Inequalities in breast screening uptake among South Asian women in the UK: The role of service providers*

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Abstract

Objective: To asses how Breast Screening Units in the UK communicate with their South Asian screening population.

Design: Survey sent via mail to all 95 Breast Screening Units in the UK in summer 2009. Survey received a response rate of 70%.

Results: A majority of Breast Screening Units agree that it would be useful to record the patient's language to improve services to patients (79%), yet only a minority of units record the patient's language when attending mammography (27%). Only one unit sent out the initial invitation letter for screening in a South-Asian language. The most common mode of communicating the breast screening programmes to South Asian women are translated leaflets and 85% of units can access them, yet only 38% hand them out to women when attending mammography.

73% of units arrange interpreters in advance, but 39% of the units rated their communication with South Asian women as poor or very poor. Finally, 75.8% of units revised the breast screening information locally, yet only 12% of units consulted South Asian women for this.

Cluster analysis showed that the majority of units ie: 47 (71%) do the minimum to reach out to South Asian women (Routine Outreach Units) while only a minority of units tend to be more active in addressing South Asian women (Pro-active Outreach Units, 19 (29%)).

Conclusions: Leaflets and the use of interpreters are seen as a quick solution to communication barriers, yet this is clearly not enough to ensure informed consent and to increase the uptake rate among South Asian women. Interventions to increase uptake rates need to be more long-term and multiple in nature, tailored to the specific needs of the local community by, for example, developing close links with the community through Health Education workers. Reducing ethnic inequalities in uptake rates of breast cancer screening needs to remain a policy priority of the Government and the Breast Screening Programme.

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Introduction

South Asian women have been consistently identified as having a lower breast screening uptake rate than other groups.¹⁻⁷ Most studies that have investigated differences in breast cancer screening uptake across ethnic groups have focussed on the behaviour and attitudes of women towards screening. So, problems of uptake are typically seen as emanating from the target groups themselves, with system effects rarely examined.⁸ This study sets out to examine the practices of Breast Screening Units in the UK in relation to addressing the needs of South Asian women. It uses data from a survey carried out in 2009 with all 95 Breast Screening Units in the UK.

The Breast Cancer Screening Programme was introduced in 1988 with the aim of detecting cancer abnormalities in the breast at an early stage and thus increase the chances of effective treatment and survival rates. It was the first national breast screening programme to be set up in Europe and has evolved considerably over the past 20 years.^{9,10} Currently the programme invites over 2 million women aged 50-70 for breast cancer screening. For mammography screening to have a significant impact on reducing mortality, over three quarters of the eligible population must participate in it. Although currently this figure is achieved nationwide, there are considerable differences between regions, with deprived inner city areas having alarmingly low uptake rates. For example the uptake rate for England as a whole was 74% for women aged 50-70 in 2008/09, but in London this figure was only 61%. Similarly, although the uptake rate for the North West was around 76% for women aged 53-64 in 2008-09, in the inner city area of Manchester this was as low as 65%.¹¹

Numerous studies have shown that screening uptake rates also vary by socio-demographic characteristics, with women from lower social-economic classes and some ethnic minority groups particularly, South Asian women, being less likely to attend.^{5,7,12,13} Although breast cancer incidence is currently lower among the South Asian population, it is increasing as South Asian women are increasingly exposed to the lifestyle and environment in the UK.^{14,15} The analysis of data from the Trent Registry from 1998-2006 showed that once controlled for age, area level deprivation and PCT of residence, women from ethnic minority groups have a significantly increased risk of diagnosis with late-stage breast cancer relative to the White British group.¹⁶ Low levels of uptake rate leads to late prognosis and a poor survival rate,

which has been observed among ethnic minorities in the UK.¹⁴ It is therefore important to address the issue of low uptake rates.

While many studies have focused typically on individual attitudes and behaviours in explaining these lower attendance rates among minority ethnic women, the role played by breast screening services has rarely been examined. As some studies have suggested, attitudes of health professionals can constitute important barriers for screening uptake, as can inadequate provision and dissemination of language specific materials.¹⁷⁻²³ Ensuring equal access to health provision, including health prevention programmes, is a statutory duty of the NHS, which has most recently been reinforced through the Race Relations Amendment Act 2000 and laid out in the Department of Health's Race Equality Scheme 2005-2008. More specifically the NHS Cancer Plan of 2000 and the Cancer Reform Strategy 2007 sets out guidelines and gives recommendations on how to improve cancer services and particularly how to reduce cancer inequalities.²⁴⁻²⁵

Thus, almost ten years have passed since the government set out its plan to tackle inequalities in a number of areas including cancer prevention, which encompasses cancer screening programmes. Yet, evidence indicates that South Asian women still have a relatively low uptake rate of breast cancer screening.¹⁴ This study therefore focuses on the actual practice of Breast Screening Units and examines how units have addressed the needs of these women.

