Haringey Council

NOTICE OF MEETING

Scrutiny Review - Breast Screening Services

WEDNESDAY, 2ND DECEMBER, 2009 at 13:00 HRS - CIVIC CENTRE, HIGH ROAD, WOOD GREEN, N22 8LE.

MEMBERS: Councillors VACANT, VACANT, Alexander, Beynon, Bull and Winskill (Chair)

AGENDA

1. APOLOGIES

2. LATE ITEMS OF URGENT BUSINESS

The Chair will consider the admission of any late items of urgent business. Late items will be considered under the agenda items where they appear. New items will be dealt with at item 7 below.

3. DECLARATIONS OF INTEREST

A member with a personal interest in a matter who attends a meeting of the authority at which the matter is considered must disclose to that meeting the existence and nature of that interest at the commencement of that consideration, or when the interest becomes apparent.

A member with a personal interest in a matter also has a prejudicial interest in that matter if the interest is one which a member of the public with knowledge of the relevant facts would reasonably regard as so significant that it is likely to prejudice the member's judgment of the public interest **and** if this interest affects their financial position or the financial position of a person or body as described in paragraph 8 of the Code of Conduct **and**/**or** if it relates to the determining of any approval, consent, licence, permission or registration in relation to them or any person or body described in paragraph 8 of the Code of Conduct.

4. SCOPING REPORT (PAGES 1 - 22)

To receive a draft scoping report and proposed terms of reference for the review.

5. NHS HARINGEY (PAGES 23 - 92)

To receive a report from NHS Haringey on the provision of breast screening services in Haringey (Tamara Djuretic, Consultant in Public Health)

6. ADDITIONAL SCREENING REPORT (PAGES 93 - 112)

Improving the acceptance of breast screening services in London: key issues for London. Quality Assurance Reference Centre (2009)

7. LATE ITEMS

8. DATE OF FUTURE MEETINGS

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Agenda Item 4

Scrutiny Review of Breast Cancer Screening in Haringey

Scoping Report & Terms of Reference

November 2009

Draft for discussion

1. Introduction

1.1 Breast Screening Services in Haringey are provided through the North London Breast Screening Service (NLBSS). This is a specialist service which is commissioned by a consortium of 6 Primary Care Trusts (PCTs) in north London (Barnet, Brent Enfield, Haringey, Harrow and West Hertfordshire). The lead commissioning authority is Enfield PCT and performance is managed by a local (Enfield and Haringey) Committee.

1.2 A number of serious untoward incidents occurred at the NLBSS in 2006, which gave rise to significant safety concerns. Following a visit from the national compliance team, the decision was taken to close the service in December 2006. Although the service reopened in May 2007, a screening backlog continues at the service: the current screening round (the interval at which women are screened) is approximately 47 months instead of the national standard of 36 months.

1.3 The uptake of breast cancer screening invitations and the overall coverage of breast screening amongst the target population are also of concern in Haringey. In 2007/8, just 59% women invited to breast screening in Haringey attended, which is significantly below the national average (75%).[1] Similarly, the breast screening coverage[2] was 52% in Haringey, which is significantly below the average coverage in London (64%) and England as a whole (76%), and the third lowest nationally.[1]

1.4 Against this backdrop, in June 2009, Haringey Overview and Scrutiny Committee commissioned a panel of local councillors to conduct an in-depth review of how the uptake of breast screening services could be improved. The following report provides a detailed scoping of issues pertaining to breast cancer and associated screening services. The report also provides an overview of the national and local policy framework for the review including national, regional and local background data. The proposed terms of reference and the planned methods through which the review may be conducted are also presented.

1.5 This scoping report is intended to inform discussions around the nature of the review and more specifically, the terms of reference which will guide the work of the panel. Once agreed by the review panel, the scoping report will be sent to the Overview & Scrutiny Committee for approval. It is anticipated that the review will commence in November 2009 with a final report going to Overview & Scrutiny Committee in March 2010.

2. Breast Cancer Background

What is breast cancer?

2.1 Breast cancer is the irregular development of cells within the breast which may lead to the development of a tumour. There are two types of breast cancer; *ductal carcinoma* which is contained in ducts within the breast and *invasive* breast cancer, where the cancer has spread to broader breast tissue. If left

[1] National breast screening data 2007/8 www.cancerscreeeing.nhs.uk
[2] The number of eligible women who have screened within a three year period.

untreated, breast cancer can also spread (metastasis) through the blood stream to other parts of the body.

How common is breast cancer?

2.2 Breast cancer accounts for 31% of all female cancers and is the most common cause of cancer among women in the UK. Men may also develop breast cancer, but these account for less than 1% of all breast cancer cases. In 2006, there were 45,822 new cases of breast cancer diagnosed of which 45,508 (99%) were among women and 314 (1%) among men. The approximate lifetime risk of women developing cancer is 1 in 9 whilst for men this is 1 in 1,014.[3]

2.3 The incidence of breast cancer is a measure of the likely risk that a person will develop this condition over a specified period of time (generally a one year period). In 2006, the age standardised incidence of breast cancer was 122 per 100,000 of the female population. The incidence of breast cancer among women has risen considerably since 1977 (recorded at 75 cases per 100,000) which has been largely due to the introduction of the national breast screening programme (in 1988).[4]

2.4 Prevalence is a measure of how many people there are living with a particular condition, that is, those who are surviving after diagnosis and treatment. It is estimated that there are currently 5550,000 women in the UK surviving with breast cancer. This equates to 2% of the female population or 12% of the adult female population over 65.[5]

What are the risk factors associated with breast cancer?

2.5 There are a number of risk factors which are associated with breast cancer. The most significant factors associated with breast cancer are **sex** and age. Although both men and women can develop breast cancer, women are 100 times more likely to develop breast cancer than men.

2.6 **Age** is also strongly associated with breast cancer in women where the relative risk increases with age, where it is noted that 81% of breast cancers occur in women after the age of 50. Although the lifetime risk of a women developing breast cancer is approximately 1 in 9, the table below demonstrates the significance of age in the likelihood of women developing breast cancer.

Age range	**Breast cancer risk**
Up to 25	1 in 15,000
Up to 40	1 in 200
Up to 50	1 in 50
Up to 60	1 in 23
Up to 70	1 in 15
Up to 80	1 in 11
Up to 85	1 in 10

[3] UK Breast cancer incidence statistics. Research UK (data from 2001-2005) June 2009
[4] CancerStats Breast Cancer UK Cancer Research UK May 2009
[5] 'ibid'

2.7 **Childbearing** (parity) is also known to influence to the risk of a woman developing breast cancer. Not only is childbearing associated with a reduced risk, the higher number of full-term pregnancies a woman has undergone provides also provides further protection from developing breast cancer. Research has shown that women who have had children have a 30% lower risk than women who have no children (nulliparous).[6] Furthermore, the younger a woman is when she begins child bearing the lower the risk of developing breast cancer: the relative risk increases by 3% for every year of delay in childbearing.[7]

2.8 Following on from childbearing, women who **breast feed** their children are also known to receive greater protection from developing breast cancer. Women who breast feed reduce their risk of breast cancer and the longer a women breast feeds the greater the protection: risk is reduced by 4% for every 12 months of breast feeding[8].

2.9 A woman's **menstrual cycle** and the level of associated hormones within the body are also known to influence the risk of breast cancer. Increased risk of breast cancer is associated with the earlier age at which a woman has her first menstrual cycle (menarche). Conversely, those women who menopause at a later age also experience an increased risk of developing breast cancer: women who have the menopause at 55 rather than 45 have a 30% higher risk of breast cancer (equivalent to 3% per annum).[9]

2.10 The level of some **hormones**, whether produced naturally (endogenously) or taken as medication (exogenously), may also present an increased risk of developing breast cancer in women. Whilst naturally produced oestrogen and testosterone may increase the risk of breast cancer, taken medication such as **oral contraception** (OC) and **hormone replacement therapy** (HRT) are also associated with an increased risk of developing breast cancer: those women on HRT have an increased risk of 66% in developing breast cancer whilst those women who are taking the OC have an increased risk of 24%. It should be noted however that the relative risk is reduced to zero five years after a woman has stopped taking HRT and 10 years after taking the OC.[10], [11]

2.11 A woman's **family history** (genes) may also determine the relative risk of developing breast cancer. A woman with a first degree relative (such as a mother or sister or daughter) who has had breast cancer is twice as likely to develop the same condition as those with no such family history.[12]

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[6] Evertz et al Age at first birth, parity and risk of breast cancer: meta-analysis of 8 studies from the Nordic countries International Journal of Cancer 1990 (46) 597-603.

[7] Breast cancer and breast feeding: collaborative reanalysis of individual data from 47 epidemiological studies and 50,302m women with breast cancer The Lancet 2002 360 p187-95

[8] Breast cancer and breast feeding: collaborative reanalysis of individual data from 47 epidemiological studies and 50302m women with breast cancer Lancet 2002 360 p187-95

[9] Breast cancer and HRT collaborative reanalysis of 51 epidemiological studies. Collaborative group on hormonal factors in breast cancer The Lancet 1997 (350)1047-59.

[10] Breast cancer and hormonal contraceptives: collaborative reanalysis of individual data of 53,297 women with breast cancer and 100,239 women without cancer from 54 epidemiological studies.

[11] Breast cancer and HRT in the million women study The Lancet (2003) 363 419-427

[12] Family breast cancer: collaborative reanalysis of individual data from 52 epidemiological studies The Lancet 2001 (358) pp1389-99

2.12 There are a number of lifestyle factors which are associated with breast cancer. Post-menopausal women who are **overweight** or **obese** have an increased risk of between 10-30% of developing breast cancer; it is estimated that 7% of breast cancer cases in post menopausal women are due to being overweight.[13] Conversely, there would appear to be a reduced risk of breast cancer in pre-menopausal women that are obese (approximately 20%).

2.13 There is also an increased risk associated with **alcohol consumption**, indeed, international reviews would appear to suggest that this link is causal (as this may increase the level of hormones within the body).[14] Research would seem to infer that even low to moderate alcohol consumption can increase cancer risk, and that 11% of the total annual incidence of breast cancers may be attributable to alcohol consumption.

2.14 From a preventative viewpoint, **increased physical activity** is associated with a significant reduction in the risk of developing breast cancer (as this may reduce the level of hormones in the body). High levels of physical activity (10 hours walking or 3.5 hours running per week) have been associated with a reduced risk of developing breast cancer in women by between 20-40%.[15]

2.15 Internationally, it is noted that breast cancer occurs more frequently in **affluent** western populations which would infer that there are certain lifestyle factors associated with increased risk (perhaps some of those factors listed above). Here it is noted that there are higher rates of breast cancer in more Europe and North America than in less developed countries in Africa and Asia. Similarly, affluence would appear to influence the risk associated with more localised populations, where research has indicated that women from more affluent areas may experience up to 20% increased risk of developing breast cancer than those in more deprived areas.[16]

2.16 There are also a number of studies, mainly conducted within the USA, which suggest that there are possible associations between lesbian women and breast cancer. Evidence from this research has indicated that there were significant differences in the breast cancer risk factors exhibited among lesbian women than heterosexual women,[17] which has subsequently produced a higher level of overall risk in them developing breast cancer.[18]

Breast Cancer Mortality

2.17 In 2007, 12,082 people died from breast cancer of which 11,990 were women and 92 were men. Mortality from breast cancer has fallen dramatically since

[13] Reeves et al, Cancer incidence and mortality in relation to Body Mass Index in the Million Women Study: cohort study BMJ 2007 (335) 1134

[14] Baan et al Carcinogenicity of alcoholic beverages International Agency for Research on Cancer 2007

[15] Lahmann et al Physical activity and breast cancer risk: the European Prospective Investigation into Cancer and Nutrition. Cancer Epidemiol Biomarkers Prev. 2007 Jan;16(1):36-42. 2006

[16] Cancer incidence by deprivation 1995-2004) National Cancer Intelligence Network 2008

[17] Roberts et al, Differences in Risk Factors for Breast Cancer: Lesbian and Heterosexual Women Journal of the Gay & Lesbian Medical Association Vol. 2 No. 3 (1998) pp93-101

[18] Dibble et al Comparing breast cancer risk between lesbians and their heterosexual sisters, Women's Health Issues, Volume 14, Issue 2, pp 60-68

1989; the age standardised death rate has fallen from 42 per 100,000 (in 1989) to 27 per 100,000 (which equates to a 36% fall.[19] The reduction in breast cancer mortality is largely attributable to earlier detection of breast cancer (through the national breast cancer screening programme) and improved treatment options.

Treatment of breast cancer

2.18 The exact nature of the treatment for breast cancer will depend on the stage of development at which the cancer has been detected, the age of the patient an the size of the tumour. A combination of surgery and radiotherapy is the most common approach to the treatment of breast cancer, though most will have some form of surgery (i.e. either a lumpectomy, mastectomy).

2.19 There are two main types of treatment for breast cancer: those that are **breast specific** where the cancer is contained within the breast (usually surgery and radiotherapy) and **whole body**, where the cancer has spread to other parts of the body (usually chemotherapy or hormone treatment).

Breast Cancer Survival

2.20 The stage at which breast cancer is diagnosed can have a significant impact on the treatment options and subsequent survival rates of those women diagnosed with this condition. Generally, earlier detection leads to longer survival rates.

2.21 As a result of the introduction of the National Breast Screening Programme (NBSP), there has been a significant improvement in 1 year, 5 year, 10 year and 20 year survival rates for breast cancer. In 1971-1975 the five year survival rate for breast cancer among women was 52%, yet by 2001-2003 this had risen to 80%.[20] Similarly it is recorded that the 10 year survival rates have increased from 41% to 72% in the period 1991-2003.[21]

2.22 Social deprivation is known to be associated with breast cancer survival rates. It has been recorded that women in areas of social deprivation are more likely to first present at a more advanced stage of breast cancer development than those living in more affluent areas[22], more likely to present with another health condition (co morbidity)[23] and have a lower survival rate.[24]

Prevention of breast cancer

2.23 As has been noted earlier, there are some factors which are associated with breast cancer that are behaviour related (i.e. alcohol consumption, exercise, breast feeding). In this context, encouraging **behaviour change** may reduce the risk of developing breast cancer. Internationally it has been acknowledged

[19] CancerStats Breast Canver UK Cancer Research UK 2009
[20] CancerStats Breast Canver UK Cancer Research UK 2009
[21] Office for National Statistics Breast Cancer Survival in E & W 1991-2003
[22] Macleod et al Socioeconomic deprivation and stage of disease at presentation in women with breast cancer Annals of Oncology 2000 11 (1) p105-107.
[23] Macleod et al Primary and secondary care management of women with early breast cancer from affluent and deprived areas: retrospective review of hospital and GP records BMJ 2000 320 (7247) p1442-5)
[24] Coleman et al Trends in socioeconomic inequalities in cancer survival in England and Wales up to 2001 British Journal of Cancer 2004 90 (7) p1367-73

that that increasing the uptake of exercise and reducing levels of obesity can reduce breast cancer.[25]

2.24 **Prophylactic surgery** is also performed for those women who have a very high risk of developing breast cancer, that is, where there is strong family history of breast cancer. It is estimated that in this context, such surgery can reduce the risk by approximately 90%.

2.25 **Education and awareness** initiatives are also important tools in developing a broader understanding of breast cancer issues such as the importance of breast care and attendance at breast screening services and also how to access services if a problem is identified. In addition to a number of national campaigns, there are a number of national charities which operate awareness and education programmes for breast cancer (i.e. Breakthrough Cancer, Breast Cancer Campaign).

2.26 Although **screening** cannot prevent breast cancer, it is perhaps the most effective tool in the diagnosis and treatment of cancer. An effective screening programme can provide a number of significant benefits for women including early diagnosis, improved treatment options, better health outcomes and improved survival rates.

3.0 Breast Cancer Screening

What is breast screening?

3.1 Breast cancer screening (mammography) involves a low dose radiation scan to identify abnormal cell development or growths (tumours). Generally two scans are undertaken, both from above (craniocaudal) and from the side (mediolateral) of the breast as this increases the chances of detecting smaller cancers. Breast screening is effective in reducing mortality by approximately 35% in 50-69 year olds, this equates to 1 life is saved for every 500 women screened.[26]

3.2 The introduction of breast cancer screening was designed to detect cancers at an early stage, which would subsequently lead to an improved prognosis and survival rate of women diagnosed with this condition. The importance of breast screening in this context is underlined by that the fact that 40% of breast cancers detected by screening would not have been detected by other methods (i.e. by hand).

The National Breast Screening Programme

3.3 The National Breast Screening Programme (NBSP) was first established in 1988 and was the first such coordinated screening programme in the world. Within the NBSP, women aged between 50 and 70 years are routinely invited for a breast cancer screen every three years. Invitations are issued by a local breast

[25] World Cancer Research Fund: Food nutrition, physical activity and the prevention of cancer: a global perspective 2009

[26] International Agency for Research on Cancer (IARC), 7th Handbook on Cancer Prevention, Lyons 2003

screening unit to local women on General Practice basis (i.e. invitations issued practice by practice).

3.4 Women aged below 50 years are not included within the NBSP as breast cancer can be difficult to detect in pre-menopausal women. Those women believed to be at risk but who are outside the current screening age range can still be referred for breast screening through their GP. It is planned to extend the NBSP to women between the ages of 47 and 73 years by 2012, which will involve an additional 400,000 women in the screening process.

3.5 There are 82 breast screening units in the UK (7 of which are in London). Local breast screening units are coordinated by a national service and breast screening practice is overseen by both regional and national quality assurance network. The NBSS costs approximately £75 million to administer each year, which equates to £37.50 per woman invited or £45.50 per woman screened.

3.6 Breast screening pathway

Breast screening is a cyclical programme where all eligible women (currently aged 50-70 years) are invited to a free breast screen every three years. A radiographer will take x-rays of the breast and examine these for potential abnormalities (usually two specialists will do this). Those women identified as having an abnormal mammogram will undergo a further second assessment. If the abnormality is confirmed as malignant it will be treated (as set out above), if it is normal, the woman will be returned to the recall system and invited for screening again in 3 years time.

Breast Screening Uptake

3.7 The uptake for breast screening is defined as 'the proportion of eligible women who have been invited for screening for whom a screening result is recorded'. Currently the national minimum standard for breast screening uptake is 70% though the national target is higher at 80%.

3.8 National data from that NBSP for 2007-8 reveals that 2.25 million women were invited for a breast screen of which 1.713 million women attended, which produced an uptake of 73%. Nationally, the uptake of breast cancer screening has remained broadly static for the past 5 years (Figure 1). The proportion of women who take up their breast screening invitation in London and within the North London Breast Screening Service (in which Haringey is located) is significantly below national rate at 61% and 59% respectively (Figure 1). Like national trend data, the uptake of breast cancer screening for the London region and within the North London Breast Screening Service has also remained broadly unchanged since 2002/3 (Figure 1).

3.9 There are wide variations in screening uptake among individual breast screening units and within individual Primary Care Trust areas. In some high performing breast screening units such as Barnsley and Rotherham, 81% of women invited for a breast screen have a corresponding screening result. In the London region the average uptake for 2007/8 was 61%. There is also a wide variation in screening uptake among London breast screening units: in Barking & Havering the uptake is 73% whilst in Central North East London uptake is just 52% (Figure 2).

Breast screening coverage

3.10 The breast screening coverage refers to the proportion of eligible women who have recorded a test at least once in the previous three years. The national benchmark for breast screening coverage is 70%. Data from the NBSP for 2007/8 indicates that the breast screening coverage for women aged 53-70 in England was 75.9%, for London 63.6% and in Haringey 52.4% (see table below).

Region	Population	Women screened	Coverage (%)
England	5,115,011	3,883,130	75.9
London	599,309	381,077	63.6
Haringey	18,586	9,742	52.4

3.11 Regionally, in 2007/8, all but one area reported a breast screening coverage of greater than 70%: the one exception being in London where the breast screening coverage was 65%. The level of breast screening coverage also varied widely across local primary care organisation level (Figure 3). At the primary care organisation level, 121 out of 152 areas reported a coverage above 70% (35 of which were above 80%). Just fourteen primary care organisations had coverage below 70%.

3.12 Whilst the average breast screening coverage for the London region was 65%, there were wide variations in coverage among primary care organisations. Thus while in Havering the coverage was 78.2% this fell to 42.3% in Barnet (Figure 4). In Haringey, the coverage was 52.4%, making this the third lowest in the country. The proportion of women aged 53-70 in London who have never screened is 19%, which is far higher than the national average (11%).

Screening round length

3.13 The screening round length is the interval between the date of a women previous screening mammogram and the date of her next first appointment. The round length is measured by the percentage of eligible women whose first appointment is within 36 months of their previous screen. The national minimum standard is 90% or above and the target is 100%.

3.14 It is important that the minimum round length is met, because if women are screened within the 36 month interval the incidence of “interval cancers” (i.e. those developing cancer between screening appointments) is very low. This risk of developing cancer rises as the interval increases.

3.15 Following a number of serious untoward incidents (SUI) at the North London Breast Screening Service and a visit by the regional quality insurance service, the decision was taken to close the service in December 2006. Although the service reopened in May 2007, a breast screening backlog continues at the NLBSS. The current screening round length is below the national minimum standard at approximately 47 months.

What factors affect the uptake of breast screening?

3.16 There are clearly many factors which may influence the take up of invitations to breast screen and in the UK at least, however, there are few definitive large scale studies to guide such assessments. There are however number of smaller

scale studies which have identified a number of factors which are associated with the take up breast screening services.

3.17 There are a number of studies which have provided a link between **social deprivation** and the take up of breast screening invitations. There have been a number of studies which have highlighted that the women resident in areas of social deprivation are less likely to attend breast screening services than women from more affluent areas.[27],[28],[29]

3.18 A number of studies have also made associations between **ethnic origin** and attendance at invitations for breast screening. Research conducted in Brent & Harrow concluded that that poor knowledge, underlying health and cultural beliefs, attitudes and language were central to low attendance by BME groups.[30] Other studies among non attendees of breast screening services found that some BME groups did not perceive themselves to be at risk or were more anxious about attending.[31] There is insufficient research evidence however to conclude that there is a direct link between BME status and breast screening uptake as lower levels of attendance may be the result of other factors (i.e. socioeconomic group differences or inaccurate registers).

