Good enough?

Breast cancer in the UK

breast cancer now

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.

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

Introduction

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.

Breast cancer in the UK

The changing picture for people with breast cancer

More women in the UK are surviving breast cancer than ever before. But more people are also being diagnosed, and this combination means that more people are living with and beyond 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 women diagnosed with breast cancer now survive one year, and more than 80% survive five years or more.[26,28,29,30] Breast cancer survival rates are better than for most other types of cancer: of the other common cancers - bowel, lung and prostate - only prostate cancer currently has better survival rates.[26. 1, 2,3] 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.[4]

Increasing incidence

At the same time, the number of people being diagnosed with breast cancer has been steadily increasing. It is now the most commonly diagnosed cancer in the UK.[5] Whilst the incidence of breast cancer has also increased in similar developed countries, incidence is higher in the UK compared to Sweden, Denmark, Norway, Canada and Australia.[4]

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.[27,28,29,30] But it can affect men too, with over 350 men diagnosed each year.[6] 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,[7] 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

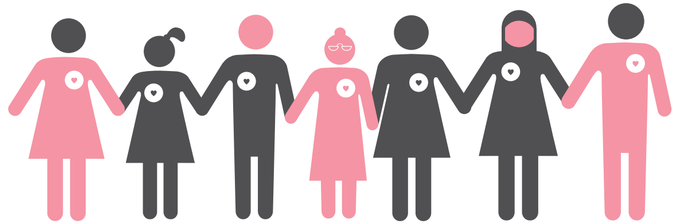
The combination of improved survival rates and the increasing number of people being diagnosed means that more people than ever before are living with and beyond breast cancer. It is estimated that in 2015, there were nearly 700,000 women living with or beyond breast cancer in the UK. [8,10] This is higher than for any of the other common cancers.[9] This is predicted to rise to 1.6 million women by 2040.[10] Whilst the fact that more women are surviving breast cancer is good news, we need to ensure that the needs of people living 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[27,28,29,30] and 80 men still die from breast cancer each year.[11] 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 life 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 live for many years with a diagnosis of incurable breast cancer.

'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.'



As a result of poor data collection – and despite a requirement for this data to be collected by hospital trusts in England[12] – 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.[13] Our work with Breast Cancer Care on the Secondary Breast Cancer Pledge shows 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.

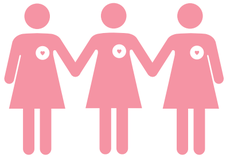
Some of the variations that exist between the different nations of the UK, which are illustrated throughout this report, may be the result of differences in policy and the health and care systems in each nation. There will also be differences depending on where people live in each nation, some of which will be the result of more local decision making. The All-Party Parliamentary Group on Breast Cancer is currently holding an inquiry to investigate geographical inequalities in breast cancer in England in more depth, which will report in early 2018.

A third of breast cancer cases in the UK occur in women over 70.[14] Five year survival rates drop from 92% for women aged 60-69 to 83% for those aged 70-79 and 70% for those aged 80-99.[15] Approximately 20% of breast cancer cases in women over 80 are diagnosed through emergency presentation, compared with around 4%

‘There is evidence to suggest that treatment is given according to age rather than a patient’s fitness to receive it.’

in all other age groups.[16] 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.[16] 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.[17] There is evidence to suggest that treatment is given according to age rather than a patient’s fitness to receive it.[18,19,20]

Breast cancer is less common in women living in deprived areas,[21] but mortality rates for women living in the most deprived areas are approximately 6% higher than those living in the least deprived areas.[22] 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.[23]