Methods

The analysis uses data from a survey of all Breast Screening Units in the UK. Fieldwork was carried out in the summer and completed in the autumn of 2009. The surveys were administered by the radiologist Prof. Anil Jain from the Nightingale Centre at the Wythenshawe hospital in South Manchester. The structure of the questionnaire followed the various stages of the breast screening procedure. Questions were designed to assess what kind of praxis the Breast Screening Units had in place to target South Asian women in the last year at each step of the screening process. Most of the questions were fully structured with fixed response options, however some questions were open ended to collect additional comments and suggestions on how to improve services.

In 2009 there were 95 Breast Screening Units in the UK, the majority being in England (82 units) with 6 units in Scotland, 4 in Northern Ireland, and 3 in Wales. A postal questionnaire

was sent to these units of which 69 were returned. However, three units did not complete the questionnaire, which means that the total number of valid survey responses was 66, giving a response rate of 70%. The survey promised anonymity and it was left to the units to identify themselves in order to receive feedback on the survey results. Although a majority gave their contact details, four units could not be identified. Of the 62 units who identified themselves, 56 units were from England, three from Scotland, one from Wales and one from Northern Ireland. The non-response did not appear to be biased towards certain regions, or to be biased according to screening uptake rates.

The analysis presented here is mainly descriptive to show the range of practices used by Breast Screening Units. In addition, cluster analysis (K-means) using SPSS has been carried out to identify whether there are meaningful types of practices that can be observed among the Breast Screening Units. Cluster analysis is a particularly suitable technique for use with categorical or nominal data, such as found in this survey. It maximises the homogeneity of cases or units within clusters while also maximising the heterogeneity between clusters. Thus cluster analysis is an explorative data analysis for organising variables into meaningful groups.²⁶

Results

Importance of recording patient's language

Breast Screening Units are commissioned by PCTs and obtain the addresses of eligible women for breast screening from these trusts. The trusts identify the screening population based on lists of women registered with their General Practioner (GP). Unless already provided by these lists, the units do not initially hold any information about the ethnicity or language requirements of their screening population. However, once they have established contact with the women there are ample opportunities to record the languages they speak, although there is currently no compulsory scheme in place to do this. Breast Screening Units were thus asked about their attitudes towards collecting data on ethnicity and the language needs of patients. More than three quarters (78.8%) of the units agree that it is useful to record the patient's language in order to improve services to their patients. Perhaps surprisingly, fewer felt that it is also useful to record a patient's language for the NHS Breast Screening Programme (NHSBSP) system (69.7%) and even less for research purposes (51.5%).

Stage One: Breast Screening Invitation	Frequency (n=66)	Percentage
Initial letter sent in South Asian language	1	1.5
Translated version can be requested	42	63.6
In case of non-response to the initial letter, second invitation letter sent in own language	1	1.5
Stage Two: Mammography		
Record language when attending mammography	18	27.3
Give leaflet out in own language when attending mammography	25	37.9
Stage Three: Routine Recall Letter		
After mammography, 'routine recall letter' sent in own language	4	6.1
Stage Four: Further Examination		
After mammography, 'breast screening assessment letter' sent in own language	3	4.5
Have easy access to interpreters in assessment clinics	50	75.8
Interpreter arranged in advance of the assessment appointment	48	72.7
Breast biopsy information leaflets available in own language	9	13.6
After further examination, 'normal breast assessment letter' sent in own language	3	4.5

Table 1: How Breast Screening Units accommodate the needs of South Asian women at different stages of the breast screening process

Stage one: breast screening invitation

After obtaining the list of the screening population from the PCT's the units make contact with the women of the screening age group through a standardised formal letter, where women are informed about the screening and invited to attend their mammography appointment, usually in mobile units situated in their local area or in hospitals. It is not common practice among Breast Screening Units to send out this initial invitation letter in a South Asian language, only one unit reported doing so. In addition, only two-thirds (63.6%) reported that a translated version of the invitation letter could be requested by patients. If the first appointment is not attended a second reminder letter is usually sent out, where women are informed that they have missed their appointment and are urged to arrange a new appointment or attend another pre-arranged appointment. Again, only one unit, the same as above, sends this letter out in languages other than English. Interestingly, this is not a unit that reports servicing a population with a large percentage of South Asian women, according to its own estimate they constitute 5-10% of their screening population.

