



## Scrutiny Review of Breast Screening Services in Haringey



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**A REVIEW BY THE OVERVIEW AND SCRUTINY  
COMMITTEE**

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## **Foreword**

In 2007 over 45 000 people were diagnosed with breast cancer.

The effects on the individuals and their families and friends is devastating and incalculable. However, like so many other cancers, early detection can increase the survival chances considerably. It is estimated that 1,400 lives are saved each year through the operation of the National Breast Screening Programme.

This scrutiny review set out to examine the reasons why women in Haringey tended to make less use of the North London Breast Screening Service (NLBSS) than their sisters in many other parts London. Working with health professionals and women themselves, our review panel looked at a wide variety of possible reasons why and have come up with a range of recommendations, most of which we feel will not only improve take up rates, but also represent value for money.

The publication of this review also coincides with the digitalisation of the NLBSS. It is expected that this will enable more sensitive imaging help improve quality assurance processes by enabling the comparison of past and present images.

While chairing this review I and my colleagues have been impressed by the depth of knowledge and commitment of those who work in the service and the broader NHS. I would like to thank them for the time and advice they gave our Panel.

I must also thank my fellow councillors who contributed so much, Martin Bradford our excellent support officer and, of course, all the women of Haringey who offered their opinions and ideas on how to improve the Service.



**Cllr Winskill (Chair of the Scrutiny Review Panel)**

**Other members of the review Panel:  
Cllr Alexander, Cllr Beynon, Cllr Bull.**

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## 1. Executive Summary

- 1.1 Over 45,000 women are diagnosed with breast cancer each year which makes this one of the biggest causes of cancer among women in the UK. Although there have been significant improvements in the detection and treatment of breast cancer, it is still a major cause of adult female mortality: approximately 12,000 women died from breast cancer in 2007 alone.
- 1.2 The National Breast Screening Programme (NBSP) was launched in 1988, and today, screens nearly 2 million women each year. The introduction of the breast screening programme has led to the earlier detection of breast cancers which has helped to improve treatment options and survival rate for those women diagnosed with this condition. It is estimated that 1,400 lives are saved each year through the operation of the NBSP.
- 1.3 Breast screening services in Haringey are commissioned by a consortium of local PCTs (including NHS Haringey) and services provided through the North London Breast Screening Service (NLBSS). As a result of the temporary suspension of this service in 2006/7, an extended round length was agreed for the service which meant that women were screened every 46 months instead of the nationally agreed standard of 36 months. As a result, the breast screening coverage (the proportion of women who have had a breast screen in the previous 3 years) in Haringey is low at just 51%, the second lowest nationally.
- 1.4 Like many other London boroughs, there is a poor uptake to breast screening invites in Haringey. In 2008/9 just 55% of women in Haringey who were invited actually attended for a breast screen. This was also a 4% decline on the uptake for breast screening invites in Haringey for 2007/8. What is clear, is that both nationally and locally breast screening uptake has been broadly static for a number of years, which would suggest that positive interventions are necessary to help increase the number of women who attend for screening.
- 1.5 The key function of any health screening programme is that it appropriately targets the population most at risk and encourages them to screen, in this case women aged between 47-73 years of age. A high uptake for screening services is also important as it is integral to the effective and efficient operation of screening services. Areas where screening services have a low uptake may exacerbate local health inequalities.
- 1.6 The Overview & Scrutiny Committee at Haringey Council commissioned a review of breast screening services to help identify ways in which local breast screening performance could be improved. As part of the review process the panel:
- heard evidence from local commissioners, breast screening providers and local GP collaborative lead
  - heard evidence from specialist screening agencies
  - consulted local women who had used the breast screening service

- visited the local breast screening service.

- 1.7 The review received evidence from a range of sources which suggested that there were a number of interplaying factors which may influence a woman's decision to take up their invite for breast screening. Although the panel identified the need for further local research a number of themes were identified which influenced the uptake of breast screening services:
- structural issues– development of screening lists, call and recall system
  - operational issues – location of clinics, appointment times, availability of out of hours services
  - socio-demographic issues – age, ethnicity, social deprivation
  - personal attitudes – individual anxiety, perceptions of individual risk
- 1.8 The panel noted that work was already being undertaken locally to help improve breast screening uptake, most notably the Social Marketing project and the Health Trainers project, but these projects were in their infancy and had not resulted in practical changes as yet. The panel also welcomed the development of the Breast Screening Action Plan with NHS London, and hoped that this would provide local impetus for prioritising and coordinating efforts to improve breast screening uptake in Haringey.
- 1.9 The panel highlighted a number of areas where it was possible to identify a number of interventions which may help improve the uptake of breast screening services in Haringey. The panel have made a number of recommendations in three key areas:
- improved accessibility of breast screening clinics
  - greater involvement of primary care in the breast screening process
  - the need to develop more localised public health information and awareness of breast cancer.
- 1.10 The panel were mindful of the fact that public finances would be tight in future years and that additional resource to drive improvements may be limited. To this end, the panel have sought to identify recommendations which do not need additional resources, though acknowledged that additional investment may be needed to bring about sustained improvement in breast screening uptake. Similarly, the panel indicated that there were as yet untapped opportunities for further involvement of the wider strategic partnership in developing breast screening uptake, and it is suggested that the newly developed Breast Screening Action Plan provides the kernel for developing a more inclusive and borough wide strategy.
- 1.11 Screening has the potential to make a significant contribution to the early diagnosis and treatment of breast cancer and can best be achieved through uptake strategies that emphasize wide coverage, improved access and equitable distribution of cancer screening services. It is intended that the following report and recommendations contained within it, will guide and inform the development of local strategies to improve breast screening uptake among women in Haringey.

## 2. Recommendations

- 2.1 Understanding why women do not attend for breast screening (DNA) is of critical importance to improving screening uptake, to this end, the panel recommended that NHS Haringey should conduct regular research with the screening population to help identify screening needs and the barriers that local groups and communities face in accessing screening services.
- 2.2 The panel recommended that NHS Haringey should ensure that more effective use is made of the lists of women who have not attended for breast screening (DNA reports). As per Westminster Model, NHS Haringey should consider commissioning GPs or local Public Health services to actively follow up non-attendees.
- 2.3 To assist with the identification and analysis of factors that contribute to compliance with breast screening, the panel recommended that there should be improvements to the way that data is collected, collated and analysed of women who **do** attend, particularly in relation to the ethnicity of attendees and other socio-demographic factors (age-group, postcode).
- 2.4 To ensure that breast screening lists are accurate and up to date, the panel recommended that GPs undertake regular, systematic and specific data cleaning to ensure that all eligible women are included in screening lists. (NHS Haringey may wish to consider this as part of a wider Local Enhanced Service for GPs).
- 2.5 The panel recommended that NHS Haringey ensure that there is adequate and fully validated information flow (e.g. eligible population lists, uptake, coverage) between key stakeholders (NHS Haringey, NLBSS and local GPs) in the breast screening pathway and that this informs local initiatives to tackle low screening uptake (i.e. at specific practices).
- 2.6 To ensure that there is adequate patient feedback in to the breast screening commissioning cycle and to help benchmark quality performance, the panel recommended that independent randomised patient satisfaction audits should be undertaken on an annual basis which should explicitly assess service accessibility (and other patient experience data).
- 2.7 To help improve service accessibility for those women who do not speak English, the panel recommended that NLBSS amend the breast screening invite to include a short statement in relevant community languages which refers service users to where they may obtain further breast screening information (this could be done in conjunction with other screening units).
- 2.8 To help improve information available to women prior to screening, the panel recommended that NLBSS amend the breast screening invite to signpost women to the NLBSS website where more detailed information about breast screening can be obtained (on screening location, making and changing appointments and information in community languages).

- 2.9 The panel noted that the invite was of critical importance to service accessibility and as such recommended NLBSS fully test the invite for readability, understanding and relevance on an ongoing basis.
- 2.10 To improve accessibility to breast screening clinics, the panel recommended that NHS Haringey should commission a feasibility study to assess potential suitable breast screening sites in Haringey. In particular this study should assess:
- shorter-term options for developing mobile screening unit access at neighbourhood health centres (polyclinics) and other community locations
  - longer-term options for the development of a static screening site in a central Haringey location.
- 2.11 The panel recommended that NHS Haringey/ NLBSS consider ways in which access to out-of-hours breast screening appointments can be improved for women resident in Haringey, in particular, to develop out-of hours access to sites within the Haringey locality (or neighbouring borders such as NMH, Whittington or Forest Road Polyclinic).
- 2.12 To support local primary care involvement in breast cancer screening the panel recommended that, and in line with other neighbouring primary care organisations, NHS Haringey should consider the implementation of a Local Enhanced Service for Breast Screening. This could be developed on the Westminster model to incentivise general practice to:
- appoint a GP screening lead in each practice
  - issue pre-invitation letters to screening population
  - develop list cleaning procedures
  - undertake training prior to breast screening round
  - promote breast screening during screening during round
  - systematically contact non-attendees at breast screening clinics (or other body named in 2.2)
- 2.13 To support the identification and dissemination of good practice, identification of training needs and effective cascading of breast cancer screening information, the panel recommended that a network of breast cancer leads are identified across the borough: at PCT wide level, local collaborative and individual General Practice level. The panel recommend that screening leads convene biennially.
- 2.14 The panel noted the importance of developing breast screening interventions that are both effective and sustainable, to this end, the panel recommended that a second timed appointment is routinely sent out to non-attendees at the breast screening unit.
- 2.15 To support population wide initiatives to improve breast screening uptake, it is recommended that a programme of community interventions is commissioned by the NHS Haringey, which seek to raise awareness of breast cancer, publicise the benefits of screening and provide interventions which target and promote uptake amongst those women known not to attend breast screening

(i.e. black and minority ethnic groups), or who are at particular risk of developing breast cancer (i.e. Ashkenazi Jewish), where uptake is low (known GP practices) or are particularly vulnerable (women with a learning disability or mental health problem).

- 2.16 To support community interventions to improve breast screening uptake, the panel recommended that newly appointed Local Health Trainers liaise with individual practices at an early stage in the screening round to undertake targeted development and awareness work with community groups and among eligible women in that practice area.
- 2.17 The panel welcomed the development of the Breast Cancer Screening Action Plan which is to be agreed and monitored through NHS London. The panel felt that this process could be supported further through the development of a more localised breast screening action plan which:
- defines how local partners and other community stakeholders can support the improvement of screening uptake
  - establishes clear priorities for directing local action and resources to improve screening uptake
  - sets clear targets and milestones for improving screening uptake.
- 2.18 Whilst there is sufficient capacity for the planned age extension for breast screening (47-73 years by 2012), the panel recommended that NHS Haringey (with other commissioners) should assess future demand and capacity at NLBSS to reflect future demographic changes and anticipated improved screening uptake.

### 3. Introduction

- 3.1 Breast cancer is the most common cause of cancer amongst women where approximately 45,000 are diagnosed with this condition each year. To help early cancer detection and to improve health outcomes, women aged between 50 and 70 years are invited for a breast screen via the National Breast Screening Programme (NBSP) every 3 years. Almost two million women are screened each year within this programme and it is estimated that this process helps to save up to 1,400 lives annually.<sup>1</sup>
- 3.2 For screening programmes to be both clinically and cost effective, it is important to ensure that as many of the target population as possible are invited for screening and encouraged to take up that appointment offered. It has been noted that screening programmes which have a low uptake can be less effective and may exacerbate inequalities in health-service provision.<sup>2</sup>
- 3.3 As a result of a number of serious untoward incidents<sup>3</sup> and safety concerns at the NLBSS, the decision was taken to temporarily suspend this service in 2006. Although the service reopened in May 2007, this was a phased reintroduction of services where breast screens were agreed to be offered at 46 months intervals instead of the national standard of 36 months.
- 3.4 The period of closure and the phased reintroduction of screening services have impacted on the breast screening performance in Haringey, particularly the breast screening coverage.<sup>4</sup> In 2008/9 the breast screening coverage for Haringey was 51% which was significantly below comparative figures for both London (65%) and England (76%) and was the second lowest nationally.<sup>5</sup>
- 3.5 The proportion of women who are invited for a breast screen who actually attend their appointment is also known to be low across in Haringey. In 2008/9, just 55% of women invited for a breast screen in Haringey attended, which was significantly below the national average (74%).<sup>6</sup>
- 3.6 Against this backdrop, the Overview and Scrutiny Committee commissioned an in-depth review of local breast screening service provision, in particular to assess how the uptake to breast screening services could be improved in Haringey. This report details the work of the review panel and the conclusions and recommendations made on assessment of the evidence it has received. It is hoped that the recommendations within this report will guide and inform local service commissioning to help improve breast screening uptake in Haringey.

### 4. Background

<sup>1</sup> Screening for Breast Cancer in England: Past and Future, Advisory Committee on Breast Cancer Screening NHSBSP Pub. No 61 (2006)

<sup>2</sup> Weller et al (2009) Uptake in cancer screening programmes *Lancet* 10 (7) 693-699

<sup>3</sup> A serious untoward incident is an event which has serious repercussions for a patient, employee or member of staff for whom the NHS has a duty of care.

<sup>4</sup> The coverage is the target population who have screened in the past 3 years i.e. women aged 50-70.

<sup>5</sup> National breast screening data 2008/9 [www.cancerscreening.nhs.uk](http://www.cancerscreening.nhs.uk)

<sup>6</sup> National breast screening data 2008/9 [www.cancerscreening.nhs.uk](http://www.cancerscreening.nhs.uk)

### Epidemiology breast cancer

- 4.1 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 untreated, breast cancer can also spread (metastasis) through the blood stream to other parts of the body.
- 4.2 Breast cancer accounts for 31% of all female cancers and is the most common cause of cancer among women in the UK. Although men may also develop breast cancer, this accounts 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.<sup>7</sup>
- 4.3 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. 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 largely been due to improved detection through the introduction of the NBSP.<sup>8</sup>
- 4.4 **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 550,000 women in the UK surviving with breast cancer which equates to 2% of the total female population or 12% of the adult female population over 65.<sup>9</sup>

### *The risk factors associated with breast cancer*

- 4.5 There are a number of risk factors associated with the development of breast cancer. The main risk factors are summarised in the table below.

<b>Risk factor</b>	<b>Detail – breast cancer risk.</b>
<b>Gender</b>	Women are 100 times more likely to develop breast cancer than men.
<b>Age</b>	81% of breast cancers occur in women over the age of 50 <sup>10</sup>
<b>Childbearing (parity)</b>	Child bearing women have a 30% lower risk <sup>11</sup> and have greater protection through the number

<sup>7</sup> UK Breast cancer incidence statistics. Research UK (data from 2001-2005) June 2009

<sup>8</sup> CancerStats Breast Cancer UK Cancer Research UK May 2009

<sup>9</sup> CancerStats Breast Cancer UK Cancer Research UK May 2009

<sup>10</sup> Cancerstats Key Facts Cancer Research UK (2010)

<sup>11</sup> 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.

	of children they have and the earlier at which child birth starts. <sup>12</sup> Uptake and duration of breastfeeding also reduces risk. <sup>13</sup>
<b>Hormones</b> Hormone Replacement Therapy (HRT) and Oral Contraception (OC)	Early menarche and late menopause are associated with increased breast cancer risk. <sup>14</sup> Women on HRT have an increased risk of 66%. <sup>15</sup> Women taking the OC have an increased risk of 24%. <sup>16</sup>
<b>Family history</b>	Women with a first degree relative with breast cancer are twice as likely to develop cancer as those with no family history. <sup>17</sup>
<b>Lifestyle</b>	Women living in more <b>affluent</b> areas may experience up to 20% increased risk than those living in deprived areas. <sup>18</sup> Post menopausal women who are <b>overweight</b> or <b>obese</b> have an increased risk of between 10-30%. <sup>19</sup> The link between <b>alcohol</b> and breast cancer is causal <sup>20</sup> where 11% of the total annual incidence attributable to its consumption. High levels of <b>physical activity</b> can reduce risk by between 20-40%. <sup>21</sup>
<b>Ethnicity</b>	A 1.5 fold increase in risk is recorded among Ashkenazi Jewish population. <sup>22</sup>
<b>Sexuality</b>	Lesbian women exhibit different risk factors which has produced a higher level of overall risk. <sup>23, 24</sup>

#### Breast Cancer treatment and care

4.6

The treatment for breast cancer will depend on the stage of development at which the cancer has been detected, the age of the patient and the size of the tumour. A combination of surgery and radiotherapy is the most common

<sup>12</sup> 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

<sup>13</sup> 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

<sup>14</sup> Breast cancer and HRT collaborative reanalysis of 51 epidemiological studies. Collaborative group on hormonal factors in breast cancer The Lancet 1997 (350)1047-59.

<sup>15</sup> 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.

