Good enough?
Breast cancer in the UK
At Breast Cancer Now our vision is that, by 2050, everyone who develops breast cancer will live and live well.

In order to make our vision a reality we fund research into four key areas: prevention, diagnosis, treatment and secondary or metastatic breast cancer. We currently support 450 researchers and are funding 90 research grants worth almost £24 million at 29 institutions across the UK and Ireland.

We also work hard to ensure that the results of research reach breast cancer patients and health care professionals.

This year marks the 25th anniversary of the Pink Ribbon, which unlocked public support for tackling breast cancer and has been critical in funding research and improving outcomes. As a result, more women than ever are surviving breast cancer, and this should be celebrated. But we are increasingly concerned that progress is now stalling. We are failing to tackle the growing number of people being diagnosed with breast cancer. Uptake of breast screening is slowly declining, and waiting times for referral and treatment vary widely. People living with breast cancer - particularly those with secondary breast cancer - are not all receiving important aspects of treatment and care.

There are solutions to these challenges, yet a lack of leadership across the UK means that opportunities to save and improve lives are being missed.

Improvements in breast cancer outcomes have acted as a beacon of hope for other cancers. So this news may worry others who consider the diagnosis, treatment and care of breast cancer to be the gold standard.

To mark Breast Cancer Awareness Month 2017, we have reviewed evidence across the patient pathway to understand the current state of play, and made recommendations to ensure that opportunities are not lost and we keep up the pace of progress.

We need to make the most of the ambition and opportunity that exists, and take action now. We are ready to work with Governments and the NHS across the UK to help implement our recommendations and ultimately save more lives.

Baroness Delyth Morgan
Breast Cancer Now
As a result of advances in diagnosis and treatment, more women are surviving breast cancer than ever before. Around 95% of women diagnosed with breast cancer in the UK survive one year, and more than 80% survive five years or more.

But whilst there is much to celebrate, there is still much more to do. Over 50,000 women and around 350 men are diagnosed with breast cancer each year in the UK. There are now 700,000 women living with and beyond breast cancer. Around 11,500 women and 80 men still die of breast cancer each year. And inequalities remain depending on where people live, their age, socioeconomic status and ethnic background.

Cancer strategies and delivery plans, which aim to ensure that the results of research are translated into improvements in outcomes and patient experience, are now in place in England, Scotland and Wales. These government strategies and plans are ambitious, and have the potential to be transformational. A similar strategy needs to be developed for Northern Ireland.

However, these ambitions exist in health and care systems under unprecedented financial and operational pressures. There is growing demand on, and expectations of, the system. But the resources to respond to this – both financial and human – have not kept pace. Furthermore, the huge uncertainty created by Brexit compounds challenges around the workforce, access to innovative new medicines and clinical trials.

We believe this has led to progress for breast cancer stalling. This report uses available data from across the UK to look at where we are with the prevention, diagnosis and treatment of the disease. It highlights the opportunities that are being missed to save more lives from breast cancer, and improve the lives of those living with it. These include tackling the lifestyle factors that can affect the risk of developing breast cancer, and ensuring that all patients – in particular those with secondary breast cancer – have access to the best breast cancer medicines and other aspects of treatment and care that we know they value, such as a clinical nurse specialist.

The report makes recommendations that will highlight the leadership we need to make further improvements in each of the UK nations and keep up the pace of progress – including identifying what we believe to be the most pressing issue for action over the next year at each point in the patient pathway.

We look forward to working with Governments and the NHS across the UK to implement these recommendations.

Introduction
The changing picture for people with breast cancer

More women in the UK are surviving breast cancer than ever before. Although fewer people are being diagnosed, this combination means that more people are living with and beyond breast cancer.

Improving survival rates

Around 95% of women diagnosed with breast cancer now survive one year, and more than 80% survive five years or more. Breast cancer survival rates are better than for any other common cancers - of the other common cancers - bowel, lung and prostate - only prostate cancer currently has better survival rates. However, while survival rates in the UK are improving at both one and five years, we are still behind other developed countries such as Sweden, Denmark, Norway, Canada and Australia.

Breast cancer is closely linked to gender and age, factors which are beyond people’s control. The disease mainly affects women, with over 50,000 women diagnosed each year in the UK. But it can affect men too, with over 350 men diagnosed each year. As people get older their risk of developing breast cancer increases. Four out of five breast cancer cases in the UK are in women over 50, and so the fact that the UK population is ageing means it is likely that more people will be affected by breast cancer.

Increasing prevalence

The combination of improved survival rates and the increasing number of people being diagnosed means that more people than ever before are living with and beyond breast cancer. It is estimated that in 2015, there were nearly 700,000 women living with or beyond breast cancer in the UK. This is higher than for any of the other common cancers. This is predicted to rise to 1.6 million women by 2040. Whilst the fact that more women are surviving and living with breast cancer is good news, we need to ensure that the needs of women with and beyond breast cancer are being given greater priority especially as their numbers increase.

Secondary breast cancer

The number of people dying from breast cancer in the UK has fallen. But around 11,500 women and 80 men still die from breast cancer each year. Almost all deaths are attributable to secondary breast cancer, also known as metastatic, advanced, or stage 4 breast cancer. This is where breast cancer cells have spread to other parts of the body, most commonly the bones, lungs, liver or brain. Secondary breast cancer is currently incurable, and has an estimated expectancy of two to three years. However, this can vary significantly depending on where the cancer has spread to, and response to treatment. Some people will be better able to manage their disease for many years with a diagnosis of incurable breast cancer.

As a result of poor data collection – and despite a requirement for this data to be collected by hospital trusts in England1 – there is still no accurate figure for how many people are currently living with secondary breast cancer, making it difficult to plan services. However, an estimate suggests there were 35,000 people living with secondary breast cancer in the UK in 2010. Our work in 2015 showed that women with secondary breast cancer often experience a poorer standard of care compared to women with primary breast cancer.

Inequalities

People’s outcomes and experience of breast cancer can be impacted by a number of factors, including where they live, their age, socioeconomic status and ethnicity. There are often complex relationships between such factors.

Some of the variations that exist between such factors may be the result of more geographical inequalities in breast cancer in England, more detailed which will report in early 2018.

A third of breast cancer cases in the UK occur in women over 70. Five year survival rates range from 95% for women aged 50-69 to 83% for those aged 70-79 and 74% for those aged 80-89. Approximately 20% of breast cancer cases in women over 80 are diagnosed through emergency presentation, compared with around 4%.
A number of factors may contribute to later diagnosis in this age group. Older women are less likely to be breast aware with one in five women over 70 reported never to touch, feel or look at their breasts for signs and symptoms of breast cancer. In addition, women over 70 are not routinely invited to breast screening. A recent audit in England and Wales highlighted a number of variations in the care received by women over 70 diagnosed with breast cancer compared with younger women, including that they are much less likely to have surgery as they age. There is evidence to suggest that treatment is given according to age rather than a patient’s fitness to receive it.

Breast cancer is less common in women living in deprived areas, but mortality rates for women living in the most deprived areas are approximately 6% higher than those living in the least deprived areas. This could be a result of the fact that women in deprived groups tend to be diagnosed with breast cancer at a later stage, suggesting late presentation to their GP with symptoms. Uptake of breast screening also tends to be lower among deprived groups.

