

Ageism in breast cancer



- Culture and society
- Finance and wealth
- Health and care**
- Infrastructure
- Productivity
- Care homes
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- Diseases and conditions**
- Immunisation
- Life Expectancy
- NHS
- Nutrition and hydration
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Summary

Age discrimination in the provision of health and care services was banned in the UK in 2012. However there continue to be age-related discrepancies in the prevalence, treatment and outcomes experienced by people with breast cancer.

Ageism can manifest in a wide range of ways – ranging from overt discrimination to unconscious bias to internalised ageist stereotypes that can affect individuals' attitudes and assumptions.

While a range of factors underlie the differences in incidence, diagnosis, treatment and outcomes for older people with breast cancer as compared to younger people, the evidence continues to suggest that ageist attitudes, both on the part of older people themselves and on that of clinicians, may impact rates of diagnosis and the treatment that people with breast cancer receive.

England has made good progress in improving breast cancer outcomes and in taking steps to address age inequalities, however there can be no room for complacency.

Robust data will be critical if we are to be able to continue to monitor, recognise, and combat age discrimination around breast cancer.

There is also a need to continue to work to address gaps in older people's awareness of the signs and symptoms of breast cancer and the risk of developing breast cancer in later life.

We also need to take steps to ensure that older people are not prevented from accessing diagnosis or treatment as a result of practical barriers caused by health and care needs or caring responsibilities.

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Introduction

About this report

This report examines the extent to which ageism plays a part in the diagnosis, treatment and care of people with breast cancer in England. It also examines some attempts by the Westminster government, and by healthcare systems at a local level in England, to address differences in breast cancer outcomes by age.

What is breast cancer?

Cancer is caused by mutations within cells that lead to unregulated growth causing tumours. When these changes occur in the breast tissue this is called breast cancer.

Breast cancer is divided into one of four stages, which describe how big the tumour is and whether it has spread. In addition, tumours may be graded according to how abnormal the cancer cells appear. Secondary (or metastatic) breast cancer occurs when breast cancer cells spread to other parts of the body causing tumours elsewhere.

Breast cancer is the most common cancer in the UK. In 2015, around 54,800 women and around 370 men were diagnosed. One in seven women in the UK develop breast cancer during their lifetime, and breast cancer is most common in older women.¹ With 11,400 people dying from breast cancer in the UK every year, it is the fourth most common cause of cancer death in the UK, accounting for 7% of all cancer deaths in 2016.²

While many risk factors are associated with breast cancer, the risk of developing breast cancer increases with age. Incidence rates for breast cancer in the UK are highest in people aged 90 and over.³

What is ageism?

Ageism can be understood as impacting any group where age is the basis of stereotyping or discrimination.⁴ Age discrimination is prohibited in the EU through Article 21 of the Charter of Fundamental Rights, which became legally binding through the Treaty of Lisbon in December 2009.⁵

There are three fundamental aspects of ageism:

- Stereotypes: what we think about people with respect to age
- Prejudice: what we feel about people with respect to age
- Discrimination: how we behave towards people with respect to age

These three fundamental aspects that constitute ageism can also be either:⁶ self-directed or other-directed; either conscious or unconscious (explicit or implicit); and either positive or negative.

In the UK, age is one of the characteristics protected from discrimination under law.⁷ The legislation extends protection from discrimination based upon age when using public services.

A ban on age discrimination in the NHS came into effect in 2012, in line with the Equality Act 2010. Under this legislation, it is unlawful for service providers and commissioners to discriminate, victimise, or harass a person because of their age. Age can no longer be used as a criterion for treatment or as a proxy for whether an individual would benefit from treatment. Instead people must be assessed individually, based on their own circumstances and needs.

However, it remains permissible for commissioners and planners within the NHS to use age as a basis on which to provide services where this is "objectively justified". For example, this might include the targeting of public health campaigns at particular age groups shown to have particular needs or responding to an individual's desire to mix with people from a similar age group to them.⁸

Non-discrimination is enshrined in the NHS Constitution, which states: "The NHS provides a comprehensive service, available to all irrespective of gender, race, disability, age, sexual orientation, religion, belief, gender reassignment, pregnancy and maternity or marital or civil partnership status."

Under the Equality Act 2010, public bodies, including NHS England and other NHS bodies, are required to publish equality information annually and equality objectives every four years relating to efforts

to promote equality across protected characteristics. However, there are no current NHS England equality objectives for the period 2016-20 that specifically focus on the issue of age discrimination.

Addressing inequalities in cancer outcomes

Assessing whether or not older people with breast cancer face age discrimination in relation to their diagnosis, treatment and care is not a simple task. It requires judgements to be made as to whether differences in the treatment and care people receive at different ages are the result of ageist attitudes and barriers or whether they are down to clinically relevant factors affecting those individuals. In the case of screening programmes, which are necessarily offered to broad populations, it requires careful judgements around the appropriateness of the use of age as a proxy for risk.

In this report we set out the evidence around the experiences and outcomes of older people with breast cancer, examine where inequalities exist and what has been done to address them, and consider whether there is cause for continued concern around the impact of ageism on older people with breast cancer.

Older people with breast cancer experience poorer mortality and survival outcomes

Breast cancer survival has almost doubled in the last 40 years from 40% to 78%.⁹ However, mortality is strongly related to age, and the highest mortality rates for breast cancer are seen in older people. Between 2014 and 2016, on average each year almost half (47%) of breast cancer deaths in the UK were in people aged 75 and over.¹⁰ As Figure 1 shows, age-specific mortality rates rise steadily from around age 30-34 and more steeply from around age 70-74. The highest rates for males and females are in the 90+ age group.

Figure 1: Breast Cancer (C50), Average Number of Deaths per Year and Age-Specific Mortality Rates per 100,000 Female Population, UK, 2014-2016

