

## **The outcomes and experiences of older women with breast cancer: driving progress in the new NHS**

### **Introduction**

As part of its aim to deliver health outcomes that are among the best in the world, the Government has made reducing health inequalities and improving the health of those with the poorest outcomes one of the key ambitions of the NHS reforms<sup>1</sup>. *Improving Outcomes: a Strategy for Cancer*<sup>2</sup> recognised that the greatest scope to make rapid improvements in incidence, survival and mortality rates for cancer is by focusing activity on disadvantaged groups such as older people. The high incidence of breast cancer among older women means that the outcomes achieved by this cohort of patients represent an important indicator of progress in addressing inequalities in cancer care.

Breast Cancer Care has a strong heritage of increasing understanding of, and tackling, inequalities issues in breast cancer. Our previous research highlighted evidence of variations in the experiences and outcomes of breast cancer patients due to age<sup>3</sup> and identified the current barriers facing older women diagnosed with breast cancer in securing a diagnosis, accessing treatment and care, and obtaining appropriate information and support<sup>4</sup>.

We must now consider what action is needed to ensure that the NHS fulfils its dual duty towards older women with breast cancer:

- to secure continuous improvements in the quality of services
- to eliminate discrimination and promote age equality

This is crucial if we are to improve the outcomes of women with breast cancer, in terms of survival and mortality but also in terms of their quality of life and their overall experiences of care – the outcomes that underpin quality improvement in the new NHS.

The purpose of this briefing is therefore to:

1. Summarise what we know about older women with breast cancer

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2. Set out the findings of a parliamentary audit to evaluate what progress has been made by the Government and the NHS to improve the quality of care available to older women with breast cancer
3. Analyse the role and responsibilities of the key actors in the new NHS in relation to older women with breast cancer and put forward clear recommendations to deliver the improvements in outcomes and experiences that are needed
4. Outline the key standards that older women should expect across the patient pathway

We would like to express our thanks to those parliamentarians who helped us to undertake this work and for their ongoing support as advocates on key breast cancer issues:

- Annette Brooke MP
- Jim Cunningham MP
- Jim Dobbin MP
- Jim Dowd MP
- Mike Hancock MP
- Julie Hilling MP
- Sharon Hodgson MP
- John Leech MP
- Justin Tomlinson MP

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## What we know about older women with breast cancer

### Outcomes

More than half the  
**11,750**  
deaths a year from breast  
cancer are among women  
aged over **70**<sup>5</sup>

Survival rates decline  
steadily after the age of **69**.  
Five-year relative survival  
for women aged **80–99** is  
**69%** compared to **84%** for  
women aged **50–69**<sup>6,7</sup>

**Many older women are  
unaware of their increased  
breast cancer risk, do not  
check their breasts regularly  
and are not confident about  
detecting breast changes**<sup>8</sup>

A survey conducted  
in 2010 showed that  
**41.5%**  
did not know that  
breast cancer risk  
increases with age<sup>9</sup>

### Awareness

### Stage of diagnosis

Older women are more likely  
to present later than younger  
women, leading to delayed  
diagnosis, with around one in  
five of women over **85 (19%)**  
diagnosed as an emergency<sup>10,11</sup>

Women aged **70–74** are  
**21%** more likely to be  
diagnosed with late stage  
breast cancer compared to  
women aged **65–69**<sup>12,13</sup>

Surgical intervention declines  
with age. For breast excision  
procedures, the rate peaks for  
patients in their **mid-60s** and  
then declines sharply from the  
age of **70**<sup>14,15</sup>

**Older breast cancer  
patients are less  
likely to receive  
radiotherapy and  
chemotherapy**<sup>16,17</sup>

### Access to treatment

### Patient experience: information and support

Patients over the age  
of **75** have the least  
access to a **CNS**,  
including patients with  
breast cancer<sup>18</sup>

Patients over **75** are least likely to  
receive information on financial  
support, local self help and  
support groups, and written  
information about the side  
effects of treatment<sup>19</sup>

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## **Understanding the challenges**

Despite our understanding of the risk associated with age, the evidence summarised on page two shows that older women with breast cancer have significantly poorer outcomes than younger patients. The gap in relative survival between older and younger breast cancer patients is understood to be caused by late diagnosis and a lack of access to the best possible treatment<sup>20</sup>. Our approach to tackling breast cancer must therefore target these specific challenges and address the wider needs of older women if we are to improve outcomes and make a real difference to individuals' lives.

