, region	The proportion of Attendance Allowance (AA) assigned to breast cancer carers will be assumed. Similarly the amount of Carer's Allowance (CA).	Costs of a range of DWP benefits paid to patients and carers attributable to breast cancer patients and carers.

For each of the columns in the table above we provide further detail below:

Inputs and sources

Many of the inputs are sourced from the NHS Digital data, labour market data sources such as the Labour Force Survey and Annual Survey of Hours and Earnings. Where assumptions are used – for example for wages of informal carers – it is made clear and should other data sources become available they can be used in future iterations. Assumptions are clearly identified as such and tested using current research – where a range of assumptions is more appropriate (to account for uncertainty) these have been used, with the assumption being easily changed in the Excel model.

Where possible UK data has been used, though in some cases English-only data is available and so it has been pro-rated to cover the whole of the UK, using the regional distribution of breast cancer incidence. This is the case for breaking down incidence data into age profiles (which is Englishonly data), also for the 5-10 year survival data (which is East-of-England data). The model can produce a breakdown of costs by UK nations.

Base Year and Forecast

The most recent year's data of 22-23 is not yet available owing to data lags, given the Covid-19 pandemic 21-22 and 20-21 data are not representative years and so we have gone to 19-20 data to get a full year of representative costs. We have run this forward to get 2024 costs and then 2034, all in 2019 prices.

The Forecast used is that of Cancer Research UK which they explain in detail on their website.⁵⁸ They say, 'Projections are based on incidence data from 1975-2018 (England, Scotland and Wales) and 1993-2018 (Northern Ireland); the above figure presents all UK data from 1993-2018 (observed) and 2019-2040 (projected). Number of new cases and agestandardised rates are presented as annual averages for each 3-year rolling period. ICD-10 codes C50.

Projections are based on observed incidence rates and therefore implicitly include changes in cancer risk factors and diagnosis. Confidence intervals are not calculated for the projected figures. Projections are by their nature uncertain because unexpected events in future could change the trend. It is not sensible to calculate a boundary of uncertainty around these already uncertain point estimates. Changes are described as 'increase' or 'decrease' if there is any difference between the point estimates.'

Variables

Independent Variables

The main variables which can be altered in the model are:

- Numbers of breast cancer patients (incidence) split by stage of breast cancer at diagnosis, age, survival rates, UK nation
- Numbers of informal carers
- Unit costs of treatments
- Labour market participation of patients and informal carers

Dependent Variables

The variables which result from independent variables above are the costs that result from applying the unit costs and assumptions to the number of patients and informal carers.

Outputs

The Burden of Costs on Different Agents

The costs are calculated over a ten-year period for the different agents in the UK economy:

- NHS
- Society
- Individuals broken out by patients and informal carers

This enables the burden of costs to be easily seen, and so policy interventions be applied that affect different groups.

Calculations and derivations

Costs of treatment and services

There are many sources from research and studies which have tried to calculate the costs of treatment. They come from a range of countries, covering a range of subsets of patients and relating to various types of care. Given this wealth of estimates we have chosen to use that from Hall, PS (2015)⁵⁹ which provides costs for cancer care for use in economic evaluations in a UK context, and for breast cancer

⁵⁸ Breast cancer incidence (invasive) statistics | Cancer Research UK

⁵⁹ Hall PS, H. P. (2015). Costs of cancer care for use in economic evaluation: a UK analysis of patient-level routine health system data. Br J Cancer, 112(5):948-956.

specifically this is £12,595 for 15 months of care. Ideally we'd have used this broken out by stage of diagnosis but that isn't presented and it is an average across all stages.