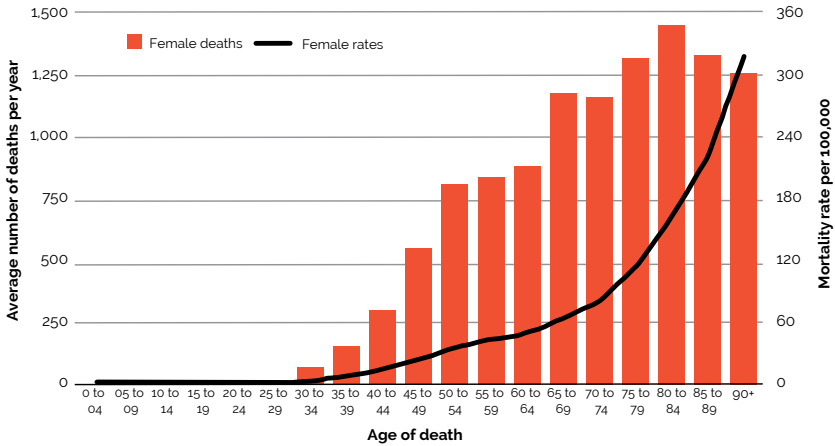
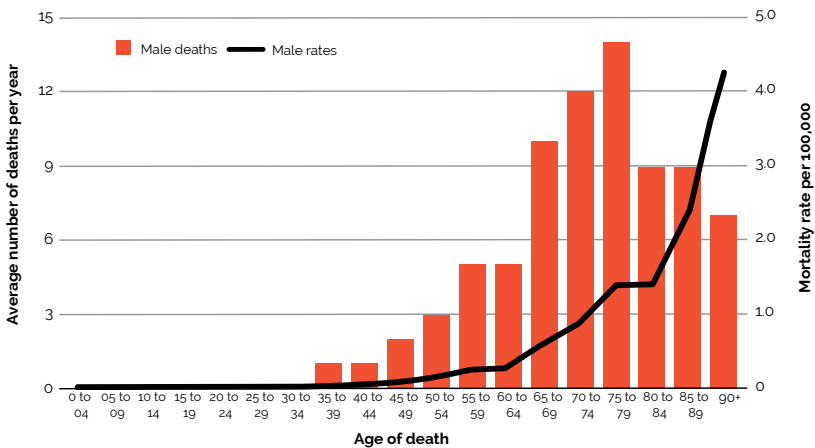
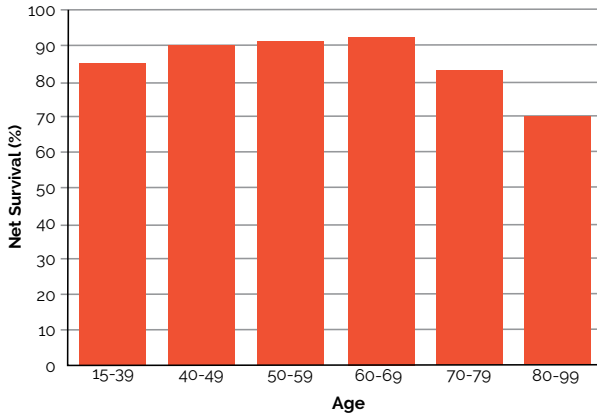


Figure 2: Breast Cancer (C50), Average Number of Deaths per Year and Age-Specific Mortality Rates per 100,000 Male Population, UK, 2014-2016



In terms of five-year survival rates, survival gradually increases from 85% in women aged 15-39 and peaks at 92% in 60-69-year-olds. However, survival falls to its lowest point of 70% in 80-99-year-olds for patients diagnosed with breast cancer in England during 2009-2013.¹¹

Figure 3: Breast Cancer (C50), Five-Year Net Survival by Age, Women, England, 2009-2013



Action to address differences in the outcomes of older people with breast cancer

Breast cancer mortality rates in the UK have decreased in nearly all age groups since the early 1970s.¹² However, rates have increased for the very oldest people with breast cancer, and discrepancies between age groups still exist.

Age groups	Change in mortality rates since 1970s
25-49	Decreased by 57%
50-64	Decreased by 50%
65-69	Decreased by 44%
70-79	Decreased by 27%
80+	Increased by 6%

There have been a wide range of initiatives on cancer in recent decades in the UK and several on breast cancer specifically to attempt to address these differences in outcomes for older people.

Addressing inequalities in cancer: National and local initiatives

Cancer has been a priority for successive governments over recent decades with the regular publication of national cancer plans to drive improvements since 2000. In recent years we have also seen a growing focus on addressing inequalities.

In 2007, the government acknowledged that serious improvements in cancer outcomes could not be made unless inequalities in outcomes for different groups were addressed. In response the *2007 Cancer Reform Strategy* focussed health leaders' attention on addressing cancer inequalities. In particular, the strategy highlighted the inequalities that exist for older people in awareness of cancer, in access to appropriate treatment and in participation in clinical trials, and it emphasised that our underlying assumption should always be that older people should be given the same level of treatment as younger people.¹³

At a national level, a National Cancer Equality Initiative (NCEI) was set up to bring together key stakeholders to develop research proposals on cancer inequalities, to test interventions, and to advise on the development of wider policy. It was also expected that further action would be taken at a local level by the, then, primary care trusts, with the support of their strategic health authorities and cancer networks.

The 2015 Cancer Strategy, *Achieving World-Class Cancer Outcomes: A Strategy for England 2015-2020*, recommended the piloting of a comprehensive care pathway for older people.¹⁴ Work on the pathway was taken forward by the UK-wide Expert Reference Group for the Older Person with Cancer (convened by Macmillan Cancer Support), which works to improve assessment and care planning for older people and to consider how the workforce may need to evolve to support older people.¹⁵

However, cancer services have not been immune to the wider churn that has occurred in the NHS since the Health and Social Care Act 2012. And as a result of reforms in the act, Cancer Networks, which had previously played a key role in providing data, support and

scrutiny to services and often drove initiatives around inequalities, were abolished. Since then cancer services have struggled, in particular with diagnostic and workforce capacity, and key cancer waiting targets have been missed.

In 2015 Cancer Alliances were created with the aim of taking on some of the lost responsibilities of Cancer Networks, such as overseeing the quality of local cancer services and improving cancer outcomes and patient experience. However there have been no specific objectives relating to reducing inequalities set out in recent iterations of guidance for Cancer Alliances.¹⁶

Third sector contribution

The third sector has also driven forward action to tackle age discrimination in the treatment of cancer. From 2010 to 2012, Macmillan Cancer Support, Age UK and the Department of Health tested interventions aimed at reducing undertreatment for older people with cancer across five pilot sites. Macmillan Cancer Support also ran a campaign to ensure older people received the treatment and care that was right for them. Moreover, the All-Party Parliamentary Group on Breast Cancer, supported by the major UK breast cancer charities, undertook an inquiry into older age and breast cancer in 2013, which it followed with a progress report two years later.¹⁷

Using data to drive improvement

In England, data about all new cases of cancer are collected by the National Cancer Registration and Analysis Service (NCRAS). The NHS has recognised that the collection and publication of such data can help determine where improvements are required, enhance understanding of why inequalities exist, and therefore can play a role in driving service providers to act.

Data from NCRAS informs the Cancer Dashboard, created for commissioners and providers to easily assess their performance against key cancer indicators. The dashboard allows for comparison of performance across the NHS in England and supports accountability.

An over 75 indicator is currently in development for the dashboard which will allow commissioners to determine whether discrepancies

in outcomes between age groups exist in their respective health systems and whether action should be taken.

