Scrutiny Review of Breast Screening Services in Haringey

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

February 1st 2010

1. Introduction

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

2. The consultation method

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

The Survey

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

Focus Groups

2.5 An invite to participate in a focus group was distributed in two ways: through inclusion with the postal survey and through a mail out to local women's groups. The invite offered women the opportunity to participate in one of two planned focus groups. Both focus groups were of one-hour duration and facilitated by a member of the scrutiny panel and scrutiny support officer (both female). Focus groups were held in the afternoon and evening to facilitate participation.

2.6 Participants in the consultation sessions were reassured that all information provided would be given in confidence and that their participation in the review would not affect their right to access future services. Participants were provided with £10 voucher in lieu of expenses incurred for attending the consultation session. The invite is contained in Appendix 1.

3. Survey and focus group results

Responses

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

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

Figure 1 – Demographics of respondents (n=62)

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

Screening Location

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

Figure 2 – The site where breast screen took place



Breast Screening Invite

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

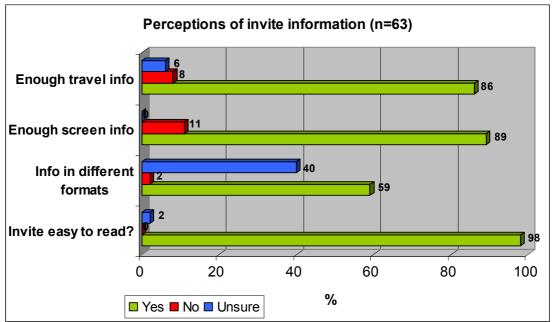


Figure 3 – Service user's perceptions of invite to breast screening service.

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

respondents indicated that they were aware that the invite information was available in different formats (large print, community languages).

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

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

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

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

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

- 3.11 Analysis of focus group data revealed that a number of participants who spoke a minority language, had concerns that the invite appeared only to be available in English. The focus groups identified a need to have some minimum translation in a key local community languages included within the invite, even if this was just a reference to where further information could be found.
- 3.12 Analysis of the survey data *and* focus group data produced clear evidence for the need to include additional travel information within the invite, to explain how women can access particular breast screening clinics. A significant number of respondents who attended the Forest Road breast screening clinic indicated that additional travel information (public transport, parking facilities or a map) should be made clear within the invite to enable them to make appropriate travel arrangements to the site:

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

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

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

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

Breast Screening Appointment

3.13 The questionnaire and focus group sought to assess respondents' perceptions of the operation of the appointment system at the NLBSS, in particular whether the preset appointments which are offered to women were convenient, and if not, the ease with which women could change these. The survey data revealed that just 34 out of 62 (55%) of respondents indicated that the first preset appointment was convenient

(Figure 4). Furthermore 8 out of 28 (29%) women who found the appointment inconvenient did not find it easy to change this appointment (Figure 4).

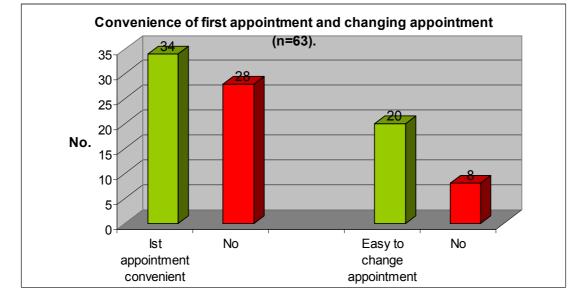


Figure 4 – Service user's perceptions of the appointment system.

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

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

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

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

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

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

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

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

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

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

'The problem for me is that the appointments are always during daytime working hours, some evening and weekend appointments could be offered. As I have a full time job I have to make sure I my work is covered (I am a Dr) during my hours of absence.'

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

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

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

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

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

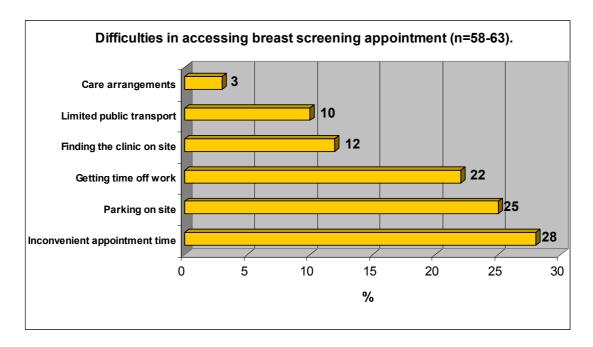
'I rang the number and there was a long wait to get through then it was engaged repeatedly. The receptionist was helpful but did not have appointments beyond the next 2 weeks – so I had to ring back again two weeks later – and go through the whole process again - which was both time consuming and expensive.'

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

Difficulties in accessing breast screening appointment

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

Figure 5 – Stated difficulties in accessing breast screening appointment.



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

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

'Parking is a problem.' (Whittington)

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

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

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

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

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

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

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

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

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

Experience of breast screening service

3.23 The survey sought to assess women's experiences of the breast screening service as this data may be useful in determining whether women would be likely to re-attend the service in the future. Analysis of service data found high levels of satisfaction with all aspects of the service (Figure 6). Here, high levels of service user satisfaction were recorded for the welcome to the clinic (84%), waiting times (84%), friendly and helpful staff (87%) and the provision of information (87%) (Figure 6).