For example, a recent study of Patient Reported Outcome Measures (PROMS) revealed that breast cancer patients over the age of 75 reported that they had the most difficulties with mobility, undertaking their usual activities and fulfilling domestic chores, compared to any other age group<sup>21</sup>. Hence there is much more the NHS can do to ensure that it is providing an appropriate level of support for older women who may have higher levels of need and to ensure that all women with breast cancer are able to lead a longer, healthier and happier life.

The factors which affect the quality of care and support that older patients receive are complex and far reaching. They relate to the attitudes and behaviours that exist in relation to age, among individuals, society and in the NHS as well as the way that services are prioritised, planned and delivered. These issues have already been well documented in research published by the National Cancer Intelligence Network, the National Cancer Equalities Initiative, the Royal College of Surgeons, Age UK, Macmillan and other partners and will not be explored further in this briefing.

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## Recent developments: research, policy and practice

### Legislative changes

Following an initial exemption, the ban on age discrimination in the NHS finally came into force in October 2012. It is now unlawful for NHS and social care commissioners and providers to make decisions about treatment and care based solely on a person's age. Differential treatment for older people must only happen on the basis of legitimate clinical reasons or individual preference<sup>22</sup>.

In addition, the *NHS Constitution*<sup>23</sup> makes clear that a core duty of the NHS is to promote equality through the services it provides and pay particular attention to social groups where improvements in health and life expectancy lag behind the rest of the population.

There are some challenges in measuring the impact of age discrimination and equality duties. Observing intervention rates at a population level can provide an indication of trends over time, but it is not possible to capture what is happening on a patient level and the factors behind individual clinical decisions. That is why the Government needs to take proactive steps to increase levels of awareness of the rights enshrined within the NHS Constitution so that patients can identify when these are breached and how they can seek recourse.

The Government's response to the written question tabled by **Jim Dobbin MP** confirmed that responsibility for assessing reductions in inequalities in breast cancer services will be a matter for NHS England<sup>24</sup> which is under specific legal duties in relation to tackling health inequalities and advancing equality. *The Mandate*<sup>25</sup> issued by the Department of Health (DH) makes clear that NHS England will be held to account for how well it discharges these duties.

### Awareness and early diagnosis

Early detection of breast cancer is important as it can mean that the cancer is diagnosed at a less advanced stage with improved treatment options and outcomes<sup>26</sup>. Many older women are unaware of their increased breast cancer risk, have little knowledge about some of the key signs and symptoms and are not confident about detecting breast changes<sup>27</sup>. To this

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end, the DH commissioned a series of pilots focused on breast cancer in women over 70 as part of its 'Be Clear on Cancer' initiative to promote awareness and early diagnosis of cancer at a local, regional and national level.

A range of resources were developed centrally to support GP practices, pharmacy teams and local community volunteers throughout the campaign. DH leadership was critical in establishing the infrastructure, guidance and momentum required to make the campaign a success.

During 2012, seven local projects ran 10-week campaigns to raise awareness about the risk, signs and symptoms of breast cancer for women over 70. Evidence from the pilot run by NHS Brent and Harrow showed that the campaign substantially increased levels of awareness, making local women almost twice as likely to contact their GP within a day of noticing changes in their breasts, and quadrupling the number of self-referrals by local women aged over 70 to their local breast screening service<sup>28</sup>. This work was continued in 2013 with regional campaigns taking place in Arden, Three Counties, pan-Birmingham and Greater Midlands cancer networks<sup>29</sup>. This campaign includes television adverts and personalised letters to eligible women.

