APPG on Breast Cancer

AGE IS JUST A NUMBER

The report of the parliamentary inquiry
into older age and breast cancer

This report has been produced in association with

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FOREWORD

STEVE BRINE MP

We are living through periods of great change in the NHS. As reforms take shape and a new health system evolves, we also find ourselves at a watershed moment for the care of older people with breast cancer. Too few people realise that risk of breast cancer increases with age, with currently a third of all breast cancers occurring in women aged 70 and over. Every year over 15,000 women aged over 70 are diagnosed with breast cancer, whilst most men who develop the disease in England are over 60 years.

Yet older women experience poorer survival outcomes, in part attributed to late diagnosis. We must take action now if we are to understand why this occurs and tackle this situation head on. The government is committed to saving more lives from the five big killer diseases and bringing mortality rates in line with the best performing countries across Europe. This report sets out a series of practical recommendations that can help achieve a much needed turnaround.

DAME JENNI MURRAY

Breast cancer is a concern for all women; it is a disease that can and does affect women of all ages. And yet, it is particularly prevalent in older women, a fact that is little known by women themselves. More than half of the women dying from breast cancer across the country today are over 70. There are around 340,000 women over 65 living with breast cancer in the UK and this is expected to increase to 1.2 million by 2040.

Yet the outcomes for older women are worse than for other ages, and we need to ask why this is and why this group has not experienced the levels of improved survival from breast cancer that other age groups have seen in recent years. We cannot and must not ignore the experiences of older women with breast cancer. While recognition of the barriers older women experience in gaining access to the same treatments and support services available to others has started to become apparent through research and the media, headlines alone will not change practice.

I therefore welcome this report as it presents an opportunity to act for older women. It is only by concerted action across health and social care bodies, researchers and others that we will see meaningful change. The urgency to act is clear – women do not have time to wait.

EXECUTIVE SUMMARY

In the last few decades huge advances have been made in the treatment of breast cancer. More women than ever before are surviving breast cancer, thanks to better awareness, screening and treatments. Despite this, older women are lagging behind.

There is evidence to show that older women with breast cancer are more likely to be diagnosed later. Older women are less likely to be breast aware than their younger counterparts and unlikely to be aware of the many non-lump signs and symptoms of breast cancer.

Once diagnosed, these women are less likely to be assessed for HER2 status and less likely to receive active treatment. Furthermore these women are also less likely than other age groups to seek additional information about their cancer and treatment options. In a society where we expect all people to be treated equally, discrepancies such as these raise serious concerns.

This Inquiry aimed to investigate these inconsistencies and establish how we can ensure older people are receiving the most appropriate treatment and support for them, based on their disease and their needs, not their age.

The Inquiry received written and oral evidence from key experts including medical experts, policy makers and older breast cancer patients. The evidence received showed that the reasons why older women are often at a disadvantage are complicated and more work is needed to fully understand the challenges facing older people with breast cancer.

This report makes recommendations aimed at improving the experiences of and outcomes for older breast cancer patients. Where there is not enough evidence to suggest a change to practice, the report recommends research and pilot studies to ensure that future changes are more likely to succeed.

NHS England, Public Health England and Clinical Commissioning Groups are asked to consider these recommendations as a priority and implement changes to reflect them. In our ageing society, breast cancer incidence is increasing every year. If we do not act to improve the situation for older people with breast cancer, we will fail to realise the promise of better outcomes for everyone affected by this devastating disease.

RECOMMENDATION 1 Invest in sustained breast awareness campaigns for breast cancer in older women	Early findings from the *Be Clear on Cancer* 'Breast Cancer in Women Over 70' pilot campaigns show that this has been successful in increasing breast awareness. Public Health England should support on-going evaluation of the campaign and, if appropriate, secure funding for national roll out.
RECOMMENDATION 2 Support targeted interventions for increasing breast awareness in older people	The Promoting Early Presentation (PEP) intervention targets older women at their final breast screening appointment to inform them about their continued breast cancer risk and general breast awareness. This pilot programme should be rolled out further to better understand the full benefits of this intervention and its role in other community settings. Other breast awareness interventions that target women who do not attend screening should also be evaluated and supported.
RECOMMENDATION 3 Gather evidence for the benefits and risks of breast screening for women above the current screening age	Women are not routinely invited for breast screening past the age of 70. This is due to the lack of evidence of the benefit of screening in this age group. The current 'age extension trial' is aiming to address this. This programme should be extended past 73 to 76, and if appropriate, should be further extended to screen women aged between 77 and 79.
RECOMMENDATION 4 Develop a practical evidence-based tool to measure patients' fitness for treatment to help inform decisions and ensure effective management of co-morbidities	It remains unclear whether older breast cancer patients are receiving the most appropriate treatment based on their condition and health rather than their age. NHS England should support a programme of work to help develop or identify a suitable assessment of frailty and ensure roll out throughout the NHS.
RECOMMENDATION 5 Support better use of data to establish the most appropriate treatments for older people with breast cancer	Data collection is essential to understand the decisions made about older people's cancer treatment. Public Health England should support continued data collection relating to breast cancer diagnosis and treatment, including data on co-morbidities and frailty.