Another key initiative using data to drive improvements around breast cancer in older people has been the National Audit of Breast Cancer in Older Patients (NABCOP). Established in recognition of the disparities that exist in treatment and outcomes for older people with breast cancer, NABCOP was established in 2016. The annual clinical audit evaluates the quality of care provided to women aged 70 years and above by breast cancer services in England and Wales by publishing high quality, comparative information from all NHS providers of breast cancer care. The audit sets out patterns of care and outcomes for women with breast cancer aged 70 years and over as compared with women aged 50-69 years and offers recommendations where improvements are needed. In this way the audit is intended to enable NHS providers to address discrepancies and to make improvements in the support they offer women with breast cancer.

Risks to, and gaps in, data collection

Data has been a key tool in the battle to drive improvement in cancer outcomes for older people generally and those affected by breast cancer specifically. However, we still do not have all the data we need.

Current gaps in the collection of cancer data leave us with a less than complete picture of the performance of breast cancer services, and we therefore risk missing inequalities that need to be addressed.

For example, 15.9% of newly diagnosed breast cancers do not have staging data recorded at the time of diagnosis.¹⁸ The 2018 national clinical audit of breast cancer services in England and Wales found that, for older age groups, recording data tended to be less complete than for other age groups, particularly in England.

Performance status (a measure of how well someone can carry on with activities of daily living while living with cancer – similar to measures of frailty in older people) at diagnosis is poorly reported, with only eight English NHS Trusts collecting this data for more than 80% of women.

The proportions of women whose ER and HER2¹⁹ status is tested and recorded are high overall, but the proportions drop among older age groups. For example, 87% of women in the 50-59 age group had their ER status recorded, and 86% in the same age group had their HER2 status recorded, whereas only 57% and 59% of women aged 90 or over had their ER status and HER2 status recorded respectively. While this may be because clinicians do not want to put those who are elderly or who have more advanced cancer through sometimes invasive stage-testing, it is clear that this lack of data could skew our picture of the diagnosis and outcomes of older people with breast cancer.

Data collection is even more incomplete for the diagnosis of secondary cancer, meaning that it is unclear what age inequalities may exist in the treatment and support provided to people with secondary cancer. Since 2013, it has been compulsory for NHS Trusts in England to record the number of people diagnosed with secondary breast cancer. However, a survey of English hospital trusts found less than a third were collecting data in full on their patients with secondary breast cancer.²⁰ This creates a lack of data on the number of people diagnosed and living with secondary breast cancer and prevents commissioners and providers from making informed decisions about the needs of their local populations. This in part may account for the lack of support and services provided to those with secondary breast cancer.

Furthermore, as NABCOP is a three-year project that is due to come to an end in 2019, there is concern that in future our data around age inequalities will be even weaker.

Addressing gaps in the collection and sharing of data for research, service provision and service improvements will be vital to the effective assessment of whether older people with breast cancer receive equal treatment. Cancer services must ensure they have adequate processes and resources in place to collect data and to upload it into the cancer registry. This must include data for secondary breast cancer.

¹⁹These refer to tests that can be done to establish the nature of the cancer, which give clinicians more information about the kinds of therapies to which cancers may be susceptible.

Are trends in the UK replicated across Europe?

Across Europe, breast cancer outcomes have been steadily improving over the last few decades. While the all-cancer European average age-standardised, five-year relative survival is 50.34% for men and 58.04% for women, for breast cancer this figure is 81.78%.²¹

However, despite improvements overall, variations exist in outcomes for people with breast cancer, among different age groups.²² Moreover, there is significant variation in outcomes across different European countries.²³

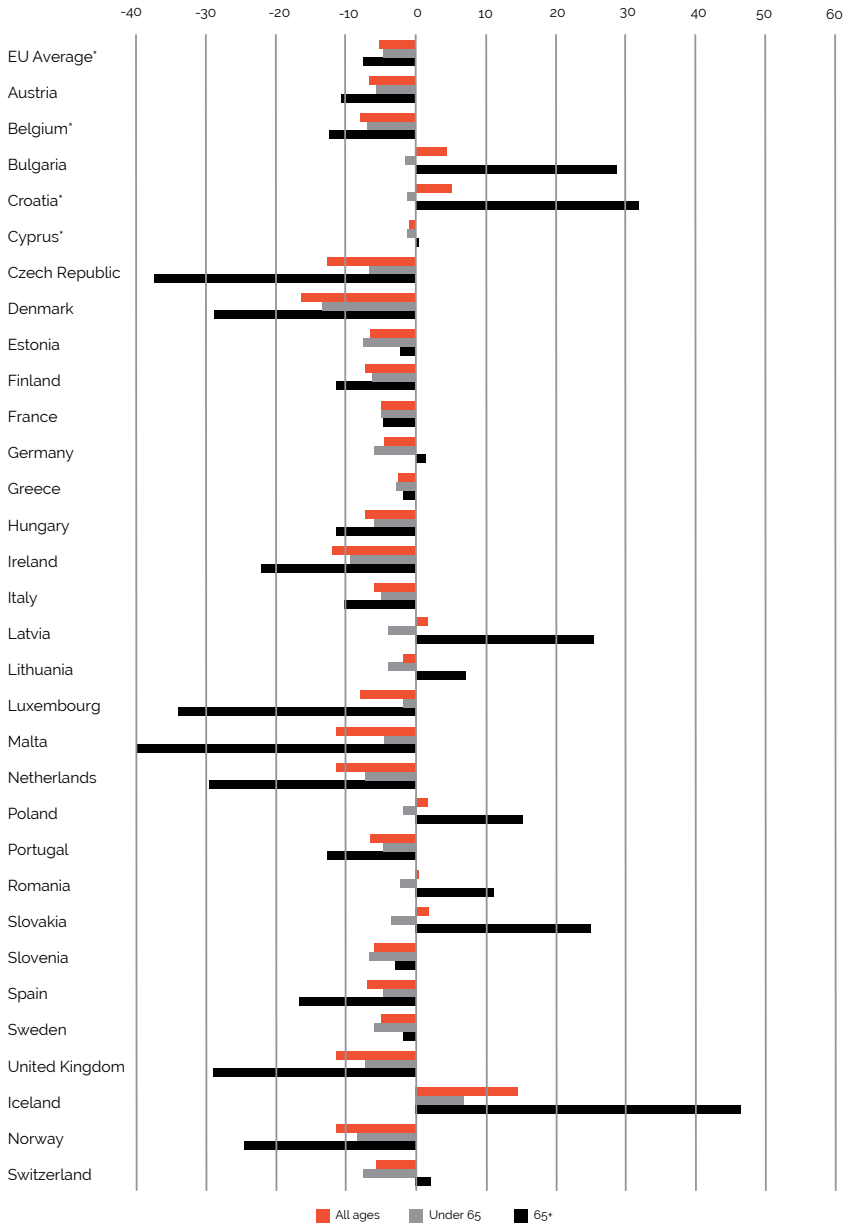
Over time, trends in deaths from breast cancer (standardised rates) have changed, for women overall as well as for those under 65 and aged 65+ (see Figure 4). Between 2001 and 2015, the EU average death rate due to breast cancer fell in all three age groups (i.e. overall, under 65, 65+). The UK experienced above average declines in all groups. Several countries also experienced large declines in the death rate for the 65+ group; however, several countries in Central and Eastern Europe witnessed large increases. No current EU Member State saw an increase in death rate for the under 65 group.

