

## **Breast Cancer 2015**

### Background

1. Breast cancer is the most common cancer in women in England with (not including cases of ductal carcinoma in situ (DCIS)<sup>1</sup>) 39,681 new cases diagnosed in 2008 (including 291 men)<sup>2</sup> and over 10,000 deaths in 2008.<sup>3</sup> Four in every five cases of breast cancer in the UK occur in women aged over 50.
2. Mean age-adjusted mortality from breast cancer from 2004-2006 in England and Wales was 28.1 per 100,000 women. This represents a substantial decrease from a rate of 41.9 per 100,000 women in 1987-1989, one of the largest drops in breast cancer mortality in Europe seen over this time period.<sup>4</sup> Breast cancer survival is also improving, with one year survival rates increasing in England from 82% for women diagnosed in 1971-1975 to 96% for women in 2004-2006.<sup>5</sup> This means there are increasing numbers of breast cancer survivors in the population.
3. Although there is a growing body of evidence on incidence, mortality and survival rates in the BME population, data on ethnicity is not yet routinely collected.
4. Approximately 35% of women will sooner or later develop distant metastases<sup>6</sup> but new treatments mean many are living longer with metastatic breast cancer.
5. Breast cancer at any age can have a significant psychological, economic and social impact on those who are diagnosed, and their families and carers.

### Improved outcomes

6. The incidence of breast cancer in England is likely to continue to rise, at least in the short term, with the expansion of the breast screening programme and an increasingly ageing population.
7. However, a smaller proportion of people in England will die from breast cancer. This will be due to a combination of factors including improved levels of public awareness of the disease, more women being screened and improvements in clinical management and adjuvant treatment.

### Prevention and Public Awareness

8. More people will be aware of what constitutes a significant family history of breast cancer allowing them to make informed choices about managing any inherited risk. All

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<sup>1</sup> DCIS is an early form of breast cancer contained within the breast ducts that has not spread to the breast tissue

<sup>2</sup> Office for National Statistics (ONS). *Cancer registration statistics England 2008*. [Malignant neoplasm of the breast]

<sup>3</sup> Cancer Research UK. [Breast cancer - UK mortality statistics](http://info.cancerresearchuk.org/cancerstats/types/breast/mortality).

<http://info.cancerresearchuk.org/cancerstats/types/breast/mortality> [29 October 2010].

<sup>4</sup> Autier, P., M. Boniol, C. LaVecchia, *et al.* *Disparities in breast cancer mortality trends between 30 European countries: retrospective trend analysis of WHO mortality database*. *BMJ* 2010;341:c3620.

<sup>5</sup> Cancer Research UK. [Breast cancer – UK survival statistics](http://info.cancerresearchuk.org/cancerstats/types/breast/survival).

<http://info.cancerresearchuk.org/cancerstats/types/breast/survival> [29 October 2010].

<sup>6</sup> Breast Cancer Care (2008) *Improving the care of people with secondary breast cancer: Final report*

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- people (particularly those over the age of routine screening invitations) will have greater awareness that their risk of breast cancer increases with age.
9. Culturally sensitive awareness programmes will mean more people will be aware that they can reduce their risk of breast cancer by maintaining a healthy lifestyle, including avoiding weight gain, reducing alcohol intake and being more physically active. People who wish to make appropriate health behaviour changes will be supported in doing so. BME groups should be involved in the design and running of such programmes, and in the production of related information.
  10. More research will have taken place into how lifestyle, environmental and genetic factors, including breast density, work together to affect risk, including risks in different ethnic groups. This will allow better stratification of women into low, medium and high risk groups. More research will also have taken place into the chemoprevention of breast cancer using established drugs (e.g. tamoxifen) as well as new drugs, but it is unlikely that there will be sufficient evidence for national prevention programmes by 2015 for all women.
  11. More women will receive evidence-based information on HRT and breast cancer risk, allowing them to make a more informed choice about HRT use.
  12. More people will be breast aware, particularly women below and above the age limits for routine breast screening invitations. They will know the signs and symptoms of breast cancer to look out for, know what their breasts look and feel like normally and report anything unusual to their doctor. Women will also understand the importance of continuing to be breast aware between breast screening appointments.

