

Interventions to reduce inequity and inequality in accessing national screening programmes

A report for the UK National Screening Committee

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Executive Summary

This report was commissioned by the UK National Screening Committee (NSC) to investigate best practice to reduce inequalities in screening uptake. The investigation was carried out between June and September 2008. A literature review and survey of primary care organisations were carried out to identify interventions to improve equity in screening uptake.

Literature review

A systematic search of literature published between 2000-2008 was carried out, focusing on interventions to improve uptake of screening in specific subgroups of populations with low uptake, rather than increasing general screening rates. 3 systematic reviews, 25 randomised controlled trials (RCTs), 7 lower quality intervention studies and 3 narrative reviews were included. The majority of RCTs were based in the United States and addressed breast, cervical and colorectal cancer screening only. Cost effectiveness of interventions was rarely assessed.

Findings from the literature were often contradictory. The evidence that exists suggests that interventions which actively engage the target audience (e.g. in-person education, telephone calls to patients) were more likely to succeed than reminder letters. The added benefit of 'tailoring' letters and phone calls culturally or by risk, was not clear, and in some cases gave worse outcomes. Practical help with booking and attending screening appointments, for example through patient 'navigators', was also generally helpful, although the use of peer educators and lay health advisors were not always associated with an increase in screening rates. However two community development models did show promise. Little robust evidence existed on the efficacy of targeted media messages. Combinations of interventions were usually more successful than single interventions.

Gathering evidence of existing practice

A questionnaire was developed to identify in which domains it was thought inequity and inequality in screening existed; on what basis these assessments were made; and what interventions were being used locally to reduce inequity and inequality. The questionnaire was sent to all primary care organisations in the UK, and Strategic Health Authorities in England, with follow-up emails and telephone calls to enquire about specific responses received.

The crude response rate for questionnaires was 15.8% (32/202). Most organisations thought there was inequity in screening in their area, most frequently cited for breast and cervical cancer screening. Population groups which were thought to have lower access rates included young women, deprived populations, individuals with learning disabilities and ethnic minorities. Nearly half of respondents did not have documented evidence of these inequities. The majority of interventions used locally had not been evaluated for their impact on screening rates, with reasons for not carrying out evaluation including lack of resources, and sufficient anecdotal evidence of success.

A small number of novel, well planned or evaluated, interventions are described in more detail in the main report, along with a critique of the methodology.

Comparing the literature and existing practice

It was notable that there was a discrepancy between the interventions supported by the current literature, and those taking place in UK localities. For example, whilst the literature suggests written literature and media campaigns, even when culturally targeted, have at most a limited impact on screening rates, these were frequently cited in questionnaire responses. Telephone counselling of non-attenders, and logistical help for patients via 'navigators', both of which have more supportive evidence, were less commonly used, the latter never explicitly mentioned at all. However, in-person education sessions do have a degree of evidence for their use, and were widely reported by respondents.

Implications for the future

In order for NHS organisations to provide equitable access to health services for their local population, interventions which are used locally to improve screening uptake should be based on existing evidence of effectiveness, and introduced for a pilot period with the results of the pilot shared widely so other organisations can also learn from its findings. If an intervention does not impact upon its target population it should be abandoned. Without evidence of the impact of an intervention it is impossible to know whether it promotes or, in some cases, decreases equity in screening.

The lack of primary research and resources to evaluate pilots in PCTs are part of the issue. However, evaluation of interventions needn't be complex, timely or complex and should be seen as integral to the organisation's governance arrangements.

Recommendations

A number of recommendations for the NSC to consider are given in the full report.

Recommendations include an expansion of the evidence base for interventions to reduce inequity in screening in the UK (trials of a small number of promising interventions in a UK context; setting up a central repository for published and grey literature concerning interventions to reduce inequity in screening; and intermittent circulation of brief guidance to local screening co-ordinators on the evidence base for interventions, and subsequent recommendations for practice), and systematic introduction of new interventions locally (ensuring interventions are introduced following documented local evidence of inequity only; basing interventions on trial evidence or grey literature from elsewhere; and piloting and evaluating interventions for impact on local population uptake).

1 Introduction

There are currently 15 national screening programmes in the UK covering 35 different conditions in the antenatal, newborn, child and adult populations.

A scoping report investigating equality in the screening programmes which reported in 2007 found that in the context of evidence of inequality in uptake among certain population groups, information systems for profiling and monitoring uptake were limited, and there was a dearth of primary research into interventions to increase uptake of screening (Fell and Gregory, 2007, Equality review: national screening programmes. A scoping report for the National Screening Committee).

Following this review, the Public Health Resource Unit was commissioned by the UK National Screening Committee to further investigate, and make recommendations on, examples of best practice in reducing inequity and inequality from local screening units and the published literature. This report examines interventions to reduce inequity and inequality in screening, through a review of the published literature and a survey of UK primary care organisations, to identify existing practice and grey literature. Based on the findings, a series of recommendations are made for the NSC to consider.

2 Methods

2.1 Literature review

A systematic search of literature published between 2000-2008 was carried out, using the terms specified in Appendix 1. A small number of additional references prior to 2000 were also included where they were deemed particularly significant. Papers were excluded if they referred to screening programmes which were not part of the current UK National Screening Committee schedule.

The literature on interventions to increase uptake of screening programmes among the whole eligible population is broad, and has been reviewed elsewhere;^{1,2} this paper focuses on interventions designed to improve uptake in particular subgroups of the eligible population, such as ethnic minorities or those from lower socioeconomic status (SES) backgrounds.

High quality evidence was sought: systematic reviews, randomized controlled trials, controlled trials, and quasi-experimental designs in which there was at least one comparator group along with the intervention group were included; other study designs were excluded. Relevant narrative reviews were also included.

Abstracts were screened for relevance, then full-text copies requested for papers which met the criteria above.

2.2 Gathering evidence of existing practice

A questionnaire was developed to be sent to all primary care organisations in England, Scotland, Wales and Northern Ireland. The principle purpose of the questionnaire was to identify:

- in what domains it was thought inequity and inequality in screening existed;
- on what basis these assessments of inequity and inequality were made;
- what interventions were currently being used locally to reduce inequity and inequality

The questionnaire and covering letter were reviewed for suitability by three public health consultants in PHRU with a variety of backgrounds, following which a number of minor revisions were made. The final versions are attached in Appendix 2.

Questionnaires were sent by first class post in early July 2008 addressed to the 'Screening Lead' at the following organisations: Primary Care Trusts (PCTs) in England (x152), Strategic Health Authorities (SHAs) in England (x10), Health Boards in Scotland (x14), Local Health Boards (LHBs) in Wales (x 22) and Health and Social Services Boards in Northern Ireland (x4). Addresses for each organisation were identified from the organisations' web sites; 'Screening Lead' was used due to varying local arrangements for screening co-ordination.

Replies were requested by post, and an email contact address was given for any queries. Respondents were asked to include with their questionnaire any documentation to support their answers (e.g. focus group studies, local surveys, detailed descriptions of interventions), and give email or phone contact details to enable follow up of their responses.

Respondents were contacted individually during August and September 2008 to request further details of the interventions they described, in particular around previous or planned evaluations of the interventions.

3 Results

3.1 Literature review

Three systematic reviews, 25 randomised controlled trials (RCTs), 7 lower quality intervention studies, and 3 narrative reviews were included.

Systematic reviews

Three systematic reviews were included.³⁻⁵

Masi et al reviewed US-based controlled trials conducted between 1986 to 2005, looking at interventions to improve breast cancer screening, diagnosis and treatment in ethnic minority women; 36 of these were relevant to screening.³ Although a detailed and thorough review, the focus on the US setting makes applying its findings difficult to the UK: for example, the authors found interventions which addressed financial barriers to screening generally successful, though these may be expected to be less significant (but not absent, for example transport to screening centres) in the UK. Their other general findings, however, that culturally tailored interventions and those reducing logistical barriers are more useful than reminder-based interventions, may be more valid in the UK.

