

CANCER CASH CRISIS

**WE ARE
MACMILLAN.
CANCER SUPPORT**



Counting the cost of care
beyond treatment

December 2015

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FOREWORD

The NHS in England is facing unprecedented pressures. The number of patients is constantly growing and people's care needs are increasingly complex. To add to this, hospitals and GP practices are struggling with staff shortages and budget deficits. Cancer is the third largest area of overall NHS spendⁱ and the number of people getting and surviving the disease is increasing year-on-year, making it one of the NHS's biggest sources of pressure.

We know that staff work hard to do their best for people with cancer and there are some examples of excellent care, but the strain on services is starting to have a significant impact. One of the key cancer waiting time targets – ensuring 85% of patients start cancer treatment within 62 days of urgent referral by their GP – has now been in breach for at least 17 months in a rowⁱⁱ. And in other areas of cancer, such as long-term support and care following treatment, the level of resource was already insufficient long before the current pressures began.

In last month's Comprehensive Spending Review, the Government pledged to boost frontline NHS services with a 3.7% increase to next year's budget. The question is, how will this money be spent?

Deciding how to invest in times of austerity can seem like an impossible choice. But the fact is that the NHS must spend wisely now to save later. Doing more of the same will only add to the increase in costs in the future.

In this report we set out new evidence to support the case for urgent action on cancer funding, with a focus on the often-neglected cost of post-treatment care. Plans to improve cancer services and mitigate rising costs must place an equal priority on living with and beyond cancer as well as early diagnosis if they are to succeed.

In recent years we have seen new short-term sources of funding for high-cost cancer drugs, but the cost of cancer care extends far beyond treatment alone and this isn't always acknowledged.

Every year, hundreds of millions of pounds are spent on long-term care and support for people with cancer, often for long after their initial treatment has ended. But the health and social care system is wasting money by spending it on the wrong kinds of care, such as avoidable and expensive emergency admissions.

Plans to address this must be spearheaded by the new Cancer Strategy for England, which Macmillan Cancer Support helped to develop as part of the Independent Cancer Taskforce. We worked to ensure the Strategy would support people both during their diagnosis and treatment and afterwards. It includes practical, tangible solutions that will help mitigate rising costs while improving patient experience and quality of life for people with cancer. The NHS must commit to fully funding the Strategy to avert a crisis in cancer funding and take a first step towards securing the future of cancer services in England.

As well as short-term action to protect the services we have now, we will also need a long-term, sustainable approach to funding to improve care in the future. The need for cancer care is only going to increase as the number of people living with cancer in England soars to at least 3.4 million by 2030. Each of these 3.4 million people deserves the best quality care and long-term support. If the Government and NHS do not take action on cancer funding now, we believe the quality of care – and people's chances of a good recovery and long-term quality of life – will only deteriorate. It will also increase rather than relieve the strain on the NHS.

We simply cannot allow this to happen.

The Government has often said that we need a strong economy to have a strong NHS. The reverse is just as true – we need a strong NHS and a healthy population to have a strong economy. As the economy returns to growth, we must invest in the long-term health of the nation.



Juliet Bouverie
Executive Director of Services and Influencing
Macmillan Cancer Support

'Plans to improve cancer services and mitigate rising costs must place an equal priority on living with and beyond cancer as well as early diagnosis.'

EXECUTIVE SUMMARY

- The cost of cancer care goes far beyond expensive drugs, technology and tests. New research from Macmillan Cancer Support has revealed the 'hidden' costs of cancer, exposing for the first time the true cost of cancer to the NHS in England.
- Our findings show that support for people with cancer beyond their initial treatment will cost the NHS at least £1.4 billion every year by 2020. Treating just the consequences of cancer treatment – such as side-effects from drugs as well as long-term after-effects – will cost the NHS at least £1 billion by 2020.
- As well as the consequences of cancer treatment, many people with cancer also have other serious health conditions and some people will live with incurable but treatable cancer for several years. So the costs of care beyond treatment continue to accumulate for many years following diagnosis.
- To improve cancer care and mitigate rising costs, the Government and NHS must place an equal priority on care during and after treatment, as well as early diagnosis. Many people still need expensive long-term care and support even when their cancer is identified early, so it isn't enough to simply focus on diagnosing people earlier.
- The NHS also needs to spend its money more effectively and efficiently because people with cancer are not currently getting the right level of care and support. Our new figures show that the NHS spends more than £500 million a year on emergency inpatient care just for people diagnosed with one of the top four cancers within the past five years. In many cases this will be because they are not receiving the right care and support to meet their needs. The NHS also uses a 'one-size-fits-all' model for follow-up care for people with cancer that leads to unnecessary appointments, and also fails to meet people's needs.
- The Government and the NHS must take action now. The number of people with cancer being treated by the NHS is at a record high and both staff and budgets are under immense strain across all areas of care.
- The new Cancer Strategy for England sets out a range of solutions that will help mitigate the increase in the cost of care beyond treatment and improve the lives of people with cancer. These include:
 - Ensuring every person with cancer in England has access to the cancer Recovery Package to better support people beyond treatment, through holistic needs assessments and other interventions, including helping people to access services that reduce emergency admissions and help people get back to work
 - Providing a wider range of options for follow-up care (stratified pathways), including supporting more patients to self-manage their care
 - Creating local Cancer Alliances to transform local cancer services and enable the Recovery Package and stratified follow-up pathways to be implemented
 - Measuring quality of life to provide a clear imperative for healthcare providers to support people to live well after treatment, as well as a better understanding of how cost-effective new services and interventions are and where resources should be focused
- To deliver the best possible value for money and better standards of care, the Cancer Strategy must be funded in full and the investment must be made upfront rather than delayed or spread out. If the Government and NHS do not fully fund the Cancer Strategy now, we risk missing out on over £400 million of potential cost savings.
- Providing more funding for cancer services now will make the best use of limited resources while improving the lives of hundreds of thousands of people with cancer.

