Approaches to increase attendance at Breast and Cervical Cancer Screening in Greater Manchester

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Executive summary

Elaine Whitby, the Associate Director for Greater Manchester Screening Programmes commissioned the Greater Manchester Public Health Practice Unit to undertake some work to identify ways to increase attendance at breast screening and cervical screening in Greater Manchester. The approach taken was holistic. It took into consideration study evidence, epidemiology, psychological theories and knowledge about determinants of attendance.

The most important findings are:

- Intention to attend screening is the key concept
- Most women have a positive intention toward cancer screening
- Women that have a positive intention need encouragement, focusing on practical issues and reminders, so they do not forget to turn up
- Women that do not currently intend to attend screening make up two main groups: never attended; attended in the past but now lapsed
- Women that stop attending are usually put off by something that happened to them during past screening rounds
- The literature is clear: simple reminders to all women work. The most plausible mechanism is that some women that intend to go to screening would, without a reminder, forget to attend
- GPs have an important role in increasing attendance but there was little evidence to support the intervention of paid community workers which are also unlikely to be cost effective
- Unclear evidence about media campaigns to promote screening but extensive media coverage of celebrity cancer cases is important

The report concludes that, for both cervical and breast screening, the central issue is a woman’s intention towards attending a screen. This intention can be influenced not only by their communities and their peers but also by outside factors such as media coverage of cancer screening. Increasing attendance should focus first on developing a system for a simple reminder on the day before a screen. The aim is to increase attendance in women that intend to attend but might forget. Women that have never attended screening require multi-focussed interventions that include support from their GPs, their peers, and tailored information about their own risk. For these women the main aim is to change minds and create positive intentions toward screening. Women that have stopped attending screening need practical information about improvements to the service and encouragement to begin attending again. All screening services should recognise the importance of a friendly efficient service in maintaining screening rates over multiple rounds.

Main Recommendation

For both cervical and breast screening a robust system for reminding women to attend screening should be developed. This should use simple telephone or text messages on the day before a screening appointment is due.
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1. Introduction

The effectiveness of a cancer screening programme in reducing mortality in a population depends on the test’s sensitivity and specificity, the treatment and care offered to those with a positive result and the proportion of people that attend. Ideally all people in the target population would attend when invited to the screening. In Greater Manchester attendance at screening varies between locations, populations and age groups. To maximise the benefit of our cancer screening programmes attendance needs to be increased. This can be done by understanding why some people do not attend screening and using simple acceptable interventions to encourage greater attendance.

Elaine Whitby, the Associate Director for Greater Manchester Screening Programmes commissioned the Greater Manchester Public Health Practice Unit to undertake some work to identify ways to increase attendance at breast screening and cervical screening in Greater Manchester. For cervical screening the population of women aged 25-34 is a particular concern as attendance is lower than in other groups. For breast screening there is a general need to maintain attendance and to increase attendance in some population groups. This work looks at the evidence and describes interventions that should increase attendance in women that receive invitations to be screened. It does not consider the issue of coverage of the invitation system which might be an issue in some places with a mobile population. The aim of the work is to review existing literature and use critical thinking to produce recommendations for increasing screening uptake at a Greater Manchester level.

The report is presented in five sections. An introduction followed by a background section which provides information about breast and cervical cancer and their screening programmes. The next section is about understanding attendance at screening. It uses the literature about correlates, barriers and facilitators of attendance at screening. It also considers some models that have been used to try, explain and predict the attendance at screening. Following this, a review of the literature about interventions to increase screening uptake is presented. The final section discusses and interprets the literature. In this section, the reasoning behind the recommendations is explained. The section finishes by recommending interventions that are likely to increase attendance at breast and cervical screening in Greater Manchester.
2. Background

2.1 Breast Cancer

Female breast cancer is the most commonly diagnosed cancer in the UK. After lung cancer, breast cancer is the second most common cause of death from cancer. In the UK approximately one in nine women will develop breast cancer at some point in their lives. The great majority of breast cancers are diagnosed after the age of 50. Most of the known risk factors for breast cancer relate to a woman’s reproductive history such as an early first period, a late first pregnancy, low parity and a late menopause. Using oral contraceptives, having hormone replacement therapy (HRT), being obese and drinking alcohol can also increase the risk. Women with a strong family history of breast cancer are also at an increased risk (source: Cancer Research UK). As breast cancer is common in all groups, whole population approaches such as breast screening have been used to reduce mortality from the disease.

2.1.1 Breast Cancer screening

The breast screening programme was introduced in 1988. Breast screening works by identifying breast cancers at an earlier stage when treatments are more effective. Originally, breast screening was offered every three years to all women aged between 50 and 64, and to women aged 65 and over on request. From 2001, this was extended to women in England aged 65 to 70 and to women over 70 on request. Full national coverage for this older age group was achieved by the end of 2004. In 2008, the age range for screening was extended further to provide for nine screening rounds between 47 and 73 years, with a guarantee that women will have their first screen by the age of 50. This expansion will be completed by 2012.

In 2006-07 around 1.6 million women were screened. Earlier detection and improved treatment have meant that survival rates have risen. Since the introduction of screening, mortality from breast cancer has fallen in the UK. This fall in mortality is due in part to earlier diagnosis and in part to improved treatment.
Figure 1: Female breast cancer incidence and mortality, England, 1971-2005

Diagram Source: National Statistics Online (http://www.statistics.gov.uk)

Table 1: Greater Manchester Breast Screening Programmes: Coverage of women aged 53-64 by Primary Care Organisation, from 2006 and 2008

<table>
<thead>
<tr>
<th>SHA PCT codes</th>
<th>Greater Manchester Primary Care Trusts</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
</tr>
</thead>
<tbody>
<tr>
<td>5F5</td>
<td>Salford PCT</td>
<td>62.8</td>
<td>62.1</td>
<td>72.1</td>
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<tr>
<td>5F7</td>
<td>Stockport PCT</td>
<td>74.2</td>
<td>76.1</td>
<td>76.4</td>
</tr>
<tr>
<td>5HG</td>
<td>Ashton, Leigh &amp; Wigan PCT</td>
<td>73.5</td>
<td>77.7</td>
<td>74.5</td>
</tr>
<tr>
<td>5HQ</td>
<td>Bolton PCT</td>
<td>74.8</td>
<td>76.3</td>
<td>78.4</td>
</tr>
<tr>
<td>5J5</td>
<td>Oldham PCT</td>
<td>65.0</td>
<td>64.6</td>
<td>73.9</td>
</tr>
<tr>
<td>5JX</td>
<td>Bury PCT</td>
<td>79.1</td>
<td>79.3</td>
<td>79.3</td>
</tr>
<tr>
<td>5LH</td>
<td>Tameside &amp; Glossop PCT</td>
<td>66.3</td>
<td>61.9</td>
<td>75.7</td>
</tr>
<tr>
<td>5NP</td>
<td>Central &amp; Eastern Cheshire PCT</td>
<td>83.4</td>
<td>83.3</td>
<td>83.1</td>
</tr>
<tr>
<td></td>
<td>Heywood, Middleton &amp; Rochdale</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5NQ</td>
<td>PCT</td>
<td>72.6</td>
<td>74.4</td>
<td>71.6</td>
</tr>
<tr>
<td>5NR</td>
<td>Trafford PCT</td>
<td>66.9</td>
<td>74.6</td>
<td>74.2</td>
</tr>
<tr>
<td>5NT</td>
<td>Manchester PCT</td>
<td>64.0</td>
<td>65.1</td>
<td>64.1</td>
</tr>
</tbody>
</table>
2.1.2 The screening invitation process

Women, from the age of 50, who are registered with a GP, are invited to a breast screening. In Greater Manchester a woman receives a standard letter of invitation from their local screening centre to attend either a static breast screening centre or a mobile screening unit. The letter describes the location and time of the screening appointment and contact details for women to change their appointment. Accompanying the letter is an information leaflet (the content of which is currently under review; a new leaflet is expected in Autumn 2009). A woman that does not attend the first appointment is given a second invitation to attend.

Cervical Cancer

Cervical cancer is caused by Human papillomavirus (HPV). This virus can be transmitted via sexual contact. HPV is more common in younger women than older women and is rarely detected in women that have had no previous sexual activity. Risk factors for HPV infection include: number of sexual partners, a relatively recent new sexual relationship and a history of previous miscarriage. Smoking is not a risk factor for HPV infection but can act with HPV to cause some cervical cancers (source: Cancer Research UK).
Cervical cancer is more common in deprived areas. Women living in the most deprived areas have rates more than three times higher than those in the least deprived areas. Similarly, cervical cancer is more common in women that do manual work.

There has also been a dramatic fall in the mortality from cervical cancer. The mortality rate in 2007 was 2.4 per 100,000 females, which is 70% lower than the rate of 7.4 per 100,000 females reported in 1977 (source: Cancer Research UK). Some of this decrease is due to increased screening activity.

### 2.2.1 Cervical Cancer Screening

The cervical screening programme aims to detect abnormalities in the cells of the cervix before a cancer has developed. Through treating these abnormalities the incidence of cervical cancer and mortality from the disease can be decreased. The Cervical Screening Programme in England in 2007-08 invited around 4.3 million women for screening. In the target age-range (25-64) approximately 3.2 million women were screened, of whom 2.6 million were screened following an invitation to the screening programme.