3.19 The **location of the breast screening unit** was also found to influence the uptake of invitations to breast screening services. One study found that the distance that women have to travel had a significant impact on the uptake for screening services,[32] whilst another study concluded that after a breast screening service was moved, attendance fell by 2% for each kilometre further women were from the unit.[33]

3.20 **Personal attitudes** have also been shown to influence a woman's decision whether to attend for breast screening. A study in Lambeth, Southwark & Lewisham found that a positive personal attitude and the perceived personal importance of screening were strongly associated with attendance for breast screening services. Conversely, the study found that some of the most common reasons women gave for non-attendance included the avoidance of anxiety, pain and embarrassment.[34]

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[27] Gatrell 1998 Uptake of screening in breast cancer in South Lancashire Public Health 112 (5) 297-301

[28] Maheswaran et al 2006 Socioeconomic deprivation, travel distance, location of service and uptake of breast screening services in North Derbyshire Journal of Epidemiology and Community Health 60 (3) 208-12

[29] Banks et al 2002 Comparison of various characteristics of women who do and do not attend breast cancer screening, Breast Cancer Research 4 R1

[30] Barriers to effective uptake of cancer screening among BME ethnic groups, International Journal of Palliative Nursing 2005 Nov 11 (11) 564-571)

[31] Barter-Godfrey & Takert 2005 Women and health: views of women aged 50—64 living Lambeth, Southwark & Lewisham, London South Bank University

[32] Maheswaran et al 2006 Socioeconomic deprivation, travel distance, location of service and uptake of breast screening services in North Derbyshire Journal of epidemiology and community health 60 (3) 208-12

[33] Maxwell 2000 Relocation of a static screening unit: a study of factors affecting attendance Journal of Medical Screening (7) 114-115

[34] Barter Godfrey and Taket 2005 'op cit'

3.21 For the most vulnerable women in the community responding to invitations to breast screening appointment may be problematic. Lower levels of breast screening have been reported among women with a **learning disability**,[35] despite that this group are now living longer and fuller lives and living to an age where screening is appropriate. Similarly, it is noted that there is evidence to suggest that there is lower attendance among women with severe **mental health** problems.[36]

3.22 There may be a number of **structural factors** associated with the organisation of the screening service which may influence the uptake of screening. A well organised breast screening programme may positively influence uptake, which might include:

- Adequate population registers
- Effective call and recall system
- Good quality control
- Reliable and safe procedure[37]

3.23 Attendance for invitations to a breast screen is clearly affected by a broad range many social, cultural and economic factors, of which just a few have been highlighted above. It is clear that the decision to attend for breast screening is undoubtedly complex and in many cases personal to the individual making this decision.

Interventions to improve breast screening uptake

3.24 There is evidence to suggest that there are a number of possible interventions which have had a positive impact in developing breast screening uptake among women. Although **GPs** are not directly involved in the breast screening process, there is evidence to suggest that planned interventions by GPs can improve screening uptake. Improved uptake has been recorded where GPs have written or made a call to non-attendees at breast screening services,[38] furthermore, such GP interventions were found to override factors associated with poor attendance such as social deprivation and ethnicity.[39]

3.25 Issuing **reminder letters** to non-attendees was found to be effective in improving the uptake of breast screening services; in a review of 28 studies, it was concluded that the issuing of reminder letters consistently increased uptake.[40] Furthermore, those reminders which offered another fixed appointment were also found to improve breast screening uptake further still.[41]

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[35] Cancer Reform Strategy 2007

[36] Werneke etal Uptake of screening for breast cancer in patients with mental health problems Journal of Epidemiology and Community Health 2006;60:600-605

[37] London Quality Assurance Reference Centre 2002

[38] Bankhead et al Improving attendance for breast screening among recent non-attenders: a randomised controlled trial of two interventions in primary care. Journal of Medical Screening 2001;8(2):99-105

[39] Majeed, et al, Do GPs influence the uptake of breast screening: a general practice based study Journal of Medical Screening 1995 4 (1) 19-29. 2005

[40] Sin & Leger. Interventions to increase breast screening uptake: do they make any difference? Journal of Medical Screening 1999; 6(4): 170-181.

[41] M J Stead Improving uptake in non-attenders of breast screening: selective use of second appointment J Med Screen 1998;**5**:69-72

3.26 The role of the **media** undoubtedly influences a woman's decision to attend an invitation for screening: a case in point being a recent celebrity death from cervical cancer from which it has been concluded, has induced a significant rise in screening uptake in some areas of the UK.[42] Other more specific local advertising campaigns have also been found to be helpful in promoting screening, reassuring attendees and improving uptake.[43]

Future considerations for breast cancer/ screening

3.27 In term of the future considerations for breast cancer and breast screening services, there are a number of generalised points that should be noted. These are summarised below.

- Although death rates from breast cancer are falling, the number of women diagnosed with cancer is likely to increase as a result of the expansion of the breast screening programme (to 47-73 years age spectrum) and the ageing distribution of the population.

- Although breast cancer is a significant cause of mortality among women, breast cancer is becoming a disease that the majority of women live with rather than die from: that is the prevalence of breast cancer is increasing. This has important implications for the provision of physical, therapeutic and emotional support service for those that are surviving breast cancer.

- There is a nationally shortage of both radiologist and radiographers which may impact on the effective operation of local breast screening services.[44] Increasing the scope and capacity of screening services will depend on successful training, recruitment and retention of such highly trained staff.

4.0 National and regional policy framework

4.1 National cancer policy and priorities were outlined in the **NHS Cancer Plan** in 2000. A number of key policy streams were highlighted within this document including improvements to cancer prevention, screening and treatment services. Of particular relevance within this report were measures to extend breast screening to women aged 50-70 years (now largely implemented) and a reorganisation of screening support staff to improve access to key staff groups (i.e. radiographers).

4.2 The NHS Cancer Plan has largely been superseded by the **Cancer Reform Strategy** which was published in 2007. This strategy identified a number of new developments and issues for the development of breast screening services which are highlighted below:

- Screening age for women is to be extended to 47-73 years, with all women guaranteed to receive their first screen before the age of 50. Service extension to be completed by 2012.

- Mammograms at all breast screening services will all be digitised by 2012.

[42] Jade Goody effect increases cervical screening rates Nursing Times March 2009
[43] Cohen, L et al (2000) Promoting breast screening in Glasgow, Health Bulletin, 58(2). 127-32
[44] Behind the Screen GLA Health Committee Report 2008

- The imminent eligibility of the baby boom generation for screening will result in increased uptake within the NBSP. This may require additional local investment to maintain the screening round length at 36 months.

- The NBSP will assume responsibility for the management and surveillance of women at high risk of familial breast cancer.

- There will be a need for local commissioners to be mindful of health inequalities and inequities in service provision, and the need to develop programmes in response.

- The need to continue to raise awareness of breast cancer and the availability of screening services, to those women outside the screening programme, especially those aged over 70 years.[45]

Greater London Assembly

4.3 The Greater London Assembly conducted a detailed investigation of breast screening services across the capital, focussing on how London's low uptake for this service can be improved (entitled *Behind the Screens)*.[46] This highlighted 4 main problems:

- Lack of knowledge as to why women attend, demographics of non attendees – this means that services are unable to target non-attendees
- Low levels of awareness of breast cancer screening, breast cancer symptoms and risks in London
- Women in London have a poor experience of breast screening services
- Waiting times for radiotherapy in 1/3 of London's trust exceed national waiting times limit.

4.4 The GLA report makes a number of recommendations to improve services across London:

- More information about non attendees needs to be collated and analysed
- Women over screening age should continue to be reminded of importance of breast screening
- A 3 year London wide media campaign to raise awareness should be developed
- GPs need to take a bigger role in promoting breast screening to their patients
- London wide call and recall system for breast screening needs to be developed as part of the Healthcare for London modernisation work.

5. Local policy context

5.1 Developing the uptake of health screening services is noted within key strategy documents for Haringey. From this documentation, it is possible to identify a number of areas where the review may potentially contribute to help support local policy objectives and achieve local targets.

[45] Cancer Reform Strategy Department of Health 2007
[46] Behind the Screens: breast screening uptake and radiotherapy waiting times in London 2008

Sustainable Community Strategy (2007-2016)

5.2 The Sustainable Community Strategy (SCS) is the overarching plan of the Haringey Strategic Partnership which details how the Council and its partners will tackle broad community wide issues. The SCS is based on a wide community consultation process and provides a ten year vision for Haringey. Key priorities embedded within the SCS include the need for helping people to become healthier with a better quality of life, reducing health inequalities and the provision of high quality services for those in need.

5.3 There is an explicit commitment within the SCS plan for 2009-2011 to "increase the uptake of cervical and breast screening including amongst non-English speaking communities. It is anticipated that the scrutiny review will contribute to this process.

Local Area Agreement (2007-2010)

5.4 The Local Area Agreement (LAA) sets out a range of targets for the Council and its partners in delivering the key priorities and objectives of the SCS. There are 80 indicators in Haringey which are made up of statutory (n=16), national (n=35) and local (n=16) targets.

5.5 The following table provides an overview of national indicators which may be of relevance to the review of breast screening services.

Indicator	LAA target	Detail
NI 119	Yes	Self-reported measure of people's overall health and wellbeing
NI 120	No	All-age all cause mortality rate
NI 122	No	Mortality from all cancers at ages under 75
Local	Yes	Prevalence of breastfeeding at 6-8 weeks from birth

Comprehensive Area Assessment (2009)

5.6 Comprehensive Area Assessment (CAA) is the new process in which local public services are assessed. The emphasis of assessments within the CAA process is on broad public perceptions of the quality of life in an area rather than on the nature and quality of services provided. As part of the assessment process, the local strategic partnership is required to submit an annual self assessment of its performance against agreed local priorities.

5.7 It is envisaged that there will be two-way relationship between the CAA and overview and scrutiny, where local in-depth scrutiny reviews may provide evidence for the completion of the local self assessments, while the CAA may assist local scrutiny committees identify and prioritise issues to investigate. The current self-assessment has highlighted that one of the key challenges for Haringey is A key priority from the CAA self evaluation 2009-2011 is to increase the uptake of breast screen screening.

6. Terms of reference

5.1 The terms of reference fulfil a number of functions for the review through: providing purpose and structure to the review process; helping to develop a

common understanding of the scope of the review among stakeholders, and; creating a framework around which future decisions are made. The terms of reference are also critical in establishing the questions that the review will seek to address and that appropriate methods to be used to collect the necessary data.

Aim of the review

6.2 It is proposed that the overarching aim of the review will be:

'To identify how the uptake and coverage of breast screening services may be improved among women resident in Haringey.'

Objectives of the review

6.3 It is proposed that the review addresses the following objectives:

1. Describe the nature and level breast screening services available to women living in Haringey.

2. To identify the barriers to improved take up and coverage of breast screening services in Haringey and possible interventions to overcome these.

3. To identify how local partners may work together better to improve services, raise awareness and increase uptake of breast cancer screening in Haringey

4. Consider the effectiveness of local breast screening services in relation to meeting local strategic and policy objectives (i.e. well being agenda, health inequalities).

5. Examine how the uptake and coverage of breast screening services impact on local equalities issues and to assess how access can be improved to minority and other community groups.

6. Evaluate policy and performance data from other screening services and other Primary Care Trusts to identify good practice and improved ways of working to further promote the uptake and coverage of breast screening services in Haringey.

7. Assess whether breast screening services achieve value for money through ascertaining whether: costs are commensurate with performance, outcomes and delivery and compare well against other boroughs.

8. Ensure that the scrutiny review process generates relevant evidence that will contribute to ongoing assessments made within the Comprehensive Area Assessment.

7. Review methods

Review Panel

7.1 A review panel of four backbench Members will be convened to conduct the scrutiny review. Members of the review panel have been confirmed as Cllr Winskill (Chair), Cllr Alexander, Cllr Bull, Cllr Beynon and two Labour vacancies.

Panel Meetings

7.2 The review will use a range of investigative methods to ensure that Members have access to the necessary evidence to assist them in their assessment of breast screening services in Haringey. A series of panel meetings will be held to approve the aims of the review, to receive oral and written evidence, oversee project progression and formulate conclusions and recommendations. Panel meetings will occur at approximately four week intervals (or as agreed by the panel).

7.3 It is proposed that approximately 3 or 4 panel meetings will be held from November 2009 through to January 2010. It is anticipated that panel meetings will focus on particular themes or topics to inform the data gathering process. It is suggested that evidence sessions be held to consider the following issues:

- What services are currently provided and what plans are there to improve and develop services?
- What can be learnt from the experience of other breast screening services or other Primary Care Trusts to improve the uptake and coverage of breast screening services?
- What can be learnt from the experiences of local women and other local stakeholders to improve the uptake and coverage of breast screening services?

7.4 A number of key informants have been identified and to participate within the review including officers from NHS Haringey, representatives from NLBSS and other relevant stakeholder groups. A plan of the proposed meeting structure, including possible informants to the review process, is contained in **Figure 5** During the course of the review members aim to hear from:

Stakeholder	Issues to be covered
NLBSS	Issues with current configuration of breast screening services, measuring the effectiveness of service, benchmarking data, comparative performance with other screening services, quality assurance data & future plans for the service.
NHS Haringey	Current and future commissioning plans for the service, future investment, coordination of services (NLBSS, NHS Haringey and Primary Care Services) how local preventative initiatives will link to the work of the NLBSS and other regional work-streams.
North Central London Cancer Network London Quality Assurance Reference Centre	Identify regional developments in breast cancer screening services
Other NHS Trusts / breast screening services	Identify best practice, innovative ways of working from other breast screening services or other NHS Trusts.

Assessing internal and external data sources

7.5 A range of information from a variety sources will be used to help meet the review objectives. It is anticipated that relevant services (NHS Haringey and NLBSS) will provide financial, operational and evaluative data to assist panel members in their deliberations of breast screening services issues.

7.6 The review will aim to draw on external research, policies and other service data where this is felt to assist to review process. Analysis of national, regional and local performance data will be undertaken to inform the review. Comparative data from other NHS trusts may also be used to help panel members identify good practice, benchmark local breast screening service provision and identify local priorities for service improvement.

Panel Visits

7.7 It is proposed that panel members undertake a number of planned visits to gain a practical insight in to the provision of breast screening services in the locality. The NLBSS have suggested that it might be helpful for the panel to visit Chase Farm Hospital to understand central operations from this site. The Panel may also wish to visit one of the mobile breast screening units (through which most local women are screened) or, undertake a visit to another breast screening service in London.

Background briefing reports

7.8 It is proposed that background briefing reports on relevant meeting topics will be prepared and circulated to the panel before each meeting. It is hoped that this these themed reports will assist the panel in their deliberations on particular aspects for the review. It is planned that background briefing reports will coincide with planned evidence sessions and focus on the following themes:

- Obstacles to breast screening uptake in inner city areas
- Best practice from other breast screening services or other NHS Trusts
- Evidence of what women would like from a breast screening service.

Community / Public Involvement

7.9 Community and public involvement is an integral part of the scrutiny process through helping to maintain local accountability. All scrutiny meetings are held in public at which, at the discretion of the Chair, local residents and community groups may also participate. To facilitate local community participation, it is proposed that a number of the planned panel meetings are held at different community venues across the borough.

7.10 Whilst it is noted that there has already been some consultation with local women about the nature of breast screening services, the panel may also wish to consult local women's group representatives for their perspectives on how services could be improved. The local women have indicated a willingness to participate in the review process. This will provide a further opportunity for local community group representatives and local residents to discuss breast screening issues with the panel (or representatives).

Independent Expert Advice

7.11 The Panel may wish to consider if their work would be assisted by the provision of independent expert advice which could "add value" to the review through:

- Giving evidence to the Panel

- Impartially evaluating current practice, providing advice on successful approaches and strategies that are being employed elsewhere
- Suggesting possible lines of inquiry
- Commenting on the final report and, in particular, the feasibility of draft recommendations.

8.0 Equalities

8.1 The scoping report has identified a number of equalities issues which will be important to explore and assess further within the work of which the scrutiny review. From the evidence presented in this report it is apparent that there may be a number of variations in the incidence of breast cancer, the take up of an invitation to screen and the outcomes of treatment which may impact unequally on equalities groups. For instance:

- Increased incidence of breast cancer among more affluent populations
- Lower take up of breast screening services among:
  - ✓ women in areas of social deprivation
  - ✓ among black and other minority ethnic groups
  - ✓ women who have a mental health problem or a learning disability
- Higher risk factors associated with lesbian women

8.2 The scrutiny review therefore will be particularly keen to assess if such variations are exhibited locally and to assess how the local partnership of services is addressing such inequities where they exist (i.e. service monitoring, service commissioning, service delivery).

Figure 1 – Uptake of breast cancer screening 2002/3 to 2007/8.

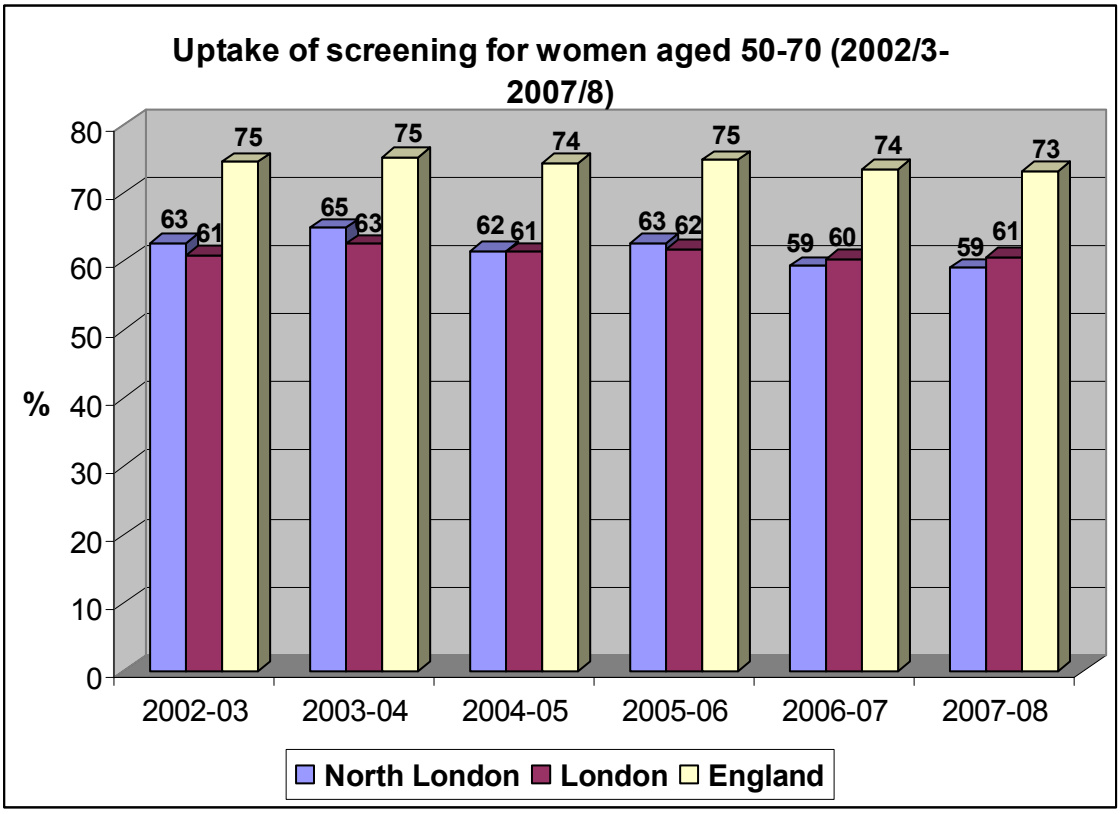


Figure 2 – Screening uptake in London Breast Screening units in 2007/8.

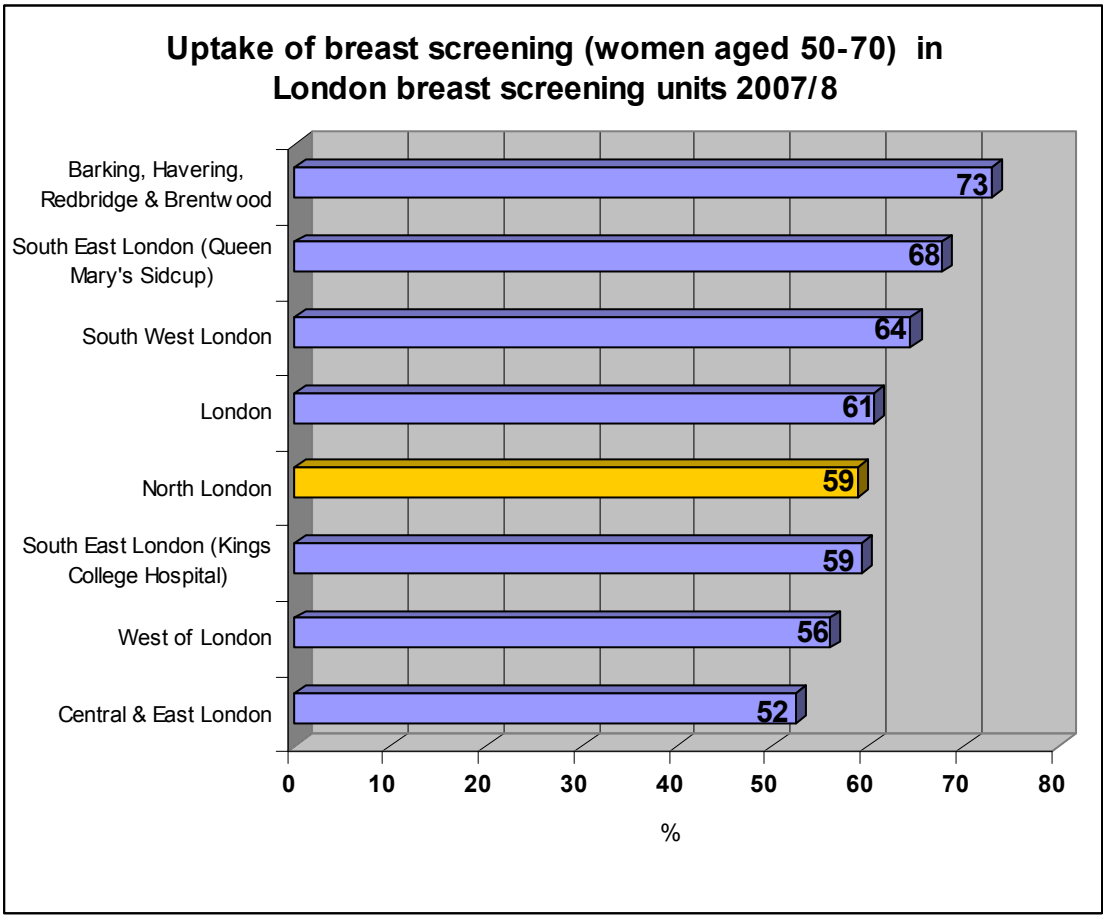


Figure 3 – National breast screening coverage (women aged 53-64 2007/8).