COUNTING THE COST OF CARE BEYOND TREATMENT

Cancer is a costly condition to diagnose and treat. When people think of the cost of cancer, expensive drugs, technology and tests are often the first thing that comes to mind. The cost of cancer drugs in particular is a major challenge for society and has been a hotly debated issue in recent years. But it's not just cancer drugs that are expensive.

New research from Macmillan Cancer Support has revealed the 'hidden' costs of cancer, exposing for the first time the true cost of cancer to the NHS.

The cost of cancer care goes far beyond treatment...

New research commissioned by Macmillan Cancer Support shows that care and support for people with cancer beyond their initial treatment will cost the NHS at least **£1.4 billion every year** by 2020 – a total cumulative increase of **over £600 million** over the next five yearsⁱⁱⁱ. This figure refers to the cost of monitoring, follow-up and consequences of treatment, and excludes care at the end of life.

It is higher than the cost of diagnosing the cancer in the first place (at least £400 million a year) and comparable to the cost of surgery, radiotherapy and other non-drug treatments (at least £1.5 billion a year).

Comparison of costs for consequences of treatment, monitoring and follow-up, diagnosis and non-drug treatmentⁱⁱⁱ



The research, carried out for Macmillan by Monitor Deloitte, also shows that **treating just the consequences of cancer treatment** – such as side-effects from drugs as well as long-term after-effects – will cost at least **£1 billion** by 2020^{iv}.

These are conservative estimates of the growth in costs, based on recent trends in spending combined with the expected increase in the number of people living with and surviving cancer over the next five years. The figures refer to a group of 13 types of cancer that account for around three-quarters of cases, so the full cost for all types of cancer will be even higher. In addition, this refers to NHS costs only. The cost of cancer to society as a whole also includes social care and welfare support as well as lost productivity and support from carers, among other costs.

2015
£0.3 billion

2020
£0.4 billion



Growth in cost for monitoring and follow-up from 2015-2020ⁱⁱⁱ
£0.3 billion – £0.4 billion

2015
£0.9 billion

2020
£1 billion



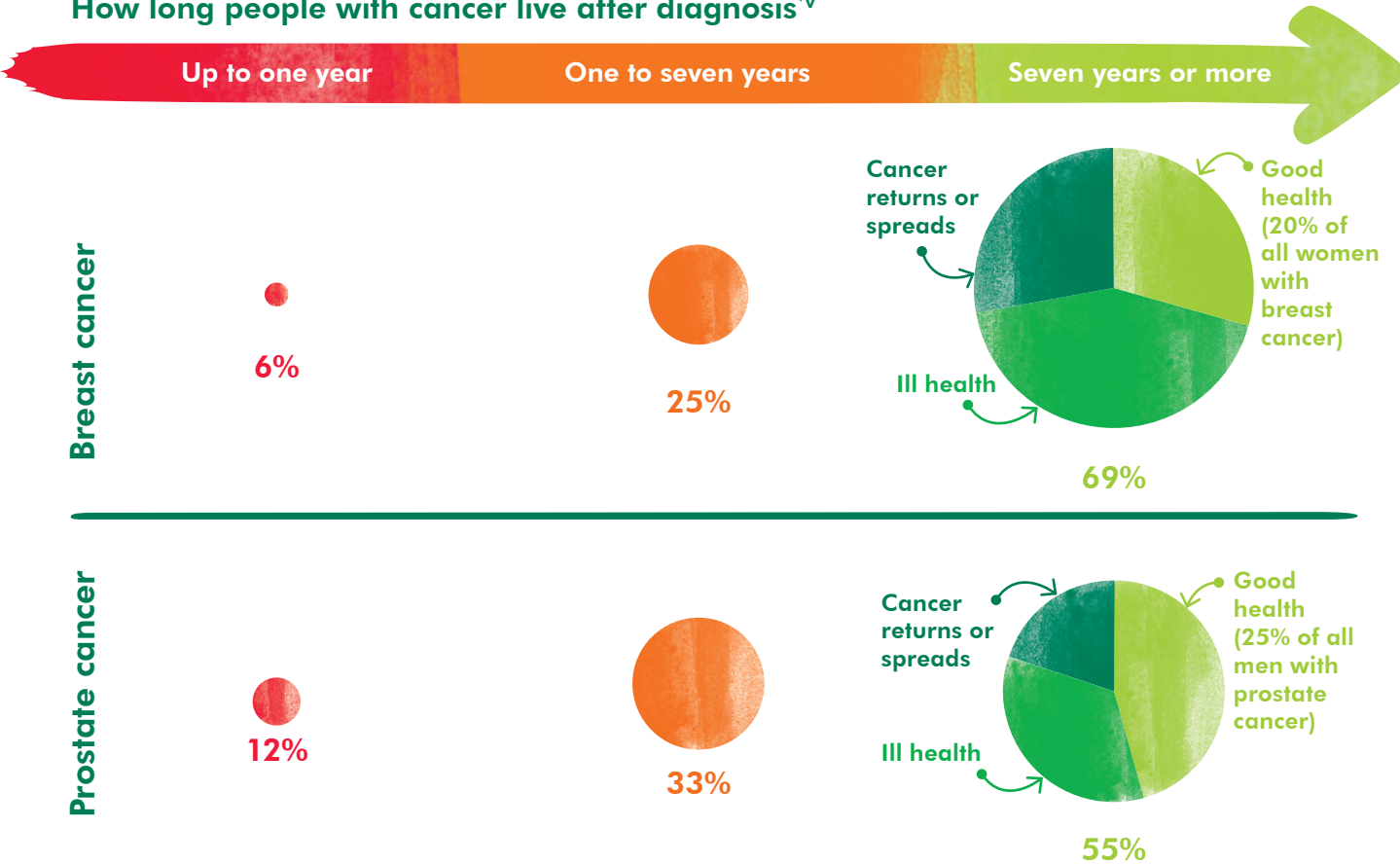
Growth in cost for managing consequences of treatment from 2015-2020ⁱⁱⁱ
£0.9 billion – £1 billion

...and the cost continues to grow for many years following diagnosis

While much of the cost of cancer treatment occurs within the first six months of diagnosis, the cost of care beyond treatment can accumulate for many years afterwards as many people need long-term care and support.