Differences in the implementation of mammography screening, the availability of new treatments, and healthcare expenditure could account for the variations in death rates, which are significant across Europe.

Mortality decreases are more likely to be observed in countries characterised by early and effective breast screening combined with rapid uptake of anti-cancer drugs. Indeed, improved treatment and response rates may explain the reduction in mortality in women below 50 years of age in several European countries including Denmark, Sweden, France, Germany, and the UK.

However, this does not explain why there has been an increase in breast cancer mortality in women over 70 years of age.

Figure 4: Change in Standardised Death Rate (per 100,000) Due to Breast Cancer - Women, 2001-2015



*Different time scales: EU average 2002-2015; Belgium 2003-2015; Croatia 2002-2015; Cyprus 2004-2015

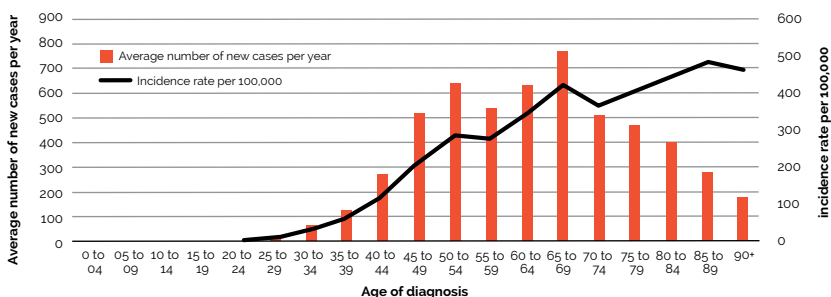
Why do older people with breast cancer experience poorer outcomes?

It is generally believed that three main causes are contributing to the higher death rate and poorer survival outcomes for older people with breast cancer: incidence, late diagnosis and poorer access to clinically effective treatments.

Incidence

First, there is a greater incidence of breast cancer among older people. While age is a risk factor for developing breast cancer due to the normal ageing process, other risk factors associated with breast cancer are also more prevalent in older people. 23% of cases of breast cancer are preventable. Preventable risk factors include being obese or overweight, high alcohol consumption and physical inactivity. Some of these risk factors are more prevalent in older people – for example prevalence of being overweight or obese is above 70% among all age groups from 45 upwards. The adult age group least likely to be obese is 16-24-year-olds, with 59% at normal weight and only 34% being overweight or obese.²⁴

Figure 5: Average number of new breast cancer cases per year and age specific incidence rates per 100,000 population, females, UK, 2013-15



These risk factors are modifiable, and taking positive action can reduce an individual's risk of developing breast cancer. Recent public health campaigns have been aimed at older people encouraging them to become or remain physically active and to eat and drink healthily.²⁵ Clearly this approach should be further encouraged in order to reduce older people's risks of developing breast cancer.

Late Diagnosis

Breast cancer is usually diagnosed in one of three ways: by the patient recognising something is wrong and presenting to a healthcare professional; via attendance at a mammography appointment through a screening programme; or by presenting at emergency care because condition and symptoms have deteriorated. Early diagnosis of breast cancer is known to increase chances of survival because treatment is likely to be more successful and, in some cases, less invasive and more tolerable for the patient. One-year net survival for breast cancer is highest for patients diagnosed at the earliest stage (stage I), and lowest for those diagnosed at stage IV. In 2016, 100% of patients diagnosed at stage I survived their disease for at least one year, versus 63% of patients diagnosed at stage IV.²⁶

Evidence shows that older people are more likely to be diagnosed at a later stage of breast cancer: late stage at diagnosis of breast cancer in England is more common in adults aged 80+ (23%), compared to those aged 60-79 (15%) and those aged 15-59 (16%).²⁷ The 2018 national clinical audit of breast cancer services in England and Wales found that women over 70 with invasive tumours were more likely to have larger tumours and/or metastatic disease.²⁸

There are also variations along age lines in how women with breast cancer present in clinical settings. In England, older women past routine screening age are more likely than younger women to be diagnosed with breast cancer via emergency presentation. However, the prognosis for women diagnosed via emergency presentation is much lower than when breast cancer is diagnosed through other routes. However, overall, the 2018 breast cancer audit noted that relatively few women were diagnosed via the emergency route.

Figure 6: Routes to diagnosis by age group (England) 2016

Age	Screen detected (%)	Two Week Wait (%)	GP referral (%)	Other outpatient (%)	Inpatient elective (%)	Emergency presentation (%)	Death certificate only (%)	Unknown (%)
Under 50	7	71	13	3	0	1	0	4
50-59	40	39	9	3	0	1	0	7
60-69	47	33	7	3	0	2	0	7
70-79	21	58	9	3	0	4	0	3
80-84	4	73	10	2	0	9	0	1
85+	1	71	9	3	0	14	1	2

Source: Routes to Diagnosis 2006-2016 workbook, Version 2.0, December 2018, Public Health England

The government included a new early diagnosis target as part of the NHS Long Term Plan published in 2019. The target states that three out of four of all cancers will be detected at stage one or two by 2028.²⁹ For breast cancer this target has already been achieved. However, this should not prevent action and progress in this area for older people.

Access to treatments

The 2018 national clinical audit of breast cancer services in England and Wales found that the picture of older women’s treatment, across some key elements, was similar to those for younger women, for example, in relation to access to a clinical nurse specialist (CNS), diagnosis via triple assessment (seen as the gold standard in diagnostic care) and time to treatment, the picture for older and younger women was similar.³⁰

Access to a CNS	
50–69 years	85%
70+ years	84%
Diagnosis via triple assessment on same day (early invasive breast cancer, and not referred from screening)³¹	
50–69 years	27%
70+ years	29%
Median time from diagnosis to treatment	
50–69 years	4.7 weeks
70+ years	4.6 weeks

However, the audit also found some differences in the treatment and care of older women compared to younger women, and these are discussed further below. The audit is supported by other evidence, which suggests older people with breast cancer are not always given the most clinically effective form of treatment.³²

Surgery

The 2018 national clinical audit of breast cancer services in England and Wales found that rates of surgical treatment for women with invasive breast cancer decreased with increasing age, from 96% for women aged 50–69 to 19% for women aged 90 and over.³³ The likelihood of surgery fell as performance status (an indication of frailty) decreased, although the size of the change was much larger for women aged 70 and over compared to women aged 50–69. This is despite research showing that, even at older ages, surgery and anaesthesia in breast cancer treatment carries very low risk of side effects and/or death.³⁴

Several reasons may be driving these lower rates of surgery. Clinicians may avoid offering older women surgery due to the higher risk of comorbidities, although research has demonstrated that surgery rates are lower independent of comorbidities.³⁵ A patient's own personal preference and the stage of their disease may also be important factors in withholding surgical treatment for those aged 80 or over.³⁶

Even when older women are offered surgery, evidence suggests that they are more likely to be offered and undergo a total mastectomy rather than breast conserving surgery (BCS).³⁷ Research also suggests that older women are less likely than younger women to be offered breast reconstruction surgery, despite evidence demonstrating that older women are similarly concerned about body image.³⁸ One study highlighted that reconstruction was rarely raised as a possibility by either clinicians or the patients themselves, although women would have liked to discuss the option.³⁹ Some of these women felt regret for missing the opportunity for reconstruction.