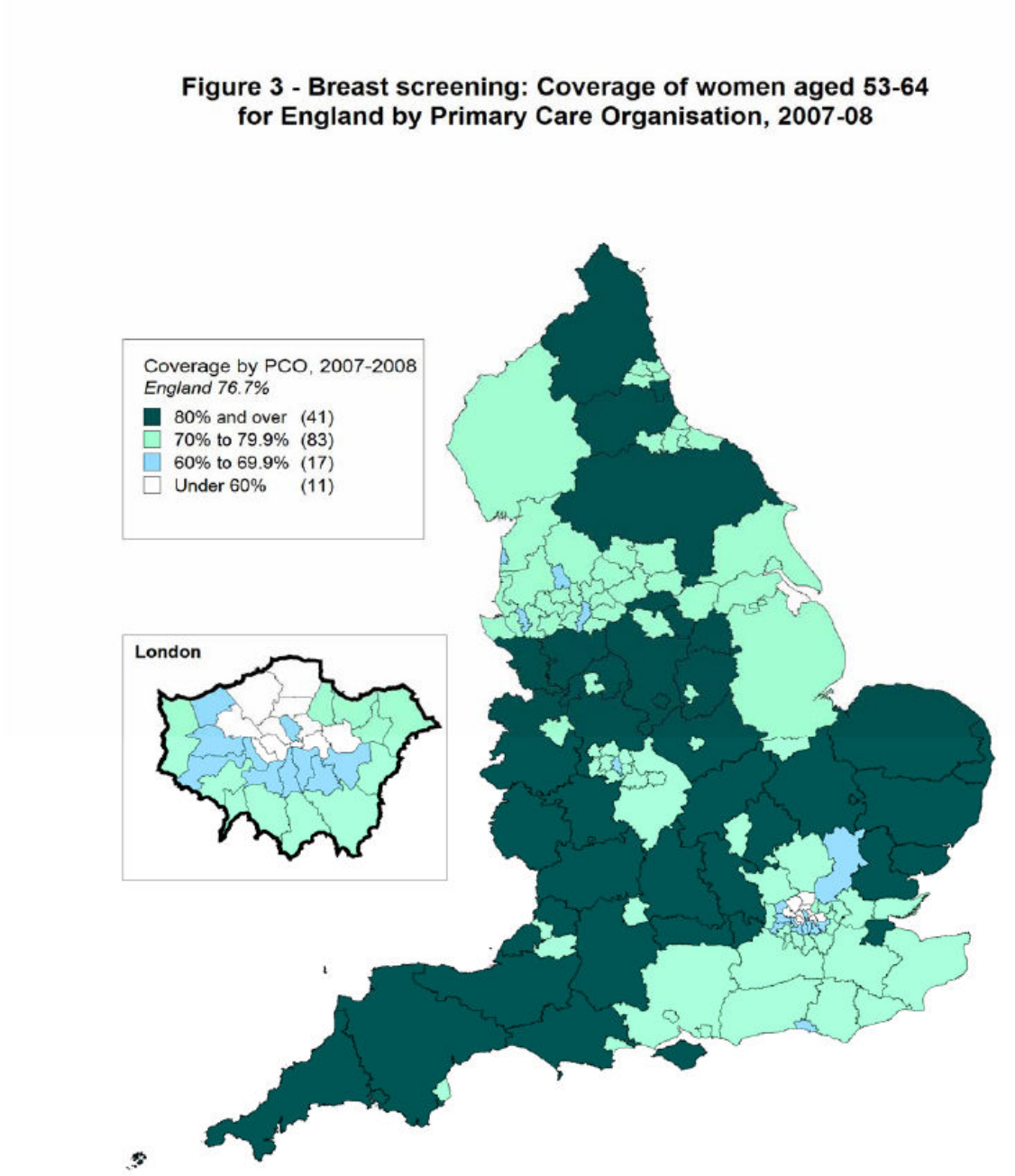


Figure 4 – Breast Screening Coverage in London PCT areas.

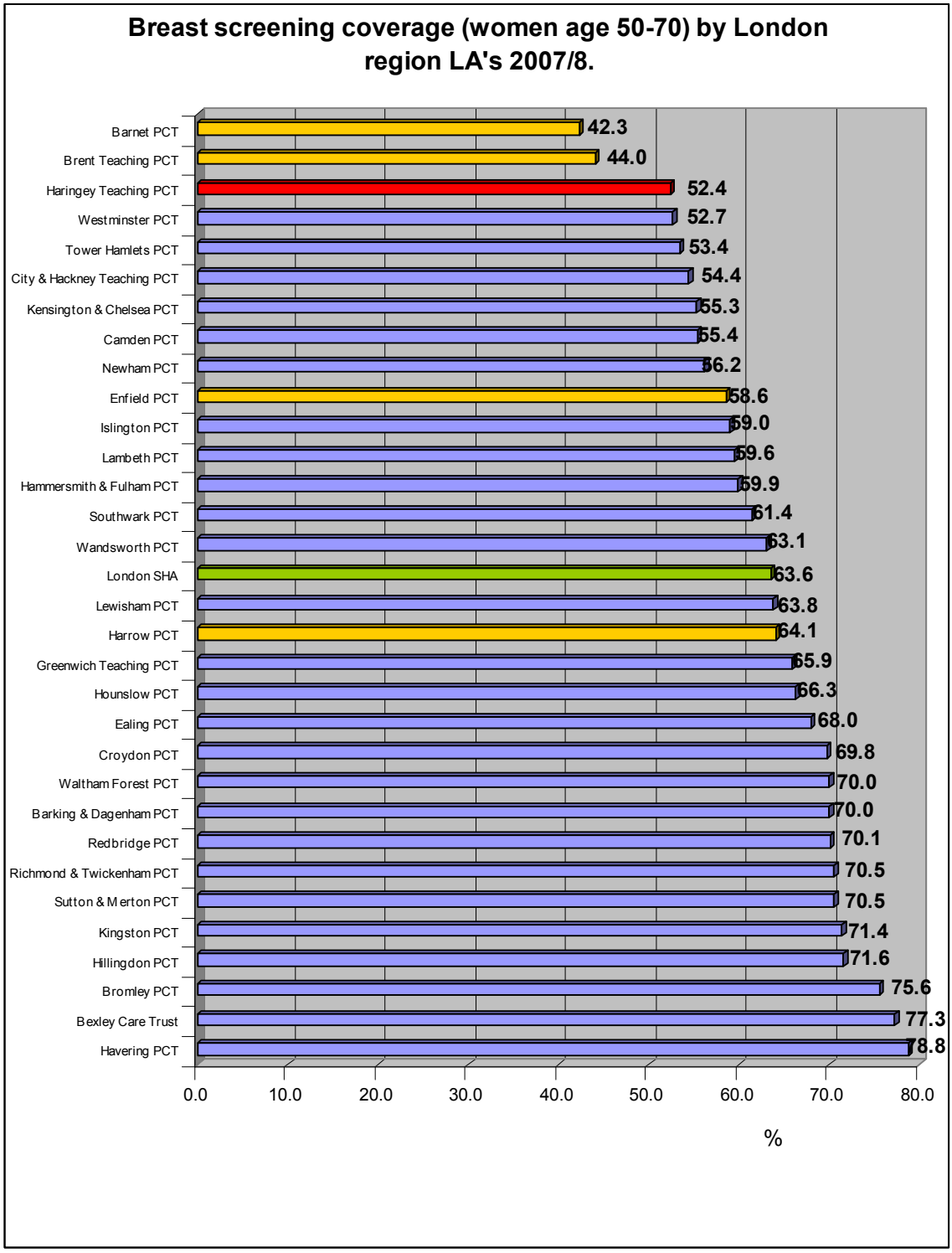


Figure 5 - Proposed work plan for scrutiny review

	Aims	Possible participants
Meeting 1 **2nd December 2009**	▪ Approve scoping report ▪ What services are currently commissioned in Haringey? ▪ What plans are there to improve and develop services? ▪ How can improved breast screening services contribute to other strategies and policies?	▪ Tamara Djuretic, NHS Haringey
Meeting 2 **TBC December 2009**	▪ How are breast screening services provided in Haringey? ▪ Regional developments in Breast Screening Services?	▪ Debbie Brazil, NLBSS ▪ Clinical Director, NLBSS ▪ London QARC ▪ NCL Cancer Network
Meeting 3 **TBC January2009**	▪ What can be learnt from the experience of other breast screening services? ▪ What can be learnt from other Primary Care Trusts?	▪ Independent adviser ▪ Other BSSs ▪ Other PCTs
Meeting 4 **TBC January 2009**	▪ What can be learnt from the experiences of local women? ▪ How can partners/ other stakeholders to improve the uptake and coverage of breast screening services?	▪ Independent expert adviser ▪ Women's Group Representatives ▪ Equalities Officer ▪ Other local stakeholders
TBC January 2009	▪ Formulation of conclusions and recommendations	

Agenda Item 5

NHS Haringey

Scrutiny review of Breast Cancer Screening in Haringey

Overview of Breast Screening Services in Haringey

November 2009

Tamara Djuretic
Public Health Consultant and Screening Lead
NHS Haringey

1. Breast Screening Programme

Breast screening is a method of detecting breast cancer at a very early stage when the likelihood of being cured is highest. The first step involves an x-ray of each breast using a mammogram that can detect small changes in breast tissue which may indicate cancers which are too small to be felt either by the woman herself or by a health professional.[1]

The NHS Breast Screening Programme was introduced in the UK in 1988 to provide free breast screening every three years for all women in the UK aged 50 and over. The NHS Breast Screening Programme is an effective part of the UK's efforts to reduce the death toll from breast cancer. Around one-and-a-half million women are screened in the UK each year. Women aged between 50 and 70 years are now routinely invited. Since 2004, women who are aged 70 years and over may request mammography every 3 years, but are not routinely invited. There is however plan to extend the age range of women eligible for breast screening to ages 47 to 73 by 2012[2].

Research suggests that the NHS Breast Screening Programme saves an estimated 1,400 lives every year in England[3]. In September 2000, research was published which demonstrated that the screening programme had lowered mortality rates from breast cancer in the 55-69 age group.

2. The North London Breast Screening Service (NLBSS)[4]

2.1. Description

[1] Annual Report on Breast Screening Services, NHS Enfield 2008/2009
[2] Effect of NHS Breast Cancer Screening Programme on Mortality from Breast Cancer in England and Wales, 1990-8: Comparison of Observed with Predicted Mortality. BMJ 2000:665-669
[3] National Health Scheme Breast Screening Programme (NHSBSP)

The North London Breast Screening Service is one of the largest breast screening services in the country and one of six breast screening programmes serving the eligible women in London. The NLBSS is based at Edgware Community Hospital and screens from two static sites: Edgware Community Hospital and Forest Primary Care Centre in Enfield, as well as a number of mobile units including St. Ann's Hospital, the Whittington Hospital and North Middlesex Hospital. The service provides a screening and assessment service for eligible women resident within Barnet, Brent, Enfield, Haringey, Harrow and the southern half of West Hertfordshire. The service is commissioned by the 6 Primary Care Trusts through a consortium arrangement with NHS Enfield currently serving as the Lead commissioner.

The Department of Health (DoH) Guidance '*Commissioning and Managing Screening Programmes*[5] sets out the requirements for PCTs in relation to screening programmes. A service specification is in place that details the requirements and quality standards for NLBSS.

2.2 Governance arrangements

Whilst the responsibility for planning, commissioning and performance managing the screening programme rests with PCTs, NHS London holds the following responsibilities:

- Ensure and 'sign off' robust commissioning arrangements;
- Ensure performance improvement in line with the National Plan;
- Assist in resolution of disputes;
- Commission the regional Quality Assurance Reference Centre (QARC) and performance manage QARCs.

[5] Department of Health (2005): Commissioning and Managing Screening Programmes

In order for the service to be commissioned in accordance with the national guidelines, the North London consortium has agreed the following:

- A *Lead Commissioner* working for the Lead PCT (Enfield) who has authority to act for the commissioning consortium as a whole and is responsible for leading the commissioning in line with the national guidance;

- A NLBSS *Commissioning Steering Group* (CSG) - to plan, shape and lead a robust, streamlined, coherent cancer-screening programme across the North London Consortium in conjunction with the cancer network. The group meets on a quarterly basis but may meet more often when required. In 2007/08 this group was meeting on a monthly basis to deal with the challenging situation at NLBSS.

- Specific *Sub-Groups* were formed such as the call/recall subgroup, health promotion subgroup, quality and governance subgroup and finance planning subgroup. All subgroups report to the CSG.

- Barnet, Enfield and Haringey Screening Committee – chaired by NHS Enfield Director of Public Health, this Committee has responsibility for outer North London performance management including uptake, coverage and interface with primary care.

- NHS Haringey Cancer Screening Steering Group – chaired by Screening Lead/Consultant in Public Health. This group has the overall responsibility for performance management of Haringey breast screening services including uptake, coverage and primary care performance.

2.3 Temporary suspension of NLBS services

A Serious Untoward Incident (SUI) is an event such as serious Injury or death of a patient, employee, visitor, contractor or member of the public to whom the NHS organisation owes a duty of care. The principle definition of a SUI is **"Any incident on an NHS site or elsewhere, whilst in NHS- funded or NHS regulated care involving:**

a) NHS patients, relatives, visitors, staff, students undertaking clinical or work experience and/or their tutors;

b) contractors, equipment, buildings or property; which:

- causes death (including suicide) or serious injury or was lifethreatening;
- involves a hazard to public health, including major toxic or food contamination, radiation hazard etc;
- involves the absconding of a detained mental health patient who has died, killed or seriously injured or been seriously injured by a third party
- involves fraud or suspected fraud (see HSC 1999/062);
- contributes to a pattern of a sustained fall in standards of care;
- causes serious disruption to services;
- causes significant damage to the assets of an NHS organisation;
- may cause significant damage to the reputation of an NHS organisation or its staff;
- may or did give rise to a significant claim for damages or to legal proceedings;
- involves (in exceptional circumstances) the suspension of a member of clinical staff or a student on clinical grounds or for reasons associated with patient care;
- causes concern following an inquest;
- may create adverse media coverage of potential regional or national interest".

A Serious Untoward Incident (SUI) involving 11 clients was reported by the NLBSS in December 2006. The incident was of administrative nature and it was decided to temporarily suspend NLBSS between December 2006 and May 2007.

The London Quality Assurance Team (QA) identified weaknesses in the 'Right Results' procedures and process errors during an audit of the service. In addition the NHS Breast Screening Programme's national review team was brought in by the commissioning PCTs to investigate failures and to provide advice on the future development of the service.

Screening gradually recommenced in May 2007 and full screening started again in October 2007. On the advice of the national team, a new Three Year Screening Plan was produced based on a 48 -month screening interval or "round length" (the NLBSS original plan was to revert back to the 36 months "round length", standard by October 2010). The national team also advised against a backlog catch up exercise as this was seen as potentially putting the service at risk. The commissioners have worked closely with NLBSS to improve performance and meet target.

At the time of the suspension, the PCTs in the consortium commissioned an independent management consultant to explore availability of alternative screening services with the aim of continuing screening while the service was suspended. However, there was no spare capacity in London and therefore the backlog that has accumulated was incorporated in the three year plan, as recommended by the national team.

2.3 Funding arrangements

Following the national team review of NLBSS, it was made apparent that financial contribution from PCTs in the Consortium was not adequate to meet the cost of running the screening service by NLBSS. North London Breast Screening Consortium therefore commissioned a study in August 2008 to look at the current and projected eligible population and screening statistics and to propose a mechanism for deriving appropriate allocation of the funding across the different PCTs in the consortium.

The study revealed that the NLBSS cost per patient (£52) was lower than other units in London. It was further highlighted that PCTs in the consortium did not fund the service on an equitable basis in terms of cost per patient. It was therefore seen as necessary for the PCTs to agree a mechanism to facilitate a system of 'fair shares' funding for both current and new costs.

The study proposed screening tariff and invitation tariff (Table 1) that is comparable to a similar proposal made at CELBSS following a bottom-up costing exercise by McKinsey on behalf of Barts and the London and the PCT consortium (CELBSS). The recommended single Screening Tariff for CELBSS was £103 per screen.

Table 1: Proposed tariff payment for NLBSS

	Equivalent Tariff based on alternative denominators	Rate
	Equivalent rate if applied on a per woman invited (pwi) basis	£56.00
	Equivalent rate if applied on a per woman screened (pws) basis at 60% conversion (38,000)	£93.33

The following table (Table 2) describes original and proposed pays on the predicted 'Fair share' basis for each PCT in the Consortium. This funding arrangement was agreed in autumn 2009 and NHS Haringey secured sufficient resources to contribute to the 'Fair share'. Funding for 2009/2010 is currently being finalised.

Table 2: 'Fair Share' funding proposal for North London Breast Screening Consortium

PCT	Original 2008-2009 SLA	PROPOSED FAIR SHARE per PCT	2008-2009 'Fair Share' of Re-basing supplement based on Screened %	Total estimated annual payment 2008-2009 £(,000)
Barnet	£471,971	22.35%	£103,017	**£575**
Brent	£559,000	12.47%	£57,490	**£616**
Enfield	£507,510	17.11%	£78,898	**£586**
Haringey	£419,118	13.70%	£63,140	**£482**
Harrow	£474,179	13.62%	£62,770	**£537**
W Hertfordshire	£654,725	20.80%	£95,903	**£751**
Total	£3,086,503		£461,219	**£3,548**

3. Breast Screening Performance for Haringey

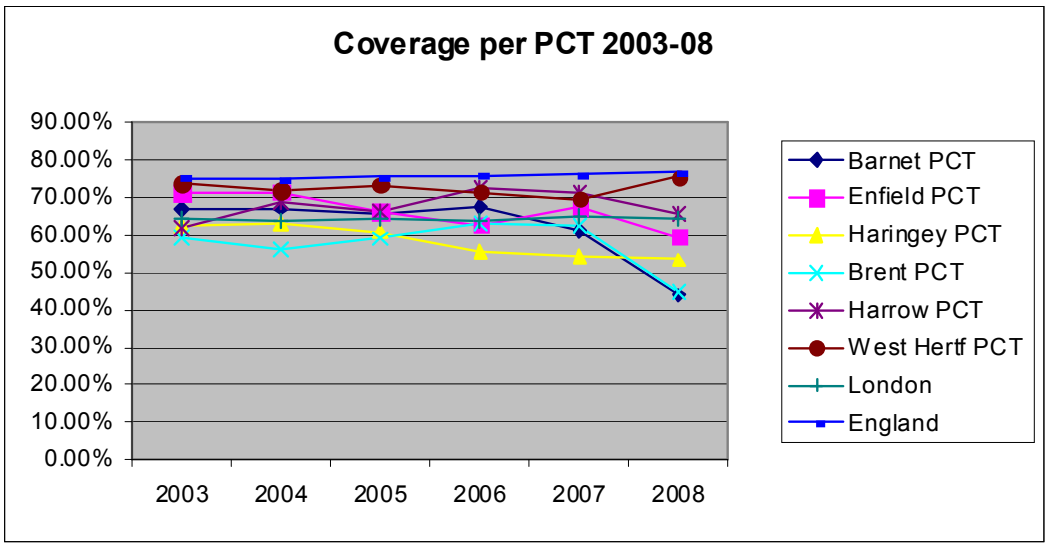
3.1 Coverage

Coverage is the proportion of women resident and eligible (53-64 years excluding those with bilateral mastectomy) at a point in time (31st of March each year) that have had a test with a recorded result at least once in the previous 3 years. The national target for PCTs is 70% coverage.

Uptake on the other hand is the proportion of women invited for screening, over the year, for whom a screening test result is recorded. Uptake is a measure used for breast screening services.

NLBSS uptake has been consistently below national average and it has dropped even further in the last two years to less than the London average, following the suspension of the service. For majority of the PCTs, including Haringey, the closure of the service between December 2006 and May 2007 followed by the partial re-opening till

October 2007 has had a negative impact on coverage, which is clearly shown in the graph below.



Health and Social Care Information Centre. Breast Screening Programme, England:2004-05, 2006-07 and 2007-08

3.2 Round Length

Round length is the measurement of time between the date of last screening film and the date of first offered appointment usually in the current episode. The standard is for 90% of women to be offered an appointment within 36 months of their previous screen.

Following the recommencement of screening in 2007, it was agreed locally that the target for round length would be 46 months up to the end of the current round of screening i.e. until October 2010 on the advice of the National NHS Breast Screening Programme's review team. Performance data by Barnet and Chase Farm Hospital showed that NLBSS was running at 96.5% within target in 2008/09 (see Table 3). Haringey was within round length target for 2007- 08 and 2008-09 at 99.4% and 97.7% respectively.

Table 3: North London Breast Screening Service Round Length

% with 46 months	2007-08	2008-09	Apr-09	May-09	Jun-09	Jul-09	Aug-09
Barnet	**96.3**	**95.9**	90.3	99.7	87	92.1	90.2
Brent	**99.5**	**97.5**	98.7	92.8	54	98.0	99.1
Enfield	**98.9**	**95.1**	50.1	72.0	43	54.4	96.6
Haringey	**99.4**	**97.7**	97.8	97.8	96	97.6	95.9
Harrow	**99.3**	**97.1**	98.1	99.5	96	99.6	85.2
W Hertfordshire	**68.8**	**98.3**		100.0	99	100.0	99.4
Others	**29.9**	**84.9**	100.0		54		81.8
Service-wide (average)	**84.6**	**96.5**	**82.0**	**82.4**	**78**	**81.7**	**96.5**

3.3 Screen to assessment and Screening to Notification of normal result

Overall, waiting times for screening to assessment are 99% and screening to delivery of normal results are 99% within target, against a national target of 90% within 3 and 2 weeks respectively. For Haringey, waiting times to screening were within national targets at 99% in 2007-08 and 98% in 2008-09. Similar figures were also recorded for screening to notification of normal result. (see Tables 4 and 5)

Table 4: Performance on Screening to Assessment

%	2007-08	2008-09	Apr-09	May-09	Jun-09	Jul-09
Barnet	**99**	**100**	100	100	100	100.0
Brent	**100**	**100**	100	100	100	100.0
Enfield	**100**	**100**	100	98	100	100.0
Haringey	**99**	**98**	100	100	100	100.0
Harrow	**99**	**99**	100	100	100	100.0
W Hertfordshire	**99**	**99**	100	100	100	100.0
Others	**100**	**97**	100	100	100	
Service-wide (average)	**99**	**99**	**100**	**99**	**100**	**100**

The national minimum standard is > 90% within 3 weeks.

Table 5: Performance on Screening to Notification of normal result

%	2007-08	2008-09	Apr-09	May-09	Jun-09	Jul-09
Barnet	**98**	**99**	99	99	98	98.9
Brent	**98**	**99**	100	100	100	100.0
Enfield	**98**	**99**	99	99	98	98.1
Haringey	**99**	**98**	99	100	100	99.4

Harrow	**99**	**100**	100	100	100	100.0
W Hertfordshire	**98**	**99**	98	100	100	98.7
Others	**99**	**99**	100	100	100	100.0
Service-wide (average)	**98**	**99**	**99**	**99**	**99**	**99.0**

The national minimum standard is >90% within 2 weeks.

4. Local initiatives to develop breast screening uptake/coverage

In Enfield, Barnet and Haringey PCTs, funding provided by the North London Cancer Network Improvement Fund in 2006 helped set up a project to identify primary care needs. From that project, a multilingual breast screening booklet in 9 languages and a breast screening step by step poster were produced, which were made available to the general public in most of the health promotion events that took place in the Barnet, Enfield and Haringey boroughs. In addition workshops and focus groups with different community groups were held and breast screening was discussed. Profile of breast screening was raised with primary care practices through the Screening Newsletter and by including them recently as an item in the training of clinicians around screening.

NHS Haringey recently conducted a social marketing campaign project to gather an insight into perceived barriers for access to services among specific ethnic groups that were not attending screening services. Barriers were found to be both intrapersonal and structural in nature that can act in isolation as well as in combination to influence screening attendance.

At an intrapersonal level, non-attendance at screening can be driven by fear of cancer or a low perception of breast cancer risk. It is vital to ensure that women are better educated on the risk factors for developing breast cancer as well as the benefits that screening can offer to ensure that women feel empowered and motivated to attend their screening appointments when invited.

At a local level the mobile population and cultural diversity of Haringey has proven to be challenging for the NLBSS. With more informed and up to date patient lists as well as new promotional material the programme can ensure a wider understanding of the screening programme in the borough.

The Health Belief Model maintains that the factors influencing breast screening attendance are motivation, perceptions of breast cancer risk, and beliefs that the benefits of screening outweigh the cost of participation. This is certainly found to be true among many women who attend screening. However, in order to drive positive behaviour change among women who do not attend breast screening it is the causal components underlying these broad factors that must be addressed and it is these components that can vary between ethnicity.

Therefore, an intervention to increase uptake and coverage of the NLBSS in Haringey must be both multi faceted, to address the many issues which influence breast screening attendance, and easily adaptable, to suit the ethnic diversity of the borough.

Findings of the local social marketing project informed development of promotional material that is currently being tested among local population.