For example, previous findings from Macmillan’s *Routes from Diagnosis* research programme shows that only one in five (20%) women diagnosed with breast cancer, and one in four (25%) men diagnosed with prostate cancer, will survive both long-term and in relatively good health. In the years following diagnosis the remaining long-term survivors will experience a range of other serious health conditions, have their cancer spread or come back, or get another type of cancer^v.

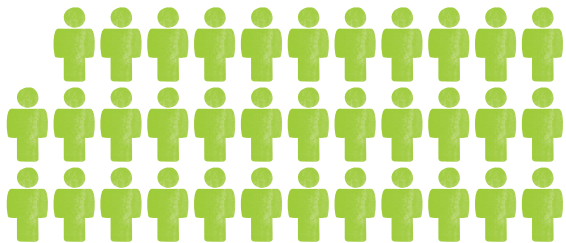
How long people with cancer live after diagnosis^{tv}



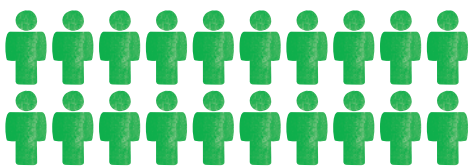
* Proportions may not add up to 100% due to rounding.
Ill health = having at least one of a range of serious health conditions

The other serious health conditions that drive up the cost of care for people with cancer are generally either linked to their cancer and its treatment, or co-exist alongside the cancer.

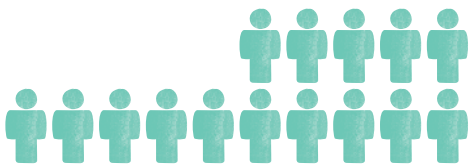
In our *Cured – but at what cost?* report^{vi}, Macmillan highlighted some of the specific long-term health issues people living with cancer experience as a **result of the cancer and its treatment**. These include:



Around **350,000** people in England living with severe fatigue



Around **200,000** people living with moderate to severe pain after treatment to cure their cancer



Around **150,000** affected by urinary problems such as incontinence



Around **90,000** experiencing gastrointestinal problems, including faecal incontinence, diarrhoea and bleeding^{vii}

One figure = 10,000 people

'I was diagnosed with oesophageal cancer over two years ago. I had chemotherapy followed by surgery but have since suffered from several serious health problems as a result of my treatment, from depression to mobility issues and even my eating has been severely affected. It means that I am now registered disabled and have been forced to take early retirement on medical grounds. I need constant support and hospital visits, and I can't see that's going to change in the future.'

Paul, 50, from Kent

More than two in three (70%) people with cancer are also living with one or more other potentially **serious long-term health conditions** as well as cancer, such as high blood pressure, chronic heart disease or mental health problems. Almost half (47%) have two or more conditions as well as cancer, and more than one in four (29%) have three or more conditions as well as cancer – representing 600,000 people in England^{viii}.

The presence of other health conditions significantly drives up the cost of care beyond treatment. Take prostate cancer – the most common cancer diagnosed among men. Each year in England around 40,000 men are diagnosed with prostate cancer^{ix}. Looking at the cost of all inpatient care after six months post-diagnosis, in men who survive long-term without their cancer spreading, coming back or developing another cancer, the cost of care is at least **10 times as high** among those who have at least one other serious health condition compared with those who do not have another condition.

'I had a heart attack in the same year that I was diagnosed with metastatic melanoma. One month I was having stents put into my heart and the next I was having a biopsy taken from my heel. And just to keep things interesting, I've had a couple of minor strokes and a pacemaker fitted because of ongoing heart problems. I'm on regular check-ups and CT scans, which keeps me and the NHS busy.'

Ron, 83, from Kent

4,400 will have two or more other serious health conditions.
Their care beyond treatment will cost at least **£30.6 million**



10,200 will have no other serious health conditions.
Their care beyond treatment will cost at least **£3.4 million**

3,200 will have one other serious health condition.
Their care beyond treatment will cost at least **£8.9 million**



The other factor that drives up the cost of care beyond treatment is the number of people living with **incurable but treatable cancer**. By this we mean a type of cancer that has spread around the body, as in most cases this is incurable, or a type of cancer that is highly likely to keep coming back after treatment^{xi}. For example, myeloma is a type of blood cancer that can be controlled for many years but that cannot be completely cured. On average it costs more to treat per patient than any of the top 10 most common cancers, but only 17% of this cost is accounted for by drugs. Among other costs, 37% is spent on non-drug treatments and 35% on treating the consequences of treatment and monitoring^{xiii}.

As these figures show, the cost of supporting people who are living with and beyond cancer and its treatment is a significant challenge. To improve cancer care and mitigate rising costs, the Government and NHS must place an equal priority on care during and after treatment, as well as early diagnosis.

Early diagnosis won't solve the problem alone...

Unfortunately, there's no simple answer to managing the cost of cancer. Diagnosing cancer earlier should reduce the cost of treatment and care to some extent – as well as improve people's chances of survival and their long-term health – but many people still need expensive long-term care and support **even when their cancer is picked up early**.

Further findings from Macmillan's *Routes from Diagnosis* research, published earlier this year, showed that **fewer than one in three people** (31%) **diagnosed early** with a common cancer (breast, prostate or lung cancer) will survive **both long-term and in good health**^{xiv}. This is despite their early diagnosis and the cancer not spreading, and the figures represent tens of thousands of patients every year.



diagnosed early with breast, prostate or lung cancer will survive both long-term and in good health^{xiv}.