RECOMMENDATION 6 Ensure that the requirements of older people are fully taken into account when developing and updating guidelines	While breast cancer guidelines should apply to older breast cancer patients, very few make this explicit. Geriatricians should be involved in the future development and update of guidelines and the needs of older patients should be taken into account.
RECOMMENDATION 7 Ensure all older breast cancer patients have the information they need about their treatment, in the way that they wish to receive it	Information provision is an essential part of breast cancer treatment. While older patients often prefer to receive information directly from healthcare professionals, this is not always possible. All breast units should make sure a range of healthcare information in a range of formats is on offer to all patients to ensure that they can access the information they need in the way they wish.
RECOMMENDATION 8 Ensure all breast cancer patients have their needs fully assessed	All breast cancer patients, including older people, should have all of their needs assessed to ensure that any additional support services they may require are made available to them. NHS England should commission a review of available needs assessment tools to identify a practical and cost-effective tool for use in the breast clinic.
RECOMMENDATION 9 Ensure all necessary support services, including psychosocial support, for breast cancer patients are in place to allow cancer treatment to begin within cancer waiting time targets	National cancer waiting time targets state that cancer treatment must begin within a set time period from diagnosis or referral. However, support services needed by older patients so they can receive treatment, are often not in place within these time periods. Local agreements are needed, with all relevant service providers, to address this.

INTRODUCTION

In January 2013 the APPGBC assembled a panel of nine MPs and peers, chaired by Steve Brine MP, to undertake an Inquiry into the diagnosis and access to treatment, care and support for older people with breast cancer[i].

[i] For the purposes of this inquiry, 'older people' are defined as those over 65.

[ii] The APPGBC is co-chaired by Steve Brine MP, Annette Brooke MP and Sharon Hodgson MP and is supported by Baroness Delyth Morgan as vice-chair.

The All Party Parliamentary Group on Breast Cancer (APPGBC)[ii] is one of the most dynamic cross-party groups in Westminster and is committed to keeping breast cancer high on the political agenda. This Inquiry was supported by Breakthrough Breast Cancer, Breast Cancer Care and Breast Cancer Campaign. As well as providing the secretariat to the APPGBC, Breakthrough Breast Cancer has led the evidence review and the drafting of this report. As health is a devolved matter, this Inquiry is limited to England.

More than half of breast cancer deaths in the UK are in women aged over 70[9].

People are now living longer than ever before, resulting in a worldwide increase in cancer diagnoses in older people. Breast cancer risk increases with age and a third of breast cancer cases in the UK now occur in women over the age of 70[1]. Breast cancer in older women is predicted to roughly quadruple over the next three decades[2]. Women in this age group with breast cancer are more likely to die from the disease than their younger counterparts[3]. Although breast cancer survival rates are increasing, five-year survival for women aged 70-79 is 81 percent, compared to 90 percent for women aged 60-69[4].

By 2040, almost three-quarters of all women living with breast cancer in the UK will be aged over 65. The proportion of older women (aged 65 and over) living with breast cancer will increase from 59 percent today to 73 percent in 2040[2].

Discrimination on the basis of age in health and social care has been unlawful since October 2012 when new provisions of the Equality Act 2010 came into force[5]. In addition, documents such as the National Institute for Health and Care Excellence (NICE) Breast Cancer Quality Standard, the NICE guidelines for early and local advanced breast cancer and the NHS Constitution make it clear that treatment decisions should never be made on the basis of age[6,7,8].

Today there are around 340,000 older women (aged 65 and over) living with breast cancer in the UK. By 2040, this is projected to increase to 1.2 million – an almost four-fold increase[2].

Despite this, it appears that many older people may not be receiving the level and type of support, treatment and information they need. The APPGBC therefore set out to understand more about these variations and identify the barriers preventing all patients diagnosed with breast cancer having access to the services, treatments and care that will benefit them most, regardless of their age. The Inquiry Panel received written evidence from a range of clinical experts, organisations and patients as well as hearing oral evidence from experts and patients in three evidence sessions. These sessions focused on the three themes of the Inquiry – breast cancer risk and early detection, access to gold standard treatments and access to information and support. After reviewing all of the evidence heard and received, this report makes recommendations in these three key areas to ensure that older breast cancer patients receive the treatment and care that is most appropriate to them.

Older women are 46 per cent more likely to be diagnosed with an advanced stage of breast cancer than younger women[10].

Whilst the APPGBC acknowledges the importance of the care and support of men with breast cancer, the evidence submitted and subsequent recommendations reflect that the overwhelming majority of research and interventions relate to breast cancer in older women. In addition, the Inquiry Panel is aware that, historically, older people have been excluded from clinical trials, which has led to a lack of evidence regarding the treatment of older people with breast cancer. However, this Inquiry has focused on the treatment and information needs of older people, rather than research.

“I am really pleased the all-party group are conducting this Inquiry into older people with breast cancer and wish it well. We have made solid progress in fighting breast cancer in recent years, but there is so much more to do. Of course we must do better with cancer outcomes across the board in this country and that absolutely includes breast cancer. I look forward to seeing the final report and the specific recommendations within it. I’ve asked the Department for Health to engage with the Inquiry and respond to its recommendations.”