NHS Haringey recently secured additional funding from the North Central London Cancer Network to commission health trainers project that will specifically focus on improving access to breast screening services. Health Trainers will be based at various community settings including voluntary organisations and health centres and their main role will be to raise awareness of breast cancer screening services among various community groups. Social Marketing findings will enable Health Trainers to target their intervention at the communities with the lowest attendance rates.

5. Key issues for commissioning and delivery of services

NHS Haringey, in line with the NHS London has identified breast screening services as one of the commissioning priorities for 2009/2010. Recent significant additional investments locally will drive improvements in NLBSS, including increased capacity to reduce round length for local women by October 2010. NLBSS will be one of the first units in the country to be fully digitalised by December 2009.

Low uptake has been one of the major concerns locally and across London. Sector initiatives are underway to modernise services across London and to introduce centralised call/recall system. NHS Haringey and NLBSS are actively participating in London-wide initiatives.

Further actions should focus on engaging communities and primary care in the concerted efforts to increase the uptake and improve access to services across the borough.

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Breast Screening Monitoring Data (Q1: April - June 2009)

UNIT	West London Breast Screening Service (ECX)		North London Breast Screening Service (EBA)		Central & East London Breast Screening Service (FLO)		South West London Breast Screening Programme (HWA)		Barking, Havering & Brentwood Breast Screening Service (FBH)		South East London Breast Screening Service King's (GCA1)		South East London Breast Screening Service Queen Mary's (GCA2)	
Uptake (National Minimum Standard n°1: ≥70% of Invited Women) 50-70 QALON009	59%	7707 / 13044	61%	10566 / 17249	52%	5881 / 11297	63%	6940 / 11021	79%	5107 / 6501	62%	5526 / 8931	75%	3716 / 4940
Repeat Examination (National Minimum Standard n°6: <3% of Total Examinations) SR011 (SR020 GCA1&2)	1.48%	128 / 8669	2.32%	285 / 12260	1.71%	115 / 6706	3.31%	257 / 7772	1.87%	104 / 5557	1.42%	110 / 7723	1.29%	53 / 4115
National Roundlength (National Minimum Standard n°11: ≥90% within 36 months) 50-70 SR002	97%	7606 / 7868	12%	1186 / 9992	76%	4724 / 6251	86%	6096 / 7068	99%	5448 / 5515	97%	5641 / 5824	99%	3607 / 3636
National Screen to Normal (National Minimum Standard n°12: ≥90% within 2 weeks) SR005	98%	7969 / 8147	99%	11527 / 11618	96%	6002 / 6277	97%	7062 / 7290	99%	5199 / 5264	98%	7261 / 7433	93%	3632 / 3908
National Screen to Assessment (National Minimum Standard n°13: ≥90% within 3 weeks) SR001	86%	301 / 348	88%	448 / 509	68%	188 / 277	85%	352 / 413	87%	193 / 223	72%	156 / 216	89%	163 / 183
National Screen to Assessment (National Minimum Standard n°13: ≥90% within 3 weeks) SR008	99%	369 / 371	99%	534 / 535	82%	253 / 310	99%	414 / 419	100%	244 / 244	91%	233 / 257	98%	185 / 189
No of result within 5 days/No of Non Operative Biopsy (National Standard n°14: ≥90% within 5 days) *	100%	52 / 52	No Data Submitted	No Data Submitted	75%	98 / 130	No Data Submitted	No Data Submitted	87%	20 / 23	No Data Submitted	No Data Submitted	No Data Submitted	No Data Submitted
No. of Open Episodes Older than 6 Months	0		77		70		14		15		64		28	

Key: Not reaching the Minimum Standards | Reaching the Minimum Standards | Reaching the Minimum Standards and the Targets

* No 14 is the only Waiting Times collected for this quarter

Please contact the Breast Screening units for explanations when the Minimum Standard is not achieved

PCTs Figures

January - March 2009: Coverage 53-64 yrs old (Minimum Standard ≥ 70%)

Havering	Barking & Dagenham	Redbridge	Camden	Islington	City & Hackney	Newham	Tower Hamlets	Bromley	Waltham Forest	Barnet	Enfield	Haringey	Brent	Harrow	Surrey	West Hertfordshire
79%	74%	72%	59%	67%	59%	56%	65%	76%	71%	55%	53%	51%	50%	51%	77%	67%
Bexley	Greenwich	Lambeth	Southwark	Lewisham	Croydon	Kingston	Richmond & Twickenham	Wandsworth	Sutton & Merton	Hillingdon	Ealing	Hammersmith & Fulham	Hounslow	Kensington & Chelsea	Westminster	Essex
78%	81%	59%	62%	65%	61%	73%	73%	86%	73%	69%	70%	61%	68%	55%	54%	80%

Open Episodes Older than 9 months (from BCO - the BCO report is the same for some PCTs)

Havering	Barking & Dagenham	Redbridge	Camden	Islington	City & Hackney	Newham	Tower Hamlets	Bromley	Waltham Forest	Barnet	Enfield	Haringey	Brent	Harrow	Surrey	West Hertfordshire
0			26		0			12	6	1	8	2	1	1	5	1
Bexley	Greenwich	Lambeth	Southwark	Lewisham	Croydon	Kingston	Richmond & Twickenham	Wandsworth	Sutton & Merton	Hillingdon	Ealing	Hammersmith & Fulham	Hounslow	Kensington & Chelsea	Westminster	Essex
13		3			2	358		22		0	0		9	11	5	0

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NHS Haringey

Increase Uptake of Breast Cancer Screening

Scoping Report

March 2009

Contents

Introduction

The following report forms the initial part of a planned Social Marketing Intervention which will aim to increase uptake and coverage of The NHS Breast Cancer Screening Programme by women aged 50-70 in the London Borough of Haringey.

Breast cancer is the most common type of cancer detected among women living in the UK with one in every nine females facing a breast cancer diagnosis during their lifetime. Both breast cancer survival rates and breast screening attendance are linearly related to socio-economic status (SES), with deprivation cited as a major risk factor for breast cancer development. Haringey is the 18th most deprived Borough in England. Therefore, it is no surprise that breast cancer has a high prevalence among its residents.

In December 2006 The North London Breast Screening service at Edgware Community Hospital was suspended due to system process errors. Although the service re-opened October 2007, it left a ten-month backlog of appointments with women struggling to arrange routine breast screening[1].

At present uptake and coverage of the NHS Breast Cancer Screening Programme among Haringey residents is dramatically lower than the national average. In order to remedy this, it is of key importance to understand the different attitudes, perceptions and behaviours that contribute to non-attendance.

Secondary research was carried out reviewing a wide range of literature on Breast Cancer and The NHS Breast Cancer Screening Programme. The literature reviewed included both academic and scientific research papers as well as recent government health reports. This desk research helped to identify key segments within Haringey's population who do not regularly attend breast screening.

Primary research in the form of generative focus groups discussions and in depth interviews were carried out with women from two of these key segments and this data was then analysed alongside the findings from a focus group discussion composed of women who do recently attended screening. This comparative analysis allowed us to gather insights into the knowledge, attitudes, beliefs and behaviours within these segments of Haringey's population in order to identify any key characteristics which might influence breast screening attendance or non attendance.

Note that under the National Social Marketing Centre research ethics guidance 2009 this social marketing study constitutes an audit and service evaluation.

The following report outlines findings from both the primary and secondary research.

The Challenge

The London Borough of Haringey is an ethnically diverse and socially deprived Borough with breast cancer cited as the 3rd most common cancer among its residents[2]. Social deprivation is often linked to negative lifestyle factors, such as smoking and poor diet, which increase the risk of developing breast cancer. Therefore the women living in this deprived Borough already represent a high risk group. Deprivation is also associated with poorer breast cancer survival rates, which has at least in part been attributed to low screening attendance[3].

Breast screening uptake in Haringey was 55.4% in 2005-2007; around 20% lower than the national average. The poor rate of screening attendance in Haringey means it is likely that many cases of breast cancer will not be diagnosed at an early stage and may in fact not be diagnosed at all. Survival rates from breast cancer are significantly higher when it is diagnosed at an earlier stage because screening allows abnormalities in the breast tissue to be detected before they are sizable enough to be detected by hand and before the disease has progressed further. This illustrates the importance of increasing uptake and coverage of The NHS Breast Cancer Screening Programme within the Borough.

Haringey has an ethnically diverse population. The female population eligible for breast screening in Haringey is made up of around 66% White British and White other, 21% Black and Black British, and 11% Asian[4]. This ethnic diversity provides a population pool with varying backgrounds and beliefs. Cultural variation can impact upon screening attendance variations and therefore it is of key importance to investigate this.

In short, the challenge is to better understand the factors that govern attendance/non-attendance at screening among the target population and to design an intervention that will drive screening uptake, reduce health inequalities and save lives.

UK Policy

Tackling cancer is a national priority for the NHS. This is evidenced by the NHS Breast Screening Programme, set up in 1988 following the Forrest report which concluded that screening could prolong the lives of women over 50 years old. The programme included routine breast screening as a priority, providing free screening every three years for all women over 50 years of age[5]. The 2000 Cancer Plan announced the extension of two view mammography to all screens by 2003 and that the upper age limit for screening invitations would be increased from 64 to 70 years by 2004.

Since its onset, The NHS Breast Screening Programme is thought to have been successful in helping to decrease breast cancer mortality rates, partly as a result of earlier diagnosis. The less advanced the disease, the better the chance that treatment will be successful and therefore increases survival rates. Breast cancer mortality rates have fallen in females since the programme's onset in 1988[4].

Between 1988 and 2006, breast cancer mortality rates decreased in the following age groups:

- 43% in women aged 40-49 years
- 39% in women aged 50-64 years
- 37% in women aged 65-69 years
- 32% in women aged 15-39 years
- 16% in women over 70 years

In 2006/2007, 76% of women were screened nationally and 52% of invasive cancers detected were 15mm or less, which could not have been detected by hand[6]. Therefore, without breast screening many cancerous masses would go unnoticed until the disease had progressed and developed to be large enough to be detected by hand. The latest research has shown that the NHS Breast Screening Programme is saving 1,400 lives every year in England[7]. This is due to earlier detection, diagnosis and treatment.

The NHS Breast Cancer Screening Programme does not routinely invite women over the age of 70 years for a screening appointment. For these women, a decision about whether or not to attend screening is generally taken at an individual level, bearing in mind personal circumstances, rather than by offering a blanket invitation for screening[8].

Furthermore, although 20% of breast cancer cases in the UK are diagnosed in women under the age of 50[9], they are not routinely invited for screening. For women in this age group, a referral would be made by a General Practitioner (GP). Only around 20% of patients who attend breast screening clinics for investigation have been identified through the NHS Breast Screening Programme. Some 80% of patients are referred by GPs indicating that potential signs or symptoms of breast cancer are suspected[10].

The National Context

Prevalence

Despite screening and medical advances, which have helped to greatly reduce breast cancer mortality rates, the prevalence of the disease is still high. Each year more than 44,000 women in the UK are diagnosed with breast cancer which equates to more than 100 women a day[2].

In fact, breast cancer rates have increased by 12% in the past decade[11]. However, instead of indicating an increased likelihood of developing breast cancer, this finding may signify the success of The NHS Breast Cancer Screening Programme. With an increase in the uptake of breast screening, more women are being diagnosed with breast cancer when it might have previously remained undetected.

Breast cancer incidence rates vary according to socio-demographics:

- Prevalence of breast cancer is higher among women in more affluent communities[12]
- Prevalence of breast cancer increases with age
- Breast cancer has a much higher prevalence in women

Risk Factors

At least a fifth of breast cancer cases in Western countries are likely to be due to modifiable lifestyle factors such as alcohol consumption, exercise, obesity stress, smoking and diet[12].

Social deprivation has a negative effect on breast cancer survival[2] with women living in the 10% most deprived areas in the UK associated with a significantly poorer outcome[13].

There is currently a poor understanding of how ethnicity affects the development of breast cancer, but a small study in Hackney suggested that black women may develop breast cancer earlier than white women of the same age[14].

A lack of knowledge about breast cancer is a major risk factor. It is thought that late diagnosis of breast cancer is linked to a low uptake of breast screening services. This low uptake is often attributed to low awareness of breast cancer symptoms and risk factors[15].

In 1991, the UK abandoned systematic breast self-examination and replaced it with a policy which encouraged women to be breast aware from 18 years old. This new policy was based on work by Cancer Research UK scientists[16].

Being breast aware is about women knowing how their breasts look and feel normally so that they feel confident enough to take action if they notice any change that might be unusual for them.

However, the evidence suggests that many women do not engage in breast awareness and are frightened and confused about their role in breast health promotion. Therefore, educating women on how to be breast aware, the risks associated with developing breast cancer and the importance of screening could help to encourage women to attend breast screening as well as adopt preventative behaviours.

Few women understand that the risk of getting breast cancer increases with age[8]. The relationship between breast cancer development and age is so strong that more than 80% of cases occur in women aged 50 and above[17]. This emphasises the importance of breast screening at this age, but also the importance of breast cancer education.

Many women believe that breast cancer is primarily linked to genetic trends[18]. Therefore, they do not take into account the effects of their lifestyle choices such as smoking, diet and exercise, alcohol consumption and stress[19].

In essence, a key barrier to screening attendance is a poor understanding of breast cancer and its associated risk factors[17.] However, the principle risk factor for breast cancer mortality is a failure to attend screening.

Mortality

Breast cancer is one of the UK's most prolific killers with more than 12,300 women dying of the disease annually. This equates to over 1,000 a month[11]. The chances of surviving breast cancer have improved significantly over the past decade[2]. However, a 2007 report published in the Lancet Oncology Medical Journal showed that breast cancer survival rates in England are lower than the European average.

According to Cancer Research UK, the two main reasons for the UK's poor results are due, in part, to advanced disease at first presentation and problems with the radiotherapy service. The main cause for the advanced disease at first presentation is linked to a low uptake of the breast screening service.

The Local Context

Haringey is an area with high levels of deprivation and currently ranked the fifth most deprived Borough in London. It has an estimated population of 224,000 residents[20] of which almost 20,000 are eligible for breast screening. Poor breast screening attendance, which is thought to be related to social deprivation, is a major concern in Haringey.

Within the Borough there are major variations in deprivation levels with inequalities in health following the same pattern. Breast cancer related deaths are relatively high in the North East, South East, and Central Haringey GP comparator zones[21].

It is suggested that breast cancer mortality rates are related to screening attendance which, in these areas, is found to be moderate to low and vary significantly between clinics. A decision to attend screening has life saving potential.

Screening services in the West of Haringey are well attended, but early deaths from breast cancer are still higher than expected[22]. It is, therefore, important to increase both knowledge of breast cancer and breast screening attendance throughout Haringey.

Risk factors for cancer include a poor diet, obesity, sedentary activity and alcohol abuse[8]. These factors are more commonly found in low socio-economic areas like Haringey. Therefore, it is not surprising that cancer is responsible for around 25% of deaths annually and that breast cancer is the third most common type diagnosed in the Borough.

Annual screening coverage rates reported in March 2008 found that average breast screening coverage within women aged 53–70 years was 75.9% in England, 63.6% in London, but only 52.4% in Haringey.

A high prevalence of breast cancer, coupled with the lower chances of survival in the Borough, emphasis the need to increase uptake and coverage of The NHS Breast Screening Programme.

If both uptake and coverage of The NHS Breast Screening Programme is to be increased in Haringey, we must understand the ethnic diversity of the Borough. With some 190 languages spoken[21] as well as a range of different cultural and religious beliefs, we must understand that reasons for non-attendance might be wide ranging and even unique to distinct groups of women.

Service Overview and Assessment

Breast Screening Pathway in Haringey

Invitation to Attend Screening

The 'Exeter' computer system selects women aged 50-70 by the PCT. GPs are sent the relevant list identified by the system and are asked to advise if any of the women should be removed from the list e.g. if they have moved away, had a double mastectomy since last screening (single mastectomy women still require to be screened), or are part of the family history screening programme.

Invitations are then sent out, from the main screening unit based in Edgware, inviting women on the list to a mammogram appointment on a certain date, time and location. The letter includes a number to call if women would like to change their appointment date or time or if they are disabled and have to re-arrange an appointment at the static unit (the mobile unit can not accommodate disabled women). As part of informed consent requirements the national information leaflet 'Breast Screening - The Facts' is sent along with the invitation letter.

If a woman does not attend (DNA) her appointment a second invitation to attend is issued. If she does not attend this second appointment she will be invited again in three years' time. Failure to attend this second appointment results in the GP surgery being informed.

Screening will take place at a specialist screening unit which can be hospital based, mobile, or permanently based in another convenient location such as a shopping centre. In Haringey there is one static unit (North Middlesex Hospital) and two mobile units (North Middlesex and St Ann's). The mobile units are in use across six primary care trusts.

In December 2006 screening service at Edgware Community Hospital was suspended for 10 months due to system process errors. This left a backlog of appointments and women struggling to arrange routine breast screening.

The Breast Screening Procedure

A screening appointment takes about half an hour. Women are asked about any symptoms or history of breast disease and a mammogram is taken of the women's breast.

The mammogram is a low dose x-ray of which one is taken from a frontal view and another is taken from a lateral view. The breast is placed between two metal plates to carry out the x-ray, and although this can be uncomfortable it is not usually painful. Perception of pain, however, differs for each woman.

The findings are sent to Edgware for analysis and results are returned to the patient within 2-3 weeks. If the results are negative, the women are sent a letter confirming this and will be invited back in 3 years' time.

If the results are abnormal, the woman is sent a letter asking her to attend an Assessment Clinic in Edgware where further tests will be carried out. These tests may include clinical examination, further mammograms, and ultrasound or core biopsy, depending on the initial results. This letter also contains further information about what to expect at the Assessment Clinic.

Breast care nurses are available at the assessment clinic to offer advice and support to women and answer any questions they have during or following diagnosis.

If results are found to be normal the woman will be invited back for screening in three years.

Breast Cancer Treatment

If a woman is found to have breast cancer she is taken off the screening programme list and referred to a consultant surgeon to discuss the treatment options available to her. Treatment usually involves some form of surgery either a lumpectomy which involves removal of the lump and a small amount of the surrounding tissue, or a mastectomy where the whole breast is removed. Surgery is then often followed by radiography, chemotherapy or hormone therapy or a combination of these.

Irrespective of breast screening result, women are advised to be vigilant between screenings – as a tumour could grow or appear in space of three years.

Stakeholder Feedback

An online consultation was sent to 153 stakeholders, of which 35 were completed by GPs and their staff. 24 health professionals were approached to take part in an in depth telephone interview of whom 16 participated. All participants worked within the following roles: GPs, GP practice staff, development nurses, public health consultants, screening coordinators, equality and diversity officer, community link coordinators and health promotion officers.

Data from these interviews and the online surveys were consulted in order to assess perceptions of the NHS Breast Screening Programme and the challenges it faces in Haringey. Strengths and weakness of the programme were also highlighted identifying the effects of these on subsequent uptake. Using a SWOT framework we outlined the key findings on the NHS programme and the situation as it is in Haringey.

The national target for breast screening is for at least 70% of eligible women to be screened annually. However, with an average uptake of only 55.4% in 2005-2007, Haringey is significantly underperforming. Stakeholders believe this is a serious issue that must be addressed. They also agree that many factors combine to drive non attendance and feel that these must be considered in any attempt to increase uptake of the programme. Stakeholders believe that the complexity of achieving the national target for breast screening in Haringey is compounded by the mobility, volume and diversity of the population.

The highly mobile population of Haringey poses a particular challenge due to the current methodology behind screening invitation and engagement. Stakeholders believe that the population of Haringey is particularly difficult to engage with due to the fact they move around a lot. Therefore, attempts at direct contact such as via a letter of invitation to screening can fail to connect with the audience. GP surgery patient lists provide the

programme with contact information of eligible women, but even these are often out of date due to the high incidence of patient mobility.

With ethnic diversity comes variation in knowledge, attitudes and beliefs about the Breast Screening Programme. This variation, stakeholders believe, can result in misconceptions about the programme as well as difficulties in communication and therefore has a huge impact on screening attendance. With around 190 languages spoken in Haringey translation needs alone are hugely complex and can effectively render the current system of invitation ineffectual for some women. It also makes it very difficult to inform women about the importance of screening and therefore has an effect on screening attendance. Moreover, within some groups, attitudes and beliefs might be culturally dependent and therefore attempts at engagement using a 'one size fits all' approach simply will not work.

Among stakeholders it is well recognised that deprivation is endemic in the Borough. This deprivation, they believe, has an indirect impact on breast screening attendance through a lack of understanding on the programme. They suggest that illiteracy and other reading problems are high and therefore believe that current methods of written invitation and communications are not always appropriate.

Therefore, the distinctive socio-demographic make up Haringey is recognised by stakeholders as fundamental to the low uptake of the breast screening programme. These characteristics are thought to pose real and serious challenges to the Breast Screening Programme.

"London is one of the worst cities in the UK when it comes to breast screening uptake and Haringey is easily one of the worst boroughs in London. I think that puts the gravity of the current situation into perspective."

Strengths of the NHS Breast Screening Programme in Haringey

Stakeholders believe that free screening for eligible women offered by the NHS Breast Screening Programme has unseen but positive effects on screening attendance in Haringey. They agree that if women were required to pay for breast screening, as they do in most countries, this would have a detrimental effect on screening attendance not only in Haringey but across the country.

"I know uptake is still low, but if they [Haringey residents] had to pay for it like you do in so many other countries then it would be much lower. Money is tight for many here."

Stakeholders also believe that the call and recall system inviting women to attend screening appointments is a major strength of the NHS Breast Screening Programme. They agree that current uptake of the programme would be lower if it were not for this systems ability to increase awareness among eligible women by inviting them to attend appointments and remind them to re-attend at set intervals. Although they admit the system is in need of further refinement to address the needs specific to the population of Haringey, it is nonetheless praised as an asset to the programme.

"Without these invitations and reminders many women would forget to make an appointment for a mammogram and those that did would be unlikely to remember when they should attend again years later."

"It has its faults and I think it should be adjusted to meet the local needs at the level of the PCT, but in reality it is one of the most effective systems around."

The replacement of non-specialist professionals with dedicated multi-disciplinary breast teams is cited by many stakeholders as a key strength in the system. These specialised teams are praised by stakeholders for providing expert knowledge and unrelenting support to eligible women.

Weaknesses of the NHS Breast Screening Programme in Haringey

As previously noted, population mobility is thought to have a negative impact on breast screening attendance rates within Haringey. Stakeholders believe that the current method of invitation to attend breast screening has many flaws in relation to Haringey's highly mobile population.

The GP patient lists used to identify women eligible for screening are not always up to date which immediately causes problems for the screening programmes current method of invitation. List inflation occurs when patients move away from an area but do not inform their GP practice. Therefore, letters of invitation to attend are sent to the wrong address resulting in eligible women being left unaware of their upcoming screening appointment and inaccurately inflating local DNA data.

Unless patients inform their GP about an intended move the practice will not be informed until those women register elsewhere. Stakeholders believe this too causes problems for the breast screening programme as unless women are registered with a GP practice the Breast Screening Programme cannot recognise if they are eligible for invitation to attend screening.

"When they move registering at a new GP is not always the first thing on their mind. Sometimes people won't register until they become ill enough to have to see the doctor and that can take years."

"It is very common here [in Haringey] for breast screening invitations to be sent to the wrong address."

They felt the current system of invitation was further flawed in its efforts to address the language barriers faced by an ethnically diverse population such as in Haringey. The national NHS Breast Screening Programme leaflet 'Breast Screening – The Facts' has been translated into 17 languages, but getting the translations to those who need them is difficult since the screening offices which issue the invitations have no means of initially identifying ethnicity.