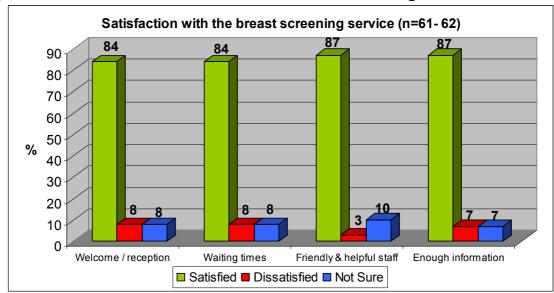


Figure 6 – Service user satisfaction with breast screening service

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

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

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

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

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

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

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

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

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

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

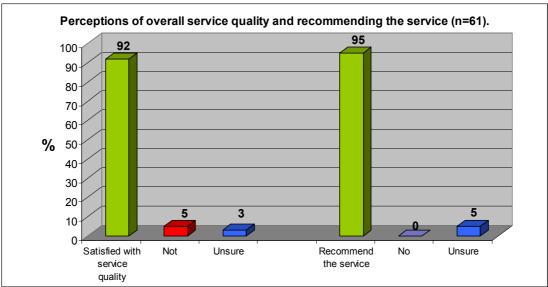


Figure 7 – Service user perception of overall service quality.

Suggested ways to improve screening take up

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

More Convenient locations

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

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

'People in my areas would be far more likely to attend of the clinic was more local and on public transport i.e. Whittington fine, somewhere in Enfield - not good.'

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

'Any women in west Haringey will struggle to attend in Edmonton, if the wish is to increase uptake then a location in the west which is accessible by public transport is essential.'

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

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

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

Improve out-of- hours access

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

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

…perhaps evening or Saturday appointments?' (Forest Road)

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

Community outreach work

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

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

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

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

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

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

Service personalisation

3.33 Analysis of the survey data and focus group data confirmed that many women access the breast screen service with a range of anxieties. The concern among participants within the consultation was that if these concerns were left unaddressed

then this may affect a woman's decision to attend for a screen. In this context, it was felt that developments which personalised the service may reassure women who have concerns or anxieties about attending for a breast screen.

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

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

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

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

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

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

Work with GPs and primary care

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

….there needs to be more adverts in the GPs…….'

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

Community languages

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

• The inclusion of a pictorial guide to breast screening

Service promotion / promoting prevention

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

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

'its better to find things out sooner rather than later...'

3.41 Reminder letters/ calls

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

'Phone call reminders would be helpful.'

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

Appendix 1 – Invite to Consultation

Overview & Scrutiny Team 7th Floor, River Park House, 225 High Road, Wood Green, London N22 8HQ Tel: 020 8489 6922 Fax: 020 8489 2533 Minicom: 020 8489 2535 www.haringey.gov.uk



Head of Policy & Performance Eve Pelekanos

Dear Client of the North London Breast Screening Service

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

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

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

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

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

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

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

Yours sincerely

Cllr David Winskill Chair, Scrutiny Review Panel (Scrutiny Review Breast Screening Services)

Appendix 2 – Breast Screening Survey

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Breast Screening Survey
1. Which breast screening site did you attend? North Middlesex Hospital Forest Road Whittington Hospital
About the letter inviting you to attend for a breast screen
2. Was the invite easy to read and understand? Yes No No Not sure
3. Was the information you received about breast screening available in other formation for example, in other languages, in large print or in audio form? Yes No No Not sure
4. Were you given enough information about what would be involved in attending for a breast screen?
Yes No Not sure
5. Were you given enough information about how to get to the breast screening service (i.e. where the unit was located, public transport routes)? Yes No No Not sure
6. Would you have liked any other information before your screening appointment (Please describe)
About your appointment at the breast screening clinic
7. Was the appointment for your breast screen convenient for you to attend? Yes (go to Q9) No
8. If your appointment was not convenient, was it easy to make another at a more suitable time? YesNo
Getting to the screening service
 9. Did you experience any of the following difficulties in accessing your breast screening appointment?
Yes No Not sure

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

	Your ex	perience at the	breast s	creening clinic	
1. How satisfied or	[,] dissatis	sfied were you	with the	following at the	breast screening
clinic?					
Welcome/ reception Waiting time in the Friendly and helpt Provided with enc	e clinic ful staff	Satisfied	1	Dissatisfied	Not Sure
Do you have any	other co	mments?			
2. On the whole, he	ow satis	fied were you v	vith the c	uality of the bre	east screening
service?				satisfied or diss	_
	Dissati		neimer	satisfied of diss	
3. Would you reco		_	-		?
Yes 4. Is there anything would like to hea appointment for	ar how y	ou would like to ou think we ca		out your visit? Ir	
4. Is there anything would like to hea	g else yo ar how y	ou would like to ou think we ca	add abo	out your visit? Ir	
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you contact details below:

Name:

Contact telephone:

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