There are

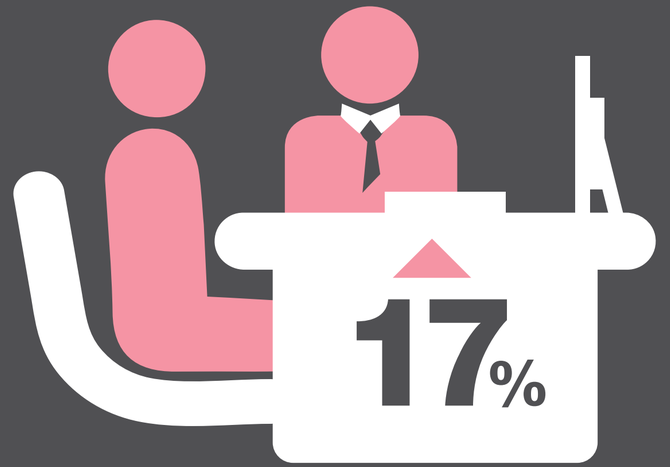
691,000

women living with or beyond breast cancer in the UK

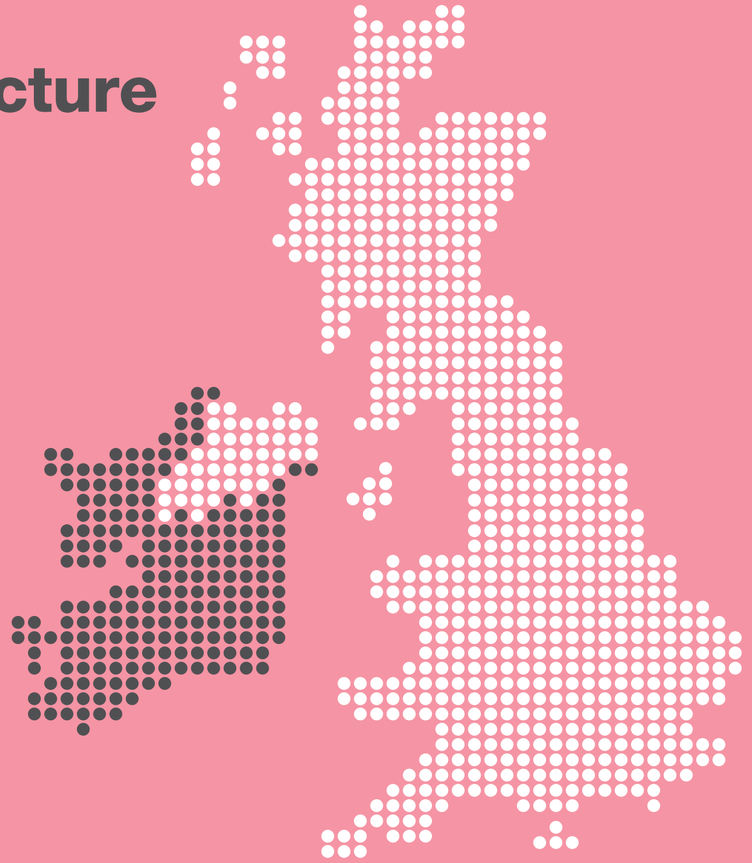
Breast cancer is less common in Black and Asian women than White women,[24] but again, their survival rates are lower.[23] Black women in particular are more likely to be diagnosed with more advanced breast cancers and breast cancers that are more difficult to treat, such as triple negative breast cancer.[25] 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.[23] 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.

We would like to see more research into the inequalities associated with breast cancer, including socioeconomic status and ethnicity, to ensure this is better understood and appropriate action can be taken – including raising awareness of breast cancer in these groups.

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.[28]

82.8% of women diagnosed between 2007 and 2011 survived five years, compared to 66.2% diagnosed between 1987 and 1991.[28]

4,738 women were diagnosed in 2015, compared to 4,147 in 2006: an increase of 14.3%.[2]

24 men were diagnosed in 2015, compared to 20 in 2006.[28]

989 women died from breast cancer in 2015, compared to 1,108 in 2006: a decrease of 10.7%.[28]

3 men died from breast cancer in 2015, compared to 4 in 2006.[28]

An estimated 52,300 women were living with or beyond breast cancer in 2013.[9]

England

95.6% of women diagnosed between 2011 and 2015 survived one year, compared to 92.8% diagnosed between 2001 and 2005.[26]

86% of women diagnosed between 2011 and 2015 survived five years, compared to 78.1% diagnosed between 2001 and 2005.[26]

45,764 women were diagnosed in 2015, compared to 39,104 in 2006: an increase of 17%.[27]

319 men were diagnosed in 2015, compared to 273 in 2006.[27]

9,556 women died from breast cancer in 2015, compared to 10,243 in 2006: a decrease of 6.7%. [27]

70 men died from breast cancer in 2015, compared to 59 in 2006.[27]

An estimated 494,000 women were living with or beyond breast cancer in 2013.[9]

Wales

96.7% of women diagnosed between 2009 and 2013 survived one year, compared to 93.7% diagnosed between 2000 and 2004.[29]

86.9% of women diagnosed between 2005 and 2009 survived five years, compared to 78.8% diagnosed between 1996 and 2000.[29]

