

Maximising Screening Attendance

A Reference Guide

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Foreword

The North West London Cancer Network (NWLCN) is the largest of the 5 Cancer Networks in London, covering a population of approximately 1.8 million people, 7 acute trusts and 8 primary care trusts.

NWLCN is the lead network for screening in London and has designated responsibility for this area on behalf of the other cancer networks. It has close ties to the cancer screening quality assurance reference centre and a high level of expertise in the field.

The Cancer Reform Strategy was published in December 2009 and builds on the National Cancer Action Plan in setting out the direction for cancer services over the next 5 years. One of the key areas identified for action in the strategy is diagnosing cancer earlier, and within this screening plays a vital role. Across London participation in screening programmes is persistently lower than elsewhere in the country with efforts to improve attendance rates having been fragmented.

This reference guide endeavours to spotlight areas of good practice and share them with Breast Screening Services, providing a holistic approach to services across the capital. Although the guide is primarily aimed at screening services and commissioners it hopes to support all stakeholders to improve performance against the national screening targets.

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Executive Summary

Breast Screening is one of three key public health priorities in London and programmes should ensure that they achieve national minimum standards by April 2010. North West London Cancer Network (NWLCN) acts as the lead London Network for cancer screening. Within this role they aim to support PCTs and screening services in their pursuit of improved uptake to meet the minimum standards.

This reference guide is intended to support all stakeholder organisations to improve and maybe to reach the required standards through:

- Provision of information as to the current level of uptake
- Suggestions of actions which providers can take to realise increased uptake
- Promotion of both strategic and operational plans within provider organisations to address low uptake levels

The key points are:

Interventions/actions can be carried out by the three main organisations involved in breast screening: the Breast Screening Services, Primary Care Organisations (PCOs) and GP Practices. Different aspects of the breast screening pathway can be targeted, with the aim of improving uptake of services.

For **breast screening service providers** actions may include:

- Wider and more effective use of GP “do not attend (DNA) reports”
- Second-timed appointment letters to women who DNA
- Offering women a number of methods to contact the screening unit for re-arranging screening appointment e.g. telephone or website

For **PCOs** actions may include:

- Ensuring that the screening team hold good quality information which is exchanged with breast screening services in a timely way
- More pro-active and direct involvement from Primary Care
- Engagement with the Primary Care community, utilising incentives such as LES's or QOF to drive improvements in Primary Care.
- Contacting women prior to screening using pre-invitation letters, birthdays cards or reply slips.
- Addressing access issues by bringing breast screening to the community

Actions to improve attendance by **GP Practices** may include:

- Ensuring that each practice has a named screening lead responsible for actioning routine and initiative work
- Adequate information displayed in GP practices

- Practice staff trained and up-dated
- Involvement by practice staff during time of screening
- Adequate system of flagging and following up DNAs in practice
- Positive endorsement by GP's communicated to eligible women
- Monitoring QOF

In addition to taking practical steps to improve screening attendance, there are a number of strategic considerations which should be taken into account.

- Women who do not attend for screening are not a homogenous group, and the diversity of this group needs to be understood in order to develop effective engagement strategies.
- The reasons why women chose to opt for private screening rather than within the NHS are not yet fully understood. Private screening is not considered within coverage and uptake figures. Anecdotal evidence indicates that screening within private facilities happens more frequently in London than in others parts of the country.
- There is persistently low attendance amongst women never screened before. More sustained work needs to be carried out on prevalent women.
- Interventions may impact on coverage and uptake differently (many DNA projects impact only on coverage and not on uptake)
- To date few interventions to improve uptake or coverage have been fully evaluated and so evidence on effectiveness is not robust
- It is essential that evidence based interventions are supported by sustainable financial and staffing resources. Once they cease performance drops back to previous level.

1. Introduction & Background

1.1. Rational for Reference Guide

NHS London recently wrote to all PCTs alerting them that Breast Screening is one of three key public health priorities (alongside smoking cessation and immunisation) that must reach the national minimum standards by April 2010. NWLCN is the lead London Network for cancer screening and in this role aims to support screening services to improve uptake and coverage. This reference guide is intended to support all stakeholder organisations in implementing service improvements and interventions.

1.2. Background

The purpose of the NHS Breast Screening Programme (NHSBSP) is to reduce morbidity and mortality from breast cancer. The programme routinely invites women aged between 50 and 70 for screening by mammography. The recently published Cancer Reform Strategy (CRS, DoH, 2007) announced, amongst other items, an extension of the existing programme to screen women aged 47 to 50, and 70 to 73 that needs to be completed by 2012.

The ability of the NHSBSP to impact on public health is dependent on a high proportion of women attending their first and subsequent screening rounds. The programme must therefore reach all eligible women irrespective of their socio-economic status, race or any special needs requirements.

1.3. Measuring screening attendance

There are two conventional approaches to measuring breast screening acceptance - uptake and coverage – the detail of which is occasionally misunderstood or confused.

- Uptake is the proportion of women who have responded to an invitation for screening and for whom a screening result is recorded
- Coverage refers to the proportion of women resident within an area (excluding those ineligible e.g. those who have had a bilateral mastectomy) who have had a test within a recorded result at least once in the previous 3 years (Health and Social care Information Centre, HSCIC, 2009).
- Women who refer themselves for screening are included in coverage figures, but not uptake.
- Uptake therefore is a quality measure of Breast Screening Service Providers whereas Coverage is measured by Primary Care Trust.
- Coverage figures are reported for women aged 53-70 being screened, because Breast Screening is based on a three-year screening round. Women are not necessarily invited on their 50th birthday, but must be invited before their 53rd birthday.

