Ethnicity: UK Colorectal Cancer Screening Pilot

Final Report

The UK CRC Screening Pilot Evaluation (Ethnicity) Team, May 2004

Address for correspondence:
Professor Ala Szczepura
Faculty of Health and Life Sciences
Coventry University
Priory Street
Coventry CV1 5FB

Email: ala.szczepura@coventry.ac.uk

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Study Team

The study team members are shown below together with their contribution to the research:

- **Professor Ala Szczepura** Centre for Health Services Studies (CHESS), University of Warwick: *Responsible for co-ordination of project, uptake rate analyses by ethnic group and (jointly with MJ) for the literature review.*

- **Professor Mark Johnson** Mary Seacole Research Centre, De Montfort University: *Responsible for focus group study and (jointly with AS) for the literature review.*

- **Professor Sheina Orbell** Department of Psychology, University of Essex: *Responsible for psychosocial survey of invitees to screening.*

- **Dr Anil Gumber** CHESS, University of Warwick: *Conduct of analyses of uptake rates by ethnic group using routine data.*

- **Dr Ian O'Sullivan** Department of Psychology, University of Essex: *Conduct of postal survey of invitees to screening and analysis of responses.*

- **Diane Clay** CHESS, University of Warwick): *Responsible for literature review searches.*

- **Dr David Owen** Centre for Research in Ethnic Relations (CRER), University of Warwick): *Responsible for geographical extrapolation of pilot findings.*

Executive Summary

Background

1. The UK Colorectal Cancer Screening Pilot was established to determine the feasibility of screening for colorectal cancer (CRC) in the UK population using faecal occult blood testing (FOBt). It followed demonstrations of mortality reductions in a UK randomised controlled trial in Nottingham. The Pilot commissioned two sites (one in central England, the other in Scotland) to confirm that the uptake of FOBt screening achieved in the trial settings (60%) could be repeated in population-based programmes.

2. CRC screening differs from cervical and breast screening in that it is undertaken by the individual themselves, and patient compliance requires that individuals follow instructions, complete a home kit (FOBt) over a period of time, and mail this to the laboratory. If the FOB test proves positive, this is then followed by an invitation to attend a local hospital for a diagnostic procedure (colonoscopy).

3. A major evaluation of the Pilot was commissioned in 1999. The brief of the main Evaluation Group was to produce an independent report for the Department of Health on the outcomes of screening in the Pilot.

4. A separate study focusing on potential issues for ethnic populations associated with the introduction of CRC screening was commissioned two years later in 2001. This research, led by the University of Warwick, was conducted in the English site only (i.e. Coventry and Warwickshire), since the ethnic minority population in the Scottish Pilot area was very small. The main ethnic minority population groups in the English pilot site were of South Asian origin; the African-Caribbean population was much smaller and geographically dispersed.

5. Our study adopted a multi-disciplinary approach. The research team brought together individuals with a range of academic expertise including ethnicity, epidemiology, psychology, and health services research. The team comprised academics from the Universities of Warwick, Essex and De Montfort. The team liased closely throughout with the main Pilot evaluation team, led by the University of Edinburgh.

FOBt screening uptake

6. Analysis of FOBt uptake rates for the ethnic minority population living in the Pilot area was dependent on the use of name recognition software (*Nam Pehchan*) since adequate ethnic monitoring data were not available. This method could not distinguish African-Caribbeans. But since this was the only method available to us, South Asians constituted the largest ethnic minority population in the English Pilot site, and there was evidence from the literature indicating adequate uptake of other UK cancer screening programmes by African-Caribbeans (unlike for South Asians), this was viewed as an acceptable strategy for analysing ethnic uptake rates using the Pilot site routine dataset.

7. The findings of the main evaluation demonstrate that it was possible to achieve an overall FOBt screening uptake in the two locations close to the target of 60%. Uptake was slightly lower in Scotland than in England. Since the observed screening outcomes in the UK Pilot overall generally compared favourably with the results of the Nottingham trial, this has led the main Evaluation Group to conclude in its February 2003 Final Report that the benefits observed in the trial setting should be repeated in a national roll-out.

8. However, our research indicates that the apparently acceptable overall uptake figure we calculate for the English site (62.2%) masks a significantly lower uptake for the South Asian community, with FOBt uptake figures (i.e. return of an initial kit) up to half as low as for non-Asians. Of major concern is the particularly low uptake rate in the Muslim community (31.9%), compared to 63.7% for the non-Asian population. Even for the highest uptake Asian group (Hindus) only a 43.7% level was recorded. There was no indication of an initial unwillingness to be screened among the Asian community, in fact levels of FOBt refusers were lower than for non-Asians.

9. Multivariate analysis confirms that the observed low uptake of FOBt screening in the Asian community cannot be explained by differences in other factors such as age, gender, date of screening invitation, or deprivation index. The likelihood of uptake of screening remains two and a half times lower among Muslims and Sikhs, and about twice lower among Hindus even if these other factors are taken into consideration.

10. As well as estimating the FOBt uptake rates for the South Asian population groups, the views of a wider variety of religious and linguistic/cultural groups, including African-Caribbeans, were researched using focus groups. These demonstrated that the majority of concerns were shared by different groups[1]. Furthermore, once explained, the minority communities appeared to be highly positive about the CRC screening programme. Nevertheless, certain themes recurred. In particular, there were low levels of knowledge and awareness of bowel cancer and CRC screening indicating a requirement for improved educational interventions. Certain other issues (such as literacy levels varied between groups and may indicate the requirement for more targeted interventions for particular population groups.

11. A psychosocial survey of the ethnic population invited to FOBt screening indicated that Asians perceive their susceptibility to CRC as lower, and they also appear to be less aware of bowel cancer. Although confidence in colorectal cancer screening effectiveness was generally high, Asians were less confident than non-Asians. Notably, also, neither perceived susceptibility nor perceived severity of bowel cancer is associated with FOBt uptake amongst Asians.

12. From responses to the psychosocial surveys, the most important factors affecting FOBt response amongst Asians related to the ease or difficulty of completing the kit. Muslims reported particularly low self-efficacy with regard to completing the kit.

13. Analysis of routine data also indicated that as well as having a lower FOBt uptake, significantly more individuals in the Asian community were recorded as being ‘under process’. Linked to this, a higher proportion of Asians had been sent 4 or more kits (6.8% to 27.7%, compared with 3.4% for non-Asians). These figures may be indicative of problems in the Asian community with understanding how to use the kit, or with other mechanical aspects of the process of testing.

14. Our research also provides some evidence that FOBt uptake rates are significantly lower for individuals (regardless of ethnicity) registered with an Asian GP. The situation is found to be worst for Muslim subjects registered with a Muslim GP (only 23% returned a kit). This may indicate a need for interventions targeted at practices, as well as individuals, in order to improve FOBt uptake.

Colonoscopy uptake and cancer detection

15. If the FOB test proves positive, this is then followed by an invitation to attend a local hospital for a diagnostic procedure (colonoscopy). The English Pilot demonstrated an overall 72.8% attendance rate for colonoscopy.

16. However, colonoscopy uptake rates were once again found to be significantly lower among Asians (54.9% compared with 74.4% for non-Asians). Uptake figures ranged from 43.5% to 64.7% in the Muslim and Sikh communities respectively. Multivariate analysis shows that the colonoscopy uptake rate for the Asian community is half to one third of that for non-Asians, even once other factors such as deprivation are taken into account. A much higher proportion of South Asians with a positive FOBt result (19.6% vs 8.3% for non-Asians) were recorded as refusing to continue to colonoscopy.

17. Overall rates of detection of cancers and potentially pre-malignant lesions (e.g. adenomas) in both sites compared favourably with data from the Nottingham trial.

18. An overall neoplasia detection rate of 407 per 1,000 FOBt positives was calculated for the English Pilot site population overall. This positive predictive value (PPV) compares favourably with the Nottingham trial value. However, the PPV was much lower (157 per 1,000) among Asians.

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[1] Gujerati, Bangladeshi (Bengali), Pakistani/Urdu (Kashmiri), Punjabi Sikh, African-Caribbean, and Vietnamese/ Cantonese.

19. PPV increased with advancing age, and was higher in males, once other factors were taken into account. The influence of deprivation was, however, found to be insignificant. Our multivariate analysis also confirmed a significantly lower PPV in the Asian community. This would be anticipated because most South Asian groups are at lower risk than White-Europeans, but it may also be partly linked to lower colonoscopy uptake rates among Asians who are at higher risk of CRC e.g. Muslims (red meat eaters).

Implications for UK roll-out of CRC screening

20. Modelling, using the English Pilot Site data, has enabled spatial predictions of uptake rates in other parts of the UK. In England, the unitary authorities with the lowest[2] predicted uptake rates are those with the largest percentages of their populations from minority ethnic groups (e.g. Tower Hamlets and Newham (45.5% and 45.6% uptakes predicted). The overall pattern is of higher predicted rates in suburban and rural areas and lower predicted rates in the inner cities, especially in Inner London (53.4%), Leicester (49.4%) and Birmingham (51.3%). Although ethnicity influences the geographical pattern of predicted screening uptake in England, with the areas of lowest uptake having largest Asian minority populations, ethnic origin has a much smaller effect in Wales, Scotland and Northern Ireland.

Available published research evidence base

Uptake levels

21. A review of the existing research evidence on ethnic minorities and cancer screening, particularly colorectal cancer screening, was undertaken as part of the study; 727 papers were identified, including international literature on CRC screening and UK papers on breast/ cervical screening and ethnic minorities.

22. The literature on CRC screening and ethnic diversity is dominated by studies from the United States of America. There is consistent evidence of low CRC uptake by ethnic minorities, although the ethnic groups studied in the USA are different from those of interest in a European or UK settings. Low levels of knowledge of colorectal cancer, poor knowledge and understanding of tests and screening procedures, and low accuracy in terms of risk perception are consistently reported among ethnic minority groups. There is also evidence that, for established minority populations (e.g. African Americans), 'ethnic' differences remain an important factor associated with low FOBt uptake even once socio-economic status is taken into account; and that acculturation (including language fluency) is a key factor limiting FOBt uptake for immigrant populations. For colonoscopy, an important influence on uptake by ethnic minority groups appears to be physician recommendation.

23. Analysis of the UK literature on cervical and breast cancer screening provides similar, consistent evidence of lower screening uptake for South Asian women. Early studies identify poor record keeping, language needs, inferior knowledge of the screening service, professional perceptions and poor communication as important barriers to uptake. Later papers continue to report lack of knowledge and the need for active physician encouragement. None of these studies have examined uptake corrected for women’s socio-demographic characteristics. More recent research (2001) appears to indicate that observed early low uptakes of both cervical and breast cancer screening by South Asian women have not yet been rectified.

Interventions to improve uptake

24. Published research on interventions to improve CRC screening uptake in ethnic minority populations is extremely rare. Only two intervention studies were identified, both from the USA. Neither was a randomised controlled trial, both targeted mixed populations (predominantly African American women, and only one intervention was reported to be effective in improving FOBt uptake (an educational intervention adapted for older people). Neither study considered cost-effectiveness.