Breast cancer is less common in Black and Asian women than White women, but again, their survival rates are lower. Black women in particular are more likely to be diagnosed with more advanced breast cancers and breast cancers that are more difficult to treat, such as triple negative breast cancer. Black and Asian women are also more likely to have breast cancer diagnosed at a younger age. The median age at diagnosis for Black women in 2006 was 50, compared to 62 for White women. As screening is not routinely offered until the age of 50, this means that a higher proportion are being diagnosed as a result of breast cancer symptoms.

There was a 17% increase in the number of people diagnosed with breast cancer between 2006 and 2015 in the UK.
The changing picture around the UK

Scotland
94.6% of women diagnosed between 2007 and 2011 survived one year, compared to 87.7% diagnosed between 1987 and 1991.
98.6% of women diagnosed between 2007 and 2011 survived five years, compared to 90.3% diagnosed between 1987 and 1991.
4,738 women were diagnosed in 2015, compared to 4,147 in 2006: an increase of 14.3%.
24 men were diagnosed in 2015, compared to 20 in 2006.

Wales
96.7% of women diagnosed between 2009 and 2013 survived one year, compared to 93.7% diagnosed between 2000 and 2004.
86.9% of women diagnosed between 2005 and 2009 survived five years, compared to 78.8% diagnosed between 1996 and 2000.
4,738 women were diagnosed in 2015, compared to 3,910 in 2006: an increase of 14.3%.
319 men were diagnosed in 2015, compared to 273 in 2006.

Northern Ireland
96% of women diagnosed between 2010 and 2014 survived one year, compared to 91.5% diagnosed between 1993 and 1999.
81.1% of women diagnosed between 2005-2009 survived five years, compared to 74.8% diagnosed between 1993 and 1999.
1,456 women were diagnosed in 2015, compared to 954 in 2006: an increase of 47%.
285 women died from breast cancer in 2015, compared to 300 in 2006: a decrease of 5%.

An estimated 31,900 women were living with or beyond breast cancer in 2013.

An estimated 16,300 women were living with or beyond breast cancer in 2013.

England
95.6% of women diagnosed between 2011 and 2015 survived one year, compared to 94.1% diagnosed between 2001 and 2006.
88% of women diagnosed between 2011 and 2015 survived five years, compared to 74.1% diagnosed between 2001 and 2006.
45,764 women were diagnosed in 2015, compared to 39,104 in 2006: an increase of 17%.
319 men were diagnosed in 2015, compared to 273 in 2006.

An estimated 454,000 women were living with or beyond breast cancer in 2013.

An estimated 52,300 women were living with or beyond breast cancer in 2013.

An estimated 31,900 women were living with or beyond breast cancer in 2013.

An estimated 16,300 women were living with or beyond breast cancer in 2013.
The changing environment for people with breast cancer

The changing environment in which we all operate impacts on our ability to save more lives from breast cancer. There are challenges and opportunities to both the ability to undertake impactful research and ensure the results reach impactful research and to improve cancer outcomes.

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The Government should seek close affiliation with EU research programmes, enabling the UK to participate in and shape future programmes such as Framework Programme 5, the successor to Horizon 2020.

The EU provides access to funding and opportunities that are vital for medical research in the UK. The Government has said it will guarantee bids for projects for Horizon 2020 – the biggest EU research and innovation programme – from funding for research and healthcare workforce, through to access to treatments and clinical trials.

The EU currently operates within strong regulatory frameworks across the EU which govern, amongst other things, clinical trials and access to medicines. Patients of the UK leaving the EU have yet to be published.

The Government should develop a simple immigration framework for those working in healthcare and research that is flexible enough to allow for changing research and healthcare priorities and the skills required.

Brexit

Brexit, the unprecedented financial pressures in health and care systems across the UK, and the availability of patient data for research. Equally there are opportunities presented by both government strategies for the life sciences sector, and to improve cancer outcomes.

The potential impact on patients of the UK leaving the EU cannot be underestimated – from funding for research, the research and healthcare workforce, through to access to treatments and clinical trials.

The Government has clarified the status of EU citizens living in the UK before the ‘cut off’ date, which has yet to be agreed but will be no earlier than 29 March 2017 and no later than the date the UK leaves the EU. However, details of leave to remain for EU citizens who arrive after the ‘cut off’ date, but before we leave the EU, are still being agreed, and proposals for the immigration system after we leave the EU have yet to be published.

The Government should ensure continued close operation between UK and EU organisations, including the European Medicines Agency, which licenses new medicines for use and oversees clinical trials, and make sure there is a smooth changeover to future arrangements.

Brexit: the unprecedented financial pressures in health and care systems across the UK, and the availability of patient data for research. Equally there are opportunities presented by both government strategies for the life sciences sector, and to improve cancer outcomes.

We want the Government to extend Research and Development tax credits to medical research charities, to increase the amount of research they are able to fund.

The CRSF helps fund the overheads of Universities, which undertake the majority of charity research, so charity funding can be spent on the research itself. It has been fixed at £198 million a year since 2010 – a real terms decrease.

To enhance the CRSF we want the Government to commit to a real terms increase to £264 million by 2020/21.

£80bn

Horizon 2020 80 billion euros of funding over 7 years across the EU

Horizon 2020

The changing environment for people with breast cancer

The changing environment for people with breast cancer
The Accelerated Access Review set out a range of recommendations to make it quicker and easier for patients to access innovative medicines, including evolving technologies. The Government should accept all the recommendations to make the medicines appraisal system to ensure that it is fit for the future in terms of assessing emerging technologies. The Government should set out a clear and comprehensive plan for implementing the national opt-out system in England.

The Government should stop deaths from breast cancer by 2020. The strategy is ambitious and committed to implementing. The strategy is a five year strategy ‘Achieving World Class Cancer Outcomes: A Strategy for England 2015-2020’, which the Government has committed to implementing. The strategy is ambitious and has the potential to transform cancer outcomes and patient experience. However, two years into the strategy, we are concerned about the pace of implementation, and the lack of transparency surrounding this. The two Cancer Alliances offer the opportunity to improve outcomes and experiences for breast cancer patients. However, as the release of funding for the Alliances from NHS England is conditional on all Trusts in an Alliance’s area meeting the target for the 62 day wait between urgent referral for cancer and beginning treatment, the lack of transparency around this could further exacerbate geographical inequalities in quality of care. If patients and the public are not willing to share their health information because they do not trust the system to keep it secure, future progress will be seriously hampered.

In Scotland, the Government launched its cancer strategy ‘Beating Cancer: Ambition and Action’ in 2016. The strategy, developed in consultation with a number of charities including Breast Cancer Now, sets out over 50 actions to improve cancer care over the next five to ten years. In the strategy the Scottish Government makes a clear commitment to help stop deaths from breast cancer.

| £1.6 billion | Amount spent by medical research charities on funding research in 2016 |

The changing environment for people with breast cancer

The changing environment for people with breast cancer

| 6.6% | Predicted public spend on health in the UK as a share of national income by 2020 |

The Institute for Fiscal Studies reports that real public spend on health in the UK has increased hugely over time. Although it has increased at a much slower pace since 2009/10, the health budget is one of only three budgets that has been protected from the large cuts experienced by other government departments. Spend as a share of national income also peaked in 2009/10 at 7.6% and fell back to 7.4% in 2015/16 and is predicted to fall further to 6.8% by 2020. Total (public and private) spend on health in the UK in 2015 as a share of national income was below many other EU countries including Germany, France, Denmark and Sweden.