In measuring attendance, women are further divided into prevalent and incident screening (HSCIC, 2009).

Prevalent screening is for women being screened for the first time. Within the NHSBSP there is a distinction between:

- Women between their 50th and 53rd birthday¹.
- Women older than 53 who failed to attend previously and who therefore attended for the 1st time.

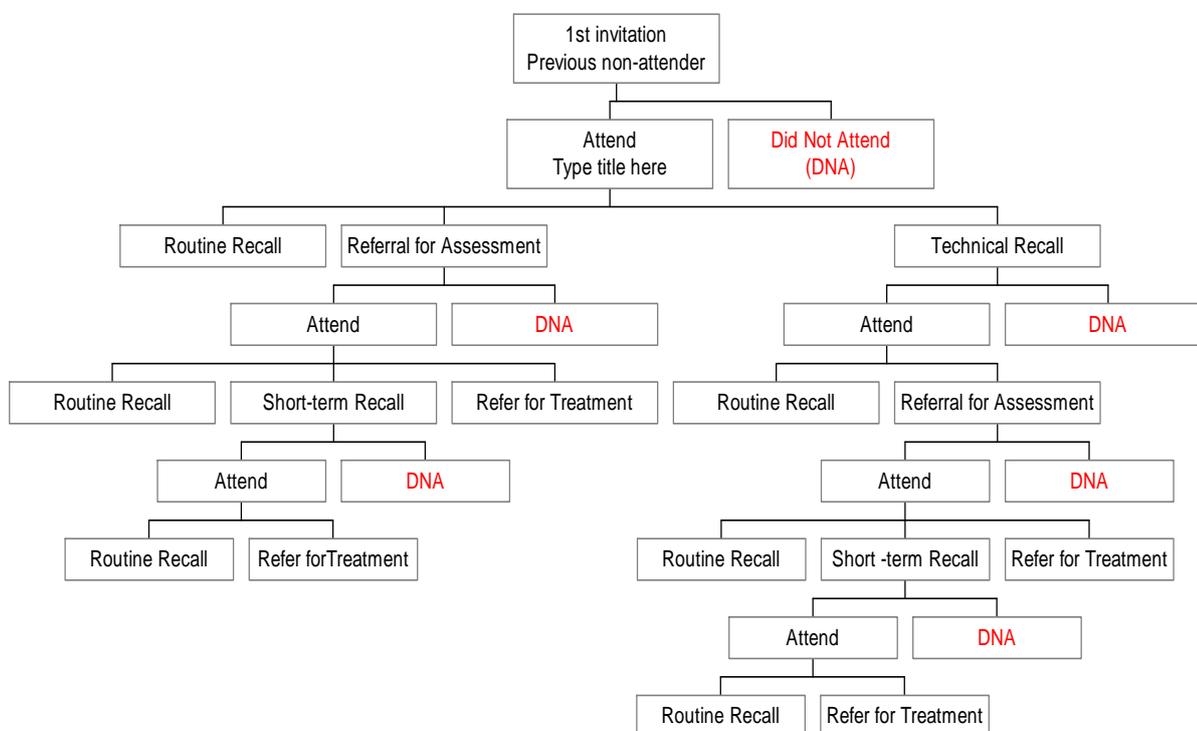
Incident screening is for women who previously attended for their routine NHSBSP mammograms. This group of women can also be further divided into.

- Women who had their last screen within the previous 5 years
- Women whose last screen was more than 5 years ago.

Acceptance and attendance of this potentially life saving screening programme is persistently low across London. This has been flagged up by a range of organisations, including the Chief Medical Officers Report (DoH, 2003), Care Quality Commission and a range of others. A number of interventions have been undertaken to address this area but, on the whole, no sustainable improvements were recorded.

1.4. The screening pathway

Below is a graphical representation of the screening pathway, beginning with prevalent round (first invitation or previous non-attender) and showing the number of instances where women may decide to drop out of the screening program. The pathway repeats itself for incident round women



- ¹ Women who have had a mammogram taken before but not within the screening programme, for example private mammograms, would still be viewed as prevalent women within the NHSBSP.

1.4. Structure of the Reference Guide

This report will follow the screening pathway and identifies opportunities for tailored interventions at each stage. This report will deconstruct the screening pathway and suggest a number of interventions, both generic and specific that should improve awareness and attendance.

The reference guide should be viewed as a working document that does not claim to propose all possible interventions that could be carried out to improve attendance. NWLCN will continue to monitor and incorporate new changes and/or projects if they are shown to improve breast screening attendance, and will ensure the new information is disseminated widely.

Achieving and maintaining national minimum standards (and targets) on screening acceptance cannot be delivered by the PCTs alone. There will need to be active and continuous engagement between all key stakeholders; screening services, primary care, acute trusts, the public, communities and voluntary organisations. Financial resources and good stewardship of such resources are paramount if any sustainable improvement is to be seen.

2. The Pre-invitation stage

The present chapter briefly outlines what happens prior to women receiving their letter inviting them for their screening and describes a number of useful interventions.