Stage two: mammography

The next stage of the breast screening procedure is the mammography appointment. At this point women meet the breast screening personnel and problems of communication should become apparent. Only just over a quarter (27.3%) of the units state that they record patients'

languages at this stage, despite this being an obvious opportunity for the breast screening staff to update their records. Breast screening appointments also offer a unique opportunity to discuss patients' concerns with regards to the screening procedure and to provide them with more information, typically supplemented with information leaflets. However, the large majority of the units (62%) fail to offer translated leaflets at this stage.

Stage three: routine recall letter

Following the mammography most women are sent a results letter to inform them about the normal results of their screening and asking them to take up their screening appointment in the future. In this letter they are also asked to continue examining their breasts regularly and to watch for any abnormalities, as lumps can develop in the period between screening visits. Only 6% of units send out a translated version of this letter.

Stage four: further examination

While most women are invited again for a mammography after three years, for a minority of women the screening results indicate possible abnormalities and they are invited to the clinic for a breast screening assessment. Once again, only a few units send out these letters in the patients' own language (4.5%). However, once patients attend the clinic for further examination, three-quarters (75.8%) of the units state that they have easy access to interpreters in the assessment clinics and almost the same number (72.7%) say that they can arrange interpreters in advance of the assessment appointment. Thus, the use of interpreters seems to be fairly widespread. However, in response to open ended questions some units commented that they have never used an interpreter due to lack of demand, or difficulties of arranging for an interpreter to come to the screening site. Other comments indicated that it is quite common for patients to bring along family members to act as an interpreter.

In some cases a biopsy needs to be carried out at this point, and patients are given leaflets providing information on the biopsy procedure. Only 13% of the units have translated biopsy leaflets available. Again if the results of this further examination are normal, only 4.5% of the units send patients a translated version of the normal breast assessment letter, where they are cleared from any abnormalities and encouraged to carry out examining their breasts regularly and continue attending their usual breast screening appointments.

Additional material for South Asian women

Most units have leaflets on the breast cancer screening process available in South Asian languages (84.8%). However, other types of material to promote breast screening are much less likely to be used. Just under one quarter of units have audiotapes (22.7%), posters (21.2%) and videos/DVDs (21.2%) available in a South Asian language. Pictorial leaflets are even less common (9.1%). In addition to these materials, about one third (30.3%) of the units also give Community and Health Promotion Talks to promote the breast screening service to South Asian women. A small minority of units (9.1%) use the radio to promote breast screening to South Asian women in their area.

When asked which of these methods they are most likely to use, Breast Screening Units identified translated leaflets as their main approach, with 59.1% of units stating this is their main mode of communication with South Asian women. Interpreters and Videos/DVD's (at 4.5%) and Community and Health Promotion Talks (at 3%) were very rarely identified as the main method to convey breast screening information to South Asian women. Perhaps worryingly, nearly one third (28.8%) of the units did not identify any strategies as their main approach for communicating with South Asian women. Further comments on the questionnaire demonstrated that units are aware of translated material and their availability online, yet they do not appear to pass these materials on to their intended users.

Targeting South Asian women

One of the major problems that emerged from this survey is the lack of funding that units were allocated to target South Asian women to promote breast screening. Only one unit states that they received funding and only one unit has a separate team who specifically target women of South Asian origin. About 31% of the units have a breast screening link officer and/or a breast screening promotion officer. The open ended comments to questions on this indicated that some units had a special team to target South Asian women in the past, but not in the last year, the reference period of the survey. Moreover, comments about the link workers suggested that they are either not well integrated into the breast screening programme, or that they have a limited capacity, for example working only part time.

Table 2: Targeting South Asian women

	Frequency (n=66)	Percentage
Breast Screening Unit received extra funding for targeting South Asian women		
for breast screening and promotion	1	1.5
BS Unit has breast screening link officer/promotion officer	21	31.3
Breast screening information locally revised	50	75.8
South Asian women consulted when revising breast screening information	8	12.1
Translated means of communication requested by patients in the last year		
Many (more than 6, les than 13)	3	4.5
Few (less than 6)	13	19.7
None	29	43.9
Don't know	21	31.3
Total	66	100.0
How well does your unit communicate information on breast cancer screer	ing to South Asian wor	nen?
Very well/well/fair	32	48.5
Very poor/poor	26	39.4
No answer	8	12.1
Total	66	100.0

Moreover, while three quarters (75.8%) of the units stated that they have locally revised the breast screening information produced by the NHS Breast Screening Programme, only one in eight (12%) actually consulted South Asian women when revising breast screening information. With respect to assessing whether there has been a demand for translated materials by women, only one fifth (24.2%) of the units noted that there has been a request for translated material, although this demand was in most cases very low, almost half of the units stated that they did not receive any request at all (43.9%), while a third (31.3%) did not answer this question.

