Good enough?
Breast cancer in the UK
A message from our Chief Executive

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.

Over the last 25 years, Breast Cancer Now, created by the merger of Breast Cancer Campaign and Breakthrough Breast Cancer, has played a vital role in ensuring improvements in knowledge and understanding reach clinical practice so that the benefits are felt by patients: for example extending the age limit for breast screening; the development of clinical guidelines on family history and chemoprevention; and access to specialist surgery and life-extending medicines.

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.

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
Introduction

As a result of advances in diagnosis and treatment, more women are surviving breast cancer than ever before. Around 85% 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.
More women in the UK are living with breast cancer than ever before. But more people are also being diagnosed, and this combination means that more people are living with and dying from breast cancer.

Although fewer people are dying from breast cancer, too many still do. Factors such as where people live, their age and ethnicity can all affect their risk of developing and dying from breast cancer.

Improving survival rates

Around 95% of people 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 most other common cancers - bowel, lung and prostate - but breast cancer currently has better survival rates. However, while survival rates in the UK are improving at both all 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.

Inequalities in survival rates

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.

It is higher than for any of the other common cancers. This is predicted to rise to 1.6 million woman by 2040. Whilst the fact that most women are survived by 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 people get breast cancer in the UK 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 need 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 England – 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.

A third of breast cancer cases in the UK occur in women over 70. Five year survival rates drop from 92% for women aged 40-49 to 43% for those aged 70-79 and 70% for those aged 80-89. Approximately 20% of breast cancer cases in women over 80 are diagnosed through emergency presentation, compared with around 4% standard of care compared with around 4%.

Improving patient experience

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 can be impacted by geographical inequalities in breast cancer care in England, as well as policy and the health and care systems in each nation, which will report in early 2018.

The changing picture for people with breast cancer

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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.

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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 97.7% diagnosed between 1997 and 1999. 4,738 women were diagnosed in 2015, compared to 4,347 in 2006: an increase of 9.2%. 24 men were diagnosed in 2015, compared to 20 in 2006.

98% of women diagnosed in 2015, compared to 98% in 2006: a decrease of 0.4%.

8 men were diagnosed in 2015, compared to 8 in 2006.

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

96% of women diagnosed between 2010 and 2014 survived one year, compared to 89.5% diagnosed between 2001 and 2005. 1,456 women were diagnosed in 2015, compared to 1,389 in 2006: an increase of 4.7%.

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Wales
96.7% of women diagnosed between 2009 and 2013 survived one year, compared to 95.3% diagnosed between 2005 and 2009. 2,788 women were diagnosed in 2015, compared to 2,642 in 2006: an increase of 5.5%.

16 men were diagnosed in 2015, compared to 14 in 2006.

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

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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 those with, or at risk of, breast cancer by being translated into clinical practice.

Challenges include 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.

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

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 — with 80 billion euros of funding over 7 years — that are submitted while the UK is still a member of the EU.

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 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.

The European Commission 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 how 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 cooperation between UK and EU organisations, including the European Medicines Agency, which licenses new medicines for use and oversees clinical trials.

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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 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.

Funding for health and care

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.

Spending as a share of national income also peaked in 2009/10 at 7.7% 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.

Governments across the UK should increase public spending across the whole health and care system so we do not lag behind other countries.

Cancer strategies

Governments in England, Scotland and Wales have all recently committed to improving outcomes for cancer through cancer strategies and plans.

In England, the Independent Cancer Task Force published 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 new Cancer Alliances offer the opportunity to improve outcomes and experience 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, this could further exacerbate geographical inequalities in quality of care.

The changing environment for people with breast cancer

The Institute for Fiscal Studies recommends a national opt-out for health and social care data where it is not anonymised, for use beyond informing their direct care. The UK Government has agreed to implement a national opt-out system in England.37

The changing environment for people with breast cancer

The Government should accept all the recommendations of the Accelerated Access Review and set out how and when it will implement them.
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.

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

- Solid evidence of progress made in implementing strategies and plans to improve cancer outcomes and experience. This includes:
  - 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.

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.
Prevention of 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 environment.