The response to a parliamentary question tabled by **Jim Cunningham MP** confirmed that the evaluation of this work will inform the future work of NAEDI<sup>30</sup>. We would urge NHS England and Public Health England to maintain investment in targeted awareness programmes beyond 2013 in order to ensure that progress in this area is sustained and extended across the country.

Cancer screening is an important way to detect cancer early. Currently, women aged 50-69 are invited routinely and women over the age of 70 can request free screening every three years.

Evidence from the local 'Be Clear on Cancer' pilot run by NHS Brent and Harrow showed the positive impact of awareness raising on the uptake of screening. In February to July 2011, 90 women over 70 self-referred; while in February to July 2012 this figure almost quadrupled to 366<sup>31</sup>.

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The extension of the age range of women eligible for breast screening (to women from aged 47 up to 73) is due to be completed by 2016. For those in older groups, screening services should ensure that women are notified at their last invited breast screening appointment that they continue to be entitled to breast screening and can access screening by self-referring<sup>32</sup>.

#### Defining high quality care for older people with breast cancer

In 2011, NICE published the breast cancer quality standard (BCQS) which set out, for the first time, a specific quality statement which made a direct reference to age.

“Statement 6: People with early invasive breast cancer, irrespective of age, are offered surgery, radiotherapy and appropriate systemic therapy, unless significant comorbidity precludes it”<sup>33</sup>

It also includes a number of supporting metrics covering the proportion of people over 70 with early invasive breast cancer:

- who receive breast conserving surgery
- who receive radiotherapy after breast conserving surgery
- that is oestrogen-receptor (ER) positive who receive endocrine therapy
- that is hormone receptor-negative who receive chemotherapy

It is important to note, however, that quality standards set out what constitutes excellent care but are not mandatory nor are NHS organisations required to publish data against the metrics set out in the standard. In addition, the statement above only covers early breast cancer, which means that older women with secondary breast cancer may continue to receive differential access to treatment compared to younger patients.

Breast Cancer Care agrees with the recommendation of the National Cancer Equality Initiative (NCEI) that guidance developed for commissioners, providers and healthcare professionals (beyond the BCQS) should be sensitive to the needs of older people and should make additional provisions to drive up quality where there is clear evidence that older people have been receiving substandard care<sup>34</sup>.

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### Treatment and assessment

Important progress has been made in gaining insights into the clinical decision-making process that may preclude some older women from accessing the best possible treatment for them. A detailed study conducted by NCEI and the Pharmaceutical Oncology Initiative (POI) showed the extent to which age is a factor in oncology treatment decisions. The study showed that chronological age was found to be a significantly more important factor in decision making than either co-morbidities or social support<sup>35</sup>.

The findings demonstrate the need to provide additional support to enable clinicians to conduct an objective assessment of need for older patients so that they may access the most appropriate treatment without delay.

A series of pilot studies led by the DH and Macmillan Cancer Support tested methods for assessing the suitability of people over 70 for different forms of cancer treatment and supporting effective shared decision-making regarding their treatment. *Cancer services coming of age*<sup>36</sup> highlighted the benefits of using the Comprehensive Geriatric Assessment (CGA) to determine an older person's medical conditions (including mental health), functional capacity and social circumstances to inform the development of a holistic plan for treatment, rehabilitation and long-term follow up. Hence, breast cancer services must ensure that they support the early engagement of elderly care specialists as part of the multidisciplinary team as a priority.

### Research and clinical trials

To address the challenges related to clinical trial participation for older people, the Department of Health recommended that the National Cancer Research Network (NCRN) should consider working with the principal investigators of large scale clinical trials to assess whether or not the demographics of trial participation is representative of the demographics of the wider population of people affected by cancer<sup>37</sup>. It will be important that the NCRN takes this work forward as a priority and that, in future, research funding calls stipulate that study participants must reflect the demographic of the patient population.