Indeed, it is apparent that while almost all questions were responded to in full by Breast Screening Units who returned the questionnaire, a subset of questions had high rates of nonresponse, perhaps reflecting a lack of awareness of issues relating to addressing the needs of South Asian women. This is particularly evident when looking at how units rate their practices of communicating information on breast screening to South Asian women. While just under half of the units (48.5%) are happy with the way they communicate with South Asian women, and a lower percentage of units (39.4%) are not satisfied, a small but considerable minority (12%) did not answer this question. Similarly, a third of the units replied that they did not know how often women requested a translated version of the breast screening information. And more than half (57.6%) of the units did not reply to the question asking them to estimate the proportion of South Asian women in their target population.

Comments made by Breast Screening Units on how communication can be improved

Units were asked to make suggestions about how communications with South Asian women could be improved on a local and national level. These comments can be grouped into three main categories: communication between Primary Care Trusts (PCT), General Practitioners (GP) and Breast Screening Units (BSU); availability and dissemination of translated material; and involvement of communities. Many Breast Screening Units expressed the need to improve the communication between BSU and PCTs as well as GPs. The ethnicity of patients and their first language should be recorded by GPs, but this information is not always passed on to BSU via PCT databases. Thus, some BSUs commented that it would be a great advantage to have this information ready before inviting the women for screening for the first time. Moreover, other comments suggested that GPs should have posters and other translated materials, such as a set of standardised letters and guidance, available and ready to be distributed, rather than having to download them from the internet and print them on demand, as should BSUs. Finally many comments stressed the importance of reinstating link workers and health promotion officers, who have a more face-to-face approach and are more likely to have long term effects. Other comments indicated that such staffing is under-resourced.

Proactive Outreach Breast Screening Units and Routine Outreach Units

To explore the data further, cluster analysis has been applied to identify groups of BSUs that behave similarly with respect to how they approach South Asian women. K-means cluster analysis requires the prior specification of the number of clusters that are wanted. Two clusters emerged as the most viable option, differentiating between two groups of BSU's that made sense, while 3 clusters separated just an additional two observations. Thus, the number of clusters was set to 2 clusters. After the number of clusters was specified the initial clusters are randomly selected. The observations are reassigned by moving them to the cluster whose centroid is closest to that observation. Reassignment continues until every observation is assigned to the cluster with the nearest centroid. Such a procedure implicitly minimizes the variance within each cluster. In the first step all 27 variables were included in the cluster analysis. This resulted in cluster 1 having 56 observations and cluster 2 having 10 observations. However, some variables did not separate well between the clusters. At the next step these variables were excluded and the analysis was carried out based on 10 variables that clearly separated between the two clusters: Additional information available in South Asian languages (poster, DVD, audio, community talk, radio, pictorial leaflets), BSU has breast screening link officer or promotion officer, South Asian women consulted in revising breast screening information, useful to record patients language for research, happy to share information and local initiatives with other BSU's. A new variable was created indicating the final cluster membership of each BSU. This resulted in 47 BSU's being assigned to cluster 1 and 19 cases being assigned to cluster 2. Table 3 shows the frequency of activities carried out by BSU for the two clusters.

Table 3: Frequency of activities by two clusters of units

	Routine Outreach	Pro-Active Outreach
	(n=47)	(n=19)
Pro-Active Outreach	%	%
Additional information available in South Asian languages:		
Audio/Tape	10.6	52.6
Video/DVD	10.6	47.4
Community/Health promotion talk	8.5	84.2
Posters	4.3	63.2
Pictorial leaflets	2.1	26.3
Radio	0	31.6
South Asian women consulted in revising breast screening information	0	42.1
Unit has breast screening link/promotion officer	21.3	52.6
Pro-Active Outreach, but only practiced by very few units		
Initial breast screening invitation letter in South Asian language	0	5.3
In case of non-response to the initial letter, second invitation letter sent in own language	0	5.3
After mammography, 'routine recall letter' sent in own language	4.3	10.5
After further examination, 'breast screening assessment' sent letter in own language	4.3	5.3
Breast biopsy information leaflets in own language available	10.6	21.1
After further examination, 'normal breast assessment letter' sent in own language	2.1	10.5
Unit received extra funding to target South Asian women for breast screening promotion	0	5.3
Routine Activities		
Record language when attending mammography	29.8	21.1
Give leaflet in own language when attending mammography	36.2	42.1
Have easy access to interpreters in assessment clinics	74.5	78.9
Interpreter arranged in advance of the assessment appointment	68.1	84.2
Additional information available in South Asian languages: Leaflets	78.7	100
Breast screening invitation: translated version can be requested	63.8	63.2
Breast screening information locally revised	76.6	73.7

