Improving Acceptance of Breast Screening: The Challenge for London

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Executive Summary

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

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

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

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

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

Introduction

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

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

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

NHSBSP

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

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

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

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

What does the screening pathway entail?

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

Breast Screening Services in London

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

1. Barking, Havering & Brentwood Breast Screening service (BHBBSS)

2. Central & East London Breast Screening Service (CELBSS)

3. North London BSS (NLBSS)

4. South East London Breast Screening Service (SELBSS)

5. South West London Breast Screening Service (SWLBSS)

6. West of London Breast Screening Service (WOLBSS)

7. Whipps Cross Breast Screening Service (Whipps Cross BSS)

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

- 23,000 women from South West Herts are currently served by North London Breast Screening Service

- 9,000 women from Brentwood are currently served by Barking, Havering & Brentwood Breast Screening Service and

- 9,000 women from North West Surrey are currently served by West of London Breast Screening Service.

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

Breast Screening Services Uptake Problems

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

Six of the most cited difficulties are:

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

1. High population mobility

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

2. Population diversity

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

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

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

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

3. Areas of deprivation

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

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

These are:

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

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

4. Recruitment difficulties within the NHSBSP workforce

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

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

5. Accessibility

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

6. Private mammograms

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

Roles and Responsibility for Breast Screening: 3 Levels

1. Strategic/Regional Level: Roles and Responsibilities

- **StHA Platform**

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

- **Cancer Network Platform**

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

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

- **Breast Screening Commissioning Platform**

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

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

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

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

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

2. Breast Screening Service Level: Role and Responsibility

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

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

3. Local Primary Care Level: Role and Responsibility

3.1. PCT

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

3.2. Local Health Promotion Departments

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

3.3. Local Delivery Plan (LDP)

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

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

Initiatives to improve uptake

Initiative to improve uptake from the strategic/regional level:

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

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

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

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

Initiatives to improve uptake from the breast screening service level:

- **Second timed appointments**

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

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

- **Pre-invitation letter**

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

- **Attenders Survey**

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

- **Non-attenders Survey**

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

- **Primary Care Information Pack**

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

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

- **GP feedback**

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

- **Press release prior screening**

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

- **Women with learning disability**

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

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

- **Collecting ethnic data**

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

- **Round length**

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

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

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

- **Multi-lingual Breast Screening leaflets**

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

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

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

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

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

Initiatives to improve uptake from the primary care level:

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

Summary

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

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

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

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

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

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Appendix I

Cancer Top Priorities

Appendix II

Copy of the ‘Discussion Paper’

Appendix III

Copy of the Terms of Reference