As a result, letters of invitation are written in English and give an option for future correspondence and information to be translated into in one of 17 languages. However, this current system essentially fails to reach two groups of women whom stakeholders believe to bulk large in Haringey's ethnically diverse and socially deprived population; those unable to read English, and those unable to read at all. The use of images in leaflets is suggested by as a universal method to disseminate information.

Therefore, stakeholders believe the current system of invitation to attend breast screening is flawed in relation to a mobile population like in Haringey.

Stakeholders were in agreement that most women in Haringey are not adequately informed on breast cancer or the breast screening programme and believe this is a major factor in non attendance at breast screening. They feel there is a lack of local promotion on the issue and that this must be addressed if uptake is to be increased.

"If they don't know much about it they won't know they should attend."

Opportunities for the NHS Breast Screening Programme

Stakeholders believe that GP practices and ethnic community groups should work more closely to increase awareness and uptake of the Breast Screening Programme in Haringey. Community groups are very common and well attended in Haringey, but most importantly they often have close and trusting relationships with their members. Stakeholders believe that training could be given to community workers by the GPs and nurses so that they could then educate and inform women eligible for breast screening on the importance of attendance. This method, they believe, would ensure that information is communicated to 'hard to reach' groups accurately and without the need for translation, and also in a manner that is sensitive to their ethnic and/or religious beliefs.

Furthermore, stakeholders believe GP practices to be trusted sources of both influence and information within communities. And they have the added bonus of access to a database of women they could reach to remind them about upcoming appointments and provide information to those who need. Stakeholders believe that GPs should play a more active role considering the level of access they have with eligible women and suggest that an incentive to meet targets might be beneficial to increase uptake at a practice level.

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Possible opportunities to mutually address the previously cited weaknesses in the Breast Screening Programme are also tasked to the GP practices. Stakeholders complain there is currently a lack of information on the characteristics of eligible women who fail to attend breast screening appointments and feel this could be tackled alongside the issue of GP patient list inflation and inaccuracy.

It is recommended that six-monthly patient address checks should be carried out to ensure that patient lists are up to date, therefore reducing the number of invitations that are sent to the wrong address as well as reducing inflated DNA data. Stakeholders also suggest that patients should, when registering at the GP surgery, be asked to state a language preference and that this information be added to the database. The invitation could then be written in their preferred language alongside an image leaflet to better enhance the chances of women taking notice of and understanding the purpose of the invitation.

Possible threats to the NHS Breast Screening Programme

The lack of data on the characteristics of the DNAs is seen by many stakeholders to be a significant threat to uptake of the NHS Breast Screening Programme in Haringey. Data on DNA is available by geographical area and then analysed taking into account the ethnic make up of that area. However, assumptions then have to be made about who is not attending. If these assumptions are wrong, then attempts to encourage the perceived DNA population could be targeting the wrong women.

Some stakeholders also voiced concern over the characteristics being analysed to assess why women DNA. They felt that women of the same ethnicity should not be grouped together based on ethnicity alone, but that shared backgrounds were more

important:

"A group of 100 women from one ethnic group may base their views about screening on their background rather than their ethnicity. If half of these women were born in the UK and spoke English while the other half grew up elsewhere with not a word of English it is likely that this will influence their views more than ethnicity".

For a screening service to be cost effective a 70% uptake is required. At 55.4% Haringey is significantly below the cost effective target. This threatens the non-target reaching clinics with closure which would add yet another barrier to screening in Haringey. Some stakeholders suggest that although they do not want to see any clinics in Haringey closed the money spent on a service that is not cost effective might be better spent on other areas of the breast screening programme such as new equipment, more staff elsewhere, new research, technologies, and interventions.

There is a lot of discussion around the effect that private screening has on the NHS Breast Screening Programmes performance targets. Although in general stakeholders admit this is unlikely to have a huge impact on Haringey's DNA rates, it is seen as a threat to the programme's perceived success rate as a whole. That is, private mammograms are not counted for the purposes of NHS breast screening. Therefore, areas where private mammograms are common will be identified as a low uptake rate for the screening programme.

Media Landscape

Media coverage of breast cancer and breast cancer screening is of high importance. It acts as a channel by which information is communicated directly with the public and within local communities and can be used to increase both awareness and understanding of breast cancer and the importance of breast cancer screening.

Exactly what is reported and how information is communicated however is key. Confusing, inconsistent or misleading coverage about breast cancer related issues can heighten fears of being screened or even make breast cancer appear irrelevant. Both would have a negative effect on breast screening uptake and/or coverage.

A review of recent press coverage identifies that the key messages being communicated about breast cancer and breast screening are:

- There is a high prevalence of breast cancer
- There is a low uptake of breast cancer screening and furthermore in many areas it is declining
- There is a negative linear relationship between SES and breast screening uptake
- There is a general lack of awareness of the risks factors for breast cancer

Please see Appendix 3 for full articles.

Audience Insight and Segmentation Using Mosaic

Data Usage

Haringey Primary Care Trust (PCT) provided local census data as well as NHS Screening service data on breast screening attendance. Analysis of this data has allowed us to ascertain the number of women eligible for screening in Haringey, the ethnic diversity of these women, and then highlight the number of women who did not attend (DNA).

A Mosaic map was analysed along with the Mosaic profiles of Haringey PCT to identify which wards and profiles were found to have the poorest screening attendance.

Mosaic demographic profiles were identified for Haringey PCT and the percentage of DNAs per profile were identified and matched against postcodes. Mosaic profiles were mapped for Haringey PCT and overlaid on the Haringey PCT ward map to identify key wards with high DNA rates.

Mosaic

Mosaic is an annually updated geo-demographic classification tool that provides detailed information about UK consumers. It covers 24 million UK households and classifies them into 11 groups, 61 types and 243 segments.

Consumers are grouped by household or postcode and Mosaic then classifies according to:

- Socio-demographics
- Lifestyles
- Culture
- Behaviour

Classifications help to identify the varying characteristics of consumers at a local, regional and national level thus providing a detailed picture of the target audience of interest.

Audience Segmentation

The following presents the key findings from the data analysis explained above.

Table 1 is a summary of the ethnic diversity of the female population aged 50-70 years living in Haringey as well as their representation within each ward.

Table 2 highlights the representation of each mosaic type by postcode.

Table 1 Number of Women in Haringey Aged 50-70

White	11,831	66%
Black Caribbean	2,131	12%
Black African	1,344	7%
Black Other	277	2%
Indian	663	4%
Pakistani	133	1%
Bangladeshi	207	1%
Chinese	282	2%
Other Asian	491	3%
Other	650	4%
All Ethnicities	18,009	100%

Source: Haringey PCT – projected all resident population 2008

Alexandra	1,031	6%
Bounds Green	957	5%
Bruce Grove	923	5%
Crouch End	979	5%
Fortis Green	998	5%
Haringay	809	4%
Highgate	884	5%
Hornsey	916	5%
Muswell Hill	1,038	6%
Noel Park	921	5%
Northumberland Park	915	5%
St. Ann's	1,115	6%
Seven Sisters	1,048	6%
Stroud Green	802	4%
Tottenham Green	985	5%
Tottenham Hale	1,027	6%
West Green	1,020	6%
White Hart Lane	1,115	6%
Woodside	964	5%
HARINGEY	18,446	100%

Table 2 Representation of each Mosaic Type by Postcode

Mosaic Type			POSTCODE											AGE CATEGORY						
			East Finchley	Finsbury Park	Highgate	Turnpike Lane	Muswell Hill	Bounds Green	Palmers Green	South Tottenham	Tottenham	Upper Edmonton	Wood Green								
			N2	N4	N6	N8	N10	N11	N13	N15	N17	N18	N22	Total	49-54	55-59	60-64	65-69	70-74	Total	
A1	Symbols of Success	Global Connections	1	1	16	21	7							46	15	10	13	8		46	**1%**
A2	Symbols of Success	Cultural Leadership	2	1	4	34	23	1					6	71	23	17	22	8	1	71	**2%**
A3	Symbols of Success	Corporate Chieftains	2		3		2							7	3	2	2			7	**0%**
B8	Happy Families	Just Moving In				3							1	4	2		2			4	**0%**
C19	Suburban Comfort	Original Suburbs						6			3			9	3	3		2	1	9	**0%**
C20	Suburban Comfort	Asian Enterprise						2	3	31	23		28	87	28	21	18	15	5	87	**2%**
D26	Ties of the Community	South Asian Industry								2				2	1			1		2	**0%**
D27	Ties of the Community	Settled Minorities		106		147	2	13	16	433	614	3	535	1,869	543	482	382	330	132	1869	**45%**
E28	Urban Intelligence	Counter Cultural Mix		106	7	135		5		151	26		175	605	166	162	131	111	35	605	**14%**
E29	Urban Intelligence	City Adventurers		40	8	73	3						11	135	46	49	20	20		135	**3%**
E30	Urban Intelligence	New Urban Colonists		51	5	124	13	4		4			77	278	71	84	61	50	12	278	**7%**
E31	Urban Intelligence	Caring Professionals		21		18				9				48	7	18	15	5	3	48	**1%**
E33	Urban Intelligence	Town Gown Transition									4			4	3		1			4	**0%**
F35	Welfare Borderline	Bedsit Beneficiaries			2									2		1			1	2	**0%**
F36	Welfare Borderline	Metro Multiculture		9		47		4		262	409		176	907	277	227	176	170	57	907	**22%**
F37	Welfare Borderline	Upperfloor Families									5			5	1	1	1	1	1	5	**0%**
F38	Welfare Borderline	Towerblock Living									3		2	5		1	1	3		5	**0%**
F39	Welfare Borderline	Dignified Dependency								1	5			6	1		2	1	2	6	**0%**
F40	Welfare Borderline	Sharing a Staircase									3			3	1		1	1		3	**0%**
G41	Municipal Dependency	Families on Benefits									3			3			1	2		3	**0%**
G42	Municipal Dependency	Low Horizons				1					8			9	5	2	2			9	**0%**
G43	Municipal Dependency	Ex-Industrial Legacy									6			6	2		2	2		6	**0%**
H46	Blue Collar Enterprise	White Van Culture					1				15			16	4	5	3	3	1	16	**0%**
I49	Twilight Subsistence	Low Income Elderly								1	1			2	1		1			2	**0%**
I50	Twilight Subsistence	Cared for Pensioners				2				2	18		7	29	2	5	7	11	4	29	**1%**
J51	Grey Perspectives	Sepia Memories				2		1						3			1	1	1	3	**0%**
J52	Grey Perspectives	Childfree Serenity	1		1	4							4	10	1	2	2	4	1	10	**0%**
N/A						3		1			1			5	1	1	2	1		5	**0%**
		Total	6	335	46	614	51	37	19	896	1,147	3	1,022	4,176	1207	1093	869	750	257	4176	
			0%	**8%**	**1%**	**15%**	**1%**	**1%**	**0%**	**21%**	**27%**	**0%**	**24%**	**100%**	**29%**	**26%**	**21%**	**18%**	**6%**	**100%**	

Haringey's Key Mosaic Profiles[22]

In Haringey the four key Mosaic profiles are:

- Group A – 'Symbols of Success' represent 10.42% of Haringey households
- Group D – 'Ties of the Community' represent 29.6% of Haringey households
- Group E – 'Urban Intelligence' represent 35.97% of Haringey households
- Group F – 'Welfare Borderline' represent 19.37% of Haringey households

Mosaic Group Descriptions

Group A - 'Symbols of Success'

'Symbols of Success' residents tend to be socially and economically successful, living in sought-after locations. High education levels mean that this group is well-informed on health matters. Lifestyle is relatively healthy and people take regular exercise. Serious illness is low.

Group D - 'Ties of the Community'

'Ties of the Community' residents often live in close-knit inner city and manufacturing town communities, responsible workers with unsophisticated tastes. Most own their own homes, cars and hold down responsible jobs. Educational attainment is generally low. These are mixed communities where English is not the mother tongue. Many have an unhealthy lifestyle, with a tendency towards a bad diet and smoking.

Group E - 'Urban Intelligence'

'Urban Intelligence' residents are generally young, single and mostly well-educated. They are cosmopolitan in tastes and liberal in attitudes. A significant number are foreign-born, giving cultural and ethnic variety. They endeavor to adopt a healthy lifestyle, eat well and exercise, but there is a tendency to suffer from mental disorder. Almost 40% have a degree, and many are interested in further evening courses.

Group F - 'Welfare Borderline'

'Welfare Borderline' residents are often struggle to hold down rewarding/well paid jobs, and rely on the council housing, public transport and benefits to fund even the bare essentials. These are neighbourhoods with high levels of social deprivation including crime, health and education. They generally follow a very poor lifestyle; poor diet, heavy smoking and insufficient exercise.

Mosaic Type Descriptions

Each Mosaic household group is further divided into household types. Below we have detailed the three household types most prominently associated with women living in Haringey who do not attend breast screening. In fact 81% of women who do not attend breast screening in Haringey belong to one of these household types.

Group Type D27: Settled Minorities

45% of women who did not attend breast screening belonged to this household type.

Residents in this group type are generally of Caribbean, African, Cypriot or Pakistani origin. Housing tends to be affordable, accessible and suitable for single family accommodation. This group is generally viewed as economically 'deprived', because income is spent quickly on living costs and large families.

There are often a large number of small self-employed businesses offering the community goods for sale. High value is placed on hard work and providing for their families. Spending tends to be high on fashion products, takeaway foods and DVDs. Residents in this group are constantly exposed to marketing messages which could register strongly if there is an aspirational component and an appeal to vanity.

These do not tend to be seen as good areas to live in due to various signs of social disorder including robbery, serious wounding and racial attack.

Group Type F36: Metro Multicultural

22% of women who did not attend breast screening belonged to this household type.

Residents are generally a multi-ethnic mix, particularly Black Africans and those of Asian origin. The real or perceived threat of racial attack concerns many residents. These areas are not highly sought after due to threat of noise pollution, robbery, vandalism, drug abuse and other urban ills being fairly common.

Households are often very large with some overcrowding due to very large numbers of children. Few residents are over 45 years of age. The absence of conventional family units means that many residents are full-time carers.

Cooking and healthy eating are not a high priority and frozen, oven-ready meals are popular, as well as takeaways. The majority of residents will be in elementary, menial occupations in the service sector, notably in hotels and catering.

Most residents earn a modest income and have little by way of formal education. Educational attainment is low, but those qualified up to degree level enjoy much higher incomes.

There is a lack of savings and investments. Unemployment rates are high. Most residents in this group type live and spend in the present, following a hand to mouth existence.

Group Type E28: Counter Cultural Mix

14% of women who did not attend breast screening belonged to this household type.

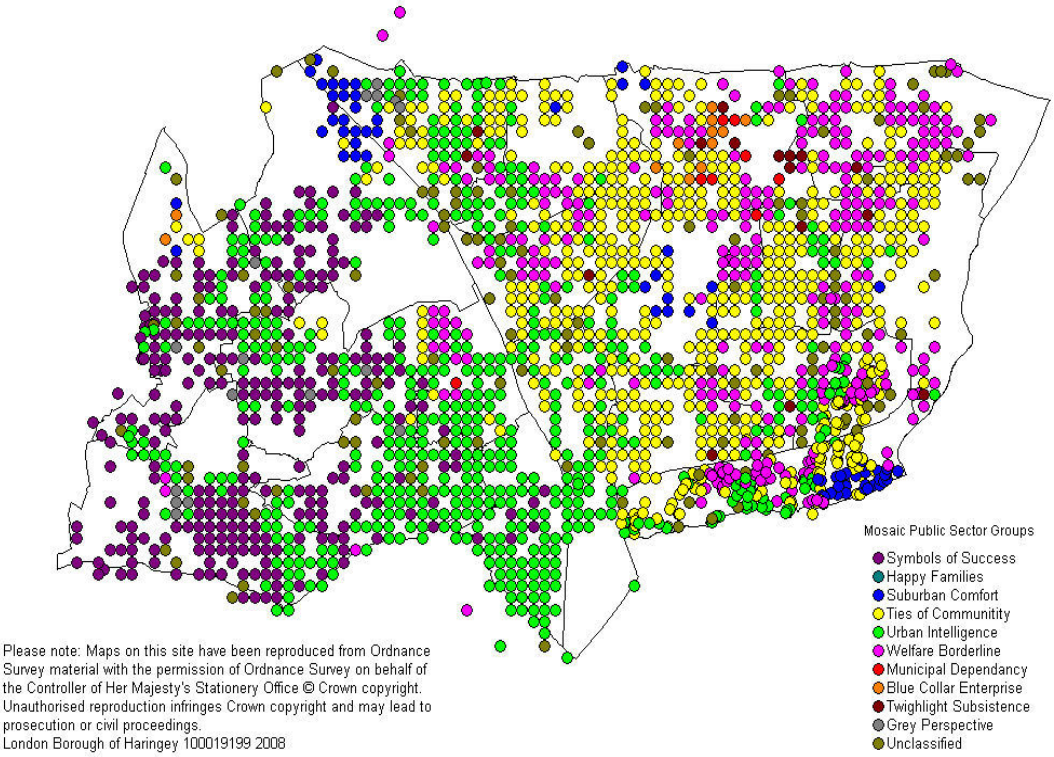
Residents tend to be stylish, creative individuals who engage in consumption, partly as a means of creating and sustaining image and identity which are both very important.

Exposure to marketing information comes from a wide variety of sources, such as the Internet, TV and other media sources. The group is highly receptive to advertising messages, whether it is posters at the roadside, advertising in taxis, the press, or on TV. They want to know about the latest advertisements.

Many available jobs are in unskilled positions that do not appeal to all local residents. Better paid jobs often require levels of qualification and experience that are beyond the reach of residents, resulting in higher levels of unemployment than would be expected from a population that is not poorly qualified.

Residents often over-spend in order to live the high life: spending in trendy bars or going on exotic holidays. Spending rather than saving is often the case and people are unlikely to have savings and investments. They live for today and don't worry too much about tomorrow.

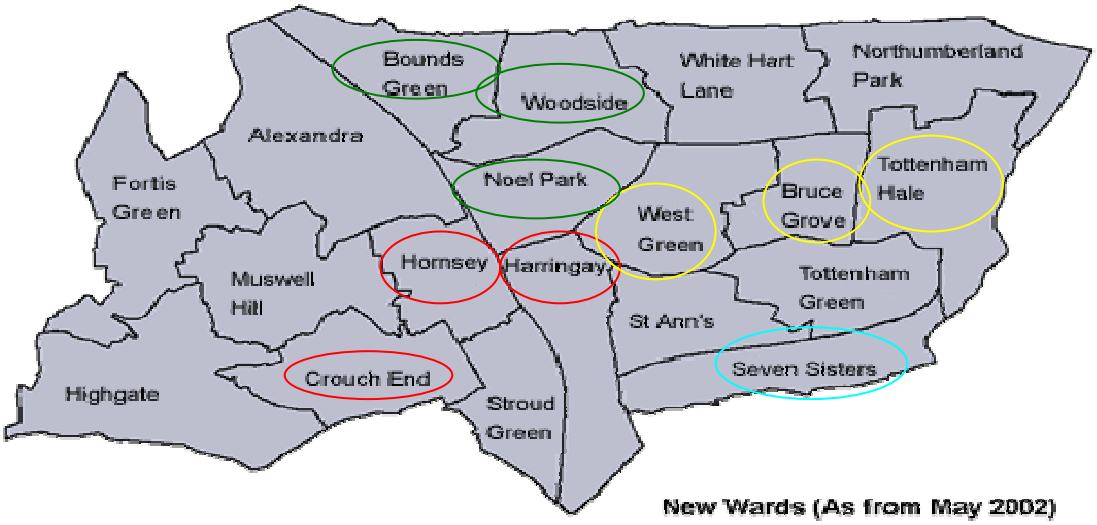
Mosaic Public Sector Groups in Haringey



Breast Screening – DNAs

DNAs are prominent in four postal code areas:

- N8 - Hornsey / Crouch End / Haringey
- N15 - Seven Sisters
- N17 - Tottenham Hale / West Green / Bruce Grove
- N22 - Bounds Green / Woodside /Noel Park



Highest DNA Rates per Demographic Profile

The demographic profile for 45% of DNAs is **D27 'Settled Minorities'**, where residents are a mix of Caribbean, African, Cypriot and Pakistani origin.

The second highest DNA profile (22% of DNAs) is **F36 'Metro Multiculture'**, where residents are generally a multi ethnic mix, particularly Black Africans and those of Asian origins.

The third highest segment (14% of DNAs) is **E28 'Counter Cultural Mix'** for which there is no defined ethnic breakdown.

Audience Insight: Critical Factor Analysis

Critical factor analysis allows us to gain insight into the way our target audience think and behave. The decision to attend breast screening is dependent on many different influencing factors. The most common factors are detailed below.

Key Barriers

The main factors that influence non-attendance are:

Lack of Knowledge[14]

Not knowing the facts about:

- Risk factors, including age, family history, smoking, alcohol & being overweight
- About screening unit locations
- The benefits of screening
- The procedure involved

Practical issues[4]

- Lack of awareness of how to self-examine
- Language barriers
- Lack of time or access to child-care
- Difficulty getting time off work
- Loss of money taking time off work
- Travel availability/costs to hospital

Fear[15]

- Of pain
- Of medical establishments
- Of radiation
- Of embarrassment
- Of the unknown screening procedure
- Of what might be found

Motivations / Incentives to Attend Screening[4]

Factors that influence attendance are:

- Knowledge and / or experience of the long-term health consequences, e.g. understanding that survival rates are lower from secondary to late presentation
- The idea that a long-term illness such as breast cancer can be a substantial financial burden to family and friends may motivate women to attend screening
- Recognising that screening enhances the chance of being alive and well to enjoy their children and grandchildren
- Understanding the great emotional burden that a long-term illness such as breast cancer can have on family and friends
- Positive role models – e.g. Jane Tomlinson, other celebrities, sports personalities, family, friends, peer groups

Competition

Internal and external factors that compete for the audience's time & attention include:

- Other priorities at home, such as looking after the family
- Religious commitments that may take up their spare time
- Preventative health activities not being high on the agenda if symptoms are not present
- Confusing, inconsistent and/or misleading coverage about breast cancer related issues in the media (can make cancer appear irrelevant)

Perceived and Real Costs and Benefits of Adopting the Desired Behaviour (i.e. Attending Breast Screening) [8]

Costs include:

- Fear of finding cancer
- Fear of mastectomy
- Fear of embarrassment about procedure
- Time to takeout for screening
- Religious values and beliefs
- No guarantee of cure

Benefits include:

- Early identification of breast health problems
- Increased survival rate from breast cancer
- Feeling empowered about personal health
- Being informed and in control – not being a victim
- Being there for children / grandchildren

Primary Research

It is important to understand the variations in knowledge and awareness of breast cancer and its risks, attitudes, knowledge and misperceptions about the screening service as well as real and perceived barriers to attendance. Primary research in the form of generative focus groups discussions and in depth interviews were carried out to assess this.

The rationale behind the focus groups was to allow us to us to:

- Assess attitudes to health in general and their knowledge of breast cancer and its risk factors
- Consider perceptions of the NHS National Screening Programme, and the breast screening process to identify key barriers to screening attendance or non-attendance
- Identify key areas of improvement in the breast screening process which would lead to increased screening attendance
- Identify any cultural or religious triggers that govern attitudes and behaviour towards breast screening

Focus Group and In Depth Composition

Service Users (mixed Ethnicity)

Women aged 50 -70 who attend regular breast screening appointments and have been screened within the last year.