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[2] These extrapolations should be treated with some caution at present since the amount of ethnic-specific data that can be derived for Census Enumeration Districts (EDs) is limited, and these extrapolations were largely based on the 1991 Census data. Furthermore, in terms of ethnic minority groups only South Asian uptake by ED could be considered because of the very dispersed geographical distribution of African Caribbean people.

25. The UK literature reports a large number of trials (the majority RCTs) evaluating interventions to improve uptake of cervical/ breast screening by South Asian women (the majority for breast cancer). Reminder letters appear to have a limited role in improving uptake, and there is little robust evidence that home visits by a linkworker are effective in improving screening uptake.

26. More complex, multi-strategies are identified as likely to provide the best approach to improving uptake. These include practice receptionist training, GP follow-up letters in various languages, offer of transport, health advocates on site, and screening mobile units (breast) available for longer. Large increases in uptake (reaching 59% for breast screening and 87% for cervical screening) have been reported by a number of studies. However, these studies have not used a randomised controlled trial design and the cost-effectiveness of such multi-strategy interventions has not been measured.

Conclusions

27. In summary, the overall evaluation of the UK Pilot has demonstrated that key parameters of test and programme performance observed in randomised studies of FOBt screening can be repeated in population-based pilot programmes. However, our study provides strong evidence of very low CRC screening uptake for ethnic groups in the Pilot area. This is coupled with a very low uptake of colonoscopy for individuals from ethnic groups with a positive FOBt result.

28. It has long been acknowledged that a diverse population may require diverse responses. Following the implementation of the Race Relations Amendment Act 2000, there has been a statutory duty laid upon all NHS agencies to ‘have due regard to the need to eliminate unlawful discrimination’, and to make explicit consideration of the implications for racial equality of every action or policy.

29. Because the observed overall outcomes in the UK Pilot generally compare favourably with the results of previous randomised trials of FOBt screening, the main Evaluation Group has concluded that benefits observed in the trials should be repeatable in a national roll-out.

30. However, our study indicates that any national colorectal cancer screening programme would need to very carefully consider the implications of ethnicity for roll-out, and develop a strategic plan on how best to accommodate this at both a national and local level. Based on our findings, consideration will clearly need to be given to improved access and screening service provision for ethnic minorities.

31. In order to ensure adequate CRC screening provision for a diverse UK population, and to address the explicit implications for racial equality highlighted by our findings, interventions now urgently need to be evaluated to improve access for ethnic minorities. This work should be undertaken as part of the second round of CRC screening currently underway in the English Pilot.

1. The UK Pilot and the Evaluation of Ethnic Access

This report was commissioned by the Department of Health to inform decision making on the implementation of a national screening programme for colorectal cancer (CRC).

The main aim of the primary research was to gather and assess the research evidence on differences in access and uptake of screening by CRC minority ethnic groups, and possible reasons for these. In addition, the research team undertook a review of the literature in order to provide further insights into inequalities in access to cancer screening for minority ethnic groups, and interventions that could possibly help to reduce these. The team also considered the demographic profile of geographical areas in England and Wales, and how this might be predicted to influence uptake of CRC screening locally. Finally, the study team also aimed to identify any key gaps in the available evidence in order to inform future decisions on research priorities.

It is recognised that a diverse population requires diverse responses. Following the implementation of the Race Relations Amendment Act 2000, there has been a statutory duty laid upon all NHS agencies to 'have due regard to the need to eliminate unlawful discrimination', and to make explicit consideration of the implications for racial equality of every action or policy. Our study has highlighted a range of issues which will be relevant to planning for roll-out of CRC screening, and potentially for existing cancer screening programmes. Clearly one of the aspects which will influence the perceived success of any national CRC screening policy will be its success in addressing the question of improved access and service provision for ethnic minorities.

1.1 Background

The Colorectal Cancer Screening Pilot arose from a recommendation from the National Screening Committee (NSC), following an appraisal of evidence about primary and secondary prevention of colorectal cancer. This appraisal led to the conclusion that the quality of evidence in favour of faecal occult blood test (FOBt) screening was sufficiently high for policy recommendations to be made. The NSC recommended the establishment of a Pilot, conducted at two sites, to assess the effectiveness of screening for colorectal cancer using the FOBT. The Pilot has been conducted at Tayside, Grampian and Fife in Scotland and the West Midlands; Coventry and Warwickshire in England. This is the final report from a multidisciplinary inter-university evaluation commissioned by the Department of Health to address issues associated with ethnicity and colorectal cancer screening.

Screening began in early 2000. Routine data from the Pilot sites were downloaded to the evaluation group on a monthly basis. Approximately 490,000 people have been offered screening at the two sites. Data collection for the present study was limited to the English pilot area since the Scottish pilot site did not include a significant ethnic minority population.

The overall aims of the study were to:

- review the literature on cancer screening uptake and ethnic minority groups;
- examine colorectal cancer (CRC) screening uptake rates by ethnic group in the English Pilot site;
- extend the main evaluation psychosocial analysis to include a survey of ethnic minority invitees to screening, and to conduct focus groups with ethnic minority groups to explore uptake issues;
- extrapolate the English Pilot site findings to populations in different geographical locations in the UK in order to provide indicative data for roll-out on the likely impact of population diversity on CRC screening uptake in different areas.

This final report provides results from our analyses of routine data downloaded from the Pilot site, from special surveys and focus groups conducted by our research team, and from modelling of projected uptakes nationally. We consider, in separate chapters: the available research evidence on ethnicity and cancer screening; uptake and acceptability of FOBt screening by the diverse population; uptake of colonoscopy; screening outcomes (neoplasia and cancer detection rates); projected uptake of CRC screening in different UK locations. Within most of these chapters a multidisciplinary approach has been followed with results from different methods and/or addressing specific topics presented as separate sections, each with its own discussion. Each chapter ends with its own ‘Conclusions and Recommendations’ section. In the final chapter we provide a summary of our findings, and a description of future research that is urgently needed now that the first round of the UK Pilot has ended, including a study to identify and evaluate a cost-effective intervention to improve uptake of FOBt and colonoscopy by the South Asian population.

1.2 Structure and Functions of the Pilot Sites

Two sites were established following a competitive commissioning process. Both sites have had lead clinician/Directors (Ron Parker in England and Bob Steele in Scotland) and Managers (Pat Ramsell & Sue Elwell in England, and Linda Bradley & Carolyn Smith in Scotland). The screening centres have comprised teams of clinical and support staff including nursing staff, office managers and data managers. Both sites have worked within the framework of their national screening offices. In England, this has been under the direction of Julietta Patnick and the project manager has been Kathryn Robertshaw. In Scotland it has been under the direction first of Jan Warner and then Carol Colquhoun, and the project manager has been Carole Morton.

The Pilot sites were commissioned in 1999, and were required to undertake all of the necessary developmental work to commence screening in early 2000. The Scottish Pilot site commenced screening in March 2000 – it comprises a central laboratory based at King’s Cross Hospital in Dundee . The English Pilot site commenced screening in September 2000; it is based at Hospital of St. Cross, Rugby. The two Pilot centres have largely followed the same screening protocol (which was determined as part of the commissioning process). All of the tests and associated information were sent to the target population from the screening Units. All FOB test kits were returned to the Units for testing and results sent to the individual direct from the office. Following an overall positive result individuals were provided with an appointment to see a specialist nurse to explain the result and the implications of further diagnostic investigations. In the first instance this has been colonoscopy, with barium enema undertaken if the colonoscopy has been incomplete.

There were some procedural differences between the two sites, particularly relating to the scheduling of appointments and provision of information on results of tests and investigations. In England, all individuals were invited for an appointment with a nurse, regardless of their FOBt result. However, part-way through the course of the Pilot it was considered that appointments for test-negative individuals were not generally being taken up and, indeed, that the invitation may cause unnecessary anxiety. The protocol was, therefore, changed to only offer appointments to test-positive (or weakly positive) individuals. All participants who underwent colonoscopy (or other investigation) were also given a nurse appointment to provide the results of this procedure.

In Scotland, test results were also sent to participants, and those with ‘positive’ results were offered a nurse appointment. Nurse appointments were not routinely offered post-colonoscopy.

1.3 Population Diversity

The Department of Health, along with other major Departments of State in the Government and its executive bodies have recognised that issues of ‘race’, ethnicity and diversity are among the most pressing priorities for action in terms of combating disadvantage, discrimination and social exclusion. The commitment of the leadership to change has been demonstrated in a number of reports and policy pronouncements since the publication of the Chief Medical Officer’s report (Calman 1992). This was recently underlined in terms of both service delivery and human resources in The Vital Connection (Department of Health, 1999). The publication in the summer of 2000 of the new NHS Plan also focused attention on particular areas for action, including inequalities in health linked to ethnic and racial diversity. In particular, Chapter 13 of the NHS Plan discusses the fundamental priority attached to improving health and reducing inequality. This includes ‘recognising the specific health needs of different groups...’ (para 13.2); tackling inequalities in access experienced by people in minority ethnic communities (sometimes described as the ‘inverse care law’: para 13.8), and setting explicit targets. Access to services for ethnic minority populations has recently been shown to be an important issue in a broad range of health care provision, including health promotion activities (Atkinson M et al 2001).

The relevance of the issue of ethnicity and diversity to the possible implementation of a third national cancer screening programme, and to those planning provision of screening at a local level, should be readily apparent.

1.3.1 ENGLISH PILOT SITE

At the outset of the study, a preliminary analysis was carried out using corrected Census data in order to estimate the approximate total numbers of each ethnic minority group available for invitation for colorectal cancer screening in the English Pilot site area. This analysis was based on the number of individuals on practice lists in the requisite age range, practice postcodes, and 1991 Census data adjusted for the "under-count" using factors calculated by the ESRC-sponsored "Estimating With Confidence" project and made available on the MIMAS national computing service at Manchester.

The results indicate a South Asian population in this age range of over 10 thousand, or 2.8 per cent of all people aged over 50 in 2001 (see Table A1.1 in Appendix A1). The minority population of Coventry and Warwickshire is geographically concentrated, being predominantly located in Coventry (mainly the north-east quadrant of the city), Nuneaton, Rugby and Warwick district (mainly Leamington) see Figure 1.3.1 (and Table A1.2 in Appendix A1). The total size of the minority population in different areas is represented by the size of the circles. Within each area, the size of each ethnic group is represented by the size of segment. The Figure demonstrates that the South Asian population is much larger than the African-Caribbean in the Pilot site (Coventry and Warwickshire), and the Table indicates that it is also more geographically concentrated whereas the African Caribbean population is much more widely dispersed.

