



NHS Haringey

Increase Uptake of Breast Cancer Screening

Scoping Report

March 2009

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Introduction

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

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

In December 2006 The North London Breast Screening service at Edgware Community Hospital was suspended due to system process errors. Although the service re-opened October 2007, it left a ten-month backlog of appointments with women struggling to arrange routine breast screening¹.

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

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

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

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

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

The Challenge

The London Borough of Haringey is an ethnically diverse and socially deprived Borough with breast cancer cited as the 3rd most common cancer among its residents². Social deprivation is often linked to negative lifestyle factors, such as smoking and poor diet, which increase the risk of developing breast cancer. Therefore the women living in this deprived Borough already represent a high risk group. Deprivation is also associated with poorer breast cancer survival rates, which has at least in part been attributed to low screening attendance³.

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

Haringey has an ethnically diverse population. The female population eligible for breast screening in Haringey is made up of around 66% White British and White other, 21% Black and Black British, and 11% Asian⁴. This ethnic diversity provides a population pool with varying backgrounds and beliefs. Cultural variation can impact upon screening attendance variations and therefore it is of key importance to investigate this.

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

UK Policy

Tackling cancer is a national priority for the NHS. This is evidenced by the NHS Breast Screening Programme, set up in 1988 following the Forrest report which concluded that screening could prolong the lives of women over 50 years old. The programme included routine breast screening as a priority, providing free screening every three years for all women over 50 years of age⁵. The 2000 Cancer Plan announced the extension of two view mammography to all screens by 2003 and that the upper age limit for screening invitations would be increased from 64 to 70 years by 2004.

Since its onset, The NHS Breast Screening Programme is thought to have been successful in helping to decrease breast cancer mortality rates, partly as a result of earlier diagnosis. The less advanced the disease, the better the chance that treatment will be successful and therefore increases survival rates. Breast cancer mortality rates have fallen in females since the programme's onset in 1988⁴.

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

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

In 2006/2007, 76% of women were screened nationally and 52% of invasive cancers detected were 15mm or less, which could not have been detected by hand⁶. Therefore, without breast screening many cancerous masses would go unnoticed until the disease had progressed and developed to be large enough to be detected by hand. The latest research has shown that the NHS Breast Screening Programme is saving 1,400 lives every year in England⁷. This is due to earlier detection, diagnosis and treatment.

The NHS Breast Cancer Screening Programme does not routinely invite women over the age of 70 years for a screening appointment. For these women, a decision about whether or not to attend screening is generally taken at an individual level, bearing in mind personal circumstances, rather than by offering a blanket invitation for screening⁸.

Furthermore, although 20% of breast cancer cases in the UK are diagnosed in women under the age of 50⁹, they are not routinely invited for screening. For women in this age group, a referral would be made by a General Practitioner (GP). Only around 20% of patients who attend breast screening clinics for investigation have been identified through the NHS Breast Screening Programme. Some 80% of patients are referred by GPs indicating that potential signs or symptoms of breast cancer are suspected¹⁰.

The National Context

Prevalence

Despite screening and medical advances, which have helped to greatly reduce breast cancer mortality rates, the prevalence of the disease is still high. Each year more than 44,000 women in the UK are diagnosed with breast cancer which equates to more than 100 women a day².

In fact, breast cancer rates have increased by 12% in the past decade¹¹. However, instead of indicating an increased likelihood of developing breast cancer, this finding may signify the success of The NHS Breast Cancer Screening Programme. With an increase in the uptake of breast screening, more women are being diagnosed with breast cancer when it might have previously remained undetected.

Breast cancer incidence rates vary according to socio-demographics:

- Prevalence of breast cancer is higher among women in more affluent communities¹²
- Prevalence of breast cancer increases with age
- Breast cancer has a much higher prevalence in women

Risk Factors

At least a fifth of breast cancer cases in Western countries are likely to be due to modifiable lifestyle factors such as alcohol consumption, exercise, obesity stress, smoking and diet¹².