Table showing the various treatment cost estimates available in studies and research:

COUNTRY	PATIENT POPULATION COVERED	YEAR	COST IN ORIGINAL CURRENCY	BASIS (ANNUAL / LIFETIME)	AMOUNT PER CASE ANNUAL / LIFETIME (£)	SOURCE
US	BC patients over and above non- BC	2004	US\$ 12,828	Annual	7,127	(Barron, 2008)
US	One annual cohort BC metastatic cases	1994	US\$ 60,000	Lifetime	40,000	(Berkowitz, 2000)
Canada	Attributable costs to BC	2008	CA\$ 31,732	2 yrs	Average: 9,916	(Mittmann N, 2014;)
					Stage I: 9,356	
					Stage II: 14,654	
					Stage III: 20,428	
					Stage IV: 20,821	
UK	BC costs of treatment per case	1998		Annual	7,247	(Dolan P, 1999)
UK	BC hospital-based care	2010		Lifetime	Age 18–64: 13,659	(Laudicella, 2016)
					Age ≥65: 7,812	
UK	BC hospital-based care	2013		15 months	12,595	(Hall PS, 2015)
UK	BC Stage 4 only	2002		Lifetime	12,500	(Remák E, 2004)

COUNTRY	PATIENT POPULATION COVERED	YEAR	COST IN ORIGINAL CURRENCY	BASIS (ANNUAL / LIFETIME)	AMOUNT PER CASE ANNUAL / LIFETIME (£)	SOURCE
UK	BC hospital- related costs	2020		12 months	Stage I: 5,167 Stage II: 7,613 Stage IIIA:	(li Sun, 2020)
England	BC Cost per case	2013		One yr	13,330 573	(Briggs, 2018)

Employment and Productivity Effects

The most widely used methodology for calculating productivity losses in cost of illness studies is the human capital approach. This approach has a long history in economic and health services research as a robust and reliable method to calculate the expected life-time output that would have been realised had the disease or death been avoided. This methodology includes estimates for both work that is paid for through wages and activities that are not paid such as caring duties or housework. These are calculated using data from the Labour Force Survey and Annual Survey of Hours and Earnings, multiplying by the forecast Breast Cancer incidence each year. Using this we establish the cost to the UK Economy of the loss of employment and loss of productivity resulting from Breast Cancer sickness, periods of treatment and removal from the labour market. This is also estimated for informal carers assumptions about the impact on the labour market participation of informal carers coming from research estimates. Because the human capital method can overestimate productivity losses, given workers can be replaced, we have used conservative estimates. We also account for gender and age disparities (HC method tends to overestimate using male and average age of worker) by breaking down the data by gender and age to ensure the estimates are specific to the Breast Cancer patient population.

We have also presented the corresponding costs of 'unpaid' work that is lost through illness and caring, this is £776-951m in 2024. This is calculated using a study⁶⁰ which covers all European countries and shows the relationship between paid and unpaid loss of work owing to cancer. This shows the UK ratio to be 1:0.90, so the unpaid loss of work is equivalent to 90% of the cost of the paid loss. This is not breast cancer specific - it is for all cancer - and isn't as robust as other estimates so we have left out of totals but shown for completeness.

Breast cancer is a predominantly female disease, a small number of men are diagnosed each year, and so the labour market loss is smaller than it would be if breast cancer mainly affected men. If we use the data for male wages, male labour market participation, and male unemployment we get a resulting economic cost - through the labour market loss - that is much higher. Labour market loss through illness and death if breast cancer were a majority-male disease would be £929m higher in 2024. This is 25% higher than for the current case of majority-female breast cancer.

Economic transfers

We were asked to 'quantify the cost to DWP of benefits'. Whilst these are possible to calculate, an economic cost model should not include economic transfers of resources between people (e.g. benefit payments and taxes). These types of payments transfers - pass purchasing power from one person to another and do not involve the consumption of resources. Transfers benefit the recipient and are a cost to the donor and therefore do not make society as a whole better or worse off.