But demand for healthcare is rising; the population is increasing, people are living longer – often with multiple long term conditions – and significant advances in science mean new treatments are available. This has led to well documented concerns about missed targets, rationing of some services and quality of care being reduced.}

Patient data

Data about patients' health and care is essential to enable researchers to help prevent, diagnose and treat disease, as well as improve services for patients. If patients and the public are not willing to share their health information because they do not trust the system to keep it secure, future progress will be seriously hampered. Last year the National Data Guardian for Health and Care in England published a review of data security, consent and opt-outs, which recommended a national system that enables patients to opt-out of sharing their health and social care data where it is not anonymised, for uses beyond informing their direct care. The UK Government has agreed to implement a national opt-out system in England.

Funding for health and care

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The Government should set out a clear and comprehensive plan for implementing the national opt-out for health and social care data which maximises the potential of this data by clearly explaining the benefits and risks of data sharing to patients. The strategy is ambitious and has the potential to transform cancer outcomes and patient experience. However, two years into the strategy, we are concerned about the pace of implementation, and the lack of transparency surrounding this. The two Cancer Alliances offer the opportunity to improve outcomes and experiences for breast cancer patients. However, as the release of funding for the Alliances from NHS England is conditional on all Trusts in an Alliance’s area meeting the target for the 62 day wait between urgent referral for cancer and beginning treatment, the lack of transparency around this could further exacerbate geographical inequalities in quality of care.
The changing environment for people with breast cancer by 2050. We welcome the Scottish Government’s commitment to breast cancer within the strategy. It is an ambitious plan and we are working with them to put it into action.

In Wales, the Government published a refresh of its Cancer Delivery Plan in 2016. While the refresh was welcome, we believe the plan could be much more ambitious. We are also concerned about accountability given the plan includes a number of unmeasurable actions which will make it difficult to evaluate progress.

We urge the Welsh Government to upgrade its ambition in relation to improving cancer outcomes and make sure targets in the delivery plan are measurable, and supported by adequate funding.

In Northern Ireland the last cancer strategy – the Regional Cancer Framework – was published in 2008. A recent research paper on cancer in Northern Ireland highlights disparities for patients in terms of access to treatments and services, workforce issues and missed waiting times targets.

Breast Cancer Now wants to see... By October 2018...

- We welcome the Scottish Government’s commitment to breast cancer within the strategy.
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Documents underpinning the strategy are not publicly available and a formal evaluation has never been published.

- An updated, integrated strategy for improving cancer outcomes in Northern Ireland should be developed and implemented, and supported by adequate funding.

- NHS England reporting on progress to date in implementing the cancer strategy and setting out plans and funding for its remaining work.

- Working with the Scottish Government to deliver progress against its strategy.

- The Welsh Government ensuring all targets in its plan are measurable, and reporting on progress to date against the plan.

- An updated, integrated strategy being developed in Northern Ireland.

By October 2018, solid evidence of progress made in implementing strategies and plans to improve cancer outcomes and experience. This includes:

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- NHS England reporting on progress to date in implementing the cancer strategy and setting out plans and funding for its remaining work.

- Working with the Scottish Government to deliver progress against its strategy.

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Breast Cancer

Preventing breast cancer

Preventing breast cancer, where possible, can save lives. A wide range of factors can affect the risk of developing breast cancer, including genes, lifestyle and environment.

Unfortunately, there is nothing that can be done to change the biggest risk factors: being a woman and getting older. However, we know from research that action can be taken on other factors to reduce the risk of breast cancer developing, including lifestyle choices, and where family history puts people at increased risk.

There are a number of factors linked to lifestyle that can increase the risk of developing breast cancer (Table 3). These include regularly drinking alcohol and being overweight or obese. Specifically, putting on weight as an adult can increase the risk of breast cancer after the menopause, as can being overweight or obese after the menopause. Factors that can decrease risk include being physically active.

Although the percentage of women drinking more than recommended by national guidelines for alcohol consumption has decreased, the highest percentage of women doing so were generally aged between 45-64, and were also in households with the highest incomes. These include regularly drinking alcohol and being overweight or obese.

As a result of research we believe that by 2025 we will be able to prevent up to 15% of breast cancer cases, and that 25% fewer people will develop secondary breast cancer. By 2050 we believe we will be able to prevent 30% of breast cancer cases.

Lifestyle choices

Lifestyle choices

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Both Governments and the NHS have recognised the importance of encouraging and supporting people to live healthier lifestyles to reduce their risk of developing a range of conditions, including cancer and heart disease. Strategies addressing some of these lifestyle factors - or certain aspects of them - already exist; and commitments to fill gaps, and update and improve existing strategies have also been made. However, in some nations this commitment has been undermined by cuts to public health funding. In 2015/16 £200 million was cut from public health funding in England, and the Spending Review in 2015 announced a further cut of nearly 4% a year, adding up to a spending reduction of at least £600 million a year in real terms by 2020/21, reducing the highest percentage of women doing so were generally aged between 45-64, and were also in households with the highest incomes.

The percentage of women who are overweight or obese has increased, with the highest percentage generally being over 45. The percentage of women meeting guidelines on active living has increased, with the highest percentage generally being over 45. The percentage of women with a healthy body mass index (BMI) is generally reducing.

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Prevention of breast cancer

Increase in obesity across the nations

% of women that are obese or overweight

<table>
<thead>
<tr>
<th>Country</th>
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<tr>
<td>England</td>
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<td>15%</td>
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<tr>
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<td>2015</td>
<td>14%</td>
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<td>Wales</td>
<td>2015</td>
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<tr>
<td>Northern</td>
<td>2016</td>
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Preventative measures

Preventative measures

Governments should consider the findings from the ActWELL research when complete and implement actions shown to support healthier lifestyles.

Family history

Family history

Medicines that can reduce the risk of developing breast cancer in women with a family history are known as chemoprevention (or cancer chemotherapeutic). These medicines should be offered to everyone that have a family history of breast cancer. There are services available to help people that have a family history of breast cancer.

Specialist family history clinics or regional genetics centres can assess whether people are at increased risk, and if they are, options are available to help reduce that risk, including surgery and medicines.

Preventive breast cancer

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Preventive breast cancer
Prevention of breast cancer

As a result of not being licensed for preventative use, healthcare professionals are often unaware of, or unwilling to take responsibility for prescribing, chemoprevention. Research has shown that despite guidelines being in place, only just over half of GPs in the UK were aware tamoxifen could be used to reduce the risk of breast cancer.47 The effect of this is that many women that could benefit from these medicines are unable to access them, and the opportunity to reduce their risk of breast cancer is being missed.

Reducing the risk of developing secondary breast cancer

The aim of treatment for primary breast cancer is to stop the disease before it spreads, reducing the risk of developing breast cancer in other parts of the body, known as secondary breast cancer. In addition to treatment for primary breast cancer – which can include surgery, chemotherapy and radiotherapy – research published in 2015 showed that a group of medicines called bisphosphonates could reduce the risk of developing secondary breast cancer in some cases. The research showed that when prescribed for post-menopausal women within 6 months of their diagnosis of primary breast cancer, bisphosphonates can reduce the risk of breast cancer spreading to the bone within 10 years by nearly a third (28%) and reduce the risk of death from breast cancer by nearly a fifth (18%). Prescribing bisphosphonates for these women could also lead to net savings to the NHS of £5 million each year across the UK.48 Bisphosphonates are licensed for use in treating osteoporosis, but not for preventing the spread of breast cancer and – like chemoprevention medicines – because they are off-patent, patient access is inconsistent. Whilst surveys across the UK suggest that the number of breast oncologists who have access to bisphosphonates to prevent secondary breast cancer has increased,50 there are still large gaps in their availability. In response to a Freedom of Information (FOI) request by Breast Cancer Now 20% of Clinical Commissioning Groups (CCGs) in England said they routinely funded bisphosphonates. A further 6% said they had agreed to fund them and were implementing the decision.