Bailey et al reviewed 24 randomised controlled trials between 1980-2003, focusing on educational, community-based interventions to improve uptake of breast screening in low-income and ethnic minority women.⁴ Regarding logistical assistance with screening, eight of nine studies showed an increased mammography rate in the intervention group, but five of these included vouchers to reduce mammography cost; three of four studies employing home visits as the primary intervention were successful at significantly increasing screening uptake. Of printed materials, only two of five reviewed studies showed gains in screening; and seven of eight studies using peer-led interventions were deemed successful. The authors concluded that the use of peer educators, home visits, logistical support, or multiple interventions, were the most effective methods.

Legler et al conducted a meta-analysis of interventions addressing screening in 'under-served' (particularly low income, ethnic minorities, and rural and inner city) populations in the US.⁵ Studies between 1984 and 2000 were included. Effect size was found to be largest for access-enhancing interventions (e.g. reducing transport or cost barriers) directed at the individual, which boosted screening rates by 26.9% (CI 9.9-43.9). Media campaigns were found to not significantly raise uptake (OR 1.3, 1.0-1.8). As above however, the relevance of findings relating to cost barriers is likely to be low in the UK. Although the authors report testing for homogeneity and using a random effects model when heterogeneity was encountered, publication bias was not assessed.

Randomised controlled trials (RCTs)

Twenty-five RCTs were included.⁶⁻³⁰ For ease of reading these have been presented by the population group they were targeting, although they could equally have been categorised by intervention type or screening programme. A few of the studies could also have been listed under alternative headings since, for example, many African-American communities in the US also coincide with lower socioeconomic status (SES) areas.

A number of general observations can be made about the included RCTs. First, the majority of studies (20/25) are based in the United States. Second, the trials focus on interventions for only three particular cancer screening programmes: breast, cervical and colorectal cancer. Third, given the screening interval for most programmes, the follow-up period was generally short, between 3 and 18 months. Fourth, sample size was highly variable, ranging from 21 to over 145,000. Fifth, few studies included any data on the costs of interventions. Finally, for the majority of the RCTs an inherent selection bias may be present: those who agree to take part in such studies are more likely to respond to being prompted to undergo screening than the rest of the population; and participants in a 'usual care' group may not be given the same opportunity to display this heightened response, compared with the intervention groups.

Lower socioeconomic status

Ten studies investigated interventions to improve screening uptake in low SES groups, all based in the US. They assessed various combinations of letters to eligible patients; telephone calls to eligible patients; 'patient navigation' help; 'lay health advisors' and reminders for clinicians. 4 studies looked at breast screening alone, 3 at breast, cervical and colorectal screening together, 2 at colorectal screening alone, and 1 at breast and cervical screening. The trials are summarized in Table 1. 'Low' SES was defined by participants' attendance at a particular community health centre, or by their income.

Reminder letters for patients were included in four studies, alone or in combination with other interventions.⁶⁻⁹ The largest trial by far was conducted by Slater et al,⁶ involving 145,467 low-income women through the Breast and Cervical Cancer Early Detection Program in Minnesota, which found that 2 letters prompting women to access free mammography increased screening rates modestly, by 0.23% (0.09-0.37, $p < 0.005$), whilst this increased to 0.75% (0.58-0.92, $p < 0.001$) if a small monetary incentive for a completed mammogram was offered. Given the sample size of this study these small effect sizes are probably fairly accurate for this setting. Jibaja-Weiss et al randomized women to receive either a letter containing generic information on breast and cervical cancer or one containing tailored information based on a risk profile for each patient.⁷ Interestingly, after 1 year those receiving the generic letter were significantly more likely to have received cervical and breast cancer screening ($p < 0.001$) than those in receipt of the tailored letter. Simon et al recruited 1717 women to receive a letter directing them to a primary care physician; a letter directing them to a mammography clinic; or no letter.⁸ In all three groups a letter was also placed in the physician's notes. Regression analysis found that there was no significant difference in screening rates between the three groups, although the study can't reveal if the physician reminder masked any differential effect of the patient reminder. Champion et al used a factorial design to assess the impact of combinations of either, both or no tailored telephone or print counselling, in improving breast screening uptake.⁹ All participants underwent a baseline interview, with subsequent telephone and print interventions tailored by computer algorithm to their responses. The print intervention included a physician-signed letter and colour newsletter. All three intervention groups improved screening rates above control at 4 months (range of OR 1.6 to 1.91), with the group receiving both phone and print counselling improving most (OR 1.91, 1.30-2.83, $p = 0.001$); unfortunately baseline characteristics for the groups were not reported. Those who just received print counselling were also significantly more likely to undergo screening (OR 1.71, 1.16-2.53, $p = 0.006$).

Telephone calls were included in three studies,¹⁰⁻¹² one of which has already been described. In Champion et al's study,⁹ women assigned to receive the telephone intervention were called by a trained counsellor who used a tailored script. Individuals who received just telephone counselling were more likely than controls to undergo mammography (OR 1.60, 1.07-2.38, $p = 0.021$). The other two studies were by the same research group (Dietrich et al), and involved a combination of telephone call and patient navigation help.^{10,11} Their first trial, in 2006, randomized 1,413 women to receive 4 telephone calls over an 18 month period from 'prevention care managers', which included both motivational and logistic support in attending screening for breast, cervical and colorectal cancers.¹⁰ The prevention care managers received 7 hrs of training each and were carefully monitored to ensure they were all delivering the same level of intervention. A modest but significant increase was seen in the intervention group for all screening programmes (breast 12% increase [0.06-0.19], cervical 7% [0.01-0.12], colorectal 13% [0.07-0.19]), and the proportion of women who were up-to-date in all 3 programmes was improved by 14% (0.08-0.20). A subsequent study used similar methods, but delivered the prevention care management through a Medicaid managed care organisation (MMCO), which the authors felt would be more sustainable in the long-term.¹¹ This time, the intervention was less effective, with only colorectal screening rates improving over comparison (adjusted OR for being up-to-date with colorectal screening: 1.69, 1.03-2.77, $p = 0.04$). The authors, reasonably, discuss that the apparent effect of the intervention may have been reduced because the comparator group in this study involved the MMCO usual care, which also included up to 3 telephone calls.

Help with 'patient navigation' – e.g. logistical support with booking and travelling to appointments – was included in 5 studies.¹⁰⁻¹⁴ The Dietrich et al studies involving prevention care managers have been described already, above.^{10,11} A small study (n=21) by Christie et al found a potentially large improvement (54% vs 13%) in patient attendance for colorectal screening by colonoscopy when a patient navigator was used, although this difference was not significant, possibly because the study was underpowered.¹² Jandorf et al also employed a patient navigator for colorectal screening, and found an increased rate of endoscopy (15.8% vs 5% in control group) at 6 months, although faecal occult blood (FOB) testing was not significantly higher.¹³ Paskett et al investigated the use of trained lay health advisors (LHA) who provided an individually tailored health education programme over a 9-12 month period, through 3 visits and 2 follow-up telephone calls.¹⁴ Help was also provided with scheduling a mammogram. 433 women received the intervention and 418 were in the comparison group, in which they received a letter advising the need for regular cervical screening. At follow-up, 42.5% of the women in the LHA group had had a mammogram during the year compared with 27.3% in the comparison group (RR 1.56, 1.29-1.87, p<0.001), and women in the LHA group declared fewer barriers to breast screening at follow-up than the controls (p<0.001). The direct marginal cost of each additional mammogram was estimated at US\$4986.

Physician-directed reminders were investigated by Roetzheim et al in a cluster RCT involving 8 primary care clinics.¹⁵ The intervention included a cancer-screening 'checklist' completed by the patient to indicate when specific tests were due, and specified staff responsibilities for confirming and following up the checklist to improve uptake. After 12 months the odds of patients receiving a mammogram (1.62, 1.07-9.78) and FOB test (2.5, 1.65-4.0) were significantly higher among patients in the intervention clinics than controls. Changes in cervical screening uptake were non-significant. Although an interesting finding, studies on provider-side interventions such as this are particularly difficult to apply to other screening programmes which are organised differently, as in the UK.