<sup>16</sup> Breast cancer and HRT in the million women study The Lancet (2003) 363 419-427

<sup>17</sup> Family breast cancer: collaborative reanalysis of individual data from 52 epidemiological studies The Lancet 2001 (358) pp1389-99

<sup>18</sup> Cancer incidence by deprivation 1995-2004) National Cancer Intelligence Network 2008

<sup>19</sup> Reeves et al, Cancer incidence and mortality in relation to Body Mass Index in the Million Women Study: cohort study BMJ 2007 (335) 1134

<sup>20</sup> Baan et al Carcinogenicity of alcoholic beverages International Agency for Research on Cancer 2007

<sup>21</sup> Lahmann et al Physical activity and breast cancer risk: the European Prospective Investigation into Cancer and Nutrition. Cancer Epidemiology Biomarkers Prev. 2007 Jan;16(1):36-42. 2006

<sup>22</sup> Ferris et al (2007) A population-based audit of ethnicity and breast cancer risk in one general practice catchment area in North London, UK: implications for practice Hereditary Cancer in Clinical Practice 5 (3). pp. 157-160.

<sup>23</sup> 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

<sup>24</sup> Dibble et al Comparing breast cancer risk between lesbians and their heterosexual sisters, Women's Health Issues, Volume 14, Issue 2, pp 60-68

approach though most will have some form of surgery (i.e. either a lumpectomy, mastectomy).

- 4.7 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. Generally, earlier detection leads to longer survival rates. One year, five year, 10 year and 20 year survival rates for breast cancer have all improved. In 1971-1975 the five year survival rate for breast cancer among women was 52%, yet by 2001-2003 this had risen to 80%.<sup>25</sup> The 10 year survival rates have also increased from 41% to 72% in the period 1991-2003.<sup>26</sup> Improved survival rates are attributable to earlier detection (through the NBSP) and improved treatments.
- 4.8 Despite improving survival rates, breast cancer is still a major cause of mortality: 11,990 women died from breast cancer in 2007. Mortality rates however, have fallen dramatically since 1989: the age standardised death rate has fallen from 42 per 100,000 (in 1989) to 27 per 100,000 (a 36% fall).<sup>27</sup> This reduction in mortality is, again, largely attributable to earlier detection through the NBSP and improved treatment options.
- 4.9 In seeking to reduce the impact of breast cancer, there are a number of preventative strategies which can be employed:
- For those with a high risk of developing breast cancer **Prophylactic surgery** is available, which can reduce the risk by approximately 90%
  - **Education and awareness** campaigns can seek to modify behavioural risks (alcohol consumption, obesity) or seek to promote positive health behaviours (exercise, breast care, screening)
  - Although **screening** cannot prevent breast cancer, an effective screening programme can help to detect cancers earlier which can lead to improved treatment options, better health outcomes and improved survival rates.

Breast cancer screening (National Breast Screening Programme)

- 4.10 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. It is noted that breast screening helps to detect up to 40% of cancers which could not be detected by other methods (i.e. by hand).<sup>28</sup>
- 4.11 Breast screening services are coordinated through the NBSP, which was first established in 1988. 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. Invitations are issued by a local breast screening unit to women on a local area, General Practice basis (i.e. practice by practice).

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<sup>25</sup> CancerStats Breast Cancer UK Cancer Research UK 2009

<sup>26</sup> Office for National Statistics Breast Cancer Survival in E & W 1991-2003

<sup>27</sup> CancerStats Breast Cancer UK Cancer Research UK 2009

<sup>28</sup> CancerStats Breast Cancer UK Cancer Research UK 2009

- 4.12 Those women responding to the breast screen invite will be screened by a radiographer who will take x-rays of the breast and these images will be examined for potential abnormalities (usually two specialists). 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 (e.g. lumpectomy, chemotherapy), if it is normal, the woman will be returned to the recall system and invited for screening again in 3 years time. The full breast screening pathway is depicted in Figure 7.
- 4.13 Women aged below 50 years are not included within the NBSP as breast cancer can be difficult to detect in pre-menopausal women. Other women who may be symptomatic or believed to be at risk but who are outside the current screening age range can still be referred for one-off breast diagnosis or onto a family history programme through their GP to a symptomatic service and remain outside the screening programme until they reach 50 years. 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.
- 4.14 There are 82 breast screening units in the UK. Local breast screening units are coordinated by a national service and breast screening practice is overseen by both a national and regional quality assurance network. The NBSP costs approximately £75 million to administer each year, which equates to £37.50 per woman invited or £45.50 per woman screened.

Breast screening services in Haringey

- 4.15 Breast screening services for women in Haringey are provided through the North London Breast Screening Service (NLBSS), one of seven such screening units in London. This specialist service is commissioned by a consortium of 6 PCTs (Barnet, Brent, Enfield, Haringey, Harrow & West Hertfordshire). In 2008/9, this service screened almost 39,000 women across all 6 PCTs making this one of the largest breast screening units in the country.
- 4.16 In 2008/9, there were 19,116 women in Haringey eligible to be part of the screening programme (i.e. aged between 50-70 years). As screening is every three years, approximately 1/3 of this eligible population would be invited for a breast screen each year (though the actual annual number would vary depending on what practices are scheduled in each of the three years of the screening round). Thus on average, about 6,000 women in Haringey would be screened each year.
- 4.17 Responsibility for the planning, commissioning and performance management of breast screening providers rests with Primary Care Trusts (PCT), though quality assurance and other governance issues are managed through NHS London and specialist commissioned agencies (London Quality Assurance Reference Centre). The cost of the NLBSS in 2008/9 was approximately £3.5 million of which NHS Haringey contributed £482k.
- 4.18 As a result of a number of serious untoward incidents in 2006 an evaluation of the NLBSS was undertaken by the London Quality Assurance Reference

Centre (QARC). This identified weaknesses in results procedures, process errors in the issuing of invites and non compliance with established radiography protocols. As a result the decision was taken to suspend the NLBSS in December 2006.

- 4.19 Although the NLBSS service reopened in May 2007, services were reintroduced on a phased basis. It was agreed that the service would operate with a screening round length<sup>29</sup> target of 46 months until 2010, which would allow the service to manage screening catch-up in a planned manner. The extended round length has however, severely impacted on other local breast screening performance measures.

#### Breast Screening Uptake

- 4.20 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'. The national minimum standard for breast screening uptake is 70% though the national target is higher at 80%.

- 4.21 National data from that NBS for 2008-9 reveals that 2.28 million women were invited for a breast screen of which 1.68 million women attended, which produced an uptake rate of 74%. Nationally, this uptake rate has remained broadly static for the past 6 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 60% 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**).

- 4.22 There are wide variations in screening uptake among individual breast screening units. In 2008/9, some breast screening units an uptake of over 80% has been achieved (Leicestershire, Norfolk & Norwich). In the London region uptake was much lower averaging 61%. Wide variations in uptake were also recorded among London breast screening units: in Barking & Havering the uptake was recorded at 67% whilst in Central & East London uptake this was just 56% (**Figure 2**).

- 4.23 Breast screening uptake in Haringey in 2008/9 was recorded to be 55%. This represented a fall of 4% from previous years figures.

#### Breast screening coverage

- 4.24 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 target for breast screening coverage was raised to 75% from 70% in 2009/10. Data from the NBS for 2008/9 indicates that the breast screening coverage for women aged 53-70 in England was 76.5%, for London 64.5% and in Haringey 50.7% (as per table below).

<sup>29</sup> The round length is the measurement of time between the date of last screening and the first offered appointment. The standard is for 90% of women to be offered an appointment within 36 months of a previous screen.

Region	Population	Women screened	Coverage (%)
England	5,166,515	3,954,050	76.5
London	607,605	391,676	64.5
Haringey	19,116	9,691	50.7

- 4.25 Regionally, in 2008/9, all but one area reported a breast screening coverage of greater than 70%: the one exception being in London (as above). The level of breast screening coverage also varied widely at the primary care organisation level: whilst 38 PCTs achieved coverage above 80%, 13 PCTs had coverage below 60% (a full distribution of PCT coverage is given below).

Distribution of breast screening coverage across all PCTs (2008/9)				
Coverage	50-59%	60-69%	70-79%	80%+
No. of PCTs	13	15	86	38

- 4.26 Whilst the average breast screening coverage for the London region was 64.5%, there were wide variations in coverage among primary care organisations. Thus while in Havering the coverage was 78.9% this fell to 50.2% in Barnet (**Figure 3**). In Haringey, the coverage was 50.7%, making this the second lowest in the country.<sup>30</sup> The proportion of women aged 53-70 in London who have never screened was 19%, which is far higher than the national average (11%).

#### Screening round length

- 4.27 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%.
- 4.28 The round length is an important measurement because if women are screened within a 36 month interval the incidence of “interval cancers” (i.e. those developing cancer between screening appointments) is very low. The risk of developing cancer rises as the interval between screening increases.
- 4.29 The average round length in London was 68.2%, indicating the proportion of eligible women who were screened within a 3 year period. However, the round length figures varied across screening units: two units (South East London Queen Mary and West of London) had coverage above 90%, though in City and East London this was just 47%. The round length for all screening units for London in 2007/8 is given in **Figure 4**.
- 4.30 As part of service recovery plan for NLBSS, a 46 month round length was agreed with the service thus it was not surprising to record that just 15.6% of women in this area had a screen within the national target length (36 months).

## **5.0 Legislative and policy framework**

<sup>30</sup> This is operating with a 46 month round length.

5.1 National cancer policy and priorities were originally outlined in the **NHS Cancer Plan** in 2000, though this has largely been superseded by the **Cancer Reform Strategy** (2007). This strategy identified a number of priorities for the development of breast screening services which are summarised below:

- Extended screening age to 47-73 years by 2012
- Digitalisation of mammograms by 2012
- Improved surveillance of women at high risk of familial breast cancer
- Develop service capacity to meet expected population growth
- Ensure that screening services do not reproduce health inequalities
- Raise breast cancer awareness to women outside the screening programme.<sup>31</sup>

5.2 Arrangements for national screening programmes are set out in Department of Health (DH) guidance.<sup>32</sup> This guidance provides a framework for breast screening service provision which detail essential features of a screening programme, how services should be commissioned and processes to ensure proper governance and quality assurance mechanisms are in place.

Local policy context

5.3 Developing the uptake of screening services is noted within key strategic documents for Haringey. The Sustainable Community Strategy 2017-2016 (SCS) is the overarching plan of the Haringey Strategic Partnership which details how the Council and its partners will tackle broad community wide issues. Key priorities embedded within the SCS include the need to help 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 Within the SCS plan for 2009-2011 there is an identified need 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 the scrutiny review of breast screening service may contribute:

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

<sup>31</sup> Cancer Reform Strategy Department of Health 2007

<sup>32</sup> Commissioning and managing screening programmes in the NHS in England DH, (2005).

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 process through 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 specific 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. Aims of the review**

- 6.1 The aims and objectives provided a structure for the review process, helped to develop a common understanding of the scope of the review among stakeholders, and created a framework around which review decisions were made. The panel agreed that the overarching aim of the review was:

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

#### Objectives of the review

- 6.2 It was agreed that the review would aim to address 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**

### *Panel Meetings*

- 7.1 The Overview & Scrutiny Committee commissioned a review panel to undertake this review. The panel consisted of Councillors Alexander, Beynon, Bull and Winskill (Chair).
- 7.2 The review incorporated a range of investigative methods to ensure that the panel had access to information to meet the review objectives (as set out above). A series (n=4) of panel meetings were held to approve the aims of the review, receive oral and written evidence, oversee project progression and formulate conclusions and recommendations.

### *Evidence Sessions*

- 7.3 A number of organisations gave evidence to support the review process, including representatives from local health services commissioners (NHS Haringey), the local breast screening unit (NLBSS) and screening representatives from regional bodies (e.g. NHS London, London Quality Assurance Reference Centre). In total, evidence was heard from 9 representatives from 6 organisations. A full list of all those who gave evidence to the panel is contained in Appendix B.

### *Assessing internal and external data sources*

- 7.4 The panel commissioned reports and ad hoc briefings from the NHS Haringey and North London Breast Screening Services to provide operational, performance and financial data to help assessments of local breast screening services. Comparative data from other NHS trusts and breast screening units was also used to help panel members identify good practice, benchmark local breast screening service provision and identify local priorities for service improvement.
- 7.5 The panel also assessed external data (research, policies and practice) from regional (NHS London) and other healthcare organisations (Screening Improvement Board) to assist the review process. This included *Behind the Screens* (GLA report in to breasts screening in London) and Maximising Screening Attendance (a reference guide developed by the North West Cancer Network). All reports used in the review are referenced within the body of this report.

*Panel Visits*

- 7.6 The panel also visited the North London Breast Screening Service to help gain a practical insight in to the provision of breast screening services in the locality. The panel met the Chair and Director of Clinical Services at Barnet & Chase Farms Hospital (who operate the North London Breast screening Service), toured facilities with the General Manager and met with key staff (i.e. radiographers).

*Community / Public Involvement*

- 7.7 Community and public involvement is an integral part of the scrutiny process through helping to maintain local accountability. To this end all scrutiny panel meetings were held in public.
- 7.8 To help understand local patient perspectives of the breast screening service, the scrutiny service conducted a consultation with local women who had recently used the NLBSS. This consultation involved both quantitative and qualitative methods. 200 women from Haringey who had recently attended for a breast screen were sent a questionnaire which sought to ascertain views around the accessibility of the service and ways in which breast screening uptake could be improved. Almost 70 women from Haringey completed and returned the survey. The questionnaire is contained in Appendix D.
- 7.9 Breast screening service users were also offered the opportunity to provide more detailed data through attendance at a focus group. Two groups were held locally and were facilitated by a scrutiny officer and a member of the scrutiny review panel. The focus group offered participants the chance to discuss issues relating to their visit (i.e. service accessibility) and to identify ways in which local uptake could be improved. In total 10 local women participated in the focus groups. The focus group invite is contained in Appendix C.

## **Part 2**

### **Key findings from the review**

## 8. Current performance of breast screening services in Haringey

### Issues arising from the closure of the NLBSS in 2006/7

- 8.1 As a priority, the panel sought clarification from both commissioners (NHS Haringey) and the service provider (NLBSS) on events that lead to the closure of the breast screening service and sought reassurance that these issues had been resolved.
- 8.2 The panel noted that a serious untoward incident had occurred at NLBSS in 2006 which involved 11 patients. Both regional and national review teams were brought in to investigate failures and advise on the future development of the service. The panel received written and verbal evidence which noted that safety concerns at NLBSS related to administrative rather than clinical functions at the service. In particular, concerns related to weaknesses in the 'Right Results' procedures.
- 8.3 The panel noted that as a result of these process weaknesses, the decision was taken to suspend the service in December 2006. Although the service was reopened in May 2007, full screening did not recommence until October 2007. The national support team advised against a catch up programme to tackle the backlog as this may have put the service at further risk. Instead, it was recommended that the service operated with a 46 month round length (the interval in which women were screened) and gradual return to the 36 month national standard by October 2010.
- 8.4 The panel heard evidence that the closure of the NLBSS and the decision to operate with a 46 month round length has had longer term repercussions on service performance for NLBSS and indeed, London wide. Most notably, the decision to operate with a 46 month round length severely impacted on the coverage of breast screening services (the proportion of women who have had a screen in the past 3 years). The panel understood that given the complexities of the screening round, it would take a number of years, possibly until 2013, for coverage performance figures to come back in line.
- 8.5 The panel received evidence from a number of sources (NHS London and London QARC) which indicated that the NLBSS was now fully functioning and performing on a par (or greater) with other breast screening units in London. During the course of the review, the panel felt that this was not widely understood among stakeholders and the public and that the fact that the service was fully operational needed to be publicised more widely in the local community.

### Breast Screening Uptake

- 8.6 Breast screening uptake is the proportion of women invited for a breast screen for whom a breast screening result has been recorded. The panel received evidence from London Quality Assurance Reference Centre on the screening uptake for Haringey and other primary care organisations within the NLBSS area in 2008/9. The panel noted that this recorded that screening uptake in Haringey was 55%, which was the lowest in the NLBSS area (Figure 5). The

panel noted that this is lower than achieved for 2007/8 (59%) and continues to fall well short of the national target (75%).