Prime Minister David Cameron

TACKLING LATE PRESENTATION

The earlier breast cancer is detected the better the chance of successful treatment. Older people are more likely to be diagnosed with breast cancer later, when the disease is more advanced.

BACKGROUND

Approximately 20 percent of breast cancer cases in people over 80 years of age are identified through emergency presentation[iii], compared with four percent of breast cancer cases across all age groups[11].

Later presentation is one of several factors that have been linked to poorer breast cancer survival in older women[12]. Increased time to identifying a sign or symptom of breast cancer, increased time to seeking the advice of a healthcare professional, and/or increased time to receiving appropriate diagnosis and referral to specialist services can all contribute to a later presentation and diagnosis for breast cancer[13]. A lower rate of breast screening in older women may also be a contributing factor.

The Inquiry heard that key to tackling late presentation is improving awareness of breast cancer amongst older people, in particular age-related risk, and encouraging older people to seek the advice of their doctor if they notice any unusual breast changes. Additionally, the Inquiry has found that in order to form a judgment with regards to breast screening in women over 70 years, further research is required.

[iii] An emergency route via A&E, emergency GP referral, emergency consultant outpatient referral, emergency transfer, emergency admission or attendance.

RECOMMENDATION 1

Invest in sustained breast awareness campaigns for breast cancer in older women

Most breast cancers are found by women being breast aware, that is, knowing what their breasts look and feel like normally, being on the lookout for any unusual changes and following-up any changes with a healthcare professional as soon as possible. Evidence suggests, however, that older women are less likely to be breast aware, with one in five women aged over 70 years reported to never touch, feel or look at their breasts[14].

Knowing the many different signs and symptoms of breast cancer is a vital component of being breast aware. However, many older women are unlikely to be aware of the many non-lump signs and symptoms[15].

> “Prior to my diagnosis I only knew that a lump in the breast could be cancer.”
>
> **Written submission received from anonymous older breast cancer patient**

Awareness of age-related risk for the development of breast cancer has been found to be poorly understood across the UK[15,16]. The frequent use of younger women in breast cancer campaigns was identified during the Inquiry as contributing to the misconception that breast cancer is a disease more common in younger women.

> Cancer awareness campaigns aimed at younger women may have the unintended consequence of making older women think they are less likely to get cancer.
>
> **Written submission received from the Royal College of Surgeons**

The 'Breast Cancer in Women Over 70' component of the Department of Health's *Be Clear on Cancer* campaign was developed in recognition of the need for older women to be aware of their risk and the importance of targeting this age group.

The campaign was initially piloted in 2012 in seven local areas[iv] and incorporated a number of initiatives, including health information publications for general practitioners (GPs) and patients, campaign posters and personalised letters to women over 70 years. These local pilots were followed by a regional pilot with the additional inclusion of television and print media. This pilot concluded in March 2013.

Early findings from the local pilots suggest that the campaign has been successful in raising awareness of breast cancer in older women, demonstrated by an increase in the number of breast cancer referrals made by GPs for possible signs and symptoms of breast cancer[v]. Evidence presented to the Inquiry has also indicated that the *Be Clear on Cancer* campaign more broadly has been effective in raising cancer awareness amongst healthcare professionals[17,18].

Whilst further information on the impact of the local and regional pilots will not be available until mid-2013, it remains essential for all older women in England to have timely exposure to these breast awareness messages.

Recommendations

It is strongly recommended that as the overarching *Be Clear on Cancer* campaign develops, the specific focus on breast cancer in women over 70 should not be lost, given the clearly identified need for tailored breast cancer awareness messages for older women.

Public Health England should support on-going evaluation and, if appropriate, national roll-out of the *Be Clear on Cancer* 'Breast Cancer in Women Over 70' campaign across England by 2014.

RECOMMENDATION 2

Support targeted interventions for increasing breast awareness in older people

Across the entire population in England, barriers to timely presentation for cancer symptoms have been linked with worry associated with wasting a doctor's time in addition to embarrassment and fear of what might be found. One study has shown that for older women, this issue is amplified[19]. Whilst approximately 35 percent of young women will report being worried about wasting a doctor's time, for older women this figure is closer to 70 percent.

Poor knowledge of age-related risk for breast cancer is also of particular concern in older women, and this has been attributed in part to women incorrectly assuming they are no longer at risk of developing the disease after routine NHS breast screening invitations cease.

[iv] Lambeth, Southwark and Lewisham, Brent and Harrow, South Yorkshire and Bassetlaw, Brighton and Hove City, Medway, Berkshire (East and West), and Lancashire and South Cumbria.

[v] There was a 13.2 percent increase in the number of non-urgent GP referrals for breast cancer symptoms following implementation of the pilot campaign, compared with areas that did not receive the campaign where there was only a 0.7 percent increase.

> “I had seen information [about breast cancer signs and symptoms] but since I was over 70 I assumed it did not apply to me. I had no more invitations for mammogram tests after the age of 70.”
>
> **Written submission received from anonymous older breast cancer patient**

The Inquiry found that, in addition to broad awareness campaigns, more needs to be done on an individual level to ensure that older women know that their risk of breast cancer increases as they age. In addition, these women need to be confident and competent to regularly check their breasts and be made aware that opportunities for breast screening do not cease along with routine breast screening invitations.