Ethnic minorities

Eleven studies looked at interventions to increase screening uptake in minority ethnic groups (Table 2). As mentioned above, many of the samples for the studies focusing on lower SES groups also had high ethnicity.

These studies assessed combinations of the following interventions: letters to eligible patients; telephone calls to eligible patients; individual or group education programmes; lay health advisors; and the use of 'linkworkers' to encourage screening. Seven studies were based in the US, 2 in the UK, and 2 in Australia. A diverse range of ethnic groups was targeted.

Reminder letters were used in four trials.¹⁶⁻¹⁹ West et al randomized 320 rural African-American women in the US to a 2-step intervention:¹⁶ a personalised letter recommending mammography, or usual care; followed by a tailored phone call or tailored letter in the intervention group if women had not undergone screening after 6 months. At both 6 and 12 months there was no significant difference in screening rates between the trial arms. Atri et al conducted a cluster RCT for women registered to 26 inner city GP practices in London, UK, in which practice staff received a brief training session and were asked to contact breast screening non-attenders by telephone or letter (the latter translated into the woman's language where possible).¹⁷ They found that attendance in the 6 month follow-up period was significantly higher in the intervention group among Indian women (n=355, 19% cf 5%,

OR 2.2 [1.3-3.8]), and higher than the improvement seen for the sample as a whole (n=2064, 9% cf 4%, OR 2.3 [1.1-5.3]). Although this study was robust, and analysed on an intention-to-intervene basis, no subanalysis was presented for the effect of sending a reminder letter or telephone call alone; that most of the receptionists in the intervention practices spoke an Indian language may also make this less applicable to some other settings. The other two letter trials were based in Australia. Hunt et al randomized 372 Aboriginal women who were overdue for cervical smears to receive a visit, letter or no intervention;¹⁸ after 3 months few women in any arm had undergone screening, with the highest rate in the visit group (7%), little activity in the letter group (2%) and no activity in the control group (unfortunately no tests of significance were performed on these results, but small absolute numbers suggest the study was underpowered). Del Mar et al studied the use of a personalised letter to recruit to cervical screening in 689 women of Vietnamese origin, and found no change in the rate of screening after 1 year (relative rate 1.0, 0.72-1.38).¹⁹

Telephone calls were included in four trials.^{16,17,20,21} Two of these, in different settings, also involved sending letters and have already been described (Atri et al,¹⁷ and West et al¹⁶), with different outcomes on the efficacy of telephone calls in improving screening uptake. Braun et al performed a cluster RCT of civic clubs for native Hawaiians in the US, in which all participants (n=121) received a culturally-targeted education programme, a free FOB test and a reminder telephone call, for colorectal cancer screening.²⁰ In the experimental arm, the education programme was delivered by a Hawaiian physician and colorectal cancer survivor, and participants received extra follow-up telephone calls, to address emotions and barriers to screening. Interestingly, the rates of colorectal screening during the follow-up period were actually lower in the experimental group than the control group (OR 0.364, 0.14-0.97), although it is difficult to distinguish the contribution of the educators' background and number of telephone calls to participants, on the outcome. Allen et al randomized 430 women to receive ethnically-tailored telephone counselling.²¹ 83% of the participants were Latinas or African-American, and counselling was provided in English or Spanish. At 6 months' follow-up, tailored counselling improved breast screening uptake by 8% over the control groups, but this was not statistically significant (p=0.121).

Three studies investigated in-person education programmes, all in the US.^{20,22,23} Braun's study on colorectal screening in Hawaiians, which also included telephone follow-up, is described above.²⁰ Young et al conducted a small (n=94) trial on breast screening involving African-American women who received either 1hr targeted cancer education and free on-site screening, or neither.²² After 3 months there was a higher rate of mammography in the intervention group (p<0.05); although the contribution of free on-site screening is difficult to elucidate, the authors found that women in the intervention group also had improved knowledge of screening over the control group (p<0.001). A study by Champion et al also investigated an educational intervention to improve breast screening uptake among low-income African-American women.²³ In this study, 329 women received either routine care or an in-home appointment addressing perceived risks of breast cancer, and benefits and barriers to screening, along with written literature. After a year of follow up there was an increase in breast screening rates in the experimental group (17%) over and above that seen in the control group (7%), although a statistical analysis of this increase was not shown in the paper.

Lay health advisors were used in two studies, both based in the US.^{24,25} Sung et al recruited 321 African-American women, 163 of whom received up to three visits by lay health workers, the remainder (n=158) in the control group.²⁴ The lay health workers delivered a culturally

sensitive educational programme which focused on the need for breast and cervical cancer screening. After 6 months, there was no significant difference between the intervention and control groups for cervical screening, but mammography rates increased by 9.8% (2.9-16.7, $p < 0.05$) in the intervention group. In a cluster RCT by Navarro et al, 36 lay community workers delivered one of two educational sessions to 512 Latinas women recruited to the trial.²⁵ The percentage of women receiving cervical smears ($p = 0.02$), but not mammography ($p = 0.08$), had increased significantly in the 'Por la vida' group immediately after the 3m intervention, compared with controls.

In a 1994 trial by Hoare in the UK,²⁶ 527 Asian women were randomized to receive information and encouragement about breast screening by a linkworker who visited them, or to a control group which received no visits, prior to screening invitations being sent out. For the round of screening under study, there was no significant difference in the rate of attendance between the two arms (49% intervention vs 47% control). However, since this study had an intention-to-treat design, and only 59% of women in the intervention arm actually received the intervention (the rest could not be contacted), it is possible that the true effect size for the intervention is higher.

Learning disabilities

Only one RCT was identified which involved individuals with learning disabilities, based in Australia. Lennox et al used a cluster design to assign 453 adults with learning disabilities in 34 clusters, to a health assessment programme or usual care.²⁷ The 'Comprehensive Health Assessment Programme' (CHAP) intervention was a booklet for use and completion by the carer and GP to encourage discussion of the participant's medical history and a health action plan, with changes in screening behaviour one of the outcomes. After 1 year, cervical screening had been carried out in female participants in 12.9% of women in the intervention group, and 7.5% in the control group; breast screening rates were, however, higher in the control group (9.4% vs 4.3%). Although both these results were statistically significant, the study lacked power for this outcome (total women undergoing cervical screening: 20; mammogram: 14), and a larger trial may give a less equivocal answer. Furthermore, 8% of GPs (10/130) refused to take part in the trial, which could indicate issues with the acceptability of the intervention (reasons were not given for the GPs' refusal).

Older women

Three studies were found which investigated different interventions to improve uptake among older women, all of them for breast cancer screening in the US.²⁸⁻³⁰

Harrison et al recruited 1229 pairs of women aged over 70 to investigate whether a personally-addressed letter from the Medical Director of the local Medicare organisation, impacted on breast screening uptake.²⁸ After 13 months, a significantly higher rate of screening was found in the intervention group (OR 1.6, $p < 0.005$), but interestingly this rise primarily consisted of diagnostic mammographies (for women at high risk or positive physical findings) rather than screening mammographies, for which there was a very modest (0.7%), non-significant increase ($p = 0.31$).

A cluster RCT by Reuben et al involved 499 women aged 60-84,²⁹ all of whom received an education session at one of 60 community sites where older people were known to gather; sites either included on-site mammography (intervention) or none (control). No patient in the trial paid for mammography. After 3 months, significantly more mammograms had been

conducted in the intervention arm (55% vs 40%, $p=0.001$, OR 1.83 [1.22-2.74]), and the authors note the gains were particularly prominent in Asian-American women.