2.1. Operational processes prior to invitation

Breast Screening Services (BSS) invite women for screening who are registered with a GP². The order of invitation varies from service to service but is normally either by area/postcode or by GP practice³. Regardless of invitation criteria there are a number of stages that take place before the invitation letter is sent:

- 1 BSS contacts the relevant Primary Care Organisations (PCOs) that provides call/recall support.
- 2 The PCO is informed that the specific BSS will be inviting a certain postcode or GP practice in the next 2-3 months.
- 3 The PCO will then send out a notification letter to the GPs due to be invited by the BSS, requesting a list of names of women who are ineligible for screening within a specified time frame (usually a fortnight). The PCOs usually send the information to the GPs 6-8 weeks prior to screening.
- 4 This also provides the opportunity for the practice to identify women with special requirements e.g. women who have a physical or learning disability (these women would then be invited to a static screening site which is bigger and a longer appointment time can be provided).
- 5 After receiving a completed notification document (including the names of any ineligible women) back from the GPs the PCOs then amend the screening list accordingly.
- 6 The completed list is then transferred to BSS, so that eligible women can be invited for screening. Invitation letters, containing a timed appointment and supplementary information are usually sent 2-3 weeks prior to screening.

In certain circumstances women can be removed (ceased) from the programme. Ceasing⁴ a woman from the call/recall system has the effect of stopping all invitations for breast screening being sent unless action is taken to revert her status to 'normal'

Women can only be ceased from the programme if they:

- Have had a bilateral mastectomy
- Have made an informed decision that they no longer wish to be invited for screening or if they
- Lack the mental capacity to consent to screening and a decision has been made appropriately that it is in her best interest to remove her from the screening list (NHS Cancer Screening Programme, 2009).

² Please note that there are some groups of women who are eligible for routine screening who are not registered with GPs. These include women in prison, travellers, homeless women or zzz women. For more detailed information see NHBSP (Good Practice Good No 2, 1999).

³ There is currently a debate about changing the way how women are invited (post code or GP practices) to their "due date". This would enable Breast Screening Services to focus on women who are due to be invited and will therefore reduce the proportion of women invited earlier than 36 months.

⁴ Good Practice Guide on Ceasing Women from the NHS Breast Screening Programme is currently being reviewed.

For further information on ceasing women from the screening programme please see NHS Cancer Screening Programme (2009). Consent to Cancer Screening (2nd ed). NHS Cancer Screening Programme, No 4.

After making all the necessary amendments, invitation letters alongside other material such as the “NHS Cancer Screening Programmes: Breast Screening: The Facts” and local information for screening are sent directly to women. This is an ideal opportunity for carrying out interventions helping and supporting women in their decision to accept or reject their routine screening invitation.

2.2. Suggested actions during Pre-screening stage

A number of general and specific interventions are suggested.

2.2.1. General Primary Care Interventions/Actions

A great deal of important ground work can be carried out within Primary Care, which includes the following:

- GP Register validation to ensure the accuracy of eligible women invited for the screening programme.
- Education of practice staff in the eligibility criteria for breast screening. Information such as special needs and the implications it has for the screening appointment (e.g. longer appointment time, being invited to static site and not on a mobile because of accessibility and space) is essential to allow women that have special needs to attend their screening in a comfortable and appropriate environment.
- Accurate and timely return of information sent from the GP back to the PCO, to avoid shortening timeframes and limiting the amount of notice women have of their appointment.
- Ensuring GP practices have relevant and up-to-date screening information displayed in the waiting area. This will help to raise awareness of breast screening.
- GP practices can also help the screening service by informing them:
 - Whether women have recently changed address (this would ensure that they receive their invitation and result letter to the correct address. Otherwise letters would be sent to the old address)
 - Whether women have a physical disabilities (women would then be invited to a static, a more spacious screening unit with better access)
 - Whether women have carer requirement (and so could attend a static screening site with a longer appointment time)
 - Of any known language difficulties (do women need information in a different language, would they like to have an interpreter when they attend the screening unit?)

It is of enormous benefit to have a nominated screening lead within each practice

2.2.1.1. Local Enhanced Service (LES)

Primary care teams traditionally have less direct involvement in breast screening compared to cervical screening. One way to address this and to more actively involve GPs in supporting breast screening is to offer a financial incentive using a locally enhanced scheme (LES) which aims to build on the work of GP practices to improve screening acceptance. A

number of PCTs across London have or are in the process of implementing a LES; however payment and inclusion criteria vary. No evaluation of the usefulness or effectiveness of breast screening LES's has been found during this review.

2.2.2. Specific Primary Care Interventions/Actions

- **Sending Pre-invitation letters** to women. There is some evidence to suggest that sending pre-invitation letters to women before they receive their routine invitation letter will improve awareness, and perhaps attendance of breast screening. These letters can be sent by GPs, PCO or by the BSS, however most evidence indicates that letters showing endorsement of screening by the woman's GPs will have a positive effect on a woman's decision to accept their screening invitation.

South West London Breast Screening Service (SWLBSS) piloted a pre-invitation letter and reported a 7% increase in uptake. Other anecdotal evidence available from other screening services in the capital reports an increase between 5 – 7%.

- **Communication with women.** A proactive approach by GPs or practice nurses to raise the subject of breast screening when women come for any other appointment has also been shown to be of benefit.
- **Pre-retirement health check:** Some practices have offered pre-retirement health checks events discussing breast screening and breast awareness during the consultation period.