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.

Both Governments and the NHS across the UK 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 to public health funding. In some nations this commitment has been undermined by cuts to public health funding. In 2015/16 £200 million was cut to public health funding. In some nations this commitment has been undermined by cuts to public health funding.

These medicines should be offered to everyone that would benefit from them. The National Institute for Health and Care Excellence (NICE) guidelines on familial breast cancer, which apply in Wales and Northern Ireland as well as England, recommend that women at high or moderate risk are offered tamoxifen, anastrozole or raloxifene, depending on their medical history.

Medicines that can reduce the risk of developing breast cancer in women with a family history are known as chemoprevention (or cancer prevention) medicines. These medicines should be offered to everyone that would benefit from them. The National Institute for Health and Care Excellence (NICE) guidelines on familial breast cancer, which apply in Wales and Northern Ireland as well as England, recommend that women at high or moderate risk are offered tamoxifen, anastrozole or raloxifene, depending on their medical history.

Prevention of breast cancer

Lifestyle choices

There are a number of factors linked to lifestyle that can increase the risk of developing breast cancer. 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.

Both Governments and the NHS across the UK have recognised the importance of encouraging and supporting people to live healthier lifestyles to reduce their risk of developing breast cancer.

Given trends in alcohol consumption, obesity and physical activity we need to see a renewed focus by Governments and the NHS across the UK on the development of robust strategies to help tackle these lifestyle factors, with funding to underpin their implementation.

The Scottish Government’s Cancer Strategy includes a partnership with Breast Cancer Now to trial a new approach to supporting healthy lifestyles through the breast screening service (ACTWELL).

Specialist family history centres can assess whether a woman has a significant family history of the disease. If so, they can offer genetic testing and advice on how to reduce the risk of breast cancer.

These medicines are licensed for use in helping women with familial breast cancer. However, because their effectiveness in preventing breast cancer was discovered after they came off-patent and became available cheaply, there is no commercial incentive for manufacturers to licence for this new preventative use.

15% of women have a significant family history of the disease.

Increase in obesity across the nations

% of women that are obese or overweight
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 prevent breast cancer. 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 prevent 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%).48 Prescribing bisphosphonates for these women could also lead to net savings to the NHS of £5 million each year across the UK.49 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.

GPs unaware that tamoxifen could be used to prevent breast cancer in women with a family history

48%

GPs not willing to prescribe tamoxifen

23%

Prevention of breast cancer

GPs not willing to prescribe tamoxifen
Scotland

The percentage of women drinking more than 14 units a week decreased from 23% in 2001 to 17% in 2015, 24% of women aged both 45-54 and 55-64 drank more than 14 units per week. 26% of women in households with the highest income drank more than 14 units a week, compared to 11% 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 2008, 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. 59

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The percentage of women that are overweight or obese in 2015, 41% in women aged 45-54 were overweight or obese in 2015. 55

England

The percentage of women drinking more than the recommended 14 units a week decreased from 16% in 2015 to 13% in 2015. In 2015, 65% of women aged 55-64 drank more than 14 units a week. 52% of women meeting the physical activity guidelines peaked at 66% in areas with the highest income drank more than 14 units a week. compared to 2% of those in households with the lowest. 55

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Wales

The percentage of women drinking more than the recommended 14 units a week decreased from 17% in 2008 to 13% in 2015. In 2015, 41% of women aged 45-54 drank more than the guidelines. 46% of adults living in the least deprived areas drank more than the recommended guidelines, compared to 37% in the most deprived areas. 52

The percentage of women that are overweight or obese in 2015, 64% of women met physical activity guidelines in 2015. 57

Northern Ireland

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. 57

The percentage of women drinking more than the recommended 14 units a week decreased from 16% in 2010/11 to 11% in 2015. 44% of women aged 55-64 were overweight or obese in 2010/11. 58

The percentage of women that are overweight or obese has increased from 49% in 1993 to 56% in 2015. 69% of women aged 55-64 were overweight or obese in 2015. 58

Bisphosphonates are routinely available to patients in Scotland if proven effective. Bisphosphonates are routinely available to patients in Scotland if proven effective. 60