Mixed Asian women

Women aged 50 -70 who have not attended a breast screening appointment within the past 5 yrs or ever. It was important to talk to this audience as DNA rates for this audience were 22%.

African Caribbean/ Somalian Women

Women aged 50 -70 who have not attended a breast screening appointment within the past 5 yrs or ever. It was important to talk to this audience as data highlighted a high DNA rate of 45% within this group.

White British and White Other

With a DNA rate of 14% we felt it important to talk to this audience. However, after continued and varied efforts to engage with this audience we were unable to recruit women who fit the research criteria.

Please see Appendix 5 for details of recruitment.

Focus group data is qualitative, and provides a picture of the issues that affect the participants. Is not quantitative research, and can not be used to create a statistical model of the entire population. It is affected by group dynamics and creates a record of a conversation. It uses small numbers of people, and aims to get *"deep"* answers from a *"narrow"* slice of the community.

The following section details the feedback from these discussions.

Behavioural Analysis

Insight into Breast Screening Attendance from Service Users

Perceptions of General Health

Awareness on the health benefits of diet and exercise were high. Service users felt good health was achieved by following a low fat, high fibre diet and taking regular exercise. However, they admitted that they did not always follow their own advice so strictly, but that was not such a bad thing. They felt depriving oneself of the things you enjoyed was not good for the mind and thought there needed to be a balance between the two. The idea of a connection between physical and mental health was very clear for these women.

"It's about balance, everything in moderation, eat well, exercise, don't smoke, don't drink too much."

"You need a healthy mind too. These silly diets that are too strict, you just end up going crazy. You need to take care of yourself but that means being happy too."

They felt responsible for their own health and that the decision to look after it was their own. *"You are the first person to take an interest in your health – nobody can make you!"*

The women in this group were very aware of health issues, but their awareness comes from a variety of sources ranging from exchanges with others in their community to the television. The accuracy of this information was often somewhat dubious. For example, a discussion ensued on cholesterol levels. One woman advised the others to:

"…drink three large glasses of water 45 minutes before eating breakfast, drink unsweetened pomegranate juice for antioxidants, and boil pineapple rinds with ginger in a pot to make tea."

It was clear that women listen to each other when it comes to health and that this type of exchange was normal. They also believed it was very important to listen to your GP and follow any advice they gave.

They tended to start thinking about their health when they had heard of illness close to them. Stories about cancer and other health problems clearly travels fast among tight-knit groups centred in the community centre, and they each had a store of such stories.

"My colleague was diagnosed with breast cancer and this made me realise it does actually happen. I knew it did but it really hit home when she was diagnosed and I went for screening."

Knowledge of Beast Cancer and Breast Screening

The women were all aware of the relationship between breast cancer and age and believed that women over 50 were at high risk. It must be noted, however, that they perceived this age group to be more prone to all types of cancer. One woman, who had survived breast cancer, and those who had been referred for screening after the development of a lump were very well informed about the cause, development and possible progression of the disease as they had researched it thoroughly when they had previously felt at risk.

Those who were prompted to attend screening after receiving a letter of invitation were less well informed about the risks of breast cancer other than age and genetics, and in terms of prognosis they shared a very a pessimistic view of cancer's terminal nature. The exception

to this was if it was *"caught early enough".* This, they revealed, was their primary motivation to attend screening appointments when invited.

"It needs to be caught early or I don't think you can hold out much hope of living very much longer."

There was, however, considerable debate about what being caught early enough actually meant in practice: whether it was defined by the size of the lump; implied any pain; or was cancer identified by machinery but not far enough advanced to be identified by examination. Although they accepted that, as a general rule, most lumps were benign, the immediate conclusion was that a lump they found *themselves* is bound to be malignant. This individualistic pessimism is very revealing. Although this is usually related to feelings of helplessness, in this case it is found to be a key motivator to screening attendance, their personal perception of risk being unusually high.

"I know they [lumps] are usually nothing but if I found a lump I just know it would be cancer so I would at least want to catch it and treat it as soon as I could."

Invitations to Attend Breast Screening

The majority of women who had attended screening had done so after receiving a letter of invitation. All found the information sent with the invitation clear and understandable. They admitted their initial feelings on receiving the letter were worry and panic, but this feeling quickly subsided to one of relief.

"It did make my heart skip a beat but just because it makes you realize these things can happen to you but then you think well if I don't know I can't do anything about it."

For those who had not received a letter of invitation, they attended screening after a referral from their GP following the development of a lump.

With respect to experiences at the screening centre, most of the women felt positive about the experience. They were relieved to find that staff members were female and that the facilities were separate from the general hospital facilities. They felt staff were very understanding and supportive and made them feel at ease despite the fact the procedure itself was very uncomfortable.

Attitude to Breast Self-examination

Only the women who had had breast cancer and those who had previously found a lump in their breast ever practiced breast self-examination (BSE). They felt that it was essential for their peace of mind in the interval between screenings as BSE might reveal a lump which had developed during this interval and therefore prior to their appointment. Others in the group admitted they did not engage in BSE, despite their belief that it is a valuable practice, but that this was because they are unsure of how to do it properly.

Reason for Attendance and Perceived Barriers

The women admitted that they attended screening for two main reasons; for peace of mind when they get the all clear, and to do as much as they can to increase their chances of survival if they develop the disease.

Several women mentioned that their employers were *"not happy"* when they took time off

work for screening and believed that this could be a factor contributing to non attendance. They also recognised that for many women taking time off work will also mean a loss in income.

They thought that if the opening times of a screening centre were more flexible it would encourage attendance. A number of the women were unhappy about the fact that the screening centre displayed the word 'breast' so obviously. They agreed this was very embarrassing, with a small minority even admitting that they had actually walked around outside the centre until they were certain that nobody who knew them was around before entering.

Commonly Shared Insights among Women who Do Not Attend (DNA) Breast Screening

Perceptions of General Health

There was reference to diet and exercise when discussing factors relating to health. However, in general most of the women talked about these factors in terms of what might cause ill health rather than good health. They each talked about concerns salient to them at that moment and this was usually a concern that they or someone close to them was suffering from. For example, two of the women felt that good health was dependant on the health of your heart. Each of them had a family member with heart problems.

"If your heart if not healthy then you are not healthy, it is the most important thing to look after."

"You need to eat right and make sure the pipes [heart valves] are clean."

Others cited different types of cancer as their key health concern and explained that they were concerned because a family or friend had been diagnosed with it in the past. Therefore, understandably the health concerns of their loved ones were first to come to mind when they thought of health. Almost all of the women felt they did not have time to think of their own health let alone act to improve it. They all felt their health was a secondary concern to them, with the health of their family coming first.

Mental health was very important to these women and there was general agreement that good physical and mental health are mutually dependant.

"What's the point of having a healthy heart without a healthy mind or vice versa? I don't even think you can have one without the other."

Knowledge and Beliefs about Breast Cancer and Breast Screening

All participants were aware of breast cancer and agreed that screening was important. However, they felt screening was not important for every women and, surprisingly, they underestimated the prevalence of the disease in the UK.

Only those at risk of the disease were thought to be in need of screening. Factors that place an individual at risk of developing the disease were not well known and very few women appreciated the fact that the risk of developing breast cancer increased with age. Those who did felt this age group was most likely to be those over 65 years old.

The only symptom for breast cancer that there was unanimous awareness and agreement on

was finding a lump in the breast. They were not aware that most breast lumps are not due to cancer and almost all of the women believed that once diagnosed with cancer it will inevitably spread to other parts of the body.

They hesitantly suggested a genetic link with breast cancer, citing stories of families they knew, or had heard about, that had more than one female member suffering from the disease. However, they admitted they were also not sure if this was perhaps instead just bad luck or a coincidence.

"I know a woman who had breast cancer and her mum died of it. I thought it was so sad that it happened twice to one family."

Worryingly, the notion that physical trauma could cause breast cancer was not uncommon among the women who DNA.

"If you are in a car accident and get hit hard in the breast I think that would make you scared you might get it."

Many of the women felt they were not at risk and admitted they had never thought about screening. *"I have never seriously considered breast screening because I know I'm not really at risk of it yet".* This is a highly significant finding. Many women who do not attend breast screening perceived their risk of the disease to be minimal and, as a result, did not feel personally motivated to attend.

For a number of the women the idea of attending screening was too difficult. It brought with it a fear of susceptibility that they did not feel equipped to deal with.

"It's like admitting you might have it. Oh, I can't even think of that."

The women who preferred not to think about breast screening or its consequences might well have been demonstrating a common coping mechanism. Not only did they fail to respond to invitations to attend screening, but they had also effectively avoided any further stress by refusing to even think about the subject.

"I don't think I'd even want to know if I had cancer."

"I don't go. So what? I prefer to remain happy and unaware as stupid as that might sound to you."

Women were aware of where to go to attend breast screening and were all able to cite at least some form of screening facility. When discussing the mobile units they admitted they had in the past felt sorry for women walking in because when the title on the unit made it so obvious what they were going for.

Almost half of the women did not remember getting a letter inviting them to attend screening. Those who did admitted they had ignored it without much thought.

Attitude to Breast Self-examination

None of the women practiced BSE. They did, however, feel it was an important routine carried out by women checking for lumps in the breast. A discussion then ensued around BSE with a small minority of women coming to the realisation that without doing this they would not know if they had any lumps that needed to be screened. However, they soon consoled themselves with the idea that they wouldn't know how to do it anyway.

Perceived Barriers to Breast Screening

Fear and the desire to avoid this feeling was found to be a significant barrier to breast screening attendance. The primary fear relating to a potential breast cancer diagnosis was death. Almost half of the women had lost a loved one to breast cancer or knew someone who had. However, another highly emotive fear surrounding a breast cancer diagnosis was the association with a possible mastectomy.

The psychological implications of such a procedure were as follows: the feeling that they would not feel complete as a woman, that they would no longer feel feminine in themselves or be perceived as so by their partners, that their relationship with their husband would be different, and coping with a world in which losing a breast is regarded as abnormal. Despite being aware of the availability of breast reconstruction surgery, there were also fears of being visibly abnormal and that people would know.

Some women said they could get over all of the above if it was guaranteed to save their lives, but knew this was not the case.

"To go through all that and feeling wrong as a woman I would need to be sure it would save my life. I'd only do it for that reason so I could live for my children."

Another barrier to attendance was based on the screening procedure. The perception that the procedure would be very painful and embarrassing was voiced by all and this was cited as a factor which would out them off if they felt they might attend.

"One woman told me that she wouldn't advise me to go as it hurts so much."

"Do they not have to press really, really hard?"

Although it was recognised on an intellectual level that breast disease would have a profoundly negative effect on their family responsibilities, around half of the women claimed that day to day considerations prevented them from attending screening.

Preventive behaviours, such as attending screening appeared to offer nothing positive in any tangible sense, only the negative possibility of "*finding something."*

Media Channels

Radio and TV, together with family and friends, seem to be important sources of information about screening. This finding highlights the potential value of encouraging the media to provide accurate information.

Segment Specific Insight into Mixed Asian Women who DNA

These women believed that sleep was very important to health and felt that adjustments to their set routine could have a negative impact on their health. A significant number of the women believed that thinking positively about life was a successful method to ensuring good health. Although participants were aware of what they needed to do to be healthy, the majority also mentioned that due to other issues such as stress, depression, lack of time, and high blood pressure, they were sometimes unable to be as healthy as they would like.

More than half the participants were aware that they were at risk from diseases such as diabetes, heart disease and blood pressure because of their age and ethnicity. They understood that if they led a healthy lifestyle they would be at less risk.

All participants believed that attending screening was important. However, they did not recognise the risks posed by non-attendance. In general, it was believed that screening only confirms or denies the presence of the disease, which would be visible by a lump on the breast, and that other than this there probably wasn't much more to be gained through the screening.

"If you have the disease then the screening will confirm that, I guess maybe its better not to have the test for this reason."

All participants were aware of the age at which a woman is entitled to attend screening and a minority understood that further screening was required every 4-5 years. Participants were also aware of a strong relationship between age and breast cancer risk and as a result believed that there was also a relationship between age and screening importance.

Reasons for non-attendance within this group stemmed from the psychological stress they felt when they thought breast cancer might be detected. The fear of being diagnosed with breast cancer among this group was too much to bear so much so that they avoid it. This was heightened by the fact that they believed there was little to be gained from knowing. They did not see a correlation between attending breast screening and breast cancer survival.

"No news is good news."

"I would rather live knowing I may not have cancer then knowing I have it."

Segment Specific Insight into African-Caribbean/Somalian Women who DNA

General health within this group was measured by *"being well enough to do everything you need to do for the family without the need for complaint".* They were highly aware of diabetes and heart disease affecting people in their community, but stated that this was usually found in men.

Women in this group had serious misconceptions about breast cancer. All women agreed that this was a 'white' person's disease and as a result they had nothing to worry about. They were very confident that if the disease was something to worry about then their GP would have told them and their mothers would have attended.

They had no idea who was entitled to attend screening and had never received a letter inviting them to an appointment. They believed breast screening would be carried out by a GP at the surgery but admitted they did not ever think about it because they were not at risk.

They were unable to accurately cite any of the risk factors for the disease and displayed a serious lack of knowledge on breast cancer when describing how it develops. They discussed the development of a painful lump in the breast that would be visible to the naked eye and suggested that this developed due to either a blockage or an infection which then caused breast cancer.

Women felt self-examination was *"wrong".* This was primarily due to the fact that breasts were seen to be sexual in nature and anything sexual was very much a repressed subject. They were simply not comfortable touching their breasts or even talking about touching them. Furthermore, although they generally accepted on a logical level that self-examination should be carried out to find any abnormalities in practice they felt that the sexual nature of the act diminished this benefit.

They did not see an association between breast screening and survival chances and believed that women did not attend because it was frightening to know about something they could not control. They felt it was easier not to attend as this way they could put it to the back of their mind and forget it.

Feedback on the NHS Breast Screening Programme Materials

Almost all of the women believe they have seen some form of Breast screening promotional material although they admitted they were not sure if the material they saw was from the NHS Programme or a breast cancer charity.

"They are all the same colour of pink so they look the same."

However, only around a quarter of the women had picked up the material or actually read it and those who had could not remember what it had said. All cited the GP surgery as the location they saw the materials and all admitted that it had been boredom and not interest that had caused them to pick up the materials.

They believed breast screening materials needed to be more eye-catching to get women's attention and they need to be available at community centres and libraries.

Actionable Insight

- Service users perceived themselves to be very much at risk of breast cancer while DNA did not. Educating women and increasing awareness of the risks and symptoms of breast cancer alongside the benefits of breast screening is vital to ensure women realise they are at risk and that they should be screened. Women need to feel as though breast screening is personally relevant to them.

- A major barrier to breast screening was the fear of *"finding something".* This fear is so significant for many women that they resort to avoidance coping mechanisms "*What I don't know I'm not afraid of".* Promotions and education must address these fears to reassure women that a breast cancer diagnosis is not a death sentence. Promoting the fact that women diagnosed with early stage breast cancer have an unaffected life span should reassure women of this and hopefully tackle some of the fear prohibiting attendance.

- In order to help tackle the myths and misconceptions of breast cancer and breast screening which are found to be rooted in the beliefs of many BME communities BME nurses should be asked to attend community centres to help educate and inform those who work there. Staff at the centres could then continue help to inform and educate the women who attend their centre. This would ensure that accurate information reached these women in a culturally sensitive manner from a source they trust and respect. This should then help to dispel some of the many myths believed within these communities.

- Mobile units should be more inconspicuous within communities. Renaming them as health units would reduce the embarrassment associated with attending. Units must also embrace more flexible opening hours to further reduce barriers.

  If they were placed near BME community centres they could offer block booking times in which the women are free to attend. This would help to tackle the barriers of childcare and time as it could then be easily incorporated into their routine when visiting the centre.

  An added benefit of this would be that the women being screened could talk about the experience with others in their centres; they could promote screening through word of mouth, and tackle myths associated with the experience. It would also allow these women do attend without the feeling of isolation as they would be going through the experience at the same time as others in their centre.

- Data lists used for inviting eligible women need to be updated regularly to avoid invitations being sent out to the wrong address. This data must also hold other vital information such as language preference to ensure invitations are sent in a known language more fully understood.

- Leaflets using images to explain the procedure from invitation to appointment were thought to be helpful not only for those who can't read but also as a 'gentler' method of explanation. The process was thought to sound painful and too clinical but might come across as more accessible in image format.

Critical Factor Analysis Summary

Target audiences PRIMARY	Valued benefits of desired behaviour	Cost of participation of desired behaviour	Competitive factors and behaviours practiced	Information channels /potential touch points	Level of readiness to change
Service users	A feeling of control over health Peace of mind	Time to attend appointment Embarrassed attending a mobile unit	They feel it is their responsibility to take control of their health	GPs & GP practices	N/A
Afro-Caribbean/ Somalian	Feel cancer screening not relevant to them	Fear of cancer because they have no control of it	*Feeling that breast cancer is: "a white persons disease"*	Community groups, family	Held back by lack of knowledge and awareness
Mixed Asian	Little to be gained from knowing you have cancer	Fear Knowing they have cancer	Don't see a correlation between screening and survival	Community groups, Religious leaders	Held back by lack of knowledge and awareness

Conclusion

Low uptake of the NHS Breast Screening Programme in Haringey is a complex issue. Barriers are found to be both intrapersonal and structural in nature and can act in isolation as well as in combination to influence screening attendance.

At an intrapersonal level, non-attendance at screening can be driven by fear of cancer or a low perception of breast cancer risk. It is vital to ensure that women are better educated on the risk factors for developing breast cancer as well as the benefits that screening can offer to ensure that women feel empowered and motivated to attend their screening appointments when invited.

At a local level the mobile population and cultural diversity of Haringey has proven to be challenging for the NHS Breast Screening Programme. With more informed and up to date patient lists as well as new promotional material the programme can at ensure a wider understanding of the screening programme in the borough.

The Health Belief Model maintains that the factors influencing breast screening attendance are motivation, perceptions of breast cancer risk, and beliefs that the benefits of screening outweigh the cost of participation. This is certainly found to be true among many women who attend screening. However, in order to drive positive behaviour change among women who do not attend breast screening it is the causal components *underlying* these broad factors that must be addressed and it is these components that can vary between ethnicity.

Therefore, an intervention to increase uptake and coverage of the NHS Breast Screening Programme in Haringey must be both multi faceted, to address the many issues which influence breast screening attendance, and easily adaptable, to suit the ethnic diversity of the borough.

Next Steps

This report contains insight into the knowledge, attitudes and beliefs held about breast cancer and breast screening within certain populations of Haringey. These insights indicate where and how further steps are needed to influence screening behaviour. A period of reflection is required to understand the insight and determine appropriate behavioural goals. In order to set SMART objectives baseline data will also need to be established with a mechanism to measure changes.

Subject to a joint review between Barkers Social Marketing and Haringey PCT the behavioural goals and strategy can then be set ready for Phase 2 - intervention development and delivery.

Appendix 1: Local Breast Awareness Campaigns

The following section looks at what some other local areas have done by way of campaigns and related activities around breast cancer screening and what possible lessons we might learn from them.

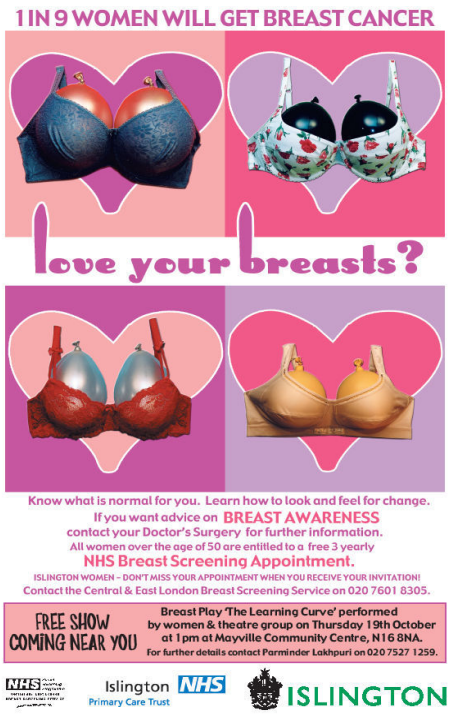
Manchester PCT

Health professionals from Manchester Primary Care Trust (PCT) raised awareness of the importance of breast screening during International Women's Week 4 -11 March 2007.

In a joint initiative with Manchester City Football Club, women living in Central and North Manchester were invited to the mobile breast screening unit at City Stadium for their appointment.

The PCT hosted a number of events during International Women's Week, one of them being Bosom Buddies – BBC TV presenter Ranvir Singh launched a look at breast screening and breast cancer from a female perspective at Longsight Library. A representative from the Pakistani High Commission attended, with translations available in Punjabi, Urdu and Somali.

"*Since we launched the joint breast screening initiative with Manchester City FC, the uptake of appointments has improved significantly, with an average of 140 women a week now being screened,"* said Julie Pickford, cancer screening co-ordinator for Manchester PCT. *"This success has been the result of a proactive campaign which has involved health professionals working with local communities over the past six months. If this level of attendance continues, Manchester will become a leading centre in the North West for breast screening".*



Islington PCT

Islington breast screening short film (08/11/06)
Islington PCT produced a short film called 'What every woman should know – breast screening the facts'. It featured the experience of real women and follows a patient's journey through the breast screening process. The film was available on DVD and video and translated into 6 different languages including English, Bengali, Somali, Turkish, Arabic and Spanish. The film has a British Sign Language option and will be used by Camden PCT, Tower Hamlets PCT, City & Hackney PCT and Newham PCT.
Helen O'Keefe, Islington's Breast Screening Coordinator, said: "We decided to make this DVD as there simply wasn't the right information available to suit the multicultural London population. Breast screening saves lives, but our research showed that many women didn't know what happened at a breast screening appointment. Others were too scared or embarrassed to attend an appointment. This DVD was used in surgeries and community centres all over Central and North London".

Sandwell PCT

Campaign to Increase Breast Health Awareness, 2007

An advertising campaign to increase women's awareness of good breast health was launched in the summer of 2007 on buses across Sandwell.

The campaign encouraged women to examine and look closely at their breasts, in the hope of catching early cancer symptoms at the earliest opportunity. The posters, which were on local buses and at Metro stations, were funded by Sandwell Primary Care Trust (PCT). The posters were unveiled next to the mobile breast screening unit.

Community Development Specialist for Sandwell PCT, Caroline Southern, explained: "This bus campaign is one of a number of ways the PCT is promoting the importance of being breast aware. One in nine women will develop breast cancer at some time in their life, so early detection of any changes to how your breasts look and feel is vital, as well as of course attending screening appointments".

Camden PCT

Breakthrough Breast Cancer is developing a campaign, which first pilots in the London Borough of Camden, which will encourage women aged 50 to attend breast screenings when invited by the NHS Breast Screening Programme. It will include a door-drop of more than 20,000 DVDs, which help explain and show the screening process to alleviate fears.

Executive creative director and managing partner, Dylan Bogg, said: "We really felt we'd developed a very strong communications strategy capable of taking our message out to a hard-to-reach audience, and we had some fantastic creative work to complement the thinking. We look forward to creating a campaign that will, we hope, really create a big impact for the target group".