Take breast cancer – the most common cancer diagnosed among women. Each year in England around 45,000 women are diagnosed with breast cancer and nine in 10 cases (90%) are caught before the cancer has spread around the body^{xv}. Almost all of these women (an estimated 99%) will survive at least a year from diagnosis, and most for at least five years or more^{xvi}.

Yet despite these relatively high survival rates, Macmillan’s research shows that all inpatient care after initial cancer treatment for the 40,000 women diagnosed with early-stage breast cancer each year^{xvii} will cost at the very least **£250 million** during their lifetimes – almost **£100 million more than the cost of inpatient care during their diagnosis and initial treatment**^{xviii}.

This is just the cost of inpatient hospital care for up to seven years of follow-up after treatment^{xix}. The full cost of their total care and support needs will be much higher.

The cost of inpatient hospital care for women diagnosed with early-stage breast cancer during diagnosis and the first six months following diagnosis is ...



The cost of care after six months post-diagnosis is around



For the **40,000 women** newly diagnosed with early-stage breast cancer each year, this cost equates to:

around **£155 million** for the first six months following diagnosis

around **£250 million** after six months post-diagnosis

‘My youngest child was just a year old when I was told I had breast cancer. I was diagnosed early, but it’s years later with all the after-effects that have been unexpectedly tough. I thought I’d have treatment and that was the end of it, but I’ve suffered depression, severe joint pain and all the symptoms of the menopause. I just want to feel normal again.’

Brenda, 42, from Oxfordshire

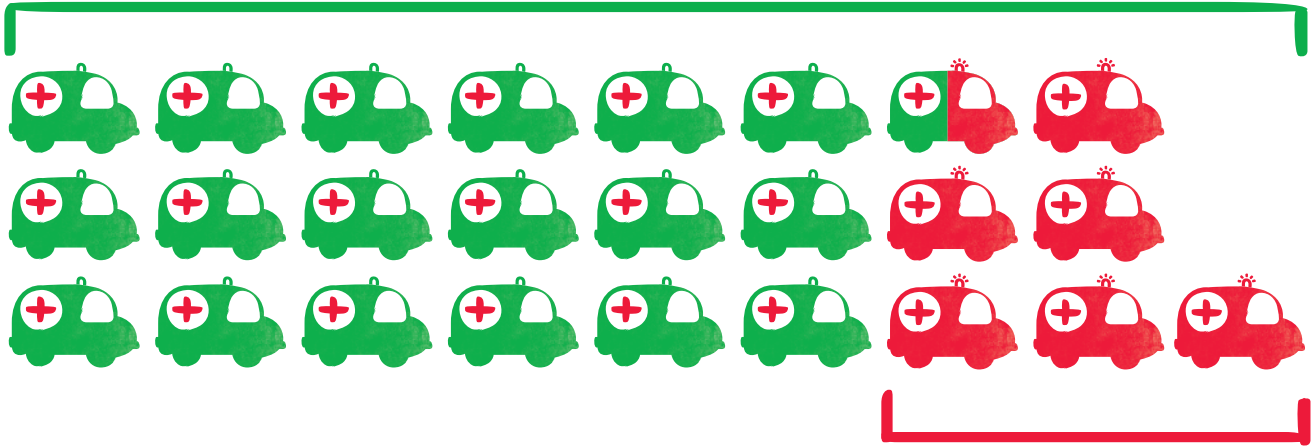
... and money is spent on the wrong things

Emerging findings from another research study, funded by Macmillan and led by researchers from City University, shows that the NHS is spending more than £500 million a year on **emergency inpatient care** just for people diagnosed with one of the top four cancers within the past five years^{xx}.

Of this, more than £130 million is spent on emergency inpatient care for people who will mostly have finished their


initial treatment^{xxi} but are not in the last year of life. These are people who should be receiving appropriate long-term support to help prevent the need for emergency care. Both emergency and inpatient care are already at breaking point in England^{xxii}, and A&E departments in particular are one of the most vulnerable points in the NHS. The NHS cannot afford this added pressure on emergency care and patients should not be forced to seek it unless it is the most appropriate course of action.

The NHS is spending more than **£500 million a year** on emergency inpatient care for the top four cancers^{xx}.



More than £130 million is spent on emergency inpatient care for people who will mostly have finished their initial treatment^{xxi} but are not in the last year of life.

 = £20 million spent on emergency inpatient care

 = £20 million spent on emergency inpatient care for people who have mostly finished treatment but are not in the last year of their life

As shown by the low proportions of people who survive cancer in good health, the resources the NHS allocates to long-term care and support are not sufficient to help most people with cancer to recover well and have a good quality of life. For example, routine follow-up care for people with cancer costs around £250 million per year. This is usually delivered via a ‘one-size-fits-all’ medical model based around repeat outpatient consultations^{xxiii}. However, the focus of these appointments tends to be checking for signs of the cancer spreading or coming back, despite there being a lack of evidence to support the effectiveness of this approach.

Furthermore, the conversations patients are having with their care team during routine follow-up appointments are failing to fully meet their needs. Four in 10 patients (43%) going through follow-up care want more information and advice and one in three (31%) need help with one or more physical concerns such as fatigue, problems sleeping or problems with their bladder or bowel functioning^{xxiv}.

‘Following radiotherapy I wasn’t told that my skin was so thin it was prone to infection and that in fact I had cellulitis. After my treatment, I was given a leaflet and a number to call but I could never get through. I couldn’t even get hold of my GP for two days so I was admitted to A&E with a giant abscess. If I’d had better support after my treatment, five very expensive days in hospital could have been avoided.’