Cervical screening can prevent around 75% of cancer cases in women who attend regularly. One way of examining the effectiveness of the screening programme is to look at the coverage rate, i.e. the proportion of eligible women that attend. In England the proportion of eligible women attending cervical smear tests has improved from just over 40% in 1989 to 82% in 1995. In 2007-08 the coverage rate was 78.6% and in Greater Manchester 87.1 %.(See Table 2 for Greater Manchester coverage).

**Table 2: Cervical Screening Coverage in Greater Manchester from 2005-08**

<table>
<thead>
<tr>
<th>SHA Codes</th>
<th>Greater Manchester Primary Care Trusts</th>
<th>Coverage (less than 5 years since last adequate test (%))</th>
</tr>
</thead>
<tbody>
<tr>
<td>5HG</td>
<td>Ashton, Leigh and Wigan PCT</td>
<td>81.1, 80.7, 80.0</td>
</tr>
<tr>
<td>5HQ</td>
<td>Bolton PCT</td>
<td>81.1, 80.6, 79.4</td>
</tr>
<tr>
<td>5JX</td>
<td>Bury PCT</td>
<td>82.4, 82.0, 81.3</td>
</tr>
<tr>
<td>5NP</td>
<td>Central and Eastern Cheshire PCT</td>
<td>83.6, 83.2, 82.3</td>
</tr>
<tr>
<td></td>
<td>Heywood, Middleton and Rochdale</td>
<td></td>
</tr>
<tr>
<td>5NQ</td>
<td>PCT</td>
<td>80.0, 79.3, 77.9</td>
</tr>
<tr>
<td>5NT</td>
<td>Manchester PCT</td>
<td>74.4, 74.0, 73.3</td>
</tr>
<tr>
<td>5J5</td>
<td>Oldham PCT</td>
<td>80.7, 80.2, 79.1</td>
</tr>
<tr>
<td>5F5</td>
<td>Salford PCT</td>
<td>78.3, 77.9, 77.2</td>
</tr>
<tr>
<td>5F7</td>
<td>Stockport PCT</td>
<td>81.5, 81.3, 81.0</td>
</tr>
<tr>
<td>5LH</td>
<td>Tameside and Glossop PCT</td>
<td>81.1, 80.3, 79.3</td>
</tr>
<tr>
<td>5NR</td>
<td>Trafford PCT</td>
<td>80.9, 80.8, 80.4</td>
</tr>
</tbody>
</table>

The coverage rate in Greater Manchester seems to be better than the national average but there is marked variation in the coverage rates between different areas e.g. Manchester city and Salford have coverage rates below the national average. (Figure 3)

**Figure 3:** Graph showing coverage rates of cervical cancer screening across Greater Manchester PCTs. See SHA (Strategic Health Authority) PCT codes in Table 2).

![Cervical Screening Coverage in Greater Manchester according to Primary Care Trusts](image)


Screening coverage in the younger age group, 25 to 29 years, and that of 60 to 64 years has been falling below the required benchmark of an 80% coverage rate. In the younger, 25 to 29 age group, it was 68% in 2008-09.
Table 3: Cervical cancer screening coverage rates according to age group in Greater Manchester from 2008-09

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Eligible Population in Greater Manchester</th>
<th>No of women screened in last 5 years</th>
<th>Percentage of women screened in last 5 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>25 - 29</td>
<td>118425</td>
<td>80924</td>
<td>68.3%</td>
</tr>
<tr>
<td>30 - 34</td>
<td>104865</td>
<td>83477</td>
<td>79.6%</td>
</tr>
<tr>
<td>35 - 39</td>
<td>115175</td>
<td>94727</td>
<td>82.2%</td>
</tr>
<tr>
<td>40 - 44</td>
<td>117936</td>
<td>98106</td>
<td>83.2%</td>
</tr>
<tr>
<td>45 - 49</td>
<td>104649</td>
<td>86627</td>
<td>82.8%</td>
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<tr>
<td>50 - 54</td>
<td>82922</td>
<td>67752</td>
<td>81.7%</td>
</tr>
<tr>
<td>55 - 59</td>
<td>72770</td>
<td>57537</td>
<td>79.1%</td>
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<tr>
<td>60 - 64</td>
<td>71535</td>
<td>54549</td>
<td>76.3%</td>
</tr>
<tr>
<td>25 - 64</td>
<td>788277</td>
<td>623699</td>
<td>79.1%</td>
</tr>
</tbody>
</table>

Figure 4: Graph showing Cervical Cancer screening coverage in Greater Manchester from 2006-09 according to age group.

Percentage of women screened in the last 5 years for Greater Manchester PCTs Apr 06 to Mar 09. Source KC53 data. Target=80%
2.2.2 The screening invitation process
The NHS call and recall system invites women who are registered with a GP. It also keeps track of any follow-up investigation. Women aged 25-49 are invited every three years and women aged 50-64 are invited every five years. It is therefore important that all women ensure their GP has their correct name and address details and women inform their GP if these change.

Women are invited via the call and recall system. Those women who do not attend a first two appointment are termed as final non-responders. GPs are informed that the woman has not attended and should communicate with her, inviting her for a test. This should be clearly documented by the practice. If the woman then fails to respond she will return into the system to be invited in either three or five year’s time.

In October 2006 the policy for inviting women for a cervical smear test changed. It is now national policy that invitation letters be sent six weeks before a woman’s test due dates. This applies to first tests at age 25, ‘call’ tests at any other age, routine recalls and early repeat invitations.

3. Understanding the uptake of screening invitations

The review process included a systematic search of the available literature. This is described in section 4.1. From the literature search, 74 papers were identified that were broadly about barriers and predictors of cancer screening attendance. Many of these papers reported similar findings and some looked at the issue in relation to theoretical models of health behaviour. The following sections appraise this literature and present what, in our opinion, are the most important findings. The aim is to present information that is useful for understanding attendance at cancer screening rather than a rigid systematic review of the available literature.

3.1 Determinants of attendance

Quantitative studies look for correlations between a factor and observed attendance at screening. This evidence can be used to describe the type of people that do not attend but cannot provide information about why they do not attend. Qualitative determinants are drawn from people’s responses to questions and can provide an insight into the reasons why some people do not attend.
3.1.1 Breast Screening

**Quantitative determinants of screening attendance**

In the UK, attendance at breast screening has been linked to age (however there was no overall agreement between the studies as to whether older or younger women were significantly more likely to attend for mammography), previous attendance, affluent social class and ethnicity (Jepson, 2000). There is some evidence that distance from a screening unit affects attendance at the population level but for an urban population such as Greater Manchester this is not relevant. Ethnicity and religious group appear to be important, a study by Professor Szczepura from Warwick medical school found that approximately 75% of non-Asian women, 66% of South Asian women and 50% of Muslim women attend screening.

**Examples of determinants and their classification into the five categories**

**Socio-demographic**

- Age
- Gender
- Education
- Income
- Ethnic origin
- Employment status
- Sexual orientation

**Knowledge, behaviour, attitudes and beliefs**

- Knowledge of disease
- Knowledge of screening test
- Past screening behaviour and attendance for tests
- Tobacco, alcohol or drug use
- Perceived seriousness of disease or condition
- Expressed intention to attend screening
- Participation in regular exercise

**Barriers and facilitating conditions**

- Lack of transport
- Costs involved in attending screening
- Inconvenience
- Embarrassment of attending
- Fear of finding test positive
- Fear of pain or discomfort of test procedure
- Recommendation by physician or other healthcare professional
Social influences

- Knowing someone with the disease or condition
- Support of family, friends or significant others
- Support of physician or other healthcare provider
- Membership of a club, church or other organisation
- Knowing someone who has been screened

Health status

- Family history of the disease or condition
- Experiencing symptoms of the disease or condition
- Number of previous visits to doctor
- Self-reported health status
- Able to perform activities of daily living

Jepson’s HTA systematic review about the determinants of screening uptake found, for many of the possible determinants, no strong evidence to support an association. The report concludes that:

- The majority of studies did not find a significant association between the uptake of mammograms and level of education.
- The majority of studies did not find a significant association between the uptake of mammograms and marital status.
- The majority of studies did not find a significant association between the uptake of mammograms and knowledge about breast cancer or mammography.
- The majority of studies did not find a significant association between the uptake of mammograms and smoking.
- The majority of studies did not find an association between the uptake of mammograms and perceived vulnerability or susceptibility to disease.
- The majority of studies did not find a significant association between the uptake of mammograms and concern over finding cancer or fear of finding cancer.

The review did find strong evidence that having previously attended a breast screen is a significant determinant of attending another screen and that intending to attend is a significant determinant of actually attending a screen. In addition there is also evidence to link socio-economic deprivation to non-attendance. This evidence appears to indicate an inverse association between deprivation and attendance. The more deprived you are the less likely you are to attend (Banks, 2002).
Reported barriers to attendance

A survey in Scotland of women that attended and did not attend breast screening found that significant differences existed between the two groups in their knowledge of breast cancer, their ease of attending and their previous experience of breast screening. Half of the women who failed to return for screening implicated their initial visit in this decision, 41% implicating pain, 6% stress and 3% embarrassment. The authors note the importance of previous experience of mammographic screening in future attendance and suggest that all efforts should be made to minimise negative experiences (Marshal, 1994).