1.3.2 DEFINITION OF ETHNICITY USED IN STUDY

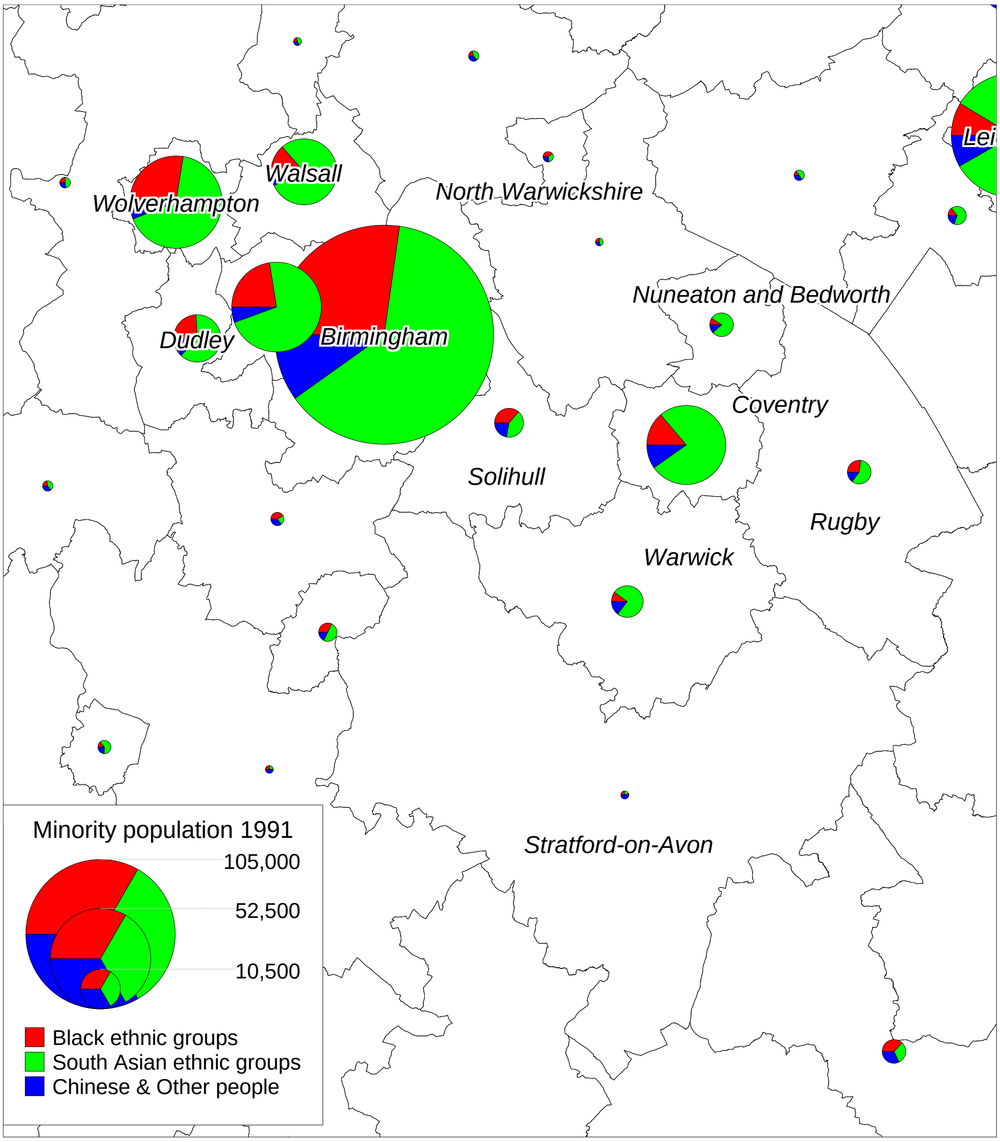
There are many ways of defining an 'ethnic minority' (Pringle *et al* 1997), and there has been considerable debate and controversy about the categories in use within the NHS (Bhopal 1991, Ahmad, Sheldon and Stuart 1996, Sheldon and Parker 1992, Aspinall 1995, McKenzie and Crowcroft 1994). The crucial point made by many authors is that the categorisation used must be 'fit for purpose' i.e. it must be relevant to the delivery of the service being considered and to the recognition of client need.

> The trouble with using nationality, birthplace, ethnic origin or language spoken at home as indicators of ethnic categories is that this implicitly assumes that such criteria all refer to the same clear-cut entities .... It is more effective to use different criteria to pursue different policy objectives ...
> (Vermeulen 1997: 12)

In approaching the issue of ethnicity in the present study we have taken account of the evolution of ideas and terminology in this area (see Appendix A2 for more detailed discussion).

(i) We were unable to utilise ethnic monitoring data on the ethnic origin of individuals registered with general practices who were invited to attend for screening. This was due to the inadequate ethnic monitoring data available in primary care.

Figure 1.3.1: Minority composition of Coventry and Warwickshire districts, 1991



(ii) Birthplace has not been used in the present study, apart from as a possible explanatory variable in modelling uptake rates by enumeration district in Chapter 6. This is because birthplace provides a poor indicator of cultural or 'ethnic' origin. It is now estimated that less than 40% of the black and minority ethnic population can be identified by birthplace, and increasingly few by the birthplace of their parents.

(iii) Where possible we have utilised the 'ethnic group' categories used in the 1991 census data, against which some baseline for comparison can be established. These have been refined for the 2001 Census (see Table 1.3.1).

(iv) Other indicators of ethnicity include: language and religion. Language can be seen to relate directly to the needs of a person in terms of a requirement for interpreting and translation services. Religion may also play an important part in the response to services such as screening, as well as influencing diet (e.g. red meat eating) and therefore risk of colorectal cancer. We have therefore used both of these indicators in our analysis.

(v) Data on ethnic groups can be aggregated at various levels (Modood 1997) and considerable differences can exist even within the meta-category (broad level of aggregation) of 'South Asian' i.e. between sub-categories such as 'Indian' (which in Britain may include Sikh Punjabis, Muslim Gujeratis and Hindus of various linguistic origin as well as other smaller groups), and the predominantly Muslim Bengali or Bangladeshi group whose health status is almost invariably shown to be less advantaged. We have therefore, where possible, used these sub-categories, rather than broad meta-categories such as 'South Asian'. In some cases this level of analysis was not possible because of limited sample size (e.g. malignancy rates).

In general, we have taken a pragmatic approach to defining ethnicity and we have used the most appropriate indicators available in a particular situation.

The response of individuals to the screening invitation (uptake rate) had to be estimated by analysis of routine data without the benefit of ethnic monitoring data being available. We therefore used a name recognition software package (*Nam Pehchan*[3]) to identify the religious and linguistic background of invitees. The *Nam Pehchan* computer programme was developed by Bradford City Council and Health Authority in the 1980's. It contains a dictionary of South Asian names that are matched against the complete name or the name stem (usually the first five characters of an individual's name) in order to provide a list of South Asians together with a language and religion marker for each person.

Five distinct religion-language groups are currently[4] identified: Hindu-Gujerati, Hindu-Other, Muslim, Sikh and Other Asian. Table 1.3.2 shows that, besides the difference in their language and religion, other important features distinguish these groups from one another such as the nature of their diet (vegetarian, non-vegetarian, consumption of red meat etc.) and their literacy levels. The rest of the population is categorised as 'non-Asian' by the software since name recognition software cannot be used to distinguish ethnic groups whose members do not have distinctive names e.g. African Caribbeans. However, since the South Asian population is much larger than the African-Caribbean population in the English Pilot site, this was viewed as an acceptable strategy.

Focus groups were held with a broad range of ethnic groups, including African Caribbeans, in order to counter-balance any shortcomings due to the constraints imposed on the analysis of routine data and the conduct of the psychosocial survey.

Usually, the level of refinement discussed above is not apparent in the literature we have reviewed.

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[3] The *Nam Pehchan* programme has been assessed for sensitivity and positive predictive value in populations from Yorkshire and the Thames region (see Cummins et al. An assessment of the Nam Pehchan computer programme for the identification of names of south Asian ethnic origin. *Journal of Public Health Medicine.* 1999 Vol 21, No 4, pp 401-406).

[4] A new version due for completion in 2003 will distinguish other groups e.g. Chinese.

Table 1.3.1: Categories of ethnic group recorded in the UK Censuses of 1991 and 2001

1991	**2001**
White	White – British
	White – Irish
	White – Any other White background (please write in)
(Other...)	Mixed – White/Black Caribbean
	Mixed – White/Black African
	Mixed – White/Asian
	Any other mixed background (please write in)
Black- Caribbean	Black or Black British: Caribbean
Black- African	Black or Black British: African
Black- Other (Please describe)	Black or Black British: Any other background (please write in)
Indian	Asian or Asian British Indian
Pakistani	Asian or Asian British Pakistani
Bangladeshi	Asian or Asian British Bangladeshi
Asian- Other (Please describe)	Asian or Asian British Any other background: (please write in)
Chinese	Chinese or Other Ethnic group Chinese
Any Other Ethnic Group (Please describe).	Chinese or Other Ethnic group Any other: (please write in)

(Adapted from ONS forms: reproduced with permission)

Table 1.3.2: Characteristics of Ethnic Groups Identified by Nam Pehchan

Ethnic Group	***Characteristics***				
	% Population 50-69 yrs Born Abroad	**Language**	**Religion**	**Diet** Male Female	**Literacy#** Male Female
1. Hindu-Gujerati	>95%	Gujerati	Hinduism	M: Vegetarian F: Vegetarian	M: Good F: Fair
2. Hindu-Other	>95%	Hindi/ Bengali	Hinduism	M: Mostly veg F: Vegetarian	M: Fair F: Poor
3. Muslim	>90%	Urdu	Islam	M: Non-veg* F: Non-veg*	M: Fair-poor F: Very low
4. Sikh	>90%	Punjabi	Sikhism	M: Non-veg* F: Vegetarian	M: Fair F: Poor
5. Other Asian	>95%	Mixed	Mixed	M: Mostly veg F: Mostly veg	M: n/a F: n/a

Literacy levels are discussed further in Appendix A3

* Diet includes red meat

1.4 The Evaluation Process

The evaluation team

The evaluation of ethnicity was commissioned by the R&D Directorate of the UK Department of Health, following the commissioning of a major evaluation of both Pilot sites. The present research required a multi-disciplinary approach to address this complex and sensitive topic and the evaluation team brought together individuals with the range of expertise necessary to do this; the report includes input from a range of disciplines and academic areas, including ethnicity, epidemiology, psychology, and health services research. The main evaluation of the Pilot was commissioned in late 1999. This separate component focusing on issues of ethnicity was commissioned two years later in October 2001.

The evaluation team comprised individuals from the Universities of Warwick, Essex and De Montfort. The project was coordinated from Warwick and face-to-face meetings of the research team were held periodically to share information and monitor progress, with communication via email and telephone between these meetings.

Accountability and interactions

The study team collaborated closely throughout this research with the main Pilot evaluation group, led by the University of Edinburgh. Two members of the current study team were also members of the main evaluation team (AS & SO).

The research was also carried out in close association with the English Pilot site; in particular, support was provided for mailing of the psychosocial survey, and for confirming ethnic malignancy rates calculated from the data downloads.

Our main accountability has been to the R&D Directorate, UK Department of Health. We have also provided progress reports for the meetings of the DoH's Advisory Group for the main evaluation, which comprises a group of experts with relevant fields of expertise. We have also held periodic meetings and discussions with Dr Ursula Wells in the Department of Health which have been of considerable value.

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2. Available Evidence on Ethnicity and Cancer Screening

Chapter Summary

- A literature review of research on ethnic minorities and their response to colorectal cancer (CRC) screening, and to cervical and breast cancer screening within the UK, identified 737 papers. A minimum dataset was extracted from all their abstracts. Based on these, 47 key papers were identified and reviewed in full; these included 20 studies of CRC screening and 27 articles describing UK studies of cervical or breast cancer screening.

