

Research paper

A critical review of the literature on the uptake of cervical and breast screening in British South Asian women

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ABSTRACT

Objectives To consider the recent evidence which examines factors that are associated with uptake of cervical and breast screening in the British South Asian community and to consider the effectiveness of interventions to improve uptake in this group.

Methods A search strategy was developed and key databases were searched to identify primary research studies that examined the uptake of cervical and breast screening in British women of South Asian origin. Studies published prior to 1996 were excluded from the review.

Results Seventy-eight studies were identified and ten were included in the review. Observational studies demonstrated mixed results on the effect of ethnicity on uptake of screening. Controlling for confounders attenuated the effect in all studies and removed its effect entirely in some. Investigation of low uptake in qualitative and quantitative research indicates that South Asian women were more likely

to have incorrect addresses and language or cultural barriers to screening than other women.

Few interventional studies were identified and all varied in their design. The success of interventions was mixed and the lack of control groups in some studies made it difficult to draw conclusions on their effectiveness.

Conclusion There is a poor uptake of cervical and breast screening by South Asian women compared with the general population in Britain. Evidence is inconclusive as to whether this is due to a residual effect of ethnicity following control for socio-demographic and local health service variables. Currently there is a lack of robust experimental studies on which to base interventions intended to increase uptake in this population.

Keywords: breast screening, cancer, cervical screening, review, South Asian

How this fits in with quality in primary care

What do we know?

Uptake of cervical and breast screening is lower in South Asian women than in the rest of the population.

What does this paper add?

The uptake of screening is dependent on a large number of factors but the independent effect of ethnicity remains unclear. The influence of socio-demographic and practice factors on screening uptake varies across populations. There is a lack of evidence to support interventions to increase the uptake of screening in this population.

Introduction

The UK National Screening Programmes for cervical and breast cancer are now well established following their introduction in 1988. Women aged 50–64 are invited for breast screening once every three years and

those aged 25–64 are invited for cervical screening every three or five years depending on their age.¹ Following their introduction, uptake of these programmes has gradually increased until recent years. In England, breast

screening coverage (the percentage of women screened within three years) has remained static at just under 70% since 2000.² However, coverage of cervical screening has fallen over the last ten years and in 2007–2008 fell below 80% for the first time since the early 1990s.³

Screening coverage is not uniform across the population. For example, cervical screening data demonstrate that younger women are less likely to have had a cervical screen (66.2% coverage in women aged 25–29) and coverage at a primary care trust level varies between 66.7% and 85.7%.³ It is estimated that 7.9% of eligible women have never had a cervical screen.³ A similar pattern exists for breast screening.² Other factors that have been associated with low screening coverage include economic and social deprivation⁴ and non-white British ethnicity.^{5,6} However, as identified in a review conducted by Hoare in 1996, it is not clear to what degree these factors confound one another⁷ and evidence of size of effect or causal relationship is weak. Many of these studies were published at an early stage of the National Screening Programmes and as such may not reflect the current picture;⁸ the public health challenge of identifying and targeting groups with low uptake remains.⁹

The aim of this scoping review was twofold: to consider the recent evidence examining socio-demographic, healthcare and other factors that are associated with coverage of cervical and breast screening in the British South Asian community and to consider the effectiveness of interventions to improve uptake in this group. For the purpose of the review South Asia was defined as the countries of Bangladesh, Bhutan, India, the Maldives, Nepal, Pakistan and Sri Lanka.

Methods

Ovid MEDLINE (1996 to August week 4 2009), EMBASE (1996 to week 36 2009), the British Nursing Index (1994 to September 2009) and CAB Abstracts (1990 to week 35 2009) were searched on 7 September 2009. Database content from 1996 onwards was searched in order that the review would reflect the current picture of cancer screening. Search terms were designed to elicit studies considering the following parameters: 'South Asian', 'cancer screening' and 'UK' (details of the search strategy and search terms used can be found in Figure 1). Titles and abstracts of studies were reviewed by the author for inclusion according to the search strategy. Only primary research studies from the UK published after 1996 were included. The reference lists and new citations of selected studies were reviewed to identify any additional studies. No attempt was made to identify unpublished or grey literature. A total of ten studies was identified and included in the narrative review.