The results of cluster analysis show that the Breast Screening Units can be grouped into two different types of units, which we have labelled 'Routine Outreach', covering 47 (71%) of the units, and 'Proactive Outreach', covering 19 (29%) of the units. The Routine Outreach group do what can be considered the minimum to address the language needs of South Asian women. So, they are just as likely as the proactive group to provide access to interpreters, send a translated version of the invitation letter if requested, and provide translated versions of leaflets. These units are also just as likely as those in the proactive group to record the language of patients and give out translated leaflets at the mammography appointment, and to have revised information promoting breast screening locally. However, they are much less likely to have consulted South Asian women when revising this information.

The proactive outreach units do all these routine activities to the same extent as units from the routine group. In addition, they are much more likely to have a range of additional material available for South Asian women, such as posters, pictorial leaflets, video/DVDs and audio/tapes. They are also more likely to have link/breast screening promotion officers available in their units to facilitate access for South Asian women. These pro-active outreach units are also more likely to carry out activities that are in general only practiced by very few units. For example, although only one unit sends out the initial invitation letters and reminder letters in a South Asian language, this unit is in the proactive outreach group. Similarly, the only unit that received separate funding in the last year to target South Asian women is again a member of this group. Moreover, units in the proactive group are much more likely to send translated breast screening assessment letters and routine recall letters, and to have translated breast biopsy information.

Discussion

This study highlights the general failure of Breast Screening Units in the UK in addressing the needs of South Asian women, and also that there are considerable differences between them. The majority of units (71%) fall into a category that we have described as operating a Routine Outreach approach, offering at best basic services to South Asian women, which includes providing translated versions of leaflets and letters if requested and arranging interpreters for meetings between patients and clinical staff. A minority of units (29%) are more proactive in addressing the needs of South Asian women, being more likely to offer material that is particularly suitable for a population with relatively low levels of literacy, as well as relatively low levels of fluency in English, such as posters, audio tapes, videos/DVDs, community talks and appearances on the radio.

One of the key aims of the NHS Cancer Information Strategy is to provide "accurate, comprehensive and comprehensible" health information on cancer and ensuring that it is accessible to those who need it.²⁷ A particular challenge has been "(...) overcoming barriers, such as language difficulties, which prevent women from attending the screening programme".²⁸ Thus, to ensure that women have an understanding of the benefits and limitations of breast cancer screening, and to ensure informed consent for ethnic minorities, the NHS has invested in the development of interpreting services and in ensuring the availability of translated health material.²⁸ The Cancer Screening Programme specifically produces a number of leaflets, booklets and posters that are disseminated through the 95

Breast Screening Units in the UK and are downloadable from the NHSBSP webpage. Key leaflets are translated into several languages, including the major South Asian languages.²⁹

Our study showed that translated leaflets and interpreters are used by Breast Screening Units as a standard solution to language barriers. Yet, relying on these modes of communication is inadequate as it does not guarantee the quality of translated material, either verbally or written, nor how widely it is disseminated. ^{19,21,22} For example, while an overwhelming majority of units have leaflets available in different languages, only a fraction of the units actually give them out at the screening appointment.

Similarly, the widespread use of interpreters raises other important issues. Most health staff are not trained in using an interpreter and many interpreters do not have the relevant medical vocabulary to convey information about the breast screening procedure effectively.^{21,30} Also, it is not clear whether patients are given sufficient time at meetings that involve an interpreter.³¹ Patients need to develop trust in the interpreter in order to feel confident about expressing their worries; it is questionable how far they can do this if they meet an interpreter for the first time, and for only a short time. Also, it is unclear whether patients are informed in advance of their meeting that an interpreter will be available and whether they are advised to think beforehand of the kind of questions they may want to ask, so that they can make the best use of interpreters. Most units ensure that staff at the breast screening sites are female, yet it is unclear whether interpreting agencies are also able to do this. Without undermining the positive role interpreters play in reducing communication barriers,^{32,33} solely relying on interpreters does not ensure that women are well informed about the screening procedure so this service needs to be provided along with other materials.^{18,21.}

Ethnicity a special case?