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### Improving data collection

Data on cancer help to further our understanding of the burden of disease, evaluate the impact of interventions, and monitor and improve the way that services are planned and delivered<sup>38</sup>. In recognition of this, the NCEI/POI has recommended that data on clinical practice – including national clinical audits and datasets on surgery, radiotherapy and chemotherapy – should, wherever possible, be published in such a way to enable analysis by age<sup>39</sup>.

Following on from the findings of the *Recurrent and Metastatic Breast Cancer Data Collection Project Pilot*<sup>40</sup>, the Government also confirmed plans to make data on metastatic and recurrent breast cancer routinely available by age in common with other registry based statistical publications as noted in the response to the written questions from **Sharon Hodgson MP**<sup>41</sup>.

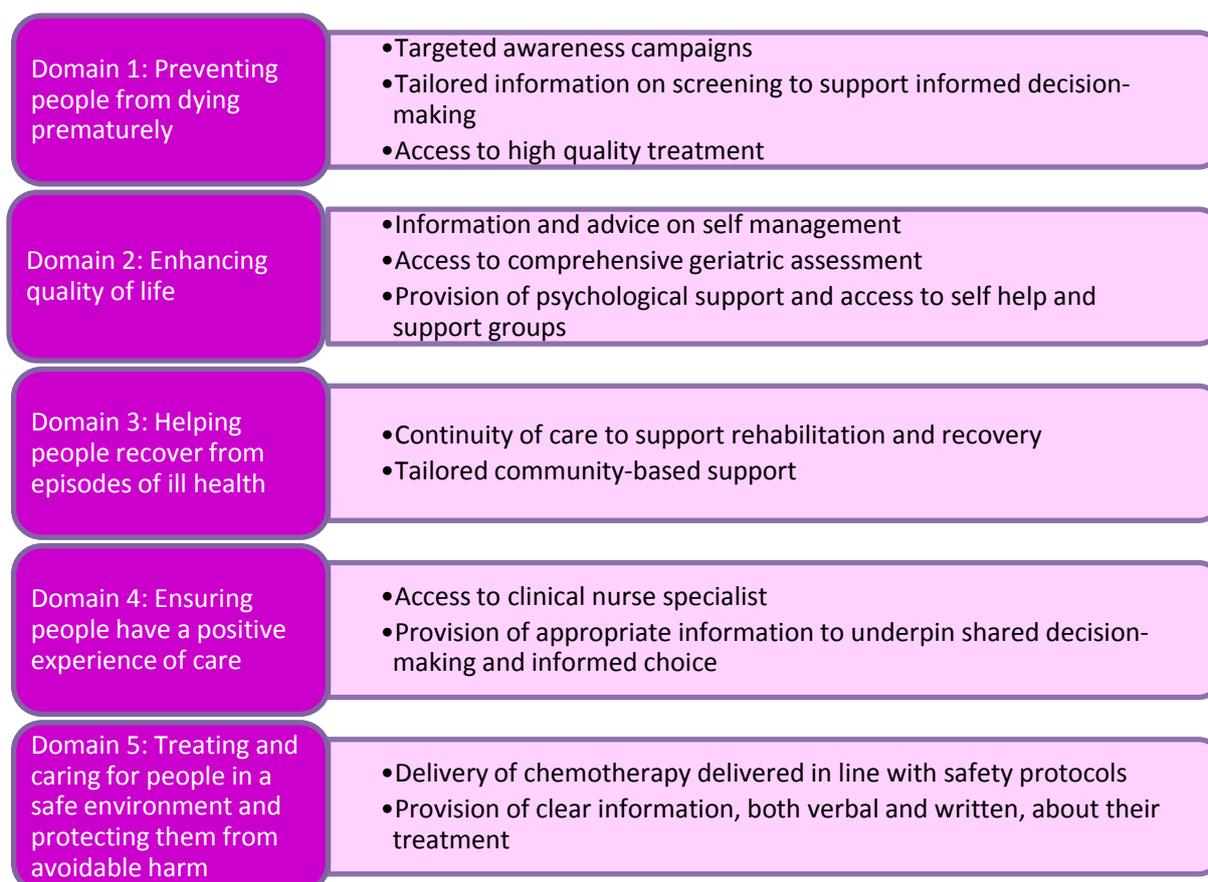
In addition, NHS Improving Quality (NHS IQ) is now responsible for coordinating the development of patient characteristics profiles for breast cancer multi-disciplinary teams (MDTs), and working with cancer networks to develop MDT equity audits. The Government's response to **Annette Brooke MP**'s written questions stated that equity audits will be included in future iterations of the National Cancer Peer Review Programme self-assessment reporting specifications, under the key theme of structure and function of the service, with MDTs requested to comment on how many patients by equality characteristic (race, age and gender) they diagnosed or treated in the previous year<sup>42</sup>.