Social deprivation has a negative effect on breast cancer survival² with women living in the 10% most deprived areas in the UK associated with a significantly poorer outcome¹³.

There is currently a poor understanding of how ethnicity affects the development of breast cancer, but a small study in Hackney suggested that black women may develop breast cancer earlier than white women of the same age¹⁴.

A lack of knowledge about breast cancer is a major risk factor. It is thought that late diagnosis of breast cancer is linked to a low uptake of breast screening services. This low uptake is often attributed to low awareness of breast cancer symptoms and risk factors¹⁵.

In 1991, the UK abandoned systematic breast self-examination and replaced it with a policy which encouraged women to be breast aware from 18 years old. This new policy was based on work by Cancer Research UK scientists¹⁶.

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

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

Few women understand that the risk of getting breast cancer increases with age⁸. The relationship between breast cancer development and age is so strong that more than 80% of cases occur in women aged 50 and above¹⁷. This emphasises the importance of breast screening at this age, but also the importance of breast cancer education.

Many women believe that breast cancer is primarily linked to genetic trends¹⁸. Therefore, they do not take into account the effects of their lifestyle choices such as smoking, diet and exercise, alcohol consumption and stress¹⁹.

In essence, a key barrier to screening attendance is a poor understanding of breast cancer and its associated risk factors¹⁷. However, the principle risk factor for breast cancer mortality is a failure to attend screening.

Mortality

Breast cancer is one of the UK's most prolific killers with more than 12,300 women dying of the disease annually. This equates to over 1,000 a month¹¹. The chances of surviving breast cancer have improved significantly over the past decade². However, a 2007 report published in the Lancet Oncology Medical Journal showed that breast cancer survival rates in England are lower than the European average.

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

The Local Context

Haringey is an area with high levels of deprivation and currently ranked the fifth most deprived Borough in London. It has an estimated population of 224,000 residents²⁰ of which almost 20,000 are eligible for breast screening. Poor breast screening attendance, which is thought to be related to social deprivation, is a major concern in Haringey.

Within the Borough there are major variations in deprivation levels with inequalities in health following the same pattern. Breast cancer related deaths are relatively high in the North East, South East, and Central Haringey GP comparator zones²¹.

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

Screening services in the West of Haringey are well attended, but early deaths from breast cancer are still higher than expected²². It is, therefore, important to increase both knowledge of breast cancer and breast screening attendance throughout Haringey.

Risk factors for cancer include a poor diet, obesity, sedentary activity and alcohol abuse⁸. These factors are more commonly found in low socio-economic areas like Haringey. Therefore, it is not surprising that cancer is responsible for around 25% of deaths annually and that breast cancer is the third most common type diagnosed in the Borough.

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

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

If both uptake and coverage of The NHS Breast Screening Programme is to be increased in Haringey, we must understand the ethnic diversity of the Borough. With some 190 languages spoken²¹ as well as a range of different cultural and religious beliefs, we must understand that reasons for non-attendance might be wide ranging and even unique to distinct groups of women.

Service Overview and Assessment

Breast Screening Pathway in Haringey

Invitation to Attend Screening

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

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

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

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

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

The Breast Screening Procedure

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

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

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

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

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

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

Breast Cancer Treatment

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

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

Stakeholder Feedback

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

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

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

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

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

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

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

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

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

Strengths of the NHS Breast Screening Programme in Haringey

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

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

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

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

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

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

Weaknesses of the NHS Breast Screening Programme in Haringey

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

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

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

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

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

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

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

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

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

“If they don’t know much about it they won’t know they should attend.”

Opportunities for the NHS Breast Screening Programme

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

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

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

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

Possible threats to the NHS Breast Screening Programme

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

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

important:

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

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

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

Media Landscape

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

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

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

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

Please see Appendix 3 for full articles.