Results

Factors that affect the uptake of screening are likely to differ between breast and cervical screening programmes, in part due to the different age groups. However, due to the scarcity of literature, for the purpose of this review breast and cervical cancer have been considered together. All studies included in the review have been summarised in Table 1.

Socio-demographic and healthcare system factors associated with cancer screening uptake

Four large-scale observational studies investigating the effect of ethnicity on screening uptake whilst controlling for other factors were identified and are discussed below.

Sutton, Storer and Rowe⁸ investigated the uptake of breast and cervical screening programmes by South Asian women compared with non-Asian women. Pairwise matching was used to control for the effect of age, residence and general practice. Significantly higher rates of breast and cervical screening uptake were found in non-Asians compared with South Asians (78% vs 53%, $p < 0.01$; 75% vs 67%, $p < 0.001$, respectively). One of the criticisms of this paper is that women's ethnicity was determined by two researchers 'flagging women whose names appeared to be of South Asian origin' (p. 183). It is therefore impossible to ascertain how accurate this method was in comparison to the standard method using computer software with known sensitivity and specificity;¹⁸ any misclassification would lessen the effect detected between groups. Questions also arise with regard to the exclusion criteria used. The authors excluded only non-European women from the control group. However, the factors that affect the uptake of screening in South Asian women may be due to migrant status and therefore may also impact upon European migrant groups, e.g. language barriers, transience, etc. Including European migrant women within the control group may have lessened the effect of ethnicity detected. Additionally, the uni-classification of all South Asian women may have masked subgroup characteristics.

Szczepura, Price and Gumber¹⁸ considered breast screening uptake patterns in South Asian groups compared with non-Asians ($n = 210\,000$). Ethnic origin of individuals was determined using computer software validated against local name datasets and results were verified by manual checks. This approach also allowed for identification of five South Asian subgroups (Hindu–Gujarati; Hindu–other; Muslim; Sikh; South Asian other). Lower rates of screening in South Asian groups remained after controlling for age and