The NHS Cancer Screening Programme's training pack on breast screening for primary care nurses advises health practitioners to pay attention to the specific needs of minority ethnic women.³⁴ Health practitioners are informed about the availability of translated material for ethnic minority women, including invitation letters, videos and picture books, and they are also advised to pay attention to the customs and health beliefs of local ethnic minority communities and to provide information about breast screening that is culturally relevant and appropriate. However, there is little guidance on how to do this and, despite training, health professionals often still feel lacking in cultural competence.³⁵ A focus group with health

professionals working with ethnic minorities in the Midlands showed that health staff are reluctant to engage effectively with BME communities out of fear of offending patients of other cultures and religions.³⁶

Our study also suggests that a majority of Breast Screening Units know little about South Asian women. Most were not able to estimate the percentage of their South Asian population, nor were they able to state the demand for translated material. This general lack of awareness of the needs of ethnic minority people, and attention to their needs, can also be observed in NHS BSP publications. While there is a special section on publications and studies on ethnic minority women, other relevant publications have no or little reference to ethnic minorities. For example, the NHS Breast Screening Programme refers specifically to improving the quality of written information about breast screening, but does not include any information on practices targeted at the needs of ethnic minority women. ³⁷ Subsequently, a policy recommendation that emerged from this work (NHSBSP no 65) did not pay attention to the needs of ethnic minority women. This issue is not particular to the NHSBSP, but is a wider problem within the NHS as the chair of the BME Review Group on access to GP services, Prof. Mayur Lakani, remarks:

"Sometimes when organisations [NHS] appoint an equality and diversity champion, this can separate the issue from the main business of the board or lead other board members to consider that it is not 'their job'. The review group endorses previous guidance that anyone being allocated such a role should be seen as a co-ordinator rather than the sole agent for race equality" ³⁸

Perhaps more alarmingly, in the Department of Health's latest policy document on future cancer strategies, very few recommendations are made with respect to improving inequalities faced by ethnic minority people.²⁴ This is also the case with the leading professional voluntary organisation Cancer Research UK. Its 2020 goals on cancer do not address the elimination of inequalities faced by ethnic minority people.³⁹

This study complements other studies in understanding the low uptake rate among ethnic minority women, and particularly South Asian women, however in comparison to most studies it looks at service provision and the practices of Breast Screening Units in raising participation among South Asian women. Moreover, the study also assesses the fairly recent implementation of new guidelines on how to reduce ethnic inequalities within the NHS

Breast Screening Programme, such as making translated leaflets available to patients, recording their language and using interpreting services to ensure that communication problems are minimised and informed choice is ensured. The limitation of this study is that it focused only on how Breast Screening Units communicate with South Asian women rather than with ethnic minority groups in general. In addition to that, more insight into the practices of Breast Screening Units could have been achieved by following up particular units with indepth interviews and case studies. This should be an area for future research.

Conclusions and recommendations

With the establishment of the Breast Screening Programmes and its development and extension over the last 20 years, the NHS has clearly demonstrated the priority it has given to cancer prevention and treatment. Special attention has been given to the importance of providing patients with adequate information and of effective communication between health professionals and patients in ensuring optimal use of cancer services.²⁸ However, despite apparent communication problems between ethnic minority populations and health staff, there is little support offered on how to develop a culturally sensitive screening programme and health awareness material. In addition to translated leaflets the NHS Breast Screening Programme provides some breast awareness material in pictorial leaflets, posters, audio and DVDs. Yet, our study showed that these additional materials, which are particularly suitable for a group with low literacy levels, are rarely handed out to South Asian women. Other studies have also suggested that despite its availability, health information for ethnic minorities is not always accessible.^{19,22} This raises important questions about the quality of dissemination of these materials and the role of health professionals in communicating the information to the intended target population.

In line with the report written by Chui and commissioned by the NHSBSP,¹⁷ this paper argues that communication with ethnic minority women still needs to be improved in order to ensure that they are able to make informed choices about breast screening services. The current practices, even among those units who engage in more proactive outreach work by providing translated materials and letters, may not be effective in communicating the advantages and risks of the screening programmes. Chui suggests a more interpersonal approach to communication using the Community Health Educator Model.¹⁹ These community health workers can also play a crucial role in the creation and production of new and appropriate health materials. The community development approach to increasing cancer screening

uptake and promoting cancer awareness to ethnic minority people has also been recommended by the NHS Cancer Information Strategy,²⁸ yet despite this our study showed that only a small minority of units have these resources available. Nevertheless, comments made by these units clearly expressed a need for them.