Telephone counselling was investigated by Stoddard et al, in a meta-analysis of five separate trials run locally, some of which were randomized by individual, and some by cluster.³⁰ 3,461 women aged over 50 were included in the trials, all of which involved a telephone counselling (TC) arm, but with different control arms. The TC protocol was similar in all 5 studies, and included addressing women's individual barriers to getting a mammogram. The follow-up period ranged from 2 to 3 years; synthesis of the five study results found no significant difference between breast screening uptake among those receiving the intervention compared with other participants (OR 1.08, 0.91-1.27).

Other intervention studies

Seven further studies of lower quality were included but which still involved both an intervention and comparator group.^{31-36,41}

Fang et al found a significant increase (22% to 83%, $p<0.001$) in cervical cancer screening following an education and navigation intervention by bilingual Korean health educators in a Korean community in the US.³¹ Katz et al found an increase in positive beliefs in, but not rates of, colorectal screening in low-income women in the US following combined outreach (media campaign, direct mailing, education classes) and inreach (waiting room posters) strategies.³² In a study with poor matching of controls, Juon et al reported that developing culturally appropriate educational material (in this case an innovative 'phonovel' around breast cancer screening) in concert with the US Korean community they were investigating, led to a significant rise in intention to have a mammogram (RR 2.95, 1.17-7.66), although screening as an outcome was not recorded.³³ Also working with the US Korean community, Kim et al found no effect of a peer-group education programme in encouraging mammography uptake.³⁴ In the Vietnamese community in the US, Nguyen et al reported that neighbourhood-based educational activities and continuing medical education (CME) for physicians around breast cancer screening were not successful in improving uptake of mammograms.³⁵ In a UK study, McAvoy et al identified a higher rate of cervical screening in Asian women who had been given health promotion materials in person (37-47%) rather than by post (11%), or not at all (5%, $p<0.0001$).³⁶ The health promotion materials were videos and factsheets in the participant's language. Finally, in another UK study involving a community intervention with minority ethnic populations in Bradford, trained health promotion facilitators conducted formal and informal workshops over a few weeks in participants' own languages, with a video and one-to-one counselling available also.⁴¹ 1000 of the women who took part were sampled and, 6 months after the intervention, familiarity with breast cancer and mammography had increased in all ethnic groups ($p<0.05$), and of cervical cancer in Asian women in particular. Self-reported uptake of breast and cervical screening also increased (22% to 59% for breast screening; 67% to 87% for cervical screening), although no statistical analyses are given, and there was no control group.

Narrative reviews

Three narrative reviews were included.³⁷⁻³⁹

Szczepura reviews the evidence on access to health care for ethnic minorities.³⁷ Of particular note is a discussion on three dimensions of equitable access to care: equal access to appropriate information; access to services that are relevant, timely and sensitive to the person's needs; being able to use the health service with ease, and being treated with

respect. The author notes that equity of access does not just refer to service uptake or receipt of care, but also the process of accessing care and the quality of subsequent care. In addition, Szczepura uses as a case example access to three UK screening programmes by ethnic minority populations, concluding that little research has been carried out to identify clinically or cost effective interventions to improve screening uptake, but that the evidence which exists points to the use of complex multi-strategy interventions, including practice receptionist training, follow-up letters in various languages, and offers of help with transport.

Chiu reviews the literature from 1998 to 2003 on inequalities in access to cancer screening.³⁸ The author notes that the majority of studies involve low income ethnic minority groups in the US, and most use the 'positivist' (i.e. scientific) model to examine the success of interventions, without paying particular attention to the process of conducting the research used, for example, in action research. Chiu cites research into the use of lay health educators as particularly problematic, with standardisation of the intervention practically impossible, and difficulties in attributing outcomes to the intervention alone, rather than social networks and social capital. A new approach to research in this field is recommended, with better development of theoretical frameworks to underpin interventions and research methods. Indeed, this was accompanied by an innovative participatory action research project conducted by Chiu, to promote cervical screening among ethnic minority women.³⁹ This investigated both barriers to screening through focus groups and semi-structured interviews, and potential solutions to these issues. Improved communication and explanations of procedures with patients, including the use of an advocate or interpreter, were identified. Empowerment of women through the use of community health educators, and the development of a glossary of explanations of medical terminology, were also found to be successful. An improvement of 66% in uptake among women who had previously failed to attend appointments was reported, although no absolute figures are given, nor was there a comparison group.

A review of the literature concerning cervical screening in women with learning disabilities (LD) is given by Broughton.⁴⁰ Unfortunately no descriptions or critiques of study designs are included in the review, although it does discuss NHS policy and guidelines in addition to the published literature. Broughton describes the generally lower level of access to primary care by individuals with LD, compared with the rest of the population; and that many GPs are not aware of which of their patients have LD. Difficulties with understanding traditional health promotion literature are discussed, along with consequent problems in obtaining informed consent for screening procedures. Little trial-based evidence is available or reviewed, and the author recommends better evaluation and sharing of existing practice, in order to improve uptake of screening in this cohort.

Table 1. RCTs of interventions to improve uptake of screening in groups with lower socioeconomic status

Lead author and publication year	Study design	Participants, setting and intervention groups	n	Follow up	Results	Comments
Christie, 2008 ¹²	RCT	Low-income minority men and women, US Colorectal screening Patient navigator / Control	21	6m	Improved colonoscopy rates but not significant (p=0.058)	Small, underpowered
Champion, 2007 ⁹	RCT	Low-income women, US Breast screening Tailored print counselling / Tailored phone counselling / Tailored print + phone / Control	1,244	4m	Mammography increased in all intervention groups (OR 1.6-1.91), with phone+print group largest rise (OR 1.91, 1.3-2.83, p=0.001)	No detailed baseline characteristics given; 54% African-American
Dietrich, 2007 ¹¹	RCT	Women receiving care at community health centres, US Breast, cervical and colorectal screening Prevention care managers / Control	1,316	8m	Borderline significant increase in women up-to-date for colorectal screening (OR 1.69, 1.03-2.77, p=0.04). No difference in rates for cervical and breast screening	Follow up to Dietrich, 2006 ¹⁰ – attempt to be more pragmatic, with less intensive intervention
Dietrich, 2006 ¹⁰	RCT	Low-income minority women, US Breast, cervical and colorectal screening Prevention care managers / Control	1,413	18m	Modest but significant increase in screening for all three conditions	Prevention care managers received 7hrs of training and were rigorously monitored. Generally robust – intention to treat analysis

Lead author and publication year	Study design	Participants, setting and intervention groups	n	Follow up	Results	Comments
Paskett, 2006 ¹⁴	RCT	Rural, low-income white, native and African-American women, US Breast screening Lay health advisor (LHA) / Control	851	1yr	Mammography increased in intervention arm (RR 1.56, 1.29-1.87); cost of additional mammogram US\$4986	Intention-to-treat; significant proportion of African-American and native American women
Jandorf, 2005 ¹³	RCT	Low socioeconomic status, minority men and women over 50, US Colorectal screening Patient navigator / Control	78	6m	Higher rate of endoscopy in intervention group (15.8% vs 5%, p=0.019); faecal occult blood test rates higher but not significantly (p=0.086)	Not intention-to-treat – individuals lost to follow-up were excluded from analysis. Navigation included telephone calls, written reminders and assistance with appointments; navigator from similar cultural background as patient
Slater, 2005 ⁶	RCT	Low income underinsured women, 40-64, US Breast screening Letter / Letter + incentive / Control	145,467	1yr	Both intervention groups had mammography rates above control – Letter + incentive highest (0.75% [0.58-0.92] above control)	Apparently very small effect size
Roetzheim, 2004 ¹⁵	Cluster RCT	Disadvantaged population, US Breast, cervical and colorectal screening Cancer screening checklist / Usual management	1,237	1yr	Intervention increased odds of mammogram (OR 1.62, 1.07-9.78) and FOB (OR 2.5, 1.65-4.0). Nonsignificant result for cervical smears	Applicability of provider-side interventions to UK limited