There is, therefore, evidence to support concerns that older women with breast cancer may not always be receiving surgical treatment, even in circumstances when this might be the most appropriate option for them. The type of surgery may be influenced by other treatments, as some evidence hints that older women may be more likely to receive mastectomies instead of BCS, to avoid postsurgical radiotherapy. Moreover, when surgery is offered, the surgical treatment might not best suit their needs and preferences. This underscores the need for a person-centred approach to treatment

decisions, recognising the impact of breast surgery on aspects of life such as body confidence and sexuality. More research into surgery on older women and why and when it is provided is also required.

Radiotherapy

Radiotherapy is recommended for certain breast cancer patients dependent on their type of cancer, the type of surgery they may have undergone, and their risk of recurrence.⁴⁰ Research has demonstrated that the use of radiotherapy as a part of breast cancer treatment declines with the patient's age.⁴¹ This is despite the fact that older women seem to cope relatively well with radiation therapy, specific conditions and comorbidities aside.⁴²

The 2018 national breast cancer audit found that women who were 70 and over were less likely to have radiotherapy than younger women. The proportion of women who received radiotherapy after BCS among women 70 and over also varied across NHS organisations but did not for women aged 50-69 (see Figure 7). This raises the possibility of different attitudes to ageing within different NHS organisations affecting the offering of radiotherapy to older women.

Figure 7: Radiotherapy treatment after BCS or mastectomy

	Women with DCIS	Women with early invasive disease with breast conserving surgery	Women with early invasive disease treated with mastectomy
50-69	57%	85%	37%
70 and over	85%	80%	31%

Chemotherapy

Chemotherapy refers to the treatment of breast cancer using anti-cancer drugs. Chemotherapy can either take place before surgery (neoadjuvant chemotherapy) or after surgery (adjuvant chemotherapy).

Decisions about whether to use chemotherapy as part of treatment are based on tumour characteristics (e.g. the risk of relapse and mortality), the patient's characteristics (e.g. their functional status, comorbidity, support networks, or risk of toxicities), and the patient's preferences.⁴³ Chemotherapy treatment often results in side effects, and some of the common ones include: feeling sick, loss of appetite, losing weight, feeling very tired, a lower resistance to infections, bleeding and bruising easily, diarrhoea or constipation, and hair loss.⁴⁴ Older age and/or comorbidities can complicate side effects, thereby heightening the risks of chemotherapy for some older patients. This can make the decision of whether to use chemotherapy even more challenging for both physician and patient.

Toxicity is likely to be a key factor when considering adjuvant chemotherapy in older people, because treatment-related mortality has been found to be related to age. Age is also a significant risk factor in congestive cardiac failure in women receiving adjuvant chemotherapy. One tool that can help with this is the Chemotherapy Risk Assessment Scale for High-Age Patients (CRASH), which is used to help judge the suitability of chemotherapy and the potential risks of side-effects and toxicities.⁴⁵

However, a key challenge for both physicians and patients in relation to decision around chemotherapy is a lack of high-quality data. In general, studies conflict when exploring the efficacy of chemotherapy for older women with breast cancer. Moreover, with few older women historically included in trials of chemotherapy, studies have been hampered in their ability to draw firm conclusions.⁴⁶ Nonetheless, it has been generally concluded that chemotherapy should not be withheld from women based on age alone.

The 2018 National Clinical Audit of Breast Cancer Services in England and Wales found that chemotherapy use declined with increasing age of the woman at diagnosis, regardless of tumour characteristics. However, the audit concluded that this "might be expected given the increasing levels of poor health among older women and the relative lack of trial-based evidence for older patients".

Endocrine therapy

There are two main routes for endocrine therapy for breast cancer: tamoxifen and aromatase inhibitors (AIs). The latter are used in the treatment of post-menopausal women. Primary endocrine therapy is usually offered to women who would be less able to tolerate surgery or who have expressed a preference to avoid surgery and is considered to be an appropriate treatment for those with a limited life expectancy of less than two to three years, either due to the patient having multiple comorbidities or because of extreme old age.⁴⁷ Endocrine therapy is also a popular therapy choice for older women as the biological features more typical of breast cancer in older women are often effectively treated hormonally.

However, it has been argued that the pattern of older women receiving treatment for breast cancer with endocrine therapy alone, based on the idea that they are less fit for surgery, is less a response to actual clinical circumstances and more a "trend" that emerged in the 1980s.⁴⁸ More evidence is required to determine if older women are likely to have been undertreated as a result of preconceived ideas or whether these treatment choices are justified objectively.⁴⁹

Why do differences exist?

The factors contributing to these differences in incidence, stage of diagnosis and treatment choices are complex and potentially varied. While not all age-related differences should be attributed to age discrimination, where differences exist, they should be investigated to ensure that discrimination is not a factor. While the ban on age discrimination removed more formal barriers that existed, less explicit and even unintentional ageism within the system and on behalf of patients and healthcare professionals may continue to exist.

Awareness, choice and beliefs

Older people with breast cancer may hold certain views and beliefs about their own health, life expectancy and breast cancer, which may impact their access to diagnosis and treatment.

It has been shown that among the general public there is a lack of awareness of the associated risk of breast cancer with age. A survey of 1,499 women carried out for Public Health England (PHE) found that two-thirds of women aged 70 years or over incorrectly thought that women of all ages are equally likely to get breast cancer.⁵⁰ Myths that older women are less or equally likely to develop breast cancer as younger women may also be perpetuated by the fact that the breast cancer screening programme has an age cut-off of 69/70 in the UK and other countries.