### Screening

13. More women will be aware of their screening entitlement and understand the benefits, risks and possible outcomes of screening before attending. GPs will routinely discuss screening with eligible women where appropriate to allow them to make an informed choice about attending. Women at their last breast screening appointment will receive a targeted intervention informing them that, as their risk increases with age, they should self-refer for breast screening every three years and remain breast aware. GPs will be encouraged to enrol their patients over the age limit for routine screening.
14. A greater proportion of women will attend breast screening appointments when invited and will seek appointments above the age range for routine invitations. More women from socio-economically deprived and BME groups will take up their invitations for screening following evidence based and targeted health promotion interventions.
15. A maximum screening interval of three years will be maintained across England and all mammography screening carried out by the NHS will be direct digital.
16. The surveillance of all women identified at high risk of breast cancer will be managed by the NHS Breast Screening Programme (NHSBSP). This will mean that all women at high risk of developing breast cancer due to their family history, or for other reasons, will receive appropriate breast screening from an earlier age than the general population. This will include MRI screening for women where there is evidence of benefit. More women in the general population will also be stratified into different risk groups (e.g. by

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measuring mammographic breast density or incorporating polygenic (SNP) data) and screening/surveillance will be tailored as appropriate.

17. The randomisation project, inviting some batches of women aged 47 to 49 and some aged 71 to 73, will be into its second screening round, as recommended by the Advisory Committee on Breast Cancer Screening. Women aged over 73 years will continue to be able to self refer for screening.
18. The evidence for any new developments in breast screening technology or for extending breast screening to additional groups will be evaluated in a timely fashion to expedite the implementation of clinically effective technologies and screening protocols across the NHSBSP.
19. All breast units in England will either take part in, or have close professional and operational links with the NHSBSP, leading to a higher quality of service for people with symptoms and allowing more efficient use of digital mammographic equipment currently available in many symptomatic units. The integration of screening and symptomatic services may lead to breast units in fewer locations where this is not detrimental to patient care. Some smaller units will merge, whilst larger screening units may split into two to manage the higher workload.
20. The NHSBSP will be increasingly client-focussed with all screening units, whether static or mobile, being fully accessible for all people, including those with physical and/or mobility issues. The timing and location of appointments will be more flexible, allowing women to choose the most appropriate place and time for them to attend.
21. More employers will recognise the benefit of allowing time off work to attend breast screening appointments.
22. As a result of the screening programme expansion, larger numbers of women will be diagnosed at an earlier stage, with small invasive tumours or with DCIS.

#### Genetics

23. Each local area will have developed protocols for identifying people at high risk of breast cancer due to their family history, enabling them to access appropriate services to manage their risk. People who are concerned about their family history but who do not meet the criteria for management in secondary or tertiary care will be reassured and given information appropriate to their level of risk, including information on the importance of being breast aware.
24. All people with a strong family history of breast cancer will have access to appropriate genetic counselling to help them understand their risk and to support informed decision making. Training for health care professionals on comprehensive genetic assessment (including taking an accurate family history) will have improved the quality and appropriateness of care.
25. The support and expansion of tertiary cancer genetic services will continue. All people will receive the results of diagnostic genetic tests within 8 weeks of testing and the results of predictive tests within 2 weeks of testing to allow them to make informed

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decisions about managing their risk. As technology improves these waiting times will decrease further.