Lead author and publication year	Study design	Participants, setting and intervention groups	n	Follow up	Results	Comments
Jibaja-Weiss, 2003 ⁷	RCT	Low-income, minority women, US Breast and cervical screening Generic letter / Letter with tailored risk information	1,574	1yr	Tailored risk information letter associated with lower uptake of cervical and breast screening than generic letter (p<0.001)	
Simon, 2001 ⁸	RCT	Lower SES, mostly African-American women, US Breast screening Letter directing to primary care / Letter directing to clinic / No letter	1,717	1yr	No significant difference between all three groups	

Table 2. RCTs of interventions to improve uptake of screening in ethnic minority groups

Lead author and publication year	Study design	Participants, setting and intervention groups	n	Follow up	Results	Comments
Allen, 2005 ²¹	RCT	African-American and Latinas women, US Breast screening Tailored telephone counselling / Control	430	6m	Non-significant increase in uptake of breast screening in intervention group	
Braun, 2005 ²⁰	Cluster RCT	Native Hawaiian men and women, US Colorectal screening Culturally targeted education programme, telephone call, free FOB test / Ditto, but programme	121	10w	Members of experimental arm significantly less likely to be screened post-intervention than control (OR=0.364, 0.14-0.97)	Poor response rate to post-intervention questionnaire (50%), very short follow-up

Lead author and publication year	Study design	Participants, setting and intervention groups	n	Follow up	Results	Comments
		delivered by Hawaiian physician and colorectal cancer survivor				
West, 2004 ¹⁶	RCT	Rural, low-income African-American women, US Breast screening Personalised letter followed by tailored call or letter if no response at 6m / Usual care	320	12m	No difference in screening rates at first or second stage	
Young, 2002 ²²	RCT	African-American women, US Breast screening Education and on-site screening / No intervention	94	3m	Higher mammography rate in intervention group	
Champion, 2000 ²³	RCT	African-American, low-income women, US Breast screening In-person tailored intervention / Control	329	1yr	Compliance with mammography increased more in experimental group (17%) than control group (7%)	High baseline rate of screening (59% experimental, 63.8% control) may not be representative
Del Mar, 1998 ¹⁹	RCT	Vietnamese women, Australia Cervical screening Letter / Control, on background of whole population media campaign	689	1yr	No difference in number of cervical screens conducted between groups (RR 1.0, 0.72-1.38, p=0.93)	Whole population media campaign could have masked difference between groups

Lead author and publication year	Study design	Participants, setting and intervention groups	n	Follow up	Results	Comments
Hunt, 1998 ¹⁸	RCT	Aboriginal women, Australia Cervical screening Personal approach / Letter / Control	372	3m	Only 11 women in total had cervical screening during follow-up period, 6.7% in personal approach group, 2.4% in letter group, none in control; no significance tests performed	Very few participants in 'personal approach' group actually received intervention – only 18.5% (22/119); 29.6% of letters were returned to sender
Atri, 1997 ¹⁷	Cluster RCT	Women registered to inner city GP practices, UK Breast screening Training programme for staff to contact non-attenders by telephone & letter / No training programme	2,064	6m	Improved screening attendance in Indian women particularly, OR 2.2 (1.3-3.8)	Intervention group paid more than control to participate. Most receptionists in intervention group spoke an Indian language. Practice-level costs not given to allow assessment of cost-effectiveness
Sung, 1997 ²⁴	RCT	African-American women, US Breast and cervical screening Visits by lay health workers / Control	321	6m	No significant difference in cervical screening rates between groups; mammography increase 9.8% (2.9-16.7) in intervention group (p<0.05)	
Navarro, 1995 ²⁵	Cluster RCT	Latinas women, US Cancer screening Education programme around cancer prevention / Education programme on Community Living Skills	512	Post-intervention	Increase in cervical screening in cancer prevention arm (p=0.02), but not for mammography (p=0.08)	Training delivered by lay community workers

Lead author and publication year	Study design	Participants, setting and intervention groups	n	Follow up	Results	Comments
Hoare, 1994 ²⁶	RCT	Asian women, UK Breast screening Home visit by linkworker / No linkworker	527	After invitation to screening	No difference in screening rates between two arms	Intention-to-treat design; only 59% of women in intervention arm received intervention (rest could not be contacted)

3.2 Gathering evidence of existing practice

Response rate

Questionnaire replies were received from 31 individuals representing 32 NHS organisations in the UK (23 PCTs and 2 SHAs in England; 4 Health Boards in Scotland; 2 LHBs and 1 national response in Wales; 0 in Northern Ireland). Contributing organisations are listed in Appendix 3.

The crude response rate was thus 15.8% (32/202). Nationally, the response rates were 15.4% (25/162) for England, 28.6% (4/14) for Scotland, and 0% (0/4) for Northern Ireland. The local response rate in Wales was 9.1% (2/22), although since screening is organised nationally in Wales, the receipt of a reply from the national lead represented, in effect, a 100% (1/1) response rate.

There was more than one response from some organisations, usually when screening was co-ordinated by a number of people, each reply referring to the screening programmes managed by that individual.

In order to preserve anonymity, responses are referred to below by 'NHS organisation' which refers to any of the polled organisations, including a national response on behalf of Wales.

Evidence of inequity

Five replies, representing 5 NHS organisations (5/32, 15.6%), indicated that they were not aware of any inequity or inequality in screening in their area. (Paradoxically, in one of these replies literature was enclosed with the questionnaire which gave evidence of local inequity in cervical screening.) The remainder, 84.4%, thought there was inequity or inequality in one or more screening programmes.

Inequity or inequality was most frequently cited for cervical and breast cancer screening, by 25 (78.1%) and 21 (65.6%) NHS organisations respectively. Inequity or inequality in bowel screening, and childhood or antenatal programmes, were cited by 2 organisations each (6.3%), and diabetic retinopathy by 1 (3.1%).

Population groups in which cervical cancer screening was considered inequitable were young women (56% of organisations listing cervical screening as inequitable), deprived populations (48%), learning disabled (24%), ethnic minorities (24%), particular geographical areas (8%), and travellers (4%).

Population groups in which breast cancer screening was considered inequitable were deprived populations (57%), ethnic minorities (48%), learning disabled (14%), travellers (10%), and particular geographical areas (5%).

18 organisations (56%) indicated that they had evidence for at least one of the inequities they cited, although only 11 (34%) were able to provide a hard copy of this as requested. Organisations provided local health equity audits (or equivalent) most commonly (5/11, 45%), and also cited national evidence for inequities (4/11, 36%) and in one case reported conducting a local focus group to establish inequities (1/11, 9%). In three instances, surname analysis was used as a proxy for ethnicity in establishing inequities of uptake. Although the health equity audits were generally thorough, on occasion they did not include full details of

their data sources, making it hard to determine their accuracy or make comparisons with other areas.

Interventions to improve equity of screening uptake

Questionnaire respondents cited 55 interventions to reduce inequity of screening uptake, of which 40 were old or current, and 15 proposed. Some of the interventions were similar or overlapped; for ease of reading they are presented below categorised by the population group which they target.

It was notable that the majority of descriptions of interventions were not accompanied by any evidence of efficacy. Out of all 55 interventions, evidence to support their introduction was cited in 17 (31%) instances, and 8 (20%) of the 40 current or old interventions; evidence came from local focus groups, equity audits, pilot projects, or published literature. All respondents were contacted to confirm whether any evaluation was in place for interventions they described. Of the current or old interventions, only 4 (4/40, 10%) had been formally evaluated for their impact on uptake rates, although a further 7 evaluations were planned (7/40, 18%). Unless otherwise stated below, interventions have not been evaluated after their implementation.

When asked why evaluations had not been carried responses included a lack of resources, and that it may not be ethical (if the interventions should have been considered 'usual care'). Some respondents cited anecdotal, but not quantitative, evidence of success.

"As yet there has not been any formal evaluation of this initiative, however we have anecdotal evidence that there has been a positive uptake... it is something that we wish to do when time and resources allow"

*"Unfortunately we didn't have the resources for a formal evaluation of the project"
"I can't commit resources to evaluating everything"*

Some examples of interventions which were novel, or thoroughly planned, implemented or evaluated, are discussed in greater depth.