- 8.7 The panel discussed uptake performance data for London. It was noted that regional uptake was 60.1% well below other regions (range 73.2-78.4%). It was noted that most London screening units are also performing at below national target level, which suggested to the panel that breast screening uptake is very much a regional problem. Indeed, it was noted that no London service had attained the national screening uptake target.
- 8.8 The panel received more detailed data from London QARC and NLBSS on screening uptake in Haringey. From this data the panel noted that breast screening uptake varied:
- month by month (variance 50-67%)
  - from general practice to general practice (variance 33%-74%)
- 8.9 The panel noted that because breast screening is performed on an area basis (general practice by general practice), this resulted in variations in breast screening uptake (assumed to be as a result of socio-demographic characteristic of that practice and other factors in specific areas). The panel were particularly interested in the variations among local practices, and were strongly of the opinion that uptake monitoring data should provide a focus for initiatives to improve screening uptake in specific general practices in Haringey.
- Breast Screening Round Length
- 8.10 The screening round length is the time interval between the date of a woman's previous mammogram and the date of her next screening appointment. The round length is measured by the percentage of eligible women whose next screening appointment is within 36 months of their previous screen. The national minimum standard is 90% or above and the target is 100%.
- 8.11 The panel noted that due to the suspension of the NLBSS and its phased reintroduction from May 2007, a screening round length target of 46 months was agreed with service commissioners (i.e. 10 months longer than the national standard). From evidence submitted to the panel it would appear that NLBSS is just about achieving the 46 month target: average quarterly performance from Q3 08/09 to Q2 09/10 was 89.8%.
- 8.12 NLBSS performance against the national round length target of 36 months was understandably poor. In 2007/8 just 15.6% of women were screened within 3 years of their last appointment which is significantly lower than for other screening units (e.g. SW London at 80.6%) and London wide average (68.2%) (Figure 4).
- 8.13 The panel heard evidence from the London Quality Assurance Reference Centre and the NLBSS itself that considerable progress had been made in reducing the round length in Haringey. It was estimated that the round length would be back to 36 months by the end of June 2010, 4 months ahead of schedule.

Breast Screening Coverage

- 8.14 It was noted by the panel, that the extended round length at the NLBSS had impacted on the breast screening coverage (the proportion of women who had been screened within a 3 year interval). Breast screening coverage in Haringey was recorded to be 50.7% which is the second lowest in London, and indeed, nationally (Figure 3). The panel noted that all of those PCTs in the NLBSS area (Brent, Harrow, Enfield and Barnet) recorded similarly low coverage rates as a result of the 46 month round length operating in NLBSS (Figure 3).
- 8.15 The panel also received evidence which suggested that screening coverage varied widely among local general practices. Evidence received from NHS Haringey indicated that breast screening coverage for individual practices at end of 08/09 varied from below 10% through to above 60% (Figure 6).
- 8.16 The panel heard that, because of the way that the screening programme operates it would take approximately 3 years for an accurate recording of local coverage to be obtained. In this context, an accurate coverage figure would not be obtained until June 2013 (i.e. 3 years on from the date of the planned resumption of a 36 month round length at NLBSS).

## 9. What factors affect the uptake of breast screening services?

- 9.1 The panel heard that there are many factors that may influence the take up of invitations for a breast screen, however, it was noted that there were few definitive large scale studies to guide such assessments. From the evidence it received, the panel were however able to deduce that number of key factors would appear to influence the take up of breast screening services in Haringey.

Socio-demographic factors

- 9.2 The panel noted research which made an association between ethnic origin and uptake of breast screening services. Research conducted in Brent & Harrow concluded that that poor knowledge, differing health and cultural beliefs and language were central to low attendance by black and minority ethnic groups at breast screening services.<sup>33</sup> Other studies found that BME groups were less likely to attend as they did not perceive themselves to be at risk or were more anxious.<sup>34</sup> The panel noted that a study concluded that 28% of the variation in breast screening uptake rates among Primary Care Trusts is due to the ethnic group of potential attendees.<sup>35</sup>
- 9.3 The panel received evidence from NHS Haringey which would appear to support the link between **cultural and ethnic group** and low uptake of breast screening at the local level. A report commissioned by NHS Haringey

<sup>33</sup> Barriers to effective uptake of cancer screening among BME ethnic groups, *International Journal of Palliative Nursing* 2005 Nov 11 (11) 564-571)

<sup>34</sup> Barter-Godfrey & Takert 2005 Women and health: views of women aged 50—64 living Lambeth, Southwark & Lewisham, London South Bank University

<sup>35</sup> Eilbert et al, Approaches to improving breast screening uptake: evidence and experience from Tower Hamlets *British Journal of Cancer* 101(S2): S64–S67 (2009)

identified that the highest did not attend (DNA) rates for breast screening were among (using MOSAIC Classifications) settled minorities (Caribbean, African, Cypriot and Pakistani origin) and metro multicultural (black Africans and Asian Origins) groups.<sup>36</sup>

- 9.4 The panel also noted that a number of studies suggest a link between **social deprivation** and the take up of breast screening invitations. Here, research would appear to suggest that women resident in areas of high social deprivation are less likely to attend breast screening services compared to women from more affluent areas.<sup>37 38 39</sup>
- 9.5 For the most vulnerable women in the community responding to an invite for breast screen may be problematic. Despite that women with a **learning disability** are now living longer and fuller lives and live to an age where screening is appropriate, lower levels of breast screening are still reported among women in this group.<sup>40</sup> Similarly, the panel noted that there was evidence to suggest that there was comparatively lower attendance among women with **severe mental health** problems.<sup>41</sup>
- 9.6 The panel heard evidence to suggest that the **age group** of women was an influence on uptake rates. Whilst screening is open to women aged between 50 and 70 years of age, the panel heard evidence from London QARC that uptake rate among younger women in this screening target group was lower.
- 9.7 **Personal attitudes** have also been shown to influence a woman's decision whether to attend for breast screening. The panel noted a study in Lambeth, Southwark & Lewisham which found that a positive personal attitude and the perceived personal importance of screening were strongly associated with attendance at 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.<sup>42</sup>
- 9.8 A more recent study has also suggested that there is a link between **personal wealth and mobility** and women attending for a breast screen. Here it was found that women who have access to a car and who own their own home (indicators of personal wealth) were more likely to attend for breast screening than those women who did not have these personal assets.<sup>43</sup>

### Structural factors

<sup>36</sup> Increase breast Screening Uptake in Haringey, Barkers Social Marketing/ NHS Haringey (2009)

<sup>37</sup> Gatrell 1998 Uptake of screening in breast cancer in South Lancashire Public Health 112 (5) 297-301

<sup>38</sup> 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

<sup>39</sup> Banks et al 2002 Comparison of various characteristics of women who do and do not attend breast cancer screening, Breast Cancer Research 4 R1

<sup>40</sup> Cancer Reform Strategy 2007

<sup>41</sup> Werneke et al Uptake of screening for breast cancer in patients with mental health problems Journal of Epidemiology and Community Health 2006;60:600-605

<sup>42</sup> Barter Godfrey and Taket 2005 'op cit'

<sup>43</sup> Moser et al Inequalities in reported use of breast and cervical screening in Great Britain: analysis of cross sectional survey data BMJ 338 2009

9.9 The panel also noted that structural factors, such as the way the screening service are organised, may influence the take up of breast screening services. The panel heard evidence which indicated that that an accurate and up to date **population register** (Exeter Dataset) is integral to the success of breast screening as this is used to invite women from local general practices. This is particularly important in London where there is populations can be transient and population mobility high. The panel noted that if General Practice lists (on which this data set is based) are not routinely cleaned and up to date:

- invites may be sent to the wrong address
- invites may be sent to women for whom screening is not appropriate (i.e. mastectomy)
- inflate local DNA rates (e.g. by including women who have moved).

9.10 The panel also noted that the uptake rates were also influenced on how effectively local breast screening programmes were organised such as the operation of the **call and recall** system and other quality control procedures.<sup>44</sup> The panel noted that these were monitored by local and national quality assurance centres (e.g. London QARC).

9.11 Other structural problems which were felt to affect local uptake of breast screening services was the non-receipt of breast screening invitations. A number of regional specialists who gave evidence to the panel suggested that anecdotally up to 40% of invites may not reach the intended recipient because of incorrect details were listed, or where the recipient lived gated communities or had shared/communal mailboxes.

#### Experiential factors

9.12 During the course of the review, the panel understood that other factors may influence the take up of breast screening appointments, such as women's experience of breast screening services. Whilst it is clear that women who have previously attended for breast screening are more likely to do so in the future it is not apparent which factors underpin such differences (i.e. quality of services, reduced anxiety, improved understanding).

9.13 From the range of evidence presented in this review however, the panel noted that the following factors influence women's perceptions of screening services and perhaps subsequent intentions to screen or not to screen:

- Personal anxieties about screening
- Location and accessibility of the clinic
- Accessibility of appointments (appointment system)
- Quality of care and services provided.

9.14 Attendance for invitations to a breast screen is clearly affected by a broad range social, cultural and economic factor, 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 individual women making this decision.

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<sup>44</sup> London Quality Assurance Reference Centre 2002

- 9.15 The panel were mindful that there were variations in the uptake of breast screening and the impact that this may have on local health inequalities. The panel hoped that local commissioners and service providers would acknowledge such variations in take up and take affirmative action to prevent the exacerbation of local health inequalities (e.g. further research supported by targeted interventions)

## 10. Commissioning Breast Screening Services

### Commissioning

- 10.1 The panel noted that the responsibility for planning, commissioning and performance managing breast screening services rests with Primary Care Trusts (PCT). In Haringey, breast screening services (NLBSS) are commissioned through a consortium of 6 PCTs. The panel understood that whilst there was an overall breast screening lead for the PCTs (located with Enfield PCT), each PCT had a screening lead to deal with breast screening issues.
- 10.2 The panel noted that the commissioning structure for breast screening was in accordance with national guidelines and in widespread operation throughout the London. The panel noted that no specific problems were identified in this commissioning arrangement from any of the stakeholders in the review, or regional governance bodies (NHS London, London QARC).
- 10.3 In their evidence to the panel, local commissioners indicated that funding arrangements had recently been changed to allow for an uplift in funding for the NLBSS. This was identified as a requirement from the national team inspection which was undertaken in 2006/7. Within this new agreement, PCTs in the consortia were required to pay an additional 'fare shares' portion based on the number of women screened in their locality. The new funding agreement also introduced a new tariff based system, from which it was hoped to incentivise providers to improve uptake rates (i.e. proportion of funding now being paid per capita for screens undertaken).
- 10.4 As a result of these funding changes Haringey's funding for breast screening services rose from £419,000 to £482,000 and total funding for NLBSS rose from £3,086,000 to £3,548,00 (as per table below).

PCT	Original SLA 08/9	Proposed fair Share	Fair Share supplement	Total annual payment 08/09
Haringey	£419,000	13.62%	£63,000	£482,000
Total NLBSS	£3,086,000		£461,000	£3,548,000

### Data quality and management

- 10.5 The panel noted high quality and up to date information was integral to the screening uptake and the overall effectiveness of the local breast screening programme. In developing interventions to support screening uptake, the panel understood that it was important to develop a more detailed local picture of women who do not attend (DNA) for screening. The Panel noted from

evidence from NHS London, that it was the responsibility of local PCTs to commission such research and shape breast screening programmes and interventions accordingly.

- 10.6 The panel noted that NHS Haringey had begun to research the local breast screening DNA population through a social marketing approach (as described in 9.3), and hoped that this would filter down in to positive local action within the community. This being said, the panel wished to underline the importance of local knowledge about the breast screening population and suggested that ongoing research and intelligence gathering on the breast screening DNA population should form an integral part of local commissioning.
- 10.7 The panel understood that the PCT were responsible for the compilation of accurate and up to date lists of the population eligible for breast screening (i.e. women aged 50-70 years). That is, ensuring that there is effective information flow between Public Health Departments, GPs (from whose practice lists data is derived) and NLBSS (who send out the breast screening invites) to ensure that invitations are appropriately sent out to the relevant population.
- 10.8 The panel received evidence which suggested that there could be improvements to the way that data is shared between stakeholders (these issues were common across London and more locally in the NLBSS consortia area):
- More effective list cleaning processes to ensure the removal of women no longer at the general practice
  - Timely presentation of lists to GPs for effective notation (i.e. removal of women not appropriate to screen).
- 10.9 During the course of the evidence sessions to the panel, it was apparent that the NLBSS develop a list of patients who have not attended for their breast screening appointment (so called **DNA list**). This DNA list is routinely sent to local GPs. From evidence received by the panel, it was apparent that this list is not consistently used by GPs to follow up women who have not attended, indeed, there was some evidence to suggest that active follow up of DNA's in primary care was minimal. The panel felt that this was significant missed opportunity to improve local breast screening uptake.
- 10.10 In fairness to NHS Haringey, the panel noted that the failure to act on DNA lists was a London wide problem, as GPs were not incentivised to follow up on breast screening DNAs from their practice. The panel felt however, that it was imperative that further use be made of DNA lists, and that NHS Haringey as a priority, should commission GPs or their own public health department to actively follow up non-attendees at breast screening services.
- 10.10 In planning and developing breast screening services and interventions to improve uptake, as well as understanding the DNA population, it is also important to know the characteristics of those who do attend for a screen. The panel understood that there were many opportunities to collect data on the women that do attend for screening, yet there was insufficient systems in place to collect, collate and analyse such data.

10.11 For example, a registration form is competed each time a women attends the breast screening unit (NLBSS), yet this information is not collated, analysed or shared across the stakeholder partnership. Thus while socio-demographic data is collected at this point (age, ethnicity, postcode), this is not collated or used to inform local commissioning or service development.

#### Capacity of breast screening services

10.12 The panel were keen to assess the future capacity of the NLBSS given the expected increase in demand within the breast screening programme. The panel noted that increased demand was likely to stem from:

- age extension of the screening programme to include women from 47-73 years (from 50-70 years) by 2012
- demographic changes in the screening population i.e. ageing female population
- improved uptake rates as a result of planned local interventions.

10.13 NLBSS gave evidence to the panel which noted that there was sufficient capacity within the service to manage the expected 30% age extension growth in the screening programme through to 2012. The panel noted that excess capacity needed to meet this additional demand would be derived from the return to the 36 month round length from June 2010.

10.14 The panel noted evidence from a number of sources (including the NLBSS) which indicated that the eligible breast screening population would increase in future years due changes in the demographic profile (i.e. the growth of the aged female population). As was noted in the Cancer Reform Strategy, PCT commissioners may be required to make additional planned investment in the medium term to meet this increased demand for services.<sup>45</sup>

10.15 The panel noted that whilst breast screening uptake in the borough was currently low (55%), it was anticipated that uptake rate would improve as a result of focused interventions within the borough in the future (e.g. resulting from the Breast Screening Action Plan and other local initiatives).

10.16 Although it was understandably difficult to predict what increase may result from the above circumstances, the panel felt that such factors should be considered in assessing future demand and planned capacity for local breast screening services.

#### Breast Screening Action Plan

10.16 The panel noted that given the inclusion of breast screening within the vital signs<sup>46</sup> indicator set ensured that NHS London was playing a prominent and active role in local breast screening commissioning arrangements. To this end, the panel understood that NHS London signs off commissioning agreements, manages performance and commissions the local Quality Assurance Reference Centre (London QARC).

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<sup>45</sup> Cancer Reform Strategy Department of Health (2007)

<sup>46</sup> Vital Sign VSA09 the percentage of wom en aged 47-49 and 71-73 invited for breast screening.

- 10.17 More recently, NHS London has required all PCTs to produce a Breast Screening Action Plan. This is a template of key breast screening activities for local stakeholders (PCT, Breast Screening Units and GPS) which local PCTs are required to self assess. The panel noted that PCTs have been required to submit self assessments and subsequent actions for 2010/2011. NHS London will manage the performance of PCTs against these action plans.
- 10.18 The panel warmly welcomed the development of the local Breast Screening Action Plan as this was felt to provide an important first step in developing a local breast screening strategy. The panel were of the opinion that the Breast Screening Action Plan could be developed further through the following inclusions:
- establish shared priorities across the partnership
  - establish how local partners can work together to breast screening
  - identify clear priorities for action
  - establish clear targets and milestones for improving screening uptake.
- Patient surveys to assess service quality and accessibility
- 10.19 As part of the scrutiny review process, the panel commissioned a survey of breast screening service users to assess the service accessibility and quality. The survey (Appendix D) and analysis of its findings are included within this report (Appendix F).
- 10.20 Both the review panel and local commissioner were in agreement that the survey had produced a range of informative data: physical access to screening sites, convenience of allocated appointments and the quality of screening services provided. The panel felt that such patient satisfaction surveys provide a helpful tool in the commissioning process, and that this should be an ongoing process to help measure and benchmark the accessibility and quality of local breast screening services.

## 11. Improving screening uptake – operation of breast screening services

### Quality of breast screening services

- 11.1 How people experience health services is clearly an important factor service usage. Where service users are welcomed, treated in friendly manner, provided with sufficient information and perceive that their concerns have been dealt with, re-attendance at the service may be more likely. To this end, the panel wished to understand further about how local women experienced the breast screening service.
- 11.2 The consultation with service users undertaken as part of this review identified high levels of service satisfaction with many aspects of the breast screening service. The report found that (Appendix F):
- 84% were satisfied with their welcome to the clinic
  - 84% were satisfied with waiting times at the clinic
  - 87% indicated that staff were friendly and helpful
  - 87% indicated that they were given enough information
  - 92% were satisfied with the overall quality of the service
  - 95% said they would recommend the service to a friend.
- 11.3 In terms of the more qualitative aspect of the service, the main area identified for improvement through the consultation was the need for more personalisation of services, to help reassure women who have anxieties about accessing and using the service. In this context, respondents to the survey and focus groups suggested:
- Opportunities to speak with someone ahead of the appointment
  - More personalised statements in literature
  - Encouraging people to attend with friends for support.
- 11.4 The panel were reassured from the consultation data that an acceptable service was being offered for local women, that women were on the whole having positive experiences of this service and in doing so, encouraged to attend in the future. The panel also noted the importance of ongoing patient surveys to assess service quality.