2,786 women were diagnosed in 2015, compared to 2462 in 2006: an increase of 13.2%.[29]

16 men were diagnosed in 2015, compared to 18 in 2006.[29]

612 women died from breast cancer in 2015, compared to 673 in 2006: a decrease of 9.1%.[29]

An estimated 31,900 women were living with or beyond breast cancer in 2013.[9]

4 men died from breast cancer in 2015, compared to 9 in 2006.[29]

Northern Ireland

96% of women diagnosed between 2010 and 2014 survived one year, compared to 91.5% diagnosed between 1993 and 1999.[30]

81.1% of women diagnosed between 2005-2009 survived five years compared to 74.8% diagnosed between 1993 and 1999.[30]

1,456 women were diagnosed in 2015, compared to 989 in 2006: an increase of 47%.[30]

285 women died from breast cancer in 2015, compared to 300 in 2006: a decrease of 5%.[30]

8 men were diagnosed, and 2 men died from breast cancer in 2014.[6,11]

An estimated 16,300 women were living with or beyond breast cancer in 2013.[9]

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 EU 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.[31]

The Government should seek close affiliation with EU research programmes, enabling the UK to participate in and shape future programmes such as Framework Programme 9, the successor to Horizon 2020.

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.[32]

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 UK currently operates within strong regulatory frameworks across the EU which govern, amongst other things, clinical trials and access to medicines. Patients in the UK must continue to benefit from early access to innovative medicines, including through continued participation in clinical trials.

The Government should ensure continued co-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.

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

Life Sciences Industrial Strategy and Accelerated Access Review

The life sciences sector is one of the biggest parts of the UK economy. Medical research charities, such as Breast Cancer Now, are a vital part of the life sciences sector, investing over £1.6 billion in funding research in 2016.[33] A strong Government commitment to the sector will be critical to its success following the UK's departure from the EU.

The life sciences industrial strategy published for England in August 2017 made recommendations to government on the long term success of the sector. These included ensuring that the tax environment supports growth, enhancing the Charity Research Support Fund (CRSF), and adopting the recommendations of the Accelerated Access Review.[34] In response to the strategy, the Government is expected to announce a deal with the life sciences sector in Autumn 2017.

The tax environment helps to support growth in the life sciences sector through tax credits, which enable companies to claim back a percentage of the money they spend on research and development, encouraging them to spend more.

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.[35]

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

'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.'

The Accelerated Access Review set out a range of recommendations to make it quicker and easier for patients to access innovative medicines, including evolving the medicines appraisal system to ensure that it is fit for the future in terms of assessing emerging technologies.[36]

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

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,[37] 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.[38]

£1.6 billion

Amount spent by medical research charities on funding research in 2016

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.

Spend as a share of national income also peaked in 2009/10 at 7.6% and fell back to 7.4% in 2015/16 [39] and is predicted to fall further to 6.6% by 2020.[40] 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.[39]

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',[54] 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 16 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.

6.6%

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

NHS England should urgently publish a two year report on progress in implementing the Cancer Strategy, setting out plans and funding for its remaining work.

In Scotland, the Government launched its cancer strategy 'Beating Cancer: Ambition and Action' in 2016.[56] 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

‘We welcome the Scottish Government’s commitment to breast cancer within the strategy.’

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.[38] 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.[41] 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. Documents underpinning the strategy are not publicly available and a formal evaluation has never been published.[42]

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

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:

- 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.

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.

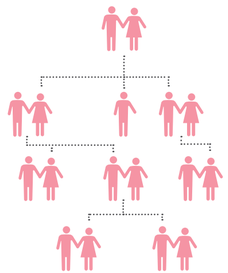
Unfortunately, there is nothing that can be done to change the biggest risk factors: being a woman and getting older. However, we know from research that action can be taken on other factors to reduce the risk of breast cancer developing, including lifestyle choices, and where family history puts people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

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

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 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[43] has decreased, the highest percentage of women doing so were generally aged between 45-64, and were also in households with the highest incomes.[51,55,57,59] The percentage of women who are overweight or obese has increased, with the highest percentage generally being over 45.[51,55,57,59] The percentage of women meeting guidelines on physical activity generally reduces with age.[52,55,57]