Governments and the NHS should take action to significantly improve patient access to off-patent medicines, including preventative medicines such as chemoprevention and bisphosphonates.

Prevention of breast cancer

Bisphosphonates could cut 10% of all UK breast cancer deaths, that’s an extra 1,180 women each year.
Preventing breast cancer around the UK

Scotland

The percentage of women drinking more than 14 units a week decreased from 25% in 2003 to 17% in 2015. In 2015, 20% of women aged 55-64 drank more than 14 units a week. 32% of women in households with the highest income drank more than 14 units a week, compared to 9% of those in households with the lowest. The Scottish Government’s Cancer Strategy includes a commitment to focus on the potential causal links between excessive drinking and the risk of cancer in the next phase of its Alcohol Framework. 56

Almost two thirds of women (62%) were overweight or obese in 2015: the same percentage as in 2003. 71% of women aged 45-54 and 69% aged 55-64 were overweight or obese in 2015. The Scottish Government is expected to consult on a new Obesity Strategy by the end of the year. 57

59% of women met physical activity guidelines in 2015. 49% in 1993-1994, 48% in 2015. 49% of women were overweight or obese in 2015. 59% of women met physical activity guidelines in 2012. The percentage of women meeting the guidelines peaked at 66% between those aged 35-44, and then decreased. 58

The NHS England Five Year Forward View highlighted the need to “get serious” about prevention. Find the Cancer Strategy for England recommended that national strategies to address obesity and alcohol consumption should be developed. 59

In response to an FOI request from Breast Cancer Now, only 42% out of 208 Clinical Commissioning Groups said they were routinely funding bisphosphonates for the prevention of secondary breast cancer. A further 13 said they had agreed to fund them and were working towards implementing the decision. 60

The Cancer Delivery Plan for Wales includes a key action for Public Health Wales to lead a comprehensive prevention programme to minimise population level risk of disease, including breast cancer. 61

Arrangements for the provision of bisphosphonates for the prevention of secondary breast cancer are in place in two of the three cancer centres in Wales (North Wales and South West Wales) for women at moderate to high risk of recurrence of breast cancer. 62

England

The whole system strategic framework for public health commits to developing and implementing strategies to reduce the number of people who are overweight or obese, and drink above recommended alcohol limits. 63

Northern Ireland

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The percentage of women drinking more than the recommended 14 units a week decreased from 15% in 2010/11 to 11% in 2015/16. 64

The percentage of women that are overweight or obese has increased from 38% in 2008 to 34% in 2015. In 2015, 33% of women aged 45-64 were overweight or obese in 2015. 65

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Wales

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By October 2018, Breast Cancer Now wants to see...

- action to improve access to chemoprevention and bisphosphonates to reduce the risk of developing breast cancer. This should include:
  1. The British National Formulary including chemoprevention and bisphosphonates in the Formulary as a matter of urgency, and routinely considering the inclusion of new uses for off-patent drugs not yet covered by NICE guidelines - such as bisphosphonates to raise healthcare professional awareness of these medicines and increase their confidence in prescribing them.
  2. Stakeholders including the British Generic Manufacturers Association developing proposals for incentives to encourage manufacturers in the UK to license off-patent drugs for new uses.
  3. Governments and the NHS across the UK ensuring that processes are in place, or are working well, to improve consistency of access for patients to off-patent medicines with robust evidence of clinical effectiveness for new uses. Breast Cancer Now is working with stakeholders in England to agree and test such processes. An interim commissioning process has been established in Wales, although so far, only one off-patent medicine has been through it.

Sarah, 54, is an opera singer living in Cardiff, Wales. Sarah has a family history of breast cancer and takes lifestyle measures to try to reduce her risk of developing breast cancer.

I lost my mum to breast cancer when she was 53. My maternal grandmother and paternal grandmother both had breast cancer. I’m aware that this places me at a higher risk of getting the disease. Due to my family history, I take a strong interest in how I can lower my risk of breast cancer and I’m particularly interested in any evidence about the difference that lifestyle factors such as physical activity can make. I’m seen annually at the hospital where I’m a patient in the Family History clinic and I have had an annual mammogram from the age of 35. Other interventions to reduce my risk, such as tamoxifen have been discussed. I’m a big fitness fan and I do as much exercise as I can to help prevent breast cancer. I believe that by running, cycling, practising yoga and weight training I’m doing what I can to reduce my risk. As well as being physically active I take care in what I eat and my alcohol consumption is minimal as drinking is known to be associated with breast cancer. Life is too short not to have the odd cake, bar of chocolate or the occasional glass of Prosecco but I believe everything in moderation!

I think it’s incredibly important to have a good routine of checking your own body and being vigilant to any changes. For me, personally being proactive goes a long way to dissuading me of this disease which took my mother far too soon.”
Early detection and diagnosis of breast cancer can save lives.

The earlier breast cancer is detected, the greater the chance that treatment will be successful. In order to ensure that breast cancer is diagnosed at the earliest possible time, it is important for women to be aware of and looking out for the signs and symptoms of breast cancer, that they attend screening, and that they are seen quickly by a specialist.

Breast awareness

Knowledge of the signs and symptoms of breast cancer is key to ensuring early diagnosis. Most cases of breast cancer are found by women reporting any unusual changes to their tissues. There is no right way to be breast aware and no set time for women to check their breasts. Breast Cancer Now advocates women getting to know what their breasts look and feel like at different times of the month and knowing what is normal for them.

National campaigns, such as Be Clear on Cancer in England and Detect Cancer Early in Scotland, have been successful in raising awareness raising among women. National campaigns in Wales, Scotland, and Northern Ireland, Hard to reach groups should be targeted by these campaigns.

Screening

All nations in the UK have well-established breast screening programmes, inviting women aged 50-70 for mammography screening every three years. Mammograms are the gold standard technology for breast screening as they can pick up changes in the breast before they can be seen or felt, meaning that treatment can start sooner and, for some women, be less invasive.

Women under 50 are not routinely invited for screening as there is not enough evidence to suggest that screening in younger women is beneficial. Women aged 70 and above are still entitled to attend breast screening but have to make their own appointments.

Screening uptake has been slowly but steadily declining over the past decade. Although attendance at screening is currently slightly above the target of 75% in all four nations of the UK, screening at population level is only effective at preventing deaths from breast cancer if people attend.

The screening programmes across the UK should do more to promote attendance at screening to enable the programmes to remain clinically and cost effective.

Governments and the NHS should continue awareness raising campaigns for breast cancer in England and Scotland. We would welcome similar campaigns in Wales and Northern Ireland, Hard to reach groups should be targeted by these campaigns.

Governments and the NHS should promote awareness raising campaigns for women aged 70 and above as they access mammography screening for the first time.

Governments and the NHS should continue evaluating the effectiveness of breast screening programmes across the UK, and identify which breast cancers are found at different stages.