Breast Cancer Now is piloting a scheme to deliver the £1 million Wales Cancer Network areas in Scotland (South East Scotland and West of Scotland) for women at moderate to high risk of recurrence of breast cancer. Arrangements for the provision of bisphosphonates for the prevention of secondary breast cancer in areas in places of two of the three breast cancer centres in Wales (North Wales and South West Wales) for women at moderate to high risk of recurrence of breast cancer. 60

The NHS England Five Year Forward View highlighted the need for “get serious” about prevention. The Breast Cancer Strategy for England recommended that national strategies to address obesity and alcohol consumption should be developed. 44

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 considering the decision. 44

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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:
  
  - The British National Formulary including chemoprevention medicines 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.
  
  - 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.
  
  - 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.
  
  - We are funding research to better understand the causes of breast cancer so we can help prevent it; predict which women will respond to chemoprevention medicines, and find alternatives for those that don’t benefit from them.
  
  - We produce a wide range of information and resources about risk factors for breast cancer and what women can do to reduce their risk.
  
  - In October 2015, Marks Spencer pledged to raise a further £13 million for Breast Cancer Now over five years. This will fund our scientists to understand more about the causes of breast cancer, which will lead to better ways of predicting a woman’s individual risk of developing the disease.
  
  - We are working with researchers in Scotland on ActWELL, a trial of a healthy lifestyle intervention programme delivered by Breast Cancer Now volunteers for women who attend breast screening.
  
  - We are working with the Department of Health in England, and other stakeholders with an interest in off-patent medicines for which new uses have been found, to help improve consistency of access for people that would benefit from them.

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. 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 of your own body and being vigilant to any changes. For me, personally being proactive goes a long way to dissuading my anxiety of this disease which took my mother far too soon."

What is Breast Cancer Now doing to improve prevention of breast cancer?

We are funding research to better understand the causes of breast cancer so we can help prevent it; predict which women will respond to chemoprevention medicines, and find alternatives for those that don’t benefit from them.

We produce a wide range of information and resources about risk factors for breast cancer and what women can do to reduce their risk.

In October 2015, Marks Spencer pledged to raise a further £13 million for Breast Cancer Now over five years. This will fund our scientists to understand more about the causes of breast cancer, which will lead to better ways of predicting a woman’s individual risk of developing the disease.

We are working with researchers in Scotland on ActWELL, a trial of a healthy lifestyle intervention programme delivered by Breast Cancer Now volunteers for women who attend breast screening.

We are working with the Department of Health in England, and other stakeholders with an interest in off-patent medicines for which new uses have been found, to help improve consistency of access for people that would benefit from them.

...action to improve access to chemoprevention and bisphosphonates to reduce the risk of developing breast cancer. This should include:
Diagnosis of breast cancer

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 stage, it is important for women to be aware of the signs and symptoms of breast cancer and for them to attend breast screening, and that they are seen quickly by a specialist.

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 40 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, especially among women aged 40-49.

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.

Screening

63

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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. The Cancer Strategy committed to phasing out any breast cancer that did develop would be picked up as quickly as possible.

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 a specialist by their GP is increasing, the target has generally been met – although in recent months it has been missed for people referred where breast cancer is not initially suspected.

In the UK, women who present to their GP with a symptom of breast cancer that is not initially suspected are referred where: 32% are seen by a specialist within two weeks of GP referral, 3% are seen as an emergency, or 1.5% are referred to hospital. It is impossible to know whether this is not initially suspected. The Cancer Strategy committed to phasing out any breast cancer that did develop would be picked up as quickly as possible.

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The target for the number of people seen within two weeks is 93%. Although the numbers of people being referred to a specialist by their GP is increasing, the target has generally been met – although in recent months it has been missed for people referred where breast cancer is not initially suspected. We know that waiting to hear the outcome of tests can cause distress and anxiety.

NHS England should clarify how the change from a two week wait from GP referral to seeing a specialist, to a four week wait from referral to diagnosis, will be implemented and ensure that people referred with breast symptoms do not face longer waits as a result.