Audience Insight and Segmentation Using Mosaic

Data Usage

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

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

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

Mosaic

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

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

- Socio-demographics
- Lifestyles
- Culture
- Behaviour

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

Audience Segmentation

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

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

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

Table 1 Number of Women in Haringey Aged 50-70

White	11,831	66%	Alexandra	1,031	6%
Black Caribbean	2,131	12%	Bounds Green	957	5%
Black African	1,344	7%	Bruce Grove	923	5%
Black Other	277	2%	Crouch End	979	5%
Indian	663	4%	Fortis Green	998	5%
Pakistani	133	1%	Haringay	809	4%
Bangladeshi	207	1%	Highgate	884	5%
Chinese	282	2%	Hornsey	916	5%
Other Asian	491	3%	Muswell Hill	1,038	6%
Other	650	4%	Noel Park	921	5%
All Ethnicities	18,009	100%	Northumberland Park	915	5%
			St. Ann's	1,115	6%
			Seven Sisters	1,048	6%
			Stroud Green	802	4%
			Tottenham Green	985	5%
			Tottenham Hale	1,027	6%
			West Green	1,020	6%
			White Hart Lane	1,115	6%
			Woodside	964	5%
			HARINGEY	18,446	100%

Source: Haringey PCT – projected all resident population 2008

Table 2 Representation of each Mosaic Type by Postcode

Mosaic Type	POSTCODE											AGE CATEGORY							
	East Finchley	Finsbury Park	Highgate	Turnpike Lane	Muswell Hill	Bounds Green	Palmers Green	South Tottenham	Tottenham	Upper Edmonton	Wood Green	Total	49-54	55-59	60-64	65-69	70-74	Total	
	N2	N4	N6	N8	N10	N11	N13	N15	N17	N18	N22	Total							
A1 Symbols of Success	1	1	16	21	7							46	15	10	13	8		46	1%
A2 Symbols of Success	2	1	4	34	23	1					6	71	23	17	22	8	1	71	2%
A3 Symbols of Success	2		3		2							7	3	2				7	0%
B8 Happy Families				3							1	4	2	2				4	0%
C19 Suburban Comfort						6			3			9	3	3		2	1	9	0%
C20 Suburban Comfort						2	3	31	23		28	87	28	21	18	15	5	87	2%
D26 Ties of the Community								2				2	1			1		2	0%
D27 Ties of the Community		106		147	2	13	16	433	614	3	535	1,869	543	482	382	330	132	1869	45%
E28 Urban Intelligence		106	7	135	5			151	26		175	605	166	162	131	111	35	605	14%
E29 Urban Intelligence		40	8	73	3						11	135	46	49	20	20		135	3%
E30 Urban Intelligence		51	5	124	13	4		4			77	278	71	84	61	50	12	278	7%
E31 Urban Intelligence		21		18				9				48	7	18	15	5	3	48	1%
E33 Urban Intelligence									4			4	3		1			4	0%
F35 Welfare Borderline			2									2	1				1	2	0%
F36 Welfare Borderline		9		47		4		262	409		176	907	277	227	176	170	57	907	22%
F37 Welfare Borderline									5			5	1	1	1	1	1	5	0%
F38 Welfare Borderline									3		2	5		1	1	3		5	0%
F39 Welfare Borderline								1	5			6	1	2	2	1	2	6	0%
F40 Welfare Borderline									3			3	1	1	1	1	1	3	0%
G41 Municipal Dependency									3			3			1	2		3	0%
G42 Municipal Dependency				1					8			9	5	2	2	2		9	0%
G43 Municipal Dependency									6			6	2	2	2	2		6	0%
H46 Blue Collar Enterprise									15			16	4	5	3	3	1	16	0%
I49 Twilight Subsistence								1	1			2	1	1	1			2	0%
I50 Twilight Subsistence				2				2	18		7	29	2	5	7	11	4	29	1%
J51 Grey Perspectives			1	2		1						3		1	1	1	1	3	0%
J52 Grey Perspectives	1		1	4							4	10	1	2	2	4	1	10	0%
N/A				3		1			1			5	1	1	2	1	1	5	0%
Total	6	335	46	614	51	37	19	896	1,147	3	1,022	4,176	1,207	1,093	869	750	257	4,176	
	0%	8%	1%	15%	1%	1%	0%	21%	27%	0%	24%	100%	29%	26%	21%	18%	6%	100%	