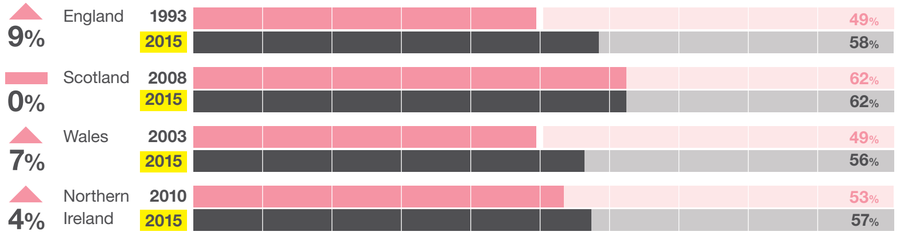


15%

of women have a significant family history of the disease

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 from public health funding in England, and the Spending Review in 2015 announced further cuts of nearly 4% a year, adding up to a spending reduction of at least £600 million a year in real terms by 2020/21.[44]

Increase in obesity across the nations
% of women that are obese or overweight



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).

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

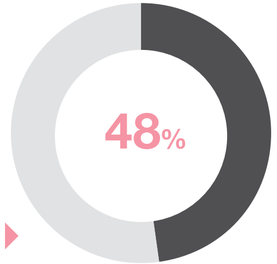
Family history

In some cases, breast cancer runs in families. Of all women who develop breast cancer, up to 15% have a significant family history of the disease and about 5% have inherited a fault in a gene linked to breast cancer.[45] 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.

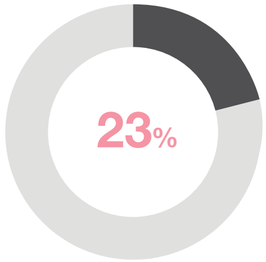
Medicines that can reduce the risk of developing breast cancer in women with a family history are known as chemoprevention (or cancer preventing medicines). These medicines should be offered to everyone that would benefit from them. The National Institute for Health and Care Excellence (NICE) guidelines 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.[45] Health Improvement Scotland guidelines recommend that women at high risk are offered tamoxifen.[46]

These medicines are licensed for use in treating 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.

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



GPs not willing to prescribe tamoxifen



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%).[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.

Preventing breast cancer around the UK

Scotland

The percentage of women drinking more than 14 units a week decreased from 23% in 2003 to 17% in 2015. In 2015, 20% of women aged both 45-54 and 55-64 drank more than 14 units per week. 24% 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.[55]

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.[55]

The Scottish Government is expected to consult on a new Obesity Strategy by the end of the year.

59% of women met physical activity guidelines in 2015.[55]

Breast Cancer Now is working with the Scottish Government and the University of Dundee to deliver the £1 million ActWELL trial. The project is piloting a scheme delivering personalised advice on lifestyle change to women attending their screening appointment. The Scottish Government committed in its Cancer Strategy to invest up to £1 million to offer similar opportunities across Scotland if proven effective.[56]

Bisphosphonates are routinely available to help reduce the risk of secondary breast cancer in two of the three Cancer Network areas in Scotland (South East Scotland and West of Scotland). It is unclear whether Health Boards in the North of Scotland Cancer Network have the same guidance in place.

England

The percentage of women drinking more than the recommended 14 units a week decreased from 18% in 2011 to 16% in 2015. In 2015, 24% of women aged 55-64 drank more than 14 units a week. 22% 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.[51]

The percentage of women that are overweight or obese has increased from 49% in 1993 to 58% in 2015. 69% of women aged 55-64 were overweight or obese in 2015.[51]

54% 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. [52]

The NHS England Five Year Forward View highlighted the need to 'get serious' about prevention[53], and the Cancer Strategy for England recommended that national strategies to address obesity and alcohol consumption should be developed.[54]

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 implementing the decision.

Northern Ireland

The percentage of women drinking more than the recommended 14 units a week decreased from 15% in 2010/11 to 11% in 2015/16.[59]

The percentage of women that are overweight or obese increased from 53% in 2010/11 to 57% in 2015/16.[59]

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.[60]

Wales

The percentage of women drinking more than the recommended guidelines on at least one day a week decreased from 38% in 2008 to 34% in 2015. In 2015, 41% of women aged 45-64 drank more than the guidelines. 46% of adults living in the least deprived areas drank more than the recommended guidelines, compared to 33% of those in the most deprived areas.[57]

The percentage of women that are overweight or obese has increased from 49% in 2003/4 to 56% in 2015. 63% of women aged 45-64 were overweight or obese in 2015.[57]

53% of women met physical activity guidelines in 2015.[57]

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 cancer.[58]

Arrangements for the provision of bisphosphonates for the prevention of secondary breast cancer are in place at 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.