Deprived populations or particular geographic areas

Five interventions were cited with the aim of improving screening uptake among deprived populations or particular geographic areas, three old or current and two proposed. The proposed interventions were to provide support to GPs in following up screening non-attenders; and to target a particular geographic area by using an on-site screening 'bus'.

The old or current interventions were: a project working with a local inner-city community to find ways to increase accessibility to breast screening for women in that area; the use of 'screening promotion officers' to work with community groups such as Sure Start, to increase screening among deprived groups; and setting up a new cervical smear clinic in the local community, to increase uptake. This latter intervention is described in more detail in Box A. Unfortunately there have been no formal evaluations of the impact of any of the old or current interventions.

Box A. Improving access to cervical screening in Edmonton, London

Following a successful bid to the Neighbourhood Renewal Fund, the 'Edmonton Access Project' ran between August 2004 to March 2006, with two stages. The first was to assess the needs of local communities and primary care practices regarding cervical cancer screening, and the second was to implement the recommendations from the needs assessment. Primary care practices and community groups were interviewed by semi-structured questionnaire, and local cervical screening data analysed. Recommendations relevant to equity of uptake included improving the availability of multilingual leaflets, piloting a smear clinic in Edmonton to relieve staff shortages and improve choice for women accessing local services, and developing a learning tool for local community groups. A pilot for a smear clinic in Edmonton was started in July 2005, with leaflets sent to community groups to encourage attendance. Attendance at the clinic was very good; after the pilot period the clinic closed and cervical screening rates fell again, so recently the clinic has been reinstated. An audit was carried out of languages spoken by the local population, and multilingual leaflets prepared based on the audit, which were popular with the local community groups. Extensive health promotion and community development work also took place as part of the Access Project, including the launch of a screening poster developed in consultation with the community groups, and a learning tool for use by the communities over the coming years.

Source: Enfield, Barnet & Haringey PCTs

Ethnic minorities

Twenty-two interventions were cited to improve uptake among ethnic minority populations, 15 of which were old or current interventions, with the remaining 7 proposed.

The proposed interventions were to develop a communications strategy to target black and minority ethnic (BME) communities; BME women to counsel non-attenders for cervical smears; provide multi-lingual information in screening invitations; improve ethnicity data collection in GP practices; set up focus groups with local young Asian women to identify barriers to screening; provide help with travel arrangements; and set up talks with groups of local women, aided by a local link worker. The development of a BME-specific communications strategy was suggested following a detailed needs assessment in four London PCTs (Box B).

Box B. Breast screening in North East London

Research was undertaken in City & Hackney, Newham, Tower Hamlets and Waltham Forest PCTs, to analyse local breast screening data to identify non-attenders. Non-attenders were interviewed in focus groups by ethnicity, along with screening staff, to identify reasons for non-attendance. Health beliefs in different cultural groups were identified, with levels of awareness and knowledge of breast screening lower among BME women. One of the subsequent recommendations of the report was to develop a communications strategy targeting women from BME communities.

Source: Newham PCT

Of the old or current interventions, seven related to outreach or targeted health promotion sessions; four related to language translation (e.g. interpreters, leaflets and letters in languages other than English); two related to targeted media messages, and the remaining two involved a signposting service, and equality training for staff.

Unfortunately no formal evaluations of interventions in this category have been carried out, although a number are planned, making it impossible to currently assess the interventions' effectiveness.

Particular age groups

Ten interventions were described to target screening in particular age groups. Most of these related to cervical screening in young women, although one was for bowel screening in older people. 8 of the 10 interventions were currently being employed, with two proposed for the future.

The proposed interventions are to provide GPs with support in following up non-attenders for cervical screening; and to conduct focus groups among older people in care homes, to establish ways of increasing bowel cancer screening in this age group. It is not clear at this stage whether either intervention will be evaluated.

Current interventions being employed are: a cervical screening health promotion campaign aimed at young people, including posters on buses, in pub toilets, high street shops and Sure Starts, and targeted leaflets sent to non-attenders; campaigns targeted specifically at non-attenders; media publicity on local radio stations aimed at young people and BME groups; screening promotion officers working with community groups including Sure Start; a research project looking into increasing cervical screening uptake; allowing cervical smears to be taken by a local charity, with results also stored by the charity, increasing the likelihood that young women can access these even if they change registered GP; providing cancer health promotion sessions in the workplace (see Box C); and a pilot to allow women to access smears out-of-hours (see Box D).

Box C. Cancer awareness sessions in Sandwell, West Midlands

An intervention to improve awareness of two types of cancer was carried out between December 2007 and April 2008 among employees of two housing associations in Sandwell. In the local area cancers account for 25% of deaths. Four cancer awareness sessions (two for breast and two for prostate cancer) were delivered to 36 workers. Feedback from attendees at the breast cancer session suggested 95% had not been to similar workplace sessions before, and 100% found it beneficial, for reasons including that they didn't get time to see their GP; there was privacy away from family and friends; and they were worried about their health. All attendees also said they would attend similar sessions in future and would recommend it to others. Employers were also very positive about the sessions. The authors of the report conclude the sessions were very valuable, in particular as a way of liaising with and delivering programmes to, previously 'hard to reach' groups. They also recommend cost-benefit analysis of such interventions would prove useful in future.

Source: Sandwell PCT

Box D. Pilot of out-of-hours smear clinic in Darlington

Between January and April 2008 County Durham PCT ran a pilot out-of-hours smears clinic, in an attempt to improve uptake of cervical screening in women aged under 50. Two clinics were held each week, on a weekday evening and a Saturday morning, for three months, with the budget for the pilot (£1,600 from £4,000 allocated) coming from the public health department of the PCT. 1,014 women, principally aged 25-50, who had never attended for cervical screening, were sent an invitation letter to the new clinic. In a pre-pilot audit, 60% of 30 respondents indicated they would attend a walk-in screening centre out-of-hours. During the pilot period only 33 women attended, 25 following the pilot invitation letter, and a number of clinics were cancelled because no patients were booked. Feedback from patients attending the pilot was, however, very positive, with all respondents indicating their preference for future smears would be the walk-in clinic rather than their GP or a family planning clinic. The pilot identified that invitation by letter to an out-of-hours clinic was not a successful strategy, and some money left over from the original budget allocation will be used to trial telephone contact of non-attenders, which had previously been found to be worthwhile in Newcastle.

Source: County Durham PCT

Although the smear clinic pilot found that the intervention was not successful, this was a positive result because had the pilot not been carried out, valuable resources could have been wasted on an ineffective intervention. No evaluations were reported for any of the interventions apart from those highlighted in Boxes C and D; one campaign in which young women who fail to attend for cervical screening are sent a postcard reminder is currently running as a two year pilot.

Disabled

Eighteen interventions were described to increase screening uptake in individuals with different types of disability; of these, 5 were proposed interventions and 13 current or old interventions. An evaluation was only reported for one of the interventions.

Many of the interventions were aimed at individuals with learning disabilities (LD). These were: giving patients extra trips to the breast screening clinic to familiarise themselves before the mammogram; providing specific follow-up for women with LD; provide general staff with equalities training and contact details for the LD team; establish a referral protocol to community LD nurse specialists, and improve information on cervical screening to enable individuals to make an informed decision; make contact details for LD services available to breast screening clinic; develop training resources on breast awareness for LD support staff; develop an educational package on cervical screening for women with LD; raise profile of community LD nurses among primary care teams in supporting access to cervical screening; meet training needs of social care staff around cervical screening in women with LD; provide easy-read/picture leaflets for those with LD (x3); and provide outreach sessions on breast screening for women with LD.

Other interventions were: allowing cervical screening smears to be taken at family planning clinics as well as GPs, especially targeted at women with disabilities or who had previous bad experiences (a 2yr evaluation of this pilot found that it was not reaching its target audience, and had a high non-attendance rate); making a DVD available which included an example of

a deaf lady attending breast and cervical screening; making special arrangements for women in wheelchairs, for breast screening in their closest hospital or a special centre where 2 radiographers were available to assist with screening; installing a hearing loop system in receptions at mobile and static screening centres; making information on screening available in audio, large print, Braille, or with pictures; and screening promotion officers attending disability forums to enable women to make informed choices about screening.