### Location of screening clinics

- 11.5 The panel noted that there was substantive evidence to suggest that the location of the breast screening unit was an important factor in the uptake of invites to breast screening services. The panel received research which found that the distance that women had to travel to a screening site had a significant impact on the uptake of screening services,<sup>47</sup> 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.<sup>48</sup>

<sup>47</sup> 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

<sup>48</sup> Maxwell 2000 Relocation of a static screening unit: a study of factors affecting attendance *Journal of Medical Screening* (7) 114-115

- 11.6 The panel noted that breast screening services are offered by NLBSS through both static and mobile units at various sites across the 6 boroughs in which the service operates. Mobile units are deployed at a range of locations on a periodic basis (minimum 3 months), usually specific to which general practices are being targeted in the screening round. The panel noted that the main sites where Haringey women could be screened were as set out below:

Location	Screening unit type
Forest Road, Edmonton, Enfield.	Static
North Middlesex Hospital, Enfield.	Mobile
Whittington Hospital, Islington.	Static (periodically commissioned)
St Ann's Hospital, Haringey	Mobile
Edgware Hospital, Barnet	Static (Out of Hours appointments)

- 11.7 In the survey of service users conducted as part of this review, the panel also noted the importance that local women attached to the location of the screening clinic and perceptions of service accessibility (Appendix F). A summary of the main points of relevance from this survey were that:

- women in Haringey were generally required to access screening sites outside of the borough
- the physical distance women needed to travel presented a number access problems (transport, length of journey, time off work)
- more choice was wanted in the location of the screening clinic.

- 11.8 The panel noted that women who participated in the consultation indicated that the availability of more convenient locations for breast screening clinics would improve service accessibility and may help improve uptake of breast screening services in Haringey.

*'If it was nearer home or a more convenient location, I think more people would attend.'*

*'People in my area would be far more likely to attend the clinic if it was more local and on public transport....'*

*'If you could give appointments closer to where people live it would help.'*

- 11.9 The panel noted the complexities that NLBSS faced in delivering accessible screening sites across 6 PCTs at differing times within the 3 year screening round. Potential sites for the mobile clinic were constrained by the physical space required, physical security, personal safety issues for staff and service users and access to utility services (electricity and toilet facilities). It was also noted that the mobile unit would have to be deployed for a minimum of 3 months in any one location to be cost effective.

- 11.10 The panel noted that early developmental work had commenced in modernising the call and recall system for breast screening, which would see women called for screening on the third anniversary of their last screen, rather than on the geographical rotation on where their general practice was located. The panel noted that if fully implemented, this system would see a

shift in service format were services would primarily be delivered through static screening sites. The panel heard evidence to the effect that it would cost a minimum of £150k to equip a static site.

- 11.11 In light of the above, the panel felt that options for developing the accessibility of screening locations in Haringey required further appraisal and assessment. In particular, the panel felt that the development of new neighbourhood health centres (at Park Road and Lordship Lane) had to date remained largely unconsidered as possible sites for mobile breast screening despite their physical accessibility, hours of access (8am-8pm) and that another screening service in London had developed a similar approach (South West).

Access to out of hours appointments

- 11.12 As many women eligible for breast screening were still likely to be working, the panel assessed whether the availability of out-of-hours appointments was a factor in the accessibility of breast screening clinics. The panel noted evidence from NLBSS which indicated that operational hours for breast screening clinics were generally between 9am and 4pm. The panel also noted that whilst out-of-hours appointments were available, these were generally restricted to Saturday mornings and more importantly, were only generally available at one screening site: Edgware Community Hospital in Barnet.

- 11.13 Evidence from the patient survey verified the difficulties that patients experienced in accessing breast screening appointments outside of normal working hours; 28% of women were given an inconvenient appointment time and 22% indicated that they had difficulty to get time off work to attend (Appendix F). Furthermore, qualitative evidence from the survey indicated that where out-of-hours appointments were available, accessibility was restricted because of the physical distance that women resident in Haringey would have to travel to attend (i.e. travelling from Haringey to Barnet).

- 11.14 Analysis of both quantitative and qualitative data from the survey would appear to suggest the need to develop the availability of out-of-hours appointments at breast screening clinics and physical accessibility of these to women resident in Haringey. The panel agreed and concurred that this would be an important process in helping to improve the uptake of screening appointments.

The screening invite

- 11.15 Given the importance of the invite to screening uptake, the panel assessed the screening invite which is sent to women by NLBSS (this is contained in Appendix E). The panel heard that although standard information was required to be included in the letter, there were some variations in the text and layout of screening invites issued by local screening units. The panel also noted that a booklet on breast screening (Breast Screening the Facts) is distributed with the invite letter.

- 11.16 The breast screening invite was tested through the patient survey which was conducted as part of this review. Data analysis found that a majority of

respondents indicated that the invite was easy to read (98%), contained enough information about breast screening (89%) and how to access/ travel to breast screening sites (Appendix F). Proportionally far fewer respondents were satisfied (59%) that the invite was available in different formats (e.g. large print or different community languages).

- 11.17 In assessing the invite to screening services the panel had a number of concerns. Most importantly, the panel noted that there was no detail in the invite in any community language. Furthermore, for recipients who could not understand English, the panel noted that the invite contained no signpost to where further information could be obtained. The panel felt that this was a significant omission given the ethnic and cultural makeup of the residents in the borough.
- 11.18 The panel also made a number of other assessments about the breast screening invite and made the following conclusions:
- It did actively signpost women to the NLBSS website where further information could be obtained (including community languages)
  - It contained a lot of information and the layout was dense
  - It had not been systematically tested for relevance, understanding and readability.
- 11.19 The panel heard that other screening services in London had issued talking invitations which invited women in a number of key languages. Other services had enclosed pictorial guides to breast screening services alongside the invite to help those who do not speak English or who cannot read. The panel noted that whilst these may be effective as short term interventions, they were not sustainable for the target population as a whole.
- 11.20 The panel noted that as a priority, participants in the scrutiny review consultation identified the need to develop local screening information in community languages (Appendix F).

#### Breast Screening Appointments

- 11.21 The panel noted that invitations for a breast screen are usually sent by NLBSS out 2-3 weeks in advance of the appointment date. The invite provides details of the date, time and location of the breast screening appointment and further information on how to change the preset appointment time if this is not convenient.
- 11.22 If women had not attended this screening appointment and had not contacted the breast screening service, the panel noted that NLBSS issued another letter requesting them to contact to service and to make another breast screening appointment.
- 11.23 The survey of breast screening service users conducted as part of this review brought a number of issues to the attention of the panel (Appendix F). These were noted as thus:
- Just 55% of respondents indicated that the first preset appointment was convenient

- 29% of women who wanted to change their appointment said that it was not easy to do so
- Women were not allocated an appointment at a clinic nearest to where they live (presenting numerous accessibility problems)
- Women had difficulty in contacting the NLBSS to change their appointment
- There were insufficient appointment alternatives (dates, times and locations).

11.24 The NLBSS acknowledged that there had been a number of problems with the appointment system during the time when the survey was administered and that a number of developments had been made since the survey was undertaken. The service changes included:

- Staggering dispatch of breast screening invites so as not to create bottlenecks with women trying to contact the service
- Extending the period in which women may book appointments in advance from 3 weeks to 6 weeks.

11.25 It was noted that the availability of radiographers was critical to service capacity (and availability of appointments) and that the service had worked hard to retain a pool of these skilled workers across acute hospital sites in North London (currently 9 radiologists are employed on a sessional basis). Although the system has its disadvantages, the panel heard that it was less susceptible to service disruptions through staff absence.

11.26 The panel also received evidence which suggested ways in which the breast screening appointment systems could be improved. The panel noted research which suggested that the issuing reminder letters to non-attendees was found to be effective in improving the uptake of breast screening services in 28 reviewed studies.<sup>49</sup> Furthermore, those reminders which offered another fixed appointment time were also found to improve breast screening uptake further still.<sup>50</sup> The offering of a second timed appointment was also seen as a key development from regional reports to encourage breast screening uptake.<sup>51</sup>

11.27 The panel found this evidence persuasive and felt that this should form one strand of a programme to improve screening uptake in Haringey. The panel also anticipated that the appointment system would continue to be assessed through ongoing patient surveys recommended elsewhere in this report.

#### Digitalisation

11.28 The panel heard that all breast screening services would be digitalising their service in the coming years. The panel understood that there were a number of benefits from digitalising mammography, which included:

- Improved quality assurance processes (i.e. comparing past and present images)

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<sup>49</sup> Sin & Leger. Interventions to increase breast screening uptake: do they make any difference? Journal of Medical Screening 1999; 6(4): 170-181.

<sup>50</sup> M J Stead Improving uptake in non-attenders of breast screening: selective use of second appointment J Med Screen 1998;5:69-72

<sup>51</sup> Maximising screening attendance – a reference guide. North West London Cancer Network

- The production of more sensitive images to help identify abnormalities
- Faster production of images which may minimise delays in screening pathway
- Improved image quality may minimise requirement for duplicate screens.

11.29 The panel noted that NLBSS was one of the first services which was fully digitalised which was already producing benefits for the service and for service users. The panel also heard NLBSS is undertaking a pilot project to digitalise past screening images (taken via film) to assess what benefits this would bring for breast screening service.

## **12. Improving breast screening uptake – involvement of Primary Care**

### Current involvement of GPs in Breast screening

12.1 Through the process of the review, the panel understood that although GPs involvement in the breast screening process was generally limited, there was further scope for them to become more actively involved at all stages of the breast screening process.

12.2 It was noted that the list of women to be invited for a breast screen was derived through GP practice data (via the national Exeter database). Local lists of invitees are developed by local public health directorates in consultation with local GPs to ensure that lists are up to date and sent to relevant patients (i.e. removal of women with mastectomy). The panel understood that GP list cleaning was critical to ensure that up to date data was being used to formulate lists to issue breast screening invites.

12.3 Ahead of women being screened from a particular practice, the NLBSS writes to GPs to notify that screening is about to take place. In addition, posters and leaflets are distributed to the practice to help publicise breast screening services to local women.

12.4 The panel heard that at the end of the screening operation in a particular practice, GPs receive a list of women who have not attended (the DNA list). The panel heard evidence that although some GPs actively follow up those women who have not attended, this process is not widespread and not routinely undertaken.

12.5 In the course of the review, the panel heard evidence to suggest that primary care involvement in the breast screening process could be supported through strengthening:

- GP contact with the patient in advance of screening
- Improved list cleaning processes
- Active follow up of DNAs
- Systematic processes to refer women to breast screening programme.

### Evidence for further involvement for GPs

12.6 The panel noted that there was strong evidence to suggest that interventions which originated within the primary care setting may have positive impact in developing breast screening uptake among women. Although GPs are not

directly involved in the breast screening process, the panel noted that there was national and local evidence to suggest that planned interventions by GPs may prove to be highly influential in a woman's decision to undertake breast screening.

- 12.7 National research has identified that improved breast screening uptake was recorded where GPs have written or made a call to non-attendees at breast screening services.<sup>52</sup> Furthermore, given the personal influence of GPs, other research has found that interventions by GPs to improve breast screening uptake override other factors associated with poor attendance at breast screening clinics such as social deprivation and ethnicity.<sup>53</sup>
- 12.8 From data provided on the uptake of breast screening services at individual GPs in Haringey, the panel noted that there were wide variations in uptake: 37% in the lowest practice to 74% in the highest. Interestingly, the panel noted that from evidence presented, the general practice with the highest breast screening uptake in Haringey was one which was known to systematically follow up women who had not attended for breast screening (i.e. active use of the DNA list).
- 12.9 The consultation with service users undertaken as part of this review also found that local women would be receptive to interventions from their local GP to help improve breast screening uptake, indeed, this was an expected role (Appendix F). Data from the focus groups with breast screening service users found that there were opportunities to:
- improve advertising of breast screening in local clinics
  - improve structured interventions by GPs (i.e. developing a flag system or carry out as part of vascular checks programme)
- 12.10 The panel heard that in some localities, the uptake rate of breast screening services from individual general practices was published to enable local practices and other professionals to performance and help target developmental work. The panel hoped that such an initiative here might also focus support on those practices where uptake was known to be low.
- Local Enhanced Service
- 12.11 The panel heard that GPs are not paid for breast screening work within the general medical contract (GMS) or through the Quality and Outcomes Framework (QOF). The panel heard evidence however, which suggested that the development of a Local Enhanced Service (LES) for GPs, may help to incentivise GPs to become more involved in the breast screening process and help improve uptake.
- 12.12 The panel heard that LES represents an extension of GP medical contract where additional health services are provided for a specified area (in this case breast screening). LES are an agreement between commissioners (PCTs)

<sup>52</sup> 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

<sup>53</sup> 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

and GPs to ensure that local services are in place meet local needs or priorities. The panel understood that a growing number of PCTs had developed LES for breast screening in London, most notably Westminster and Tower Hamlets. The panel noted with interest, that other PCTs in the NLBSS area have recently launched a LES for breast screening (e.g. Barnet, Brent).

- 12.13 The panel assessed a number of LES's from other PCTs. Although the precise specifications varied there were a number of common components:
- Awareness invite (sent to women by GP ahead of screening)
  - List cleaning (up to date lists)
  - Practice training prior (to improve staff awareness and interventions)
  - Structured/ opportunistic promotion of screening
  - DNA follow up / reminder
  - Incentive payments (per capita) underpinned by practice sign up payments
- 12.14 The panel understood that LES developed by Westminster PCT was being used as a model by a number of other PCTs (including other PCTs in the NLBSS area).
- 12.15 Estimated costs of developing a LES were put at between £50k and £90k. Although LES for breast screening are in the early stages of operation and few have been operational long enough to be fully evaluated, the panel did however note encouraging preliminary data from the Heart of Birmingham PCT. Data from this PCT would appear to indicate that the LES developed here had been successful in improving breast screening uptake.<sup>54</sup> Data from the first 4 practices in the screening round have shown a marked improvement as shown below:
- average uptake at practices before LES intervention 66%
  - average uptake at practices after LES intervention 81%.
- 12.16 Given the substantive evidence received by the panel as to the acceptability and effectiveness of greater involvement of GPs in the breast screening process, the panel were in agreement that NHS Haringey should lead further work to develop local GP involvement in the breast screening process.
- 12.17 Whilst the panel were mindful that a LES may initially require additional local investment, it was agreed the development of a LES for breast screening may represent a significant opportunity to improve breast screening uptake as this offered a planned and coordinated approach to increasing GP involvement.

### **13. Improving breast screening uptake – other community interventions**

#### Principles for improved screening uptake

- 13.1 The panel heard that it was important that initiatives to improve breast screening uptake were sustainable. One-off projects were perhaps useful in raising awareness, but given the nature of the breast screening programme, these would only bring a short lived improvement to breast screening figures. Instead, it was recommended to the panel that there should be a **dedicated**

<sup>54</sup> Report to Professional Executive Committee, Heart of Birmingham PCT (2009)

**programme** of initiatives to develop and maintain upward momentum for screening uptake.

13.2 It was also suggested from regional screening representatives that approaches to improving screening uptake should be **multi-layered**, that is, should be undertaken at both the macro (local screening population) and micro (specific community/ group) level. In this context, it was suggested that broad awareness raising campaigns or the sending out of pre-invitations by GPs (macro) should be accompanied by more targeted interventions with local community groups (as evidenced by local research through the PCT).

13.3 It was emphasised to the panel that any interventions to bring about long term improvement to breast screening uptake, should also be **sustainable**, both practicably and financially. Interventions which could be embedded within the screening process and which were of relatively low cost were more likely to impact on breast screening uptake over the longer term, than one off interventions (e.g. pre-invitation letters, 2<sup>nd</sup> fixed appointment, systematic list cleaning).

Evidence to support more local community interventions

13.4 The panel noted that role of the **media** undoubtedly influences a woman's decision to attend an invitation for screening: as illustrated by the case of Jade Goody and subsequent increase in cervical cancer screening.<sup>55</sup> The panel also noted that other more specific local advertising campaigns have also been found to be helpful in promoting screening, reassuring attendees and improving uptake.<sup>56</sup>

13.5 The panel heard evidence from regional representatives that the use of different media can be an effective tool in promoting breast screening uptake. This view from those giving evidence to the panel however, was that whilst mass media marketing was not effective in encouraging service uptake (i.e. avoiding the worried well), locally commissioned and targeted campaigns could be effective.