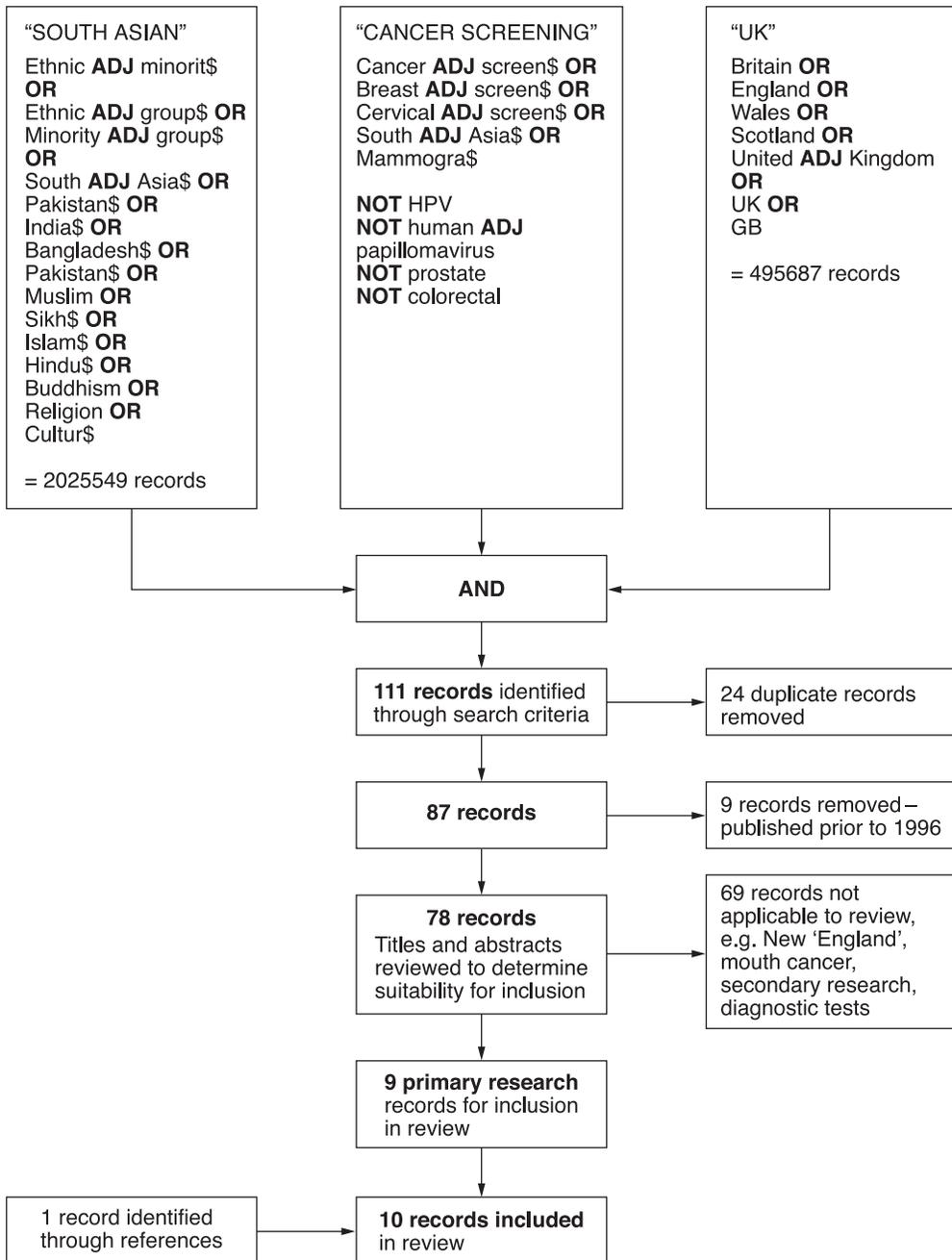


Figure 1 Search strategy and search terms used

socio-economic deprivation. Subgroup analysis showed that between 2001 and 2004 South Asian women were significantly less likely to have had breast screening compared with non-Asian women (Muslim women odds ratio (OR) 0.40, 95% confidence interval (CI) 0.35–0.46; Sikh women OR 0.79, 95% CI 0.72–0.88). One of the strengths of this study is that it included Asian subgroups in the analysis rather than assuming ethnic homogeneity. This can be highlighted by considering the different likelihood of screening compared to non-Asian women across these groups.

By contrast, other studies published around the same time did not identify an effect of ethnicity after controlling for confounding variables. Webb, Richardson, Esmail *et al*⁹ considered cervical screening uptake by ethnicity and place of birth in 72 000 women. They found that the lower screening uptake in South Asian women (69.5% vs 73% ‘others’, $p < 0.001$) was explained by area and practice-level variables. Practices with small South Asian populations were found to be associated with lower rates of screening uptake. The authors used computer software to identify the ethnic

Table 1 Summary of studies identified for inclusion in the review

Author	Aims and objectives	Setting	Participants	Study design	Method	Analysis	Key results
Attri <i>et al</i> 1997 ¹⁰	Investigate whether a two-hour training programme for general practice reception staff could improve uptake in women who had failed to attend for breast screening, and whether different ethnic groups benefited equally	Inner London Borough of Newham, England	2064 women aged 50–64 years who had failed to attend for breast screening 26 general practices (12 intervention, 14 control) in Newham, London 31% were white, 17% were Indian, 10% Pakistani, 14% black, 6% Bangladeshi, 1% Chinese, 4% were from other ethnic groups, and 16% ethnicity unknown	Randomised control trial (centre based)	Reception staff followed up non-attendees by letter and/or telephone call Staff in intervention group underwent two-hour training session re. breast screening programme and common concerns Translated materials supplied to intervention group practices	Change in attendance rate analysed by chi-squared test Analysis by intention-to-intervene	Attendance among the intervention group was significantly better than among the control group (9% v 4%) The response was best in Indian women – it was 19% in the intervention group and 5% in the control group
Bell <i>et al</i> 1999 ¹¹	To increase breast cancer screening uptake in women, especially those from ethnic minority groups	Cardiff, Wales	369 women invited for screening. 59% non-English speaking, majority of whom were South Asian	Experimental (non-randomised, no control)	Local knowledge and surname used to identify language All women provided with/offered: Leaflets and general practitioner (GP) 'endorsement letter' in language spoken Transport to screening centre Interpreters at screening centre	Change in uptake rate from previous screening round analysed by chi-squared test	190 women attended screening, 53% non-English speaking Increased screening uptake by 15% (pre/post intervention) in all women