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## Delivering improvements in outcomes – the way forward

Recent initiatives and research led by Government and the wider breast cancer community (summarised in the ‘recent developments’ section of this briefing) has helped to improve our understanding of the kind of interventions that help older women to achieve the outcomes that matter to them – improving breast cancer awareness and driving up the quality of care and treatment from first presentation through to the end of life. Figure 1 provides some examples of these actions and interventions and how they help the NHS to deliver against each domain in the NHS Outcomes Framework, against which its performance will be held to account.

**Figure 1: Interventions to help improve outcomes for older women with breast cancer**



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What is still unclear is how to ensure that the right interventions and approaches are embedded within routine NHS provision and are made available to every woman with breast cancer in a systematic way.

It is therefore essential that the key actors in the new NHS demonstrate leadership on this issue and use the opportunities present within the new NHS architecture to drive forward the changes that are needed.

### Department of Health (DH)

The DH provides strategic leadership for public health, the NHS and social care in England. The provisions of the Health and Social Care Act 2012 mean that the DH will no longer directly manage NHS organisations. This responsibility has now passed to NHS England.

To deliver on its objective of putting people's health and wellbeing at the centre of the health and social care system and delivering better outcomes, the DH is considering how the NHS Constitution can be strengthened and gain greater traction so that patients, staff and the public are clear what to do, and who to turn to, when their expectations under the Constitution are not met.

**The DH should ensure that the forthcoming strategy to improve traction with the NHS Constitution includes a dedicated awareness campaign on patients' rights in relation to age discrimination and age equality. The campaign should be piloted among older women with breast cancer in order to test feasibility and impact**

**DH should ensure that outcome metrics support equal access to high quality care for all ages. Measures that are limited by age, such as that in the NHS Outcomes Framework 2013/14 on reducing breast cancer mortality in those aged under 75, should be reviewed**

**To support the provision of more personalised care tailored to the needs and preferences of the individual, the DH should mandate the wider use of Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs)**

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## NHS England

NHS England provides national leadership on cancer policy and services that would make a difference to the quality of breast cancer care. From April 2013, NHS England has taken on many of the functions of the former primary care trusts (PCTs) with regard to the commissioning of primary care health services, as well as some nationally-based functions previously undertaken by the DH which have been identified as too specialist or complex to be commissioned across a smaller footprint by CCGs.

NHS England has established three interim Equality Objectives for April to October 2013 which will ensure that its own policy making, decisions and activities are compliant with the public sector Equality Duty, and provide system leadership to clinical commissioning groups (CCGs) and other parts of the NHS<sup>43</sup>:

- NHS England will ensure that the public sector Equality Duty is embedded and reflected within all of its core business processes, including direct commissioning and workforce development
- NHS England will implement the Equality Delivery System (EDS) and use it to help it deliver on the general and specific duties of the public sector Equality Duty
- NHS England will ask CCGs to adopt the EDS where they have not already done so, and will support CCGs to meet the public sector Equality Duty and to publish their own Equality Objectives by October 2013

Dedicated Clinical Reference Groups (CRGs) have been formed by NHS England to support greater consistency and fairness in access and provision for patients in areas such as chemotherapy which includes advice on the operation of the Cancer Drugs Fund (CDF) which provides funding for a number of treatments not routinely funded by the NHS for people with advanced breast cancer.