CRC Screening and Ethnic Minorities

- The majority of CRC screening studies were from the United States of America, reflecting the routine use there of racial/ethnic categories in data, and attention to ethnic diversity issues in all research. Studies consistently identify low FOBt uptake levels for ethnic minorities, both established populations (e.g. African Americans) and immigrants.

- Where studies have examined FOBt uptake and socio-demographic factors such as income and education level, it is reported that these cannot fully explain the variations in ethnic uptake, especially for older people. There is also evidence that acculturation (including language fluency) is a key factor limiting FOBt uptake for immigrant populations. For colonoscopy, an important influence on uptake by ethnic minority groups appears to be physician recommendation.

- Research evidence on effective interventions to improve CRC screening uptake is lacking. Only two intervention studies were identified, both from the USA and neither a strong study design.

- In general, papers reporting interventions to increase uptake of cancer screening among ethnic minorities primarily focus on provision of free access (relevant in USA) and/or peer-supported means of raising awareness and acceptability, although none provided adequate examples of structured evaluation.

UK Breast/ Cervical Cancer Screening Studies and Ethnic Minorities

- UK literature provides consistent evidence of lower cervical and breast cancer screening uptakes for South Asian women. African-Caribbean uptakes do not appear to be depressed. There is little evidence for other groups e.g. Chinese.

- Early studies identified poor record-keeping by health agencies, language needs, poor knowledge of the screening service, and a failure of communication by health professionals as important barriers to uptake for South Asian women. More recent research indicates that early differences in uptake for both cervical and breast cancer screening have not yet been rectified.

- The UK literature contains a reports of several trials (the majority RCTs) of interventions to improve uptake of cervical/ breast screening by South Asian women. Reminder letters appear to have a limited role in improving uptake, and there is little robust evidence that home visits by a linkworker are effective in improving screening uptake either.

- Multi-strategies (including practice receptionist training, follow-up letters in various languages, offer of transport, health advocates on site) have been reported to produce larger increases in screening uptake, although the cost-effectiveness of such complex interventions has not been measured.

2.1 Literature Review Approach

In the first instance, a review was undertaken of the available literature on ethnic minorities and their response to colorectal cancer screening (and to cervical and breast cancer screening within the UK). The main aims were to identify any research that might provide supportive evidence for the findings of our own analyses, surveys and focus groups, and to highlight any research gaps remaining. The literature reviewed included articles reporting ethnic minority uptake of cancer screening, papers discussing barriers to uptake for different ethnic groups, and research evidence demonstrating the effectiveness and cost-effectiveness of any interventions designed to improve minority population uptakes.

2.1.1 REVIEW OBJECTIVES AND FRAMEWORK

In this review we addressed the following hypotheses:

1. Differences exist in the uptake of colorectal cancer (and breast and cervical) screening programmes by ethnic minority populations and these differences cannot be explained solely by socio-economic / demographic factors;
2. Identifiable barriers exist that limit the uptake of cancer screening programmes by ethnic minority groups and these might be addressed through tailored interventions;
3. Interventions tailored to the needs of ethnic minority groups can significantly improve uptake rates for cancer screening programmes;
4. Interventions to improve uptake of cancer screening by ethnic minority populations are cost-effective.

The review encompassed all methods recommended for colorectal cancer (CRC) screening in different countries, from screening tests (e.g. FOBt, flexible sigmoidoscopy) to diagnostic investigations (e.g. colonoscopy). Since most of the CRC literature identified is from the USA, of particular interest are the American Cancer Society (ACS) recommendations that beginning at age 50 both men and women should have: annual FOBt (double sample at home procedure) and a flexible sigmoidoscopy (FS) every 5 years with other screening techniques also possible e.g. colonoscopy, repeated every 10 years, or double contrast barium enema (DCBE), repeated every 5-10 years. These guidelines are essentially in agreement with those of the US Preventive Services Task Forces, as well as those of the American Gastroenterological Association.

Other cancer screening programmes were also considered, although there are differences which might limit the generalisability of findings to CRC screening. The two current population cancer screening programmes in the UK differ in their organisation and delivery, and the behaviour required for compliance (or patient concordance), both of which may influence recruitment and retention for ethnic minority groups. In terms of organisation, cervical cancer screening is usually undertaken by GPs; patient concordance requires that women attend their family practice for a smear to be taken. In contrast, breast screening is carried out by professionals in mobile mammography units, and compliance requires that women attend at a specified location and time, not necessarily at the site of their family practice. Both screening programmes exclude men, so studies of these programmes can provide no evidence of how the UK male, ethnic minority population would respond to the offer of CRC screening.

CRC screening differs in that it is undertaken by the individual themselves (male or female); patient concordance requires that invitees follow instructions, complete a home kit (FOBt) over a period of time, and mail this to the laboratory. If the FOB test proves positive, this is then followed by an invitation to attend a local hospital for a diagnostic procedure (colonoscopy). To complete colorectal cancer screening successfully, therefore, an individual must complete several steps. Achieving maximum benefit also requires repetition (i.e. of the FOBt) at specified intervals and this may increase the potential for non-compliance.

2.1.2 REVIEW INCLUSION CRITERIA

Papers were considered for inclusion in the review if they met the following four primary inclusion criteria:

1. included an abstract (so that a decision could be made on content);
2. considered cancer screening **and** specified ethnic minority groups (even if ethnicity was defined at a crude level e.g. ‘black’,);

3. **either** reported research findings on screening uptake patterns **or** identified barriers to uptake **or** reported evaluations of interventions to improve uptake.
4. **either** presented UK based findings **or** generic findings that might be relevant to the UK.

No study designs were excluded from the review; papers therefore included randomised controlled trials, controlled clinical trials, quasi-experimental, pre-test post-test design studies, observational studies and qualitative research.

Because of the very large number of articles identified, a further inclusion criterion was defined as follows. To be included in the final detailed review, a paper had to:

5. **either** report research findings on ethnic minorities and *colorectal cancer screening* (in any country) **or** screening for cervical or breast cancer *in the UK;*

Thus, the review focused on international studies of CRC screening (wherever conducted), but only UK articles on other forms of cancer screening (i.e. breast and cervical cancer), since these are now both well established programmes in the NHS.

2.1.3 LITERATURE SEARCH STRATEGY

Search strategies for electronic databases were developed using selected MeSH terms and free text terms relating to ethnicity and screening. These terms were reverse-engineered from known studies by examining the terms under which they had been indexed. A search strategy was tested and refined for each database. Articles were limited to English language publications. Searches covered the period 1993 on for most databases.

The following electronic databases were searched:
(a) The Cochrane Clinical Trials Register and the Database of Abstracts of Reviews of Effectiveness.
(b) Medline, Embase, CINAHL, AMED.
(c) The NHS National Research Register (NRR), HMIC (including King's Fund, Nuffield Institute etc), HTA, and the NHS Economic Evaluation Database (NHS EED).

Additional papers were located by hand, or through examination of the bibliographies of retrieved articles. A small amount of grey literature was also identified.

2.1.4 DATA COLLECTION AND ANALYSIS

All articles located by the literature search were reviewed for potential relevance. Each abstract was assessed by two reviewers independently to see whether the paper met the 4 primary inclusion criteria listed above; any disagreements were discussed and agreement reached in all cases. Details of all these articles were entered on a bibliographic register of papers of interest. These papers were then examined to identify any articles that met the final inclusion criterion for full review. Full text copies of all such papers were obtained.

A minimum dataset (MDS) sheet was use to extract summary information for all articles selected. This included information on: the type(s) of cancer; country of study; descriptors of the study populations (gender, ethnic group, religion, non-English language); whether a 'white' comparator was included; whether confounding socio-demographic factors were considered; type of study design; brief details of key research findings; and free text comments.

For uptake studies, where possible we report the main results in natural units, with absolute differences and 95% confidence intervals or p values stated. For intervention studies, given the variety of study designs, settings, participants, and intervention types, a quantitative meta-analysis was clearly inappropriate. For an individual intervention to be considered positive, it had to show a statistically significant improvement in a targeted screening activity (either an increase in intended screening uptake or an improvement in actual uptake), improved patient outcomes or reduced cost of screening.

2.2 Overview of Papers

2.2.1 NUMBER, TYPE AND LOCATION OF STUDIES FOUND

The total number of studies potentially of interest, identified by the searches of electronic databases, exceeded 1,000 papers. After reviewing their abstracts using the first 4 inclusion criteria, 737 articles of likely interest were identified and their details were entered on the bibliographic register (see Appendix A8). A sub-set of 47 papers were selected for full review using the final inclusion criterion. Of these, 20 were reports of international studies of colorectal cancer screening and the remaining 27 papers presented findings of UK studies related to cervical or breast cancer screening and ethnic minorities.

Papers were excluded for various reasons, including that the study focused on predictive genetic testing rather than screening, that ethnicity was mentioned only in passing, or that screening was for cancers other than CRC, cervical or breast cancer.

2.2.2 GENERAL OVERVIEW OF LITERATURE

The 737 items identified by the literature search all had the agreed minimum dataset or MDS extracted from the abstracts. The MDS data tabulated for all papers is shown at Appendix A9.

Overwhelmingly, and not simply because of the need to rely on the PubMed MEDLINE database, the majority of studies located were based on work undertaken in the United States of America – over 66% were clearly restricted to North American populations, including a few from Canada. UK studies represented about 13% of the total number of citations found. A small number were also identified from other locations including Finland, Japan, Israel, South Africa, Australia and New Zealand, and the Netherlands. There were also a small number for whom it was not possible to identify the population or country of interest from the abstract, although perusal of the journal title is suggestive that they were largely also of American origin. American papers were by and large well resourced and based on substantial datasets, often part of longer-term programmes or drawing data from major national surveys and data registries. A very substantial number described interventions and their outcomes, although the majority still appeared to be documenting or demonstrating ethnic differences in uptake, prevalence or outcome.

2.2.3 MAIN FINDINGS OF LITERATURE OVERVIEW

For those studies which identified a single-sex study focus, the vast majority (nearly 70%) dealt with female subjects or cancers which are normally regarded as gender-specific to women (i.e. cervical and/or breast), while a small number (under 7%) were specific to 'male' cancer – primarily prostate disease. The remainder were assumed to be, or explicitly said that they were, dealing with whole populations. Out of the total, rather more than half (53%) covered Breast cancer, while nearly a third (30%) focused on Cervical (or in a few cases, unspecified gynaecological) cancers, and in about 12% of the total, papers dealt with both. The next most common cancer was Prostatic (7%) and a slightly higher proportion (8%) covered Colorectal or Bowel cancers. A very small proportion (about 2%) explicitly dealt with a broad range of cancers or 'all forms', and single-figure numbers of papers were identified on screening for skin, oral, liver, endometrial, neurological and lung cancers. There were also a few (16 in all) on ovarian cancer.