The motives and reasons for regular attendance, irregular attendance and drop-out were studied by Scaf-Klomp et al. 1977. Women who were enrolled in a biennial breast screening programme and who were invited to each subsequent screening round until 1992. Three compliance groups were compared: ‘attended all rounds’ (group A, n=79), ‘missed 1 or 2 rounds’ (group B, n=73) and ‘missed more than 2 rounds’ (group C, n=64). The study found that the groups did not differ with respect to socio-demographic characteristics, actual health problems or preventive health orientations, but it found significant differences in general attitudes to breast screening. The authors suggest that during the course of a screening programme, for a substantial group of not strongly motivated women, the recurring negative aspects of mammography (pain and anxiety) become a burden.

It is argued that circumstantial factors, like waiting for one’s turn, the distance to the screening centre and dissatisfaction with handling by screening staff, can trigger the decision to skip screening rounds or to drop out of the programme. The authors conclude that over multiple rounds of screening, special efforts must be made to encourage women to stay in the programme (Scaf-Klomp et al, 1997).

An important barrier to screening may be a lack of awareness about the importance of the disease. A study investigating breast awareness and knowledge and understanding in women from different black and minority ethnic (BME) groups in Britain found disparities in levels of breast awareness knowledge and behaviours between women from different BME groups.

The study conducted face-to-face interviews with 816 BME women and telephone interviews with 552 women from the general population. It was found that BME women knew much less about breast cancer, symptoms and risk factors compared with the general population. There were also differences in behaviour, with 43% of BME women reporting that they did not practise breast awareness, often because they did not know what to look for. BME women also reported lower uptake of screening invitations (Scanlon, 2005). No UK studies were found that had interviewed women about their reasons for not attending a first round breast screening appointment.
3.1.2 Cervical Cancer

Quantitative determinants of screening attendance

Five year cervical cancer screening coverage statistics in the UK were analysed in a study. Overall coverage remained at about 82% or over between 1995 and 2000. Since 2000, however, coverage has drifted slowly down to just over 80% in 2005. Coverage has long been observed to be related to age. In 2005, the coverage rate was 71% in women aged 25-29, 83% in those aged 35-54 and 75% in those aged 55-64. This pattern still persists but it was found that at ages below 50, the rate has been falling while at ages above 55, the rate has been rising. The authors concluded that the fall in screening coverage appears to be a cohort effect, with women born in the 1960s and later being increasingly less likely to participate (Lancuck et al., 2008).

Women in the youngest age group, 25-29 years, were found less likely to participate in the cervical cancer screening programme in Stockholm, Sweden. Registry data on the women invited to the screening (n= 307,552) was matched with the population database. The study also found that married women or widows attended the programme more often. Additionally, women in the labour force were more likely to participate (Odds Ratio = 1.82, 95% Confidence Interval 1.78-1.87) than those who were not in the labour force (Rodvall et al., 2005).

Data from the British Household Panel Survey was analysed by Sabates and Feinstein to estimate the importance of education level on attendance. It was found that adult learning leading to qualifications was statistically associated with an increase in the uptake of screening. The authors conclude that these findings enrich existing evidence on the socio-economic determinants of screening for cervical cancer and enable policy makers to better understand education as a barrier to increase uptake (Sabates and Feinstein, 2006).

Computerised records of screening histories for the eight general practices in central Wakefield were searched to measure the cervical and breast screening coverage of South Asian women. It was found that 67% of South Asians and 75% of non-Asians had acceptable cervical screening histories ($\chi^2 = 13.75, p<0.001$). 53% of South Asians and 78% of non-Asians had acceptable breast screening histories ($\chi^2 = 8.5, p<0.01$). The authors concluded that interventions should be designed to improve coverage for breast screening among South Asian women (Sutton et al., 2001).

Attendance at cervical screening has been linked to age, marital status, race, earnings, employment status and educational status. In the HTA systematic review by Jepson nine studies were found that looked at whether there was an association between age and attendance for a Pap smear. All but two of the studies found that the age of the participant was a significant predictor of attendance. However, the age group that was most likely to attend screening varied between the studies. The review concluded that the majority of studies found an association between the uptake of Pap smears and age but they reported conflicting effects.

For marital status the review found five papers and concluded that there was evidence that married women are more likely to attend than those that are single. In Jepson’s review they found five studies that looked at the level of education, but did not find this to be a significant factor in predicting attendance (Jepson, 2000).
Researchers in Ireland found that socio-economic grouping is the strongest predictor of knowledge and uptake of cervical smears and women with higher risks are less likely to have opportunistic cervical smears. The research compared the knowledge, attitudes and practice of 395 Irish urban women with 323 high-risk women, recruited from genitourinary medicine (GUM) clinics. 55% of the general practice sample and 45% of the GUM sample correctly identified the purpose of a smear. Both groups expressed a preference for a female provider. The authors conclude that information programmes must build on pre-existing knowledge and focus on the relevance and acceptability of the test (Ni Riain et al, 2001).

Reported barriers to attendance

A review by Fylan that examined reasons for women's non participation in cervical screening programmes, found that administrative failures, unavailability of a female screener, inconvenient clinic times, lack of awareness of the test's indications and benefits, considering oneself not to be at risk of developing cervical cancer, and fear of embarrassment, pain, or the detection of cancer were the reasons for non-participation (Fylan, 1998).

Johnston et al interviewed 307 non-users and 307 matched users of a cervical screening programme. Participants were asked about who they would prefer to take the Pap smear, where it was carried out and at what time. A female screener was preferred by most non-users and most users, 77% and 60% respectively. In all women the most favoured place to have the test carried out was the GP surgery or health centre. There was little demand for workplace services or weekend clinics from either group but 15% of all women who wanted to attend preferred an evening service. Preferences for smear-taker and location were not associated with age, social class or marital status. The authors concluded that service providers should take into account the requirements of all women if voluntary participation in the screening programme is to be encouraged (Johnston et al, 1996).

Leach & Schoenberg examined the data from the National Health Interview Survey focusing on the correlates of screening for women aged 55 or older. 25 women who were rarely or never screened were questioned about factors and circumstances underlying their decision not to obtain a Pap smear. Results indicated an association between Pap smears and demographic factors (being married, being younger and having suburban or urban residence) and access to preventive care (obtaining mammograms, having a regular source of health care and having contact with an obstetrician/gynaecologist).

It was found that women with weak social ties, who were older, and who lived in rural areas had inadequate use of preventive services. The authors noted a vicious cycle that can emerge when women decline preventive care. Women that do not attend can then feel uncomfortable when they do go to the doctors because mentioning their lack of compliance can result in them feeling chastised, which alienated them and impeded them seeking future preventive care (Leach and Schoenberg, 2007).
A Swedish study explored how women who declined participation in the cervical cancer screening programme reasoned about their decision. Qualitative telephone interviews and fax messages from women who actively declined participation were analysed.

The following reasons for non attendance were identified:

- Lack of confidence in benefit of screening
- Previous negative experiences
- Belief in one’s ability to discern health changes
- Negative risk perception
- Political and social viewpoints
- Invitation letter and views about organised screening programme

The authors concluded that the manner in which women defined and conceptualized distinctions between the roles and responsibilities of both private and public spheres were central (Bloomberg et al, 2008).

As a part of community awareness sessions on cervical cancer, 172 black and minority ethnic women in Newham, East London completed questionnaires on their knowledge, attitudes and experiences of cancer-screening services. Of these women, 17 also took part in individual in-depth interviews. 11 of the session facilitators were interviewed individually, and 11 health advocates took part in two focus group discussions. It was found that many of the women surveyed were unaware of the screening services and many others held misconceptions about the smear test. Fear, embarrassment and previous negative experiences all inhibited initial or repeat attendance for screening (Box et al, 1998).

A series of focus groups among African Caribbean, African, Gujarati, Pakistani, Greek and Arabic groups living in Brent and Harrow in London were held to discover their perceptions of cancer screening, the barriers to effective uptake and some strategies for intervention. This consisted of 135 participants of which 85 were women and 50 were men. Analysis of focus group data revealed poor knowledge, underlying health and cultural beliefs, attitudes, language and unhelpful attitudes of health professionals to be important barriers. In terms of strategies for improving uptake of screening, the women supported community-based cancer awareness education, sensitive to religious and cultural needs (Thomas et al, 2005).

A study in Amsterdam found that women aged 40-50 who felt high personal moral obligation, who had only ever had one sexual partner, and who were invited and reminded by their own general practice, had the greatest likelihood of attending screening. Those unscreened thought they had less risk of cervical cancer, were less motivated, intended to get future screening less often and were more convinced that cervical cancer cannot be cured. The authors concluded that to improve the uptake rate, we should focus on the personal moral obligation, beliefs about the risks of cervical cancer and available cures (Tacken et al, 2007).
Disability was also found to be a barrier towards screening. The papers that discussed disability issues addressed women with physical disabilities, mental health problems, learning difficulties and hearing difficulties. It was found that deaf women benefit more from culturally sensitive interventions and it was important to ensure the availability of teaching facility, literature and education material for disabled groups (Sadler, 2001).

3.2 Theoretical understanding of attendance at screening

A number of psychological models have been used to try and better understand the reasons for attending and not attending screening. These models often attempt to explore the processes that occur before a woman chooses a course of action.

