

Breast Cancer Campaign and Breast Cancer Care response to the All-Party Parliamentary Group on Cancer consultation on 'Cancer across the Domains'

1. For each Domain below what should be the priorities to improve cancer outcomes and services?

May we kindly request that your response to each of the questions below is no more than 300 words.

The information below considers each of the domains in turn. However, we believe there is a broader point to consider in relation to cancer outcomes and services and that is ensuring the right level of resource, capacity and expertise in the new system in order to deliver the identified outcomes. With the changes to the health service, there have been structural shifts that have seen teams with considerable cancer knowledge either move or cease to exist. We believe there needs to be a review of the difference in levels of cancer policy expertise now compared to in the past and activity to establish whether resources are sufficient to deliver the identified objectives.

Domain One: preventing people from dying prematurely

Early diagnosis

Early diagnosis is key to improving outcomes of people affected by breast cancer. Working with Public Health England, NHS England should prioritise the promotion of early diagnosis, particularly with certain groups.

The *Be Clear on Cancer* awareness programme should continue, and, subject to emerging evidence, the 'Breast Cancer in Women Over 70' pilot campaigns to increase early detection of breast cancer in older patients should be rolled out nationally in 2014 to help address a lack of awareness amongst many older people that the risk of breast cancer increases with age. National leadership is also needed in raising awareness among other groups that the evidence suggests are often diagnosed with later stage breast cancer – for example, BME groups (black and minority ethnic), women with learning disabilities and women living in socially deprived areas.

We are pleased that breast screening is being extended to include women aged 47-50 and 70-73 and that this process includes a trial to gather evidence of the impact of the age extension. Many older women are unaware that they are eligible for screening after 70, and mistake the 70 cut-off to mean they are no longer at risk, whereas risk actually increases with age. Public Health England should now consider the recommendation in the All Party Parliamentary Group on Breast Cancer's *Age Is Just a Number* report to further extend the age extension trial to women aged 74-76 to assess the benefits or risks of extending screening to this age group.

Outcomes indicators

We welcome the inclusion of indicators in the NHS to measure one and five year survival for all cancers and the composite indicator relating to breast, lung and bowel cancer. Previously, however, breast, lung and bowel cancer were each covered separately in the Outcomes Framework in terms of one and five year survival and we believe that these indicators should be re-introduced into the Framework and the CCG Outcomes Indicators Set (CCG OIS).

Additional indicators that should be considered in the Framework and the CCG OIS are: cancers diagnosed via emergency routes and stage at diagnosis. The CCG OIS should also include an indicator on 'cancers diagnosed via emergency routes'.

Optimal treatment for older patients

There is evidence to suggest that older patients with breast cancer do not always receive the optimal level of treatment, which may lead to poorer survival rates for this group. (APPG on Breast Cancer, 2013 & Breast Cancer Care, 2011).

The recommendations of the APPG on Breast Cancer *Age Is Just a Number* report should be considered in this context, including that all breast cancer patients should receive optimal treatment taking into account their tumour characteristics, pre-existing medical conditions, co-morbidities and informed personal preferences, not purely on chronological age and/or assumptions about ability to tolerate treatment or preferences of the patient (APPGBC, 2013). Breast Multi-Disciplinary Teams (MDTs) should consider using Comprehensive Geriatric Assessment (CGA) tools in the treatment decision-making process.

Access to treatments

Although it is due to come into effect in January 2014, there is a lack of clarity over how the new value-based pricing system for assessing new drugs will operate. Ensuring the system works for both primary and secondary breast cancer patients is vital and the level of patient involvement in the process should also be increased.

We are also concerned about the lack of information on the transition from the Cancer Drugs Fund (CDF), which is due to end in March 2014. The protection of patients' access to drugs which are currently available via the Fund should be a priority, as well as maintaining or improving access to new drugs under any new system adopted.

The Government has shown commitment to improving access to Intensity Modulated Radiotherapy (IMRT) and it is vital that all breast cancer patients who are able to benefit from this treatment are able to access it. NHS England should ensure that the infrastructure is in place to meet the need for radiotherapy, including new machines and training staff to operate IMRT. NHS England needs to have a clear schedule for meeting radiotherapy resource requirements.

Domain Two: enhancing quality of life for people with long-term conditions

Cancer survivorship: on-going information and support needs

NHS England must show national leadership in ensuring that people living with and beyond cancer are able to access (culturally appropriate) specialist support and information. People affected by breast cancer often continue to face on-going physical, emotional and financial challenges after hospital-based treatments have ended and need to be able to access appropriate information and support. This includes support on issues relating to altered body image and intimacy as a consequence of breast cancer diagnosis and treatments.

Incidence data: secondary breast cancer

Secondary breast cancer cannot be cured, although it can be treated and controlled, sometimes for years, often making it a long-term condition. Until January 2013, NHS trusts were not required to collect data on the number of people diagnosed with secondary (metastatic) breast cancer. That this has now become mandatory is a great step forward in ensuring services can be planned effectively for people living with secondary breast cancer but a priority must now be encouraging and monitoring its implementation.

Access to a clinical nurse specialist and MDTs: secondary breast cancer

As per NICE's Breast Cancer Quality Standard (BCQS), people living with secondary breast cancer should have access to a 'key worker' who is a clinical nurse specialist (CNS) with the skills and knowledge to effectively manage their care and they should have their treatment

and care discussed by a multi-disciplinary team, providing the consistency of holistic support from one key worker and also the benefits of a widely-skilled team.