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 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.

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.

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

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, we need to make sure that women are aware of - and looking out for – the symptoms of breast cancer, that they attend screening, and that they are seen quickly by a specialist.

By 2025, we believe we will have identified those at increased risk of breast cancer with a further 2,850 women each year diagnosed early. And by knowing which breast cancers require treatment and which don't, we aim to eliminate overtreatment, saving around 4,000 women from unnecessary treatment each year.

Unfortunately some women will be diagnosed with breast cancer when it has already spread to other parts of their body. In order to ensure that they are able to live well for as long as possible, both they, and their GPs, should be aware of the signs and symptoms of secondary breast cancer and the action they should take to be diagnosed quickly.

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 GP. 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.

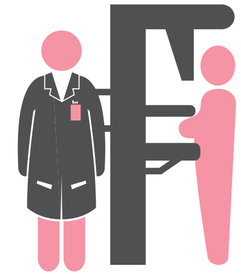
National campaigns, such as *Be Clear on Cancer* in England and *Detect Cancer Early* in Scotland, have been run by the Government and the NHS across different cancer types. Specific breast cancer campaigns have aimed to increase knowledge of symptoms and increase attendance at breast screening. The breast cancer campaign in England focused on women aged 70 and over. These campaigns have been successful in raising awareness amongst women.[68,81]

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

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 70% in all four nations of the UK.[70,83,84,87] Screening at population level is only effective at preventing deaths from breast cancer if people attend.



'Current vacancy rates for radiographic practitioners in England are 15%. This is likely to have a significant impact on the ability of the screening programmes to meet current demand'

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

The screening programmes are facing a workforce crisis with 32% of breast radiologists across the UK due to retire between 2015 and 2025.[61] There are currently 60 unfilled breast radiologist posts across the UK and fewer than half of these are expected to be filled in the next 12 months.[61] Current vacancy rates for radiographic practitioners in England are 15%.[62] This is likely to have a significant impact on the ability of the screening programmes to meet current demand and to introduce any new technologies or ways of working.

Governments and the NHS across the UK should address the crisis in the diagnostic workforce by setting out a long term vision to ensure the cancer workforce is sustainable and able to meet projected increasing demand for services over the next decade.

Breast screening is considered controversial by some – it can detect very slow growing cancers which would never cause harm within the woman's lifetime. However, at present there is no way to tell which of these cancers will become invasive at the point of diagnosis. 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.[63] 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 a non-invasive cancer known as ductal carcinoma in situ (DCIS). There were around 7,900 new diagnoses of in situ carcinomas in 2014. If left untreated, over half of DCIS cases will become invasive, so being able to accurately identify these cases will mean

‘We hope to see risk stratified screening introduced. This would provide every woman with a tailored estimate of her risk of developing breast cancer’

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 and offer screening and other interventions according to her individual risk. For some women this will mean additional screening or possibly screening using new and different technologies.

32%

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

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.

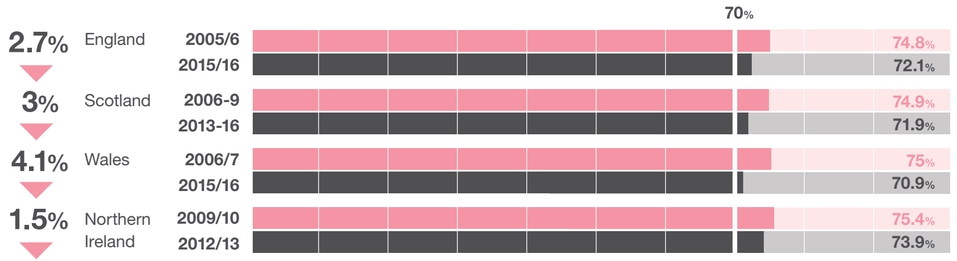
Referral waiting times

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.[65] 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. [72,73,76]

The Cancer Strategy committed to phasing out the two week wait from GP referral to seeing a specialist, in favour of a four week wait from referral to diagnosis for all urgent referrals. It is currently unclear what the impact of this change will be on breast cancer waiting times, 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.

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.

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



None of the other three nations has a referral waiting time, 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 this has not been met since October 2014 and performance varies greatly.[90]

A clear plan for how the target that all people will be seen by a specialist within two weeks of GP referral will be routinely met in Northern Ireland needs to be set out.