Other authors also emphasise the importance of community interventions and community based cancer education programmes to disseminate health information and to increase screening uptake rates.⁴¹ Thus it seems that recommendations on how to improve services to ethnic minority people are often not implemented at all, or only on a very small scale.

References

- 1. **Hoare TA**. Reasons for non-attendance for breast screening by Asian women. Health Education Journal 1992;**51**:157–61.
- 2. Bell TS, Branston LK, Newcombe RG, *et al.* Interventions to improve uptake of breast screening in inner city Cardiff general practices with ethnic minority lists. *Ethnicity and Health* 1999;**4**:277–84.
- 3. **Kernohan EE.** Evaluation of a pilot study for breast and cervical cancer screening with Bradford's minority ethnic women; a community development approach, 1991–93. *British Journal of Cancer Supplement* 1996;**29**:S42–6.
- 4. Hoare TA. 1996 Breast screening and ethnic minorities, British Journal of Cancer, 1996; 74(Suppl. XXIX): S38-S41.
- 5. Szczepura A, Price C, Gumber A. Breast and bowel cancer screening uptake patterns over 15 years for UK south Asian ethnic minority populations, corrected for differences in socio-demographic characteristics. *BMC Public Health* 2008; **8**: 346.
- 6. **Sutton GC**, Storer A, Rowe K. Cancer screening coverage of south Asian women in Wakefield. *J Med Screen* 2001; **8**: 183–6.
- 7. Moser K. Patnick J, Beral V. Inequalities in reported use of breast and cervical screening in Great Britain: analysis of cross sectional survey data. *BMJ* 2009; **338**: b2025.
- 8. Chiu LF. *Inequalities of access to cancer screening: a literature review*. Sheffield: NHS Cancer Screening Programmes, 2003.
- 9. Westlake S, Cooper N. Cancer incidence and mortality: trends in the United Kingdom and constituent countries, 1993 to 2004. *Office for National Statistics: Health Statistics Quarterly* 2008; **38**: 1-14.
- NHS Breast Screening Programme. Screening for breast cancer in England: past and future. Sheffield: NHS Screening Programmes, 2006. <u>http://www.cancerscreening.nhs.uk/breastscreen/publications/nhsbsp61.pdf</u> (accessed 12 July 2010).
- The NHS Information Centre, Workforce and Facilities. Breast Screening Programme, England 2008-2009. The Health and Social Care Information Centre. <u>www.parliament.uk/deposits/depositedpapers/2010/DEP2010-1335.pdf</u> (accessed 12 July 2010).
- 12. NHS Breast Screening Programme. All breast cancer report: a UK analysis of all symptomatic and screen-detected breast cancers diagnosed in 2006. National Cancers Intelligence Network, West Midlands Cancer Intelligence Unit, 2006.

- 13. **Taylor A**, Cheng KK. Social deprivation and breast cancer. *Journal of Public Health Medicine* 2003; **25(3):** 228-233.
- National Cancer Intelligence Network and Cancer Research UK. Cancer Incidence and Survival by Major Ethnic Group, England 2002-2006. London: National Cancer Intelligence Network Coordinating Centre, 2009. <u>http://info.cancerresearchuk.org/prod_consump/groups/cr_common/@nre/@sta/doc</u> uments/generalcontent/crukmig_1000ast-2749.pdf (accessed 12 July 2010).
- 15. **Smith LK**, Botha JL, Benghiat, Steward WP. (2003). Latest trends in cancer incidence among UK South Asians in Leicester. *British Journal of Cancer* 2003; **89**: 70-73.
- 16. Cuthbertson SA, Goyder EC, Poole J. Inequalities in breast cancer stage at diagnosis in the Trent region, and implications for the NHS Breast Screening Programme. *Journal of Public Health* 2009: 31(3): 398-405.
- 17. Chiu LF. Promoting informed choices on cancer screening in a diverse community. Sheffield: NHS Cancer Screening Series No 6, 2009.
- 18. Chiu LF, Moore J. and West R. *Communicating risk information about breast and cervical cancer and cancer screening to women from minority ethnic and low income group: a participatory action research project.* Sheffield: NHS Cancer Screening Series No 5, 2009.
- 19. Chiu LF. Straight talking: communicating breast screening information in Primary Care: a participatory action research report. Nuffield Institute for Health, 2002.
- 20. **Chiu LF**. Balancing the equation: the significance of professional and lay perceptions in the promotion of cervical screening amongst minority ethnic women. *Critical Public Health*1999; 9: 5–22.
- Szczepura A, M Johnson, A Gumber, K Jones, D. Clay, A. Shaw. An overview of the research evidence on ethnicity and communication in healthcare: final report. London: Department of Health, University of Warwick, 2005. <u>http://www2.warwick.ac.uk/fac/med/research/csri/ethnicityhealth/research/communicationsreview.pdf</u> (accessed 12 July 2010).
- 22. Watts T, Merrell J, Murphy F, Williams A. Breast health information needs of women from minority ethnic groups. Journal of Advanced Nursing 2004; 47: 526-535.
- 23. **Thomas VN**, Saleem T and Abraham R. Barriers to effective uptake of cancer screening among Black and minority ethnic groups. *International Journal of Palliative Nursing* 2005; **11(11)**: 562-71.
- 24. **Department of Health**. *Cancer Reform Strategy*. London: Department of Health, 2007. <u>http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_081007.pdf</u> (accessed 12 July 2010).
- 25. Department of Health. The NHS cancer plan: a plan for investment, a plan for reform. London: Department of Health, 2000. <u>http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/ documents/digitalasset/dh_4014513.pdf</u> (accessed 12 July 2010).
- 26. SPSS Inc. (2001) SPSS Base 16.0 User's Guide. www.hanken.fi/student/media/3618/spssbaseusersguide160.pdf
- 27. NHS Executive: *Cancer information strategy*. 2000: 3. www.worcestershirehealth.nhs.uk/EXTRANET_Library/GreeningC/whip_strategy/nat_st rat/ict/NSF_IS/Cancer/nsf_cancer_is.pdf) (accessed 12 July 2010).
- The NHS Information Strategy Team and NHS Information Authority. *Towards a Cancer Information Strategy*. Winchester: NHS Information Authority with the National Cancer Director, 2000:
 <u>http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAn dGuidance/DH 4005424</u> (accessed 12 July 2010).