**As part of its required response to the Mandate, NHS England should clearly set out how it plans to meet the objectives in relation to reducing age inequalities and variations in breast cancer care through its work programme**

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**NHS England should instruct Quality Health to publish data from the NCPES broken down by age groups and by tumour type to enable NHS organisations to benchmark performance and act swiftly to identify improvement areas and share examples of best practice**

#### Public Health England (PHE)

PHE is responsible for helping people live healthier lifestyles, prevent cancer, raise awareness of the symptoms of cancer and support informed decision-making on screening. As part of this remit, from 1 April 2013, PHE assumed responsibility for designing and delivering 'Be Clear on Cancer' campaigns from DH, including oversight of the pilots for the awareness campaigns for the signs and symptoms of breast cancer among women over 70.

In addition, the cancer registration, surveillance and intelligence functions delivered by the NCIN have also moved to PHE, which provides an opportunity to develop the current regionally based services into a single comprehensive national cancer registration and intelligence service.

**Public Health England should maintain investment in targeted breast cancer awareness programmes for older women beyond 2013 in order to ensure that progress in this area is sustained and extended across the country**

#### *Health Education England*

Health Education England has an essential role in ensuring that the NHS workforce is appropriately equipped and qualified to deliver high quality patient care. People with breast cancer have contact with a wide range of healthcare professionals throughout their care pathway, from practice nurses and GPs, through to surgeons, radiotherapists, oncologists and specialist nurses.

Health Education England must ensure that the requisite training and resources are made available to NHS staff to enable them to conduct a comprehensive assessment of older people with breast cancer and deliver care based on their individual needs and preferences.

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**Mandatory training modules on geriatric oncology care and shared decision making should be introduced for clinical and non-clinical healthcare professionals involved in delivering breast cancer services to improve communication with older patients and underpin shared decision-making**

National Institute for Health and Care Excellence (NICE)

NICE has a key role in defining what high quality care for older women with breast cancer through the BCQS which describes markers of high quality care that, when delivered collectively, should improve the effectiveness, safety and experience of care for adults with breast cancer. The BCQS has the capacity to be a key mechanism for monitoring the provision of treatment.

It is crucial that data on the performance of local services against the quality statements and measures are routinely collected and used to assess the extent to which high quality treatment for older people with breast cancer is being delivered and where improvements are required.

**NICE should lead on the development of standardised metrics and processes for measuring local service performance against all the quality statements included in the BCQS, broken down by age groups (including five year age groups over the age of 70), to assess the extent to which high quality treatment for older people with breast cancer is being delivered and where improvements are required**

Clinical commissioning groups (CCGs)

Under the new system architecture, CCGs have replaced PCTs as the organisation responsible for designing and contracting services for their local populations. It is essential that the relevant services are commissioned to meet the ongoing needs of all cancer patients, whatever the stage of their cancer journey or individual characteristics.

The Clinical Commissioning Group Outcomes Indicator Set (CCGOIS) will hold CCGs to account for, and provide clear, comparative information for patients and the public about the quality of health services commissioned by CCGs and the associated health outcomes.

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Because it takes time to observe tangible improvements in clinical outcomes such as long term survival, it is important that CCGs establish both interim and proxy metrics to evaluate the performance of providers. Collecting and publishing service performance data such as active treatment rates, patient experience and patient reported outcome measures by age enables greater transparency and accountability. This in turn helps NHS organisations to critically evaluate activity and performances in relation to their peers.

**Local commissioners should develop CQUIN schemes to incentivise providers to deliver improvements in the quality of care for older people with breast cancer such as the proportion of patients receiving a CGA**

**Commissioners should require evidence of compliance with the breast cancer quality standard as part of the standard contract with providers**

#### Strategic clinical networks (SCNs)

NHS England has confirmed that strategic clinical networks for cancer will operate across 12 geographical areas in England with a remit to improve outcomes through strong clinical relationships across a system. SCNs need to build on the work of the previous cancer networks and should be focused on ensuring continuity of care and reducing variations in quality of care. It will be imperative that through this transition skills, expertise and funding are retained or replaced to enable SCNS to realise their full potential.

