

Appendix 23: Cancer screening (See Article 12)

It has been found that younger women presenting with breast cancer symptoms are more likely to experience delay by healthcare providers¹ and these groups of women also experience delays and different outcomes in terms of screening and cancer care and support. Most women (regardless of their age) are unaware that breast cancer risk increases with age.² The NHS automatic breast cancer screening, 'by invitation', a screening programme that predominantly affects women, currently has an upper age limit of 70 despite the incidence rate for female breast cancer remaining high beyond that age.³

Recommendation:

Remove the upper age limit for automatic invitation to breast cancer screening

For disabled women breast cancer diagnosis can be delayed because people with learning disabilities may have difficulties in recognising and communicating symptoms or because of 'diagnostic overshadowing' where changes in behaviour are attributed to the learning disability rather than interpreted as possible signs of physical ill health. The barriers to attending screening for women with learning disabilities may also include not receiving an invitation (perhaps through not being registered with a GP); inability to understand the invitation due to poor literacy skills; lack of access to information about screening in an appropriate format to enable informed decisions about attendance; inability of screening unit staff adequately to obtain consent; and lack of appropriate support by screening unit staff. Evidence from Wales shows that uptake of breast screening is low among women who use wheelchairs.⁴

Black and Asian women diagnosed with breast cancer in the UK have poorer relative survival rates than white women.⁵ Women from Asian and African Caribbean communities have similar information and support needs to the wider population with breast cancer. However, they do have unique information needs that should be addressed, particularly regarding skin healing after treatment and practical support concerns. Research⁶ has found that younger Asian and African Caribbean women reported that their diagnoses were delayed, often as a result of their breast health concerns being dismissed by healthcare professionals. Women felt they had to be proactive and ask questions that related to specific cultural concerns they had, as appropriate information was often not offered by healthcare professionals. Some women wanted consultations in their own language to ensure they could express themselves accurately, and understand information being given. Some Asian women mentioned

¹ Breast Cancer Care (2011) *Breast Cancer and inequalities: A review of the evidence*

<http://www.breastcancercare.org.uk/campaigning-volunteering/policy/breast-cancer-inequalities>

² Breast Cancer Care (2011) *Breast Cancer and inequalities: A review of the evidence*

<http://www.breastcancercare.org.uk/campaigning-volunteering/policy/breast-cancer-inequalities>

³ Centre for Policy on Ageing (2009) *Ageism and age discrimination in primary and community health care in the United Kingdom*. <http://www.ombudsman.org.uk/care-and-compassion>

⁴ Breast Cancer Care (2011) *Breast Cancer and inequalities: A review of the evidence*

<http://www.breastcancercare.org.uk/campaigning-volunteering/policy/breast-cancer-inequalities>

⁵ Breast Cancer Care (2011) *Breast Cancer and inequalities: A review of the evidence*

<http://www.breastcancercare.org.uk/campaigning-volunteering/policy/breast-cancer-inequalities>

⁶ The Better Access Better Services Project (2009) *Accessing information and support from the NHS and voluntary sector: Experiences of Asian and African Caribbean women with breast cancer*. Breast Cancer Care and Kings College London

http://www.breastcancercare.org.uk/sites/default/files/files/pdf/babs_bme_final_report.pdf

requesting female doctors as they felt uncomfortable undressing in front of male doctors. Access and signposting to culturally appropriate practical support services, including prostheses and hair loss services, varies across the UK. Culturally appropriate services and signposting should be provided and improved Black and minority ethnic representation and imagery to ensure that statutory and voluntary sector organisations are seen as accessible and culturally relevant organisations to women from these communities. Women felt the media portrayed breast cancer as a 'white woman's disease' and they would prefer locally-based voluntary services, in settings they trust and feel comfortable in.⁷

A study of Scottish Cancer Registry data on six common cancers found that increasing distance from a cancer centre correlated with poorer survival, with people in remote areas being less likely to have their breast cancer detected before they died. It is unclear from evidence whether women living in rural or remote settings are more or less likely to attend breast screening. However, geographical barriers to breast screening can be overcome to a certain extent with the use of mobile mammography units.⁸ (See Annex 1)

There is a clear deprivation gap in terms of survival, with breast cancer patients in the most deprived groups having significantly lower relative survival rates. People from more deprived groups tend to be diagnosed with more advanced disease which may indicate late presentation to a doctor with breast cancer symptoms. There is also evidence from both national and regional studies that breast screening uptake tends to be lower among more deprived groups but more research is needed into this issue.⁹

There is poor provision of specialist services for lesbian and bisexual (LB) women with breast cancer, despite evidence of the need for this among some women, and poor signposting of women to/from LB community groups by health/charity services.¹⁰ LB women aged 50-79 are more at risk of breast cancer because of a lack of early diagnosis - one in 12 have been diagnosed with breast cancer compared to one in 20 of all women. Lesbian women have a lower rate of breast self-examination despite studies indicating that they are at a higher risk of breast cancer, and report not knowing what to look for or how to check their breasts, therefore a targeted approach to screening and services is needed,¹¹ such as the Lesbian and Gay Foundation's campaign on cervical screening.¹²

In 2008 one in 50 LB women were also being excluded from routine testing for cervical cancer. Additionally, one in five women who had not had a cervical smear test were told, wrongly, by healthcare practitioners that they were not at risk. 15% of LB women over 25

⁷ The Better Access Better Services Project (2009) *Accessing information and support from the NHS and voluntary sector: Experiences of Asian and African Caribbean women with breast cancer*. Breast Cancer Care and Kings College London

http://www.breastcancercare.org.uk/sites/default/files/files/pdf/babs_bme_final_report.pdf

⁸ Breast Cancer Care (2011) *Breast Cancer and inequalities: A review of the evidence*

<http://www.breastcancercare.org.uk/campaigning-volunteering/policy/breast-cancer-inequalities>

⁹ Breast Cancer Care (2011) *Breast Cancer and inequalities: A review of the evidence*

<http://www.breastcancercare.org.uk/campaigning-volunteering/policy/breast-cancer-inequalities>

¹⁰ Breast Cancer Care (2011) *Breast Cancer and inequalities: A review of the evidence*

<http://www.breastcancercare.org.uk/campaigning-volunteering/policy/breast-cancer-inequalities>

¹¹ Women's Resource Centre (2010) *In All Our Colours: Lesbian, bisexual and trans women's services in the UK*. Briefing 10: LBT women and health. WRC: London

¹² Lesbian and Gay Foundation, Are you ready for your screen test? <http://www.lgf.org.uk/Our-services/Campaigns/Are-you-ready-for-your-screen-test-/> Accessed: 12/05/2013

years old - almost double the number of women in general - had never had a cervical smear test.¹³

Case study:¹⁴

"I was treated for cervical cancer after receiving a positive smear. I was originally told that I didn't need a smear as I had never had sex with a man."

¹³ Hunt, R. and Dr. Fish, J. (2008) *Prescription for Change: Lesbian and bisexual women's health check*. Stonewall: London http://www.stonewall.org.uk/documents/prescription_for_change.pdf

¹⁴ Hunt, R. and Dr. Fish, J. (2008) *Prescription for Change: Lesbian and bisexual women's health check*. Stonewall: London http://www.stonewall.org.uk/documents/prescription_for_change.pdf