The screening techniques addressed in the studies under review were frequently immediately obvious from the type of cancer under study, although in many cases (25%) they were not specified. For cervical cancer research the term 'smear' was used in some cases , and 'pap' (or Papanicolou smear) in others (15%); it was not always clear if a physical examination (pelvic) was included, while Breast cancer studies usually did distinguish between CBE (Clinical Breast Examination) (8%), BSE (Breast Self Examination) (6%)and Mammography (30% of all papers identified). More of the Prostate studies examined PSA (specific antigen testing – 3% of all studies reviewed), slightly more than as considered DRE (Digital Rectal Examination). Very few indeed considered colonoscopy (18 'Sigmoidoscopy') or FOBt (28 – 4%) despite the particular focus and wider inclusion criteria set for the review. A small number were concerned with genetic testing (4%), MRI (Magnetic Resonance Imaging), biochemical tests or fine needle aspiration. These latter tended to be highly technical studies of methodological sensitivity. A small number of studies were included that did not appear from abstracts or title to be about screening, but focused on treatment or other interventions, and epidemiology.

In up to a fifth of the studies retrieved it was not possible to identify precisely which minority ethnic groups were covered or referred to in detail, from the abstracts and titles, although in some cases the term ‘minority’ (or, in USA studies, ‘of color’) was used. A very small number were referring to minorities defined in terms of sexual orientation (primarily lesbian) and almost none made explicit citation of religion as a defining characteristic, although a significant number of USA studies described interventions or approaches using church-based registers or activities. Rather less than a quarter (23%) could be seen from the abstract to use a white comparator, the majority clearly being focused on a single (or in some cases, a small number of) minority group(s). Most, however, considered only Black/African American (33%) or Hispanic (including Latino/a and Mexican American - ~12%) people, although a few did describe the population of interest as including both of these groups. A small proportion of those examining Hispanic population sub-divided these into groups such as Puerto-Rican, Ecuadorian, Mexican or Cuban. Some of these studies also had a white comparison group or were based on population surveys that divided the sample into these three groups (in USA). Using a variety of terms, the next most frequently occurring ethnic group was ‘First Nation’ or Native American (American Indian), and/or other indigenous minorities such as Hawaiian and Pacific Islander, and in most cases being single group studies (Cherokee, Houma, Alaskan, Inuit etc). UK studies were usually into ‘Asian’ (sometimes broken into Indian, Pakistani, Bangladeshi – the three main 1991 census defined groups) or ‘Minority’ (including African-Caribbean and/or Chinese/Vietnamese) with a few micro-studies of one or another of these groups: ‘Asian’ in the USA context normally refers to Korean, Japanese, Chinese or South-East Asian (Khmer, Vietnamese, ‘refugee’) groups. Many of the UK studies did not refer explicitly to, or by design were included despite not being explicitly about, minority groups, or failed to describe which minority they were concerned with. One study used the term ‘non-English speakers’ but otherwise language was exceptionally rarely used as a descriptor or defining characteristic. Language, indeed, tended to refer to Spanish (in studies of Hispanic/Latino groups) although this was not always said.

While we had intended that the MDS tabulation should provide information on other aspects of the studies, in particular whether studies covered language, religion, and socio-demographic factors, it was very rarely possible to ascertain this from the abstract – or it was not included in the reported study design. In most cases those studies which took account of, or controlled for, ‘socio-demographic’ data (about 5%) were North American and were primarily using major national survey datasets, using education, income and access to health insurance as major proxy variables (which are of little direct relevance to UK practice). The findings were, in any case, generally inconclusive or contradictory across those studies, except that it appeared that the clinician/ physician’s tendency to refer was in many cases mediated by his/her perception of the patient’s ability to pay.

We had particularly hoped to identify intervention studies that evaluated the effectiveness of particular interventions. Very few studies were described as randomised controlled trials (RCTs) although a minority (4%) were located which indicated this design. Several of those which were intervention studies proved actually to be describing the protocol for, or the development of, the intervention. These studies did not then provide robust evaluations of the impact, but most of the American intervention studies did so. Overall, the most common form of study located was a survey (not always based on a random sample), representing about a third of all studies located, while about one in five described an intervention. The most common intervention in the USA was community or peer-led education, often through outreach or community-based programmes and activities, while this was also often a recommendation of UK-based studies. American studies also tended to find that provision of free screening had a significant impact, which is less relevant to UK practice. There were a significant number of studies that were best described as ‘audit’ although this term was not used – these were based on the use of administrative data, registers and observation, while other papers simply described ‘good practice’ and the development of projects, and a few were essentially policy or exhortatory papers, sometime based on substantial literature reviews. About 10% of our cited papers were essentially or avowedly literature reviews. Methodological developments were included, and a number of studies (another 5%) used focus group methodology to elicit themes or psychosocial information about barriers to accessing and uptake of services, or as a form of evaluation. A small number of studies used respondents to screening programme invitations as the basis for a survey, often of psychosocial factors in relation to cancer and/or screening, but did not provide information on, or insight into, the motivation of non-attenders and non-invitees.

2.3 Key Papers Selected for Review

The final 47 key papers reviewed included 20 studies of colorectal cancer screening and 27 articles describing UK studies of cervical or breast cancer screening. Articles were collated into two main groups; (i) those reporting differences in uptake, barriers to screening, or differences in knowledge, beliefs, risk perception, and practices; and (ii) papers describing intervention studies or strategies to improve uptake. There were 32 papers in the former category and 15 intervention studies. Articles identified by the literature review process are referenced by their number in the bibliographic register (see Appendix A8). Other articles referred to are listed at the end of the chapter. Minimum datasets for all the key papers reviewed are provided in Appendix A4.

2.4 CRC screening uptake & barriers to recruitment (see Table A4.1 in Appendix A4)

- Most of the papers identified that addressed CRC screening uptake and barriers to recruitment are from the USA. Studies consistently identify low FOBt uptake levels for ethnic minorities, both in established populations (e.g. African Americans) and immigrants. Where studies have examined other socio-demographic factors such as income and education level, these cannot fully explain the observed variations in uptake, especially for older people.

- Non-UK papers generally report that ethnic populations have lower levels of knowledge of colorectal cancer, poor knowledge and understanding of tests and screening procedures, low accuracy in terms of their risk perceptions, and negative attitudes to screening.

- Other factors influencing CRC screening uptake by ethnic minority groups are reported to be language fluency, fatalism, and (possibly) race discrimination.

- For FOBt screening, the two main factors identified as quantitative predictors of uptake in ethnic minority populations include age (>64 years) and acculturation or length of residence.

- For digital rectal examination (DRE), knowledge and length of residence are reported to be predictors of uptake; and for flexible sigmoidoscopy (FS) screening, perceiving fewer barriers and active physician encouragement are reported to be significant factors. For colonoscopy, an important influence on uptake by ethnic minority groups appears to be physician recommendation.

No UK literature was identified on CRC screening and ethnicity. Only one European study was identified, and the remaining papers were either from the USA or Japan. The articles identified mostly focused on FOB testing; only two papers reported on colonoscopy uptake.

In the UK, the Nottingham trial of FOBt screening has demonstrated an overall uptake of 60%, but uptakes for different ethnic minority groups were not estimated (Hardcastle et al 1996). Similarly, a more recent UK randomised trial of mass screening by flexible sigmoidoscopy provides no separate data on ethnic uptakes, and in fact the authors point out that the catchment area used has a lower ethnic minority population than in England and Wales as a whole (678).

The international literature does, however, provide evidence of lower uptake of FOB tests, flexible sigmoidoscopy, and colonoscopy among minority ethnic populations, and it identifies a number of barriers to recruitment and retention of these populations in cancer screening programmes.

2.4.1 EUROPEAN LITERATURE

The one European paper identified (355) was of a randomised CRC screening study in Sweden, started in 1982, in which subjects are offered FOB tests, with two letters of reminder, and those with a positive test result are offered diagnostic follow up with rectosigmoidoscopy and double contrast barium enema. 34,144 subjects were offered re-screening at a 1½ to 2 year interval and overall participation in one or both rounds of screening was 62%. The authors compare uptake among immigrants without Swedish citizenship with that for Swedish citizens. No difference was observed for younger (age < 50 yrs) immigrants, but uptake was lower in the older (age > 64 yrs) immigrant group (44% vs 69% for the whole age group). No details are provided on the ethnic origins of these immigrants. Telephone interviews were held with a random sample of 91 non-responders. These showed that the most common reason for non-response was lack of time or forgetting about the test (26%), test troublesome/unpleasant to perform (20%), disease or disability prevented individuals from participating (18%), or that they had been checked by another physician (20%). The authors suggest that either attitudes to screening or language barriers might be an explanatory factor for the effect observed with the older immigrant group.

2.4.2 AMERICAN LITERATURE

The literature from the USA reports studies of CRC screening uptake and barriers to uptake for a wide range of minority populations, including African Americans, Hispanics, and Asian Americans, although there is relatively little literature on Hispanics. Several studies focus on women only. Because of differences in funding of health care and organisation of cancer screening in the USA, as well as the difference in minority groups, it is not clear how generalisable findings for the different US population groups will be to the UK. Some studies have involved the provision of free CRC screening and are therefore more likely to be generalisable.

2.4.2.1 African Americans

In the USA there has long been evidence of low levels of participation in FOBt screening by African Americans, especially older members of the population (Boring 1992, Weinrich 1990, ACS 1990, South Carolina 1990). Apart from differences in the ethnic group, findings can be difficult to compare with the UK since there is no centrally coordinated population screening programme in the US and the initiative is therefore with the individual to choose when to be screened. Definitions of 'uptake' used in these studies therefore vary. Some studies report on the extent to which individuals are compliant in terms of the ACS guidelines for different screening modalities (see section 2.2.1 above), others on whether an individual has ever been screened. Furthermore, because there is no centralised screening programme many studies use self-report information on screening status and there is some evidence that there may be problems with the validity of this.

An early study of both males and female reported findings based on telephone interviews with 547 predominantly low-income African Americans. This study recorded higher digital rectal examination rates (90%); FOBt rates (75%); and sigmoidoscopy rates (33%), and high levels of accordance with recommended guidelines than national norms (Isaac *et al* 1996, 357). However, subsequent medical audit *failed to confirm these self-reports* and so the authors suggest that self-report data for CRC screening adherence needs to be interpreted with care. A significant number of the individuals interviewed also either identified their CRC risk as below average (36% of sample) or did not know their risk (37%). Individuals who provided a risk estimate were younger and held more accurate beliefs about CRC.

In a 2-year follow-up to this baseline study, Isaac *et al* (359) examined whether perceptions of risk were related to subsequent CRC screening intentions. 435 out of the 547 original participants completed a follow-up interview. Baseline perceived personal risk of CRC did not predict screening intentions two years later or compliance i.e. whether participants had an FOBt on schedule. In addition, whether a person was on schedule for FOBt (compliant) at baseline did not predict whether FOBt would be on schedule at follow-up. The authors suggest that educational efforts are needed to enhance knowledge and accuracy of risk perception for low-income minority populations.