**In their annual accountability agreement submitted to NHS England setting out their programme for delivering quality improvement, SCNs should clearly set out what steps they are taking to achieve the best possible outcomes for older women with breast cancer**

**SCNs should appoint a dedicated health inequalities lead with responsibility for coordinating activities across the region**

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**SCNs and the intelligence function of PHE should support providers to ensure the timely submission of monthly data returns to their local cancer registry for all tumour types including breast cancer**

#### Acute providers

Secondary care providers of breast cancer services are accountable for the delivery of acute care and treatment of patients. The NCPES provides rich data on the quality of care delivered to cancer patient nationally and locally, broken down by tumour type. Detailed reports on the performance of local breast cancer services are available for local providers to benchmark the quality of care they offer and to help identify areas for improvement. To demonstrate how this information is being used to drive progress, providers should set out what practical steps they have taken to address those aspects of care where improvements are required.

To support the provision of high quality cancer services, both locally and nationally, providers of cancer services are required to submit a monthly return to their local cancer registry covering all cancer patients diagnosed which is fed into the Cancer Outcomes and Services Dataset (COSD) which replaced the previous National Cancer Dataset.

**All providers of breast cancer services should set out in their next Quality Account what steps they are taking to improve patient experience (measured by the CPES) and patient reported outcome measures for older women with breast cancer and should report on their progress on an annual basis**

#### Local health and wellbeing boards

Health and wellbeing boards are responsible for developing joint strategic needs assessments (JSNAs) and joint health and wellbeing strategies (JHWBs), which will be used in assessing local requirements for different clinical services. These documents must be robust and evidence based as they will underpin commissioning decisions for local services.

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**Health and wellbeing boards should evaluate local breast cancer risk based on population demography and make recommendations within their JHWBS to ensure high quality commissioning based on local priorities**

Monitor

As part of its new enhanced responsibilities, Monitor has a critical role in setting appropriate tariff levels and providing incentives to providers. It is imperative that tariffs promote behaviours which support high quality care for older women with breast cancer and avoids embedding sub-optimal practices. The 2013/14 tariff guidance stipulates that local arrangements for reimbursement should be made for breast cancer MDTs.

**To inform future national Payment by Results (PbR) policies, Monitor and NHS England should develop a best practice tariff for the provision of geriatric input to MDT attendances for older women with breast cancer**

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## **High quality care for older women with breast cancer – raising expectations**

It is one of the first principles of the NHS that each individual patient has the same rights and entitlements in respect to their treatment and care with the provision of services based on clinical need alone. In this sense the services that are provided to older women should be no different to those accessed by younger patients. But given the historic challenges and inequities in both outcomes and access to high quality treatment and support, it is important to reflect on the key standards that older women should expect in relation to their care.

These standards should be read in conjunction with the BCQS and are intended to stimulate a discussion and encourage older women to reflect on their own expectations of treatment and care.

Older women with breast cancer should expect to:

- 1. Receive accessible and tailored information about the signs and symptoms of breast cancer that improves their understanding of breast cancer risk, supports informed decisions regarding screening and enables them to present to their GP in a timely way**
- 2. Receive an objective and comprehensive assessment of their complete needs. This assessment should be used to underpin decisions about the treatment, and care and support that they are offered**
- 3. Be given opportunities to engage with their healthcare professional on all aspects of their care and receive the information they need to allow them to make informed decisions**
- 4. Be offered a tailored care plan which reflects their individual physical, psychological, social and financial needs which is reviewed on a regular basis**
- 5. Have access to a named clinical nurse specialist and be able to call on them for support when they need it**
- 6. Be offered the opportunity to participate in clinical research where this is clinically appropriate and where relevant trials are taking place in their area**

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The extent to which these expectations are met and come to represent routine NHS practice for older women with breast cancer will be a key test of progress in improving the quality of care available to older women with breast cancer over time.

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