Older women also appear to be less aware of the signs and symptoms of breast cancer and of the importance of self-checking. One in five women aged over 70 years reported to never touch, feel or look at their breasts.⁵¹ They are also less familiar with the non-lump symptoms associated with breast cancer.⁵² Many breast cancers are found by women themselves, so this understanding is crucial if an improvement in early presentation among older women is to be seen.⁵³

Recent campaigns in England have focused on raising awareness of breast cancer specifically amongst older women in order to address misconceptions about incidence and the need for self-checking. PHE and Cancer Research UK's 2015 *Be Clear on Cancer* "Breast Cancer in Women over 70" campaign's key message was,

"1 in 3 women who get breast cancer are over 70, so don't assume you're past it." As older women more frequently self-report to be worried about "wasting" a GP's time than younger women, the campaign also encouraged older women to visit their GP if they had any concerns about their breasts.⁵⁴ This campaign has concluded, however, without a clear successor.

Another programme, Promoting Early Presentation (PEP), aimed to design and implement evidence-based interventions to promote cancer awareness and encourage people to present with any symptoms early. The intervention, designed by King's College London, was delivered by a radiographer during a woman's final routine screening appointment. One randomised control trial (RCT) demonstrated that this intervention increased older women's breast cancer awareness after two years, although evidence was inconclusive regarding the effect on self-referral to breast screening.⁵⁵ The All-Party Parliamentary Group (APPG) on Breast Cancer published a report, *Age is Still Just a Number*, calling for PHE to support further roll out of PEP through funding.⁵⁶ The APPG also called for PEP to be tested in a range of community-based healthcare settings in order to reach a range of different population groups, including ethnic minorities, deprived groups and women with additional needs.

As well as being unaware of their risk of breast cancer and concerned about "time-wasting", older people may harbour misinformed views about cancer and their ability to tolerate treatment. As discussed earlier, survival for breast cancer has improved dramatically over the previous decades, but people's understanding may not have kept pace. The APPG on Breast Cancer's inquiry into breast cancer and older people, concluded that older people prefer to receive information face-to-face and emphasised the importance of the availability of clinical nurse specialists for all age groups. The inquiry noted that "there is evidence that many older patients are willing to accept the toxicity associated with cancer treatment if it increases their chance of survival".⁵⁷ Access to tailored information will help people to make the decisions about their treatment and care that are right for them and will dispel any misconceptions.

The design of clinical trials

The design and delivery of clinical trials may be inherently ageist and consequently may be entrenching ageism in the treatment of breast cancer, first by restricting older women from joining trials in the first place and then, because older women have not been included in trials, restricting the availability of suitable treatments and evidence on what works for older women.

Evidence from the NHS England Cancer Patient Experience Survey shows that older people are less likely to have cancer research discussed with them.⁵⁸ Among the over 75s, 21% of patients report having research discussed with them, compared to nearly 37% of the 51 to 65 age group. Older people are also less likely to go on to participate in research. Of those who had research discussed with them, 55% of the over 75 age group participated compared to 65% for the 51 to 65 grouping.

Part of the reason for lower levels of discussion and participation may be because many older people would not meet the qualifying criteria to take part in a trial. In the past, many clinical trials excluded people on the grounds of their age, imposing upper age limits. Although these have largely been removed, criteria relating to fitness and/or frailty and prior treatment can act as barriers to participation and this has a range of ramifications:

- Clinical trials often allow patients access to the most scientifically advanced forms of treatment.
- Clinical trials are associated with more positive experiences of care as people are more likely to have access to other forms of support such as a clinical trial nurse and information.
- Limiting older people's access to clinical trials restricts the availability of clinical data and evidence for these older age groups. Without the evidence available, patients or their clinicians may find it challenging to make decisions about treatment.
- If clinical trials do not include older women, this impacts on the availability, efficacy, and appropriateness of treatment options. Much research focuses on treatment options for early breast

cancer. Since older women are more likely to be diagnosed with breast cancer at a later stage, this could suggest that older women are further being underserved because they do not have access to treatments for their more advanced disease.

Trials should be designed and conducted to include older women. The use of more real-time, real-world clinical studies would help to address the lack of evidence in this area.

Screening programmes

The potential influence of ageism in the design of routine screening programmes requires greater attention by policy-makers and clinicians, especially in the context of an ageing population.⁵⁹ Breast cancer diagnosed via screening tends to be at an earlier stage when successful treatment is more likely. Yet most screening programmes across Europe have an age range of 50 to 69.

The age ranges of these programmes may have been derived due to ageism, as historically, clinical trials of screening have typically excluded older women, especially those aged 75+, so there is little evidence on the value of screening for older women. More research is required into whether older women could benefit from breast screening.

However, extending breast screening to women over 69 is controversial because there are conflicting views on the efficacy and cost-effectiveness of routine breast screening. England already invites women aged 70 and is trialling extending its programme, offering screening to some women aged 47-73. Roughly five in six of the 80 breast screening services in England are currently participating in this trial, AgeX. Age extension trials and programmes with wider age targets, if conducted, should provide valuable evidence to support policymakers and clinicians in defining these age brackets with greater confidence.⁶⁰

As well as being offered screening services, women need to be encouraged to accept the invitation to attend. In England, the number of women aged 45 and over invited for screening increased by 3.7% from 2.85 million in 2015-16 to 2.96 million in 2016-17. The age group with the lowest uptake were those aged 45-49 at 65.2%, while for those aged 71-74 take-up was 68.5% in 2016-17. A range

of factors could be driving participation rates, including women's perceptions of the interplay of age and breast cancer incidence. Research is required to understand specifically whether ageism is at play.

A review of cancer screening services in England led by Sir Mike Richards was announced at the end of 2018. This followed problems with the breast screening programme, where it was found that some older women had not been invited to screening due to a misunderstanding of the interpretation of the upper age limit.⁶¹ The review will "look at how latest innovations can be utilised, including the potential use of artificial intelligence, integrating research and encourage more eligible people to be screened."⁶² The review will advise NHS England and Public Health England on the best operational delivery model for current screening programmes. This should include consideration of whether the age range should be extended and how to ensure increased uptake across all ages.

Clinical assessments

While more formal barriers to treatments were generally removed by the ban on age discrimination, ageism can still, intentionally or otherwise, impact the judgements that are made by clinicians around their older patients.