Mammographic screening is the only form of breast screening that can prevent deaths from breast cancer. The breast screening programmes in England and Scotland are 15%. This is likely to have a significant impact on the ability of the screening programmes to meet current demand.

However, a 2012 review of the evidence concluded that mammography screening, if continued, would never cause harm. Breast Cancer Now researchers are investigating non-invasive cancers known as ductal carcinoma in situ (DCIS). There were around 7,000 new diagnoses of DCIS in 2014. If left untreated, over 50% of DCIS cases will become invasive, so being able to accurately identify these cases will mean it prevents around 1,300 deaths every year in the UK.

Breast Cancer Now therefore encourages women to attend breast screening appointments when invited.

In the future it is hoped that tests will be available to predict which cancers will or won’t grow and cause harm. Breast Cancer Now researchers are investigating new technologies or ways of detecting breast cancers that would never cause harm. Therefore, treatment is usually recommended for all women diagnosed with breast cancer.

It is believed that as some people will have unnecessary treatment, screening causes more harm than good by detecting some cancers before they become invasive. However, a 2012 review into the benefits of breast screening estimated that it prevents around 1,300 deaths every year in the UK.

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patients who need treatment receive it, and those at low risk can be spared unnecessary treatment.

As we learn more about breast cancer, particularly the genetic and lifestyle factors that contribute to its development, we hope to see risk-stratified screening introduced. This would provide every woman with a tailored estimate of her risk of developing breast cancer.

For others, it may mean less or no screening as it is unlikely to be beneficial. Tailored lifestyle and breast awareness advice would be provided to ensure that the individual’s risk remained low and that any breast cancer that did develop would be picked up as quickly as possible.

Screening programmes across the UK should commit to implementing risk-stratified screening when strong evidence is available.

Referral waiting times Currently, everyone in England who presents to their GP with a symptom of breast cancer, regardless of whether breast cancer is suspected or not, should be referred to see a specialist within two weeks. The target for the number of people seen within two weeks is 93%. Although the numbers of people being referred to specialists by their GP is increasing, the target has generally been met – it is not initially suspected. We know that waiting to hear the outcome of tests can cause distress and anxiety.

The Cancer Strategy committed to phasing out any breast cancer that did not initially suspects. It is impossible to know whether this expectation will be met. In Wales and Northern Ireland both have ‘ministerial expectations’ that over a two-week period, particularly for people who are referred with breast symptoms where cancer is not initially suspected. We know that waiting to hear the outcome of tests can cause distress and anxiety.

32% of breast radiologists in the UK are due to retire between 2015 and 2025.

A clear plan for how the target that all people will be seen by a specialist within two weeks of GP referral, and an evaluation of the pilot pathway for cancer diagnosis.

Diagnosis of secondary breast cancer

Research by Breast Cancer Care shows that awareness of the signs and symptoms of secondary breast cancer amongst women that have been diagnosed with it is lower than a quarter (22%) know what to look for. The fact that around a fifth (21%) of women with symptoms of secondary breast cancer that had a previous diagnosis of primary breast cancer were initially treated for another condition by their GP, and 8% were seen as an emergency or at A&E, suggest that awareness is also low amongst GPs. Only a fifth (20%) of patients contacted their breast care team with their concerns.

Amongst those women whose primary breast cancer had spread to other parts of their body before it was diagnosed, the majority were referred by their GP, some were picked up at screening, and 9% were seen as an emergency or at A&E.

More should be done to ensure that people are aware of the signs and symptoms of secondary breast cancer and are provided with information on this, and how to get back into hospital care, when completing their treatment for primary breast cancer. GPs still need to be supported to identify possible cases of secondary breast cancer and to refer people appropriately.

Fall in screening uptake across the nations % of women aged 50-70 that attended screening within 6 months of invitation

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Diagnosis of breast cancer
Diagnosis of breast cancer around the UK

Scotland

An evaluation of Detect Cancer Early shows that a higher proportion of breast cancers is being detected early, with stage 1 diagnoses increasing from 35% between 1 January 2011 and 31 December 2016, to 41% between 1 January 2015 and 31 December 2016. Stage 2 diagnoses have increased slightly from 34% in 2011 to 35% in 2016. Screening uptake was 71.3% in 2015/16. This compares with 72.1% in 2014/15 and 71.5% in 2013/14. 35% of breast radiologists are expected to retire in Scotland between 2015 and 2025. The Scottish Government has made a commitment to improve the situation, and Audit Scotland makes clear in its recent NHS workforce planning report that better long-term planning is needed to ensure that workforce pressures across the NHS are fully addressed.

Wales

Screening uptake has fallen over the past few years with 74.8% in 2014/15 falling to 71.9% in 2013-16. Cancer Early Screening uptake has fallen from 74.9% in 2006-9 to 71.3% in 2010 and 31 December 2016. 39% between 1 January 2015 and 31 December 2016. Stage 1 diagnoses increasing from 44% to 44.4% during the same period. 81 Stage 2 diagnoses have increased slightly from 34% in 2011 to 35% in 2016. In addition, the percentage of breast cancers where stage of diagnosis was unknown has decreased significantly from 14.9% in 2012 to 7% in 2015, suggesting that the NHS in Wales has improved processes for recording staging data.

Staging data by tumour type is not publicly available for Wales.

England

During the Be Clear on Cancer breast campaign there was a 5.4% increase in suspected breast cancer referrals in women over 70 compared to the same period the year before. There was also a 19% increase in referrals where breast cancer was not initially suspected. However, there was no corresponding increase in the number of breast cancers diagnosed in the target age group. Screening uptake has fallen from 74.9% in 2006-9 to 71.9% in 2013-16. In the same period the percentage of women referred where breast cancer was not initially suspected increased from 194,715 in 2011-12 to 209,791 in 2016-17.

In quarter 1 of 2017/18 there was a 14.9% increase in referrals where breast cancer was not initially suspected. In addition, the percentage of breast cancers where stage of diagnosis was unknown has decreased significantly from 14.9% in 2012 to 7% in 2015, suggesting that the NHS in England has improved processes for recording staging data. Approximately 6% of breast cancers in England are diagnosed through emergency presentation.

Northern Ireland

The percentage of breast cancers diagnosed at an early stage (stages 1 and 2) has increased significantly from 70.7% in 2012 to 79.1% in 2015. In addition, there was a 26% increase with suspected breast cancer was not initially suspected. In March 2017, 93.8% of patients were seen by a specialist within two weeks of an urgent referral for suspected breast cancer. This compares with 88.4% in March 2016. Performance on this target varies greatly – since January 2016, figures have fluctuated from 7.5% in June 2016 to 99.4% in October 2016, with most of the time spent between 97.04% in quarter 3 of 2016/17 and 98.91% in quarter 4 of 2016/17. In quarter 1 of 2017/18 63.2% of women referred where breast cancer was not initially suspected were seen within two weeks of being referred. This compares with 52.2% in quarter 4 of 2016-17 and 56.2% in quarter 3 of 2016-17.

There are currently no unfulfilled radiologist posts in Northern Ireland. A high proportion of breast cancers in Northern Ireland are diagnosed at early stages – in 2011-15, 41.9% were diagnosed at stage 1 and 3.2% were diagnosed at stage 2. 7.5% of breast cancers did not have staging data recorded.