We calculate the cost to DWP/Government of benefits paid to Breast Cancer patients, and the taxes forgone from their inactivity, but these sit alongside the overall cost model. These figures add

⁶⁰ Paid and unpaid productivity losses due to premature mortality from cancer in Europe in 2018 - Ortega, Ortega - 2022 - International Journal of Cancer - Wiley Online Library

weight to the arguments showing the costs of Breast Cancer but as they are transfers they should not be included in the economic cost to the UK.

Discount Rates

The final forecasted costs from the economic model (in say 2024 and 2034) are in 2019 prices to be comparable, this is called a 'present value' basis. To do this a 'discount rate', accounting for future inflation, needs to be applied. The public sector discount rate adjusts for social time preference, defined as the value society attaches to present, as opposed to future, consumption. It is based on comparisons of utility across different points in time or different generations.

The Green Book discount rate, known as the Social Time Preference Rate (STPR), for use in UK government appraisal is set at 3.5% in real terms. This rate has been used in the UK since 2003. Exceptions to the use of the standard STPR include for risk to health and life values. The recommended discount rate for risk to health and life values is 1.5%. This is the discount rate which has been applied for the wellbeing costs.

Sensitivity Analysis

Sensitivity analysis is essential to establish the robustness of estimates and the extent to which the independent variables affect the dependent variable. In this case, how the various elements of the cost model contribute to the overall outputs. Testing of the variables and the assumptions has been carried out using standard scenario analysis and testing of extremes.

The main determinants of the Economic costs are:

- Incidence rates: a 10% increase in incidence increases economic costs by £300m, which is 11% from base case.
- Survival rates: An improvement in the survival rates feed through mainly into the economic cost of labour market loss through mortality in the productivity estimates. A 1% improvement rate in all survival rates, across all stages and ages, decreases economic costs by £42m in 2024 and decreases total wellbeing costs (through reduction in mortality rates) by £422m in 2024.
- Cost of treatment: a doubling of the average treatment costs per patient doubles the total

NHS treatment costs, and increases the total economic costs by 16%.

• Labour Market return and participation: a halving of the number of patients out of work produces a £100m cost saving in 2024, a large proportion of the productivity loss through illness.

This is important when we come to scenario analysis as any policy which impacts on these areas will have the greatest impact on changing the costs.

Quality Assurance

The model has been fully checked and separate estimates compared to existing sources and previous work. The overall costs have also been compared to other work to assess the validity of the estimates.

There is, for example, the 2021 work from the University of East Anglia (Parsekar K, 2021) looking at the societal costs of chemotherapy in early stage breast cancer patients. This put 'the costs of chemotherapy in the UK economy at over £248m. Societal productivity losses amount to £141.4million, which includes £3.2m associated with premature mortality, short-term and long-term work absence (£28.6m and £105m, respectively). £3.4m is associated with mortality losses from secondary malignancies due to adjuvant chemotherapy. A further £1.1m in lost productivity arises from informal care provision. Out-of-pocket costs per round of chemotherapy account for £4.2m, or an annual average of almost £1100 per patient. Interview findings support the cost burden modelled and also highlight the impact on cognitive function of patients and how this could increase the cost burden to patients, their families and wider society. In addition, estimated costs for carer emotional well-being are £82m in lost quality of life.'

Given this is a subset of patients and a subset of treatment the estimates are comparable within our overall costs for all stages and all treatments.

Similarly older estimates of the costs of various cancers from the University of $Oxford^{61}$ put the cost of breast cancer to the UK Economy, in 2012, at £1.5bn, within a £15.8bn estimate of all cancer costs.

We can also draw on Demos' own previous work⁶² on the costs of cancer which put total cancer in the UK at an economic cost of £7.6bn in 2020. Within that context and the discussion around the impacts of the costs on individuals and wider society the estimates presented here are reasonable.

⁶¹ https://www.ox.ac.uk/news/2012-11-07-cancer-costs-uk-economy-%C2%A3158bn-year

⁶² https://demos.co.uk/wp-content/uploads/2023/02/Cancer-Costs-FINAL-Jan-2020-1.pdf

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