The health belief model has been used most often. This model attempts to explain an individual’s choices about health in terms of their perceptions about their own risk, the severity of the condition, the barriers to adopting health behaviour and the positive benefits that they will get from adopting behaviour. For cancer screening this model implies that an individual’s perception about their own risk of getting cancer, the ease of accessing the service and the belief that the service will personally benefit them are likely to be important. However, an analysis of 16 studies that used the health behaviour model to predict attendance at breast screening found it often could not explain the patterns of attendance seen (Yarbrough, 2001).

A study by Savage used a theoretical framework comprising elements from the Health Belief Model, the Theory of Reasoned Action, and illness representations from the self-regulatory model to investigate factors associated with the use of screening for breast cancer and cervical smear tests. The research used a highly structured interview schedule and involved telephone interviews with 1,200 women aged 50-70. The research found considerable similarities between the factors associated with both mammography and cervical smear test behaviours. The factors associated with screening mammography behaviour were: perceived barriers, perceived benefits, social influence, the illness representations and marital status. The factors associated with cervical smear test behaviour were: perceived barriers, perceived benefits, emotions as a cause of cancer, feeling frightened of cancer, the illness representations, having a usual general practitioner and being younger (Savage, 2001).

The trans-theoretical model has also been used to explain attendance at screening and consists of stages which can be applied to screening. These are: pre-contemplation (no intention to be screened, not been screened), contemplation (intention to be screened, not yet been screened), action (intention to be screened, attended initial screening), maintenance (intention to be screened, regularly attend), relapse (no intention to be screened, attended a previous screen).
A study by Kelaher, 1999 in Australia applied the trans-theoretical model of behaviour Change (TTM) to determine the level of support for cervical cancer screening required by different language and cultural groups. Focus groups and structured interviews were used to classify women in terms of the model and collect information regarding knowledge, health service contact barriers and enhancing factors and sources of information in relation to cervical cancer screening.

Kelaher’s study found that women who intended to be screened in the future were more likely to have positive decisional balance scores and higher knowledge scores than women who did not. Women who had had Pap smears were significantly more likely to have received information from their general practitioner (GP) than women who had not had Pap smears. Women in pre-contemplation were more likely than women who had Pap smears to agree that they would travel a long way to see a practitioner who spoke their own language. The authors found that classification into the groups indicated by the model was supported both by the decisional balance scale and measures of knowledge. Women in earlier stages of the model were more likely to express preferences for the provision of services in their own language and by a female. The authors concluded that using TTM may significantly improve the effectiveness of interventions for women of diverse cultures and ethnicities (Kelaher et al, 1999).

4. Review of the interventions literature

4.1 Review process

The following electronic databases were searched for the literature review: NHS specialist screening Library, Cochrane Collaboration (Central Register of Controlled Trial), Medline and CINAHL. The search focussed on papers about interventions to increase attendance at cancer screening or those about barriers to attending or predictors of attending screening. Papers were included if they were: published in English, between January 1989 and December 2008 and the study was undertaken in Europe, the Americas, or Australasia. The search strategy was developed in consultation with a librarian who used Mesh terms and key words to identify relevant papers (Appendix 1).
Screening the literature

The initial search identified 416 papers, abstracts of which were initially reviewed. Papers that were solely about epidemiology, clinical guidelines and treatment modalities, mortality statistics or performance evaluation of screening services were excluded. Papers that only included ethnic groups with a small presence in Greater Manchester, such as Native American Indians and Australian aborigines, were also excluded. This initial screening resulted in 261 papers being excluded.

Mapping the literature

The remaining 155 papers were divided into 74 papers concerning predictors and barriers to screening and 81 papers dealing with interventions. The papers about barriers were discussed earlier. In the 81 papers about interventions, ten were systematic reviews.

A researcher maintained an electronic database of the relevant studies. After final screening of titles and abstracts of the articles, the interventions were mapped into five groups (see Figure 2).
Initial search \( n = 416 \)

Mapped \( n = 155 \)

Interventions \( n = 81 \)

Rejected \( n = 261 \)

Predictors and barriers \( n = 74 \)

- Reminder systems \( n = 24 \)
  - Leaflets \( n = 6 \)
  - Community-based \( n = 30 \)
  - Office systems \( n = 11 \)
  - Systematic reviews \( n = 10 \)

- Invitations and patient appointments
- Physician reminder
- Out-reach interventions
  - Mass media
  - Minorities
- Letters
- Phone Call
- Pocket cards
- Computer Systems
- Chart Reminders
- Flags in Files

Figure 5: Map of literature search
4.2 Findings

4.2.1 Reminder systems

A total of 24 studies evaluated interventions that involved some form of reminding strategies. Most of the studies (n=16) evaluated screening uptake for breast cancer. The majority of the studies were about the best ways of inviting patients to the screening. A number of studies considered reminders to GPs so that they would raise, when appropriate, the issue of screening with their patients.

Invitations and patient appointments

Much of the research about invitations and reminders focussed on the role of GPs in the uptake of cancer screening. GP endorsed letters and phone calls were the main interventions that were evaluated in these studies. Seven studies showed that GP endorsed letters were effective in increasing the uptake for breast cancer screening.

Turner et al (1994) conducted a randomised trial to determine whether the acceptance rate of the second invitation for breast screening might be increased by an accompanying letter from a general practitioner (GP letter) and what the additional costs of sending such a letter may be. 465 women, registered with four practices in a single health centre, were recruited into a randomised controlled trial in which the intervention was the inclusion of a standard, photocopied letter signed by the doctor of the non-attender, with the second invitation to attend for breast screening. The control group received only the standard invitation from the breast screening centre. The costs associated with the intervention were assessed from data supplied by the breast screening centre. The attendance rate of the test group one month after the second invitation for screening was significantly higher than that of the control group (21% v 10%, P < 0.01). In this study the average cost of including the photocopied GP letter was 1.1 pence and the marginal cost for each extra attendee was 9.6 pence. The authors concluded that the inclusion of a GP letter appeared to be effective and feasible in increasing the attendance rate to the second invitation.

A randomised controlled trial In Italy evaluated the effectiveness of four different invitation systems. They compared the effectiveness of a GP-signed letter with a pre-fixed appointment time to a similar letter with an open appointment time, a letter signed by the screening coordinator with a fixed appointment time and a letter signed by the GP with a fixed appointment time and additional material about the benefits of screening. It was found that personal invitation letters signed by the woman's GP, with pre-allocated appointments, induced a significant increase in compliance with screening. Keeping this group as reference, the overall compliance with cervical cancer screening was reduced by 39% and by 14% with open appointment times, and a letter signed by the screening coordinator, respectively. No difference was observed for the intervention that included additional study material. The authors concluded that the worst approach was having an open appointment time. The best approach was having a fixed appointment time and a letter from the GP with or without additional material (Segnan, 1998).
Tailored information has also been used in two studies. A randomised study in Glasgow in previous non-attenders compared a letter that mentioned their past history of attendance with a standard reminder letter. The study did not find a significant difference in uptake between the two methods (Meldrum, 1994). A randomised controlled trial in London found no significant difference between an approach that used GP-endorsed letters and one involving home visits by nurses (Sharp, 1996).

A randomised controlled trial in Sweden evaluated three interventions to increase compliance in 12,240 women invited to screening. They compared: a modified invitation with the standard invitation letter; a reminder letter to non-attenders after the first intervention with no reminder letters, and a phone reminder to non-attenders after the reminder letter with no phone reminder. The study analyzed the proportion of women attending screening after each intervention and the cumulative proportion after the interventions as well as the cumulative proportions of cytological abnormalities. The study found that a modified invitation made no difference but reminder letters increased attendance by 9% and phone reminders increased attendance by 31.4%. The authors conclude that simple reminders by mail and phone can drastically increase women's participation in cervical cancer screening (Eaker et al. 2004).

Other studies evaluating the effectiveness of phone calls in combination with invitation letters and reminders indicate that telephone reminders increase attendance. One of the studies evaluated the individual as well as the combined effects of tailored letters and phone calls. The study found a 6% improvement in uptake when a tailored letter was combined with a phone call (Saywell, 2004). Another controlled trial evaluated the effectiveness of a physician-endorsed letter and a phone call. The group with both interventions had a 20% increase in attendance rate for mammography (Bodiya, 1999).

Researchers analysed the response to second and third postal invitations from a group of patients previously invited for mammography screening and identified demographic differences between responders and non-responders. Females aged 50-64 in North Dublin were included in the study. Non-responders to an invitation for screening were re-invited by computer-generated letter to attend for screening six weeks after the issue of the first invitation and a final invitation was issued at 12 weeks. There were 1,310 females in the target age group who were eligible for screening. The response rate to the first invitation was 61%. The issue of a second invitation increased the response rate by 20%. A third invitation increased the response rate by a further 8%. The authors concluded that a second mailed invitation is cost effective and should be incorporated into routine policy but the third invitation was not cost effective.
Computerised and automated systems

A study in the United States evaluated a computer-assisted telephone interviews intervention. This automated phone call was capable of interacting with the patient and provided tailored messages as well as the scheduling of appointments. There was an 8% improvement in uptake in the intervention group (Allen, 2005). Similarly, interactive voice response telephone systems have been used in Australia and America, they use random digit dialling and have the capacity to undertake automated interviews and deliver tailored interventions.