2.2.3. Specific Breast Screening Service Interventions/Actions.

A number of interventions can be carried out by the BSS. One of the biggest advantages screening services and PCOs have is that they can target large numbers of women at once.

- **Pre-invitation letter.** As previously suggested pre-invitation letters can also be sent by the screening unit.
- **Birthday cards:** Messages around 'Happy birthday and welcome to the NHSBSP', introducing and/or reminding about screening, and intend for receipt before the first routine invitation to screening. Birthday cards are similar to pre-invitation letter but it has the purpose of simply raising and alerting women of the existence of the screening programme.
- **Telephone reminders:** Some BSS have carried out telephone reminders prior to the offered screening appointment. This is often very time consuming and there is a question as to how cost-effective this type of intervention might be.
- **Pre-paid reply slip:** Including a pre-paid reply slip into the invitation letter was carried out by one of London's existing six screening units. Women were asked to return the reply-slip to the screening units informing them that they need to change their given screening appointment or that they have no intention to undergo screening. This has the advantage that it will allow the screening service to rebook an appointment and/or to give this appointment to someone else. This will reduce the number of unattended screening appointments.
- **Website:** Another method of giving women the opportunity to re-arrange their screening appointment is using the screening unit's own website. This has the advantage that women have another method of contacting the screening unit, usually

by phone and it also acknowledges that fact that many people make use of internet. This has the benefit that it will reduce the number of incoming calls to the breast screening service. It also offers women the opportunity to contact the screening office outside office hours, which is helpful to those women who have work or family commitments during day time.

- **Extending opening hours or weekend:** Offering longer opening hours and screening on Saturdays has been suggested to address the issue that some women are unable to attend for screening during conventional opening hours due to work or family commitments.

Please note that offering additional screening session on Saturdays does not always result in an increase in uptake (e.g. Readman and Asbury, 1999). However, whilst offering Saturday sessions did not improve uptake in Manchester, this does not imply that it would not improve uptake in a different area with a different screening population.

- **Bridging the gap between women's intention and subsequent screening attendance.** Empirical research studies show that many women despite showing high intention to accept their invitation to screening subsequently fail to do so. Using the concept of implementation interventions, Rutter, Steadman, Field (2002) identified that asking women to make **specific plans** (organising travel arrangements, taking time of work if necessary and changing the appointment if it was inconvenient) for attending breast screening will help to bridge the gap between intention and attendance. Main findings included the result that attendance was 10% in the intervention group (in women who made all three planning activities) when compared with the control group. The strongest effect was identified amongst women who were invited for the first time who initially reported low intention to accept their routine screening invitation when compared to women who reported strong/high intention to undergo screening.
- **Community work:** Many screening units across London carry out community and outreach work. Often local Clinical Nurse Specialists (CNS) provide information about the local screening service and breast awareness. This is particularly useful when given prior to screening commencing in that specific area. This also has the benefit that it carries the message that screening is coming into the community and is a valuable and important part of raising awareness and knowledge about screening. Often these are not stand alone events but are coupled with a general health event/ women's group meeting or something similar.

2.3. Funding interventions/projects

In order to ensure that interventions are carried out and sustained an essential consideration is funding. This is of particular importance when looking at large scale projects such as sending pre-invitation or second-timed appointment letters to all women who did not accept their routine screening invitation. Resources need to be made available to ensure that such projects can be carried out and maintained. Lessons learned from previous interventions have repeatedly shown that any success and improvement in terms of coverage or uptake gained will be lost if successful projects are discontinued.

There is considerable debate about the source of such funding. If for example, interventions such as sending pre-invitation letters or second timed appointment letters to all women who did not attend are issued by the BSS then they will seek appropriate resource to convert not insignificant costs of postage and printing. One option might be to secure funding for these

projects in the Service Level Agreements (SLAs) for provision of breast screening between PCTs and acute NHS Hospital Trusts. Often these SLAs only detail provision of breast screening and assessment for eligible women.

It is therefore recommended that:

- Financial resources as well as staff capacity for intervention needs to be put in place to ensure that there is money available to fund a project
- Systems for evaluation should be agreed from the onset and this should include cost effectiveness of the intervention
- Financial resources for these intervention needs to be secured long term to ensure that it can be sustained if proven successful.
- It is reasonable for commissioners of BSS to include interventions aimed at increasing uptake in the SLA's, and to expect some resources to be released by cost savings through service improvements.

2.4. Chapter Summary: Key Points

The pre-invitation phase is a vital part in women's screening pathway. Providing accurate information about the eligible screening population is vital and an important aspect of getting it right and setting the ground work for an effective service delivery. There are a number of interventions/projects suggested in this chapter that aimed at raising the awareness of breast screening and providing support in women's decision to accept or reject their routine screening invitation.

The key messages are:

- Ensure accurate and validated information between Primary Care and PCO
- Train primary care staff
- Adequate information display
- Sending pre-invitation letters/birthday cards/reply slip
- Provide support for bridging the gap between intention and behaviour
- Reach out to your local community
- Resources, secure and sustain the finance of these interventions

3. Screening

3.1. At the Breast Screening Unit

Women are invited for their routine mammogram at either a mobile or static breast screening unit. Access to a screening unit is an important part of the service provision and is an important factor in women's decision to accept or reject their screening invitation.