13.6 Within the consultation with service users, participants could not recall any local awareness or public health campaigns to promote the use of breast screening services and none of those who participated in the focus groups said that they had seen promotional literature in their general practice (Appendix F). Despite the lack of community interventions currently taking place in Haringey, the consultation not only suggested that such interventions to promote breast screening would be acceptable, but were also expected.

13.7 There was a broad consensus among both survey respondents and focus group participants that there was a need to actively promote the breast screening service to women in Haringey. In this context, it was felt that there should be more outreach work targeted at women eligible to participate in the breast screening programme.

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<sup>55</sup> Jade Goody effect increases cervical screening rates Nursing Times March 2009

<sup>56</sup> Cohen, L et al (2000) Promoting breast screening in Glasgow, Health Bulletin, 58(2). 127-32

*'It would help some women to hear about the importance of screening from someone in the local community where they come. An idea would be to set up meetings with local community workers with the aim of encouraging women to attend.'*

*'How about issuing information to churches, women's centres and clubs so that they can make a list of names and addresses of women that are interested that could be referred.'*

*'...you could offer over 60's groups a chance to attend together?'*

- 13.8 It was noted from NHS London it was the responsibility of individual PCTs to undertake health promotion and public health programmes to support breast screening i.e. breast cancer awareness, breast care and promoting of breast screening. Regional screening representatives noted that that PCTs may wish to seek partnerships in developing these roles, for example with the local council, community or voluntary sector. It was noted however that whilst approaches may be collaborative, there should be consistency in the public health message (i.e. breast management, importance of breast screening).
- 13.9 The panel heard that community engagement techniques were important in reaching local target populations (e.g. women aged 50-70, black and minority ethnic groups). NHS Haringey conceded that this was an area where the locality may require additional input from either through a specialist adviser or through the experience of other PCTs where similar work has been undertaken.
- Local initiatives to promote screening uptake
- 13.10 The panel heard evidence which noted that NHS Haringey had initiated a number of projects which were hoped to improve breast screening uptake, these being Social Marketing Project for Breast Screening and Health Trainers Project. The panel noted that these projects were in the early stages of development and had yet to be fully applied within the community.
- 13.11 The panel heard that the most significant piece of work undertaken to date to promote breast screening in Haringey was the **Social Marketing Project**. This project sought to engage local breast screening population to help improve understanding about the barriers that local women face in accessing breast screening services, particularly among local ethnic and cultural groups.
- 13.12 The panel noted some of the key findings from the social marketing exercise concurred with conclusions reached from the consultation with service users in this report, namely the need to:
- to commission more culturally specific/ sensitive intervention
  - to tackle physical and structural accessibility issues
  - to develop a multi-faceted programme of interventions to support breast screening attendance.
- 13.13 Whilst it was recognised that this was a very valuable piece of work, the panel noted that there had been problems with the project and that tangible

developments arising from this initial engagement with the breast screening population had to date been limited. The panel were therefore keen to see the understanding and learning developed from this first stage of the project could influence local initiatives, and more generally, how social marketing principles could be used to promote breast screening.

13.14 NHS Haringey also noted that the **Community Health Trainers** project may also help to promote breast screening services to local women. Within this project, local volunteers would be recruited to conduct community outreach initiatives across the borough. The panel noted that whilst these trainers would be generic (i.e. focussing on a broad range of community health interventions), breast screening would figure prominently in their work programmes given that this was a priority for the locality.

13.15 The panel welcomed the development of community health trainers and their subsequent recruitment and deployment within the community. The panel were particularly welcoming of this community role, as they felt it could work well the operation of the breast screening round. Because the breast screening operates on a locality basis (practice by practice) the panel felt that this offered a significant opportunity for health trainers to undertake targeted work within that community to promote breast screening.

Breast screening and health inequalities

13.16 The panel also noted that a number of key strategy documents have highlighted the range of health inequalities associated with breast screening. These documents<sup>57, 58</sup> and additional research<sup>59</sup>, conclude that it is important for local commissioning services to investigate and research local service uptake to help identify inequalities and to make appropriate service developments.

13.17 The review of breast screening services also highlighted areas within the established equalities strands (age, gender, religion, disability, ethnicity and sexuality), where potential local inequalities may exist. These are summarised below:

Incidence of breast cancer	<ul style="list-style-type: none"> <li>• Gender: women 100x more likely to develop breast cancer than men</li> <li>• Age: 4 in 5 cases of breast cancer are diagnosed in women aged 50 years and over</li> <li>• Ethnicity: Ashkenazi Jewish women from this group are 1.5 times more likely to develop breast cancer</li> <li>• Lesbians – convergence of multiple risk factors may make this group more susceptible to developing breast cancer</li> </ul>
Take up of breast	<ul style="list-style-type: none"> <li>• Age: younger women in the age screening</li> </ul>

<sup>57</sup> Cancer reform Strategy 2007

<sup>58</sup> Expanding our Reach NHS Breast Screening Programme Annual Report

<sup>59</sup> Moser et al Inequalities in reported use of breast and cervical screening in Great Britain: analysis of cross sectional survey data BMJ 338 2009

cancer screening	<p>group (50-70) less likely to attend</p> <ul style="list-style-type: none"> <li>• Ethnicity: women from different ethnic groups may have different cultural beliefs about breast cancer which impact on screening uptake: e.g. attitudes toward screening, perceptions of risk</li> <li>• Disability: women with a learning disability or mental health problem known to have lower levels of attendance for breast screening</li> </ul>
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13.18 Although not an established equality strand, the panel noted that social deprivation was a prominent issue in the take up of breast cancer screening and subsequent treatment options and outcomes. It was recorded that women from poorer backgrounds often present at a much later stage of cancer development and more likely with the presence of other health conditions, which reduce treatment options.<sup>60</sup> The panel noted that this lead to lower breast cancer survival rates among women living in socially deprived areas.<sup>61</sup>

13.19 Through the course of the review, a number of actions have been identified to both commissioners and service providers to help improve access to breast screening services among women in the different equality strands. These are included within the recommendations of the report but which can be summarised as thus:

- Provider to adapt breast screening invite to include information in community languages
- Provider to signpost women to where further information in different languages can be obtained from the internet
- Commissioners to conduct ongoing research to identify and support non groups of non attendees at breast screening programme
- Commissioners to develop a programme of community interventions (public health, prevention) which acknowledge and support breast screening attendance.

13.20 The panel noted that improved uptake of breast screening was critical in helping to reduce breast cancer inequalities, and was therefore keen to ensure that a programme of community interventions was developed to promote screening among those groups known to face increased risk of breast cancer, who were known not to attend or who are particularly vulnerable.

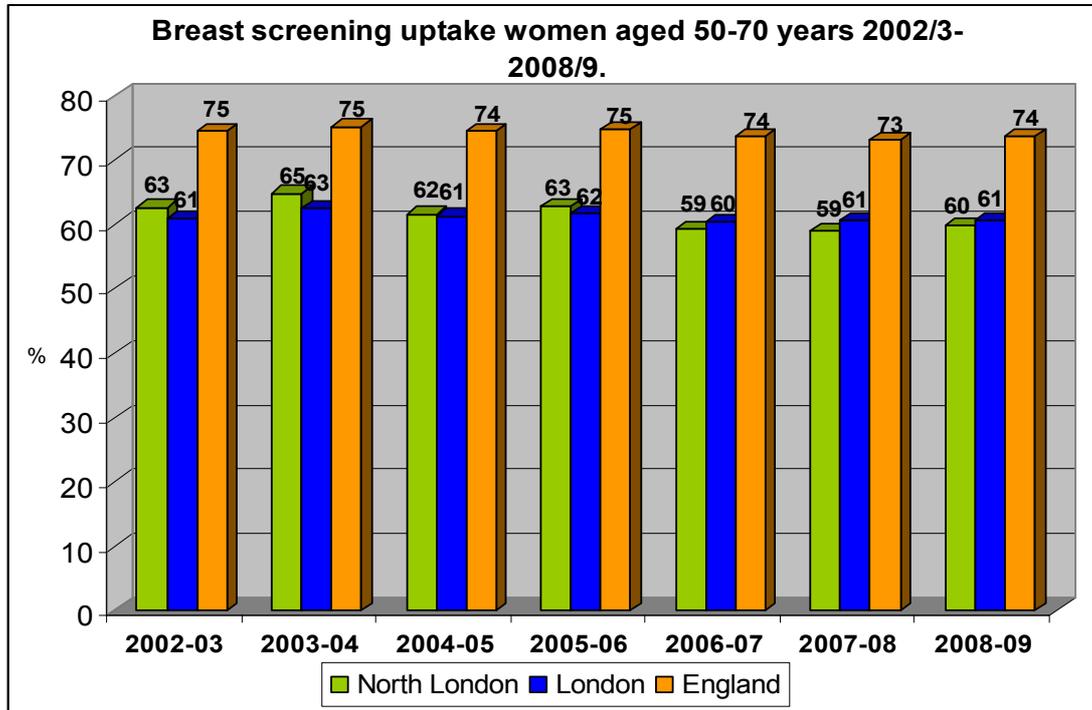
<sup>60</sup> Macleod et al Socioeconomic deprivation and stage of disease at presentation in women with breast cancer *Annals of Oncology* 11 (1)p105-107 2001

<sup>61</sup> Coleman et al Trends in socioeconomic inequalities in cancer survival in England & Wales up to 2001 *British Journal of Cancer* 90 (7) p1367-73 2004



**Appendix A – Figures**

**Figure 1 – Breast screening uptake 2002-2009**



**Figure 2 – Breast screening uptake in London.**

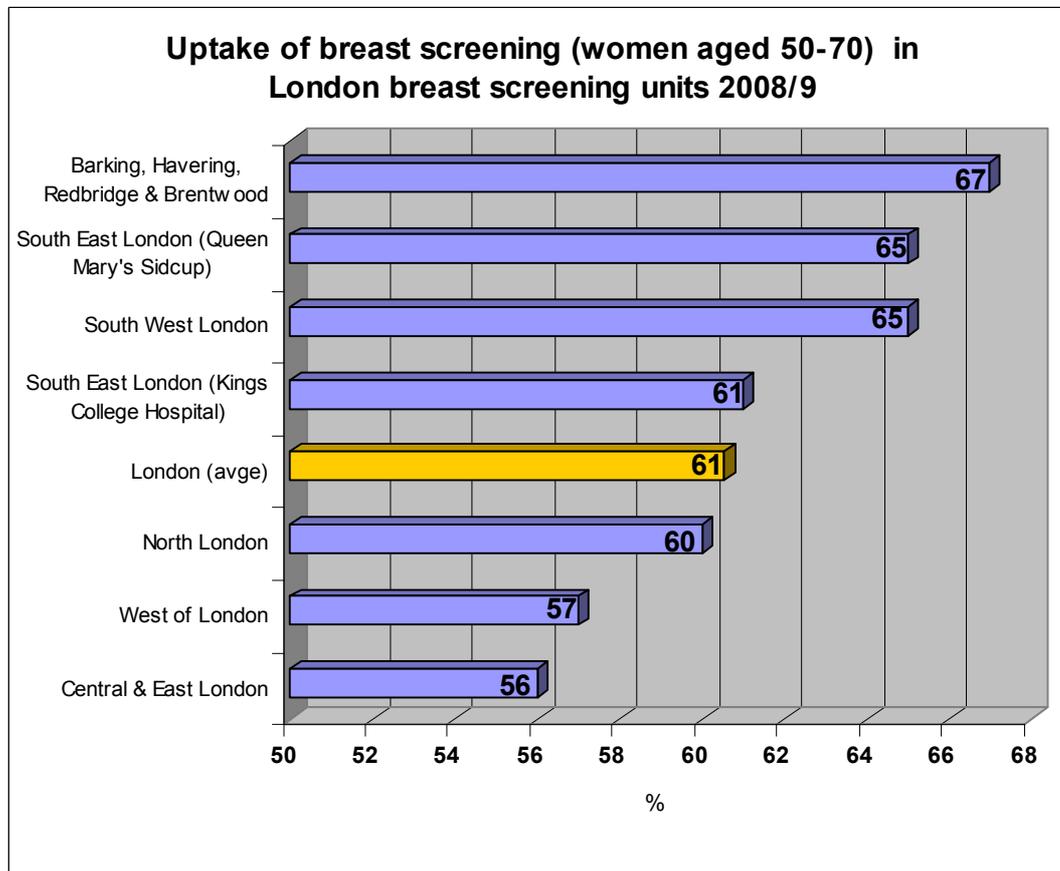


Figure 3 – Breast screening coverage across London PCTs (March 2009)

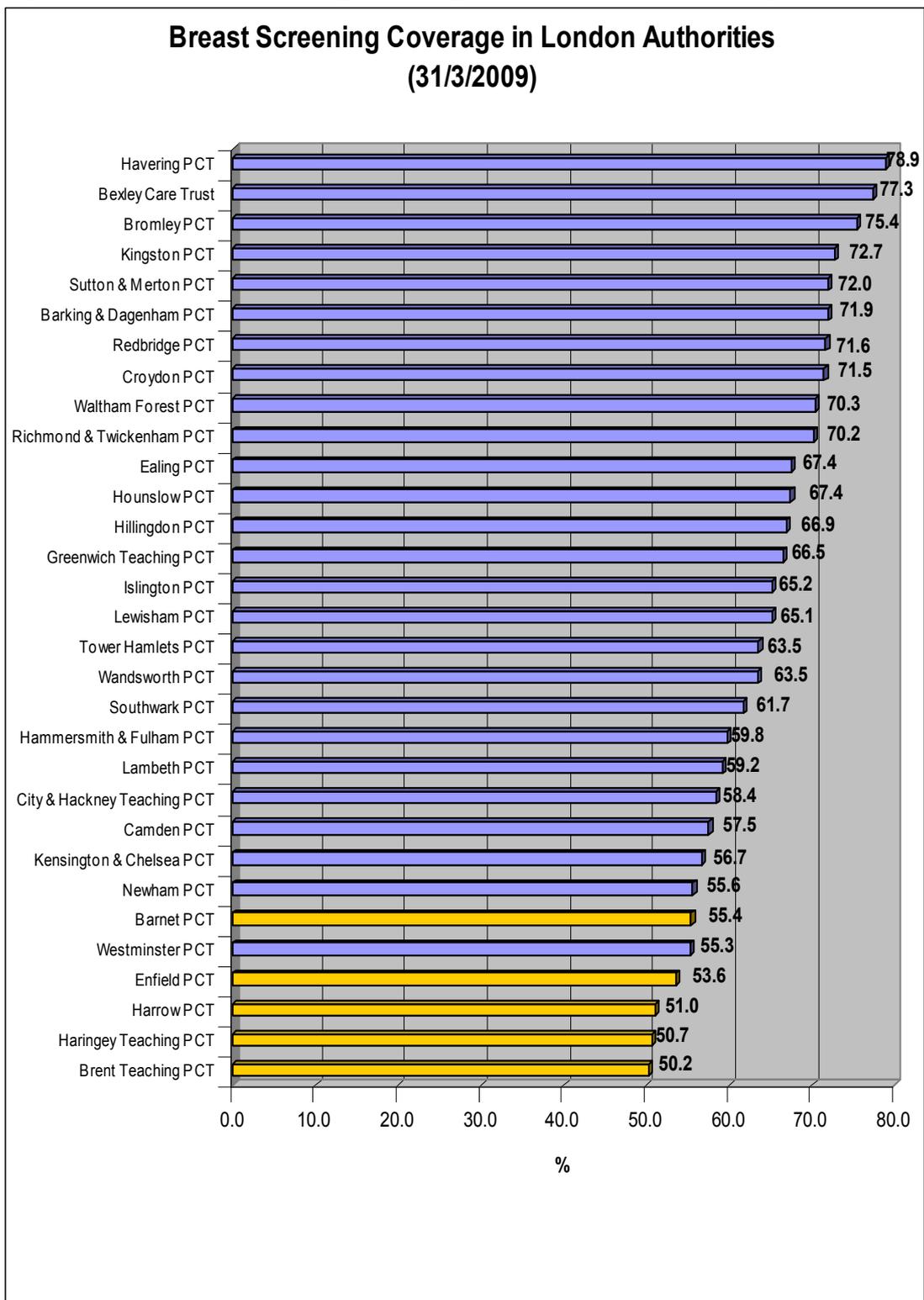


Figure 4 – Breast screening round length in London screening units (07/08).