None of the other three nations of the UK is meeting the two week referral standard, although Wales and Northern Ireland both have ‘ministerial expectations’ that people will be seen within two weeks. In Northern Ireland the target for this expectation is that 100% of people will be seen in two weeks, although numbers did not meet this target until October 2014 and performance varies greatly.

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 among women that have been diagnosed with it is low: less than a quarter (22%) were picked up as a referral, 6% were picked up at A&E, 7% were seen as an emergency and 8% 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 to hospital care, when completing their treatment for primary breast cancer. GPs also need to be supported to identify possible cases of secondary breast cancer and to refer people appropriately.

Patients who have primary breast cancer will often have a similar experience: they present to their GP with a symptom of breast cancer, and their GP will refer them to a hospital.

In the UK, women who present to their GP with a symptom of breast cancer that is not initially suspected are referred where:

- 74% are seen by a specialist within two weeks of GP referral,
- 75% are seen as an emergency, or
- 74% are referred to hospital.

Recent updates to the NHS Cancer Strategy mean that all people referred with breast symptoms should be seen within two weeks of GP referral.

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Diagnosis of breast cancer around the UK

Scotland

An evaluation of Detect Cancer Early shows that a higher proportion of breast cancer is being detected early, with stage 1 diagnoses increasing from 26% between 1 January 2015 and 31 December 2016 to 33% in 2017. 

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 73.3% of women attending their first appointment in 2013/14 compared with 76% in 2005/06. This compares with 72.1% in 2012/13 and 71.3% in 2014.

This is the first time that screening uptake has increased since 2011/12.

34% of breast radiologists are expected to retire in Wales between 2015 and 2025. Staging data by tumour type is not publicly available for Wales.

England

The number of women referred to a specialist with suspected breast cancer has increased from 137,636 in 2010/11 to 333,195 in 2016/17.

70.7% of breast cancers diagnosed at an early stage (stages 1 and 2) have increased significantly from 67.8% in 2010/11 to 73.8% in 2016/17.

In March 2017, 88.4% 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 90.6% in June 2016 to 99.4% in October 2016, with lowest performance for patients who were seen within two weeks.

In contrast to the other three nations of the UK, only one breast radiologist in Northern Ireland is expected to retire over the next ten years, comprising 7.5% of the workforce.

Northern Ireland

Breast cancer is being detected earlier, with 70.7% of breast cancers diagnosed at an early stage (stages 1 and 2) has increased from 67.8% in 2010/11 to 73.8% in 2016/17.

There are currently no unfilled radiology posts in Northern Ireland.

A high proportion of breast cancers in Northern Ireland are diagnosed at early stages – in 2015-15, 41.9% were diagnosed at stage 1, 33% were diagnosed at stage 2, and 25% were diagnosed at stage 3.
What is Breast Cancer Now doing to improve early diagnosis of breast cancer?

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 reminders 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.

April, 25, is a young mammographer based in North West England. 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 mammographer and radiographer 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 wages, and the profession continues to struggle to recruit younger female radiographers. This has to change.

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The best treatment, delivered quickly, can save lives. It can also ensure that people with secondary breast cancer live as long 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 that is chosen 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 are most pressing, including access to 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 cancer patients particularly value — in particular access to a Clinical Nurse Specialist.

Treatment waiting times for cancer treatment in each nation of the UK: patients particularly value — in particular access to a Clinical Nurse Specialist.

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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.

The targets for treatment waiting times are slightly different across the nations.

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 whether this could be rolled out.

Breast Cancer Now is funding research looking at whether clinical nurse specialists (CNSs) for breast cancer can be trained in CBT to help more women with breast cancer better manage these symptoms.

Research shows that CNSs can successfully deliver CBT, the NHS should consider how this could be rolled out.

Breast reconstruction surgery

We are aware that, in England, some CCGs have recently imposed restrictions, or have consulted on imposing restrictions, on 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 medicines have not been routinely reaching patients in the UK. The NHS has one of the lowest uptake rates in Europe, compared with the largest European economies, helping to explain some of the gap in cancer outcomes between the UK and other developed countries.