Deborah, 46, from Buckinghamshire, diagnosed with triple negative breast cancer

The scale of the challenge is only going to grow

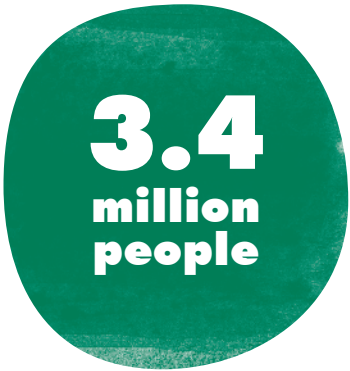
The number of people living with cancer is increasing year-on-year, mostly driven by our growing and ageing population and improvements in treatment and support leading to better survival rates. And as life expectancy increases, people with cancer are more and more likely to also have other serious long-term health conditions as well as cancer, adding to the level of care and support they need.

- There are currently 2 million people living with cancer in England and this will rise to at least 2.4 million by 2020^{xxv}
- There are now 1,000 new cases of cancer each day in the UK^{xxvi} and between now and 2020 there will be more than 1 million new diagnoses of cancer in England^{xxvii}
- By 2030 there will be almost 1 million more people with both cancer and another long-term health condition in England^{xxix}



2015

There are currently 2 million people living with cancer in England and this will rise to 3.4 million by 2030^{xxv}



2030

Action must be taken now

The NHS is under more pressure than ever before. The number of patients being treated for cancer is at a record high and both staff and budgets are under immense strain across all areas. In both cancer and the wider NHS the cracks are clearly starting to show.

In 2013-14 there were **1.3 million hospital admissions** for cancer



More than **120,000** of these were **emergency admissions**^{xxx}

The NHS is struggling to cope with the level of need for cancer care.

A key cancer waiting time target - for 85% of patients to start treatment within 62 days of an urgent referral from their GP for suspected cancer - has now been breached in England

for at least 17 months in a row^{xxxi}



In September 2015



One in three of these did so by more than 10%

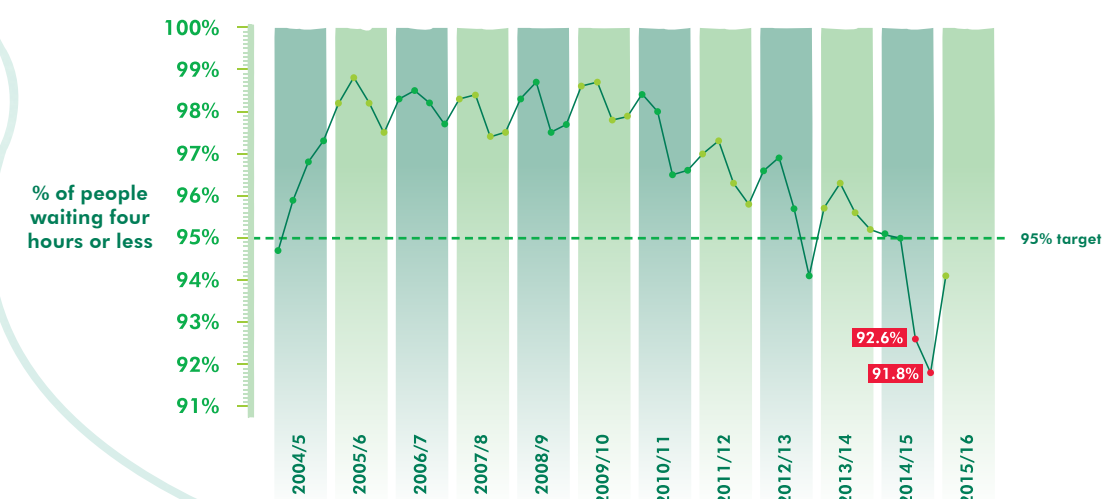
Almost

2000

people have been waiting for potentially life-saving treatment for more than two months in just September alone^{xxxi}

Performance against other NHS targets is also deteriorating.

A&E waiting times reached their worst levels in a decade, in the winter of 2014/15



Under these relentless pressures, the NHS is starting to lose control of its finances.

NHS trusts in England developed a **£1.6 billion deficit**

in the first six months of the 2015/16 financial year – more than the entire budget deficit for the previous financial year^{xxxiii}



‘Being a health professional is tough at the moment. Everyone is struggling to do their best. Understanding the ‘invisible’ costs of care beyond treatment will make it clearer for the Government and NHS how to make changes that really help staff to support people with cancer.’

**Professor Jane Maher, Joint Chief Medical Officer,
Macmillan Cancer Support**

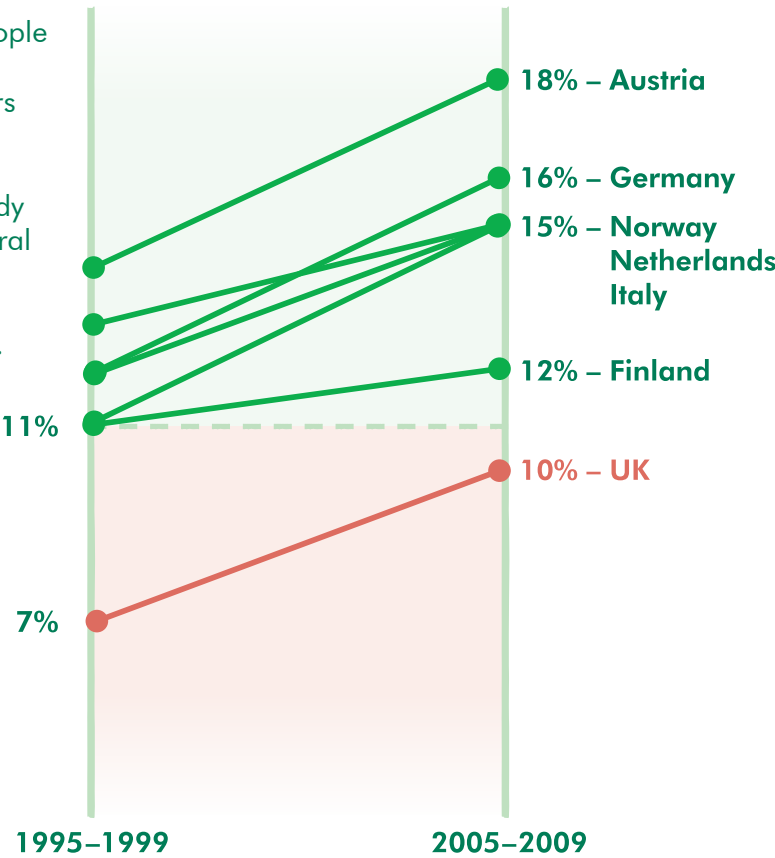
England, and the UK as a whole, is already lagging behind when it comes to cancer. Cancer survival rates in the UK are at or behind a level that many other European countries had already achieved 10 years previously^{xxxiv}.