It is impossible to know whether this expectation is being met in Wales, as data is not published. A programme piloting a new ‘Single Pathway’ for cancer diagnosis was introduced by the Welsh Government in May 2014, however no updates on progress are available.[66]

The Welsh Government should publish data on the number of people being 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 low: less than a quarter (22%) knew 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. [67]

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.[67]

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 also need to be supported to identify possible cases of secondary breast cancer and to refer people appropriately.

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 39% between 1 January 2010 and 31 December 2011, to 41% between 1 January 2015 and 31 December 2016.

Stage 2 diagnoses have increased slightly from 44% to 44.4% during the same period.[81]

Screening uptake has fallen from 74.9% in 2006-9 to 71.9% in 2013-16.[82]

20% of breast radiologists are expected to retire in Scotland between 2015 and 2025.[61]

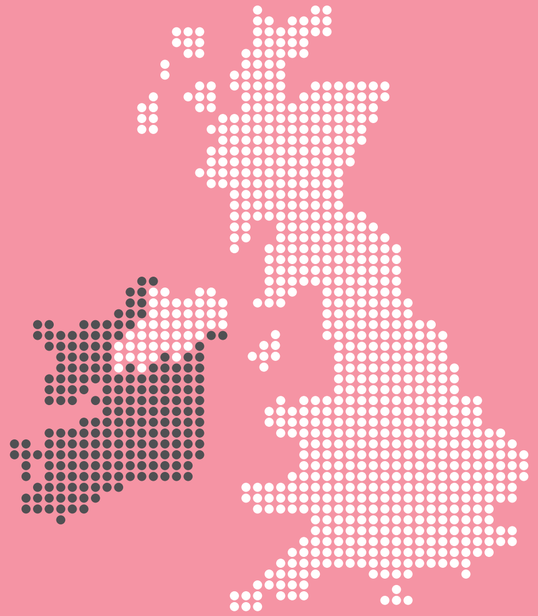
The Scottish Government has made a commitment to improve the situation,[56] and Audit Scotland makes clear in its recent NHS workforce planning report that better long-term planning is needed to ensure that workforce pressures across the NHS are fully addressed.[83]

Wales

Screening uptake has fallen over the past few years with 70.9% of those invited for screening attending their appointments in 2015/16.[84] This compares with 72.1% in 2014/15[35] and 71.9% in 2013/14.[86]

35% of breast radiologists are expected to retire in Wales between 2015 and 2025.[61]

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



England

During the *Be Clear on Cancer* breast campaign there was a 26% 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.[68]

Screening uptake has fallen from 74.8% in 2005/6 [69] to 72.1% in 2015/16.[70] The 2015/16 figure is however a slight increase on 2014/15 when uptake was 71.3%.[71] This is the first time that screening uptake has increased since 2011.[70]

34% of breast radiologists are expected to retire in England between 2015 and 2025.[61]

The number of women referred to a specialist with suspected breast cancer has increased from 220,045 in 2012/13 to 333,195 in 2016/17. In the same period the number of women referred where breast cancer was not initially suspected increased from 194,715 to 209,791.[72]

In quarter 1 of 2017/18 (April – June 2017) 94.36% of women referred with suspected breast cancer were seen within two weeks of being referred.[73] This compares to 94.91% in quarter 4 of 2016/17[74] and 97.04% in quarter 3 of 2016/17.[75]

In quarter 1 of 2017/18 90.67% of women referred where breast cancer was not initially suspected were seen within two weeks of being referred.[76] This compares to 92.93% in quarter 4 of 2016-17[77] and 95.79% in quarter 3 of 2016-17.[78]

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, the percentage of breast cancers where stage at 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.[79]

Approximately 4% of breast cancers in England are diagnosed through emergency presentation.[30]

Northern Ireland

Screening uptake in 2012/13 was 73.9%.[87] This compares with 73.3% in 2011/12[38] and 75.8% in 2010/11.[89]

In March 2017, 86% 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 63.9% in June 2016 to 99.4% in October 2016. In four months since January 2016, 90% or more of patients have been seen within two weeks.[90]

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% of the workforce.

There are currently no unfilled breast radiologist posts in Northern Ireland.[61]

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 38.2% were diagnosed at stage 2. 7.5% of breast cancers did not have staging data recorded.[91]

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

Our award-winning *Touch Look Check* breast awareness messaging reached 1.4million 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.

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 Wales.
- 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.