Haringey's Key Mosaic Profiles²²

In Haringey the four key Mosaic profiles are:

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

Mosaic Group Descriptions

Group A - 'Symbols of Success'

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

Group D - 'Ties of the Community'

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

Group E - 'Urban Intelligence'

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

Group F - 'Welfare Borderline'

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

Mosaic Type Descriptions

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

Group Type D27: Settled Minorities

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

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

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

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

Group Type F36: Metro Multicultural

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

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

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

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

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

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

Group Type E28: Counter Cultural Mix

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

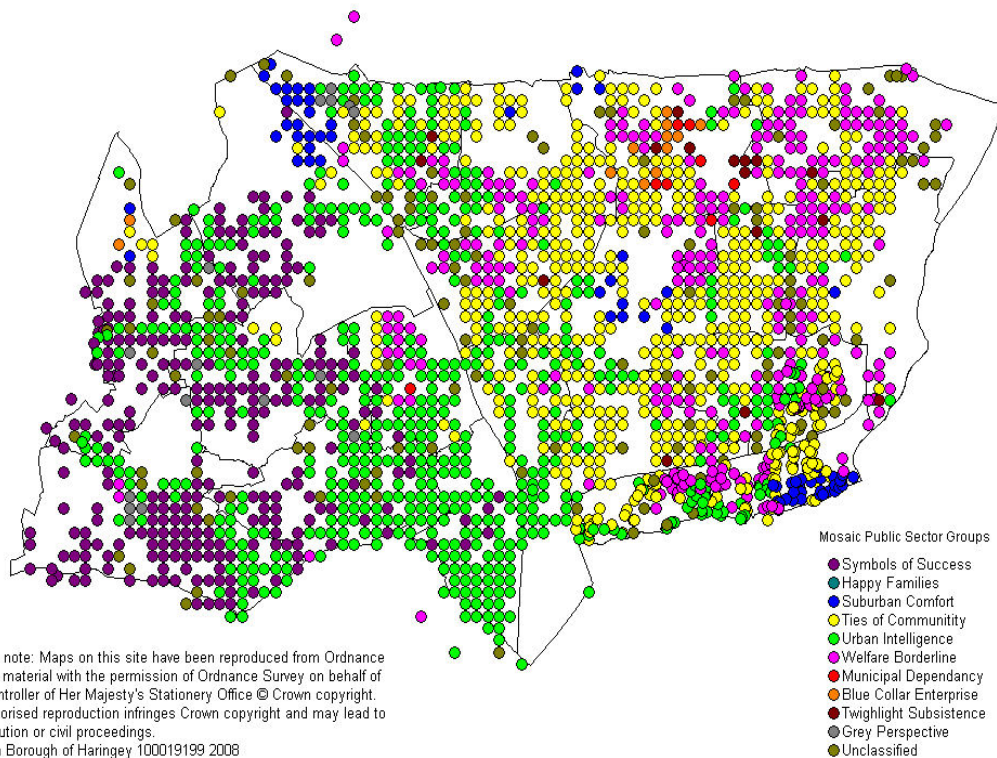
Residents tend to be stylish, creative individuals who engage in consumption, partly as a means of creating and sustaining image and identity which are both very important.