3.1.1. What happens at the screening unit?

- On arrival, women's personal details (e.g. name, age and address) are checked
- Mammography practitioner will talk about symptoms or history of breast disease and explain what happens when mammograms are taken
- Women have to undress completely to the waist
- A specialist female member of staff will take the mammograms
- Women are informed how and when they will receive their written results

Routine breast screening will take approximately 30 minutes

3.2. How well is the NHSBSP attended?

In order for a screening programme to be deemed effective relies on sufficient numbers of women attended. So how well is the NHSBSP accepted amongst the eligible screening population in the capital?

Below are uptake figures across the capital for the last four years (Table 1). It is of interest to compare the year's performance 2007-08 with those three years before 2004-05, as this represents the same cohort of women.

Table 1: Uptake⁵ (in %) for women age 50-64 from 2004-2008 (QARC, 2009)

Area	2004-05	2005-06	2006-07	2007-08
England	75	75	74	74
London	62	62	61	61

No significant improvement in the overall uptake figure for London is seen over the years. For more detailed information about the uptake figures by the individual BSS please see the "London Breast Screening Programme Annual Results April 2007 – March 31st 2008" (QARC, 2009).

Examining London's overall uptake rate in more detail (looking at prevalent and incident women) it becomes apparent that there is a particularly problem with poor uptake in the prevalent round (see Table 2 below).

Table 2: Uptake figures (in %) broken down into prevalent and incident for women age 50-64 (QARC, 2009)

	2004-05	2005-06	2006-07	2007-08
Prevalent Screen	39.30	40.48	39.49	40.18
Incident Screen	76.88	76.54	74.21	74.39

It can be seen that there is particularly low uptake across prevalent women with only small variations over the years and no significant changes and improvements over the years.

⁵ Please note that the national minimum standard for uptake is 70% (NHS Cancer Screening Programme, 2005).

Whilst this trend is broadly in line with empirical research that suggests that women who attended previously are more likely to re-attend (Jepson, Clegg, Forbes, Lewis, Sowden and Kleijnen, 2000), the persistent low attendance clearly shows that more sustained work needs to be carried out around prevalent women.

3.3. Suggested Interventions/Actions during the screening stage

There are a number of opportunities that arise during the time that screening is carried out in a specific area. The following section will outline general aspects such as displaying relevant information in GP practices and specific interventions such as actively following up women who do not attend (DNAs).

3.3.1. General Primary Care Interventions/Actions

- **Information:** Display information about the NHSBSP and the local breast screening programme in GP practices and relevant buildings where women attend (e.g. pharmacies, health centres and local libraries). This will help to raise the awareness of the screening programme and the local BSS.
- Make sure that all relevant information is regularly reviewed to ensure that the most **accurate and up-to-date information** are displayed.
- **Training practice staff:** It is of benefit when practice staff (receptionist, administrative & clerical, practice nurse) are trained with up-to-date information. Front line staff are often the first people women talk to about breast screening and so their ability to convey information well is crucial.
- **Raising subject of screening if women attend for other reasons:** There is some empirical evidence, for instance, Bekker, Morrison and Marteau (1999) that indicates that women are more likely to attend if it is endorsed and supported by their own GP.
- **Train Practice Nurses:** Currently the charity Breast Cancer Care has commenced a one day training course "Train the Trainers" that is tailored towards Practice Nurses. This provides an ideal opportunity to work collaboratively by reaching out to as many Practice Nurses as possible. They couple the course with presentations by the local BSS health professionals.

3.3.1.1. Follow-up of women who did not attend (DNA)

During the time that screening is taking place in a specific area, screening services send information to the relevant GPs about their patients who have not attended their appointment. Currently these reports are paper-based, and it is felt that they are widely under used. It would be more efficient if these could be sent electronically⁶. This would take adaptation of the National Breast Screening computer system (NBSS). Regardless of format however these reports provide a good opportunity to follow-up such women.

PCTs should determine which system (electronically or manually) practices currently have in place for the follow up of DNAs and determine whether assistance is required to identify DNAs not only during the screening year but also in the non-screening years. This would allow GPs to conduct opportunistic promotion on an ongoing basis.

⁶ Anecdotal evidence reported that GPs have already requested these reports in electronic format. This would also ensure that these reports are received in a timely manner. There is growing concern or indications that the postal service does not always deliver in a timely manner. Therefore issuing DNA reports electronically would bypass this potential time delay.

3.3.2. Specific Breast Screening Service Interventions/Actions.

- **Second-timed appointment letter:** Currently many BSS are sending a first fixed appointment letter followed by an open second reminder letter for women who did not attend after their first invitation letter. Empirical research studies (e.g. Stead, Wallis and Wheaton, 1998) have found this to be effective in improving screening attendance. There was a significant difference between sending a second open invitation letter compared to a fixed/timed appointment letters (12.3% versus 22.8%). It was shown to be more effective in women who attended previously.
- **Outreach work:** BSS often liaise with local communities or other groups to raise the awareness and knowledge about breast screening when screening is carried out in their local area. This is reinforced with other initiatives including both general health events and cancer screening events, which the Clinical Nurse Specialists or programme managers often attend. Whilst these interventions do not improve coverage and uptake they are important in bringing breast screening to the local communities. Often these events provide a platform of clarifying misunderstandings or myths about breast screening.
- **Reminder cards:** Women who have reached the upper age groups will not be re-invited when they are next due. However, they are still entitled for their routine NHSBSP mammograms. Most screening units hand out reminder cards where women can record the date when they are next due. Often these cards contain contact details of the local BSS. It is suggested that reminder cards are reviewed to ensure that they reflect the changes in eligible age group following implementation of the age extension of the screening programme.
- **Service Feedback:** Aimed at receiving feedback from users, screening services are carrying out consumer satisfaction surveys. This will help to improve the actual service delivery to the eligible screening population they serve. However this process will tend to target women that attend screening and will not reflect the views of those women who DNA their appointments. Whilst the views of attenders are valuable it is important to identify any issues which may be significant in preventing a positive response to a screening invitation.