London Quality Assurance Reference Centre

**Breast Screening Roundlength by Unit 2007-08 (Ages 50-64)**  
 (Target 90% of Women to be re-invited within 36 months of previous screen)

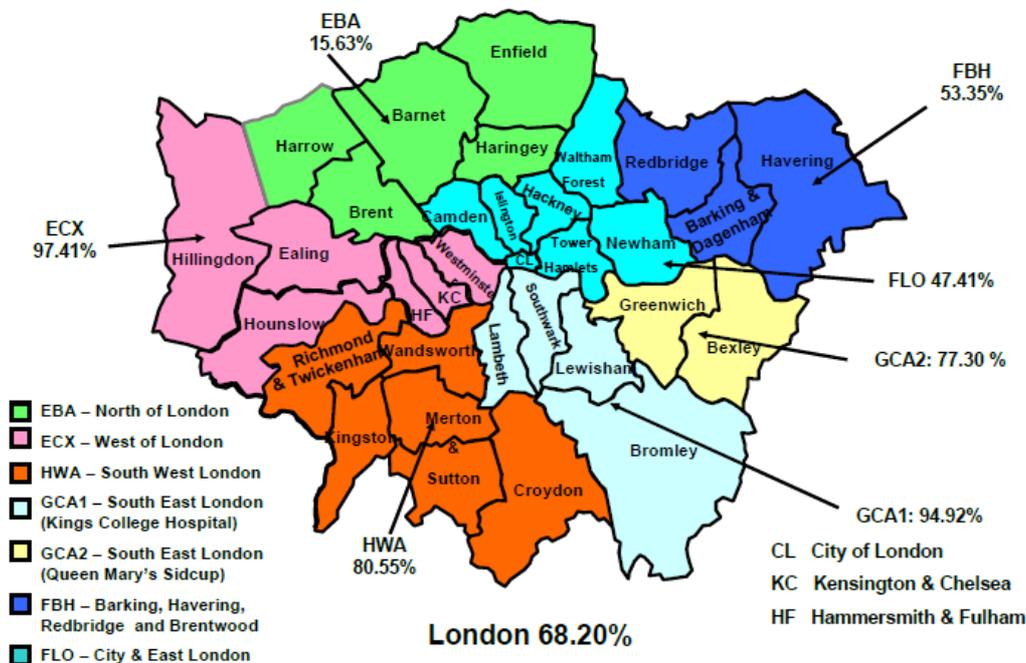


Figure 5 – Uptake of breast screening in NLBSS area (2008/9)

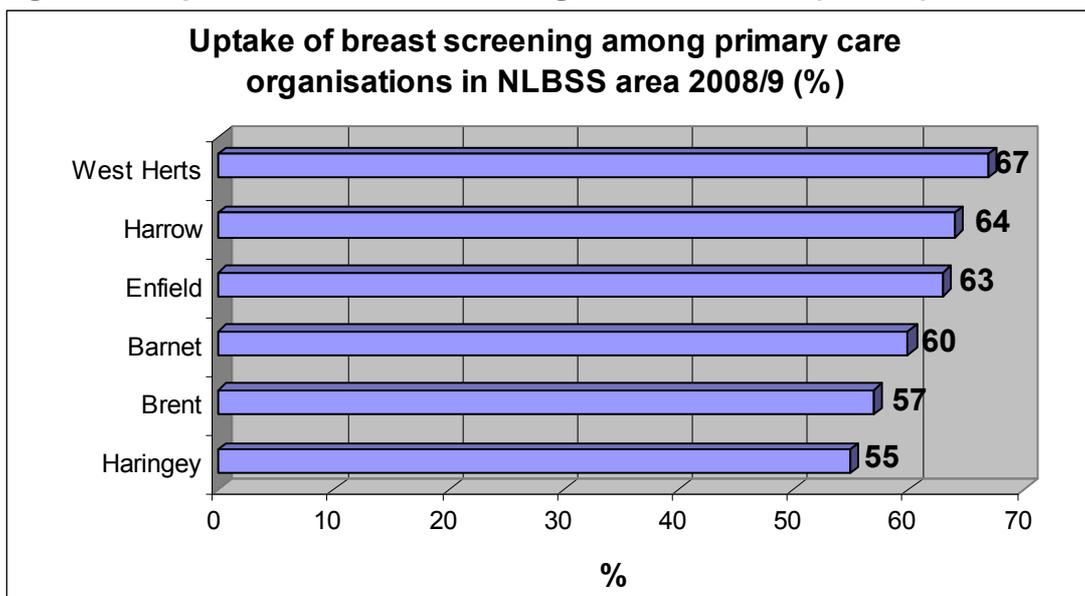


Figure 6 - Breast screening coverage by GP practices in Haringey 08/09

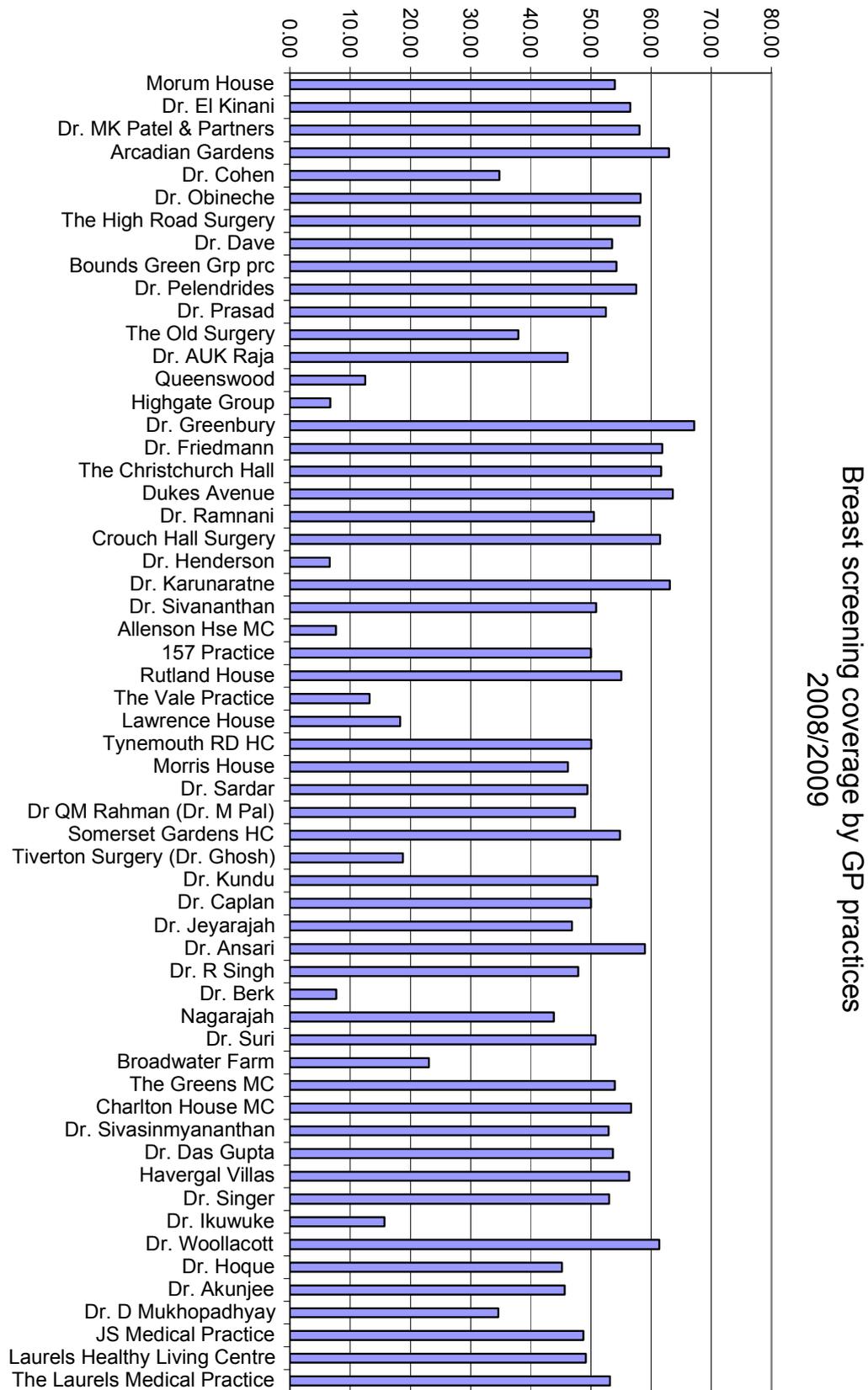
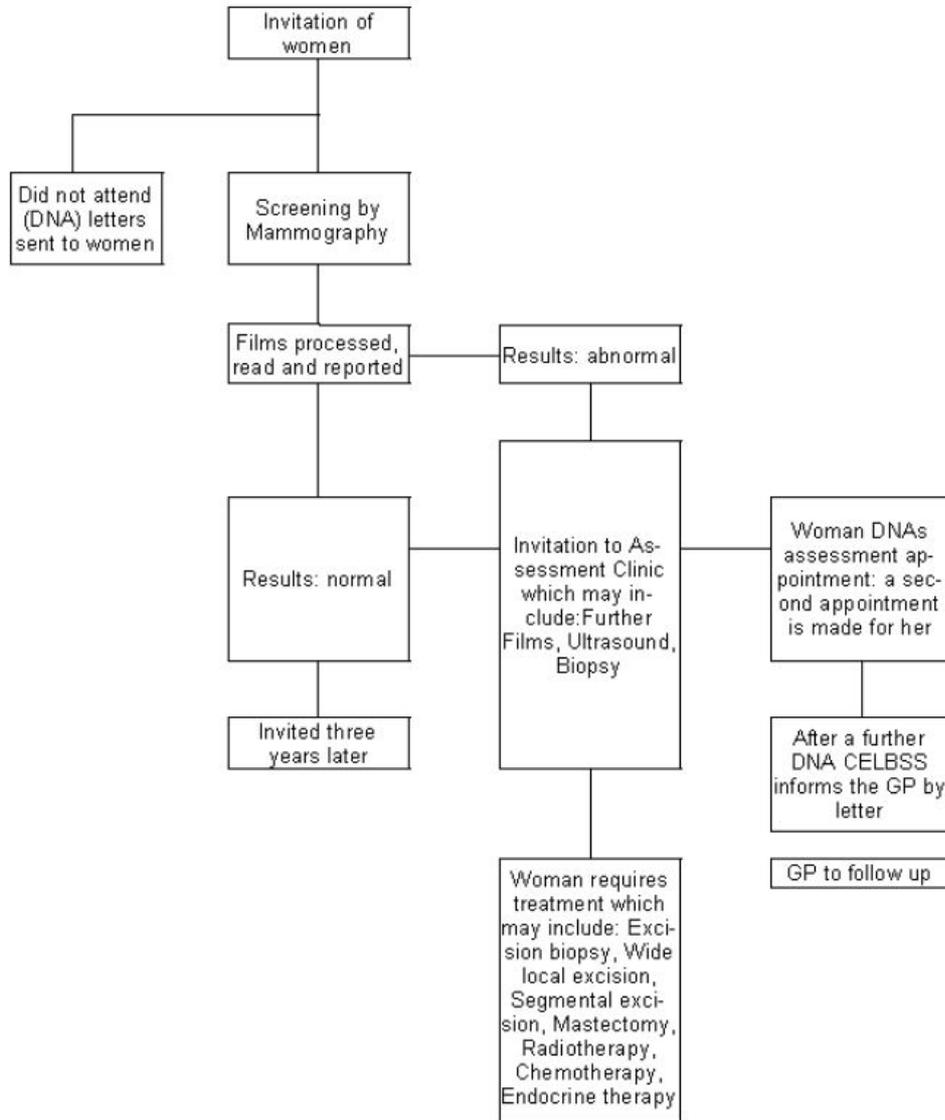


Figure 7 – Breast Screening Pathway



Taken from: Central and East London Breast Screening Service.

**Appendix B – List of participants to the review process**

<b>Name</b>	<b>Role</b>	<b>Organisation</b>
Dr Kathie Binysh	Director	London Cancer Screening Quality Assurance Reference Centre
Fiona Bonas	Network Director	North West London Cancer Network
Debbie Brazil	General Manager	North London Breast Screening Service
Tamara Djuretic	Public Health Consultant (Lead commissioner for Screening)	NHS Haringey
Alison de Metz	Performance & Programme Manager	NHS London
Dr Jane Moore	Associate Regional Director of Public Health	NHS London
Dr Helen Pelendrides	General Practitioner	NHS Haringey
Duncan Stroud	Associate Director Communications, Stakeholder Engagement and Partnerships	NHS Haringey
Dr Zelenyanselu		North West London Cancer Network

## Appendix C – Invite to Consultation

### Overview & Scrutiny Team

7th Floor, River Park House, 225 High Road, Wood Green, London N22 8HQ

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[www.haringey.gov.uk](http://www.haringey.gov.uk)



Head of Policy & Performance Eve Pelekanos

**Haringey Council**

Dear Client of the North London Breast Screening Service

The Overview & Scrutiny Committee of Haringey Council is carrying out a review of breast screening services in the borough. The aim of this review is to find out why fewer women take up their invitation to breast screening in Haringey than in many other boroughs and to suggest ways in which access to screening services can be improved.

As a recent user of the screening service, we would like to invite you to a consultation session to hear your views. The session would give you the chance to talk about your experience at the breast screening unit to find out how accessible you found the service and how you think access can be improved. If you are interested in taking part, you can attend one of the following sessions:

Tuesday 26 <sup>th</sup> January	2.00-3.00pm	Haringey Civic Centre, High Road, Wood Green. N22 8LE
Tuesday 26 <sup>th</sup> January	6.30-7.30pm	Haringey Civic Centre, High Road, Wood Green. N22 8LE

Please be reassured that the above sessions are women-only and that the information that you provide will be in confidence and will not affect your right to access services in the future. All those women who attend the consultation will be given a £10 voucher to cover any expenses incurred.

If you would like to attend I would be grateful if could confirm before the 26<sup>th</sup> January 2010 by contacting Martin Bradford either by telephone: **0208 489 6950** or email: [martin.bradford@haringey.gov.uk](mailto:martin.bradford@haringey.gov.uk). (Please note each session will be limited to a maximum of 12 women.)

For those women not able to attend the consultation event but who would like to take part in the review, a short survey is attached to this letter. The survey provides a further opportunity to feedback your views about the breast screening service. Again, all information you provide in the survey will be in confidence. All those who complete and return the survey before **22<sup>nd</sup> January 2010** will also be placed in a draw for a £25 voucher.

May I take this opportunity to thank you in anticipation of your support for the review.

Yours sincerely

**Cllr David Winskill**

**Chair, Scrutiny Review Panel (Scrutiny Review Breast Screening Services)**

**Appendix D – Breast Screening Survey****Breast Screening Survey****1. Which breast screening site did you attend?**North Middlesex Hospital  Forest Road  Whittington Hospital **About the letter inviting you to attend for a breast screen****2. Was the invite easy to read and understand?**Yes  No  Not sure **3. Was the information you received about breast screening available in other formats for example, in other languages, in large print or in audio form?**Yes  No  Not sure **4. Were you given enough information about what would be involved in attending for a breast screen?**Yes  No  Not sure **5. Were you given enough information about how to get to the breast screening service (i.e. where the unit was located, public transport routes)?**Yes  No  Not sure **6. Would you have liked any other information before your screening appointment? (Please describe)**


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**About your appointment at the breast screening clinic****7. Was the appointment for your breast screen convenient for you to attend?**Yes  (go to Q9) No **8. If your appointment was not convenient, was it easy to make another at a more suitable time?**Yes  No 

If no, please describe why:

---

**Getting to the screening service****9. Did you experience any of the following difficulties in accessing your breast screening appointment?**

	Yes	No	Not sure
Inconvenient appointment time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty getting time off-work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Making arrangements for someone you care for	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Limited public transport to site	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Parking problems on site	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty in locating the breast screening service	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Other problems (please describe)

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**10. If you experienced any difficulty in accessing your breast screening appointment, was there anything that could have been done differently to make it easier to attend?**

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**Your experience at the breast screening clinic**

**11. How satisfied or dissatisfied were you with the following at the breast screening clinic?**

	Satisfied	Dissatisfied	Not Sure
Welcome/ reception	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Waiting time in the clinic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Friendly and helpful staff	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Provided with enough information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Do you have any other comments? \_\_\_\_\_

**12. On the whole, how satisfied were you with the quality of the breast screening service?**

Satisfied       Dissatisfied       Neither satisfied or dissatisfied

**13. Would you recommend the breast screening service to a friend?**

Yes       No       Unsure

**14. Is there anything else you would like to add about your visit? In particular, we would like to hear how you think we can encourage more people to attend their appointment for breast screening?**

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**15. How old are you?**      51-60       61-70       71 and over

**16. What is your ethnic group?**

White		Black/Black British		Mixed	
British	<input type="checkbox"/>	Caribbean	<input type="checkbox"/>	White & Black Caribbean	<input type="checkbox"/>
Greek/Cypriot	<input type="checkbox"/>	African	<input type="checkbox"/>	White & Asian	<input type="checkbox"/>
Turkish/Cypriot	<input type="checkbox"/>	Other	<input type="checkbox"/>	White & Black African	<input type="checkbox"/>
Turkish	<input type="checkbox"/>	Asian/Asian British		Other	<input type="checkbox"/>
Kurdish	<input type="checkbox"/>	Indian	<input type="checkbox"/>	Chinese or other ethnic group	
Irish Traveller	<input type="checkbox"/>	Pakistani	<input type="checkbox"/>	Chinese	<input type="checkbox"/>
Gypsy	<input type="checkbox"/>	East African	<input type="checkbox"/>	other	<input type="checkbox"/>

**If you would like to take part in the free prize draw for a £25 voucher please leave you contact details below:**

Name: \_\_\_\_\_

Contact telephone: \_\_\_\_\_

**Thank you for completing this survey. Please return by  
22<sup>nd</sup> January in the prepaid envelope provided.**



**Appendix F - Consultation with service users.**

# **Scrutiny Review of Breast Screening Services in Haringey**

Report from the consultation with users of North  
London Breast Screening Service.