Automated messaging systems could be linked to a screening centre’s central database so that automated messages can be sent to patients. It has been suggested that multilingual options and tailored information could be used to reach high risk groups, older women and hard to reach population sub-groups (Corkrey, 2005).

A randomised controlled trial in the USA evaluated a touch screen computer programme that provided personalised recommendations for breast and cervical screening. Patients were included if they had visited a study practice in the previous year and were eligible for breast or cervical cancer screening. Intervention practices received a touch sensitive computer programme that was designed to provide patient specific recommendations on cancer screening and to facilitate the workflow in the practice. Patients answered 20 to 25 questions on personal and family medical history and lifestyle. The computer provided chart reminders, chart organisers and patient education materials. Control practices received no additional services.

A total of 9858 adults used the computers. Intervention practices had a greater average change in the proportion of women who had screening mammography (difference 8%, p < 0.05) and clinical breast examinations (difference 8.3%, p < 0.05). All other rates of use of screening tests showed a positive difference in favour of the intervention practices, but none of these differences reached statistical significance. The authors concluded that an easy to use, patient initiated computer programme improved screening rates for breast cancer (mammography and clinical breast examination) but not for other cancers (Kernohan, 1999).

Physician reminders

GPs can play an important role in the uptake of screening, particularly in women that have not yet attended. A physician’s active participation in inviting, recommending and reminding non-attenders has a positive effect on the uptake of screening. A study in Italy evaluated the impact of different modalities of GP involvement, on the attendance rate of organized population-based screening programmes for breast cancer including the introduction of target payments. The study was conducted between 1994 and 1996 in four Italian cities where a breast cancer screening programme was active.
It was found that an invitation letter signed by the GP and the project co-ordinator attained 4 to 7% higher participation. The offer of a target payment had a certain impact on the screening uptake, but was not easily distinguishable from that of a GP signature of the invitation letter. The authors concluded that simple strategies like chart reminders and flags in a patient’s health record can be effective in reminding GPs to talk about screening and this in turn can increase uptake. The authors also suggest that organisational factors, such as the availability of a list of non-responders, might be crucial in order to enhance the effect of the GPs action (Giorgi et al, 2000).

GPs may contribute towards increasing uptake through:

- ‘Cleaning up’ the invitation lists, especially when computerised archives with the mammography history of the target population are not available.
- Increasing women’s participation by signing the invitation letter, by counselling and active participation in the invitation phase.
- Cooperating in the reminder phase by recalling non-responders.

A UK randomised controlled trial evaluated the cost-effectiveness of two primary care-based interventions aimed at increasing breast screening uptake for women who had recently failed to attend screening. 13 general practices which had low uptake (below 60%) in the second round of breast screening in North West London and the West Midlands were included. Participants were women who were recent non-attenders for breast screening in the third round. Participants were randomised to receive either no intervention or a GP letter, or had a flag placed in their notes to prompt discussion by health professionals, or both interventions. Outcome measures were attendance for screening six months after randomisation and the cost effectiveness of the interventions. 1,158 women were individually randomised. It was found that among recent non-attenders, the letter was effective in increasing breast screening attendance. The flag was of equivocal effectiveness and was considerably less cost effective than the letter. The letter intervention had 1.5 times better attendance rates than the control group (OR 1.5, 95% CI 1.02 to 2.26; p=0.04). The flags intervention had 1.4 times better attendance than the control group (OR 1.5, 95% CI 0.93 to 2.07; p=0.10) for the flag. The additional cost to the health services for each attendance was £35 for the letter and £65 for the flag (Bankhead, 2001).

Behaviour change theories

One USA trial was found that based its intervention trial on behavioural change theory. Four groups of interventions were used: usual care; tailored telephone counselling; tailored printed materials, and tailored telephone counselling and printed materials. Participants included a total of 1244 women from two sites, one of which was a general medicine clinic setting, serving a predominately low-income clientele.
Computer-tailored interventions addressed each woman's perceived risk of breast cancer, benefits and/or barriers and self-efficacy related to mammography screening comparing delivery by telephone and mail. Women were categorised at baseline as pre-contemplators (those who intend to attend) and contemplators (those who do not intend to attend). It was found that all intervention groups increased mammography adherence significantly (odds ratio 1.60-1.91) compared to usual care. However, no intervention had a significant effect on pre-contemplators and all interventions had significant effects on those who entered the study as contemplators. The authors suggested that intensive interventions may be required for the group of women that do not intend to attend a screen (Champion, 2007).

4.2.2 Leaflets

A Dutch study examined if health education could reduce drop-outs between two breast screening rounds. Health information was tailored for women who had attended breast cancer screening before. Two versions of the tailored leaflet were made. One was a simple version and the other included additional enhanced information about the disease. 2961 women were selected for the study and the effects of the tailored leaflets on re-participation were tested against a standard leaflet. Re-participation rates were greater than 90% and there was no difference between the two groups. The authors concluded that the leaflets with tailored information did not enhance re-participation. Further, the additional costs could not be justified. They also suggest that their analysis provides indications that less painful mammograms and friendly staff might improve re-participation (Drossaert et al, 1996).

A pilot study in Cardiff suggested that identifying ethnic language groups, the use of a GP endorsement letter, translated literature including: multilingual leaflet, GP letter, screening invitation and incentives of transport to the screening centre may support an increased uptake. Out of 369 women who were invited, 187 attended for screening. This gave an uptake of 50.7% compared with an uptake of 35.2% in the previous screening round. The authors concluded that translated literature, a GP endorsement letter and language support by link workers were beneficial interventions in minority ethnic groups. However, the provision of free transport was ineffective and under-utilised. Uptake was highest amongst Urdu and Gujarati-speaking groups and lowest for Bengali and Somali speakers who were found to be the hardest to reach group. The authors suggest that there is scope for improving attendance at screening amongst ethnic minority groups but interventions can be costly (Bell et al, 1999).

The leaflet currently used by the NHS Cervical Screening Programme was evaluated in a randomised controlled trial against a leaflet containing additional information on risks and uncertainties. Three general practices in Birmingham were selected, from which 300 women aged 20 to 64 attending the practices during a one month period were included in the study. Fewer women in the intervention (79%) than the control group (88%) expressed intention to have screening after reading the information leaflet. There was a 9.2% difference between the two groups (95% CI 3.2% to 21.7%).

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Having a previous Pap smear was the only significant predictor of an intention to have screening (adjusted OR 2.54, 95% CI 1.03 to 6.21). The authors concluded that providing women with evidence-based information on the risks and benefits of screening may deter some women (Adab, 2003).

A qualitative survey in Oxfordshire evaluated the effect of the Breast Screening Programme’s leaflet in improving women’s knowledge of breast cancer screening. A random sample of 100 women aged between 49 and 64 registered with GPs, whom data from a prospective, questionnaire survey was available on knowledge and perception of breast cancer screening, was included in the study. It was found that the women’s knowledge of lifetime risk had improved significantly ($p < 0.0001$). 32% of women who previously responded that screening prevented breast cancer now responded correctly. However, 20% of women who responded correctly to that question before the leaflet now responded incorrectly. The authors concluded that some of the information was misunderstood by most people (Webster, 2007). In the UK, one in five adults are estimated to have reading difficulties (Moser’s 1999 report, ‘a fresh start’) so it is important that leaflets and invitation letters are reviewed, updated and are suitable for the target population.

4.2.3 Office systems

A two hour training programme for general practice reception staff was evaluated in the inner London borough of Newham for its effect in improving screening uptake in patients who had failed to attend for breast screening, and to see whether women from different ethnic groups benefited equally. Attendance in the intervention group was significantly better than in the control group (9% and 4%). The response was best in Indian women which was 19% in the intervention group and 5% in the control group. The authors concluded that this low cost intervention improved breast screening rates modestly. Improvement was greatest in Indian women, probably because many practice staff shared this cultural and linguistic background. It was suggested that this intervention could be effective as part of a multifaceted strategy to improve uptake in areas with very low attendance rates (Atri et al, 1997).

A study in the USA evaluated a web-based system which was developed for appointment secretaries to manage breast cancer screening. Female patients aged 40 to 75 were randomly assigned to an intervention group and a control group receiving usual invitations. 6665 women participated in the research. The intervention comprised two reminder letters, sent monthly, starting three months before the due date. A telephone call was made if the individual missed the appointment. The attendance rate in the intervention group was 64% and in the control group it was 55%. The authors concluded that attendance at screening improved significantly by having appointment secretaries proactively manage breast cancer screening needs (Chaudhry, 2007).
Use of office systems with multi-component interventions like physician education, nurses involvement, training of receptionists, use of financial incentives for GPs, computer reminders, audits and performance evaluations have been examined in the studies. These studies varied in rigour and statistical power and there is only modest evidence that use of multi-component office systems will increase screening uptake (Cockburn, 1990; Taylor, 1999; Engelmann, 2004).

4.2.4 Community-based interventions

Community outreach programmes

The community outreach programmes identified in the literature were about health visitors, volunteers, peer groups and the use of religious places of worship for health promotion. Two studies evaluated the effectiveness of health visitors on the uptake of cancer screening in minority groups. Both studies found no significant difference between the intervention group and the control population (Sung, 1992; Hoare, 1994).