The Promoting Early Presentation (PEP) Intervention is an evidence-based targeted intervention developed to increase breast awareness in older women. The PEP Intervention provides women with information on the importance of breast awareness, the signs and symptoms to look out for and also tackles the misconception that women over 70 are no longer at risk of developing breast cancer. It was developed by researchers at King's College London and is designed to be delivered by a radiographer during a woman's final routine invitational breast screening appointment[20].

A pilot in four NHS breast screening services showed that the PEP Intervention is effective in increasing breast awareness in older women, with a fourfold increase in breast awareness in older women who have received the PEP Intervention compared with those who haven't, three years following the intervention[21].

While it is too early to know whether increased breast awareness as a result of the PEP Intervention will lead to behaviour change and subsequently improve breast cancer survival in older women, the Inquiry Panel felt these early findings prompt further roll out and testing of the PEP Intervention.

There are also a range of smaller, grass roots projects, such as those piloted as part of the National Awareness and Early Diagnosis Initiative (NAEDI)[22] and those operated by charities such as Breast Cancer Care[23], which are aimed at improving breast awareness throughout England. As the Health and Social Care Act 2012 continues to take shape, organisations working on these initiatives should be encouraged to put forward any findings to local NHS Health and Wellbeing Boards to drive local initiatives to improve breast awareness in older women.

Recommendations

Funding should be secured for Public Health England to support further roll out of the PEP Intervention and gain stronger evidence for its benefits for improving breast awareness and survival outcomes for breast cancer in older women.

In addition to its use in NHS breast screening services, King's College London Early Cancer Presentation Group should be supported to test the PEP Intervention across a variety of community-based healthcare settings to maximise exposure to a range of population groups, and where possible a focus on ethnic minority and deprived groups in England, and women with additional needs.

Other grass-roots interventions, including those targeting women who do not attend screening, should be evaluated and support given to those that are shown to deliver highest impact in raising breast awareness in older women.

RECOMMENDATION 3

Gather evidence for the benefits and risks of breast screening for women above the current screening age

Breast screening plays an important role in the early identification and diagnosis of breast cancer. In England, women between 50 and 70 years of age are routinely invited every three years for breast screening by the NHS Breast Screening Programme[vi], but whilst breast screening is still available to women over 70, they are required to make their own appointments.

> "On the presumption of benefit, we allow women to refer themselves... We stop invitations simply because we don't have evidence to go beyond the age of 70."
>
> **Professor Julietta Patnick, NHS Screening Service, APPGBC oral evidence session**

Older women are not routinely invited for breast screening due to a lack of evidence to determine whether screening would be of greater benefit or harm, as historically older women were excluded from these types of research studies. One of the risks associated with breast screening is the possibility of overdiagnosis (the diagnosis of breast cancers that would not cause harm during a woman's lifetime).

In an effort to rectify this lack of evidence for the risks and benefits of breast screening in older women, several breast screening services in England have been participating in an age-extension trial, to extend routine breast screening invitations to women from 47 to 73 years. To date one million women have participated in the trial. The current trial will enable researchers to determine whether breast screening women up until age 73 will reduce the number of deaths due to breast cancer in the future. However, in order to gain further evidence for breast screening in older women, up until age 76, investigators want to extend the age-extension trial for a further round of invitational breast screening.

The Inquiry Panel were convinced that further investigation of the risks and benefits of breast screening is vital for improved decision making and future targeting of the NHS Breast Screening Programme. As life expectancy continues to climb, however, the panel also felt, if viable, a further round of screening should be incorporated into the trial to gather evidence for the benefits of breast screening in women up until age 79.

Recommendations

Funding should be secured from NHS England for Public Health England to support an additional round of invitational breast screening as part of the NHS breast screening age-extension trial. This would extend invitations to study participants aged 74-76 years of age for an additional round of screening. It is important that this is implemented quickly to ensure that those who have participated in previous rounds of the study can continue to be involved in the trial.

Providing there is sufficient take-up in the 74-76 age range, the age extension trial should be further extended to invite participants between 77 and 79 years of age.

[vi] Some screening services in England participating in the age-extension trial are offering screening to women aged between 47 and 73 years.

ACCESS TO GOLD STANDARD TREATMENT

There is evidence that older patients are experiencing inequalities in access to cancer services and treatments, which may be having a negative impact on their survival[3,24,25,26].

BACKGROUND

The 2007 Cancer Reform Strategy reported that there were 'major inequalities in access to services and outcomes according to age', which the strategy aimed to reduce[27]. There are differences in tumour characteristics associated with age that may impact on survival in older women but this does not account for all of the observed disparities[3].

The NICE Breast Cancer Quality Standard states that people with early invasive breast cancer, irrespective of age, should be offered surgery, radiotherapy and appropriate systemic therapy, unless significant comorbidity precludes it[6]. This is supported by the International Society of Geriatric Oncology (SIOG) which has conducted a review and published a set of recommendations (last updated in 2012) on the treatment of older women with breast cancer. They state that patients over 70 should be offered 'screening to assess fitness for treatment, the same surgery options as younger patients, radiotherapy following breast conserving surgery, and that decisions on chemotherapy should not be age-based'[28,29]. However, there is evidence that these recommendations are not being followed, with inequalities in treatment occurring in England[30], and it is important to understand the reasons why this might be happening.