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Our award-winning Touch Look Check breast awareness messaging reached 1.4 million people in 2015/16, helping women across the UK to be breast aware.

Our new breast awareness app, Breast Check Now, has been downloaded 17,500 times since its launch in October 2016. The app enables women to set reminder to check their breasts and record any changes they notice so they understand what is normal for them and what changes they need to get checked by a doctor.

Our public health information provides detailed advice about the signs and symptoms of breast cancer and we are currently working on increasing knowledge of signs and symptoms among GPs to ensure they are referring patients quickly and appropriately.

Our online guide to breast screening was viewed 13,987 times in 2016/17. We are working towards the introduction of risk stratified screening and are convening a panel of experts to advise us on this work. We will also be funding research into a risk prediction model and the acceptability of risk stratified screening.

One of our legacy charities successfully campaigned for the introduction of the two-week wait in England. We have actively campaigned to reduce waiting times in Wales.

Alongside access to the Breast Cancer Now Tissue Bank, we are funding our researchers to continue investigating DCIS, to help accurately identify cases that will become invasive and ensure patients that need treatment receive it, and those at low risk can be spared unnecessary treatment.

Having spent three years working for the National Breast Screening Programme, I made the difficult decision last December to resign from my job because of the pressures I was facing. My department was chronically understaffed and the workload was increasing. Often, the images we were taking were not as good as they could have been due to the time pressure, affecting the screening service in particular. Symptomatic patients would regularly have to wait for 3-4 hours only to be rushed through their results, causing them unnecessary anxiety at an already stressful time.

There is undoubtedly a staffing crisis in mammography. One barrier lies in the difficulty in getting into the mammography profession: you first have to train three years to become a radiographer, and then another year to become a mammographer. The cost of living has also increased over the past ten years, while radiographer and mammographer wages have stayed the same and workforce has increased hugely. There is only so much harder people can work for such little gain.

There are opportunities for career progression in mammography, but there are inconsistencies nationally in terms of training, responsibilities and wage, and the profession continues to struggle to recruit younger female radiographers. This has to change.

By October 2018, Breast Cancer Now wants to see...

...clear and sustainable workforce planning in each nation to address shortfalls in diagnostic capacity. This should include:

- Publication of Health Education England’s plans to address workforce shortfalls in England, with sufficient funding to underpin its implementation.
- Full public funding of a national breast imaging academy in England, and continued funding for its equivalent in Scotland.
- Publication of a long-term workforce plan that outlines in detail how the Scottish Government and Health Boards intend to address the issues with cancer diagnostic capacity in Scotland.

- Having spent three years working for the National Breast Screening Programme, I made the difficult decision last December to resign from my job because of the pressures I was facing.
- My department was chronically understaffed and the workload was increasing. Often, the images we were taking were not as good as they could have been due to the time pressure, affecting the screening service in particular. Symptomatic patients would regularly have to wait for 3-4 hours only to be rushed through their results, causing them unnecessary anxiety at an already stressful time.

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Treatment and care for breast cancer

The best treatment, delivered quickly, can save lives. It can also ensure that people with secondary breast cancer live as well as possible, for as long as possible.

There are a number of treatment options available for people with breast cancer, including surgery, chemotherapy and medicines. The treatment they receive will depend on the type of breast cancer they have, and their circumstances and preferences. But whatever treatment they receive, it should start quickly after diagnosis.

We could discuss many areas of treatment and care but have focused on those that feel most pressing, including access to clinical services, effective breast cancer medicines; and aspects of care we know patients particularly value — in particular access to a Clinical Nurse Specialist.

By 2030, we believe we will have identified what care different tumours need to grow and progress, enabling us to select the best treatment for every patient; and that 90 per cent of women with secondary breast cancer will survive five years.

Treatment waiting times

Once diagnosed, patients should agree their treatment plan with their consultant and start their treatment as soon as possible to increase the chances of its success.

There are two waiting times for cancer treatment in each nation of the UK: patients should start their first treatment within 62 days of being urgently referred by a GP to a specialist, and within 31 days of being diagnosed.

The targets for treatment waiting times are slightly shorter in Scotland.

For breast cancer, over the last year in England both targets have been met, although performance in other nations has been more variable.

Irrespective of whether targets are being met, there has been a decrease in the percentage of people with breast cancer being treated within these times in each nation over the last 6 years. However, this is more marked in relation to the 62 day target, and is largely considered to be the result of delays in diagnosis as a result of shortfalls in diagnostic capacity.

Clear and sustainable workforce planning to tackle shortfalls in diagnostic capacity — which we call for earlier in this report — should help to address this.

Governments and the NHS across the UK should monitor performance against waiting times for breast cancer treatment and take remedial action where targets are not being met.

The Scottish Government is considering what more can be done with cancer waiting times targets. We would welcome the Scottish Government introducing new national targets for subsequent treatments in Scotland.

Adherence to treatment and management of symptoms

Common side effects from hormone treatments and chemotherapy for the treatment of breast cancer can include symptoms of the menopause such as hot flushes and night sweats. These symptoms can often cause women to stop taking these treatments before they have completed the full course. Cognitive behavioural therapy (CBT) can help reduce the impact of these symptoms, but can only currently be provided by clinical psychologists and is not routinely offered to women with breast cancer.

Breast reconstruction surgery

We are aware that, in England, some CCGs have recently imposed restrictions, or have consulted on imposing restrictions, on either the number of operations that women can have to reconstruct their breasts following a mastectomy; or the time period in which they can have them; or both.

This is extremely worrying and we are working with the Association of Breast Surgery to investigate the extent of these restrictions, their likely impact on women, and provide guidance to CCGs on this issue.

Access to medicines

Research has led to the development of new medicines for breast cancer that can significantly increase the amount of good quality time that women with secondary breast cancer have before their disease progresses, and their overall survival. However, these have not been routinely reaching patients in the UK. This is not just of the lowest uptake in comparison with the largest European countries, helping to explain some of the gap in cancer outcomes between the UK and other developed countries.
The National Institute for Health and Care Excellence (NICE) makes decisions on which medicines will be routinely available on the NHS in England. In Wales, all medicines that have been recommended by NICE should be available within two months, and an £80 million Treatment Fund has been set up to provide additional support for this. In Northern Ireland the Department for Health, Social Services and Public Safety (DHSSPS) reviews NICE recommendations to decide whether they should be implemented there. However, implementing recommendations could take over a year. The Scottish Medicines Consortium makes decisions on which medicines will be available on the NHS in Scotland. Over the last decade a series of breast cancer medicines have been rejected by NICE for not being a cost-effective use of NHS resources. As a result of flexibility shown by NICE, and pharmaceutical companies being willing to compromise on price, some breast cancer medicines have recently been recommended. However, this flexibility and compromise can often delay decisions, causing unnecessary anxiety for patients.

In order to ensure the best breast cancer medicines reach patients quickly, the pharmaceutical industry must price medicines fairly and affordably for the NHS and taxpayer, and the flexibilities that we are starting to see being applied by NICE need to be incorporated in the system. Other changes to the way that medicines are appraised should include:

- Increasing the weight given to the additional quality time that medicines give patients before their disease progresses.
- Ensuring that new medicines are not disadvantaged by being compared to generically available, cheap medicines to determine their cost-effectiveness.
- Extending beyond two years the life expectancy within which a medicine can be considered an ‘end of life’ treatment and be approved at a higher cost.
- The implementation of the budget impact test by NICE and NHS England could lead to significant delays in new medicines reaching patients, and potentially shorter the lives of secondary breast cancer patients. The test could see medicines that have already been deemed cost effective by NICE, but which will cost the NHS more than £20 million in one or more of their first three years of use, have their introduction delayed for up to three years. This is unacceptable.