3.3.3. Examining reasons as to why women did not attend?

3.3.3.1. Different type of non-attenders

The screening pathway diagram at the beginning of this document shows a number of points at which women become DNA's.

Table 3: Different types of DNAs

Starting point: First initial invitation		Comment
Women attend 1 st invitation	Women do not attend 1 st invitation	
<ul style="list-style-type: none"> DNA technical recall 	<ul style="list-style-type: none"> DNA after 1st invitation 	<ul style="list-style-type: none"> The national minimum standard⁷ for technical recall is <3%
<ul style="list-style-type: none"> DNA assessment clinic 		<ul style="list-style-type: none"> National Minimum standard is <10% for Prevalent women (age 50-52) to be referred for assessment National Minimum standard for <7% for incident women to be referred for assessment GP practices should have a register to identify women who were referred for assessment. This will allow to follow women who DNA'ed.
<ul style="list-style-type: none"> DNA short-term recall 		<ul style="list-style-type: none"> National Minimum standard is <1% of women who are referred for assessment to be placed onto short-term recall Women can only be placed on short-term recall once
<ul style="list-style-type: none"> DNA assessment after having attend technical recall previously 		
<ul style="list-style-type: none"> DNA short-term recall, after assessment after having attend technical recall previously 		
Cycle repeats for 2nd and subsequent screening rounds (7 to 9 routine screening rounds)		

Looking at the different type of non-attenders, it becomes clear that non-attenders are not one homogenous group and more focused work needs to be undertaken for all these different subgroups of non-attenders.

⁷ Please see NHSBSP, No 60 (2005) that depicts the national core standards

There is an urgent need to get a better understanding about the DNA population:

- Why women do not accept their first screening invitation or subsequent invitation
- Are the needs of non-regular screening attenders different to regular attenders
- What is the proportion of women who had been previously symptomatic and who received an “all clear” and who decide not to attend further routine screening? Is the “all clear” message fully comprehended?
- Did any earlier screening experience influence women’s decision to reject their screening invitations?

3.3.3.2. Private Mammograms

Currently it is unclear how many women across the capital attend for private mammograms. Some PCTs have attempted to examine the scale of the private mammograms by incorporating the monitoring of private mammograms into the LES that was outlined above. This required GP staff to ask women whether they had a private mammogram and whether they could submit written evidence/result letters to the practice. Whilst it is a good starting point, it fails to understand **why** women choose a private mammogram. What is their perception about the NHS mammogram as opposed to the private mammogram? Do they think that the quality of the mammogram differs? Generally speaking are women aware about the quality assurance aspect of the breast screening programme?

3.3.4. BSS in collaboration with PCTs interventions/actions

- **Understanding data at PCT and practice level:** With regards to monitoring breast screening acceptance it is useful to understand the existing data looking at attendance rate from the PCTs level as well as individual GPs. This will identify individual practice performance and may help to tailor specific interventions. It is also useful to compare most recent data with the of previous screening rounds, allowing to explore whether there is a trend and if not what factors may contribute to a variation of the screening attendance.
- **Exploring population data:** Over the last few years there is an increasing trend to explore population data using socio-demographic tools. This is a useful and additional tool to investigate characteristics of the eligible screening population from a different perspective. This can help to tailor interventions based on specific characteristics.

3.3.5. Chapter Summary: Key Points

During the time of screening, there are a number of opportunities where interventions can be carried out.

The key messages are:

- Adequate information displayed in GP practices
- Practice staff trained and up-dated
- Practice involvement/approach by practice staff during time of screening
- Adequate system of flagging DNAs in practice
- Following up DNAs
- Sending second-timed appointment letters as opposed to open reminder letter
- Outreach work- bring screening into the community
- Reminder cards for future self-referrals
- Examining in-depth different type of non-attenders
- Reason for undergoing private screening

4. Non-screening years (Interval)

During the time of the non-screening years, it is of importance to encourage and promote breast awareness, conveying the message that women should contact their GPs without a delay when they discover symptoms that are unusual to them. A number of good practice initiatives, are outlined below, that can only be carried out during non-screening as well as screening years (e.g. tackling inflated GP lists).

4.1. Primary Care interventions & other organisations/actions

- **Awareness of breast screening:** Whilst it is of importance the GP practices have adequate information on breast screening displayed during the screening episode, it would be of benefit if information is displayed throughout the year as an visual reminder for all these women who DNAed or are newly registered with the GP practice to raise the awareness of the screening programme. Furthermore, this may also emphasis the fact that women who miss screening appointments do not have to wait until the next time they are invited.
- **Breast Awareness:** Whilst breast awareness should be viewed as an ongoing aspect of women's general well-being, they should be made aware that being breast aware is of particular importance during the screening intervals. This will ensure that women report any changes without a delay.