Mobile, homeless and institutional populations

Four interventions were included for these population groups, none of which were reported to have been evaluated. These were: circulating up-to-date information on screening programmes and availability with community leaders, for them to communicate with their peers (diabetic retinopathy screening); providing outreach health promotion sessions at housing associations and for asylum seekers, on breast and cervical screening; employing a breast screening support worker for the Traveller community; and supporting a GP to take cervical smears at a homeless centre and a local prison.

4 Discussion

4.1 Literature review

Despite a significant number of RCTs investigating interventions to reduce inequity in screening uptake, many of which are of a reasonable quality, findings are often contradictory and effect sizes relatively small. The vast majority of studies also took place in the United States; for social interventions and those which reduce cost barriers, the applicability of these studies to the UK is questionable. In addition, the focus of most studies was on breast, cervical and colorectal screening. Furthermore, it is also likely that there is at least some publication bias, with fewer negative than positive studies described. However, some themes do emerge.

Firstly, interventions which actively engage the target audience seem more likely to succeed: in-person education, and telephone calls to patients, gave better outcomes than reminder letters. The added benefit of 'tailoring' letters and phone calls culturally or by risk, was not clear, and in some cases gave worse outcomes. Practical help with booking and attending screening appointments, for example through patient 'navigators', was also generally helpful (in the US this help often included vouchers for free screening, an added incentive which is mostly irrelevant in the UK; although help with transport/parking costs may encourage some low-income and elderly patients). Interestingly, the use of peer educators and lay health advisors was not always associated with an increase in screening rates, although a community health educator model and community development approach both showed promise.^{39,41} Little robust evidence existed on the efficacy of targeted media messages. Combinations of interventions were usually more successful than single interventions.

There did not seem particular differences in intervention effect between target populations; this may, in part, be because many of the US studies involved ethnic minority populations which were also in lower socioeconomic groups. The only study which found a positive effect in older people was an education session which also included on-site mammography. There was little strong evidence for interventions in people with learning disabilities, although the need to ensure patients give informed consent was highlighted.

4.2 Gathering evidence of existing practice

Evidence of inequity

The majority of respondents stated that there was inequity of access to screening programmes in their area, particularly for cervical and breast cancer screening; groups which were commonly perceived to have lower service use were deprived populations, the young and old, ethnic minorities and learning disabled. Interestingly, however, only just over half (56%) of respondents stated they had evidence for these inequities, suggesting the other half were using anecdotal, limited or absent evidence to estimate inequities in their local population. The reasons for this were not investigated in this study, but would be interesting to ascertain. That some of the screening programmes were not mentioned at all in this section of the questionnaire may not indicate equity, but further gaps in evidence for local equity.

Interventions to improve equity of screening uptake

It was notable that many organisations were undertaking interventions in an attempt to improve equity of screening. Whilst this is laudable in itself, the great majority of these interventions were neither founded on robust evidence, nor accompanied by a local evaluation of their clinical and cost-effectiveness, both of which are causes for concern. In some cases respondents quoted informal, anecdotal evidence of effectiveness, whilst others (on direct questioning) stated they did not have sufficient resources to evaluate all interventions. There were a few clear exceptions to these generalisations, however, where pilot projects had been carefully planned and implemented after finding out the target populations' needs, and others where rapid but sufficient evaluation had revealed the pros and cons of new interventions. Funding for pilots was usually provided by the PCT or a combination of local agencies interested in their local population's health.

Popular interventions cited were counselling non-attenders; providing health promotion literature in different formats; carrying out a needs assessment for the target community; targeted health promotion and media campaigns; and health promotion professionals working directly with the target populations (e.g. community groups).

Critique of methods

The available time for this study was limited, leading to a number of methodological constraints.

Firstly, although much useful information was gleaned from the 32 NHS organisations which replied to the questionnaire, this was still only a 15.8% response rate, and didn't include any organisations from Northern Ireland. Further follow-up of non-responders by post and telephone would almost certainly have increased this rate. Although some general themes emerged from the responses which were received, these cannot be taken as directly representative of screening services across the UK, but evidence of some of the interventions and inequities which exist. Statistical representativeness would have required a larger sample, and a re-designed questionnaire. A contemporaneous list of addresses and email contacts for primary care organisations in the UK, made available for research such as this, would also have made the process more efficient.

Secondly, although the covering letter for the questionnaire explicitly asked for examples of interventions which weren't successful, it is likely there was still reporting bias among organisations which would prefer to describe a positive intervention. It is possible that organisations have carried out unsuccessful pilots which they did not wish to describe on the questionnaire. An additional factor which could have contributed to a falsely low impression of the number of pilots carried out is the recurrent reorganisation of primary care services, leading to the lack of 'organisational memory'.

4.3 Comparing the literature and existing practice

It was interesting, if perhaps not surprising given the lack of quoted evidence underlying interventions in current practice, that there is a discrepancy between the interventions supported by the current literature, and those taking place in UK localities.

For example, whilst the literature suggests written literature and media campaigns, even when culturally targeted, have at most a limited impact on screening rates, these were frequently cited in questionnaire responses. Telephone counselling of non-attenders, and

logistical help for patients via 'navigators', both of which have more supportive evidence, were less commonly used, the latter never explicitly mentioned at all. However, in-person education sessions do have a degree of evidence for their use, and were widely reported by respondents. No robust literature or pilots were identified which described the effect of social marketing campaigns on reducing inequity in screening.

4.4 Implications for the future

If NHS organisations are to provide equitable access to health services for their local population, interventions which are used locally to improve screening uptake should be based on existing evidence of effectiveness, and introduced for a pilot period with the results of the pilot shared widely so other organisations can also learn from its findings. If an intervention does not impact upon its target population it should be abandoned. Without evidence of the impact of an intervention it is impossible to know whether it promotes or, in some cases, decreases equity in screening.

It would appear that the lack of thorough primary research into interventions in a UK setting, and resources to evaluate pilots in PCTs, are part of the issue. However, evaluation needn't be a complex, timely or costly process, especially if it is considered at an early stage. Assuming that many of the existing interventions are a cost to PCTs in some way, from a financial governance perspective evaluation of an intervention's impact should be the norm, not an exception. Although new primary research into promising interventions would be a boon (see Recommendations, below), in most cases it would still be good practice to pilot the intervention locally, to ensure it is useful and cost-effective in that population.

5 Recommendations

On the basis of the findings presented here, the National Screening Committee is asked to consider the following recommendations:

- Expansion of the evidence base for interventions to reduce inequity in screening in the UK
 - In the first instance, a small number of promising interventions should be trialled in a UK context
 - Trials should be randomized (individual or cluster) controlled trials, funded nationally
 - The primary outcome measure should be participation in screening programmes for which individuals are eligible, by minority population groups
 - Studies should also gather and present information on the cost of interventions
 - On the basis of existing evidence, principally from the US, strategies should be trialled which involve alone and in combination: community group education; telephone follow-up; navigation/logistical assistance to patients (e.g. in booking and attending an appointment). Since no robust evidence currently exists, an evaluation of the effectiveness of social marketing campaigns to increase equity in screening would also be valuable
 - The NSC should act as a central repository for published and grey literature concerning interventions to reduce inequity in screening
 - The NSC should intermittently produce brief guidance for local screening co-ordinators on the evidence of clinical and cost-effectiveness for interventions to reduce inequity in screening, with a summary giving simple recommendations on how this might translate into local practice
- Systematic introduction of new interventions locally
 - Interventions should be introduced where there is documented local evidence of inequity (e.g. from a health equity audit)
 - Interventions should, where the literature is available, be based on existing trial evidence of effectiveness; ineffective interventions should not normally be introduced
 - Where published literature is not available, NSC-held grey literature (this review and subsequent reports of pilots collected by the NSC) should be consulted for evidence of effectiveness
 - Interventions should be introduced for a trial period, with a simple evaluation of the intervention's success on reducing inequity in screening uptake, taking into account any background trends of increasing or decreasing inequity. Where time/resources allow, evaluations should also look at the processes involved in delivering the intervention, and critique these
 - Costs of interventions should be estimated
 - At the end of the trial period, a brief report should be prepared outlining the pilot, including a description of the intervention, outcomes and costs, even if the intervention was found to be unsuccessful

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- This report should be copied to the National Screening Committee
 - Systematic piloting of existing interventions
 - Interventions which are already in place locally but never previously piloted or based on published evidence of effectiveness, should be reviewed
 - Where resources allow, interventions should undergo piloting and evaluation as outlined above for new interventions
 - Interventions which are not found to be effective should be stopped

Appendix 1. Terms used for literature search

Medline, Embase and the Cochrane Library were searched, with papers limited to RCTs, systematic reviews and meta-analyses, from 2000 to 2008, in the English language. The following is an example of the Medline search strategy.