Studies have shown that when asked to make treatment decisions based on hypothetical cases, some clinicians base recommendations for chemotherapy on age alone.⁶³ Another study found that, as the age of the patient increased, clinicians were more likely to state that comorbidities and frailty were reasons that chemotherapy was not offered, even though these factors were not recorded in a third of cases.⁶⁴

Assumptions about what should be expected as a part of old age may also exist. One study has highlighted a higher prevalence rate and poorer management of pain in older cancer patients, attributing this to the fact that "pain is often considered an expected concomitant of aging", as well as to the fact that older patients do not tolerate some pain medication as well as their younger counterparts.⁶⁵

Recommendations on care for older women with breast cancer have recently been updated to include geriatric assessment. These assessments consider an array of factors when making treatment decisions for older patients. Some studies suggest that geriatric assessments modify treatment decisions, with nearly 21% having initial treatment plans changed as a result of geriatric assessment, most commonly from chemotherapy to supportive care.⁶⁶ One review of studies related to geriatric assessments found that the evidence is conflicted on their effectiveness in predicting adverse outcomes in cancer treatment.⁶⁷

The International Society of Geriatric Oncologists has undertaken extensive research into the area of needs assessments for older cancer patients. Disappointingly, this has not led to the recommendation of any one assessment tool in particular, although there is agreement that any such assessment tool should assess functional status, comorbidities, cognition, mental health status, fatigue, social status and support, nutrition and prevalence of geriatric syndromes.⁶⁸ A survey of 640 healthcare professionals by the Expert Reference Group for the Older Person with Cancer found that most respondents would not consider using many of the common assessment tools in clinical practice.⁶⁹

National Institute for Health and Care Excellence (NICE) guidelines and quality standards also provide a method for ensuring high quality and consistency in clinical care across the health system in England. However, in the most recent update to the NICE quality standard for breast cancer treatment and care in 2016, the commitment to age equality was removed. NICE justified this on the basis that age equality was a general principle across all guidelines, and therefore did not need explicit statement, however the removal of such an explicit statement was felt to be disappointing by key stakeholders including Breast Cancer Now.⁷⁰

Clearly there are potentially justifiable, age-related reasons for making different clinical decisions in relation to older people's treatment. The health of the person with breast cancer as well as the cancer itself may also impact clinical decisions about whether and how to treat. Older people are more likely to have other health and/or social care needs compared to younger people. This may restrict the treatment options open to them. In some cases, this may be

because of the increased level of risk associated with treatment, but in other cases because of a lack of evidence about the treatment of breast cancer with other comorbidities. Older people are also likely to be frailer, and again significant risk can exist when treating such people.

Finally, the biology of the cancer itself can be different in older people. Older people are more likely to be diagnosed with advanced breast cancer when fewer curative treatment options may be available. On the other hand, younger patients often require a combination of chemotherapy, surgery, and radiation to treat breast cancer, but older women are less likely to require chemotherapy and radiation to treat their disease because of the different types of cancers they tend to develop. For example, studies have shown that women aged 70 or older with small, oestrogen-sensitive tumours may not require radiation following a lumpectomy and can do well without this treatment. Women with these types of tumours often do not require chemotherapy either.⁷¹

Robust analysis of the data, and ongoing research and education around clinical attitudes will be needed to understand the extent to which clinical judgement is affected by ageist assumptions.

Practical barriers

Older people may experience practical barriers that prevent them from obtaining an early diagnosis or accessing treatment. Older people are more likely than younger people to have comorbidities (70% of older cancer patients have three or more comorbidities) as well as health and social care needs and many have caring responsibilities either for grandchildren or older partners.⁷² This may make it difficult for them to access services because they find it hard to get out and about or are concerned about those they care for. Older people are disadvantaged when health and social care professionals fail to recognise these factors as potential barriers to accessing treatment and fail to provide adequate and timely support. In fact, the APPG inquiry held in 2013 on older people and breast cancer heard evidence that older people had been delayed from accessing treatment because support for them to do so was not in place. Such delays can hamper a person's chance of successful treatment.

A diagnosis of breast cancer can in itself add to the health and social care needs that a person experiences due to the effects of the cancer or its treatment. For example, they may require practical help shopping, cleaning and washing, they may need support to travel to hospital, they may experience emotional problems and face increased financial burdens including travel and heating costs. Older people in particular may be more prone to or affected by certain symptoms of cancer or side effects associated with treatment. Those with breast cancer and comorbidities – who are most commonly older people – report fatigue and pain more often than other groups.⁷³ Older people with breast cancer may also be more prone to "chemobrain" (a condition linked to chemotherapy in which people report difficulties processing information)⁷⁴ and the impact of bone thinning from certain treatments may present more of a risk to health and independence to people in later life.⁷⁵ As a result, older people with breast cancer may have additional support needs compared to younger people.

However, many studies have found a significant disparity in levels of support between older and younger people, with older people with cancer receiving less social and practical support.⁷⁶ This is exacerbated by the shrinking of social networks that can occur as people age. Many pensioners have low incomes so are less likely to be able to afford to pay for external help.⁷⁷ These considerations may prevent older people with breast cancer from seeking help from a medical professional and accessing treatment.

To address this, from 2010 to 2012, Macmillan Cancer Support, Age UK and the Department of Health undertook pilot studies in five sites. The aim was to test the hypothesis that improved assessment methods of older cancer patients would result in improved access to appropriate cancer treatment and to assess whether action taken to address needs identified during assessment improved the likelihood of older people benefiting from treatment. The project made several recommendations on how to ensure services were "age friendly".

It is imperative that the needs of older people with breast cancer are recognised, and that appropriate support is provided, so that people can access the treatment they need. The third sector already provides much of this support including emotional support, information and financial grants. However, austerity has led to

social care budgets dramatically decreasing in recent years, thus restricting support offered by the state. Local health and social care leaders must ensure a joined-up approach to cancer care so that restrictions in the social care system do not lead to people being prevented from accessing the health care they need.

Older People Pilot Recommendations

Engage elderly care specialists as an active part of the cancer care team and adopt a multidisciplinary approach to the assessment and management of all patients.

Ensure an early and appropriate assessment of an older person is undertaken. The assessment should not only inform a dialogue about cancer treatment but should identify and address unmet physical, psychological and social support needs. Follow-up assessments should be undertaken at defined points throughout the treatment journey to identify and address changes in need.

Ensure everyone gets the maximum benefit from cancer treatment and associated supporting therapies by effectively managing other health conditions and incorporating reasonable adjustments into care planning to address additional needs.

Establish services and clear referral pathways for both outpatients and inpatients to address needs identified by assessment. This includes establishing clear links with voluntary sector agencies, social services, and specialist teams such as falls prevention teams, continence specialists and dementia specialists.

Ensure effective communication systems are in place to facilitate coordinated care and informed decision making.

Ensure all clinical and non-clinical staff are supported with the training and access to resources required to conduct appropriate assessment and follow-up care of all patients. In order to do this, it is vital that systems allow sufficient clinic time to undertake this work in day-to-day practice.