Table 1 Continued

Kernohan 1996 ¹²	Assess the effectiveness of a community based intervention to improve knowledge and uptake of breast and cervical screening among ethnic minority women	Bradford, England	1600 from four minority ethnic groups (Afro-Caribbean, Asian, East European and 'other') were involved in the programme	Experimental (non-randomised, no control)	18-month health education strategy based on a community development approach - formal and informal sessions, local publicity campaign	Pre-/post-intervention changes in knowledge analysed by chi-squared test	Prior to intervention one-third of South Asian women had heard of cervical cancer, rising to two-thirds post-intervention 21% had heard of breast cancer pre-intervention, increasing to 96% post-intervention
Pfeffer 2004 ¹³	To understand why women do or do not accept invitations to attend for breast screening	Hackney, London, England	20 focus groups, 146 women Black Afro-Caribbean, Cantonese, Gujarati, Punjabi, Somali, Sylheti, Turkish, white 'professional', white 'non-professional', white Jewish orthodox	Qualitative - focus groups	Groups facilitated by researcher and/or health facilitator Women encouraged to talk about general health; causes, signs and symptoms of breast cancer and barriers to screening	Deductive and inductive analysis of transcripts	Poor understanding of the causes of breast cancer in non-white groups Gender of health professionals a major barrier for ethnic minority groups
Sutton <i>et al</i> 2001 ⁸	Measurement of the cervical and breast screening coverage of south Asian women, compared with other city residents, to investigate the effect of ethnicity on screening uptake	Wakefield, England	850 pairs of women (South Asian and non-Asian) matched by age, GP and residence 7 inner city practices	Case control	Women matched for age, practice and residence Ethnicity identified by name Non-European women excluded, European women included as controls	Difference in screening coverage analysed by McNemar's test	67% South Asians and 75% non-Asians had acceptable cervical screening histories ($P<0.001$) 53% South Asians and 78% non-Asians had acceptable breast screening history ($P<0.01$)

Table 1 Continued

Author	Aims and objectives	Setting	Participants	Study design	Method	Analysis	Key results
Szczepura <i>et al</i> 2008 ¹⁴	Analysis of the uptake of breast and bowel screening programmes in South Asians compared to the general population	Coventry and Warwickshire residents, England	210 000 breast screening invitations (3 rounds)	Cross-sectional	Uptakes compared for rounds 1, 2 and 5 of the NHS breast cancer screening programme	Multivariate analysis to examine screening uptake and age, gender, deprivation and ethnic group	Lower uptake in breast screening in South Asians compared with non-Asians reduced over time (15% difference in round 1, 11% in round 5) No improvement in Muslim group
Thomas <i>et al</i> 2005 ¹⁵	To describe factors that act as barriers to effective uptake of breast and cervical cancer screening services in black and minority ethnic groups	Brent and Harrow, London, England	135 BME participants including 31 South Asian women	Qualitative, focus groups	Qualitative research based on the health belief model to understand perceptions of susceptibility and severity of cancer	Content analysis of transcripts and phenomenological approach to guide analysis	Analysis of focus group data has revealed poor knowledge, underlying health and cultural beliefs, attitudes, language and unhelpful attitudes of health professionals to be important barriers
Webb, Richardson, Esmail <i>et al</i> 2004 ⁹	1 Compare uptake of cervical screening between South Asians and other women in area, adjusting for area and practice confounding 2 Assess whether uptake varies in relation to size of South Asian population 3 Estimate uptake of other ethnic minority groups	Former Manchester Health Authority area, England	Screening records of all eligible women aged 30 years and over ($n=72\ 613$), 7000 identified as South Asian	Cross-sectional	Software programme used to identify South Asian ethnicity from patient records	Multivariate analysis used to compare uptake by ethnicity and place of birth against screening uptake	A higher proportion of South Asians were recorded as 'never screened', an effect only partially explained by confounding In practices with relatively large South Asian populations, uptake was higher among South Asians