Two studies focus on the behaviour of African Americans women in relation to flexible sigmoidoscopy (FS) screening. Paskett *et al* (482) report on a survey of 300 low-income, predominately African American women, about their overall (breast, cervical and colorectal) cancer screening behaviour. When adjusted for population ages, the differences in annual FOBt and 5 year FS were not statistically significant. Perceived barriers to screening were important for breast screening; and regular check-ups were related to cervical screening ($p < 0.01$). High perceived risk of colorectal cancer was related to recent FS only for white women ($p = 0.012$). The authors conclude that since women in this homogenous, lower socio-economic group have similar rates of screening and reported barriers to screening uptake, interventions should be targeted at all low-income women and address beliefs and knowledge of risk.

A similar study has used face-to-face interviews with 202 low income, predominantly African-American (77%) women about knowledge, attitudes, beliefs and practices related to FS screening (79). Logistic regression analysis was used to determine significant predictors of adherence to FS screening. 72% of women were non-adherent to FS screening guidelines. Covariates such as city, race, age, marital status, self-rated health and education were reported not to be significantly related to FS adherence, which supports the earlier findings of Paskett. The only predictors of adherence to FS screening were perceiving fewer barriers and having a physician recommendation.

A few studies have more systematically addressed the extent to which observed ethnic disparities simply reflect social class differences. The evidence appears to indicate that for African Americans there remains an 'ethnic' effect, especially for older (>65 years) individuals. A detailed analysis of use of cancer screening modalities among 34,078 black, white and Hispanic Americans by income (<\$20,000 vs ≥ \$20,000) and education (<12 years vs ≥ 12 years) using National Health Interview Survey data has demonstrated that uptake is much lower in all three groups for FOBt and sigmoidoscopy than for breast and cervical cancer screening. Also, social class was a more powerful explanatory variable in ethnic group disparities for younger (50-64) Americans; this was attributed to universal healthcare coverage for Americans 65+ years. However, older (65-74) black Americans who were poor or less educated reported less screening than older white Americans of a similar social class; this was attribute to other barriers, including race discrimination (272).

Another study has examined the influence of income, education, age and ethnicity on uptake of free FOBt screening among elderly African and white Americans recruited from randomly selected meal sites, although the sample (192 individuals) was relatively small (505). Participants were asked to return kits within 7 days to the meal site; they received free transport, a free educational programme on colorectal cancer screening, and free FOBt kits. As well as demographic indicators, fatalism and knowledge of colorectal cancer were also examined as factors that might explain observed variations in uptake. The author used their previously developed Power Fatalism Model to measure fatalism; this is defined as ‘the belief that death is inevitable when cancer is present’. African Americans were found to have a higher fatalism score than white Americans ($p<0.0001$). There was also evidence that fatalism was the most statistically significant predictor of low FOBt uptake among African Americans (compared with age, income or education).

2.4.2.2 Asian Americans

‘Asian’ in the USA context normally refers to Korean, Japanese, Chinese or South-East Asian (Khmer, Vietnamese, ‘refugee’) groups. Lower CRC screening uptakes are reported for these populations both in terms of digital rectal examination (DRE) and FOBt. There is also evidence of the importance of length of residence in the US or acculturation.

Yu *et al* (726) examined CRC screening uptake for Chinese Americans using a Chinese translation and cultural adaptation of the Cancer Control Supplement Questionnaire from the National Health Interview Survey (administered in the individual’s home to a sample of 644 Chinese). These individuals were less likely to have been screened with FOBt (15% vs 30% for the general population); knowledge of the DRE and FOBt was poor, as was knowledge of warning signs of cancer. Multiple regression analyses found that educational level alone was associated with use of DRE, and age alone (55-69 age group higher uptake than 40-54) with use of FOBt. The most common reason given by Chinese Americans for not having DRE (88%) or FOBt (85%) was ‘not sick/ no health problems’; next most frequent (5% FOBt, 3% DRE) was ‘doctor did not recommend to me’; fewer than 2% mentioned language problems, but they had access to Chinese-speaking physicians.

Tang *et al* (638) have similarly examined factors associated with FOBt and sigmoidoscopy screening uptake in older (> 60 years) Chinese American women. One hundred women were recruited from 7 senior centres and completed a questionnaire (71% response rate). Self-reported screening rates were lower than national figures for older (> 60 years) women: for having had an FOBt at least once (25% vs 39.7%); FOBt in the past year (11% vs 19.8%); and sigmoidoscopy at least once (31% vs 41.7%). Stepwise, logistic regression analyses (including income, insurance cover, family history etc) found greater acculturation (Suinn-Lew Asian Self-Identity Acculturation Scale, including language fluency) to be a significant predictor of having FOBt at least once, and acculturation and physician recommendation to be a predictor of sigmoidoscopy at least once. No factors were predictors of regular screening.

A similar study of 263 Korean Americans (males and females) found that only 13.5% of men had had a DRE, and 10.6% a FOBt; figures for women were lower at 11.3% and 8.8% respectively (321). Overall, fewer than

6% reported having DRE or FOBt for *screening* purposes. Multiple regression analyses in this case identified knowledge of the seven cancer warning signs and length of residence in US as associated with use of DRE, but none of the variables were related to use of FOBt. Because the majority of the Korean population interviewed were unaware of colorectal cancer screening tests, the authors highlight cancer education as important.

2.4.2.3 Mixed US populations

Glober *et al* (226) have reported on the uptake of FOB tests and subsequent diagnostic procedures in a US (Hawaiian) mixed population. During a 3 week free screening programme, a total of 15,015 residents participated, of whom 12% tested positive for faecal occult blood. Overall, 34.6% of FOBt kits were returned; Japanese, whites and Chinese were more likely to send in FOBt kits, and Filipinos and Hawaiians were less likely. No specific ethnic groups were more likely to send in an invalid kit. The rate at which participants with a positive test result contacted their physician was also recorded. There were no significant differences linked to ethnicity, with at least 83% of all population groups seeking medical advice. However, the final step in the screening process (diagnosing the source of the occult blood) once again showed variations depending on the ethnic group. Chinese, Filipinos and Hawaiians were more likely to have only a repeat FOBt, and Filipinos were the least likely to undergo diagnostic procedures directed to the colon e.g. colonoscopy or sigmoidoscopy (ca 1: 2.7, Filipino:white) with Japanese figures second only to the white population. No explanation is suggested for these differences.

There is evidence of patient concordance with CRC screening for Japanese in their home country. This has been assessed over a 14 year period in a village population in Japan (689). Uptake levels for a screening programme consisting of annual FOBt, followed by colonoscopy, are reported to be comparable with those for other populations (e.g. Swedish, English). Uptake has remained higher among women than men throughout, and there is lower compliance among the very young (< 50 yrs) and the very old (>80 years old). However, over this period, overall patient concordance fell from 81.4% to 58.6%. Subjects with a previous negative result had significantly lower uptake ($p<0.01$).

Views on CRC screening have been examined in a convenience, mixed population sample of 115 urban men and women in New York (706). Participants were interviewed by telephone, and included Hispanics (32%), Blacks (24%), Asians (6%), whites (15%), and 23% other including Caribbean. More than half (54%) of those interviewed were unable to name a CRC screening test. Misconceptions were common; and only 39% believed themselves to be at risk of CRC. For FOBt the main reported barriers were having to obtain stool samples from the toilet water (16%) and having to follow dietary restrictions (16%); for flexible sigmoidoscopy (FS) the primary barrier was the need to take an enema prior to the test (29%). Only 37% believed their physician wanted them to perform FOBt; the figure was only 20% for FS. In terms of screening status, active encouragement within the past 5 years by someone (not specified) to have an FS was the only variable significantly related to screening status.

Paskett *et al* (485) similarly interviewed a random sample of 263 women (77% African American) aged 50 and older in low-income housing communities about their knowledge, attitudes, and practices related to colorectal cancer screening (FOBt and FS). Only 20% of women had had an FOBt in the last year, 26% an FS examination in the last 5 years, and 7% both tests. The most important predictor for FS and FOBt was a physician recommendation ($P <0.001$). Slightly less than half the women had "good" to "excellent" knowledge about colorectal cancer screening. Most women had positive attitudes about both FS and FOB tests; however, the majority of women reported barriers to receiving these tests. The authors conclude that interventions designed to improve colorectal cancer screening should focus both on provider and public education.

Becker *et al* (48) conducted 14 focus groups which included both white and African Americans to explore (i) knowledge, attitudes and beliefs about CRC; (ii) barriers to screening; and (iii) strategies for motivating and supporting behaviour change. Sub-groups defined by age, race, educational level, or sex were reported to be generally similar in their focus group analyses. Overall, participants were poorly informed about CRC and the possible benefits of screening - reporting little or no information from physicians or mass media, negative attitudes towards screening procedures, and fear of cancer. All participants appeared to talk candidly and comfortably in the focus groups. Because this research was aimed at helping develop interventions to increase CRC screening rates, the authors suggest that public education campaigns, decision aids, and targeted interventions are urgently needed in the US to increase awareness of prevention and early detection benefits of CRC screening.

2.4.2.4 High risk groups

Relatives of colorectal cancer patients are the largest group of individuals at increased risk of colorectal cancer. Bastani *et al* (46) conducted a pilot telephone interview survey with 67 ethnically diverse first degree relatives of colorectal cancer cases, including Hispanics (10%), African Americans (19%), and Asians (16%). Only 19% believed they were at elevated risk, and non-whites were more likely to underestimate their risk compared to whites. Reported significant (at $p<0.05$) barriers for non-whites were not knowing where to obtain screening, difficulties in making an appointment, pain associated with sigmoidoscopy, and feelings of being 'violated'. Separate focus groups of African Americans, Hispanics and Chinese, and for males and females identified that Hispanic men cited shame of being seen as sick or weak as a major barrier; African American men identified mistrust of physicians and lack of sensitivity; and Chinese participants expressed a preference for exhausting eastern forms of treatment first.

2.4.2.5 Impact of ethnicity on cost-effectiveness of CRC screening in US

Some US academics have recently conducted secondary research on ethnicity and CRC screening, modelling the cost-effectiveness of screening programmes for different ethnic groups. Theuer et al (651a) have examined how ethnic colorectal cancer patterns affect the cost-effectiveness of CRC screening in the USA. Using 1988-1995 California Cancer Registry data the 4 main racial and ethnic groups (Asians, blacks, Latinos and whites) are compared. Average annual age-specific CRC incidence rates are highest in blacks and lowest in Latinos. Screening using annual FOBt from age 50 is most cost-effective for blacks and least cost-effective in Latinos (measured as dollars spent per year of life saved). For CRC screening to be equally effective, it is argued, non-Latino groups need to begin colorectal screening at earlier ages e.g. 42 years for black Americans. However, the authors report that screening beginning at age 50 falls within the $40,000 - $60,000 per year of life upper limit considered acceptable for preventive strategies.

In another paper assessing the cost-effectiveness of CRC screening in average-risk individuals, Frazier et al (199) compared 22 different screening strategies. The most cost-effective strategy for white men was annual rehydrated FOBt plus sigmoidoscopy (followed by colonoscopy every 5 years). Because of increased life expectancy among women and increased cancer mortality among African Americans, CRC was calculated to be more cost-effective in these groups than in white men.

In the UK, the incidence of colorectal cancer in the Asian population living in Leicester has been reported to be low (214a). The relative frequency was 0.16 (Asian vs European, 95% CI 0.04-0.75), although a trend of increased relative frequency among younger age group was observed. Reports from India indicate that the incidence of colorectal cancers is rising, largely due to urbanisation which leads to changes in diet and personal habits (428).