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Programme <u>http://www.cancerscreening.nhs.uk/breastscreen/publications/publication-topics.html</u> (accessed 12 July 2010).

- 30. Cortis JD. Perceptions and experiences with nursing care: a study of Pakistani (Urdu) communities in the United Kingdom. *Journal of Transcultural Nursing*2000; **11**(2):111-118.
- 31. Fagan MJ, Diaz JA, Reinert SE, Sciamanna C. and Fagan DM. Impact of interpretation method on clinic visit length. *Journal of General Internal Medicine* 2003; 18(8): 634-8.
- 32. Jacobs EA, Lauderdale DS, Meltzer D, Shorey JM, Levinson W, Thisted RA. Impact of interpreter services on delivery of health care to limited-English-proficient patients. *Journal of General Internal Medicine* 2001; 16(7): 468-74.
- 33. El Ansari W. Newbigging K, Roth C, Malik F. The role of advocacy and interpretation services in the delivery of quality healthcare to diverse minority communities in London, United Kingdom. *Health and Social Care in the Community* 2009; **17**(6): 636-646.
- 34. NHS Cancer Screening Programmes: Breast screening resource pack for training primary care nurses. 2nd edition. NHSBSP Publication No 39, 2003.
- 35. **Thompson R**, Van der Molen B. (2009) Access to cancer services do culture and ethnicity make a difference? *European Journal of Cancer Care* 2009; **18(1):** 3-3(1). <u>http://www.onlinecancereducationforum.com</u> (accessed 12 July 2010).
- 36. Kai J, Beavan J, Faull C, Dodson L, Gill P, *et al.* Professional uncertainty and disempowerment responding to ethnic diversity in health care: a qualitative study. *PLoS Med* 2007; 4(11): e323.
- 37. **Goldsmith M**, Bankhead C, Austoker J. Improving the quality of the written information sent to women about breast screening: evidence-based criteria for the content of letters and leaflets. NHSBSP Publication No 64, 2007.
- 38. **Goldsmith M**, Bankhead C, Austoker J. Improving the quality of the written information sent to women about breast screening: guidelines of the content of letters and leaflets. NHSBSP Publication No 65, 2007.
- Lakani M. No patient left behind: how can we ensure world class primary care for black and ethnic minority people. Leeds: Department of Health, 2007: 26.www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuid ance/DH_084971 (accessed 12 July 2010).
- 40. http://www.cancerresearchuk.org/aboutus/whoweare/ourgoals/ (accessed 12 July 2010).
- 41. **Sadler G**, Dhanjal S, Bhatia N, Shah RB, Ko CM, Anghel M, Harshburger RJ: Asian Indian women: knowledge, attitudes and behaviors towards breast cancer early detection. *Journal of Public Health Nursing* 2001, 18:357-362.