Table 1 Continued

Webb, Richardson and Pickles 2004 ¹⁶	To identify and estimate the population impact of primary care service delivery factors that independently predict non-attendance for cervical screening	Former Manchester Health Authority area, England	Screening records of all eligible women aged 30 years and over ($n=72\ 613$), 7000 identified as South Asian	Cross-sectional	Software program used to identify South Asian ethnicity from patient records Logistic regression used to identify area level and practice level factors associated with no history of attendance at cervical screening	Logistic regression	Large practices, single-handed practices, South Asian male GP, part-time GP, older age and birthplace overseas, and area level deprivation and transience associated with poor uptake
Willoughby 2006 ¹⁷	To investigate the contribution of population characteristics to the rate of decline in cervical screening programmes	North East and Yorkshire and Humber regions, England	17 health authority areas	Ecological	Change in rate of cervical screening rates between 1995 and 2005 at health authority level, compared to deprivation, age profile and ethnicity/religion of populations	Correlation to age-standardised rate of change of coverage rate	Increase in coverage for women aged >55, decline in younger age groups (25–29 years, 1.3% decline) Statistically significant correlation of greater decline in areas of greater deprivation No significant association between the proportions of Asian ethnic groups

origin of women from women's names and then enhanced this by using place of birth information. However, the authors did not use these data to stratify women according to their immigration status, i.e. those of South Asian ethnicity born in the UK and those born in South Asian countries, instead analysing all 'South Asian' women as one group.

The advantage of verifying the computer identified ethnicity is the opportunity to identify subgroups. However, these subgroups were not identified and information on place of birth was only available for one third of women.

Willoughby, Faulkner, Stamp *et al*¹⁷ conducted an ecological study to consider factors that may have contributed to the decline in screening rates between 1995 and 2005. No correlation was found between declining rates of cervical screening and the size of the South Asian population ($r^2=0$, $p=0.56$). This study does little to increase the understanding of the impact of ethnicity on rates of screening; population level screening rates may not be sensitive enough to detect changes within a relatively small proportion of the population. Considering rates of screening within different ethnic groups is likely to be a more effective way of identifying whether ethnicity contributes to this rate decline. Additionally, the authors considered a static measure of ethnicity, making an assumption that these measures did not change over time. A more informative approach would have been to compare the year-on-year changes in the ethnic profile of the populations against the screening rate.

Potential mechanisms for poor uptake

Three studies were identified that investigated potential mechanisms for poor uptake; these are discussed below. Two of these studies were qualitative and one cross-sectional in design.

A study by Webb, Richardson and Pickles¹⁶ considered the effect of primary care and individual factors on cervical screening uptake. The strongest predictor of no uptake was an overseas birth place (adjusted OR 3.75; 95% CI 3.26–4.32). This finding at a population level does little to suggest possible causative factors, which may include transience, language and health service knowledge barriers. Other smaller intervention studies can help to explain low uptake in those with overseas places of birth; some have found that many South Asian women, born outside but living in the UK, often return to their place of birth either permanently or for extended periods.^{10–12} Recent estimations of the proportion of incorrect addresses for South Asian non-attendees are between 21% and 25%^{11,12} and between 8% and 15% of women have been out of the country at the time of invitation.^{10,12} This highlights the need for accurate patient registers

to ensure that women receive their invitations for screening.

Findings from qualitative studies give useful insight into the barriers to screening that South Asian women experience. Pfeffer¹³ used focus groups to explore women's perception of their risk of breast cancer and their reasons for compliance with screening. The groups were encouraged to talk about their health, and understanding of breast cancer and screening. Groups varied in their composition; some were naturally occurring whereas others were constructed for the purpose of the research; this appeared to impact on the depth and type of information gathered from each group. Understanding of breast cancer risk and women's perceptions of their own risk were found to be characterised by ethnicity and culture. The South Asian groups reported that their risk of breast cancer was low as they did not smoke or drink and breastfed their children. These groups also reported a reluctance to take up the screening invitation due to cultural issues such as being examined by a male healthcare professional and exposing their breasts. The themes emerging from this research not only offer potential explanations for the poor uptake in South Asian (and other ethnic minority) groups but also identify opportunities to intervene. However, as the authors commented, these may be common themes for all women who do not access breast screening and hence require testing within other population groups.