2.5 UK cancer screening uptake & barriers to recruitment (see Table A4.2 in Appendix A4)

- Uptake of cervical and breast screening is reported to be low among South Asian women in the UK; African Caribbean women show evidence of high uptake figures for cervical smears and no evidence of low uptake for breast screening. There is little evidence for other groups e.g. Chinese.
- Studies generally report low levels of knowledge of cervical and breast cancer among Asian women, and poor knowledge and understanding of tests and screening procedures.
- Uptake of breast screening is consistently lower than cervical screening among Asian women. Breast cancer screening rates seem to be less strongly associated with practice characteristics than cervical screening.
- At a GP practice level: language barriers; practice characteristics such as absence of female partners and smaller practices; and social deprivation (overcrowding) are all identified as factors linked to lower uptake levels for cervical and breast cancer screening by Asian women.
- At an individual level, breast cancer screening studies identify various factors that appear to influence uptake such as: inaccurate screening registers and extended visits to India; language needs; and lack of knowledge of screening. Active physician encouragement is also reported to be a significant influence on uptake.
- For cervical cancer screening, poor administration and language needs are identified as important barriers at an individual level, plus lack of knowledge of the screening service, fear and embarrassment, professional and lay perceptions, and resulting poor communication.
- UK studies do not generally correct patient-based uptake figures for differences in socio-economic status, so the possible confounding effect of deprivation has not been adequately addressed at the individual level.
- Articles also mainly report ethnic findings in terms of the meta-category ‘South Asian’. This broad level of aggregation may mask considerable differences between individual sub-groups.
- Recent research appears to indicate that the observed early differences in uptake for both cervical and breast cancer screening have not yet been rectified.

Although we could identify no published articles on ethnicity and uptake of CRC screening from the UK, literature does exist on ethnic uptake rates for the two national cancer screening programmes already in place (i.e. breast and cervical). Following the establishment of these two screening programmes, Bahl (33) described the Department of Health’s perspective on cancer and ethnic minorities, including population cancer screening. She highlighted differences in ethnic uptake of cancer screening programmes, with reported uptake of breast and cervical screening being substantially lower among Asian women. She concluded that cancer screening services in the UK are 'not always accessible and sensitive to the needs of ethnic minorities'.

Most of the research studies identified as part of the present review focus on South Asian women; research literature on African-Caribbean women is largely missing.

2.5.1 CERVICAL CANCER SCREENING

Evidence about incidence and mortality from cervical cancer among minority women shows that mortality is higher among women born in the Caribbean Commonwealth than the standardised rate for women living in England and Wales (363). In contrast, mortality among women born in the Indian subcontinent and African Commonwealth appears to be comparatively low. However, data about the incidence of cervical cancer among minority ethnic women are in short supply, and the author points out that some research findings are contradictory.

There is considerable evidence of lower uptake rates of cervical cancer screening in specific ethnic minority groups, particularly Asian women, although uptake in the African Caribbean population appears to be very high. Carr-Hill and Kudat (103) report the results of a 1995 survey into primary care, carried out by MORI's health research unit, and commissioned by the Health Education Authority. This identified relatively high cancer cervical screening uptakes (87%) for African-Caribbeans (equivalent to the 85% observed for the whole population) but much lower uptakes for South Asian women (70% Indian; 54% Pakistani; and 40% Bangladeshi women). The survey also identified language barriers as potentially important for Asians (especially women) accessing services, with 90% of older Pakistani and Bangladeshi women, and more than 66% of older men, reporting that they do not speak English to their GP.

UK studies have examined uptake at practice level and the degree to which low uptake is linked to various practice or population characteristics. Majeed *et al* (369) assessed the extent to which practice variables can explain variations in cervical smear uptake rates in 126 GP practices in the inner and outer London area over a 5 year period (1987-92). Uptake rates varied from 16.5% to 94.1%, with uptake negatively correlated with the percentage of the practice population from ethnic minorities and with variables associated with social deprivation such as overcrowding, no car and unemployment. Rates were higher in practices with a female partner, and in larger practices. In a stepwise multiple regression model five factors were significant predictors of practice uptake rates: a female partner; percentage of children under five in population; overcrowding; number women aged 35-44 as a percentage of all women aged 25-64; and change of address in past year.

A number of studies of factors influencing uptake have focused on women themselves, rather than practices. The ScanLink project carried out in Newham, East London surveyed 172 black and minority ethnic women on their knowledge, attitudes and experiences of cancer-screening services; and 17 women also took part in in-depth interviews (72). Many women were unaware of the screening service or held misconceptions about the smear test; fear, embarrassment and previous negative experiences all inhibited attendance for screening. Other themes included: that ‘cervical cancer is associated with promiscuity’; that it ‘is a western disease’; concerns about their GP maintaining confidentiality; embarrassment and the need for the smear-taker to be female; and the idea that nothing can be done about cervical cancer. The authors also identify concerns about language, the need for advocacy, and experience of racism.

Chiu *et al* (119) have examined professional and lay perceptions in order to identify factors associated with both practices and women that might have contributed to the persistently low participation of minority ethnic women in the cervical screening programme. Focus group findings demonstrated a divergence in the perceptions of smear takers and minority ethnic women (African-Caribbean, Asian and Chinese) which has contributed to negative experiences for both groups and poor clinical communication. Opportunistic screening by GPs at post-natal examination led to misconceptions among minority ethnic women about the purpose of the smear test. The authors report that the majority of women understood neither the purpose of the screening programme nor the test procedure, raising questions about informed consent and choice.

Naish *et al* (448) also report the results of focus groups to identify factors that have deterred non-English speaking women in east London from attending their GP for cervical screening. The study involved focus groups of Bengali, Kurdish, Turkish, Urdu and Punjabi, and Chinese speaking women. Previously reported attitudinal barriers such as fear of cancer were not reported to be deterrents. However, administrative and language barriers were more important, as were inadequate surgery premises and concerns about sterility. The authors conclude that women from ethnic minorities are enthusiastic about cervical cytology screening once they understand the purpose of the test and the call and recall procedures.

Bradley and Friedman (74) have reported that it is possible to achieve satisfactory uptake of cervical cancer screening among Asian women. A comparison of cervical screening uptake among 158 ‘Asian’ and 158 ‘non-Asian’ women from 4 Oldham general practices, demonstrated no difference in uptake between the two groups (uptake in Asians 61.5%, non-Asians 60.6%). Asian women were selected based on their names and the next non-Asian name that occurred in the practice list was also selected. However, non-Asian women were more likely to have had a previous smear than Asian women. Also, the register contained a higher number of inaccurate addresses for Asian women.

2.5.2 BREAST CANCER SCREENING

Hoare (267) has reviewed the UK evidence about minority ethnic women, incidence of breast cancer, and uptake of screening. The lowest incidence of breast cancer is found in Chinese, Japanese and Arabic populations and women from the Indian subcontinent; these are 2-3 times lower than that of the UK average. The author points out that very few studies have measured ethnic differences in the uptake of screening, and that the studies which exist may be confounded by factors such as socio-economic group. A 1999 review of the literature on breast screening in ethnic minorities also identifies that, although the incidence of breast cancer is reported to be low among certain ethnic groups, the number of women diagnosed with breast cancer in these groups is expected to rise as a result of changes in lifestyle and environmental factors (516).

At the same time, there is evidence that the uptake of breast cancer screening services remains low among UK minority women, and that breast cancer screening uptake rates are lower than cervical cancer ones. The main reasons for low uptake appear to be a lack of knowledge among women from the ethnic communities about screening services, and a lack of referral/recommendations by healthcare professionals and physicians. Studies that have compared cervical and breast cancer screening in diverse populations consistently indicate that breast screening uptake is lower. Boomla *et al* (63) compared uptakes in 156 practices in a highly deprived inner city east London area. Breast screening uptake was consistently lower than uptake of cervical screening. Similar results were observed by Rudiman *et al* (556) in Grampian, Scotland. The east London analysis showed a significant positive correlation between the two uptake rates, unlike the figures from Scotland, possibly linked to the higher mobility of the London population. The authors suggest that more accurate addresses would improve ethnic uptake rates in inner city areas of high mobility.

Hoare (267) also suggests that one of the most important reasons for non-attendance is inaccurate screening registers, compounded for Asian women by their return, or extended visits, to the Indian subcontinent. A further organisational issue highlighted is poor awareness of minority ethnic naming systems, causing confusion over the receipt of invitations. Hoare *et al* (268) had previously explored non-attendance for breast screening by 93 women with Asian names in inner-city Manchester. Half were found to be no longer at the address to which invitations were sent and one third of the others were on extended visits to Asia. Both attitudinal and practical reasons were given for non-attendance by those who were contacted and interviewed; improving understanding of what the invitation is for through better health promotion materials was advocated. 34 women were offered additional appointments, and after this personal intervention there was a 70% uptake.

As with cervical cancer screening, some studies have examined practice level breast cancer screening uptakes and practice and population characteristics. Majeed *et al* (368) investigated first round breast cancer screening uptake rates for 131 practices in inner and outer London. Of the 43,063 women eligible for screening, 25,826 (60%) attended for a mammogram in the first round of screening (1991-94). Uptake rates in individual practices varied from 12.5% to 84.5%. Rates were strongly, negatively correlated with social deprivation and the estimated percentage of people in non-white ethnic groups. There were no significant differences in screening rates between practices with and without a female partner, unlike in their study of cervical smear uptake rates (369). In a stepwise multiple regression model, four factors were found to be significant independent predictors (at $P = 0.05$) of screening rates: list inflation, people living in households without a car, chronic illness and the number of partners in a practice. Breast cancer screening rates were on average lower than cervical ones and were less strongly associated with practice characteristics, as might be expected because of the way in which screening is delivered.

Sutton *et al* investigated women's views and their impact on first-round attendance for breast screening in inner London (631) . A total of 3,291 women aged 50-64 years who were due to be called for breast screening for the first time were interviewed or completed a postal questionnaire. Socio-demographic factors, health behaviours, and attitudes, beliefs, and intentions were tested as predictors of subsequent uptake based on a sub-sample of 1,301. The main predictors were found to be: (i) socio-demographic factors including ethnic background (white, black, Asian) with black women found to have a higher than average attendance rate, although this relationships was not found in the interview sample); (ii) health behaviours, with attenders more likely to have had a cervical smear; (iii) attitudes, beliefs, and intentions (with women reporting a moderate amount of worry about breast cancer more likely to attend).

Similarly, a random sample of 701 inner-city women in Leicester City (stratified by neighbourhood and by women's "likely home language") were approached for interview about breast cancer screening prior to first-round screening (67). Analysis of 413 respondents showed significant (p<0.001) differences in acceptable knowledge of breast cancer and screening by language (60.4% of English-speaking and 12.5% of non-English-speaking). Despite that, 80% or more of all groups stated their intention to attend for screening and assessment if necessary, irrespective of neighbourhood, language, age, or social class. The authors suggest that the difference in knowledge between language groups arises from indirect discrimination in the way in which health-related information is disseminated in the UK.