The Government and NHS simply can’t delay in taking action on cancer funding. Failing to act will only lead to a further deterioration in care and put the long-term health, and in some cases the lives, of hundreds of thousands more patients at risk.

Stuck in the 90s – UK lung cancer survival

In the UK, 10% of people with lung cancer will survive at least 5 years after diagnosis.

That figure was already 11% or higher in several other countries in the late 1990s. In Austria it’s now up to 18%^{xxxiv}.



SO WHAT'S THE SOLUTION?

At Macmillan we believe there are two immediate steps the Government and the NHS must take to avert a crisis in cancer funding and to deliver better care for people living with and beyond the disease.

The strategy sets out a range of solutions that will help mitigate the increase in the cost of care beyond treatment and significantly improve the lives of people with cancer. These include:

First, to simply protect services at their current level the Government and NHS England must allocate enough budget to **fund the expected baseline growth in need** between now and 2020. This must include sufficient funds to meet the predicted growth in the cost of care beyond treatment to at least £1.4 billion a yearⁱⁱⁱ. However, this is only the bare minimum of what is required to maintain care at its current insufficient levels. As we have demonstrated, this level of care is not enough to support people with cancer, not now and certainly not in the future.

To improve the lives of people with cancer by delivering advances in cancer services, the NHS must go further. The second step is to commit to fully funding the recommendations set out in the **Independent Cancer Taskforce’s new Cancer Strategy, Achieving world-class cancer outcomes: A strategy for England 2015-2020**.

Macmillan helped to shape the development of the strategy and through our role on the Independent Cancer Taskforce we ensured the strategy supports the entire cancer care pathway, from diagnosis through to living with and beyond cancer and end of life care.

The cancer Recovery Package

The Recovery Package is a combination of different interventions that, when delivered together, can greatly improve the outcomes and coordination of care, including better and earlier identification of consequences of treatment and better management of co-morbidities. The interventions include:

- A holistic needs assessment and a written individualised care and support plan at key points across the pathway
- A cancer care review to discuss ongoing needs, completed by the patient’s GP or practice nurse
- A treatment summary completed at the end of every phase of acute treatment, sent to the patient and their GP
- Access to a patient education and support event, such as a Health and Wellbeing Clinic, to prepare the person for the transition to supported self-management, including advice on a healthy lifestyle and physical activity

Delivering on the Secretary of State's commitment to ensure that every person with cancer in England has access to the cancer Recovery Package by 2020 will better support people beyond treatment, including helping people access services that reduce emergency admissions and help people get back to work. We have also commissioned a cost-consequence analysis of the Recovery Package to show its impact on the cost of cancer care in more detail; results will be available in 2016.

Supporting people to achieve a healthy lifestyle and be physically active at a level that is right for them will help to manage the consequences of treatment, prevent and manage co-morbidities, reduce the risk of some cancers spreading or coming back, and can help people return to work and live independently^{xxxv}.

Helping people living with cancer to return to work if they choose to do so has benefits for both the individual and the wider economy. UK think-tank the International Longevity Centre (ILC) estimates that in 2010 the annual contribution of people living with cancer to the UK economy was £6.9 billion. And, while not everyone who has had cancer will want to or be able to return to work, the ILC estimates that if employment rates for people living with cancer were the same as for the rest of the population, this would contribute an additional £4 billion to the UK economy each year^{xxxix}.

Stratified care pathways

Providing a wider range of options for follow-up care (stratified pathways), including supporting more patients to self-manage their care, will lead to substantial cost savings for the NHS.

The concept of stratified care pathways for cancer involves three types of follow-up care:

- Supported self-management – people suitable for this type of follow-up are given advice and support about self-managing their care combined with rapid access to tests and healthcare professionals if needed
- Shared care – people with cancer who have shared care follow-up, will continue to have regular contact with professionals as part of their follow-up, although not necessarily face to face, combined with a degree of supported self-management
- Complex case management – people with cancer who need this type of follow-up care are given intensive support to manage their cancer and any other conditions

A programme set up in Northern Ireland with the support of Macmillan has successfully demonstrated the potential of stratified care pathways to remove the need for thousands of outpatient appointments (see Case study box). The NHS estimates that implementing stratified care pathways for patients with breast, prostate and colorectal cancer across England as a whole will save £86 million a year of the total current cost of follow-up care of £250 million^{xxiii}.

Cancer Alliances

In order to implement the Recovery Package and stratified care pathways we must rebuild the necessary resources and expertise at a local level. The Cancer Strategy calls for the creation of Cancer Alliances – local organisations that bring together those who use, provide and commission services to support effective delivery of care.

Quality of life metric

Measuring quality of life will enable patients and healthcare professionals to better understand the impact that different treatment pathways will have on long-term quality of life. The result will be more efficient and effective use of cancer treatment, and patients who are better prepared to identify and manage consequences of treatment. It should serve as a strong incentive to put in place the services needed to enable people to live healthy, productive lives after treatment, such as improved rehabilitation, psychological support, return to work, support to self-manage and more. In the future, it may also help provide a better understanding of how cost-effective new services and interventions are and where resources should be focused.