Thomas, Saleem and Abraham¹⁵ used focus groups to explore knowledge of cancer, and access and barriers to screening in minority ethnic groups. Key barriers for all the groups, but particularly South Asian women, included the lack of culturally and religiously sensitive services. Language was the most commonly cited barrier to accessing screening in Muslim and Gujarati communities. This included a lack of translated materials, inaccurate translations and low literacy levels. The number of South Asian women in this study was relatively small and relied on volunteer recruitment from local groups, so is unlikely to be representative of all South Asian women.

Interventions to increase cancer screening uptake

Although the rate of breast and cervical screening in South Asian populations is low there is a dearth of interventional studies that consider approaches to improving uptake. Just three studies were identified, of which only one was of a randomised controlled design. All three studies are discussed below.

Bell, Branston, Newcombe *et al*¹¹ investigated the effect of a mix of interventions to increase the uptake of screening in women registered with three inner city general practices. Women were provided with

information in a language they were able to understand, free transport to and from the practice and the support of a link worker at their appointment. Uptake of screening improved across the three practices from 35% to 51% (45% in the non-English speaking group). The authors concluded that the provision of translated literature and link workers appeared to be effective interventions in terms of increasing the uptake of screening in this cohort. However, these conclusions seem to have little supportive empirical or statistical evidence and without a control group it is not possible to directly attribute the findings to the interventions.

Kernohan¹² conducted a community development programme to improve knowledge of breast and cervical cancer and screening in ethnic minority women. The use of a community development approach fits with evidence that found that general practices with a larger South Asian population had better uptake of screening, assumed to be a result of community empowerment and social norms.¹⁶ South Asian women were found to have the lowest levels of knowledge at baseline and showed the greatest improvement (heard of mammography pre-programme 21%; post-programme 57%; $p < 0.05$). Self-reported uptake of screening also increased (breast cancer screening – threefold increase; cervical cancer screening – 30% increase, no p value given). This study is interesting as it highlights women's low level of knowledge at baseline of both screening services and cancer. This finding is even more noteworthy considering that the study relied upon a convenience sample of women already involved in a health promotion programme, so their awareness may well have been an overestimation of that of the wider population.

Atri, Falshaw, Gregg *et al*¹⁰ undertook a randomised controlled trial to investigate whether a short training session for reception staff improved the uptake of breast screening for women who had previously not attended. Reception staff in the intervention group underwent a two-hour training session informing them about the screening programme and women's fears. The reception staff in the control group did not receive this training. Reception staff in both groups were asked to contact women who had not responded to an invitation to attend mammography by letter and/or telephone call. A 5% increase in attendance of initial non-attendees in the intervention group compared to the control group was demonstrated, with a 4% increase in attendance in the control group from a baseline attendance of 49% and a 9% increase in the intervention group from a baseline attendance of 48%. No clinical or statistical significance of this absolute increase in attendance is given despite the relative increase in attendance (OR 2.3, 95% CI 1.1–5.3, $p = 0.04$). Indian women in the intervention group were more likely to subsequently attend screening compared to controls (OR 2.2, 95% CI 1.3–

3.8); other ethnic groups, including Pakistani and Bangladeshi, did not demonstrate such a significant increase. The authors suggest that the significant results seen in the Indian women may be due to many of the reception staff being fluent in several commonly spoken languages. This highlights the fact that interventions must meet local needs in order to maximise their effect.

Discussion

Role of ethnicity

All of the studies reviewed demonstrated lower screening uptake in South Asian women than non-South Asian populations. The studies reveal discrepancies in the effect of ethnicity, following adjustment for potential confounders, on the uptake of breast and cervical screening. Two studies demonstrated that ethnicity did have an effect^{8,18} whereas two of the studies indicated that ethnicity had no effect.^{9,17} The lack of agreement may be due to a number of factors: different study designs, the variation in methods used to identify the ethnicity of women, the range of variables considered and the heterogeneity of control groups.