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

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

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

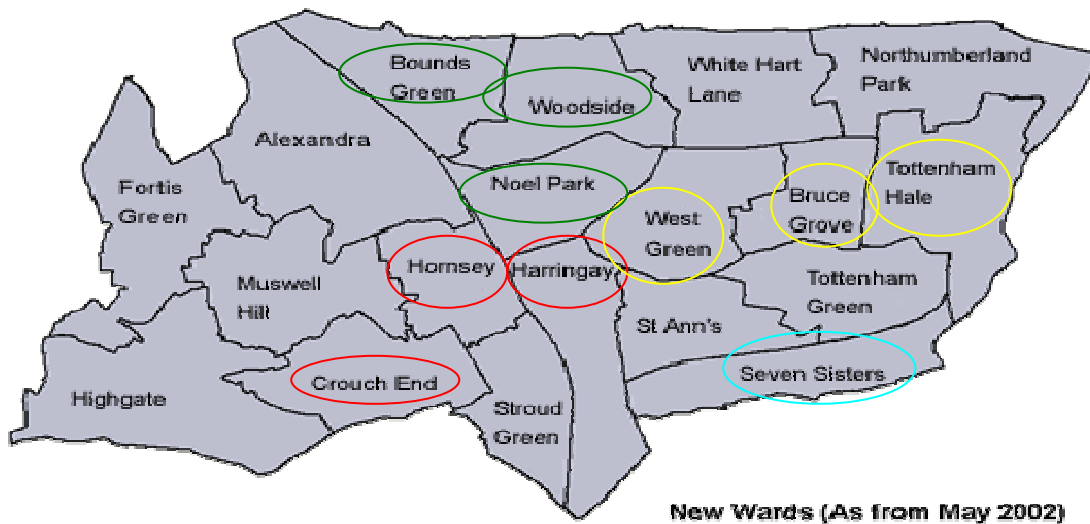
Mosaic Public Sector Groups in Haringey



Breast Screening – DNAs

DNAs are prominent in four postal code areas:

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



Highest DNA Rates per Demographic Profile

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

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

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

Audience Insight: Critical Factor Analysis

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

Key Barriers

The main factors that influence non-attendance are:

Lack of Knowledge¹⁴

Not knowing the facts about:

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

Practical issues⁴

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

Fear¹⁵

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

Motivations / Incentives to Attend Screening⁴

Factors that influence attendance are:

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

Competition

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

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

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

Costs include:

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

Benefits include:

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

Primary Research

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

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

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

Focus Group and In Depth Composition

Service Users (mixed Ethnicity)

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

Mixed Asian women

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

African Caribbean/ Somalian Women

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

White British and White Other

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

Please see Appendix 5 for details of recruitment.

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

The following section details the feedback from these discussions.

Behavioural Analysis

Insight into Breast Screening Attendance from Service Users

Perceptions of General Health

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

“It’s about balance, everything in moderation, eat well, exercise, don’t smoke, don’t drink too much.”

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

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

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

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

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

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

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

Knowledge of Breast Cancer and Breast Screening

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

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

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

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

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

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

Invitations to Attend Breast Screening

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

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

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

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

Attitude to Breast Self-examination

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

Reason for Attendance and Perceived Barriers

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

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

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

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

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

Perceptions of General Health

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

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

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

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

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

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

Knowledge and Beliefs about Breast Cancer and Breast Screening

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Attitude to Breast Self-examination

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

Perceived Barriers to Breast Screening

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

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

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

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

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

“One woman told me that she wouldn’t advise me to go as it hurts so much.”

“Do they not have to press really, really hard?”

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

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

Media Channels

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

Segment Specific Insight into Mixed Asian Women who DNA

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

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

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

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

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

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

"No news is good news."