A study in the USA used volunteers to encourage their peers and friends to attend breast screening. The American Cancer Society (ACS) designed a telephone intervention strategy (the 'Tell a friend' programme) that relied on volunteers and targeted women aged 40 and older. During a half-day training session, each volunteer provided a list of ten women she was willing to contact over a six month period and to encourage them to have a mammogram. Each list was randomised, and five names were returned to each volunteer for inclusion in the intervention. The other women served as controls and were not contacted by the volunteers. All women were subsequently interviewed at the end of the intervention period. In the intervention group 49% received their most recent mammogram since the start of the intervention period, whereas it was 34% in the control group of women. The effectiveness of the intervention remained after controlling for demographic characteristics. The strategy was effective for both black and white women of all ages, but principally among low income groups. The authors conclude that a telephone intervention strategy of personal contacts between acquainted women can significantly increase mammography use, particularly among women with low to moderate income (Calle, 1994).

Four papers used church organisations to promote screening uptake. It was found that religion influences preventive behaviour and regular church attendance was positively associated with compliance with mammography. A study used data from the health and retirement survey to examine the relationship between religious attendance, religious salience, denomination and three types of female preventive services in a sample of middle-age women (n= 4253). It was found that women who attended religious services more frequently used more mammograms, Pap smears and self-breast exams. In addition, women belonging to mainline Protestant or Jewish denominations use certain preventive services more than Evangelical Protestants. Finally, women with higher levels of religious salience were more likely to conduct self-breast exams.
The authors conclude that social factors such as religion can play an important role in either creating barriers or facilitating the use of preventive services. These findings also add to the growing field of religion and health research where preventive health care use is emerging as a possible mechanism linking religion to a wide variety of physical health outcomes (Benjamins, 2006).

Mass media campaigns and communication strategies

One paper was found that evaluated an Australian television campaign. This campaign aimed to increase cervical cancer screening uptake. The study assessed whether a mass media campaign could encourage women who were overdue for a cervical smear test to have one, without prompting unnecessary early re-screening. A telephone survey of a representative sample of 1000 women aged 25-65, assessed their recall of the advertisement and their intention to attend after seeing it. The television advertisement was recalled by 61.5% of women. Women who said that they meant to have a test every two years, but usually left it longer, indicated they would have a Pap test more often as a result of seeing the advertisement (63%), than women who had Pap tests every one (6%) or two (12%) years. Data from the Victorian Cervical Cytology Registry from mid-2002 to the end of 2004 showed that during the campaign the number of Pap smears conducted increased by 18% . The rate increased the most among those due, or overdue, for a Pap test. The authors concluded that in a population with a high level of awareness of cervical screening, it was possible to run a mass media campaign to encourage screening which is specific to women whose tests were due or overdue. (Mullins et al, 2008).

The effectiveness of an advertising campaign was evaluated by Cohen et al (2000). A press advertisement was used in inner city Glasgow. The campaign used posters, ad-shells and targeted sites like train stations, undergrounds and the interiors of buses. Breast screening uptake in the coverage area increased from 2-13%. A pilot project utilised drama entertainment as health education and provided inconclusive evidence. It was found that it could not be assured whether the final health message had been delivered (Cheney, 2006).

Another study utilised clinical waiting times to deliver a multimedia health education intervention and compared it with leaflets (Street, 1998). It was found that multimedia intervention was more effective than leaflets. Video health breast kits were given to women over 60 in the United States. There was significant improvement in knowledge about breast cancer and self-efficacy in breast self-examination (Wood, 2004).

One study discussed the use of the internet as a research source for identifying breast cancer (Thomas, 2002). However, no evaluations were found about the use of the internet as a medium for increasing screening uptake. Similarly, no study was found that evaluated the use of radio.
A multidisciplinary group of health professionals and cancer advocates from several European screening programmes collaborated to provide health professionals involved in cervical cancer screening with an insight into the complex issues relating to communication about screening and to provide a framework for more effective communication. European surveys on screening communication, literature reviews and group discussion were used for this purpose (Giordano, 2008).

The following recommendations were given:

- Information on cervical screening must be easily accessible.

- Information should be relevant, comprehensible, comprehensive, client-centred, phase-specific and multilevel.

- An effective communication strategy should consider health professionals' screening knowledge and their communication skills, consumers' health literacy skills and the communication needs of specific sub-groups in the target population.

- Co-operation between screening professionals, advocacy groups and journalists should be promoted.

- To communicate effectively and appropriately is a complex task which can be influenced by a number of factors.

- Screening workers need better information themselves and must take into account the needs and characteristics of the target population.

Minority groups

Research in ethnic communities identified poor coverage of breast cancer screening in minority ethnic groups, particularly those of South Asian women (Hoare, 1996). Similarly, uptake for cervical cancer is low in women from India, Pakistan and Bangladesh. However, in Afro-Caribbean populations it is comparatively higher (Carr, 1995). The research on the effectiveness of interventions targeted to increase cervical cancer screening uptake is limited compared to that for breast cancer.

One study found that home visits were more effective than leaflets (Mcvoy and Raza, 1991). The presence of a female doctor was found to be associated with a higher uptake of cervical screening, particularly in South Asian women (Majeed, 1994). However, for breast cancer screening there was no relationship found between the physician’s gender and screening uptake (Majeed, 1995).
Home visits by link workers were found to be ineffective in increasing breast cancer screening uptake (Hoare, 1994). One study evaluated the role of culturally and linguistically compatible university students as health educators. Asian grocery stores were targeted for breast cancer education. The intervention was found to be effective and cost effective (Sadler, 2000). A study in the American Chinese community found that bilingual lay health workers were effective in increasing the self-efficacy of breast cancer (Yu, 2007).

It has been observed that a multifaceted approach is required to design interventions that are language and culture specific for ethnic minorities. The training of reception staff, availability of a female doctor, reminder letters, leaflets in different languages, community development and out-reach programmes were found to be promising strategies for minority ethnic groups. These increased the screening uptake from 30-50% (Falshaw, 1996; Kernohan, 1996; Ahmed, 2005).

**Opportunistic screening**

Contact with the health services provides an opportunity for an invitation and recruitment to screening but very few studies have evaluated the effectiveness of opportunistic screening.

A prospective randomised trial was conducted to determine the feasibility of cervical cancer screening in an urgent care clinic. Women presenting to the urgent care clinic who required a pelvic examination for their treatment were eligible for participation. Women randomised to the intervention group had a Pap smear performed as part of their pelvic examination, while women in the usual care group were encouraged to schedule an appointment. Questionnaires regarding cervical cancer risk factors and demographic information were completed by both groups. 94 of the 111 women in the intervention group received a Pap smear, compared to 25 of the 86 in the usual care group. The authors concluded that urgent care clinic visits could be used as opportunities to perform cervical screening in women who are unlikely to adhere to cervical cancer screening recommendations but the effectiveness of this intervention required effective follow-up (Batal et al, 2000).
4.2.5 Systematic reviews

The literature search found 11 systematic reviews and two meta analyses. Figure 3 describes the different types.

**Figure 6. Map of systematic reviews**

Breast cancer screening

Sin and St Leger (1999) evaluated the effectiveness of multiple interventions targeting screening uptake. These included reminder letters, appointment cards, advice from GPs, advice from health visitors and telephone calls by GP receptionists. Medline, Embase, Psyclit and Social Sciences Index were searched from 1980 to July 1998. Randomised controlled trials and prospective randomised studies were included. 26 papers were included in the review of which 15 were randomised controlled trials and 13 were descriptive studies. The literature search was adequate but the review process was not well explained. The review found that invitation letters with fixed screening appointments increased screening uptake compared to an open invitation letter.
Also, extensive health education was equally effective as brief verbal advice by the GP. In women who did not attend their first screening round, a GP-endorsed reminder letters with a fixed appointment was found to be effective. Personalised GP letters were found to be equally as effective as home visits by nurses with or without extensive health education programmes.

Bonfill et al (2000) also reviewed the evidence on different strategies for increasing breast cancer screening participation. 16 randomised controlled trials and clinical controlled trials were included in the study. The review found five active strategies that were effective for inviting women into community breast cancer screening services: letter of invitation (OR 1.66, 95% CI 1.43 to 1.92), mailed educational material (OR 2.81, 95% CI 1.96 to 4.02), letter of invitation plus phone call (OR 2.53, 95% CI 2.02 to 3.18), phone call (OR 1.94, 95% CI 1.70 to 2.23), and training activities plus direct reminders for the women (OR 2.46, 95% CI 1.72 to 3.50). Home visits did not prove to be effective (OR 1.06, 95% CI 0.80 to 1.40) and letters of invitation to multiple examinations plus educational material favoured the control group (OR 0.62, 95% CI 0.32 to 1.20). The reviewers concluded that most active recruitment strategies for breast cancer screening programs examined in this review were more effective than no intervention.

Masi et al (2007) conducted a systematic review of literature to evaluate the usefulness of interventions targeted to enhance breast cancer screening, diagnosis and treatment among racial and ethnic minority women. Cinahl and Medline were searched from 1986 through to 2005. However, trials were only included if they were conducted in the United States. Interventions were analysed according to two main categories: patient-only interventions and patients and provider interventions.