26. More multidisciplinary BRCA carrier clinics will be established, allowing those with BRCA mutations to see relevant healthcare professionals (such as clinical geneticists, psychologists, breast surgeons and breast care nurses) in a single clinic visit and improving cancer risk management.
27. Targeted treatments will have advanced and may be available on the NHS for people with breast cancer who have a fault in one of their BRCA genes. The capacity of genetic testing services will grow to meet the increased demand for testing as a result of the availability of these treatments.
28. As new genetic tests become available, there will be continued support for the work of the UK Genetic Testing Network in developing a rigorous, evidence based system for introducing new tests into the NHS, assessing both scientific validity and clinical utility. Some genetic tests may be suitable for evaluation in the recently established NICE Diagnostics Assessment Programme.
29. The Concordat and Moratorium on Genetics and Insurance (due to be reviewed in 2011) will be extended or legislated for when the original agreement runs out in 2014.
30. Better tracking of people with a known high genetic susceptibility to breast cancer, possibly via a national register, will be in place. Information on surveillance outcomes, cancer incidence and risk reducing surgery should be collected to help inform future practice.

#### Referral

31. Primary health care teams will receive specific training to encourage them to make appropriate referrals.
32. Primary health care teams will ensure that patients have the information and support they need throughout the referral process and provide patients who do not require referral with appropriate reassurance and information.
33. People in all parts of England will be seen by a specialist multidisciplinary team within two weeks of being referred by their GP with breast symptoms.
34. The 31 day pathway will have been extended to all treatments, not just the first, including radiotherapy treatment and for patients with metastatic breast cancer. In 2015, all patients will be routinely referred on the 62 day pathway. This will include women with a suspicion of breast cancer following routine screening through the NHS Breast Screening Programme.

#### Assessment of symptomatic patients

35. Each clinic will have an identified lead consultant with appropriate assessment skills. An imaging-led breast assessment service model will have been adopted for symptomatic as well as screened women. It will improve on current quality and be more flexible, efficient and effective by:
  - making better use of skill mix

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- being based on current good practice and standards
  - meeting the individual needs of patients
  - meeting increasing demand
  - ensuring the best use of expensive technology
36. All diagnostic tests will happen on the same day, with a clinical nurse specialist present to offer general and psychological support and information. Where appropriate training has been provided, consultant nurses may lead assessment clinics. One-stop clinics that allow all investigations to be completed on the same day will be the gold standard for faster routes to the start of active treatment.
37. With increased breast awareness, more people with breast symptoms will require specialist breast assessment. The increasing number of younger women referred should be triaged effectively to allow more efficient use of resources and skill mix.
38. Breast imaging will have become more sophisticated with improved technology and clinical expertise, and should continue to be provided in specialist centres.

#### Diagnosis, classification and staging

39. National guidance will have been issued on updated staging as a result of emerging technologies. This will include MRI and other advanced imaging for staging cancer. Irrespective of age, every breast cancer patient will have the cancer clinically and pathologically staged.
40. There will be national pathology guidance and quality assurance standards in place.
41. Payment systems should encourage the use of triple assessment.
42. More research into DCIS will have taken place, allowing better prediction of the likelihood of DCIS developing into invasive cancer. Clear and consistent language will be used to describe DCIS to patients, allowing them to better understand the ambiguities of their condition and to help them make an informed choice regarding their treatment. The specific information and support needs of women diagnosed as having DCIS will be catered for.
43. All patients being investigated for early invasive breast cancer will undergo pre-treatment ultrasound evaluation of the axilla.
44. The development of an increasing number of targeted treatments will require the development and implementation of increasingly complex, accurate and rapid diagnostic and pathology services and a substantial increase in service capacity. New complex histological tests will be robustly assessed and developed in breast clinics. Through an improved understanding of breast cancer subtypes and associated biomarkers, it will be easier to predict likely treatment response and outcome.

#### Treatment

##### *General*

45. Clinical trial options, when available, will be routinely discussed with patients at all stages of breast cancer treatment alongside other treatment options. Location of

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treatment should not lead to discrimination in access to trials. The restricting bureaucracy of data collection and management will have been tackled. Increased numbers of research nurses, clinical research assistants and psychologists will be in post to support clinical trial participation. Research will have been undertaken to understand any barriers in access to clinical trials for older people and solutions identified.