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

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

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

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

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

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

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

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

Feedback on the NHS Breast Screening Programme Materials

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

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

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

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

Actionable Insight

- Service users perceived themselves to be very much at risk of breast cancer while DNA did not. Educating women and increasing awareness of the risks and symptoms of breast cancer alongside the benefits of breast screening is vital to ensure women realise they are at risk and that they should be screened. Women need to feel as though breast screening is personally relevant to them.
- A major barrier to breast screening was the fear of “*finding something*”. This fear is so significant for many women that they resort to avoidance coping mechanisms “*What I don't know I'm not afraid of*”. Promotions and education must address these fears to reassure women that a breast cancer diagnosis is not a death sentence. Promoting the fact that women diagnosed with early stage breast cancer have an unaffected life span should reassure women of this and hopefully tackle some of the fear prohibiting attendance.
- In order to help tackle the myths and misconceptions of breast cancer and breast screening which are found to be rooted in the beliefs of many BME communities BME nurses should be asked to attend community centres to help educate and inform those who work there. Staff at the centres could then continue help to inform and educate the women who attend their centre. This would ensure that accurate information reached these women in a culturally sensitive manner from a source they trust and respect. This should then help to dispel some of the many myths believed within these communities.
- Mobile units should be more inconspicuous within communities. Renaming them as health units would reduce the embarrassment associated with attending. Units must also embrace more flexible opening hours to further reduce barriers.

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

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

- Data lists used for inviting eligible women need to be updated regularly to avoid invitations being sent out to the wrong address. This data must also hold other vital information such as language preference to ensure invitations are sent in a known language more fully understood.
- Leaflets using images to explain the procedure from invitation to appointment were thought to be helpful not only for those who can't read but also as a 'gentler' method of explanation. The process was thought to sound painful and too clinical but might come across as more accessible in image format.

Critical Factor Analysis Summary

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

Conclusion

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

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

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

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

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

Next Steps

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

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

Appendix 1: Local Breast Awareness Campaigns

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

Manchester PCT

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

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

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

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

1 IN 9 WOMEN WILL GET BREAST CANCER



love your breasts?

Know what is normal for you. Learn how to look and feel for change.
If you want advice on **BREAST AWARENESS** contact your Doctor's Surgery for further information.
All women over the age of 50 are entitled to a free 3 yearly **NHS Breast Screening Appointment.**
ISLINGTON WOMEN - DON'T MISS YOUR APPOINTMENT WHEN YOU RECEIVE YOUR INVITATION!
Contact the Central & East London Breast Screening Service on 020 7601 8305.

FREE SHOW COMING NEAR YOU
Breast Play 'The Learning Curve' performed by women & theatre group on Thursday 19th October at 1pm at Mayville Community Centre, N16 8NA.
For further details contact Parminder Lakhpuri on 020 7527 1259.

 Islington  Primary Care Trust  **ISLINGTON**

Islington PCT

Islington breast screening short film (08/11/06)
Islington PCT produced a short film called 'What every woman should know – breast screening the facts'. It featured the experience of real women and follows a patient's journey through the breast screening process. The film was available on DVD and video and translated into 6 different languages including English, Bengali, Somali, Turkish, Arabic and Spanish. The film has a British Sign Language option and will be used by Camden PCT, Tower Hamlets PCT, City & Hackney PCT and Newham PCT.

Helen O'Keefe, Islington's Breast Screening Coordinator, said: "We decided to make this DVD as there simply wasn't the right information available to suit the multicultural London population. Breast screening saves lives, but our research showed that many women didn't know what happened at a breast screening appointment. Others were too scared or embarrassed to attend an appointment. This DVD was used in surgeries and community centres all over Central and North London".

Sandwell PCT

Campaign to Increase Breast Health Awareness, 2007

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

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

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

Camden PCT

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

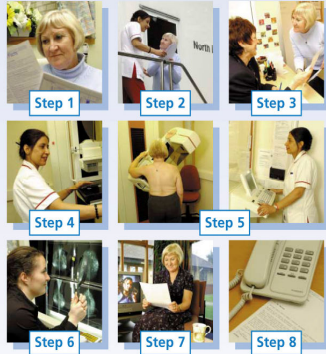
Executive creative director and managing partner, Dylan Bogg, said: "We really felt we'd developed a very strong communications strategy capable of taking our message out to a hard-to-reach audience, and we had some fantastic creative work to complement the thinking. We look forward to creating a campaign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

Tower Hamlets PCT

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

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

Easy steps to



Breast Screening

Women aged 50-70 are invited for free breast screening every 3 years. A female radiographer takes the breast x-ray to look for changes in breast tissue.
Ask your practice nurse for details.