The uptake of screening in South Asian women varied across different areas and studies. Part of this effect may be explained by factors including the absolute and relative sizes of South Asian communities¹⁶ and how established these communities are. New British South Asian communities may have a larger proportion of women who have been born outside the UK,¹⁶ poorer English language skills or social norms that reduce access to services.¹² Established communities may be larger and include a greater proportion of English speaking women. Additionally, recent immigrant communities are likely to differ in their composition from those established communities who mostly immigrated to the UK seeking labour after the Second World War. There was no attempt in any of the studies to stratify women according to whether they had been born in the UK or were first generation immigrants. The degree to which ethnicity and other variables affect screening uptake is likely to differ in these different populations due to a range of factors, including English language skills and cultural barriers.

Studies that attempt to explain the mechanisms that determine screening uptake in South Asian women identify key factors including perceived risk, cultural or language barriers and the transient population.^{11–13,19} The relative influence of these factors on the uptake of screening in comparison to socio-demographic factors has not been investigated; such studies would

assist in identifying potential areas for intervention. Poor English language skills, particularly reading skills, are important barriers to accessing healthcare in ethnic minority adults;²⁰ these are likely to be of particular importance in screening services that rely on automated, paper-based call and recall systems.

Reviewing the range of study populations, methodologies and findings of these studies highlights the variations in screening uptake, factors associated with uptake and barriers across South Asian populations. This emphasises the importance of considering the heterogeneity of these groups rather than assuming homogeneity.^{13,18,21}

Effectiveness of interventions

There are few studies that have investigated the effect of interventions to increase the uptake of screening and those that have been done have shown mixed results. This is likely to be due in part to lack of statistical power, lack of control groups or randomisation and the lack of differentiation of the populations studied. These factors perhaps reflect the challenges in conducting robust experimental studies in general healthcare settings. Despite well-intentioned and targeted interventions three of the studies demonstrated an increase in uptake across all ethnic groups, suggesting that the effect of the interventions may have been due to the contact with women rather than the content per se.^{10–12} The lack of robust evidence from these studies does not mean they should be dismissed but highlights the need for well-designed studies to evaluate the clinical and cost-effectiveness of targeted interventions in increasing screening uptake in South Asian women.

Study limitations

This scoping narrative review was not intended to be a comprehensive and systematic review of the literature and so is limited in its findings, particularly as it was restricted to the UK. The titles, abstracts and included papers were reviewed by the single author, potentially reducing the reliability of the study. Additionally, no grey or unpublished literature was included; given the role of publication bias and the lack of conclusive evidence in the published studies this may have been an important limitation as many 'non-significant' studies may not have been published and thus excluded.

Implications for policy

This review highlights the heterogeneity of the South Asian community and how variables that are associated with screening uptake vary greatly across populations

and studies. This emphasises the need for local needs assessment work to identify the size and constitution of the community and barriers to screening in this group, to ensure evidenced best practice is effectively implemented.

A common limitation of all these studies was the difficulty of identifying women of South Asian origin and establishing measures of need such as preferred language. General practices should be encouraged to improve their recording of patients' ethnic origin and key details such as preferred language. Such information would enable practices to highlight women's specific needs on receipt of prior notification lists and to ensure that women receive information in a form that is appropriate to their needs.

These studies also highlight the crucial element of individual and community support for women who fail to attend for screening even though this effect may not be exclusive to South Asian women. Local screening programmes and general practices should consider how existing resources such as multilingual workers and health trainers can be utilised to support women in overcoming their barriers to screening.

Conclusion

There is a poor uptake of cervical and breast screening by South Asian women compared to the general population. However, it remains unclear to what degree the disproportionate representation of South Asian women in deprived, inner city, isolated communities affects uptake; how other variables that are known to negatively affect screening uptake and that are more common in South Asian groups (e.g. incorrect addresses, transient population, language and cultural barriers and poor awareness of screening programmes) influence uptake; and the residual effect of ethnicity.

The few studies that have investigated the effect of interventions to increase the uptake of screening have shown mixed results. However, they all highlight the need to tailor interventions to the local population. The lack of studies and the heterogeneity of their design and of the populations studied suggest that the possibility of a large, robust, systematic review being conducted may be some time off.

Epidemiologists and front-line health professionals alike need to continue the determined efforts to increase screening coverage in this group.

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CONFLICTS OF INTEREST

None.

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