5-point breast awareness code

1. Know what is normal for you
2. Know what changes to look and feel for
3. Look and feel
4. Report any changes to your doctor without delay
5. Attend routine breast screening from the age of 50⁸

- **Train health educators/mentors:** Training lay people to become peer mentors/health advocates has been shown previously to raise the awareness of breast screening within the local communities. This entails recruiting and training health advocates who in turn support their local communities in questions or concern about breast screening. Chiu (2009) recently published a guidance aimed at service providers as well as health promoters, who can be health professionals, or community (lay) health educators, on how to promote informed choice in the context of cancer screening (including breast screening) in diverse community.

4.2. BSS in collaboration with PCOs interventions/actions

- **Tackling GP list inflation:** The GP and primary care teams have a pivotal role to play assisting PCOs to maintain an accurate database of the eligible screening population. Not only during the screening year, also during non-screening years work should be carried out in terms of tackling GP list inflation. This is of particular importance in populations of high turnover/mobility and can be carried out using a number of methods such as FP69 actions or targeted exercise (e.g. specific address, households with more than a certain number of patients registered at the same address). Note that an FP69

⁸ Note that the age needs to be lowered to 47 once the age extension of the breast screening programme has commenced

refers to a form send by the PCO to the GPs of all women for whom the invitation is returned undelivered or not known at this address. This form asks GPs to confirm whether these women are still registered with the practice.

For this reason it is of importance that women are made aware of the importance of informing the relevant organisation and also of registering with a new GP as soon as possible when they moved.

4. 3. Chapter Summary: Key Points

During the time of the non-screening years a number of interventions can be carried out that involved for example working around maintaining accurate data of the eligible screening population.

The key messages are:

- Continuation of information display about breast screening in primary care setting
- Promote breast awareness
- Educating health professionals and lay people e.g. communities, voluntary organisation, carers
- Tackling list inflation

5. Screening for All: Tackling Inequalities

The NHSBSP offers screening to all eligible women, regardless of their socio-economic status; race or any special needs requirements. Aimed at tackling inequalities and reaching out to all women the current chapter of this report outlines a number of interventions/projects the focus on minority or hard-to-reach groups.

- **Health Equity Audit:** Carrying out Health Equity will help to gain more insight of the local population.
- **Women with Special needs:** One of the groups of women who often do not attend for routine screening are women with learning disabilities. More focused work needs to be carried out to reach out to these women. This may involve Practice Nurse and Learning Disability Nurse to identify women with learning disabilities who are eligible for screening. Note that guidance is provided on issues concerning consent (see NHS Cancer Screening [2009]: Consent to Screening, 2nd ed. NHS Cancer Screening, No 4.).

As already mentioned previously, if BSS are informed that a woman has a learning disability, they will invite her to a static screening site, providing longer appointment times. Sometimes, these women may require more than one visit to the screening site before mammograms are taken. This may include a preparatory meeting whereby the women and her carer may discuss screening and showing the environment and x-machine being used. Also the NHS Cancer Screening Programmes provide guidance on good practice ensuring that disabled women have the same rights of access to the NHSBSP as all other women (see publication NHS Cancer Screening Programmes. [2006]. Equal Access to Breast and Cervical Screening for Disabled Women. [NHS Cancer Screening Programmes, No 2](#)).

Porter (2008) identified in his report a number of good practices aimed at reducing inequalities in accessing screening. For example, installing a hearing loop system in reception at mobile or static screening sites, aimed at supporting women with hearing impairments, breast screening health promotion advisors to work closely and attend disabilities forums. Please note that the NHS Cancer Screening Programmes provide the Breast Screening: The Facts leaflet in a British Sign Language DVD as well as in an audio CD set format.

- **Women from different ethnic groups:** Jack, Davies and Moller (2009) in their paper on breast cancer incidence and survival in ethnic groups in South East England, reported amongst other findings that Indian, Pakistani, Bangladeshi, Black Caribbean, Black African and Chinese women had lower age standardised breast cancer incidence rates than White women. Although, Black African women had significantly worse overall breast cancer specific survival. They recommended that more focused works needs to be carried out to these women on subjects such as breast screening and early detection. This may entails more outreach work or initiatives similar to the “Talking Invitations” described below.
 - **Talking invitation:** One area in London, NHS Tower Hamlets has recently carried out a project (Talking Invitations) that was tailored towards their local population. Essentially it involved the development of a card depicting a local Bangladeshi GP as well as another women, a well known local, white woman who conveyed a message about the usefulness of breast screening. This card was included into the “invitation letters send from the BSS”. The initial result about the effectiveness of this intervention is inconclusive.

- **Health Advocates/Link workers:** As previously described one way to link with local community is to employ and recruit health advocates/link workers (please see Chiu, 2009).

The NHS Cancer Screening leaflet: Breast Screening: The Facts is currently provided in 19 languages. Furthermore there is DVD aimed at Chinese and South Asian communities which is available that provides information about the Screening Programme.

- **Language spoken at home:** As already discussed previously all women who are routinely invited for screening receive with their invitation letter, an information leaflet (“Breast Screening: The Facts”), in English. Whilst this leaflet is available in other languages, it may not be helpful for women who speak a different language. Empirical evidence indicates that there is a significant relationship between attendance to breast screening and the language spoken at home (e.g. Achat, Close and Taylor, 2005; Taylor, Ivanov, Page, Brotherton, Achat, Close, 2003). Currently there is no facility available that would allow insertion of the leaflet in women’s preferred language with the invitation letter.