**February 1<sup>st</sup> 2010**

## **1. Introduction**

- 1.1 A review of breast screening services was commissioned by the Overview & Scrutiny Committee in 2009. The review is seeking to assess the reasons behind the low uptake of breast screening services by women resident in Haringey and to identify possible remedies to help improve service uptake. The conclusions and recommendations of the panel will be presented to the relevant commissioning agency: NHS Haringey.
- 1.2 As part of the review process, a consultation was planned with Haringey residents who had used the breast screening service (North London Breast Screening Unit). This following provides an analysis of data from both questionnaire and focus groups used in the consultation. It is hoped that these findings will guide and inform final recommendations for the review.

## **2. The consultation method**

- 2.1 It was decided that a mixed method methodology, which involved both quantitative and qualitative data collection techniques, offered the best approach for this consultation. Firstly, the use of a questionnaire would facilitate the identification of broad themes which could be followed up in greater detail within the subsequent focus groups. Also, given the sensitivity of the subject area, the two methodologies would allow differing levels of engagement and privacy to best suit women considering participating in the review.

### The Survey

- 2.2 The questionnaire was designed in consultation with the North London Breast Screening Service. The survey sought to assess service user's perceptions of the breast screening invite, the appointment system, the quality of breast screening services provided and possible suggestions for improving screening uptake.
- 2.3 As the consultation was trying to understand low service take up, it would have been ideal to target the survey distribution to those women who did not attend for their appointment. It should be noted however, that due to data limitations, this was not possible. In this context, some caution should be exercised in interpreting data, especially in terms of accessibility of services, as the survey is likely to have been distributed to those that already attended the service.
- 2.4 The survey was distributed to 200 women resident in Haringey who had been invited to breast screening in December 2009. Participants were reassured that all responses would be treated confidentially and a prepaid envelope was included to facilitate responses. As an incentive, a draw for a £25 voucher was offered to all those that returned completed responses. The survey is contained in Appendix 2.

### Focus Groups

- 2.5 An invite to participate in a focus group was distributed in two ways: through inclusion with the postal survey and through a mail out to local women's groups. The invite offered women the opportunity to participate in one of two planned focus groups. Both focus groups were of one-hour duration and facilitated by a member of the scrutiny panel and scrutiny support officer (both female). Focus groups were held in the afternoon and evening to facilitate participation.
- 2.6 Participants in the consultation sessions were reassured that all information provided would be given in confidence and that their participation in the review would not affect their right to access future services. Participants were provided with £10 voucher in lieu of expenses incurred for attending the consultation session. The invite is contained in Appendix 1.

### 3. Survey and focus group results

#### Responses

- 3.1 In total, 63 completed questionnaires were returned. This produced a response rate of 32% which can be considered to be good for a postal questionnaire. A further 10 women accepted the invitation to participate in one of the two planned focus groups. In total therefore, approximately 70 Haringey women who had used the breast screening service participated in the review.
- 3.2 The breast screening programme includes women between the ages of 50 and 70 years where invites are distributed practice by practice on a three year rotation. These factors clearly influence the demographic data of respondents. Analysis reveals that almost  $\frac{3}{4}$  (72%) of survey respondents were aged between 51-60 years and the majority (72%) of respondents were of white British ethnic origin (Figure 1).

**Figure 1 – Demographics of respondents (n=62)**

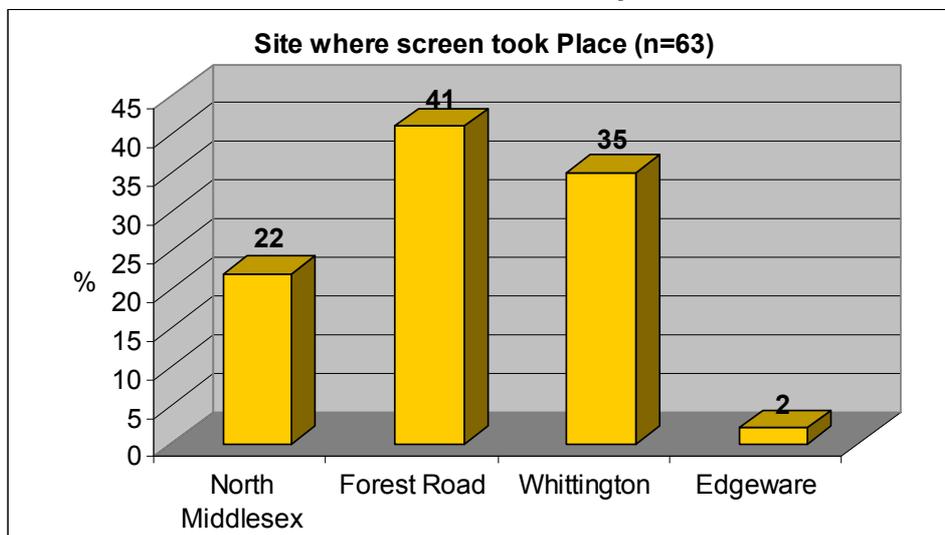
Age group (%)		Ethnic Origin (%)	
51-60	72	White British	72
61-70	28	Black Caribbean	18
		Turkish	2
		Indian	2
		Mixed ethnic origin	5
		Other	2

- 3.3 It had been noted during the review process that proportionally fewer women from the lower end of the screening age spectrum attended for screening. It was therefore interesting within this survey at least, to record that a higher proportion of women in the younger age group responding to this survey. Ethnicity data is unlikely to reflect local population estimates as breast screening invites are issued on a practice by practice basis in individual localities and subject to local population variations.

#### Screening Location

- 3.4 The NLBSS operates breast screening clinics from a number of sites in North London and respondents indicated that they attended one of four such clinics in this area (Figure 2). In this survey, approximately 2/5 respondents attended the Forest Road Polyclinic and just over 1/3 attended the Whittington Hospital. A very small proportion of respondents (2%) attended the Edgware Hospital site (Figure 2).
- 3.5 It should be noted that breast screening sites detailed in Figure 2, although close to Haringey borough boundaries, none are actually located in Haringey. Thus, 63% of respondents attended clinics based in Enfield (North Middlesex Hospital or Forest Road Polyclinic), 35% attended the clinic in Islington (Whittington) and 2% in Barnet. This is an important factor when interpreting later clinic accessibility data.

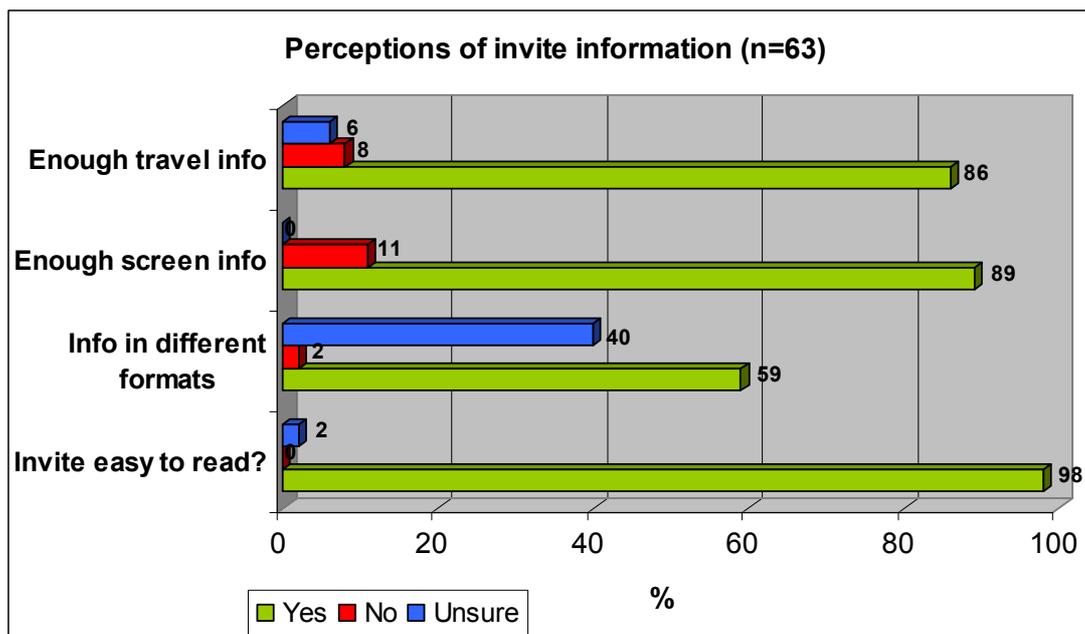
**Figure 2 – The site where breast screen took place**



#### Breast Screening Invite

- 3.6 At approximate 3 year intervals, women between the ages of 50 and 70 years are invited for a breast screen at the local breast screening unit, the North London Breast Screening Service (NLBSS). The invitation consists of a letter explaining the importance of regular breast screens and a preset appointment at one of the breast screening clinics. An information booklet on breast screening accompanies the invite letter (Breast Screening: the Facts).
- 3.7 The questionnaire sought to assess women's perceptions of the breast screening invite, in particular, whether the invite was clear and easy to understand and whether the information provided was sufficient for those women about to attend for a breast screen. Figure 3 provides a summary of these responses.

**Figure 3 – Service user's perceptions of invite to breast screening service.**



3.8 Almost all (98%) survey respondents found the invite easy to read and understand (Figure 2). Proportionally fewer, though still a clear majority of respondents indicated that the invite provided enough information about breast screening (89%) and travel information to access the clinic where there appointment was. Far fewer respondents indicated that they were aware that the invite information was available in different formats (large print, community languages).

3.9 Analysis of qualitative responses from both the questionnaire and the focus groups identified a number of key themes. Firstly, a significant proportion of women had previously attended the breast screening clinic and thus knew what was involved during a visit. As one would expect, this group of women had fewer information needs than those who had not attended before:

*'I have been screened before so I knew what would happen.'* Whittington

*'I have already been through the process.'* Forest Road

3.10 Even though there is an accompanying booklet, a number of women, perhaps first time service users, clearly wanted to know more about what would happen in the breast screening clinic. More specifically, what the data reveals was that perhaps some women wanted something more personal than the booklet to explain what would happen at the breast screen:

*'[It would be useful to know] I think it would be useful to be told in a reassuring manner what would be involved.'* Forest Road

3.11 Analysis of focus group data revealed that a number of participants who spoke a minority language, had concerns that the invite appeared only to be available in English. The focus groups identified a need to have some minimum translation in a key local community languages included within the invite, even if this was just a reference to where further information could be found.

- 3.12 Analysis of the survey data *and* focus group data produced clear evidence for the need to include additional travel information within the invite, to explain how women can access particular breast screening clinics. A significant number of respondents who attended the Forest Road breast screening clinic indicated that additional travel information (public transport, parking facilities or a map) should be made clear within the invite to enable them to make appropriate travel arrangements to the site:

*'Improved directions would help, [perhaps to] include a map would be really helpful and make sure they are detailed enough i.e. bus stops, parking, tubes....'*

*'I can't remember if there was a map, I think not, a little map of the area around the site would have helped as I wasn't sure where to get off the bus...'*

*'A little map and info about local buses which run close to the clinic would be good.'*

*'Information should be given in the letter regarding transport facilities to this particular centre such as bus routes tube and parking and this needs to be updated regularly as things do change.'*

#### Breast Screening Appointment

- 3.13 The questionnaire and focus group sought to assess respondents' perceptions of the operation of the appointment system at the NLBSS, in particular whether the preset appointments which are offered to women were convenient, and if not, the ease with which women could change these. The survey data revealed that just 34 out of 62 (55%) of respondents indicated that the first preset appointment was convenient (Figure 4). Furthermore 8 out of 28 (29%) women who found the appointment inconvenient did not find it easy to change this appointment (Figure 4).

- 3.14 Analysis of both questionnaire and focus group data found there to be a number of significant concerns around the operation of the NLBSS appointment system. The location of the clinic at which women were allocated their appointment was the subject of considerable concern among participants in the consultation. In particular, respondents could not understand why the location of their appointment was so far from the area in which they lived:

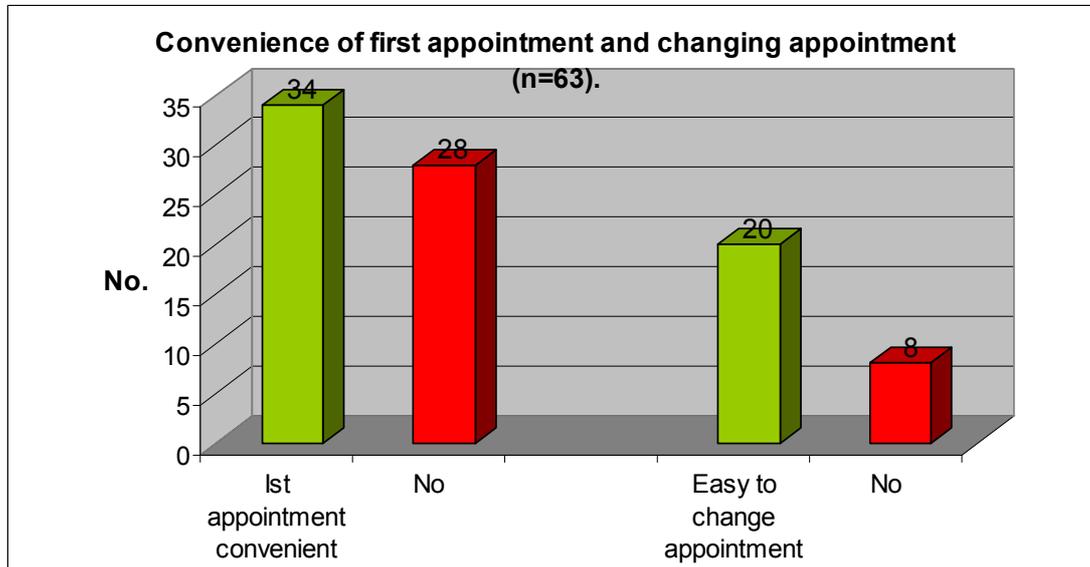
*'I would have preferred an appointment nearer home. I was given an appointment at Forest Road when I could have walked to the Whittington.'*

*'The first appointment I was given was hopeless, an impossible location and no choice of time. I live in Hornsey and was offered an appointment in Edmonton. I can only get to Edmonton by 3 buses... the Whittington [would have been] fine.... '*

*'No I was not happy, there were no more local appointments available at the Whittington so I had to travel all the way to Edmonton from N8.'*

*'I would like more choice about where I attended e.g. the North Middlesex Hospital as I only needed to get one bus to get there, in fact I could have walked. (Forest Rd appointment)*

**Figure 4 – Service user's perceptions of the appointment system.**



- 3.15 It is apparent from the analysis of survey data, that respondents are not aware that there are a number of breast screening locations *and* that it may be possible to change their preset appointment to a nearer and more convenient location:

*'I was invited to a hospital a long way away it was only when I phoned that I found out it was possible to go to the Whittington which is far more convenient.'*

- 3.16 From the analysis of the survey data, it is clear that the location of the breast screening appointment is of critical importance as to whether women attend their allocated breast screening appointment. It would appear that this represents a clear barrier to service accessibility, which perhaps only the more motivated or aware women may overcome:

*'I live 10 minutes away from the Whittington and I rang to see if there was a closer site I could attend, but was told Forest Road was the nearest – which was clearly not true! It took me over an hour and a half to get there by bus. I think it's important to attend for breast screening, otherwise given the inconvenient location, I would not have bothered.'*

- 3.17 Another strongly expressed concern about the appointment system which was evident within the survey and from the focus groups, was the lack of appointments available outside of normal working hours. Here it was evident that a significant number of women indicated that they were in employment which made it difficult to attend appointments:

*'The problem for me is that the appointments are always during daytime working hours, some evening and weekend appointments could be*

*offered. As I have a full time job I have to make sure I my work is covered (I am a Dr) during my hours of absence.'*

- 3.18 Furthermore, where out-of-hours appointments were available, these were situated a long way away for Haringey residents. Within a focus group, a participant noted that in order to be able to go for a breast screen on a Saturday morning, she would have to go to Edgware Hospital which had involved two long bus journeys. The same concerns about the accessibility of the out of hours clinics was also recorded within the survey:

*'I would have preferred an appointment outside of working hours at the Whittington but there was only one further away at Edgware.'*

*'Edgware was the only appointment available on a Saturday.'*

- 3.19 A third concern with the appointment system was that women experienced some difficulty in getting through to the NLBSS to try and change their appointment, and the apparent lack of capacity within the system to enable to change their appointment:

*'I was told to ring back twice for an alternative appointment. I then gave up and took time off work to attend the screening unit.'*

*'I rang the number and there was a long wait to get through then it was engaged repeatedly. The receptionist was helpful but did not have appointments beyond the next 2 weeks – so I had to ring back again two weeks later – and go through the whole process again - which was both time consuming and expensive.'*

*'There was no opportunity to have an alternative date / time when I rang.'*

#### Difficulties in accessing breast screening appointment

- 3.20 Survey respondents were asked to indicate, from a range of preset options, if they experienced any difficulties in accessing their breast screening appointment. Analysis of responses found that 28% of women had difficulty getting to their appointment because of the allocated appointment time slot (Figure 5). The availability of parking (25%) and getting time off work (22%) were other important factors which affected the accessibility of their appointment.