In Sue’s case, that precious time was 18 months. During that time we lived and loved as any normal couple. We enjoyed and cherished every moment that we had together. Unfortunately, my wife won’t be the last to suffer the agonising pain of realising that one day tomorrow might never come. I owe it to Sue, and to the women and their families who are being denied these life extending drugs across the UK to make sure that this issue is heard. Everyone needs to work together and sort this out.37

Simon Skinner from Bridge of Weir in Scotland lost his wife Sue, aged 55, in October 2014 after a battle with secondary breast cancer.

While living in Ireland, Sue received Perjeta as part of her cancer treatment.

40 It’s great that promises have been made to reform Scotland’s medicine system. Things need to change and they need to change quickly. We need to see action and results as soon as possible, so that women have the best chance of accessing drugs like Perjeta in the future.

There’s no cure for secondary breast cancer, but there are a growing number of drugs that can delay the spread with few side effects, buying patients time with their loved ones. In Sue’s case, that precious time was 18 months. During that time we lived and loved as any normal couple. We enjoyed and cherished every moment that we had together.
The UK has one of the lowest uptake rates of new cancer drugs compared to the largest European economies.

In England, the way that medicines are appraised and funded should be reformed to ensure that people with breast cancer can access the medicines they need, and that the patient voice is heard in these processes. The Life Sciences Strategy and associated sector deal, which sets out key recommendations for the Accelerated Access Review, and the upcoming re-negotiation of the Pharmaceutical Price Regulation Scheme (PPRS) by Government and the Association of the British Pharmaceutical Industry (ABPI) provide the perfect platform for this. Because Wales and Northern Ireland normally follow NICE guidance, reform in England should also ensure that the most clinically effective medicines are more quickly available in those nations too.

In Northern Ireland the process for implementing NICE guidance should be reviewed to allow recommendations to be implemented with greater speed. In Scotland, a review of access to new medicines was published in December 2016, setting out key recommendations for the Scottish Government to take forward the recommendations.

The Scottish Government now need to deliver the recommendations of the access to medicines review quickly and effectively.

Patient experience of care

The experience of cancer patients is measured regularly in each nation through a Cancer Patient Experience Survey (CPES) that provides valuable insight into patients’ views of their treatment and care and driving improvements in care. Breast cancer generally fares well when compared to other types of cancer; however, a recent report by NHS England is concerned that this will impact on the number and quality of responses to the CPES and is considering discontinuing it as a result. We believe that this would undermine efforts to improve patient experience and care.

In line with the Government’s commitment to take the time to get the national opt-out for health and social care data right, every effort should be made to explain to patients the benefits of agreeing to share their data in this way.

Secondary breast cancer and patient experience

The CPES does not differentiate between patients with primary and secondary cancers - although there are plans for it to do so in England if the survey continues. They therefore often limited insight into their differences in experience. This reflects poor collection of data on secondary breast cancer more widely - despite the fact that collection of data is now required in England.

Evidence from the Secondary Breast Cancer Pledge, run in collaboration by Breast Cancer Now and Breast Cancer Care in England, Wales and Northern Ireland, demonstrates that secondary breast cancer patients often report poor experiences of care. In particular secondary breast cancer patients struggle to access support for their emotional wellbeing and their families’ support and helping them manage their symptoms. Although the vast majority of breast cancer patients responding to the CPES report that they had access to a CNS, only 21% of organisations in England, Scotland and Wales report having one or more CNS dedicated to secondary breast cancer.

In some areas a great deal of work has been done to show the standards of care that should be delivered for women with secondary breast cancer, including access to a CNS with expertise in secondary breast cancer, and the discussion of these patients at Multidisciplinary Team Meetings.

Collection and analysis of data on secondary breast cancer should be urgently prioritised to enable the care experienced by those with secondary breast cancer to be understood, including access to clinical nurse specialists.

Access to a Clinical Nurse Specialist (CNS)

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Only 21% of organisations in England, Scotland and Wales report having one or more Clinical Nurse Specialist dedicated to secondary breast cancer.

We know that access to a Clinical Nurse Specialist (CNS) can make a big difference to the way people with cancer experience their care, providing patients with support and helping them manage their symptoms. Although the vast majority of breast cancer patients responding to the CPES report that they had access to a CNS, only 21% of organisations in England, Scotland and Wales report having one or more CNS dedicated to secondary breast cancer.

In some areas a great deal of work has been done to show the standards of care that should be delivered for women with secondary breast cancer, including access to a CNS with expertise in secondary breast cancer, and the discussion of these patients at Multidisciplinary Team Meetings.

Collection and analysis of data on secondary breast cancer should be urgently prioritised to enable the care experienced by those with secondary breast cancer to be understood, including access to clinical nurse specialists.
Treatment and care of breast cancer around the UK

Scotland

The target for both the percentage of patients beginning treatment within 62 days of urgent referral for suspicion of cancer, and within 31 days of decision to treat is 95%. Performance has been variable over the past year, with the targets being met in some quarters but not others. Between quarter 1 (April to June) 2011/12 and quarter 1 2017/18 performance declined from 99.7% to 96.5% for the 31 day target.

The Scottish Government’s Cancer Strategy states that by 2021 anyone who needs a specialist nurse has access to one during and after their treatment and care. In 2015, 95% of breast cancer patients reported having access to a CNS, but only 89% said they were easy to contact.

England

The target for the percentage of patients beginning treatment within 62 days of urgent GP referral is 95% and within 31 days of diagnosis is 95%. These targets have been met for breast cancer over the last year, although between quarter 1 (April to June) 2011/12 and quarter 1 2017/18 performance declined from 99.5% to 93.5% for the 62 day target and from 99.8% to 94.4% for the 31 day target.

The Cancer Strategy recommends that all patients should have access to a CNS. NHS England undertook a consultation process on how this might be achieved and will be conducting pilots in newly-established Cancer Alliances.

In 2016, 94.1% of breast cancer patients reported being given the name of a CNS that would support them through their treatment, and 95.8% said it was very easy or quite easy to contact their CNS.

Wales

The target for the percentage of patients beginning treatment within 62 days of receipt of referral is 85%; and within 31 days of diagnosis is 96%. These targets have been met for breast cancer over the last year, although between quarter 1 (April to June) 2011/12, and quarter 1 2017/18 performance declined from 94.5% to 86.8% for the 62 day target. Performance on the 31 day target rose slightly from 96.2% to 96.8% for the 31 day target.

The Cancer Strategy recommends that all patients should have access to a CNS. NHS Wales undertook a consultation process on how this might be achieved and will be conducting pilots in newly-established Cancer Alliances.

In 2016, 93% of breast cancer patients reported having access to a CNS, but only 59% found them easy to contact.

Northern Ireland

The target for the percentage of patients beginning treatment within 62 days of urgent GP referral or suspicion of cancer is 95% and within 31 days of decision to treat is 95%.

The 62 day target has been met most months over the past year, although the 31 day target has only been met in one month. Between March 2011 and March 2017 performance declined from 100% to 94.5% for the 62 day target, and from 100% to 96.5% for the 31 day target.