Tower Hamlets PCT

In 2008 a Tower Hamlets PCT text messaging campaign illustrated that text messaging contributes to improving attendance for Breast Screening. The campaign ran throughout the summer and was implemented alongside a number of tools and techniques to improve the rate of screening (e.g. posters campaigns, calling patients directly, well women clinics and focus groups), all designed to encourage women in Tower Hamlets PCT to attend their breast screening appointment.

A list provided by the Central & East London Breast Screening Service (CELBSS) was uploaded by the 9 participating GP surgeries who then sent out appointment reminders to selected patients reminding them to attend their breast screening appointment with the CELBSS screening service.

Enfield PCT

In 2006 Enfield PCT developed a multilingual step-by-step guide to Breast Screening with the help of the North London Breast Screening Service. The booklet uses photographs to explain the breast screening process, showing each stage involved from invitation through to screening and getting the results.

Although the details of each step are given in the top 9 languages spoken in Enfield the use of images ensures that women with reading difficulties and those who speak a language outside of the 9 used will still benefit from a better knowledge of the breast screening process.

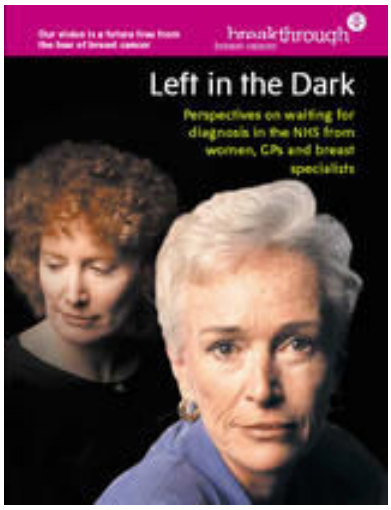
Appendix 2: National Campaigns

The following section looks at what some national-level campaigns and related activities around breast cancer screening and what possible lessons we might learn from them.

Breakthrough Breast Cancer 'Screening Saves Lives'

Breakthrough's '*Screening Saves Lives*' campaign aims to improve the early detection of breast cancer by pressing for continued improvements to breast screening services across the UK.

In 2008 Breakthrough focused on three key areas of the campaign:
Digital mammography.
Take up of breast screening appointments.
Access to family history screening services.



Breakthrough Breast Cancer's 'In the Dark'

Since 2003 Breakthrough Cancer's 'Left in the Dark' Campaign has highlighted the anxiety felt by women when waiting for an appointment. They campaigned to ensure that all women with breast problems referred by their GP would wait no longer than 2 weeks for an appointment.

The Cancer Reform Strategy 2007 committed that by December 2009, this target will be achieved across England.

Cancer Research UK 'Screening Matters'

The Screening Matters campaign aims to build on the successes of the screening programmes to date. In early 2008, cancer campaigners sent over 17,000 emails of support for the 'Screening Matters' campaign to MPs, MSPs and Welsh Assembly Members.

They campaigned to ask the UK governments to commit to:

- Screen at least three million more people over the next five years.
- Reduce the variation in screening across the UK.
- Reach out to people eligible for screening who aren't taking part.
- Provide the best possible screening programmes through funding, staffing and measuring success.

Appendix 3: Local and National Press Coverage

Haringey Independent, 4 December 2008

'Women are not being screened'
Many GPs in Barnet are not doing enough to promote breast screening, according to a top doctor. At a board meeting of the Barnet Primary Care Trust on Friday, Dr William Teh, the director of North London Breast Screening Service (NLB) said there were inconsistencies among GP practices with some doctors not "proactively" promoting the service.

Figures show that in Barnet, only 67.5 per cent of women aged 53 to 64 were screened in 2006, and although this is above the London-wide uptake of 63.9 per cent, it falls below the national figure of 75 per cent. Speaking at Edgware Community Hospital, Dr Teh said: "What I find interesting is that some GPs are proactive in encouraging women to be screened and others are not."

The comment caused concern among board members and Dr Philippa Curran, chair of the professional executive committee, has requested a confidential report highlighting which parts of the borough show poor referral figures. A Barnet PCT spokesman said: "We were not aware before the trust board meeting that this might be a problem within Barnet. "It has been requested that the Breast Screening Service provides us with more information so we can follow it up on an individual GP practice basis where there appear to be concerns."

The North London Breast Screening service at Edgware Community Hospital was suspended in December 2006, due to system process errors. The service re-opened fully in October 2007, but left a ten-month backlog with women left struggling to arrange routine breast screening appointments. Dr Teh added that the latest review had shown promising results: waiting times were reduced, staff shortages had been corrected and the service had been commended for its improvements. Breakthrough Breast Cancer, a charity that fights breast cancer through education and research, says the anomaly is not uncommon.

A study published last year found that only 16 per cent of family doctors questioned had spoken to women aged over 50 about the disease when they had an appointment and 80 per cent said they did so only when asked by a patient. Dr Alexis Willett, policy manager at Breakthrough Breast Cancer, said: "GPs have an important role to play in encouraging all women over 50 to attend breast screening and promoting breast awareness to women of all ages.

"Screening is vital as it can detect breast cancer at the earliest stages, before it can be seen or felt by hand. The earlier breast cancer is diagnosed and treated, the better the chances of treatment being successful."

Haringey Independent, 5 November 2008

'**Doctor Surgery staff wear pink in aid of breast cancer research'**
Staff at a doctor's surgery dressed in pink clothing to work to raise money for breast cancer research. About 20 staff members at the Rushey Green Group Practice, in Hawstead Road, Catford, wore pink in aid of charity Cancer Research's breast cancer awareness month which ran throughout October. Participants in the event last Friday (October 31) donated £2 each and the surgery was decorated with other pink items including feather boas and balloons.

Surgery co-ordinator Gemila Sultan organised the event and said: "The day was a huge success and everyone had a really great time".

Haringey Independent, 17 May 2007

'Breast screening is fifth worst in capital'
Fewer than half of women in Haringey aged between 50 and 70 are having the NHS recommended tests for breast cancer.

Department of Health figures revealed last week that 44.8 per cent of eligible women cared for by Haringey Teaching Primary Care Trust (TPCT) are taking up their appointments once every three years. The London average is 55 per cent and, of the 31 PCTs in the capital, Haringey has the fifth worst rate. The low uptake has not been helped by the suspension of routine breast screening at the North London Breast Screening Service (NLBSS). The facility, which serves Hertsmere, Three Rivers, Watford and north London, has not been running since December after an external audit highlighted the need for staff training in light of new procedures.

The Evening Standard, 20 February 2009

'Women are urged not to cancel breast cancer checks'
The Government's breast screening czar today called on women not to abandon appointments amid doubts over checks.

Professor Julietta Patnick, head of the NHS breast screening programme, spoke out in response to a British Medical Journal study warning that women face unnecessary surgery and chemotherapy.

In an interview with the Standard, Professor Patnick questioned the study's main finding that 10 healthy women among 2000 will be incorrectly treated. The cancer expert said: "Women should not ignore their appointments. It is obviously their personal choice to attend. But the breast screening programme saves hundreds of lives a year.'
National cancer director, Professor Mike Richards, added: "I want to reassure women that breast screening is safe and can lead to cancer being diagnosed and treated much earlier, which ultimately saves lives."

Cancer groups fear the row over screening will lead to more deaths by putting women off attending. More than 45,000 women are diagnosed with breast cancer every year and about 12,300 die.

The Evening Standard (London), 28 January 2009

‘**Thousands shun breast checks’**
London has the worst take-up rate of breast cancer screening in the country, new figures reveal today.

Nationally nearly three quarters of women eligible for free mammograms are attending appointments to check for the fatal disease. But NHS Information Centre figures published today show that between 2007 and 2008 only three out of five in the capital attended breast checks.

Under the NHS scheme, free screening is offered to women aged 50 to 70 every three years. Early diagnosis is estimated to save 1,400 lives a year in England. The Breast Cancer Campaigns charity said thousands of women are putting their lives at risk by avoiding the checks.

Its director of research and policy Arlene Wilkie said breast cancer was on the rise. She added: "We know the earlier breast cancer is detected the greater the chances of survival. We would urge all women over 50 to attend the routine NHS screening." Experts say many women do not take up the free screening because they fear finding out they have breast cancer.

Others have a bad experience and do not come back. London Assembly figures last year showed Kensington and Chelsea had the lowest attendance rates, and Havering and Bexley the highest

The Independent, 3 January 2009

Fears of rise in breast cancer as more women decline screenings
Number accepting NHS appointments falls below 70 per cent for first time.
A worrying drop in women attending breast screenings is putting lives at risk, doctors have warned.

After 20 years in which the NHS breast screening programme is estimated to have detected more than 100,000 cancers, the number of women accepting their first invitation for screening has fallen below 70 per cent for the first time. A spokeswoman for the NHS Cancer Screening Service said one reason was the "inconvenience" of screening.

"Busy women put off going because the clinic is difficult to get to or the timing of appointments does not fit their lives. They don't have time," she said.
Embarrassment, discomfort and fears that the procedure may be painful were also deterrents, she said.

Women are invited for breast screening every three years between 50 and 70. The age range is to be extended to 47-73 by 2012. Professor Julietta Patnick, director of NHS Cancer Screening Programmes said the fall in acceptances of 1.1 per cent last year had affected all target age groups.

In the programme's Annual Review she said: "The drop in acceptance of the first invitation [from 71 to 69.5 per cent] is particularly worrying as women who accept the first invitation are most likely to be regular attenders."

Almost 13,500 cancers were detected at screening in 2006-07, latest figures show. The programme is estimated to save 1,400 lives a year. Cancers detected at screening are smaller and easier to treat, with improved survival, than those which only become apparent

when symptoms develop, such as a breast lump, discharge from the nipple or unexplained soreness.

Stephen Duffy, head of cancer screening at Barts and the London Medical School, said women whose cancers are detected at screening have a 50 per cent lower death rate after 10 years compared with those detected when symptoms appear. He defended the three-year gap between screenings, saying the UK programme was more sensitive [ie picked up a higher percentage of tumours] than those with a one-year interval. He said: "I believe that is due to the expertise and diligence of the staff and the programme's commitment to quality."

Professor Duffy added that the extension of the programme to guarantee women a screening before the age of 50 and include those up to 73 would add 400,000 women to the annual total screened. "It is important that the extension of the programme does not cause the [screening interval] to slip beyond 36 months. Very long intervals are characterised by large numbers of symptomatic cancers, bigger tumours and poorer survival rates," he said.

In the early days of the programme, breast screening was viewed with distaste by many women who complained about discomfort and lack of dignity. But the number of women screened has risen by almost half (48 per cent) over the past 10 years. In England, 74 per cent of invited women accept screening but rates vary across the country and are lowest in London at 55 per cent. Rates vary with ethnicity and are lowest among Muslim women at 50 per cent compared with 66 per cent among south Asians and over 75 per cent among non-Asian groups.

The Times, 21 February 2009

‘**NHS rips up breast cancer leaflet and starts all over again’**

The NHS is tearing up its leaflet on breast cancer screenings and writing a new one from scratch after scientists criticised the information as inadequate and manipulative.
The leaflet, which is usually sent out with invitations to attend screenings, advises women that the procedure can be uncomfortable or painful but does not mention potential risks.

Professor Mike Richards, the National Cancer Director, said yesterday that the leaflet, Breast Screening: The Facts, would be scrapped, a day after the criticisms.
"A formal review is in progress and will be tested against the best available evidence," he said.

In a letter to The Times published on Thursday, 23 leading cancer experts said that women were being manipulated. "None of the invitations for screening comes close to telling the truth," they wrote.

Researchers at the Nordic Cochrane Centre in Denmark also criticised the leaflet as "inadequate as a basis for informed consent.

"No mention is made of the major harm of screening - that is, unnecessary treatment of harmless lesions that would not have been identified without screening," they said in the British Medical Journal. This violated General Medical Council guidelines, they added.

Professor Julietta Patnick, the director of NHS Cancer Screening Programmes, said that according to research, women "didn't want too thick a leaflet. "Putting too much numerical information meant women just put the leaflet down," she said, adding that fuller information was available on the screening website. Professor Patnick said that the current leaflet would be scrapped and rewritten. "We start with a blank piece of paper and look at the evidence.

That's the stage we're at at the moment." Women aged between 50 and 70 are invited to a breast cancer screening every three years. The Danish researchers say that for every woman saved by screening, ten are treated unnecessarily. Many of these women have whole or part of a breast removed and sometimes undergo radiotherapy or chemotherapy.

Professor Richards disputed the numbers: "We think it's much nearer one to one: one person having unnecessary treatment to one life saved." He estimated that screening saved 1,400 lives a year. "There are no doubts in my mind about the benefits." He said that a review of the guidance on screening began last month.

The current leaflet, which was written in 2002, would be scrapped and a new one issued in the autumn. A spokesman for NHS screening programmes said that such reviews happened regularly when there were "major shifts in research".

The Times, 19 February 2009

'**NHS is accused of leaving women in the dark about screening risks'**
Women undergoing routine breast cancer screening are not being warned of the risks, with many tests ending in unnecessary treatment, leading health professionals say today. In a letter to The Times, 23 signatories criticise the Government's "unethical" failure to provide women with the full facts in the NHS programme of checks for all women aged 50 to 70.

Instead, it offers leaflets that "do not come close to telling the truth", the health specialists claim. Many healthy women are subjected to over diagnosis of benign conditions and may undergo unnecessary surgery, radiotherapy or chemotherapy. If cancers diagnosed by screening were left to their own devices, many "might never appear in a woman's natural lifespan", they add.

The letter comes as the British Medical Journal publishes tomorrow an analysis by the Nordic Cochrane Centre of breast cancer and screening. The paper concludes that if 2,000 women are screened regularly for ten years, one will benefit as she will avoid dying from breast cancer.

At the same time ten healthy women will be treated unnecessarily, having part or the whole of a breast removed and receiving radiotherapy and sometimes chemotherapy. A further 200 healthy women will have a false alarm.

The Cochrane team, led by Peter Gotzsche, concludes that the information distributed by the NHS is onesided and misleading for screening participants. "The leaflet has the authoritative title Breast Screening: The Facts suggesting that the information can be trusted ... [but] it is inadequate as a basis for informed consent." Of the 2.2 million women invited for checks by the NHS breast-screening programme in 2007/08, 1.7 million were screened - up half a million on a decade ago.

The number of cancer cases detected by screening has more than doubled over the same period to 14,100 in 2007-08. Of these, three quarters were invasive cancers - the most dangerous form of the disease - while 20 per cent were ductal carcinoma in situ (DCIS) cases. The Cochrane study observes that, despite this, the NHS leaflet makes no mention of DCIS cases, of which fewer than half become invasive cancers.

Michael Baum, Emeritus Professor of Surgery at University College London and one of the signatories of the letter, said there was no evidence that screening was bringing big benefits and that it was "outrageous that the full facts are not being set out so women could make informed decisions".

He said that rather than pushing women into aggressive treatment, more care should be structured around the "watchful waiting" approach for prostate cancers - with many men allowed to live with cancers, and often dying of unrelated causes.

"The number of invasive breast cancers being detected is not falling, despite the number of cases picked up by screening rising dramatically," he said. "You would expect serious cancers to drop because the early detection means the DCIS cases are not progressing. It just doesn't add up." Margaret McCartney, a GP in Glasgow and another signatory, said that the pros and cons of screening were not being relayed to her patients.

Women came to her surgery in great anxiety after a screening recall, without any idea of the fallibilities of the system through which they were being processed, she said. Others who signed the Times letter include public health specialists, epidemiologists, oncologists, GPs and patient representatives.

Professor Baum said that screening should be revised to focus on those at most risk through GP assessment, factoring in family history and demographic trends. "It is complacent and arrogant to think we should carry on regardless with screening services. It is time we had a complete rethink, but anyone who dares challenge the sacred cow of screening has a terrible time," he said.

Julietta Patnick, director of the NHS breast-screening programme, said that the leaflets were being reviewed. The programme was committed to helping women to make informed choices about their breast screening invitation, she said. "Part of this is helping them assess the risks and the benefits of screening for breast cancer.

"The screening programme produces a variety of leaflets and has an extensive website to provide the information that women need to make an informed decision." Peter Johnson, chief clinician at Cancer Research UK, said that while the presentation of information could be debated, it was dangerous to scare people away from a programme that had brought substantial benefits.

The NHS programme, which was started in 1990, invites women aged 50 to 70 to be screened every three years. It is being expanded to include women from the age of 47 by 2012 as part of the Government's Cancer Reform Strategy.
'I didn't know enough to decide'

When Hazel Thornton, a businesswoman from Rowhedge, near Colchester, was called in for breast screening she was assured of the importance of the procedure and of the NHS programme, then in its second year. Mrs Thornton, who was 57, received the traumatic news that an abnormality had been detected in the milk ducts of her left breast. She had no symptoms, but the mammogram showed a form of breast cancer called ductal carcinoma in situ (DCIS). She describes the process, after diagnosis, as like a conveyor belt. She was booked in for a biopsy and DCIS was confirmed. Mrs Thornton was then put on the drug tamoxifen, a form of hormonal therapy that is normally recommended for a course of five years.

"It's a diagnosis that stops you in your tracks," Mrs Thornton said. "I had survived malignant melanoma [skin cancer] earlier, so I was all for the early detection and treatment of anything.

"My mother had died of pancreatic cancer and my father died of colon cancer. I had seen what it could do. But I found myself on a conveyor belt, without Case study any of the information I needed to give informed consent to my treatment, and it was very difficult to get off it." With her family's experiences of cancer at the front of their minds, Mrs Thornton was persuaded by her daughter that daily drug treatment was the way forward.

She had nagging doubts, exacerbated by the limited information available to her, but without any other guidance, she took up the course. It had some unpleasant hormonal side-effects, and then, after 18 months, she decided to stop taking the drugs. More than 15 years later, Mrs Thornton, now 74, has yet to have any comeback from her cancer.

"It wasn't until some time later that I realised that it was impossible for me to have made an informed decision about my treatment," she said.
Mrs Thornton became a vocal campaigner for better information for women on all details of mammography - better-informed consent and fuller disclosure of the risks and benefits of breast screening for otherwise healthy women.

"The situation is very little better now than it was 20 years ago," she said. "Is the information given out now factual, accurate, evidence based? No, it isn't."

Telegraph, June 2008

'**Women with breast cancer can have unaffected life expectancy'**
Women with breast cancer whose tumour is detected early can survive as long as those without the disease. Analysis of the latest figures shows that if a cancer was small, low grade and had not spread to the lymph nodes, women were given a normal life expectancy if they remained clear for five years after treatment. Tumours which match that description account for 61 per cent of those spotted in the screening process.

The figures were from 2000/2001 and compared to results from screening in 1990/1, where it took 15 'clear' years for women to be considered as healthy as those who had not had cancer. Overall, the 15-year survival rate for England, Wales and Northern Ireland is at 86 per cent for invasive cancers which have spread beyond the breast. One of the biggest steps forward has been in reducing the number of mastectomies required.

In 2006/7 three quarters of invasive cancers were treated with breast conserving techniques. Also, of the 6,567 women with tumours smaller than 15mm, only 18 per cent required a mastectomy. The statistics were from the Association of Breast Surgery and the NHS Breast Screening Programme.

Professor Julietta Patnick, director of the NHS programme, said: "Huge strides have been made and more women than ever are surviving breast cancer. "Many of these have benefited from early detection through routine screening."

Martin Lee, president of the Association of Breast Surgery, said: "It is vital that women are aware of the excellent survival now achieve for breast cancers diagnosed through screening." Dr Gill Lawrence, director of the West Midland Cancer Intelligence Unite, which co-ordinated the audit, said: "The data clearly demonstrates significant improvements in the quality of the service women receive: from the reduction in the number requiring surgery for a definitive diagnosis of breast cancer; to an increase in the proportion of cancers diagnosed through screening."

She predicted that survival rates would continue to improve. NHS screening, which currently offers X-rays every three years to women between 50 and 70, is to be extended to those aged between 47 and 73.

BBC News, 26 February 2008

‘Cancer screenings have low uptake’
One in nine women will be diagnosed with the disease. More than a third of women in London who are eligible for breast cancer screenings fail to attend appointments, a report has revealed. Behind the Screen, a London Assembly report also shows that poorer women are less likely to go to screenings. Although older women in more affluent areas are most at risk of developing breast cancer, survival rates are lower in deprived areas. In 2005, 1,185 people from London died of breast cancer.

BBC News, 26 February 2008

'Low awareness'

The risk increases as women get older, with 80% of cases occurring in women over 50. Woman aged 50 to 70 are invited to attend screenings.

However, a government report released last year showed that only 64% of women invited to mammogram appointments in London attended, compared to the national average of 75%.

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Appendix 5: Recruitment Methods

NHS Haringey Breast and Cervical Cancer Screening Project

Generative Focus Group Recruitment

As part of the insight gathering our proposal suggested that four focus groups per project (total of eight) would be held to explore the lifestyles, habits and attitudes to health of women aged 25-65, that may have an effect on cervical and breast screening behaviour.

Focus Group composition and routes to recruitment were agreed with the project team on 6 October 2008.

Agreed routes to recruitment included:

- Approaching relevant community groups (contacts via Project Team and Haringey Council)
- Poster in GP surgeries/Pharmacies
- Letter to Practice Nurses

On 16 December 2008 the Project Team agreed to widen the focus group criteria to include women who had been screened previously but not within the past five years.

Recruitment activity took place as follows:

Focus Group Recruitment Poster Development

October 2008
- 14 October – Draft recruitment poster (for GP surgeries / Practice Managers) sent to Project Team for approval.
- 15 October – Revised poster sent to Project Team.
- 17 October – Further revised poster sent to Project Team.
- 22 October – Further revised poster sent to Project Team.
- 23 October – Final version sent to client for distribution to GP surgeries.
- 24 October – Allison Ferdinand confirmed poster distributed.

January 2009
- 18 December – Draft poster sent to Project Team (with additional routes to recruitment document following client meeting 16 December)
- 6 January – Revised poster sent to client for approval
- 9 January – Revised poster sent to client & PCT Communications Team for approval.
- 12 January – Revised poster sent to client for approval.
- 14 January – Poster approved.

February 2009
12 February – Revised poster sent to client and approved.

Advert Placement

October 2008

- Copy of poster on Council intranet (live 20 October for two weeks).
- Advert placed on Haringey PCT website.

Output - approximately 20 telephone enquiries were received following placement of the poster on the Council intranet. The Cervical Service User group was recruited primarily from this. All those who called (including those who did not meet all the criteria were Service Users).

November 2008

Advert placed in local free newspaper the Haringey Independent. This is delivered to all Haringey households.

Output - Approximately six telephone enquiries received following placement of the advertisement. None of the ladies who called were eligible to participate.