46. Patients should not incur costs associated with treatment.

#### *Staffing*

47. Multi-Disciplinary teams (MDTs) will continue to be the required basis of providing care for all patients, including those with metastatic disease, with adequate staffing and training to undertake their role in the most effective manner.
48. Each primary / diagnostic MDT will treat a minimum of 100 cancers (1000-2000 referrals) a year. Each MDT will include a sufficient number of surgeons, oncologists, radiologists, pathologists, clinical nurse specialists and radiographers to allow for appropriate core members to be present for all decisions regarding diagnosis and oncological treatment. This will allow for constructive discussion of each case, and cover for leave. Each team member will have sufficient ongoing breast cancer practice to maintain expertise. MDT co-ordinators will be fully funded, with a key role in data collection. Links to rehabilitative care will also be provided, potentially through involving allied health professionals in the MDT. Communications technology (e.g. video conference) will be available to support MDTs operating on more than one site. MDTs will be reviewed annually to ensure they are providing high-quality care and this information will be made available to the public.
49. Every patient, including those with metastatic disease, will have access to a clinical nurse specialist to coordinate their care. The details of each patient's breast cancer diagnosis and treatment will be routinely communicated to their GP.

#### *Surgery*

50. Surgery is likely to continue to be the initial treatment for most newly diagnosed breast cancers.
51. The focus will be on minimising inpatient stay through use of more day and short stay surgery for suitable patients.
52. The importance of maintaining breast aesthetics after cancer surgery/radiotherapy will be increasingly recognised and all breast surgery should take account of oncoplastic principles, as set out in the Association of Breast Surgery's guide to good practice. The full range of breast reconstruction techniques will be available to all patients who require them, all patients will be able to discuss their options for reconstruction with an appropriately trained healthcare professional and will have sufficient time and access to appropriate information to make their decision. Culturally appropriate prostheses should continue to be offered to those women who choose not to undergo reconstruction.
53. The training of specialist oncoplastic breast surgeons and plastic surgeons within the Oncoplastic fellowships schemes will continue and be expanded.

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54. Axillary conservation will remain an important future goal. Lymph node staging will be conducted by minimal access techniques (EG sentinel node biopsy).
55. Uptake of (fully evaluated) new technology (E.G intra-operative margin assessment, sentinel node analysis etc) will help minimise the need for repeat surgery either to the breast or axilla. Healthcare professionals will discuss the pros and cons of this approach with patients to facilitate informed choice.

#### *Drugs*

56. All patients will have equal and rapid access to clinically appropriate drugs.
57. Alternative drug pricing models will have been discussed between NICE, patient groups and pharmaceutical companies and implemented where deemed appropriate. Clear patient information will be available on the benefits, risks and limitations of new treatments to clarify decisions on whether drugs will be offered on the NHS.
58. Adjuvant medical treatments will continue to have a crucial role, and resource needs for both drugs and day unit nurses to deliver these will have been expanded.
59. Treatment will be more personalised as research leads to a better understanding of the disease, the development of new treatments and new uses of current treatments.
60. More sophisticated diagnostics and better understanding of biomarkers will allow better prediction of response to treatment. This, together with ongoing monitoring of response and resistance, will minimise unnecessary side-effects and cost implications associated with administering potentially ineffective treatments.

#### *Radiotherapy*

61. Radiotherapy services will have been expanded to ensure greater capacity to reduce waiting times. There will be rapid access to radiotherapy, including new innovative technical radiotherapy such as intensity modulated radiotherapy (IMRT), image-guided radiotherapy (IGRT) and partial breast irradiation. Further research into appropriate fractionation regimes will have been carried out and guidelines developed.

#### *NICE*

62. Continued input by patients, healthcare professionals and other stakeholders into the NICE topic selection and guidance development processes will ensure that new NICE guidance covers areas of highest priority. NICE will continue to make robust, evidence-based decisions taking into account clinical efficacy of interventions and whether they improve the quality of life of patients. There will be a move towards rapid response processes to ensure that NICE can respond quickly to emerging data on breast cancer services and treatments. The recently established NICE Diagnostics Assessment Programme will also be reviewing new diagnostic techniques where these appear to offer important advances.
63. NICE clinical guidelines (including the Quality Standard for Breast Cancer) and technology appraisals will have been implemented across England so there are no unacceptable variations in standards of treatment and care. Patients will be provided with information and support that helps them understand NICE guidance and make informed choices about their care and treatment.