Overall the full range of recommendations set out in the Strategy will cost an estimated £400 million each year between 2015 and 2020.

Following the 2015 General Election and the publication of the Cancer Strategy in July 2015, the Department of Health has committed to implementing a national quality of life metric and improving access to the cancer Recovery Package. Now we must see this commitment backed up by the necessary funding as well as a commitment to the delivery of the remaining recommendations of the Cancer Strategy as a whole.

The Cancer Strategy is the essential first step towards delivering desperately needed improvements in cancer care. However, it must be followed by a genuinely long-term, fully sustainable approach to meeting the needs of people with cancer in the future.

Case study: Delivering better care without increasing costs

In January 2012, the Transforming Cancer Follow-up (TCFU) programme was launched across the five health and social care trusts in Northern Ireland. The programme aimed to improve aftercare for people with breast and prostate cancer with a more efficient use of resources, and was a collaboration between Macmillan and the Northern Ireland Health and Social Care Board (HSCB), the Public Health Agency (PHA) and the Northern Ireland Cancer Network (NICaN).

For breast cancer, some of the key features of the programme involve replacing routine follow-up appointments with more self-directed aftercare (SDA), implementing the cancer Recovery Package, giving patients access to a rapid access service if they have any concerns, and providing automatically pre-booked mammogram appointments.

As part of the evaluation of the programme, a cross-section of breast cancer patients were surveyed at the start of the programme (115 patients) and two years later (146 patients). After two years there was a significant increase in the proportion of patients who felt supported in dealing with the physical and emotional impacts of cancer (59% and 44% rising to 75% and 67%)^{xxxvii}.

These improvements in patient care were achieved while reducing the total number of appointments by 2,700 across all trusts over the two-year period. TCFU is now part of the Northern Ireland Commissioning Plan and has been rolled out to different tumour groups (including prostate, colorectal and gynaecological cancers). The success of the programme has led to the appointment of Macmillan Service Improvement Leads in each of the Northern Ireland health and social care trusts.

Act now – or count the cost

Deciding to invest in times of financial pressure can seem like an impossible choice. When it comes to cancer funding, however, **choosing to do nothing will only increase costs.**

Investing in the Cancer Strategy now, followed by delivering the savings identified by its recommendations, will result in a £420 million lower cumulative spend by the NHS over the 2016/17 to 2020/21 financial years than failing to fund it at all^{xli}. It is also likely to have financial benefits for other parts of the health and social care system as well as other areas of Government spending.

Delaying funding the Cancer Strategy towards the end of this Parliament also carries a financial penalty – late implementation will actually cost around £100 million more than doing nothing^{xxxviii}.

This shows that investing in health services now will deliver the best possible value while improving the lives of millions of people with cancer.

If the Government and NHS do not fully fund the Cancer Strategy now, we risk missing out on over £400 million of potential cost savings – money that we've shown we desperately cannot afford to lose.

CONCLUSION

The nature of cancer has changed. As new tests, treatments and types of care are being developed, it is becoming an increasingly complex and expensive challenge for the NHS. Much of the debate around the cost of cancer has focused on the price of new drugs and access to new technologies to diagnose and treat the disease. But as this report shows, we must also count the cost of care beyond treatment.

Thanks to improvements in diagnosis, treatment and care, more and more people are living with and beyond cancer. But far too few people are living well. There is also an increasing number of people living with incurable but treatable cancer, who have a particularly complex set of needs.

For these reasons and more, we have to look beyond drugs, new technologies and early diagnosis when it comes to cancer funding. The Government and the NHS must invest in services that enable people to live well, manage their own care and stay out of hospital after treatment in order to reach and improve the lives of everyone living with cancer.

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- iii Macmillan Cancer Support/Monitor Deloitte. *The cost of English NHS cancer care*. Costs based on the sum of monitoring and consequences of treatment so exclude end of life care, diagnosis and anti-cancer treatment. The costs are based on 13 cancer types that comprise 77% of cancer prevalence in 2010. The approach primarily used population projections, incidence projections, staging and survival data and assumptions about recurrence rates to model cancer cohorts for up to 15 years post diagnosis and a bottom-up health economic model built upon a set of cancer-specific 'archetypal' clinical pathways. These pathways include the probability and cost of various activities. They were initially defined using NICE and NHS clinical guidelines and refined in conjunction with internal Deloitte and external clinical experts, this means they represent a semi-optimised set of pathways, rather than capturing the full variety of real-world clinical practice. The costs of activities are primarily based on NICE technology appraisals and the National Tariff. The costs do not include the costs associated with the treatment of non-cancer long-term conditions of cancer patients, except when cancer treatment produces acute exacerbation. Please note that these figures are not necessarily comparable to the other figures in this report, as they are drawn from several Macmillan-commissioned and publicly available studies, and as such represent the costs associated with slightly different underlying cancer populations.
- iv The term 'consequences of treatment' covers three classes of consequences of cancer treatment: 1) complications from the disease itself (for example, infection resulting from an obstruction caused by the tumour), 2) complications from therapeutic treatments (such as lymphoedema for breast cancer patients), and 3) standard surveillance procedures for known and potentially severe complications of treatment (for example, routine echocardiography to monitor heart function with certain cardiotoxic chemotherapy regimens). A 15-year post-diagnosis window was used to capture relevant consequences.
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The condition is then only included in the Routes from Diagnosis analysis if it is recorded in the patient's hospital record (specifically their inpatient Hospital Episode Statistics (HES) entry).