Contact with Community Groups

Approach undertaken was to call all relevant community organisations in Haringey. Discussion with group contact to explain the nature of the research, purpose and format of the focus groups and that we were looking for help recruiting women to the focus groups. For the majority of groups the preferred method of recruitment was to provide them with a poster that they could put up in the centre and use as a starting point to discuss the groups. Phone calls were followed up with an email to interested organisations providing the poster and again explaining the purpose and format of the groups. Hard copies of the poster were sent with an explanatory letter to any organisations that did not have email. Follow up calls to all organisations to ensure the poster has been displayed and enquire about any interest shown in the groups. Follow up calls at least twice a week for the next month:

The following Community Groups were contacted:

October 2008

Salvation Army
African Woman's Welfare Group
Equal Opportunities Commission (EOC)
Samaritans
Derman (Turkish group)
The Connection at St Martins
African Caribbean Day Nursery
Haringey Mothers Group
Mothers and Daughters Group
Netmums Haringey
Red Gables Family Centre
Surestart
Anteach Irish Housing Association
Chestnut Community Centre
Haringey Somali Community
Iranian Community Centre
Islamic Community Centre
London Islamic Cultural Society
Cypriot Elderly and Disabled Group
Haringey Consortium of Disabled People and Carers
Haringey Primary Care TrustPatient
Menopausal Helpline
Pyramid Health and Social Care Association
Well-Woman Clinic
Rights of Women
Great Lakes Initiative and Support Project
Haringey Council Corporate Procurement Unit
London Asian African Caribbean Centre
Women and Manual Trades
Asian Woman's Association
Asian Woman's Association for Sustainability
Bangladeshi Women's Association in Haringey
Better Life for Woman and Families
Age Concern
Greek Cypriot Woman's Organisation
Haringey Women's Forum
Northumberland Park Women and Children's Centre
Turkish Cypriot Women's Project
Turkish Woman's Philanthropic Association
Woman's Link

November 2008

- 6 November – additional contacts sent through by Client. Phoned and emailed all contacts provided by the client including the faith groups and followed the same process as above with the poster.
- 18 November – Update: the Outreach Workers have responded to say they think it's highly unlikely that the women they thought may be able to participate in groups have never been screened.
- 25 November – Update: there have been very few calls from the poster distribution, newspaper ad and through the community groups. Women who have been in contact do not fit the criteria. We have 4 people who are eligible across the groups.

December 2008

Poster was re sent to all the above organisations due to changes in focus group criteria as agreed with client. Follow up calls again to ensure poster display and inquire about any interest shown.

February 2009

Contact with key community groups still underway.

Newsletters

- Nursery group included the poster in their monthly newsletter which is sent to all.
- Mothers. Phone call to Councillor Sheila Peacock explaining the purpose of the focus groups. She then offered to include the advert in her weekly newsletters.

Output - there was very little interest from Community Group members – we received one enquiry from a lady who had seen the poster on display however she did not meet the group criteria.

Poster/Flyer Distribution

October 2008

- Letter and poster distributed to Practice Managers and Practice Nurses.
- Follow-up call to Practice Manager to confirm poster received and encourage display.

Output - 2-3 telephone enquires were received following display of the poster in GP surgeries. None of the ladies who called were eligible to participate.

November 2008

- 18 November – Letter and Poster re-circulated to all Practice Nurses and Practice Managers.
- 28 November – Pharmacy poster and cover letter sent to client for approval.
- Libraries - Poster distributed to local libraries in the East of the borough including Wood Green Central Library, Marcus Garvey Library and St Ann's Road Library.
- Follow up call to the libraries to ensure poster display and inquire about interest.
- Leisure and Community centres - Leisure and Community centres contacted and poster distributed. Again follow up calls to ensure poster display and inquire about interest.
- Poster displayed at Sexual Health Clinic in St Ann's.

December 2008

- 1 December – Distributed to Pharmacies.
- 8 December – Follow up call to confirm poster displayed.
- 3 December - 3 hours flyer distribution at Cancer Research Road show at Wood Green.

Output - 40-50 women approached, engaged with 10-15 majority of who had been screened for either breast or cervical cancer. A number of the women approached didn't have a high level of English and whilst there were a lot of BME women in the vicinity, a number were with male companions so it was not felt appropriate to approach them.

January 2009

- Team deployed for two days of flyering – areas covered included: Job Centres (including 'The Junction', based in Wood Green Library (High Road, Wood Green, London, N22 6XD) and Tottenham Marcus Garvey Library (Tottenham Green Centre, 1 Phillip Lane, London, N15 4JA))
- Libraries: Wood Green, Marcus Garvey, St Ann's (Cissbury Road, Tottenham, London, N15 5PU)
- Nail / Beauty Salons (High Road and side roads off, Wood Green / Lordship Lane and side roads off, Tottenham, in and around Tottenham Hale Tube Station Seven Sisters Road and side roads off), Green Lanes
- Hairdressers – to include Afro-Caribbean specific (all areas mentioned above – particularly High Road, West Green Road, Lordship Lane, St Ann's Road, Seven Sisters Road)
- Sexual Health Clinic (St Ann's Road, off Seven Sisters Road)
- Tottenham Fish Market – Tottenham High Road
- Retail centre near Tottenham Hale Tube Station.
- Supermarkets (Lordship Lane, Tottenham / In and around Tottenham Hale Tube Station / High Road, Wood Green / Seven Sisters Road / Green Lanes – major chains plus Asian / African supermarkets)
- Community Centres targeted (concentrating on Wood Green & Tottenham):

  African Women's Welfare Group
  Alhijra Somali Community Association
  Derman Bridge
  Selby Centre (covers a large number of BME Community Groups)
  Council of Asian People
  Haringey Law Centre
  Haringey Women's Forum
  Integration Centre for Ivorians
  Mothers and Daughters Support Group UK Limited
  Rinnah Organisation
  Sierra Leone Family Welfare Association
  Somali Bravanese Association in London
  Tiyeseko Development Association
  Turkish Cypriot Community Association

Output - total Output - total number of calls received was 10.

February 2009

- Agreement to carry out depth interviews.
- Contacted Caribbean community centre who had initially shown interest but been put off by the group format.

- Agreed to carry out depths at the centre.
- Meeting with Leila Laksari to help arrange White British/white other Breast screening DNA group. No eligible women.
- Dr Dowler to provide Barkers details to eligible patients. No eligible women contacted as a result

March 2009
Visits to Caribbean community centre to carry out depths covering DNA Afro-Caribbean (Breast and Cervical) and DNA 'young' group

NHS Haringey contacted a number of GP surgeries in Haringey to request their assistance in recruiting for the White British and White Other Breast Screening DNA group. They contacted eligible women on their DNA list and asked if they would like to participate in a discussion. Six contacts were provided, however only two these were eligible for the group, both of whom could not attend (illness & holiday). The remainder of the proposed participants had attended screening within the last few years, or did not fit the ethnic criteria for the group.

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Improving Acceptance of Breast Screening: The Challenge for London

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Improving Acceptance of Breast Screening – The Challenge for London

Executive Summary

Improving uptake of breast screening as one of the potential life-saving health services offered to women is very important. The aim of this report is:

- To explain why London's' breast screening uptake is low
- To identify key roles and responsibilities for the programme and other organisations involved
- To identify evidence-based intervention

Five of the most important initiatives and/or necessary requirements are:

1. Availability of resources
2. Working on round length correction.
3. Sending 2nd time appointments for non-attenders.
4. Conducting 'never screened initiative'.
5. Identification of the scale of private mammograms in London

Many good initiatives and service improvements can be carried out to make screening as accessible as possible to the population they serve. Nevertheless what needs to be recognised is the fact that some women exercise choice by not accepting their routine screening invitations.

Introduction

Many changes have taken place following Shifting the Balance of Power (StBOP) in the NHS since 2002. In London the then 16 existing Health Authorities developed into 32 Primary Care Trust (PCTs) and 5 Strategic Heath Authorities (StHA) were created.

The recent publication of the Chief Medical Officers Report (DoH, 2003) as well as the Commission for Health Improvement (CHI) NHS performance ratings clearly outlined that breast screening in London is not as well attended as elsewhere in the country and falls short of reaching national targets.

This has triggered an awareness and need to identify the reasons and possible solutions to improve the acceptability of preventative health services such as breast and cervical screening offered in London. The Quality Assurance Reference Centre (QARC) has acted on this need a produced this report, which gives a brief outline on the problems, and offers some solutions.

NHSBSP

The purpose of the breast screening programme is to reduce the morbidity and mortality from breast cancer. The National Health Service Breast Screening Programme (NHSBSP) routinely invites all women aged between 50-64 for a free mammogram. From 2004 the upper age range will be extended from 64 to 70.

The success of the NHSBSP is dependent on a high proportion of women attending for screening and re-attending in subsequent rounds. The programme must reach all eligible women irrespective of their socio-economic status; race or any special needs requirements

The uptake of the screening programme in England during 2001-02 was 75.6 per cent (DoH, 2003). In London it was considerably lower (63 per cent). The NHSBSP minimum standard of the percentage of eligible women to attend for screening is currently 70 per cent (NHSBSP, 2000).

For clarification: '*The uptake of the screening programme is the proportion of women invited for screening for whom a screening result is recorded' (DoH,* 2003).

What does the screening pathway entail?

Breast Screening is a cyclical programme, which involves all eligible women being routinely invited for a free NHS breast screen every three years. At the breast screening unit (static or mobile vans) a trained radiographer and/or assistant practitioner takes X-rays of the breast. The films will be developed and then examined for potential abnormalities in the breast tissue by two specialists' radiologists or film readers. Women whose mammogram is identified as 'abnormal' then need to undergo further investigation, known as 'assessment' or second stage screening, to obtain a diagnosis. If the abnormality is confirmed to be malignant will be treated through a variety of means (surgery, radiotherapy or drug therapy). If a mammogram is normal, the woman is returned to the routine recall system, and will be invited for another screening test three years later.

Breast Screening Services in London

There are currently seven Breast Screening Services in London, which are:

1. Barking, Havering & Brentwood Breast Screening service (BHBBSS)
2. Central & East London Breast Screening Service (CELBSS)
3. North London BSS (NLBSS)
4. South East London Breast Screening Service (SELBSS)
5. South West London Breast Screening Service (SWLBSS)
6. West of London Breast Screening Service (WOLBSS)
7. Whipps Cross Breast Screening Service (Whipps Cross BSS)

Approximately 22,000 eligible women who are resident in London (in the Redbridge area) are served by Epping BSS. Also some Breast Screening Services serve women outside London.

- 23,000 women from South West Herts are currently served by North London Breast Screening Service
- 9,000 women from Brentwood are currently served by Barking, Havering & Brentwood Breast Screening Service and
- 9,000 women from North West Surrey are currently served by West of London Breast Screening Service.

That means that approximately 19,000 eligible women, who are resident outside London, are served by a Breast Screening Service in London.

Breast Screening Services Uptake Problems

It is well acknowledged that the population in London differs from areas elsewhere in the country.

Six of the most cited difficulties are:

1. High population mobility
2. Population diversity
3. Areas of deprivation
4. Recruitment difficulties within the NHSBSP workforce
5. Accessibility
6. Private mammograms

1. High population mobility

There are difficulties in maintaining accurate patient data in a mobile population, which has a detrimental impact on maintaining continuous health care services. For instance, women who move away and fail to register with a new GP could slip through the established safety net and can therefore not be contacted which may result in women missing their routine breast screening invitation. It has been postulated by Millett et al (2002) that up to 11% of patients on GP lists may miss out on invitations for cervical screening. Arguably, this has a smaller impact on breast screening given that the screening population is older (currently the eligible age group range is 50-64) in comparison to cervical screening (currently the eligible age group range is 20-64)

2. Population diversity

Over 300 languages and dialects are spoken in London (DoH, 2002). English is an additional language for 43% of school-age children in inner London. It is well acknowledged that language and translation needs are not always met and this is a major barrier for London's increasingly diverse population (Greater London Authority, 2003). This means that many women who are invited for their routine breast screening may not be able to read nor understand the invitation or the accompanying leaflet.

The mandatory national leaflet: 'Breast Screening – THE FACTS' aims is to provide women with honest information about the benefits and limitations of breast screening. It was hoped that providing information would help women to make an 'informed choice' as to whether or not to accept or decline their invitation for breast screening.

The NHSBSP has acknowledged the limitation of these leaflets in the light of the diverse population within the United Kingdom (UK) and has therefore had them translated into 17 other languages with some only available as hard copy whilst others can be downloaded directly from the Internet. Although the leaflet is available in the different languages, it is not routinely included with

women's breast screening invitation and reminder letters. Screening offices have no methods or tools of identifying a woman's ethnicity prior to her invitation.

3. Areas of deprivation

London is particularly polarised in terms of extreme wealth and poverty. Three of the five most deprived boroughs in England are in London (DoH, 2002).

Additionally, the rate of unemployment across London is 7.5 per cent (ONS, 2002) with 6 boroughs reaching unemployment levels above 10 per cent.

These are:

1. Tower Hamlets 12.3%
2. Hackney 12.2%
3. Newham 11.7%
4. Southwark 10.7%
5. Haringey 10.4%
6. Lewisham 10.3%

Empirical evidence indicates a relationship between levels of deprivation and uptake of preventative health services. Murray and McMillan (1993) demonstrated that women with employment outside the home were more likely to attend for smears than women employed within the home. The high unemployment rate in London coupled with a high level of deprivation is an additional burden on health care service providers they have to overcome for reaching the population they serve.

4. Recruitment difficulties within the NHSBSP workforce

An ongoing and well-known difficulty within the screening programme is staff 'recruitment and retention'. High levels of staff vacancies, particularly long-term vacancies, hinder high-quality service delivery as well as the implementation of the NHSBSP programme extension. Staff shortages also mean a heavier workload for remaining staff, which can affect morale and motivation and lead to staff leaving as well as an increase use of agency staff (Buchan et al., 2002).

The Quality Assurance (QA) team is currently conducting a survey, which looks at morale & motivation within the mammographer workforce in London. Good customer care is essential with staff, who take the time to listen to women's' worries and concerns. It is therefore suggested that future studies should investigate the level of stress in the NHSBSP workforce and the effect it may have on customer care.

5. Accessibility

On the 28th August 2003, the South West London Breast Screening Service opened a static screening site in a department store (Alders) in Croydon, which is the first in the country. This is a superb example of a new and innovative way to make screening more accessible to women. Other breast screening service providers may learn from this example and try to explore different locations where static or mobile vans could be situated. Without question, finding suitable sites is very difficult and time consuming. However in order to meet the needs and expectations of all our service users we must strive to identify new screening locations which are more suitable for all our users.

6. Private mammograms

There is some evidence that in some parts of London, particularly the more affluent areas, up to 25% of eligible women are having private mammograms taken. The true scale of this is currently unknown and there is an urgent demand to fully explore this issue.

Roles and Responsibility for Breast Screening: 3 Levels

1. Strategic/Regional Level: Roles and Responsibilities

- **StHA Platform**

StHA have the role to performance monitor PCTs who are in turn responsible for ensuring that a high quality breast screening programme is delivered to the population they serve.

- **Cancer Network Platform**

The role of the Cancer Networks is to implement the NHS Cancer Plan, which includes breast screening targets.

Please note that two out of five Cancer Networks in London identified 'tackling inequalities' and health promotion/education issues within screening as one of their top priorities (3 September 2003). See Appendix I, which provides a copy of the cancer – top priorities from London's Cancer Networks.

- **Breast Screening Commissioning Platform**

A London-wide Breast Screening Commissioning group, facilitated by the QA team, meets every three months in order to discuss issues on breast screening. Topics, which are addressed, involve finance and performance monitoring data such as round length and waiting times.

- **Regional Health Promotion/Consumer Affairs Group**

The aim of the group is to ensure that all of the activities in relation to Breast Screening contribute cost-effectively to improve Breast Awareness & Breast Screening and support women in their decision to make an informed choice of whether or not to attend their breast screening appointment. Please look at Appendix II, which provides a copy of the 'Terms of Reference ' (ToR) of the group.

This group is unique in its existence because nowhere else in England is there a health promotion group, which focuses solely on breast screening.

In order to get a bigger picture on 'uptake' issues, the QA team has produced a discussion paper, which was circulated through the group to identify attitudes and knowledge regarding uptake. Some of the findings are discussed in this report. Appendix III provides a copy of the 'discussion paper'.

2. Breast Screening Service Level: Role and Responsibility

Breast Screening Services have to ensure that they provide a service that is sensitive to the needs of the population they serve.

In terms of health promotion arrangements, one of the biggest deficits is that there are only a few Breast Screening Services in London who have the support of Health Promotion Advisors or Specialists. Also within most screening teams the person; with responsibility for health promotion is not trained in the field and has no dedicated time or resources.

3. Local Primary Care Level: Role and Responsibility

3.1. PCT

As a result of StBOP, the responsibility for commissioning breast screening lies within PCTs. They have to ensure that an adequate service specification between them and the breast screening service is in place. The performance of the screening service will be monitored by the PCTs.

3.2. Local Health Promotion Departments

The current situation on health promotion activities is unclear across London. For instance the former West London Health Promotion Agency has been devolved on a PCT and it is appears to be the case that the expertise in supporting breast screening as been lost.

3.3. Local Delivery Plan (LDP)

As part of the planning process for '*Improvement, Expansion and Reform: The next three years. Priorities and Planning Framework 2003-2006*' (DoH, 2002), Strategic Health Authorities (SHAs) are required to produce Local Delivery Plans (LDPs) in conjunction with their Trusts, Primary Care Trusts (PCTs) and Workforce Confederations. That means that whilst the LDP will cover a whole Strategic Health Authority area it will at the same time be based on PCT local plans. In some areas the Health Development Agencies (HDAs) are asked to contribute directly or indirectly to this process.

Improvement in breast screening uptake locally can only be achieved by addressing these issues adequately in the local LDPs.

Initiatives to improve uptake

Initiative to improve uptake from the strategic/regional level:

It is proposed to conduct a London-wide media campaign using London Transport (buses) driving through outer and inner London and advertising Breast Screening in London. This should be coupled with a poster campaign, which should be displayed at various locations such as GP practices, leisure centres and libraries. This is of importance because at present there is no national or regional poster promoting breast screening.

A second Londoner initiative suggested is to conduct a 'never screened initiative' which should be based upon the London cervical screening 'unscreened women project.

This was organised by the QA team for Cervical Screening in London, and it targeted women who never had a cervical smear test. This project was successful in various aspects. One of its successes was improvement of coverage for women in the age cohort 40-65. A second success was the project's list cleaning ability.

A third success of the 'unscreened women project' was that it identified women who should have been ceased due to clinical reasons. It is hypothesised that a similar project for breast screening will achieve good results.

Initiatives to improve uptake from the breast screening service level:

- **Second timed appointments**

In order to improve uptake in Breast Screening, one suggestion is to send a 'second timed appointment' letter to women who did not attend for their routine breast screening after they received their initial invitation. Stead et al

(1998) found a significant difference in response to a second invitation between the open invitation and fixed appointment letter. However, only two out of the seven existing Screening Units send 2nd time appointments. Some have piloted it whilst others decided to stop sending 2nd time appointment letters due to low response rate from women.

- **Pre-invitation letter**

It has been postulated that sending a pre-invitation letter will improve breast screening acceptability. In London, three out of the existing seven BSS send pre-invitation letters to women. These letters are sent to women to notify them that they will shortly receive their routine breast screening invitation. A short message about breast screening is also included.

- **Attenders Survey**

The uptake rate is not the only indicator of the quality of service provision. Another indicator is asking actual service users for their perception of service quality, which also provides direction for those responsible for improving the service**.**

- **Non-attenders Survey**

A non-attenders survey has not been conducted in recent years. However, the Quality Assurance Reference Centre (QARC) has recently decided to carry out a non-attenders survey and this is currently in the development stage.

- **Primary Care Information Pack**

Shortly before screening commences in each particular area, General Practitioners (GPs) are sent comprehensive 'Primary Care Information Packs' which contain information such as posters and leaflets for the practice staff.

All but one Breast Screening Services send 'Primary Care Information Packs' to the General Practitioners (GPs). The one Screening Service who does not send detailed information to GPs was in response to a request after they surveyed GPs and identified that they do not wish to receive detailed information.

- **GP feedback**

All but one Screening Service sends GPs feedback information, usually about six months after finishing screening in their area. This informs GPs about how many of their female patients attended for breast screening.

- **Press release prior screening**

Sending press releases using local newspapers to inform women that screening will commence shortly in their area is not done routinely by all Screening Services

- **Women with learning disability**

Women with learning disabilities have the same rights of access as all other women to the NHSBSP (NHSBSP, 2000). The NHSBSP has issued a guide 'Good Practice in Breast and Cervical Screening for Women with Learning Disabilities' (2000). However, despite this useful aide, often women with learning disabilities do not attend for their screening.

Some screening services in London provide voluntary transport to the screening site whilst another screening service works with a 'learning disability team' directly. However, there is scope for improvement in order to reach more women with learning disabilities.

- **Collecting ethnic data**

Ethnic data on women who attend for their routine breast screening is currently collected by all Screening Services. However, there exists some uncertainty as to what to do with the data. Clearly, there is an urgent need for guidance. The QA team is currently in the process of developing guidelines.

- **Round length**

Currently the breast screening interval is set at 36 months. Eligible women should be offered an appointment, which ensures that they are screened at an interval of not more than 36 months. A delay in round length has a negative impact on coverage figures. Also, London's recruitment and retention difficulties within the NHSBSP workforce and the suspension of three breast screening services over recent years have had a negative impact on round length.

The minimum national standard is that 90 per cent of women should be re-invited within 36 months of their last screen (NHSBSP, 1998).

A delay in round length also has a negative impact on the effectiveness of the local breast screening programme.

- **Multi-lingual Breast Screening leaflets**

Currently NHSBSP guidance is that all women have to receive with their invitation the NHSBSP Breast Screening: THE FACTS leaflet in English. Undoubtedly, the leaflet provides information about the benefits and limitations of breast screening. However, the leaflet cannot reach women who

are unable to read English. It is therefore proposed that the national leaflet should be modified in a multi-lingual format, which could be sent to women with their breast screening invitation. A consideration about the consequent increase in postage (due to heavier weight) and modification on the envelope stuffing/folder machine needs to be made. A possible way forward would be to include an information sheet advising them if they wished to obtain the leaflet in another language to tick the appropriate box and return the leaflet in the pre-paid envelope provided to the breast screening unit. The sentence could be in however many languages were available.

- **Intervention study based on the research project from Rutter et al (2002)**

The intervention consisted of a small paragraph asking women to make specific plans (travel arrangements, taking time off work and changing their screening appointment) if the proposed date was inconvenient for attending the breast screening unit. One of their findings was that this simple intervention increased the uptake of breast screening. They recommended that the NHSBSP should 'field trial' the project in an area with low uptake.

QA suggests that this project should be carried out within the Breast Screening Service in London. Consideration needs to be given in terms of flexibility in the invitation letter, as there is currently only limited free space available to add an extra paragraph.

Initiatives to improve uptake from the primary care level:

- Adequate funding for breast screening services
- Annual action plans should be developed by PCTs Screening Leads to outline what they intend to do to improve and maintain coverage and uptake
- LDPs need to include coverage/uptake initiatives and support
- Support and co-operation with local Health Development Agencies and/or Health Promotion Departments
- Conducting 'refresher course' or 'introductory courses' for new members practice staff possibly sector-wide in regular intervals.

Summary

The uptake of breast screening in London is considerably lower than the rest of the country. The team from the QARC looked at ways in which acceptance of breast screening service could be improved and ways in which to address the changing needs of its diverse population.

It is proposed that working in partnership across the three levels (strategic/regional, breast screening service and primary care level) needs to be improved. The awareness and understanding of the issues surrounding breast screening needs to be addressed on all levels.

Actions and interventions are required to maximise breast screening uptake. These have been discussed throughout this report. It is of importance to point out that the suggested initiatives discussed in this report are by no means the only solutions to improve uptake.

Chief Executives of all five StHA should be fully informed of the breast screening commissioning arrangements for the programme.

Finally, one of the biggest issues is funding and training. Without resources there is no real possibility of making any noticeable progress. With long-term adequate funding will come stability and with stability will come the opportunity to monitor trends and progress and to respond to opportunities as they arise.

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Appendix I

Cancer Top Priorities

Appendix II

Copy of the 'Discussion Paper'

Appendix III

Copy of the Terms of Reference

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