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64. Each MDT will have nominated a clinician to act as a “NICE champion” to provide leadership on implementation. NICE will implement support tools resulting in practical and accurate information to the NHS. For those new drugs that require a prior diagnostic response predictive test to be performed, due consideration should be given for timely guidance and recommendations on testing.

#### Metastatic breast cancer

65. The NICE clinical guideline on advanced breast cancer will have been fully implemented. A clinical nurse specialist, usually based in the oncology unit, will be available for all patients with secondary breast cancer. Palliative care specialists will be a key part of the metastatic MDT.
66. Patients with secondary breast cancer will have their information needs met from the point of diagnosis and have their physical, psychosocial and spiritual needs assessed and acted upon. Access to psychosocial support services for patients with secondary breast cancer will be provided, as will management in primary care and the community.
67. Cancer registries will collect data on the incidence of secondary breast cancer and mortality. Metastatic breast cancer will also be a key focus of breast cancer research, enabling a better understanding of how it occurs and how to prevent and treat it.

#### Information and support

68. Patients will receive appropriate information about all aspects of their treatment and care, including the standards of care they can expect to receive, at the right time and in the right format for them. Patients will be fully involved in decisions about their care and all relevant healthcare professionals will have undergone training in how to support patient decision-making and informed consent. Additional support will be provided for those without a fluent understanding of English or who have difficulty communicating for other reasons. Support provided to patients must be culturally appropriate taking into account any religious, cultural, and language requirements.
69. Accredited information will be available to patients at all stages of their cancer journey through information prescriptions. Information will also be given on local support groups, benefits advice and complementary therapies. Further information and support will be available from accredited sources and dedicated on-site support centres will be available to give patients easy access to advice and support.
70. All patients will be assessed to ascertain their psychological, social, financial and lifestyle support needs throughout their treatment. Each breast cancer team will have access to sufficient psychological support with clear referral routes. On site psychologists will be available and are key members of the breast team. Patients who require more psychosocial support (e.g. for difficult treatment decisions or the long-term impacts of treatment) will be identified and referred to specialist services as appropriate. In addition, community based support will be available to all patients as well as sources of support for families and carers. Support provided to patients must be culturally appropriate, taking into account any religious, cultural and language requirements.



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71. Clinical nurse specialists will deliver most of the supportive care to patients, and a supportive care pathway will be agreed between the nurse and patient. Good practice guidelines for specialist nurse support will have been developed to ensure equity of access and commissioning will take clear account of the importance of the role of these nurses across the patient pathway.
72. Patients will always be offered the option of bringing a carer with them to hospital appointments to support them.
73. GPs will be routinely informed of their patient's breast cancer diagnosis and treatment plan. They will have greater knowledge of breast cancer and will be better able to offer support and referral in relation to psychological issues, recurrences and long term effects of treatment.
74. Some forms of medical therapy will be delivered in the community, utilising primary care. Specialist breast cancer nurses will serve local communities on an outreach basis.