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 workload 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."

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, radiotherapy 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 we feel are most pressing, including access to clinically 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 causes different tumours to grow and progress, enabling us to select the best treatment for every patient; and that over 50 per cent of those diagnosed with secondary breast cancer will survive beyond 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 different across the nations.[92] For breast cancer, over the last year, in England both targets have been met, although performance in other nations has been more variable.[100,102,104,106]

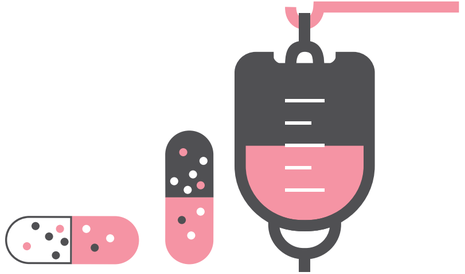
Irrespective of whether targets are being met, there has been a decrease in the percentage of people with breast cancer being treated within these times in each nation over the last 6 years. However, this is more marked in relation to the 62 day target, and is largely considered to be the result of delays 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 believe that targets for subsequent treatments (as exist in England) would help to ensure that the NHS in Scotland provides quick and effective care for patients beyond their first treatment.

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 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.[93]

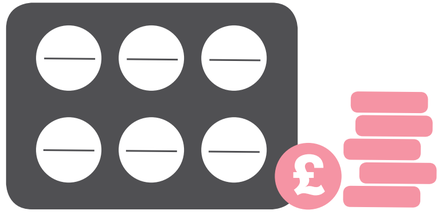
If research shows that CNSs can successfully deliver CBT, the NHS across the UK should consider how this could be rolled out.

Breast reconstruction surgery

We are aware that, in England, some CCGs have recently imposed restrictions, or have consulted on imposing restrictions, on 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.[94] 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. The UK has one of the lowest uptake rates of new cancer drugs compared with the largest European economies, helping to explain some of the gap in cancer outcomes between the UK and other developed countries.[95]



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.

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

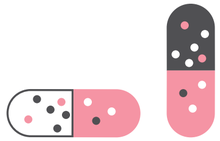
While living in Ireland, Sue received Perjeta as part of her cancer treatment.

"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.

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."



‘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, the recommendations of 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 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.[96] The Scottish Government has committed to take forward the recommendations.

The Scottish Government should now 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) providing 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: when asked to rate the overall experience of care they receive, breast cancer patients typically give a high average score.

However, the future of the CPES in England is uncertain. 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 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 offer 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 needs, and only half of pledge hospitals were routinely able to offer access to specialist nursing support. [97]

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,[101,103,105,108] only 21% of organisations in England, Scotland and Wales report having one or more CNS dedicated to secondary breast cancer.[98]

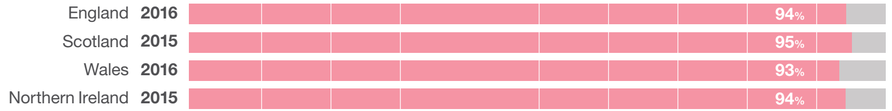
In some areas a great deal of work has been done to show the standards of care that should be delivered for women with secondary breast cancer, including access to a CNS with expertise in secondary breast cancer, and the discussion of these patients at Multidisciplinary Team Meetings.[99]

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.

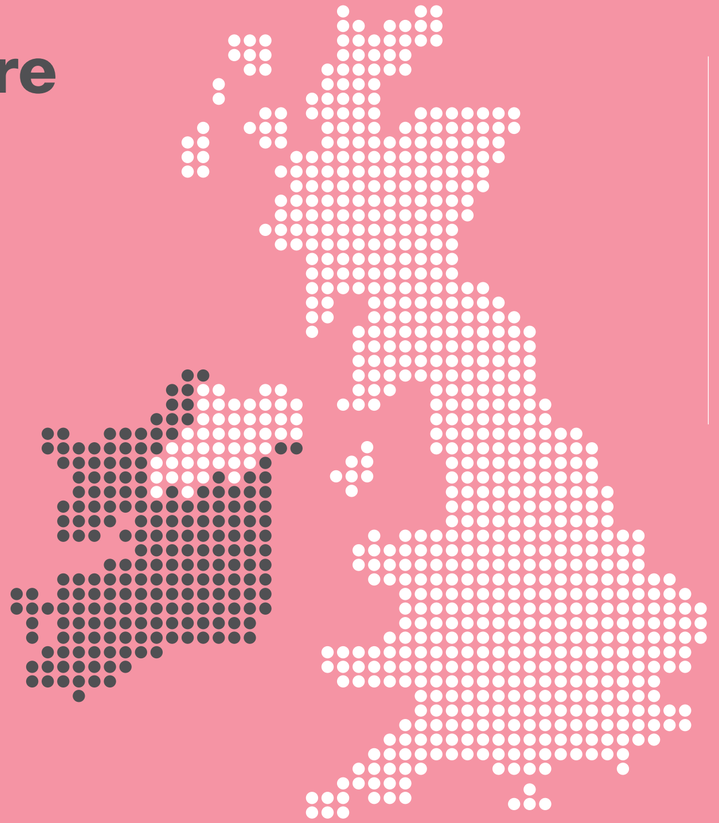
Only 21% of organisations in England, Scotland and Wales report having one or more Clinical Nurse Specialist dedicated to secondary breast cancer.[98]