1. **mass screening/ or *neonatal screening/ 2. *Mammography/ 3. *Vaginal Smears/ 4. *Genetic Screening/ 5. exp *Prenatal Diagnosis/ 6. ((prenatal or pre-natal or antenatal or ante-natal or pre-part* or prepart* or ante-part* or antepart* or neonatal or newborn or sickle cell or thalassemia or down* syndrome or cystic fibrosis or fetal anomal* or foetal anomal* or routine) adj2 (screen* or test*)).tw.*
7. *((cervical cancer or breast cancer or bowel cancer) adj (test* or screen*)) or fobt or fecal occult blood test* or faecal occult blood test* or smear test* or vaginal smear* or papanicolou or pap smear* or pap test* or mammogra*).tw.*
8. *1 or 2 or 3 or 4 or 5 or 6 or 7*
9. **health services accessibility/ or healthcare disparities/ 10. (access* or inequit* or inequalit* or disparit* or barrier*).tw.*
11. *9 or 10*
12. *exp *Socioeconomic Factors/*
13. *((social or socioeconomic or sociodemographic or sociocultural or economic) adj2 (factor* or predictor*)) or poor or poverty or low income).tw.*
14. *12 or 13*
15. *ethnic groups/ or arabs/ or jews/*
16. *religion/ or buddhism/ or hinduism/ or islam/ or judaism/ 17. refugees/ or "transients and migrants"/ 18. "Emigration and Immigration"/ 19. Race Relations/ 20. continental population groups/ or african continental ancestry group/ or asian continental ancestry group/ 21. Prejudice/ 22. Transcultural Nursing/ 23. culture/ or ethnology/ 24. or/15-23 25. (arab\$ or bengali\$ or bangladeshi\$ or cantonese or chinese or gujurati or hindi or kashmiri or korean or kurdisch or mandarin or punjabi or nepali or somali\$ or tamil or turkish or urdu or vietnamese).tw.*
26. *(buddhi\$ or islam\$ or muslim\$ or moslem\$ or hindu\$ or jew\$ or judaism or sikh\$).tw.*
27. *(african\$ or afro-caribbean\$ or caribbean\$ or asian\$ or black\$ or chinese or indian\$ or jamaican\$ or pakistan\$).tw.*
28. *(bme or ethnic\$ or minorit\$ or immigrant\$ or asylum seeker\$ or refugee\$ or ethnographic or ethnolog\$ or multi ethnic or multiethnic or multi cultural or multicultural or multiracial or multi racial or race or racial).tw.*
29. *or/25-28*
30. *(irish or polish or eastern european\$ or traveller\$ or gypsy or gypsies or romany or romanies).tw.*
31. *Gypsies/*
32. *European Continental Ancestry Group/ 33. or/30-32 34. 24 or 29 or 33 35. Vulnerable Populations/ 36. 14 or 34 or 35 37. 8 and 11 and 36 38. *health services accessibility/ or healthcare disparities/ 39. (access* or inequit* or inequalit* or disparit* or barrier*).ti.*

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40. 38 or 39
 41. 8 and 40
 42. 37 or 41
 43. limit 42 to english language
 44. limit 43 to yr="2000 - 2008"
 45. limit 44 to "therapy (sensitivity)"
 46. Meta-Analysis/
 47. (meta-analys* or metaanalys* or systematic review*).tw.
 48. 46 or 47
 49. Comparative Study/
 50. intervention studies/
 51. 48 or 49 or 50
 52. 42 and 51
 53. 45 or 52

Appendix 2. Questionnaire sent to NHS organisations

For PHRU use only

Current practice in identifying and reducing inequity and inequality in accessing screening programmes

1. Are you aware of any existing inequity or inequality in accessing screening programmes in your area (e.g. homeless or disabled groups accessing screening programmes less than you would expect)? *(please tick)*

Yes

No

2. If you answered Yes to Q1, please indicate in which programme(s) inequity or inequality is present and what form this takes. *(Please fill in a separate row for each screening programme where there is thought to be inequity or inequality.)*

	Screening programme	Description of inequity / inequality
e.g.	Cervical cancer	Young not accessing
	Bowel cancer	Travellers not accessing
1	<input type="text"/>	<input type="text"/>
2	<input type="text"/>	<input type="text"/>
3	<input type="text"/>	<input type="text"/>
4	<input type="text"/>	<input type="text"/>
5	<input type="text"/>	<input type="text"/>
6	<input type="text"/>	<input type="text"/>
7	<input type="text"/>	<input type="text"/>

Did you carry out any audit or other work (e.g. focus group studies or local surveys) to understand these inequities / inequalities in more detail? If so, please tick this box and enclose a copy of the relevant reports (e.g. audit or study reports) when you return this form.

3. Are there any existing programmes or interventions to reduce inequity or inequality in screening in your area? If so, please describe them briefly below. *(We are interested not only in interventions which have been successful, but also those which may not have worked as intended.)*

Are you able to enclose any documentation detailing these programmes/interventions? If so, please tick this box and include the document(s) when you return this form.

(continued overleaf...)

(cont...)

Please provide your name, position and organisation, so we can keep a track of replies.

Your name

Your position

Your organisation

Would it be possible for us to contact you to find out more information about any examples of current practice you've given above? If yes, please give your preferred contact method and details below (*please tick email and/or phone*)

Email – my address is: _____ @ _____

Phone – my number is: (_____) _____

Would you be interested in receiving a copy of the final report?

Yes Please give your email, if not stated above: _____ @ _____

No

Many thanks.

Please return this form to: Dr Tom Porter, Public Health Resource Unit, 4150 Chancellor Court, Oxford Business Park South, Oxford, OX4 2GX.

Please email tomporter@nhs.net if you have any queries.

Appendix 3. Organisations replying to questionnaire

The following organisations replied to the questionnaire sent to all PCTs, LHBs, Health Boards and Health and Social Services Boards (total replies: 31; total organisations represented: 32)

Organisation(s)	Separate replies received
Bedfordshire PCT	1
Berkshire East PCT	1
Bournemouth & Poole PCT	1
Bromley PCT	2
County Durham PCT	3
Isle of Wight NHS	1
Newham PCT	1
Northumberland Care Trust	1
Oxfordshire PCT	1
Sandwell PCT	1
Sheffield PCT	1
Southwark PCT	1
Suffolk PCT	1
Sutton & Merton PCT	1
Walsall PCT	1
Wandsworth PCT	1
Bristol PCT	1
South Gloucestershire PCT	
North Somerset PCT	
Bath & NE Somerset PCT	
Enfield PCT	1
Barnet PCT	
Haringey PCT	
NHS London	1
NHS East Midlands	1
Screening Lead, Wales	1
Caerphilly LHB	1
Swansea LHB	1
NHS Dumfries & Galloway	1
NHS Highland	2
NHS Lothian	1
NHS Orkney	1

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