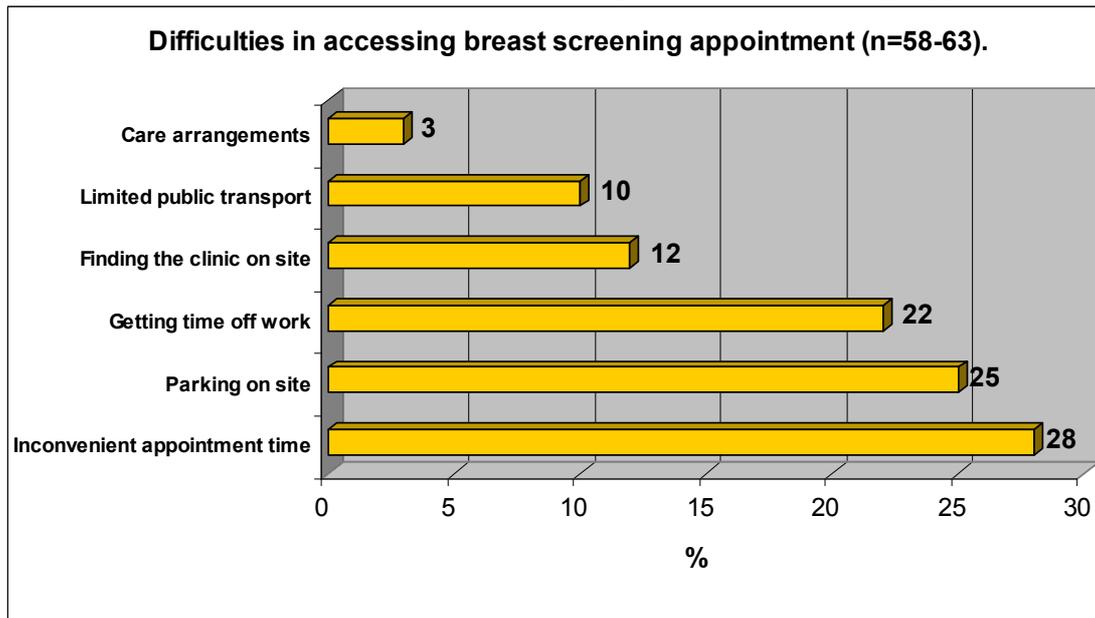
- 3.20 Given the length of journey that women are expected to take in accessing breast screening services, it is likely that many may choose to access the clinic by private car. In this context, a number of respondents highlighted the parking problems associated with a number the screening sites, particularly in relation to the availability of spaces and the cost:

*'Car park fees to be cheaper.'* (NMH)

*'Parking is a problem.'* (Whittington)

*'I am aware that parking restrictions are not within the remit of the NHS, but they are getting more chevrons year by year.'* (Forest Road)

*'Had I been arriving by car I am not sure where I would have parked or if there were any spaces?'* (Whittington)

**Figure 5 – Stated difficulties in accessing breast screening appointment.**

- 3.21 The availability and cost of parking may be one area that needs to be addressed in the provision of adequate travel information in the breast screening invite:

*'Perhaps give information about the cost of parking and also an estimation of how long screening is likely to take so that parking time can be planned for. I nearly ran out of time and had to run out to my car before the ticket expired.'*

- 3.22 Another problem to emerge from the analysis of survey data was the difficulty of accessing the breast screening service whilst on site. A number of women, particularly those that attended the Forest Road clinic, indicated that there was inadequate signage for the screening unit at the polyclinic site and the waiting area not clearly marked:

'Not very clearly signed when I arrived at the centre.' (Forest Road)

'I couldn't find it, there was NO SIGNAGE at all or instructions as to where to wait.' (Forest Road)

'I did not see any information outside the clinic to suggest that breast screening was being done in the building. (Forest Road)

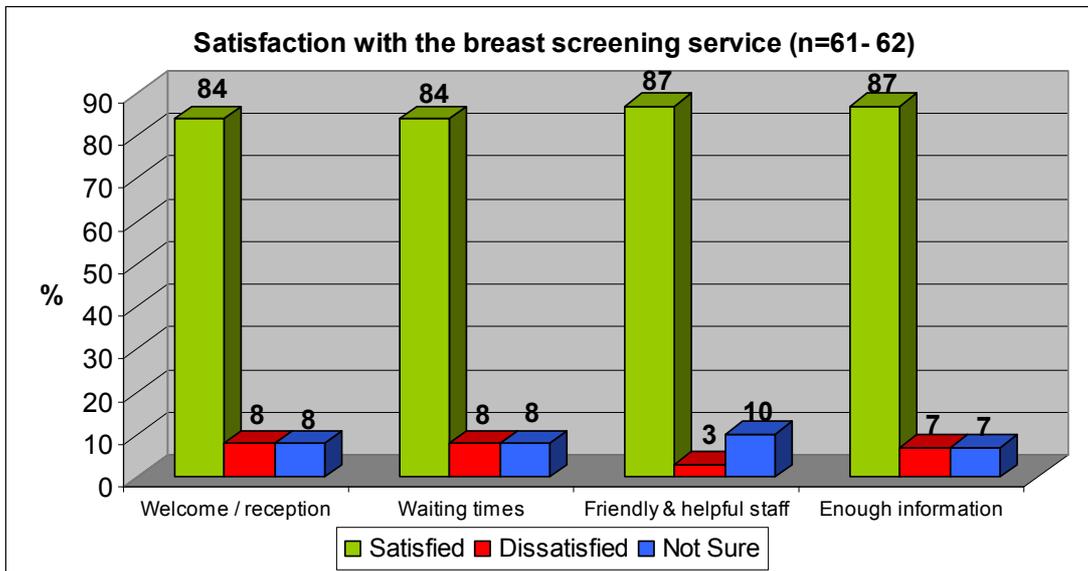
'It wasn't obvious where to go, no signs to mammography and even when I joined the three women sitting waiting I wasn't sure I was in the right place until a nurse appeared. (Forest Road)

#### Experience of breast screening service

- 3.23 The survey sought to assess women's experiences of the breast screening service as this data may be useful in determining whether women would be likely to re-attend the service in the future. Analysis of service data found high levels of satisfaction with all aspects of the service (Figure 6). Here, high levels of service user satisfaction were recorded for the welcome to the clinic

(84%), waiting times (84%), friendly and helpful staff (87%) and the provision of information (87%) (Figure 6).

**Figure 6 – Service user satisfaction with breast screening service**



3.24 The high levels of satisfaction recorded quantitatively with breast screening service was verified in the analysis of qualitative comments by respondents. Here it was evident that women found the breast screening services to be friendly, reassuring, informative and efficient:

*'The whole experience was made as pleasant as possible and the staff were very considerate.'* (Whittington)

*'Excellent staff, all very friendly and reassuring.'* (Edgware)

*'... friendly and informative, keep up the good work.'* (Forest Road)

*'...very quick and efficient.'* (Whittington)

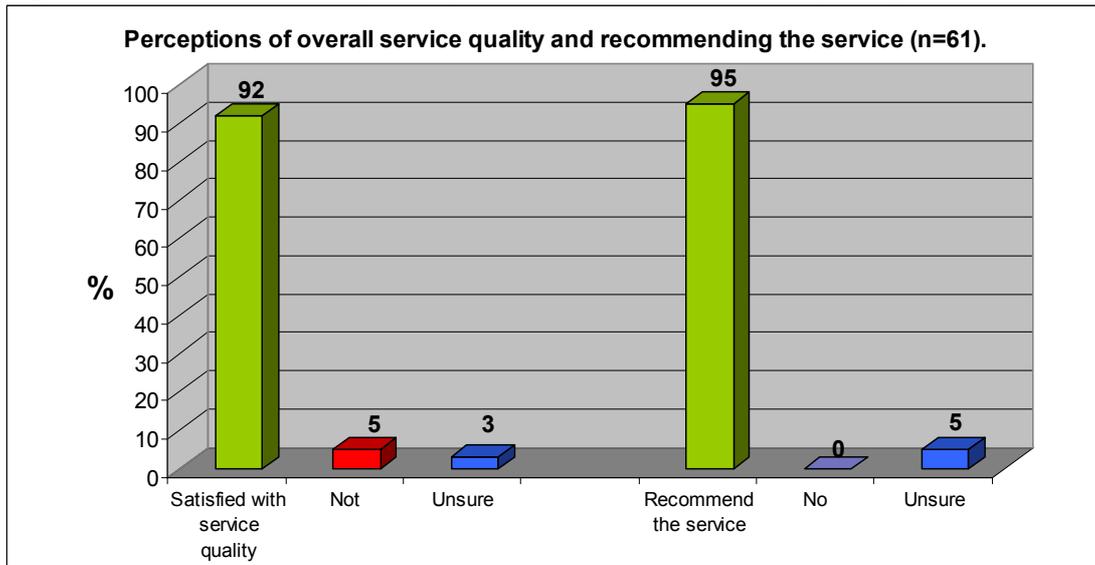
*'I think it's a great service, thanks.'* (Forest Road)

3.25 Whilst there were high levels of satisfaction with the service, this was not to suggest that there could not be areas of improvement, for example, the waiting areas were all identified as a service area which could be improved. These were not always clearly identified and there could be additional facilities or information at hand to reassure women about to have a breast screen:

*'It needs a clearly designated waiting area here.'* (Forest Road)

*'Maybe show a DVD of what will happen in the breast screen while a patient is waiting.'* (NMH)

3.26 The satisfaction that respondents felt with the breast screening service is reflected with overall service perceptions. Here, the overwhelming majority of respondents were satisfied with the quality of the service (92%). Underlining the satisfaction respondents had with the service was the fact that 95% of respondents felt able to recommend the service to a friend (Figure 7).

**Figure 7 – Service user perception of overall service quality.**

#### Suggested ways to improve screening take up

- 3.27 Both respondents and focus group participants were asked to identify ways in which breast screening uptake among women in Haringey could be improved. There were a range of suggestions put forward and these are presented in order of priority below.

#### More Convenient locations

- 3.28 The most important issue to arise from both the survey and focus groups was the need to allocate women to appointments at a breast screening clinic which was more conveniently located to where service users live. It was evident from the survey that many service users had to travel some considerable distance to their allocated appointment, which was clearly a barrier to service uptake:

*'If it was nearer home a more convenient location, I think more people would attend.'*

*'People in my area would be far more likely to attend the clinic if it was more local and on public transport....'*

*'If you could give appointments closer to where people live it would help.'*

- 3.29 Thus as a priority, respondents felt that a wider range of screening locations need to be developed for women in Haringey and ensure that these are actively promoted and developed:

*'There needs to be more options of where people can screen.'* (Forest Road)

*'I think that a broader range of sites would be helpful – none of the sites offered were even in Haringey – what about St Ann's Hospital or the new polyclinic on Park Road or Morrison's supermarket at Wood Green?'*(NMH user)

Improve out-of- hours access

- 3.30 Out of hours access to breast screening clinics was seen to be important in the survey, so it is no surprise to record this as an area which women felt should be developed to help improve uptake. The issue here is two fold, firstly to develop out-of-hours options for women seeking to use the service and secondly (as seen from earlier data) ensure that extended opening hours clinics are developed at more convenient locations to Haringey women.

*'[Should] increase the number of evening and Saturday appointments.'*  
(NMH)

*'...perhaps evening or Saturday appointments?' (Forest Road)*

*'If possible, if the appointment was offered for an evening or Saturday morning more women may take the visit up for screening.'* (Forest Road)

Community outreach work

- 3.31 There was a broad consensus among both survey respondents and focus group participants that there is a need to actively promote the breast screening service to women in Haringey. In the focus groups, none could recall seeing any posters or any other promotional literature promoting breast screening in local surgeries or other community venues. In this context, it was felt that there should be more outreach work targeted at women eligible to participate in the breast screening programme.

*'It would help some women to hear about the importance of screening from someone in the local community where they come. An idea would be to set up meetings with local community workers with the aim of encouraging women to attend.'*

*'How about issuing information to churches, women's centres and clubs so that they can make a list of names and addresses of women that are interested that could be referred.'*

*'...you could offer over 60's groups a chance to attend together?'*

- 3.32 In particular, a number of respondents suggested that there should be work to target those women who may be hard to reach or who may face particular problems in accessing the breast screening service.

*'I fully believe that the system is fine – but I assume that you already make arrangements with third parties such as care workers, Social Workers, Mental Health Workers?'*

Service personalisation

- 3.33 Analysis of the survey data and focus group data confirmed that many women access the breast screen service with a range of anxieties. The concern among participants within the consultation was that if these concerns were left unaddressed then this may affect a woman's decision to attend for a screen. In this context, it was felt that developments which personalised the service may reassure women who have concerns or anxieties about attending for a breast screen.

- 3.34 A number of suggestions were put forward for personalising the service. Firstly, it was suggested that women, particularly first time users of the service, should be encouraged to attend with a friend or relative for reassurance:

‘People who are uneasy about attending may be more likely to do so if they could be accompanied.’

- 3.35 A second way in which the personalisation of the service could be improved was through the inclusion of individual service testimonials within the invite information. Here, it was felt if more personal accounts of women who had used the service were included this may help to demystify and explain the screening process better to prospective attendees:

‘Reassurance testimonials from other women may help like “I have small breasts and so I thought it would be painful to squeeze them between two metal plates – but it wasn’t metal and it didn’t hurt. Also the screener was kind and it wasn’t embarrassing”.’

- 3.36 In both the focus groups and the surveys responses, it was also evident that there was a desire for more personalised contact ahead of the breast screen appointment to answer any personal questions or allay any personal anxieties. In the focus groups, it was felt very strongly that there should be more opportunities to speak personally to someone within the service. This was particularly the case for women who were having their first breast screen:

‘This was my first time and even though I was satisfied with the service, someone should have come and spoke to me about what to expect.’

#### Work with GPs and primary care

- 3.37 In the focus groups, there was strong support for the breast screening service to work more closely with GPs and primary care. It was felt, at the very least, that there should be more promotion of the breast screening service in local surgeries through further publications such as posters or leaflets.

*‘...there needs to be more adverts in the GPs....’*

- 3.38 It was also felt that there could be more structural developments in the primary care setting which may help boost the uptake of screening appointments. Suggestions from the focus groups included; a flag system for GPs to notify women reaching 50 that they are eligible for breast screening; checking on practice registration whether women were attending the screening programme and thirdly, validate breast screening attendance through the newly established vascular checks (three year programme of checks for 40-74 year olds).

#### Community languages

- 3.39 As has been previously mentioned within this review, it was noted that the invite and other accompanying information was not available in community languages. Analysis of data from both the survey and focus groups identified this as an area where further work could be done to improve the uptake of breast screening services. Two specific suggestions were put forward from the focus groups:

- Translation of invite and other breast screening information on a website

- The inclusion of a pictorial guide to breast screening

Service promotion / promoting prevention

3.40 Another suggestion for improving uptake was to undertake greater promotion of the breast screening service at targeted locations. It was also suggested that there should be further local public health and health promotion work to raise awareness of the risk of breast cancer, to teach women self examination and the benefits of breast screening:

*'It is important to look after yourself, the benefits of screening, what screening involves.... .'*

*'Its better to find things out sooner rather than later... '*

3.41 Reminder letters/ calls

Finally, it was suggested that reminder letters or telephone calls would be helpful in promoting attendance at breast screening service.

*'Phone call reminders would be helpful.'*

*'Phone calls or letters to women to confirm their appointment would be really helpful.'*



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