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- viii Macmillan Cancer Support. *The burden of cancer and other long-term conditions*. April 2015 www.macmillan.org.uk/Documents/Press/Cancerandotherlong-termconditions.pdf. Research commissioned by Macmillan Cancer Support from Monitor Deloitte.
- ix Office for National Statistics. Cancer Statistics Registrations, England (Series MB1), No. 44, 2013 www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-394268
- x Defined as six months from diagnosis to up to seven years afterwards. Costs include all inpatient hospital care provided during this period for any reason. Adjuvant endocrine, chemotherapy or biological therapy would go on for longer than six months, although these are non-inpatient treatments.
- xi Defined as seven years or more.
- xii Macmillan Cancer Support *Routes from Diagnosis* research programme, developed by Macmillan Cancer Support in partnership with Public Health England's National Cancer Intelligence Network (NCIN) and Monitor Deloitte. Unpublished data. Assumes all initial treatment is complete within six months of diagnosis.
- xiii As per reference iii. Average cost per patient with myeloma is £39,000, the highest cost of all 13 cancer types studied, which includes the top 10 most common cancers.
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- xv Defined as diagnosis at stage 1, 2 or 3. National Cancer Intelligence Network. 2014. Imputed stage survival workbook, 2012. www.ncin.org.uk/publications/survival_by_stage
- xvi Relative 5-year survival for breast cancer is 90% for women with stage 1 disease, 88% for stage 2 and 55% for stage 3. Ref: Cancer Research UK. Breast cancer survival statistics. www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/breast-cancer/survival#heading=Three (accessed October 2015). The rate for those diagnosed between stage 1 and 3 is estimated based on the average survival rate weighted by stage at diagnosis (National Cancer Intelligence Network. 2014. Imputed stage survival workbook, 2012. www.ncin.org.uk/publications/survival_by_stage).

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- xviii Macmillan Cancer Support Routes from Diagnosis research programme, developed by Macmillan Cancer Support in partnership with Public Health England's National Cancer Intelligence Network (NCIN) and Monitor Deloitte. Diagnosis and initial treatment is defined as all inpatient hospital care for any reason 13 weeks pre-diagnoses to six months post diagnosis. Care after their initial cancer treatment ends includes all inpatient hospital care for any reason between six months post diagnosis to death or up to seven years afterwards. Costs include all inpatient hospital provided during this period for any reason. Adjuvant endocrine, chemotherapy or biological therapy would go on for longer than six months, although these are non-inpatient treatments.
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- xxi Refers to emergency care after the first six months post-diagnosis, when we assume most patients have completed their initial treatment.
- xxii The target of 95% of patients being admitted, discharged or transferred within four hours of being admitted to A&E has been in breach since September 2014, apart from July 2015 when it hit 95% exactly. Source: NHS England. A&E Attendances and Emergency Admissions 2015-16. (Monthly) www.england.nhs.uk/statistics/statistical-work-areas/ae-waiting-times-and-activity/statistical-work-areas/ae-waiting-times-and-activity/ae-attendances-and-emergency-admissions-2015-16-monthly-3/ (accessed November 2015). As of June 2015, one of the three overall NHS treatment waiting time targets (90% of admitted patients to begin treatment within 18 weeks of referral) had been breached for 12 of the previous 13 months. This target, along with one of the other three targets, was subsequently scrapped in June 2015. NHS England. Consultant-led Referral to Treatment Waiting Times Data 2015-16. www.england.nhs.uk/statistics/statistical-work-areas/rft-waiting-times/rft-data-2015-16/#Jun15 (accessed November 2015).
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xxxviii This figure is a Macmillan estimate and considers the cumulative time period 2016/17 – 2020/21. Baseline (if we do nothing) growth in cancer spend is based on the estimates from the National Audit Office that cancer services cost the NHS approximately £6.7billion per annum in 2012/13 (National Audit Office (January 2015). Progress in improving cancer services and outcomes in England) and projections in the Five Year Forward View that indicate that expenditure on cancer services will need to grow by about 9% a year, reaching £13 billion by 2020/21. This is based on a Technical Annex published in December 2013, which included assumptions indicating that budget lines related to cancer are likely to grow by around 9% per annum over the next five years, in the absence of any efficiency savings. Described further in the 2015 Cancer Strategy: Independent Cancer Taskforce (2015), Achieving world-class cancer outcomes: A strategy for England, 2015-2020. The additional cost of the Cancer Strategy per year is taken from the midpoint of the Cancer Strategy estimates using the timetable laid out in the strategy but delayed for example, the 2016/16 cost occurs in 2018/19 instead. According to the Cancer Strategy the above savings amount to between £380m and £575m p.a. which would start to accrue from 2018 onwards. Our modelling is based on £380m saving in 2020/21 following the late implementation.

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xli This figure is a Macmillan estimate and considers the the cumulative time period 2016/17 – 2020/21. If it is never funded the cancer spend is based on the estimates from the National Audit Office that cancer services cost the NHS approximately £6.7billion per annum in 2012/13 (National Audit Office (January 2015). Progress in improving cancer services and outcomes in England) and projections in the Five Year Forward View that indicate that expenditure on cancer services will need to grow by about 9% a year, reaching £13 billion by 2020/21. This is based on a Technical Annex published in December 2013, which included assumptions indicating that budget lines related to cancer are likely to grow by around 9% per annum over the next five years, in the absence of any efficiency savings. Described further in the 2015 Cancer Strategy: Independent Cancer Taskforce (2015), Achieving world-class cancer outcomes: A strategy for England, 2015-2020. The costs of the Cancer Strategy per year is taken from the midpoint of the Cancer Strategy estimates. According to the Cancer Strategy the savings amount to between £380m and £575m p.a. which would start to accrue from 2018 onwards. Our modelling is based on the midpoint of these estimates 2018/19 to 2020/21.



Cancer is the toughest fight most of us will ever face. But you don't have to go through it alone. The Macmillan team is with you every step of the way.

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