A total of 14 trials were found that included patient-only interventions. Interventions were classified into three areas: reminder-based, culturally-tailored and multi-faceted. The review found that the effectiveness of reminder interventions like telephone calls and tailored letters varied according to the socio-economic and demographic characteristics of the population. Tailored reminder letters were more effective in a white than in a black population. In black communities a combination of telephone counselling and tailored letters were effective.

Culturally-tailored and language-specific video tapes were also found to be effective. It was also found that multi-faceted interventions, such as transport facilitation, appointment scheduling etc., that addressed logistic and cultural barriers were effective in increasing screening uptake.

18 trials included both patient and provider interventions. Seven studies compared patient interventions with provider and 11 studies compared the combination of both with provider only or user only interventions. Provider interventions were found to be more effective than patient interventions in six of the trials. It was found that chart reminders were 19% more effective than patient reminder letters. Also, a combination of these two interventions was found to be effective. The authors conclude that evidence supports the chart reminders and suggest it is a cost-effective strategy, particularly for low socio-economic, ethnic minority groups.
Cervical cancer screening

Two reviews focused on interventions for cervical cancer. One of them looked at the effectiveness of patient and GP reminder systems while the other looked at multiple interventions. Black *et al*, 2000a reviewed the literature between 1989-99 to ascertain the strategies for cervical screening uptake in clinic-based settings. A comprehensive search strategy was used and efforts were made to include unpublished literature. The quality of this review was assessed by the Centre for Reviews and Dissemination and the findings were considered to be reliable.

The main findings were:

- Personalised letters from the family physician were 12% more effective than pamphlets and invitation letters.
- Letters and telephone reminders were more effective than physician chart reminder strategies (compared to no intervention control group (p<0.005).
- Language-specific educational videotapes were effective when compared with usual care (p=0.02).
- Use of dedicated staff to promote screening in older women was found to be effective (p=<.01).
- Interventions directed at a physician’s behaviour and training were more effective than the distribution of leaflets (p<0.0001).
- Media-based interventions were effective at increasing knowledge.

Forbes *et al* (2000) searched 23 electronic databases to evaluate the effectiveness of strategies targeting cervical cancer screening. Thirty-five randomised controlled trials were included, out of which eight were quasi-RCTs. It was found that invitation letters increased attendance. Additionally, limited evidence was found for the effectiveness of using educational materials.

**Meta analysis**

Tseng *et al* 2001 performed a meta-analysis to evaluate the efficacy of patient reminder letters on cervical screening. The review searched literature between 1996 to 2000. Ten trials were included in the final analysis and odds ratios were pooled. Women who received reminder letters were more likely to attend screening compared to women who did not (OR 1.64, 95% CI 1.49 to 1.80). Further, it was found that reminder letters were less effective in lower socio-economic groups (OR 1.16, 95% CI 0.99 to 1.35) compared to mixed populations (OR 2.02, 95% CI 1.79 to 2.28).
Pirkis et al, 1998 performed a meta analysis to review both the patient and physician reminder systems. GP interventions included tags in patient notes, computerised reminders plus educational and administrative input, preventive care flow sheets in patients’ records alone and combined with GP education. GPs in control groups received education and administrative inputs.

Patient reminder systems comprised invitation letters, letters with appointments and phone call. Ten trials were included and the risk difference was calculated. It was found that those women who received patient reminders have an 11% higher uptake compared to those who received standard care (Risk Difference (RD) = 10.8%: 95% CI 8.1 to 13.6%).

The number needed to treat (NNT) was also calculated and it was found that 20 reminder letters were required to be sent to achieve one additional smear test (NNT 20.3 95% CI 13.9 to 38.2). It was found that uptake was 8% better in women whose GP received reminder interventions. (RD 7.9 %, 95 % CI 6.5-9.4%). Further, it was found that 15 GPs needed reminder interventions to achieve one extra smear.

It was also found that GP reminders are cost effective due to their opportunistic nature. The results were assessed by CRD and it was concluded that this was a well conducted systematic review. However, it included only two studies conducted in the UK.

Lay health workers community workers

Two reviews were found that reviewed literature on lay health workers. Lewin et al (2005) looked at the role of lay health workers in different areas including breast cancer screening. A very small effect was seen with the involvement of lay health workers compared to usual care. Similarly, Swider and Susan (2002) also reviewed the effectiveness of health worker interventions and found only a small number of studies which documented outcomes like increased knowledge rather than actual attendance.

Peer support phone calls

Dale (2008) reviewed the literature on peer support phone calls. Seven randomised controlled trials were included out of which two were about breast cancer screening. One study found that peer support calls may be effective in increasing uptake by 15% compared to women with usual care or no intervention. The intervention comprised peer support telephone calls up to three times during a six month period. Information support was provided by the peers. Another study in the same review found peer support phone calls effective in the maintenance of screening attendance.
Personalised risk communication and informed decision-making

Edwards et al (2006) conducted a systematic review of literature on the effects of personalised risk communication on consumers’ uptake of screening. The review included 22 randomised controlled trials of interventions with an element of personalised risk communication, for example, risk associated with age or family history. Half were about breast cancer screening.

The review found a small increase in the screening uptake in patients with personalised risk communication (OR 1.31, 95%, CI 0.98 to 1.77). It also found, in five studies, that women with a high risk of breast cancer, personalised risk communication had a significant increase in the uptake (OR 1.74, 95%: CI 1.05 to 2.88). Numeric communication of risk is also suggested to be associated with better risk perception.

Briss et al (2004) reviewed the literature on interventions promoting informed decision-making and their impact on screening uptake. Interventions like counselling, small media, small group education and provider-oriented strategies or a combination of these were reviewed. It was found that knowledge and risk perception about cancer was improved but there was limited evidence on the effectiveness of these interventions on informed decision-making to attend screening.

Effect of screening on health behaviours

Bankhead et al (2003) performed a systematic review at Oxford University to assess the impact of screening on future health behaviours and beliefs. It was found that participants who went for breast and cervical cancer screening were not given any advice on lifestyle changes. Screening programmes were found to be associated with positive health behaviours and beliefs. Attendance was found to be associated with several positive health behaviours. The evidence suggested that women who attend once are most likely to re-attend screening.
5 Discussion and recommendations

5.1 Discussion

The aim of this work is to recommend interventions that are likely to increase attendance at breast and cervical screening in Greater Manchester. Literature about the determinants of attending screening, barriers and facilitators to attending screening and theoretical models of screening were reviewed to gain a better understanding of the key issues. The literature about interventions to increase attendance at breast and cervical screening was also reviewed. These sources were then considered and interpreted for the local context to develop a series of recommendations.

Studies have indicated that marital status, age, wealth, level of education and ethnicity are associated with uptake of cancer screening. These factors allow populations that are on average less likely to attend screening, to be identified but they are not particularly helpful for the development of interventions to increase uptake. This is because many of these factors are not amenable to change via a public health intervention. Furthermore, many of the factors that can predict attendance at screening at the population level are not very predictive at the individual level. This means that population groups can be described that, on average, are less likely to attend cancer screening, but within these groups a sizeable proportion of women attend screening. The evidence therefore indicates that social, cultural and environmental factors influence attendance at screening but these factors can be overridden by an individual’s decision to attend screening.

A number of psychological models have looked at the processes that influence a person’s decision to attend screening. These psychological models have tried to explain health behaviours in terms of rational decision-making processes. The health belief model, for example, suggests that health behaviours are influenced by a person’s beliefs about the seriousness of the issue, their perception about their own risk and their perception of the barriers to undertaking the health behaviour. Whilst these models might explain reasons why some people do not attend screening, they do not fully explain observed attendance patterns. This is not surprising if observed attendance patterns at the population level are the result of an interaction between psychological and sociological forces.

Intention to attend a screen emerged as a key concept and strong predictor of actual attendance. This is important and contrasts with some other health behaviours, for example, taking sufficient physical activity. The work about intention among women that currently attend mammography concluded that factors about choice, such as barriers, may be better predictors of intention than motivational factors, such as attitudes (O’Neil, 2008). This suggests that the approach for those women that intend to go to screening or have borderline intent should mainly be about practical issues to enable them to fulfil their intention. Interventions for these women should be about reminders and making it easier for women to get and attend appointments.
A second important predictor of attendance at screening to emerge from the literature is a person’s previous pattern of attendance. Those that have previously attended a cancer screen are very likely to attend their next invitation. This observation could be explained in terms of intention. In that women that attend are clearly motivated and likely to continue the health behaviour unless something intervenes to change that intention. An analysis of reasons for not attending a subsequent screen in women that previously attended screening found that around half implicated a negative experience at their previous screen (Marshal, 1994). The authors conclude that every effort should therefore be made to make screening as acceptable as possible.

A useful way of looking at the problem of attendance at cancer screens is to consider it in relation to the trans-theoretical model of health behaviour. Figure four describes the trans-theoretical model of health behaviour in relation to screening and describes the appropriate types of interventions to consider.

Women who do not currently intend to go to their next cancer screen can be usefully divided into those that once went but have now stopped (relapse group) and those that have never been and do not intend to attend (pre-contemplators). The focus of interventions in these two groups should be different. For women that have previously attended, interventions should focus on practical matters, advances in technology and improvements to the service. The general aim is to reassure these women that the service is still worth going to and that they might find the experience has improved or has been made easier to use. For women that have been invited and have never attended the focus of interventions should be about persuading them about the importance of cancer screening.