Enfield 
Primary Care Trust

Enfield PCT

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

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

Appendix 2: National Campaigns

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

Breakthrough Breast Cancer 'Screening Saves Lives'

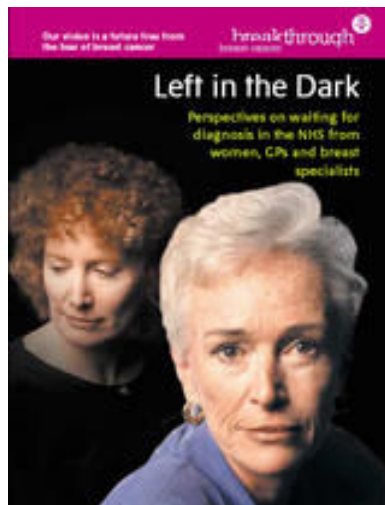
Breakthrough's 'Screening Saves Lives' campaign aims to improve the early detection of breast cancer by pressing for continued improvements to breast screening services across the UK.

In 2008 Breakthrough focused on three key areas of the campaign:

Digital mammography.

Take up of breast screening appointments.

Access to family history screening services.



Breakthrough Breast Cancer's 'In the Dark'

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

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



Cancer Research UK 'Screening Matters'

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

They campaigned to ask the UK governments to commit to:

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

Appendix 3: Local and National Press Coverage

Haringey Independent, 4 December 2008

'Women are not being screened'

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

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

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

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

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

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

Haringey Independent, 5 November 2008

'Doctor Surgery staff wear pink in aid of breast cancer research'

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

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

Haringey Independent, 17 May 2007

'Breast screening is fifth worst in capital'

Fewer than half of women in Haringey aged between 50 and 70 are having the NHS recommended tests for breast cancer.

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

The Evening Standard, 20 February 2009

'Women are urged not to cancel breast cancer checks'

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

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

In an interview with the Standard, Professor Patnick questioned the study's main finding that 10 healthy women among 2000 will be incorrectly treated. The cancer expert said: "Women should not ignore their appointments. It is obviously their personal choice to attend. But the breast screening programme saves hundreds of lives a year."

National cancer director, Professor Mike Richards, added: "I want to reassure women that breast screening is safe and can lead to cancer being diagnosed and treated much earlier, which ultimately saves lives."

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

The Evening Standard (London), 28 January 2009

'Thousands shun breast checks'

London has the worst take-up rate of breast cancer screening in the country, new figures reveal today.

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

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

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

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

The Independent, 3 January 2009

Fears of rise in breast cancer as more women decline screenings

Number accepting NHS appointments falls below 70 per cent for first time.

A worrying drop in women attending breast screenings is putting lives at risk, doctors have warned.

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

"Busy women put off going because the clinic is difficult to get to or the timing of appointments does not fit their lives. They don't have time," she said.

Embarrassment, discomfort and fears that the procedure may be painful were also deterrents, she said.

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

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

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

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

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

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

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

The Times, 21 February 2009

'NHS rips up breast cancer leaflet and starts all over again'

The NHS is tearing up its leaflet on breast cancer screenings and writing a new one from scratch after scientists criticised the information as inadequate and manipulative.

The leaflet, which is usually sent out with invitations to attend screenings, advises women that the procedure can be uncomfortable or painful but does not mention potential risks.

Professor Mike Richards, the National Cancer Director, said yesterday that the leaflet, Breast Screening: The Facts, would be scrapped, a day after the criticisms.

"A formal review is in progress and will be tested against the best available evidence," he said.