#### Survivorship and rehabilitation

75. Each patient will have a clear personalised care plan and follow-up regimen based on risk and need, possibly in the form of an information prescription at the end of their formal treatment. Making best use of the voluntary sector, emphasis will be placed on educating patients about follow-up and self-care and all patients will receive advice on minimising the risk of recurrence. At the end of follow-up, each patient will have an exit interview informing them of signs and symptoms to look out for and where to go for advice.
76. A national strategy on cancer survivorship will have been developed to support the growing number of cancer survivors. Quality standards for follow-up will have been developed. New models of evidence-based effective follow-up will have been developed, including nurse-led and open access models undertaken by appropriately trained and supported practitioners, but with a clear fast track back to the MDT if problems arise. The need for longer term endocrine therapy (beyond five years) for many patients will be recognised and built into follow up models. Better data on long-term outcomes and optimum interventions to resolve long term morbidity will be available.
77. All patients will have access to appropriate rehabilitative services that meet their needs and can help maximise their quality of life. The NICE Supportive and Palliative Care Guidance and the National Cancer Rehabilitation Pathways will have been implemented across England. All patients will receive a robust holistic assessment and be stratified by their risk of developing late effects, including psychological effects of breast cancer treatments and directed to appropriate rehabilitative care pathways. All patients undergoing surgery, and radiotherapy where appropriate, will be informed about the risk of lymphoedema prior to treatment and given instructions to reduce and limit the risk of lymphoedema occurring a long time after their primary treatment. For those requiring rehabilitative care, this should be provided at their treatment centre or in the local community.

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#### User involvement

78. The principles of Breakthrough Breast Cancer's *Service Pledge for Breast Cancer*, or an appropriate alternative model, will have been rolled out across all breast cancer units to enable health professionals and patients to work in partnership to improve local breast services.
79. There should be significant, meaningful and diverse patient involvement in commissioning boards. Patients will be involved in all service improvement initiatives and will also be involved as meaningful partners in setting the breast cancer research agenda.
80. Patient and carer reported outcome measures will be considered integral to measuring quality of care and will be developed with significant patient input.

#### Tackling inequalities

81. Breast cancer treatment will be based on clinical need and fitness for treatment rather than on chronological age and all patients will be offered real and informed choice about their care and access to clinical trials. In order to ensure evidence-based treatment for more elderly patients, there will be no upper age limit in clinical trials unless absolutely required for trial methodology.
82. It is well recognised that BME groups experience inequalities in accessing healthcare. The Department of Health will continue the work of the National Cancer Equality Initiative to better understand the reasons for this, and to advise on methodologies to tackle it. This will include: health education and prevention; access to screening; access to healthcare training for cultural competency; data collection and audit; information needs and advocacy at diagnosis; access to research trials; treatment side effects; and access to palliative, spiritual and end of life care. The Advisory Committee on Breast Cancer Screening will have reviewed the evidence on BME groups, especially African Caribbean women, being at risk of developing breast cancer at a younger age with more aggressive forms of breast cancer.
83. There is a lack of public awareness that men can develop breast cancer. They tend to be older, present with more advanced stage disease and are more likely to be hormone receptor positive. The NHS and cancer charities will work together to raise public awareness appropriately in order to both encourage men to present with earlier stage disease and identify the issues specific to male breast cancer. Most support services/groups are structured to meet the needs for female patients. Information gathering as to the specific support needs of male patients will have taken place to inform the development of services for this minority group.

#### Workforce and training

84. Clinical nurse specialists will have developed their roles around the evidenced need of patients and their families/carers. A model of integrated nursing across primary and secondary care will have been developed. Data on clinical nurse specialist caseload will be routinely collected to enable effective commissioning.
85. Investment in training, both funding and time, is essential to improve cancer services and take account of new evidence to improve the outcomes and experience of cancer patients.

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86. There will no longer be a shortage of appropriately trained staff necessary for delivering radiology services

Data collection

87. Cancer registration will be more complete and accurate, perhaps even statutory. Information on incidence, outcomes and treatment for all breast cancers, whether detected via screening or symptomatically, will be collected routinely. The data will be audited annually.
88. Metastatic disease will also be routinely registered, allowing better data collection on a national basis.
89. Existing routinely collected data will be readily accessible to researchers, MDTs and national bodies. Each MDT will have established close links with their local cancer registries and their internal data collection systems. Any new data collected will be valid and agreed by stakeholders.
90. A greater proportion of breast MDTs will participate in the Breast Cancer Clinical Outcome Measures (BCCOM) project, enabling a better understanding of how symptomatic breast cancer is managed across the UK.

***Improving Outcomes: A Strategy for Cancer Breast Cancer Working Group  
December 2010***