Persuading women that are previous non-attenders to begin going to screening is obviously a considerable challenge and the literature does not contain single interventions that are known to work in this group. Instead the literature indicates a number of approaches that might be useful in particular populations. These include, for example, efforts to communicate risk effectively, make leaflets and literature more accessible and relevant to particular population groups and use of peers and community volunteers in advocating screening. There is no evidence that professional community workers increase attendance at screening. The role of GPs is, however, worth careful consideration because there is evidence that a letter from a GP increases attendance at screening in women that have missed a screening appointment and that attendance at breast and cervical screening is higher in populations served by a female physician. It seems likely that empathy between a female patient and female physician has a role in allowing some patients to overcome barriers to attendance, such as embarrassment.

Asking GPs to raise cancer screening, whenever appropriate, appears to be sensible. Flags on patient records to prompt GPs to talk about screening produced a substantial but not significant increase in attendance in a UK trial. If these flags can be placed on computer or manual files then this should be considered. However, caution is needed not to appear to chastise women for not attending screening. One author suggested that a vicious circle of non-compliance with health care can be created if women feel uncomfortable when visiting a health professional.
Figure 7: Stages of behaviour change linked with relevant interventions

**TRANSTHEORATICAL MODEL**

**Stage of behaviour**

**Precontemplators**
- No intention to be screened
- No past action
- Non responders to 2nd Invitation

**Contemplators**
- Intention to be screened
- No past action

**Action**
- Intention to be screened
- Initial screening

**Maintenance**
- Intention to be screened
- Regular screening

**Relapse**
- Initial screening
- No intention to be screened

**Interventions**

**Education / belief**
- Peer pressure
- Increase risk perception
- Identify barriers
- Opportunistic screening
- Culture and language specific interventions
- Innovative Interventions

**Reminder letters**
- Addressing barriers
- Opportunistic screening
- Female doctors
- Preferred appointment times
- Child care facilities
- Facilitate access

**Reminder system**
- Continued education and risk perception
- Ensure initial visit is satisfactory
- Quality assurance

**Reminder systems**

**Address barrier**
- Social Marketing of recent Improvements in the system
- Confidence building
- Health education
- Innovative interventions
The bulk of women invited to screening are likely to have positive intentions towards screening. These women require information to help support that intention which should focus on practical issues and allaying concerns, and most importantly they need reminders to attend. The evidence is very clear that reminding patients to attend screening increases attendance.

The exact scheduling of reminders is not indicated in the study evidence. It would seem logical to have the first invitation with a fixed appointment time a number of weeks in advance and a second reminder close to the test. The simple logic behind this is to allow time enough to plan and make arrangements and then to remind people who might have forgotten.

For cervical cancer screening special consideration should be given to the epidemiology of the disease. The important consideration is that cervical cancer is caused by a virus that can be sexually transmitted and consequently some women have a much higher risk than others. This means that the increase in attendance wanted is in those women that do not currently attend but have been exposed to the HPV virus. It is therefore justifiable to put more effort and resources into those populations with a higher risk profile.

One conclusion to draw from the literature relating to cervical screening is that female health professionals have an important role in increasing and maintaining attendance at screening. There is evidence that more women would intend to be screened if they were guaranteed that the test was performed by a female.

Finally it should be noted that interventions to increase uptake of cancer screening do not take place in a vacuum. Outside events not considered by the academic literature can have important consequences. There has been unprecedented media coverage about cervical cancer following the untimely death of the celebrity Jade Goody at the age 27 from cervical cancer and this is likely to be important for cervical screening in younger women. It is likely that this coverage has altered many young women’s perceptions of their own risk, and had a favourable impact on the intention to attend cervical screening. A surge in attendance at cervical screening would also be expected. If there has been a positive effect on attendance it is important to focus in the future on maintaining this attendance and avoiding relapse.

To conclude, the evidence strongly indicates that the most effective way to increase attendance at screening is by simple reminders. Most women invited will have positive intentions towards cancer screening and require support to follow through with the intention and actually attend. A brief reminder to attend and simple practical information to encourage attendance is indicated. Some populations have low attendance and, whilst the evidence is not conclusive, efforts should be made to increase awareness and knowledge of screening, encourage local GPs to raise awareness of screening and encourage peers and opinion leaders to advocate screening. Women that do not attend should receive encouragement from their own GP to attend and tailored information relating to their risk.
5.2 Recommendations

The single most important intervention for increasing attendance at cancer screening is a robust system for reminding women to attend.

Patient reminders breast screening

1. Screening offices should have up-to-date contact details for their population. This should include home and mobile telephone numbers.

2. In addition to receiving a written invitation for a screening appointment, all women should be reminded about their appointment by a phone call or text message one day before the test is due to take place. The reminder should be simple and non-judgemental and can be delivered by screening centre staff. It should focus on practical issues about getting to screening and the process.

3. Women that attend a screen should confirm that their contact details are correct.

4. Women that fail to attend a first appointment for a breast screen in a screening round should be sent a second appointment time within the first week of their non-attendance. They should also receive a reminder the day before the appointment is due.

5. Consideration should be given to sending letters that are supportive of screening, and are signed by their GP, to women that do not attend screening.

Patient reminders cervical screening

1. In addition to receiving a written invitation for a screening appointment, all women should be reminded about their appointment by a phone call or text message one day before the test is due to take place. The reminder should be simple and non-judgemental and can be delivered by a GP receptionist.

2. Women that do not attend for a cervical smear should receive a letter from their GP inviting them to a second screen. This should be clearly recorded at the practice.

3. Quality assurance of the cervical screening programme should periodically liaise with GP practices to ensure that they are promoting screening and recording attendance.

GP reminders

A woman’s GP can play an important role in encouraging attendance at breast and cervical cancer screening.
1. A robust system should be in place to inform GPs about those women that did not attend screening.

2. Flags should be introduced into the files of non-attenders and GPs should, whenever appropriate, sensitively raise cancer screening with these women. Options should be explored in the current health systems for opportunistic reminders to the non-attenders.

Additional materials

It is difficult to change women’s intentions about cancer screening. The evidence suggests that some women’s views can be changed if they are informed about their own risk.

1. Before invitation, consider sending tailored materials to women that have repeatedly not attended a cancer screen. This should provide information about their cancer risk profile based upon broad factors such as their age, sexual history and attendance record.

2. For women that previously attended but missed their last appointment consider, before their next invitation, sending them tailored information about improvements to the service and about practical issues. This should focus on the ease of being screened, availability of female screeners and the ease of making appointments and getting to screening.

Community interventions

There is no strong evidence to support one approach to increasing attendance at cancer screening by work within communities. The use of professional community workers to advocate screening has not been demonstrated to work and is unlikely to be cost effective.

1. Consider providing volunteers, peers and community leaders with information and resources to promote screening.

2. Consider using available mechanisms such as health trainers, pharmacists, GP reception staff, dental staff and optician staff to promote screening.
Black and minority ethnic groups

Attendance at screening tends to be lower in some groups, for example Pakistani. These groups may require additional efforts to overcome barriers to attending.

1. In populations with low attendance, efforts should be made to understand the reasons for not attending and if possible address those reasons.

2. Information and invitations should, whenever possible, be in the most appropriate language for the patient.

3. The availability of female screeners and privacy during screens should be carefully considered.

4. In some groups men traditionally have a patriarchal relationship and play a major role in decision-making. Information and education campaigns targeting men should be evaluated for their effectiveness at increasing attendance.

Media interventions

Mass media coverage of cancers in celebrities appears to increase interest and attendance at cancer screening but the cost effectiveness of media campaigns that promote screening is unclear.

1. Consider using local media such as local radio and television stations and local newspapers for reaching particular high risk groups, only as part of an evaluation of their effectiveness.

During the screening process

Evidence indicates that reasons why women who have been screened stop going are related to practical issues such as getting there and waiting around, their perception of the experience and the friendliness of staff and also issues about embarrassment and discomfort during the screening test.

1. Screening staff should be friendly and respectful at all times and be especially mindful about discomfort, privacy and embarrassment.

2. Waiting times should be kept to a minimum, and any reasons for delays should be explained to individuals.
References


Appendix 1

Search strategy
Objectives
- Develop and run a search strategy to identify research literature reporting effective methods of increasing uptake in breast and cervical cancer screening.
- Develop and run a search strategy identifying research literature reporting the barriers to participating in breast and cervical cancer screening programmes.

Electronic database search
NHS library, Specialist screening Library, Cochrane Collaboration (Central Register of Controlled Trial), Medline and CINAHL

Gender Restrictions
Female only

Cancer
All cancer screening in women
Breast cancer
Cervical cancer

Populations
UK, Europe, USA, Canada and Australasia

Language
Only articles published in English will be included.

The researcher will screen the titles of the articles and exclude irrelevant studies. On further screening through the abstracts only relevant studies addressing breast and cervical cancer screening interventions and determinants will be retained. A data base will be maintained. Interventions will be segregated and grouped into broad categories. This database will be used to map the existing literature and summarise the evidence and effectiveness of interventions and strategies. The researcher will screen for Systematic Reviews and these will be thoroughly reviewed to maintain a reasonable weight of evidence without compromising methodological quality and for all practical reasons like timesaving and focussed review.
Table 1: Search Strategy adopted by the librarian

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<th>Limits</th>
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