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

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

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

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

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

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

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

The Times, 19 February 2009

'NHS is accused of leaving women in the dark about screening risks'

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

"It wasn't until some time later that I realised that it was impossible for me to have made an informed decision about my treatment," she said.

Mrs Thornton became a vocal campaigner for better information for women on all details of mammography - better-informed consent and fuller disclosure of the risks and benefits of breast screening for otherwise healthy women.

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

Telegraph, June 2008

'Women with breast cancer can have unaffected life expectancy'

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

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

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

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

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

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

BBC News, 26 February 2008

'Cancer screenings have low uptake'

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

BBC News, 26 February 2008

'Low awareness'

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

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

Appendix 4: References

- ¹ North London Breast Screening Service (NLBSS) Overview Report to Chief Executives Group, 2007.
- ² The Information Centre for Health and Social Care.
- ³ www.statistics.gov.uk
- ⁴ www.havcohariney.org.uk
- ⁵ NHS Breast Screening Programme Publication no 61, 2006.
- ⁶ Haringey Health Report, 2006.
- ⁷ Blanks RG, Moss SM, McGahan CE et al. Effect of NHS breast screening programme on mortality from breast cancer in England and Wales, 1990-1998: comparison of observed and predicted mortality. *British Medical Journal*, 2000.
- ⁸ <http://www.cancerscreening.nhs.uk/breastscreen/publications/nhsbs>
- ⁹ <http://www.cancerscreening.nhs.uk/breastscreen/publications/nhsbsp61.pdf>
- ¹⁰ Peto R, Boreham J, Clarke M et al. UK and USA breast cancer death down 25% in year 2000 at ages 20–69 years. *Lancet*, 2000.
- ¹¹ www.cancerresearch.org
- ¹² Cancer Research UK http://info.cancerresearchuk.org/images/pdfs/rtr_research_brochure.pdf
- ¹³ Dixon, D. Uptake and Coverage The London Perspective.
- ¹⁴ http://www.london.gov.uk/assembly/health_ps/2008/mar12/item07a.pdf
- ¹⁵ Sullivan, Cancer Research UK, quoted in the Guardian, 21 August 2007
- ¹⁶ Austoker, J., Be Breast Aware (leaflet). 1991: DH & NHS.
- ¹⁷ www.breastcancercare.org.uk
- ¹⁸ V. Peacey, A. Steptoe, S. Davíðsdóttir, A. Baban, J. Wardle. Low levels of breast cancer risk awareness in young women: An international survey. *European Journal of Cancer*, Volume 42, Issue 15.
- ¹⁹ Awareness of breast cancer incidence and risk factors among healthy women. Pöhls UG, Renner SP, Fasching PA, Lux MP, Kreis H, Ackermann S, Bender HG, Beckmann MW. Department of Obstetrics and Gynaecology, University Erlangen, Universitaetsstrasse 21-23, D-91054 Erlangen, Germany.
- ²⁰ Equality and Diversity Annual Report 2008.
- ²¹ Dr Foster, Haringey Segmentation: GP Comparator Zone Report 2009 (Central, North East, South East and West GP Comparator zone).
- ²² Mosaic UK Group and Type Descriptions.

Appendix 5: Recruitment Methods

NHS Haringey Breast and Cervical Cancer Screening Project

Generative Focus Group Recruitment

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

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

Agreed routes to recruitment included:

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

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

Recruitment activity took place as follows:

Focus Group Recruitment Poster Development

October 2008

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

January 2009

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

February 2009

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

Advert Placement

October 2008

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

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

November 2008

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

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

Contact with Community Groups

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

The following Community Groups were contacted:

October 2008

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

November 2008

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

December 2008

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

February 2009

Contact with key community groups still underway.

Newsletters

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

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

Poster/Flyer Distribution

October 2008

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

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

November 2008

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

December 2008

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

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

January 2009

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

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

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

February 2009

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

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

March 2009

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

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