Although some treatments, such as chemotherapy, may not be of overall benefit for a particular patient due to underlying health problems, such decisions should be based on the patient's fitness rather than their chronological age. Studies asking clinicians to make treatment decisions on hypothetical cases have shown that some clinicians base recommendations for chemotherapy on age alone[31,32]. Another study found that chemotherapy was less likely to be offered to older breast cancer patients and, as age increased, clinicians were more likely to state that co-morbidities and frailty were the reasons it was not offered, even though these factors were not recorded in a third of cases[33]. Patients may also choose not to undergo treatment. However, it is yet to be established whether these reasons account for all of the observed disparities in treatment of older breast cancer patients. The Government has confirmed that responsibility for assessing reductions in inequalities in breast cancer services will be a matter for NHS England[34].

RECOMMENDATION 4

Develop a practical evidence-based tool to measure patients' fitness for treatment to help inform decisions and ensure effective management of co-morbidities

More people than ever before are now sustaining good health further until an older age[35]. Older people are increasingly able to tolerate cancer treatments which would have been deemed too aggressive in the past, and research has shown that age alone is not a good predictor of how a patient will tolerate cancer treatment[36]. There is evidence that many older patients are willing to accept the toxicity associated with cancer treatment if it increases their chance of survival[37,38].

While it is true that older breast cancer patients are more likely to have particular needs than their younger counterparts, for example a recent study reported that 70 percent of older cancer patients had three or more co-morbidities[39], there is evidence that chronological age is being given undue weight in treatment decisions.

An accurate, reliable and practical method of assessing patient frailty is required to properly inform treatment decisions. Such assessments are already performed in other disease areas in England[42]. Glenfield Hospital in Leicester has pioneered the use of functional assessment for breast cancer patients considered unfit for surgery, and has reported increased surgery uptake, partly due to assessment preventing the overestimation of frailty[40].

Comprehensive Geriatric Assessment (CGA) aims to make treatment decisions on the basis of functional status rather than age to ensure that patients receive the most appropriate treatment. Assessment also enables the identification and management of underlying health problems. Many causes of frailty in older people can be successfully treated, enabling patients to better tolerate the effects of cancer treatment. A recent study reported that use of such an assessment identified that nearly 40 percent of older cancer patients required changes to the management of at least one condition[41]. Assessment and effective management of underlying health issues is likely to result in an overall cost saving[41,42].

There are several quick assessments that could potentially be used for this purpose, for example the Timed Up & Go (TUG) assessment which has been found to predict the risk of early death in older cancer patients receiving chemotherapy[43] and postoperative complications in older cancer patients undergoing surgery[44]. However, a systematic review of different methods of assessment in elderly cancer patients concluded that many assessments were lacking in sensitivity and specificity and that using the full CGA may be most beneficial[45]. The Inquiry heard from experts about the use of a CGA for older people with cancer and evidence showed that when used, clear benefits of this were seen[46]. However, some experts felt that the CGA was a lengthy process which would be difficult to implement in a busy breast clinic setting. In addition, it was felt by some clinical experts that it encouraged clinicians to differentiate patients by age before assessing them for treatment, thus compounding the problem this is designed to address. Experts also identified the need for closer working between oncology and gerontology departments.

> "Most geriatricians don't see cancer as their business at the moment. And most oncologists and surgeons definitely don't see geriatrics as their business, even though the great majority of our patients are in that population."
>
> **Professor Malcolm Reed, APPGBC oral evidence session**

Experts are in agreement that further research into frailty assessment is needed. A taskforce from the SIOG is currently investigating which assessments should be used, how assessment should be implemented and how treatment decisions will be influenced. However, there is also a need for an England-specific tool to be investigated. A frailty assessment tool would need to be used in conjunction with other needs assessments, as detailed in Recommendation 8.

Recommendations

NHS England should identify or develop a suitable frailty assessment for people with cancer and monitor implementation of this as part of the Cancer Peer Review Programme.

The professional organisations representing oncologists and geriatricians, including the Royal Colleges of Radiologists, Surgeons and Physicians and the British Geriatric Society, should establish a model for joint working between these specialities to ensure that decisions regarding the treatment and care of older people are appropriate and as informed as possible.

RECOMMENDATION 5

Support better use of data to establish the most appropriate treatment for older people with breast cancer

The National Cancer Intelligence Network (NCIN), now part of Public Health England (PHE), collects, holds and processes extensive data on cancer patients in England. Whereas information on surgery has been collected nationally for some time, data collection on chemotherapy and radiotherapy began more recently. The Systemic Anti-Cancer Therapy (SACT) information standard covers all patients receiving cancer chemotherapy in England as treatment for all solid tumours and haematological malignancies. This is currently being rolled out and from April 2014 all trusts must submit full data. Similarly, since April 2009 all facilities providing radiotherapy services have been required to return data in the National Radiotherapy Dataset (RTDS) to the National Cancer Services Analysis Team (NatCanSAT)[47]. The joining of regional networks under Public Health England (PHE) should enable easier analysis of nationwide data.