Women are made aware that they can request a leaflet with their preferred language from the screening service or they can download it directly from the cancer screening website (see www.cancerscreening.nhs.uk). That would still require someone to be able to read the letter and leaflet in English in the first place. In order to reach out to these women a more personal approach is required. Once again, this could be done by a lay person/community/link person as outlined previously.

- **Unregistered women (e.g. Travellers, homeless, prisoners):** Porter (2008) revealed in his report about interventions to reduce inequity and inequality in accessing national screening programmes, that only four studies were identified concerning mobile, homeless and institutional population and their accessibility and awareness of screening. These studies made suggestions such as providing outreach health promotion sessions at housing associations for asylum seekers, providing breast screening support officers for travellers. Porter commented that none of the four studies made any reference about the effectiveness of their interventions.
- **Sexual abuse survivors:** Little information is currently available on the screening attendance rates in women who are sexual abuse survivors and it is unclear whether current service provision is sensitive towards their needs. What safety issues and models of care are required to ensure that the service is sensitive to their specific needs.
- **Gender Re-assignment:** Individuals who are undergoing female to male gender reassignment should continue to be eligible for screening as long as they are registered as female (NHSBSP, 2004). To date little information is known about the number of women for whom this may be a concern. However, what is of importance is the fact that these individuals are entitled to their routine NHSBSP mammograms. Therefore every effort should be made to ensure that they are informed about it. In circumstances where there is a male to female gender re-assignment, these individuals may be screened as self-referrals.

5. 3. Chapter Summary: Key Points

The NHSBSP currently offers screening for all women age between 50-70. There are a number of women who may need more support and help in their decision to either accept or reject their invitation to breast screening.

The key messages are:

- Know your local population
- More focused work with women with special needs
- Train local/community link person
- Reaching out to the unregistered population
- Examine whether the screening service is sensitive towards women's needs

6. The screening pathway: Summary and Conclusion

6.1. Summary

By deconstructing women's screening pathway the reference guide outlined a number of possibilities and opportunities where intervention projects may be useful.

The basis of any screening programme relies on the identification of the eligible screening population. Therefore adequate and reliable data are one of the most important elements of an effective screening programme. Tackling the pre-invitation stage and bridging the gap before the screening programme invites women to their routine NHS mammogram provides a good opportunity of reaching out to the eligible screening population.

Identifying and addressing reasons for non-attendance is as important as exploring the views of these women who accepted and attended for their routine mammograms. Eliciting women's views of the service they received and what they think one can do to improve service delivery provides a good opportunity to get feedback from service users.

Screening is a cyclical programme, consisting of screening and non-screening years, that re-invites women every 36 months, means that in order to maintain the awareness of breast screening, different stakeholders (e.g. BSS, Primary Care, Voluntary sector) at different times should reach out to the eligible screening population.

6.1.1. Resource & Capacity

One important aspect that needs consideration is resource and capacity. Screening units are already stretched and any additional work should be adequately resourced. The CRS (DoH, 2007) have made further suggestion to improve service delivery and expand the screening programme which undoubtedly will cause further constrain to all stakeholders. No intervention can be carried out and maintained if the screening units do not have the capacity and resources for it.

6.1.2. Evaluating Interventions

The present reference guide outlines a range of interventions that can be carried out to improve screening attendance. Most of the interventions were not evaluated and while there is "anecdotal" evidence about some few have been written up. It is extremely helpful if interventions are formally evaluated and reported and this should be included within the original resource allocation. It is difficult to make a case for further investment in an intervention where its effectiveness cannot be demonstrated. Furthermore it is difficult to replicate an intervention within the screening community when the intervention is not clearly outlined. There would be some benefit in developing guidelines and a proforma describing how to plan, undertake and evaluate a breast screening intervention.

6.2. Recommendations and the way forward

In order to maximise and sustain improvements in breast screening acceptance the following main recommendations are made.

Recommendations

- Recommendation 1:** Ensure adequate resources and capacity are available at the start of the work
- Recommendation 2:** Ensure accurate and validated data information flow between relevant stakeholders
- Recommendation 3:** More direct involvement from Primary Care
- Offer financial incentives e.g. LES
- Recommendation 4:** That there is a multi-layered approach for reaching out to the eligible screening population (e.g. BSS, PCO, and other stakeholders)
- Recommendation 5:** Carry out large scale pre-invitation projects to approach as many women as possible
- More focus on prevalent women
- Recommendation 6:** Send routinely second-timed appointment letters
- Recommendation 7:** Better understanding about the DNA population
- More effective use of GP DNA reports (e.g. electronic updates)
 - Auditing different groups of DNAs
 - Cross over symptomatic and screening (e.g. do symptomatic women who receive the “all clear” message accept their next routine screening invitation?)
- Recommendation 8:** Investigate why women undergo private instead of NHS mammograms, as offered by the screening programme
- Suggesting more research to identify why whether and why women choose a private mammogram
 - What is there perception about the quality of a NHS mammogram compared to private mammograms?
- Recommendation 9:** Provide detailed guidance (proforma) on how to carry out and evaluate interventions projects

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