NHS England should report on performance in relation to these critical statements in the BCQS and the CCG OIS should include indicators relating to the MDTs and CNSs statements to ensure better care for secondary breast cancer patients. The Cancer Patient Experience Survey (CPES), CCG OIS and BCQS should be considered alongside each other in order to ensure that markers of high quality patient care for women with secondary breast cancer are formulated and monitored in line with appropriate measures and forms of evidence gathering.

Cancer Drugs Fund

Many people living with secondary breast cancer access drugs through the CDF. We are keen to know whether patients will have access to these drugs after the Fund comes to an end in March 2014. We're also concerned that value assessments used to assess new drugs through a value-based pricing system may impact negatively on those living with secondary breast cancer, because of their focus on the societal benefits of new drugs, such as whether the drug enables people to go to work, which often isn't possible for people living with secondary breast cancer (Breast Cancer Care, 2013).

Palliative care: living with secondary breast cancer

People living with secondary breast cancer should have access to information about palliative care services. Research has shown that often people living with secondary breast cancer do not access palliative care services until they are very near the end of their lives. Palliative care services have the expertise and experience to improve quality of life for these patients (for example, addressing poorly-controlled pain) and should be made available to those living with secondary breast cancer before the end of life stage. Integration of oncology and palliative care is needed to support patients and oncologists in making difficult decisions over when to stop treatment and to plan for end of life (Reed & Corner, 2013).

Domain Three: helping people to recover from episodes of ill health or following injury

Interface between health and social care

People living with breast cancer often have complex comorbidities and social support needs. It is essential that health and social care is efficiently and effectively coordinated to ensure treatment or long term wellbeing is not compromised by disjointed health and social care provision. Health and Wellbeing Boards and social services must work closely with CCGs to establish referral pathways and joint working.

Domain Four: ensuring that people have a positive experience of care

Holistic Needs Assessments

It is important that people of all ages diagnosed with breast cancer have their individual needs identified and addressed through a Holistic Needs Assessment before and during treatment and, where possible, as part of on-going follow-up.

Reducing inequalities

NHS England should provide national leadership in funding and evaluating initiatives to reduce inequalities in care and ensure access to appropriate information and support for all. This includes meeting the needs of older and younger patients; people from BME groups; people from socially deprived areas; lesbian, gay and bisexual patients; those living in rural and remote communities; and disabled people.

Cancer Patient Experience Survey

The CPES is a vital source of information, helping to improve the experiences of people affected by breast cancer. It is especially valuable in getting the feedback of minority groups whose voice may not be otherwise heard. NHS England should continue the CPES in future years and future iterations should be able to distinguish between the experiences of primary and secondary breast cancer patients and include questions to specifically capture issues relevant to people with secondary breast cancer.

Access to reliable information

It is important that *The Information Standard* and Information Prescriptions Service continue to enable patients to be able to clearly access reliable sources of information about cancer.

Domain Five: treating and caring for people in a safe environment; and protecting them from avoidable harm

Managing co-morbidities and polypharmacy

Breast cancer does not happen in isolation and care should be given to managing co-morbidities and pre-existing conditions of patients undergoing treatment for breast cancer.

Care should be taken to identify any additional medications a patient may be taking, to avoid or manage any adverse effects of polypharmacy (where a person is taking a number of medicines for different conditions).

These issues especially affect older patients. A Comprehensive Geriatric Assessment (CGA) may be helpful in these cases, as a CGA looks at functional status rather than chronological age and includes assessments, among others, on polypharmacy, pre-existing medical conditions and co-morbidity.

2. Please answer 'yes' or 'no' or 'don't know' to the following statements.

2.1 Do you understand the new NHS structure and where cancer fits into it?

Yes No **Don't know**

While we understand many elements of the new structure and how cancer relates to these, there are a number of areas that we believe either need further clarity or have not yet been fully embedded for the situation to be completely clear.

2.2 Given the changes to the NHS, do you think a new or revised national cancer strategy is needed?

Yes No Don't know

2.3 Is the Government on track to achieve the ambition set out in its 2011 national cancer strategy to save an additional 5,000 lives each year from cancer by 2014-15?

Yes No **Don't know**

2.4 Do you think the new Domain structure will improve cancer patient experience?

Yes No **Don't know**

References

APPG on Breast Cancer (2013) *Age is just a number: The report of the Parliamentary inquiry into older age and breast cancer*, available at

<http://www.breakthrough.org.uk/sites/default/files/media/Campaigns/Age%20is%20just%20a%20number%20%20APPG%20report%20on%20older%20people%20and%20breast%20cancer.pdf> [accessed 20 August 2013]

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<http://www.breastcancercare.org.uk/digital/BCC%20submission%20to%20DH%20on%20VBP%2017%2005%2013.pdf> [accessed 22 August 2013]

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http://www.breastcancercare.org.uk/sites/default/files/files/pdf/older_women_with_breast_cancer_policy_briefingfinal.pdf [accessed 20 August 2013]

Reed, E and Corner, J (2013) Defining the illness trajectory of metastatic breast cancer, *British Medical Journal*, available at

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