These datasets will allow much to be learnt. For example, it will be possible to analyse data on treatments and outcomes for different types of breast cancer stratified by patient age. This will allow researchers to establish which treatments may give the best outcomes for older patients and also to validate treatment decision making tools for use in older people.

The pressing question is whether the reduced level of diagnostic tests and treatment observed in older breast cancer patients is justified. If patients' co-morbidities and the outcome of frailty assessment (see Recommendation 4) were recorded and reported, researchers would be able to use these data, along with data on treatments and outcomes, to establish whether older people with breast cancer are being inappropriately undertreated.

Currently it is possible to obtain data on co-morbidities that result in hospital admissions. However, many co-morbidities affecting older people will not result in their being admitted as inpatients or day cases and it is important to collect this information too as it may impact on treatment decisions. This could be done using data from GPs which should be available in the latter part of 2013. Data is not collected on treatments received for co-morbidities outside of the NHS. While frailty assessment is not yet routinely conducted (see Recommendation 4), when it is the data must be collected and reported, and stratified by age as is performed for other NCIN data. A coding system for frailty data will need to be developed to enable consistent reporting. It can then be used to monitor whether older cancer patients are receiving an acceptable standard of care.

A key use of data collected by the NCIN is for analysis and reporting on the performance of individual Multi Disciplinary Teams (MDTs), and subsequently used to identify teams that are falling below the national average in their level of treatment and outcomes for older patients, so they can be investigated and improved. It can also identify centres of good practice. As cancer data is uploaded monthly, any outliers or significant changes can be picked up quickly. It is planned that performance data will be routinely fed back to Clinical Commissioning Groups (CCGs), clinicians and MDTs in the future, which can be used to review performance, and if necessary, set out ways to improve.

The Government has stated that equity audits will also be included in future iterations of the National Cancer Peer Review Programme self-assessment reporting specifications, with MDTs requested to comment on how many patients by equality characteristic (race, age and gender) they have diagnosed or treated in the previous year[34].

Recommendations

Public Health England should ensure that data on the diagnosis and treatment of older women with breast cancer, including information on co-morbidities and frailty, is collected and analysed.

Public Health England should ask the NCIN to conduct an analysis of the diagnosis and treatment of older women with breast cancer to identify differences in experience both nationally, compared to other age groups, and regionally to identify differences in performance at the local level. This information should be reported to Ministers, NHS England and CCGs.

RECOMMENDATION 6

Ensure that the requirements of older people are fully taken into account when developing and updating breast cancer guidelines

NICE and the Association of Breast Surgery (ABS) guidance sets the standard of care delivered by the NHS that everyone should expect to receive. The 2009 NICE guideline *Early and locally advanced breast cancer: diagnosis and treatment* states, 'Treat patients with early invasive breast cancer, irrespective of age, with surgery and appropriate systemic therapy, rather than endocrine therapy alone, unless significant comorbidity precludes surgery[7]'. The 2009 *ABS Surgical guidelines for the management of breast cancer* assert that each patient's care plan must take account of their age and general health and that the potential benefit of chemotherapy should be calculated taking age and comorbidities into account[48]. Statement 6 of the NICE Breast Cancer Quality Standard is that, 'People with early invasive breast cancer, irrespective of age, are offered surgery, radiotherapy and appropriate systemic therapy, unless significant comorbidity precludes it[6]'. However, it should be noted that guidelines and Quality Standards issued by NICE and the ABS relate to best practice and are not currently mandatory.

These guidelines and Quality Standards aim to ensure that everyone with breast cancer is offered all appropriate treatment regardless of age. However, there is evidence that this is not always the case in practice, for example, the lower rate of triple assessment and assessment of hormone receptor and HER2 status in older women[3,49,7,33,34] the lower treatment rates that cannot be accounted for by the presence of comorbidities[25,51,50,51,48] and the lower rate of breast reconstruction[52]. There is also evidence that some clinicians are basing treatment decisions on age alone[32,33]. It is not acceptable that guidance on the equitable treatment of older people is not being adhered to. Discrimination on the basis of age in health and social care has been unlawful since October 2012[5].

> "The assumption should be that older patients should receive the same level of treatment. The only acceptable criteria for not giving a clinically appropriate and cost effective treatment should be poor patient health or a patient themselves making a choice not to receive further treatment."
>
> **Department of Health, 2007, Cancer Reform Strategy**

The guidelines may have more of an impact on the treatment of older people if they are explicit about assessment and recording of frailty and comorbidities and the use of this information to make treatment decisions. The involvement of geriatricians in future guideline updates will also ensure that the interests of older breast cancer patients are fully represented. Geriatricians have more specific training and experience in assessing and treating older people than oncologists and surgeons who are currently involved in developing guidance.

In future, NICE and ABS updates should refer to the SIOG 2012 recommendations on the care of older cancer patients. These state that there should be screening to assess fitness for treatment, the same surgery options should be available as for younger patients, radiotherapy should be offered following breast conserving surgery, and that decisions on chemotherapy should not be age-based[29,30].