Access to a Clinical Nurse Specialist (CNS)
% of breast cancer patients that said they were given the name of a CNS that would support them through treatment

*Results from latest published Cancer Patient Experience Survey



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%. [92]

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% for the 62 day target, and from 99.7% to 96.5% for the 31 day target.[102]

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.[56]

In 2015, 95% of breast cancer patients reported having access to a CNS, but only 89% said they were easy to contact.[103]

England

The target for the percentage of patients beginning treatment within 62 days of urgent GP referral is 85%; and within 31 days of diagnosis is 96%.[92]

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 97% to 93.5% for the 62-day target, and from 99% to 98.4% for the 31 day target.[100]

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 through the newly-established Cancer Alliances.[54]

In 2016, 94.4% of breast cancer patients reported being given the name of a CNS that would support them through their treatment, and 85.8% said it was very easy or quite easy to contact their CNS.[101]

Wales

The target for the percentage of patients beginning treatment within 62 days of receipt of referral through the urgent suspected cancer route is 95%, and within 31 days of decision to treat through the non-urgent route is 98%.[92]

Neither target has been met for breast cancer over the last year. 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.[104]

In 2016, 93% of breast cancer patients reported having access to a CNS, but only 59% found them easy to contact.[105]

Northern Ireland

The target for the percentage of patients beginning treatment within 62 days of urgent GP referral for suspicion of cancer is 95%; and within 31 days of decision to treat is 98%. [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 99.1% for the 31 day target.[106]

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, 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.[108]

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,

Breast Cancer Now wants to see...

....progress on reform to the way that medicines are appraised and funded to ensure that patients have timely access to life-extending medicines, at a price that is affordable for the NHS and taxpayer. This should include:

- 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 there.

Melanie Kennedy, 39, is a single mother to two young sons from Bangor, Northern Ireland. Mel is living with secondary breast cancer.

"I was first diagnosed with HER2+ primary breast cancer in January 2013: 35 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 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."

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, to help slow 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 by raising awareness of the signs and symptoms, particularly amongst hard to reach groups, encouraging women to attend breast screening, urgently addressing the crisis in the diagnostic workforce, and monitoring how long it takes for people to be diagnosed and treated. We must also provide support to women and GPs to recognise the signs and symptoms of secondary breast cancer and get them back into hospital care as quickly as possible.

And we need to ensure that the increasing number of women living with and beyond breast cancer, which is predicted to reach 1.6 million by 2040 – in particular 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 and living with and beyond 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. These are summarised below.

We need to make the most of the ambition 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.

Summary of recommendations

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 preventive drugs for breast cancer – such as tamoxifen 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.

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

Progress on reform to the way that medicines are appraised and funded to ensure that patients have timely access to life extending medicines at a price that is affordable for the NHS and taxpayer.

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 affiliation 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 countries.
- 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.
- More being done to promote attendance at breast screening.
- 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 diagnosis, treatment and care of secondary breast cancer patients, to inform improvements to their care, including access to clinical nurse specialis.
- 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.

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 deliver the recommendations of the review of access to new medicines quickly and effectively.

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

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

NHS England should publish a year two report on progress in implementing the Cancer Strategy, and its plans and funding for the remaining three years.

Public Heath England should run further campaigns raising awareness of the symptoms of breast cancer as part of *Be Clear on Cancer.*

NHS England 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.

Northern Ireland

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 two weeks of being referred by a GP for a symptom of breast cancer should be set out.

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.

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

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