Living with and beyond cancer

In 2013, 340,000 older women (aged 65 and over) were living with breast cancer in the UK – and by 2040, there are projected to be 1.2 million older women living with breast cancer (representing almost three-quarters of all women living with breast cancer in the UK).⁷⁸ As increasing numbers of people are living with or after breast cancer, the health system has recognised the need to support people after treatment ends. This is because many people living with or beyond cancer will have ongoing needs as a result of the long-term consequences of cancer and/or treatment. These can include psychological needs such as depression and anxiety, as well as physical issues such as swelling in the arm (lymphoedema), restricted movement in the shoulder, heart problems and bone thinning.⁷⁹ Older people are at higher risk of longer-term adverse outcomes as a consequence of treatment.⁸⁰ Unlike their younger counterparts who have been shown to be mainly concerned with survival “at all costs” when considering their treatment options, older people are concerned about maintaining independence and the long-term consequences of cancer treatment can impact upon this.⁸¹ It is therefore crucial that older people are made aware of the long-term consequences of treatment and the impact this may have on their lives.

A pilot survey of patient-reported outcome measures (PROMs) from cancer survivors in England (including those with breast cancer) found that although quality of life tends to improve over time after treatment, some problems persist for long periods of time.⁸² Older age and the presence of other conditions were associated with poorer quality of life. Older people (aged 76+) are more likely than younger people (16-50-year-olds) to report difficulties with mobility, undertaking their usual activities and undertaking domestic chores.⁸³

The National Cancer Survivorship Initiative (NCSI), a partnership between NHS England and Macmillan Cancer Support, has led the redesign of cancer follow-up services and support for people living with and beyond cancer with the “recovery package”. The recovery package aims to give people with cancer more personalised care and support and includes “personalised care and support planning, based on Holistic Needs Assessments (HNAs) so that individual needs and concerns can be identified and addressed at the earliest opportunity”.⁸⁴ It is important that assumptions based on age are not

made when these assessments take place. For example, depression in older women with breast cancer is often overlooked in routine evaluations.⁸⁵

Those living with secondary breast cancer (when breast cancer cells have spread to other parts of the body) often receive poorer care and support than those with primary breast cancer. For example, only 55% of people with secondary breast cancer were given information about their condition at the time of diagnosis, and across Scotland, England and Wales, 42% of Hospital Trusts and Health Boards do not provide dedicated, specialist nursing care for people with secondary breast cancer.⁸⁶ Those with secondary breast cancer may also have a less positive experience of care: almost a fifth (19%) did not feel that all the healthcare professionals they came into contact with had a good understanding of them and their condition, and less than a third (31%) said that the different people caring for them always worked well together to give them the best possible treatment.⁸⁷

Breast Cancer Care is campaigning to improve diagnosis, care and support for people with secondary breast cancer, advocating that all those diagnosed with secondary breast cancer be given a Secondary Support Package. This includes access to a designated Clinical Nurse Specialist, a discussion of emotional, physical and information needs with a healthcare professional through a Holistic Needs Assessment, a Treatment Summary at the end of each significant phase of treatment, and a referral to a tailored health and well-being service.

End of life

Unfortunately, for some people, breast cancer will not be curable, and they will require care at the end of their lives. Whether or not to continue with treatment can be a major consideration for people with breast cancer as they near the end of life. Overtreatment of those at the end of life can lead to unnecessary pain and symptoms, unlike palliative care which aims to make a person as comfortable as possible. One study found that older people with advanced cancer were more likely than younger people to have their preferences honoured when they wanted to avoid life-prolonging care. However, they were less likely than younger people to have their preferences honoured when they wanted life-prolonging care. This may be

because such choices are counter to perceived wisdom about what older and younger people want and suggests that age biases may be influencing end-of-life decisions by healthcare professionals.⁸⁸

High quality care at the end of life includes early conversations about the end of life and early referral to palliative care services, so that interventions can be put in place and people can make choices about their care and about their death. For older people, referral to a geriatric oncologist is considered best practice, and care by a multidisciplinary team, which might include palliative care nurses, pharmacists and social care workers, is beneficial.⁸⁹ Ensuring older people are well informed about their cancer and prognosis and about the treatment and care options available to them is vital. Healthcare professionals must avoid making assumptions based on age and ensure older people are supported to exercise choice.

Conclusion and recommendations

The NHS in England has acknowledged and worked to address the poorer outcomes that exist for older people with breast cancer through the publication of audit data, research into the reasons behind inequalities due to age, and the piloting of potential interventions. While other countries can learn from the approach taken in England, more must be done to tackle age discrimination and to ensure that ageist attitudes do not impact the support offered to older people with breast cancer. All those with breast cancer, regardless of their age, deserve high-quality treatment and care that meets their individual needs.

The 2012 ban on age discrimination in the NHS removed formal barriers to older people accessing treatment and services. However, this means that any ageism experienced by older people with breast cancer in the health and social care system, whether intentional or unintentional, will now be less explicit, more subtle. It may also be harder to spot.

Age discrimination within the system may exist in several forms. The internalised views and beliefs of older people with breast cancer themselves may account for some differences in diagnosis and treatment at different ages. Also significant will be any assumptions made by health professionals about a person due to their age. The different health and social care needs people have at different ages and the barriers these present may also prevent older people from accessing treatment and care.

The use of assessments can help to guide health professionals to take a more person-centred approach, recognising the specific needs of an individual. However, the relevant clinical bodies have failed to recommend a particular assessment tool for use among older people, and evidence shows such tools are not being routinely used in clinical practice. In addition, even when these tools are used, unconscious bias can be hard to avoid.

It remains critical, therefore, that collection of data for all breast cancers be improved and that system leaders, commissioners and

providers continue to scrutinise data to determine where inequalities lie. Without this visibility it will be difficult for service providers and healthcare professionals to understand where age discrimination may exist and to determine what improvements may be needed.

To address the issues discussed above, the following needs to happen:

- The collection of data on breast cancer must remain a national priority. This must include collection of data for all older women with breast cancer.
- Working together, system leaders must address any inequalities that exist for older people with breast cancer. This should include ensuring clinicians are able to make informed assessments of their patients based on need not age and that they are aware of the potential for age prejudice.
- System leaders must ensure that wider care and support needs are not a barrier to accessing treatment for cancer. One way to address this would be through the roll-out of personalised care planning, as promised in the NHS Long Term Plan.
- The NHS should work with partners to ensure that all relevant clinical cancer trials include older cancer patients by default, where it is ethical and appropriate to do so. This will ensure that an improved evidence base is developed, enabling clinicians to make more effective decisions and provide meaningful advice. The use of more real-world testing would also help to address this evidence gap.
- In partnership with other relevant statutory and voluntary sector organisations, the NHS should promote age-relevant awareness-raising campaigns to ensure that older women are aware that age is a risk factor in developing breast cancer. This should seek to make clear that screening invitation cut-off ages do not correlate with lowered risk to help minimise this misconception. Campaigns should encourage older women to remain breast-aware and to make use of screening opportunities. Broader campaigns could help to address self-directed ageism in cancer treatment choices.

- As part of the NHS England review into cancer screening programmes, the effectiveness and implications of the AgeX trial should be considered. If this trial has proven to be effective, the NHS should consider further extensions to the national screening programme invitation procedures.

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