Other important guidelines, such as NICE's advanced breast cancer guidelines and the ABS's guidelines for oncoplastic breast surgery make no specific references to older breast cancer patients. As with the guidelines mentioned above, future updates should include unambiguous recommendations on the equitable treatment of older people. Again, this should include guidance on frailty and comorbidity assessment and the input of elderly care specialists.

Recommendations

NICE and the ABS should involve geriatricians when updating breast cancer guidelines to ensure that the needs and views of older breast cancer patients are taken into account.

NHS England should clarify how performance against the Breast Cancer Quality Standard, and in particular the statement which applies to older people, will be monitored at a national level.

All bodies responsible for developing future guidelines that impact on breast cancer patients should ensure that the needs and views of older patients are taken into account.

ACCESS TO INFORMATION AND SUPPORT

The provision of information and support is an essential aspect of good quality breast cancer treatment and care to ensure that patients have the information they need and are supported to make informed choices.

BACKGROUND

The right to good quality information and support is specified in several NICE guidelines:

'Patients are actively involved in shared decision making and supported to make fully informed choices about investigations, treatment and care that reflect what is important to them[6].'

'Information giving, support from patient groups and support from breast care nurse specialists, have shown a reduction in psychological morbidity. Excellent communication skills are paramount, as breaking bad news and the manner in which it is imparted greatly influence the distress a patient may suffer[7].'

In addition, access to appropriate information to inform decision making is now regarded as a health service in its own right, rather than as an add-on service to other treatment and care[53]. The third sector also has an important role to play as an information provider.

RECOMMENDATION 7

All older breast cancer patients are provided with the information they need about their treatment, in the way that they wish to receive it

It is essential that all older breast cancer patients are given the information they need, at the time that they need it and in an appropriate format. It is important that healthcare professionals do not make assumptions about how older breast cancer patients prefer to receive information, and that information is available in the format that the patient wishes to receive it. It is important that information provided to a patient is from reliable and trusted sources. The NHS Information Prescriptions programme has been successful in ensuring the quality of health information, but there is concern and uncertainty over its future.

> "Some people have come away, and they've said they come away with bundles of paperwork, and that's not what they want. They want to be told it face-to-face."
>
> **Judy Dadswell, Breast Cancer Care peer support volunteer, APPGBC oral evidence session**

Several studies have found that older patients are less likely than other age groups to seek additional information to that provided by their healthcare professionals[54,55,56]. The Inquiry Panel heard from a Breast Cancer Care peer support volunteer that many older breast cancer patients are less likely to want to read leaflets or websites and prefer to receive information face-to-face from healthcare professionals[57]. This was reinforced by the written evidence received by the Inquiry from older patients affected by breast cancer.

> "She spoke quickly with little empathy and gave me leaflets/ booklets, everyone is too busy to spend time talking – 'here, read the book' attitude!"
>
> **Written submission received from anonymous older breast cancer patient**

The Inquiry received written evidence from clinical experts detailing the information needs of older breast cancer patients, reinforcing the view expressed by patients that many prefer to receive information face-to-face from healthcare professionals rather than relying on a large amount of written information. This highlights the importance of the clinical nurse specialist role, which is emphasised in numerous clinical guidelines and standards for breast cancer care[6,7,58]. It is essential that all patients, regardless of age, have access to a clinical nurse specialist to help fulfil their information needs. Results from the National Cancer Patient Experience Survey show that the majority of breast cancer patients of all ages report having access to a clinical nurse specialist[59]. It is important that these professionals have the time to meet the information needs of older patients.

> "Some may need to be 'drip fed' little by little – others to be told all the possible outcomes and treatments in advance – others prefer a 'head in the sand' approach. Others prefer to talk to ladies who have 'been through it'. Each patient needs to be treated individually when giving out info."
>
> **Written submission received from anonymous older breast cancer patient**

Recommendations

Healthcare professionals discussing a diagnosis of breast cancer with a patient need to ask about the patient's information needs to ensure that high-quality information is provided appropriately. This must be followed up throughout the patient's treatment.

Breast units should make available a range of high-quality information about all aspects of cancer treatment and support services. This needs to be available in a range of formats including online, hard copy written material, large print and different languages. Breast units should also provide information on helplines, support groups and peer support services for patients who would appreciate this type of information. Commissioners should require all breast units to conduct audits of the information provided to patients.

RECOMMENDATION 8

Ensure all breast cancer patients have their needs fully assessed

The Inquiry heard evidence from experts and patients about the importance of all the needs of cancer patients being taken into account when planning treatment, not just treatment needs. Many older breast cancer patients have additional needs to be addressed before treatment can commence. This may include respite care if the patient is a carer for another family member, assistance at home after the patient is discharged from hospital or help with transport to chemotherapy and radiotherapy appointments.