Individual Patient Funding Requests provide access to drugs where they are not routinely commissioned but there is an agreed clinical need. However, given that 94% of applications are approved by the IPFR panel it seems this process is simply delaying access to drugs that could be routinely available.

In 2015, 94% of breast cancer patients said they had been given the name of a CNS who would be in charge of their care, and 83% found it easy to contact them.
Melanie Kennedy, 39, is a single mother to two young sons from Bangor, Northern Ireland. Mel is living with secondary breast cancer.

Mel was first diagnosed with HER2+ primary breast cancer in January 2013: 38 years old, and pregnant at the time. A year later, I was told my breast cancer had spread to my liver. By the time the fourth chemotherapy drug I’d taken had stopped working, I felt like I was running out of options. My oncologist put in an Individual Funding Request for Kadcyla. It was rejected because I wasn’t considered ‘exceptional’ enough; in other words, he couldn’t prove that I would respond to the treatment better than 95% of patients in my shoes.

With nowhere left to turn, I began campaigning for system change. However, continued political instability meant each time I took a step forward, I took three steps back. I was left with no choice but to crowdfund for Kadcyla—and amazingly I managed to raise my target in two days. When I heard Kadcyla would be available on the NHS in England, I never thought this would extend to Northern Ireland. Yet, as a result of my campaigning, I was able to access Kadcyla free for the first time. The decision by NICE has now been endorsed in Northern Ireland although it’s not clear when it will be routinely available.

Since starting Kadcyla, I haven’t experienced the debilitating side-effects I endured with chemo so I have continued campaigning. I’ve been fighting not only for my life, but for both men and women who are not in the same good health I am.

The system is broken. Times with the power to fix it should remember that every time a drug stops working and a patient is denied their next best option, they feel like they’re being diagnosed all over again.

We fund research which aims to improve treatment options and ensure all patients can access the right treatment for them.

We produce best treatment guidelines for both primary and secondary breast cancer patients across the nations, so they know the standards of care they can expect to receive, which are available on our website.

Working with our supporters, we champion better access to the most effective breast cancer medicines. Following successful campaigns, Kadcyla is now routinely available in Scotland, England, and Wales, and is being reviewed for routine use on the NHS in Northern Ireland.

Through our Service Pledge and Secondary Breast Cancer Pledge, we work in partnership with patients and hospital staff to improve patient experience. These programmes give patients a platform to voice what matters most to them to ensure they receive the highest quality treatment and care.

By October 2018, Breast Cancer Now wants to see...

- A commitment from the UK Government to reform the way medicines are appraised and funded in England, including through the renegotiation of the PPRS, to better reflect what patients need. This will mean that the best medicines are more quickly available in Wales and Northern Ireland.

- Demonstrable progress by the Scottish Government in implementing the recommendations of the review of access to new medicines in Scotland.

- Review by the DHSSPH of the process for implementing NICE recommendations in Northern Ireland with the aim of reducing the time it can take for medicines to become routinely available.

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- Review by the DHSSPH of the process for implementing NICE recommendations in Northern Ireland with the aim of reducing the time it can take for medicines to become routinely available.
We need to see a renewed focus on tackling the lifestyle factors that we know can affect the risk of developing breast cancer, including obesity, and physical activity. This will include actions shown to support healthier lifestyles as part of the successful research. We hope this can be a framework for the development of improved care for breast cancer patients, to inform risk-stratified breast screening.

Increased funding across the whole health and care system so that we do not lag behind other countries.

Clear and sustainable workforce planning to address the shortfalls in diagnostic capacity.

Good enough? Breast cancer in the UK

Prioritisation of the collection and analysis of data on the diagnosis, treatment and care of secondary breast cancer and get them back into hospital care.

Monitoring of targets on waiting lists for treatment, with remedial action being taken where these are not being met.

Information and support for GPs, and women that have had breast cancer, to recognise the signs and symptoms of secondary breast cancer and get them back into hospital care.

A renewed focus on the development and implementation of robust strategies, with associated funding, to tackle the lifestyle factors that can affect the risk of developing breast cancer and other conditions such as alcohol consumption, obesity, and physical activity.

National campaigns to raise awareness about the signs and symptoms of breast cancer.

Across the UK we also want to see

A simple immigration framework for those working in research and healthcare; continued co-operation with organisations such as the EMA; and close affiliation with EU research programmes, to minimise the impact of Brexit on patients.

By October 2018, Breast Cancer Now wants to see

More research into some of the inequalities associated with breast cancer, including socioeconomic status and ethnicity.

More information and help to improve the lives of those with secondary breast cancer and beyond breast cancer and get them back into hospital care.

Increased funding across the whole health and care system so that we do not lag behind other countries.

More being done to promote attendance at breast screening.

Action to significantly improve patient access to preventative drugs for breast cancer – such as medicines to reduce the risk of breast cancer in those at increased risk due to family history, and bisphosphonates to reduce the risk of secondary breast cancer in post-menopausal women.

Good progress made in implementing strategies and plans to improve cancer outcomes and experience.

We need to make the most of the situation and opportunity that exist and take action now. We are ready to work with Governments and the NHS, and the scientific community across the UK to achieve our vision that by 2050, everyone that develops breast cancer – consistently across the UK we also want to see

We have made a number of recommendations throughout this report to help keep up the pace of progress. These are summarised below.

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Important issues highlighted in this report need to be addressed. We need to see a renewed focus on tackling the lifestyle factors that we know can affect the risk of developing breast cancer, including obesity, and physical activity.

We need to make the most of the situation and opportunity that exist and take action now. We are ready to work with Governments and the NHS, and the scientific community across the UK to achieve our vision that by 2050, everyone that develops breast cancer will live, and live well.
In addition we want to see...

Scotland

The Government and NHS should continue its campaign to raising awareness of the symptoms of breast cancer as part of Detect Cancer Early.

The Government should introduce new national targets for subsequent treatments to ensure quick and effective care is provided for patients beyond their first treatment.

The Government should run a campaign to improve awareness of the signs and symptoms of breast cancer.

England

A Research and Development tax credit for medical research charities, and a real terms increase in the Charity Research Support Fund, to increase the amount of research that medical research charities can fund.

The Government should set out a clear and comprehensive plan for implementing the Accelerated Access Review, and work out how and when it will implement them.

The Government should accept all of the recommendations of the Accelerated Access Review.

The Government should publish an evaluation of the Single Pathway for cancer diagnosis.

An updated, integrated strategy for improving cancer outcomes should be developed and implemented, and supported by appropriate funding.

The Government should publish data on the number of women that are being seen by a specialist within two weeks of being referred by a GP for a symptom of breast cancer.

The process for implementing NICE guidance should be reviewed to ensure that medicines that are recommended for use in the NHS are available more quickly.

Scotland

Wales

The process for implementing NICE guidance should be reviewed to ensure that medicines that are recommended for use in the NHS are available more quickly.

The Government should upgrade its ambition in relation to improving cancer outcomes and ensure targets in relation to this are measurable and supported by appropriate funding.

The Government and NHS should run a campaign to improve awareness of the signs and symptoms of breast cancer.

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References

7. Calculated from raw data on breast cancer incidence by age, Cancer Research UK. Available at: [www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/breast-cancer/mortality#heading-One]
Breast Cancer Now is a charity registered in England and Wales (1160558), Scotland (SC045584) and the Isle of Man (1200).