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 long 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 that is chosen 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 would welcome the Scottish Government introducing new national targets for subsequent treatments in Scotland.

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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.
- Ensuring that it is possible for medicines which are taken in combination with others – where the costs of all the medicines are considered as one medicine – to be considered cost-effective.
- 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.

Furthermore, the implementation of the budget impact test by NICE and NHS England could lead to significant delays in new medicines reaching patients, and potentially shorten 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.

“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.

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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, as well as recommendations of the Accelerated Access Review, and the ongoing 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 2015, setting out key recommendations for improvements in how drugs are appraised and funded. The review proposed significant reforms including giving NHS National Services Scotland a stronger role in negotiating the cost of medicines and more flexible decision-making by the SMC. The Scottish Government has committed to take forward the recommendations.

The Scottish Government has committed to take forward 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 Access (CPS) route to share for purposes beyond their direct care — such as improving services. NHS England is concerned that this will impact on the number and quality of responses to the CPS 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 CPS 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 offer limited insight into their differences in experience. This reflects poor collection of data on secondary breast cancer, and patient experience of data on secondary breast cancer should be urgently prioritised to enable the care experienced by those with breast cancer to be improved, including access to clinical nurse specialists.

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 networks. In England and Wales, 53% of organisations 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.

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

Patients often give limited feedback on their health and care. In particular, breast cancer patients often report poor experiences of care. This refl ects the limited insight into their differences in experience. When 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.

As mentioned earlier in this report, the UK Government will be implementing a national opt-out in England that will enable people to choose whether they wish their health and care data to be shared for purposes beyond their direct care — such as improving services. NHS England is concerned that this will impact on the number and quality of responses to the CPS and is considering discontinuing it as a result. We believe that this would undermine efforts to improve patient experience and care.

Patient experience of care. The experience of cancer patients is measured regularly in each nation through a Cancer Patient Access (CPS) route to share for purposes beyond their direct care — such as improving services. NHS England is concerned that this will impact on the number and quality of responses to the CPS 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 Committee of Public Enterprise’s (CPS) 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 CPS 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 offer limited insight into their differences in experience. This reflects poor collection of data on secondary breast cancer, and patient experience of data on secondary breast cancer should be urgently prioritised to enable the care experienced by those with breast cancer to be improved, including access to clinical nurse specialists.

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 networks. In England and Wales, 53% of organisations 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 improved, including access to clinical nurse specialists.

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The target for the percentage of patients beginning treatment within 62 days of urgent GP referral for suspicion of cancer is 95%.[92] 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 96.5% for the 62 day target, and from 100% to 95.1% for the 31 day target.[94]

Individual Patient Funding Requests provide access to drugs where they are not routinely commissioned but there is an agreed clinical need. However, given that 98% of applications are approved by the IPFR panel it seems this process is simply delaying access to drugs that could be routinely available.[107]

In 2015, 93% of breast cancer patients reported having access to a CNS, but only 59% found them easy to contact.[105]
Melanie Kennedy, 39, is a single mother to two young sons from Bangor, Northern Ireland. Mel is living with secondary breast cancer. 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 the lives of women who are not in the same good health I am.

The system is broken. Those 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."

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.

What is Breast Cancer Now doing to improve treatment and care?

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 on the NHS 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, we want to see the following...
Conclusion – Keeping up the pace of progress

This report shows that although good progress has been made in diagnosing and treating breast cancer, with more women surviving than ever before, there is still much more to do.

But unprecedented financial and operational pressures, uncertainty and change mean that progress is now stalling. Opportunities are now being missed to save more lives from breast cancer and improve the lives of those living with it.

We need to see a renewed focus on tackling the lifestyle factors that we know can affect the risk of developing breast cancer, especially in the growing number of people being diagnosed with the disease. We also need action to significantly improve access to preventative medicines for breast cancer.

For those that do develop breast cancer we need to ensure that it is detected and diagnosed quickly – raising awareness of the signs and symptoms, particularly amongst hard to reach groups, encouraging women to attend breast screening, and for those with secondary breast cancer – consistently experience the highest standards of treatment and care, including quick access to the best breast cancer medicines and clinical nurse specialists.