As discussed in Recommendation 4, the Inquiry Panel heard evidence relating to the advantages and disadvantages of a Comprehensive Geriatric Assessment (CGA) for cancer patients. Carrying out a full CGA is clearly the gold standard for assessing the needs of older breast cancer patients. Hospitals that are fulfilling this should be encouraged to continue and to share lessons they have learned from their success with others. However, the Panel acknowledges that this might not be easily achievable for all trusts and implementing a CGA in a busy breast clinic setting may not always be practical[60]. Therefore, this report recommends that all patients with breast cancer should have all of their needs assessed as soon as possible after diagnosis to identify any additional needs and ensure that services are in place to meet these.

This is not a new concept – the National Cancer Survivorship Initiative (NCSI) provides numerous tools for assessing the needs of cancer patients[61] and the National Cancer Action Team has issued guidance on this[62]. However, it does not seem that this type of assessment is common across the NHS. All Clinical Commissioning Groups should require professionals to utilise a form of needs assessment for all patients with breast cancer to ensure all their needs are identified and met. While the assessment will be useful for patients of all ages, the benefits would be most apparent for older patients, as this age group tends to have more needs. Use of this assessment should be incentivised through the Cancer Peer Review programme or through the Commissioning for Quality and Innovation (CQUIN) payment scheme.

As there are many tools of this kind already in existence, it may be useful for NHS England to commission a review of the available tools and recommend one tool for use in a breast clinic. A needs assessment could be undertaken by any suitably trained healthcare professional, although it may be best suited to a clinical nurse specialist, in addition to the fitness for treatment measure, recommended earlier (see Recommendation 4), being undertaken by a consultant. The needs assessment could also be used as a tool to establish what kind of information the patient requires and in what format, to ensure that the information provided meets the needs of the patient. This may include information about body image, prosthetics after surgery and intimacy and relationship issues. Several studies have found that many older breast cancer patients are not offered this information as it is sometimes assumed that they are not as concerned as younger women about these issues[60,63].

> "I was given no information on any local support groups, 'Look Good, Feel Better', Maggie's... Again had I been younger I think someone would surely have mentioned some of the services available, but as I'm retired and I only wear make-up occasionally ... probably thought I didn't need anything. By the time I realised that these sessions were for everyone and not just younger women it was too late. I may not have used the service but nice to know it was available."
>
> **Written submission received from anonymous older breast cancer patient**

Recommendations

NHS England should commission a review of available needs assessment tools to identify the most practical and cost-effective tool for use in a breast clinic setting.

NHS England should incentivise (for example through Cancer Peer Review and CQUIN) the use of a needs assessment tool for all breast cancer patients, highlighting the CGA as an example of best practice.

RECOMMENDATION 9

Ensure all necessary support services, including psychosocial support, for breast cancer patients are in place to allow cancer treatment to begin within cancer waiting time targets

As already discussed, many breast cancer patients may have other health and social care needs in addition to those directly related to their cancer treatment. This may include help with caring for relatives such as children, grandchildren or sick or disabled partners, assistance with practical issues, such as shopping, washing or dressing once they return home from hospital and assistance with travelling to outpatient appointments, such as for chemotherapy and radiotherapy. These are needs that breast cancer patients of all ages may have, but it is likely that older patients will have more support needs than younger patients. The needs assessment will ensure that these needs are identified, but it is essential that arrangements are made to provide these support services so cancer treatment can begin. These types of support services are available from local authorities, but it is not always clear for patients and for healthcare professionals what the easiest referral pathways are. The Inquiry Panel heard evidence of patients having to delay or decline cancer treatment because support services were not in place.

The Inquiry Panel heard from experts that some local authorities have a mean waiting time of 100 days for support services. However, cancer waiting times targets state that patients referred urgently should not wait more than 31 days from decision to treat to their first cancer treatment beginning, and patients referred through the non-urgent pathway should begin treatment within 62 days of being referred. The panel believes that breast cancer patients who require additional support before they can begin their cancer treatment should not have to delay their treatment in order to allow support services to be arranged.

> “Not only do the pathways need to be in place to refer people; those services need to be able to respond in a timeframe that matches the cancer waiting timeframes. So essentially, if someone needs their surgery in two weeks’ time, we need to be able to mobilise those support services and get them in place within two weeks.”
>
> **Hazel Brodie, Macmillan Cancer Support, APPGBC oral evidence session**

Local authorities and hospitals need to have an agreement in place to ensure that older people who are diagnosed with breast cancer and require treatment have support services in place before they start treatment, in line with cancer waiting times. Every older breast cancer patient should have one named person or agency who can coordinate all aspects of their care and support services. Clinical Commissioning Groups should take responsibility for facilitating conversations between local authorities, secondary care and voluntary services to ensure that support services for older people with breast cancer are in place before cancer treatment begins. It will be for local organisations to determine who is responsible for coordinating services. It may be appropriate for local branches of relevant charities to be commissioned to provide this coordinating role.

Recommendations

Local agreements should be in place to ensure that all breast cancer patients have timely access to the support services they need. These should be led by Clinical Commissioning Groups in collaboration with local authorities and other relevant stakeholders. These are crucial to ensure that older patients in particular are not missing out on or having to delay their cancer treatment.

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Please contact Ross Kester, Secretariat to the Group
on 020 7025 2494 or rossk@breakthrough.org.uk
Breakthrough Breast Cancer,
Weston House,
246 High Holborn,
London WC1V 7EX

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