Unless we address the issues highlighted in this report, we will continue to miss opportunities to save lives from breast cancer and improve the lives of those living with it. The growing number of people being diagnosed with and living with breast cancer could place a potentially heavy future burden on the NHS which could slow progress further.

We have made a number of recommendations throughout this report to help keep up the pace of progress. We need to make the most of this opportunity and act 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 experience the highest outcomes and experience.

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

Action to significantly improve patient access to preventative drugs for breast cancer – such as tamoxifen to reduce the risk of secondary 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.

Across the UK we also want to see

- More research into some of the inequalities associated with breast cancer, including socioeconomic status and ethnicity.
- A simple immigration framework for those working in research and healthcare; continued co-operation with organisations such as the EMA; and close collaboration with EU research programmes, to minimise the impact of Brexit on patients.
- Increased funding across the whole health and care system so that we do not lag behind other counties.
- More being done to promote attendance at breast screening.
- 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 the conditions such as alcohol consumption, obesity, and physical activity.
- National campaigns to raise awareness about the signs and symptoms of breast cancer.
- More 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.
- Monitoring of targets on waiting times for treatment, with remedial action being taken where these are not being met.
- Prioritisation of the collection and analysis of data on the treatment and care of secondary breast cancer patients, to inform improvements to their care, including access to clinical nurse specialists.
- Governments and the NHS creating a culture of innovation that embraces and implements successful research. We hope this will include actions shown to support healthier lifestyles as part of the ActWELL trial, training breast cancer nurses in cognitive behavioural therapy to help patients manage the symptoms of hormone treatments, and risk-stratified breast screening.

**Summary of recommendations**

- More being done to promote attendance at breast screening.
- Clear and sustainable workforce planning to address the shortages in diagnostic capacity.
- Across the UK we also want to see
  - Improved access to preventative medicines for breast cancer – including tamoxifen, to reduce the risk of secondary breast cancer in those at increased risk due to family history.
  - Increased funding across the whole health and care system so that we do not lag behind other counties.
  - Improved access to care, including access to clinical nurse specialists.
  - Prioritisation of the collection and analysis of data on the treatment and care of secondary breast cancer patients, to inform improvements to their care, including access to clinical nurse specialists.
  - Governments and the NHS creating a culture of innovation that embraces and implements successful research. We hope this will include actions shown to support healthier lifestyles as part of the ActWELL trial, training breast cancer nurses in cognitive behavioural therapy to help patients manage the symptoms of hormone treatments, and risk-stratified breast screening.

**Good enough? Breast cancer in the UK**

By October 2018, Breast Cancer Now wants to see

- Good progress made in implementing strategies and plans to improve cancer outcomes and experience.
- Action to significantly improve patient access to preventative drugs for breast cancer – such as tamoxifen to reduce the risk of secondary 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.
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.

The Government should set out a clear and comprehensive plan for implementing the national opt-out system which maximises the potential of patient data by clearly explaining the benefits and risks of data sharing.

The Government should accept all of the recommendations of the Accelerated Access Review and set out how and when it will implement them.

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 and NHS 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 the Single Pathway for cancer diagnosis should be reviewed to ensure that medicines that are recommended for use in the NHS are available more quickly.

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.

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 Government should provide clarity about the impact on women with breast symptoms of the move from the two week wait from GP referral to seeing a specialist, to a four wait from GP referral to diagnosis.

The Government should commit to reform the way medicines are appraised and funded, including by ensuring that the patient voice is heard in the renegotiation of the PPRS.

The Government should accept all of the recommendations of the Accelerated Access Review and set out how and when it will implement them.

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.

Wales

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.

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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.

Northern Ireland

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.

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

A campaign to improve awareness of the signs and symptoms of breast cancer should be run.

A clear plan for routinely meeting the ministerial expectation that women will be seen by a specialist within one week of being referred by a GP for a symptom of breast cancer should be set out.

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Breast Cancer Now is a charity registered in England and Wales (1160558), Scotland (SC045584) and the Isle of Man (1200).