More recent research appears to indicate that the observed early differences in uptake for both cervical and breast cancer screening have not yet been rectified. Sutton *et al* (630) have examined ethnic uptakes in Wakefield using pair-wise comparison of South Asian and non-Asian women matched by date of birth and general practice. They found that 67% of the 852 South Asians and 75% of the 15,623 non-Asians had acceptable (i.e. not overdue) cervical screening histories (p<0.001). For breast screening, 53% of the 73 South Asians and 78% of the 3,255 non-Asians had acceptable histories (p<0.01). South Asian women were more likely to be overdue for breast than cervical screening (where eligible for the two).

2.6 CRC screening intervention studies (see Table A4.3 in Appendix A4)

- The published research identified on interventions to improve uptake of CRC screening by ethnic minorities is all from the USA. Papers principally focus on interventions to improve uptake in the African American population, although one paper did consider a more diverse population that included Hispanics. Studies almost exclusively focus on improving FOBt uptake.
- The main issues linked to low CRC screening uptake in diverse US populations that are amenable to intervention are identified as being: language and dialect, the appropriate use of interpreters, the reading level of educational materials, and the demographic profiles of physicians and nurses.
- Only two papers report evaluation of interventions to improve CRC screening uptake. These are not targeted exclusively at ethnic minority populations. One study reports that an educational intervention adapted for older people and applied to a mixed population is more effective than a standard educational programme. A second study concludes that a video intervention designed to reduce cancer fatalism has no impact on FOBt uptake in a mixed group (mainly African American women).
- Other literature on CRC screening clinician reminder systems, not necessarily focused on ethnic minorities, provides some evidence that computer-based physician reminders (with or without a financial incentive) can be cost-effective.

Two review articles were identified. Beeker *et al* (49) have reviewed the literature on African Americans and CRC screening, and they identify that papers on strategies to improve CRC screening are largely absent. However, drawing on the literature on promotion of breast and cervical cancer screening among African American women and prostate cancer screening for men, the authors conclude that certain barriers are more influential among African Americans than in other groups. For example, there appears to be evidence that fear of cancer, fatalism, reliance on self-care, limited opportunities to access care, and inadequate provider-patient communication all influence uptake by African Americans. These barriers largely mirror those identified in other literature. The authors conclude that, building on previous efforts to promote screening for breast cancer and other health behaviours, community-based approaches designed to affect change at the individual, community and health care system levels may be best suited to raising awareness of colorectal cancer, promoting acceptance of screening, and facilitating patient concordance in the African American communities.

Douglas (149) has undertaken a similar review of community based interventions to improve CRC screening uptake. This includes some literature on ethnic minorities, although the review did not specifically focus on ethnic minorities. The author highlights special concerns in relation to improving uptake in diverse populations (including immigrants). Those that are amenable to intervention include: language and dialect, the appropriate use of interpreters, the reading level of educational materials, and the demographic profiles of physicians and nurses.

Only two papers were identified that actually reported an intervention study to improve CRC screening uptake. Both were group educational interventions in a community setting. Neither study used a randomised controlled trial design, and both were applied to a mixed population.

Weinrich *et al* (691) used a quasi-experimental (pre-test vs post-test) design to evaluate a CRC screening programme designed to accommodate the normal changes of ageing in a diverse population. The Adaptation for Ageing Changes with Practice (AACP) method includes demonstrations and practice on how to collect the stool specimen, written material modified to a low reading age, and reminders regarding the return date for the FOBt card. Participants in the AACP group (with and without demonstration) were compared with individuals participating in the standard American Cancer Society (ACS) colorectal educational programme. Of the 135 subjects in the study, 56% were African Americans and the majority of these (82%) were women. A greater percentage of participants taught by the AACP method (94%) participated in FOBt screening than those taught by the AAC method (41%) or traditional method (65%). The AACP intervention had a similar effect on different ethnic groups; logistic regression did not identify race (white vs black) as a significant term (p value 0.85).

Powe and Weinrich (507) report the findings of a US (pre-test/ post-test) evaluation of a video intervention designed to decrease cancer fatalism, increase knowledge of colorectal cancer, and increase participation in FOB testing. Senior citizen centres serving rural, socio-economically disadvantaged elders (average age 73) were assigned randomly to intervention or control; the latter used the American Cancer Society standard video. 70 individuals, the majority African American females, participated in the study (42 intervention and 28 control). Although individuals who viewed the intervention video had a significantly greater decrease in cancer fatalism scores (p=0.003) and a significantly greater increase in knowledge of colorectal cancer scores (p=0.044), no significant difference existed in the rate of participation in FOB testing. 60% of the intervention group and 68% of the control group participated in FOBt screening within 7 days. It is not known whether the positive outcomes of the intervention in terms of fatalism and knowledge were maintained over time, and whether this had any effect on longer term screening uptake.

2.6.1 ECONOMIC EVALUATIONS OF CRC SCREENING INTERVENTIONS

Both the interventions above aimed at improving CRC uptake by African Americans targeted patients and neither study considered cost-effectiveness. A number of US studies have assessed the cost-effectiveness of clinician reminders to improve CRC screening rates, although they do not specifically focus on the impact on ethnic minorities. These are described briefly below, and referenced at the end of the chapter rather than the bibliographic register or Table 2.3.3 since they do not specify the population studied.

Frame *et al* (1994) have assessed the relative cost-effectiveness of computer-based vs manual health maintenance tracking systems to improve provider (clinician) compliance with health maintenance protocols, including FOBt, mammography, clinical breast examination, and cervical smears. A randomised controlled trial was conducted in a sample of 1,665 patients in a rural, multiple-office, non-profit, fee for service US family practice. Overall provider compliance increased by 15% in the computer-based tracking group, and by 4% in the manual paper group, compared to the control group. Patient concordance was also significantly higher with changes in overall compliance of 27.1% in the computer-based trial group, as opposed to 13.5% in the control group (p=0.02). The average cost of maintaining the computer system, generating reminders, and mailing patient reminders was calculated to be $US0.78 per patient per year. Although no attempt was made to assess the cost of the manual system, this might be expected to be higher, and therefore the computerised reminder intervention would be more cost-effective.

Bird *et al* (1990) report an RCT of 62 US internal medicine residents to evaluate the use of three strategies to improve the performance of cancer screening tests (FOBt, digital rectal examination, sigmoidoscopy, pap smear, pelvic examination, clinical breast examination, and mammography). Two of the strategies, medical audit with monthly feedback and computerised cancer screening reminders (patient's screening status when visiting the practice), were targeted at physicians. The third was a patient education strategy (reminder letter with appointment and postcard reminder if overdue). Implementation costs were respectively $US9.63 per patient, $US12.93, and $US3.11. Including any additional downstream costs (i.e. the cost of subsequent tests), the net cost per additional test performed was: $US50.40 for audit with feedback, $US18.19 for computerised cancer screening reminders, and $US51.20 for patient education. Thus the computerised cancer screening reminder intervention was similarly judged to be the most cost-effective.

A further study demonstrates the cost-effectiveness of a reminder combined with a financial incentive. Morrissey *et al* (1995) evaluated a combined financial incentive and reminder intervention to increase uptake of preventative care in physicians' offices for those aged 65 years or more. Overall 1,914 patients from 10 primary care medical practices were randomised either to a usual care control or intervention group (i.e. full MEDICARE reimbursement for physicians, making these services free to patients plus manual paper reminders to physicians to schedule preventative care visits). The 'preventative care' package included FOBt, digital rectum examination, and (for women) smear test and breast examination. At 2 years, the performance of screening tests was higher in the intervention group than the control group ($P<0.001$). The 3-year average Medicare costs were also lower in this group due to significantly lower hospital utilisation ($P<0.02$), and therefore the intervention was judged cost-effective.

One study indicates that a patient letter may be more cost-effective than a physician reminder (Belcher 1990). A randomised-controlled trial was conducted of 3 different models of delivery of preventive services to 1,224 male outpatients. These included: a) use of a physician-orientated paper reminder involving education and motivation and chart flow sheets, listing recommended activities together with periodic feedback to physicians on their performance; b) use of a patient education model whereby patients were posted an information brochure designed to encourage them to ask for preventive services which were outlined in a patient-held pocket guide; c) use of a patient invitation letter to attend a health promotion clinic. The 3 means of delivering preventative medicine were compared with a control group. The study findings indicated that only reminder intervention c) resulted in measurable improvements relative to the control group. Rates for faecal occult blood testing increased from 22% to 78% during the first year, were sustained for 5 years, and were statistically significant. Costs were also measured and demonstrate that a letter invitation to attend a health promotion clinic will be cost-effective.

2.7 UK cancer screening intervention studies (see Table A4.4 in Appendix A4)

- UK intervention studies almost exclusively focus on South Asian women; research on Chinese, African-Caribbean and other minority women is largely lacking. Almost all studies use the meta-category 'South Asian' rather than considering Asian sub-groups.

- There is limited UK research on interventions to improve cervical cancer screening uptake by Asian women. The only trial identified that home visits are more effective than a postal leaflet. International studies provide some evidence of the greater effectiveness of a linkworker versus a patient reminder letter for improving uptake by ethnic minority women.

- For breast cancer screening, a large number of UK studies have evaluated letter/ telephone follow up, linkworkers and 'multi-strategy' interventions. The use of a reminder letter appears to have a limited role in improving uptake by ethnic minorities. Unlike cervical cancer screening, there also appears to be no evidence that home visits by a linkworker are effective in improving uptake.

- The only UK study to examine the cost-effectiveness of interventions to improve breast screening uptake by ethnic minority women reports that a GP letter is more cost-effective than a flag in patient notes; linkworkers were not included in the trial.

- There is evidence from studies in London, Cardiff, Bradford and Berkshire that a multifaceted strategy can lead to a relatively high ethnic uptake of breast (and cervical) screening. The cost-effectiveness of such an intervention has not been assessed.

The literature on evaluation of interventions to improve cervical/ breast screening uptake by ethnic minority populations in the UK is much more extensive than the US literature on CRC screening interventions. Most studies focus on South Asian women and, once again, research on African-Caribbean women is largely missing.

Studies do not normally consider Asian sub-groups and instead report findings for the meta-category 'South Asian'. Only one paper considers cervical cancer screening and one both breast and cervical cancer screening; the remainder report on intervention to improve uptake of breast screening.

2.7.1 CERVICAL CANCER SCREENING

We identified only one UK evaluation of an intervention to improve uptake of cervical screening by ethnic minority women. This is a very early (1991) study comparing three interventions designed to increase uptake among South Asian women in Leicester, and a rare study in that it considers Asian sub-groups rather than just the meta-category 'South Asian' (396a). 737 randomly selected Asian women (aged 18-52) who were recorded as never having had a cervical smear test were randomised to four groups; a home visit by research assistant and being shown a 5 min health education video (in English, Gujarati, Punjabi, Urdu, Hindi or Bengali); a home visit and being shown a translated leaflet and fact sheet; a leaflet and fact sheet posted to the home address; and a control group that were not contacted. For the home visit groups, 37% of the women given a leaflet and 47% of the women shown the video attended for cervical smears within 4 months of intervention; the difference between these groups was not significant. Uptake was not correlated with age or education. Hindus has a higher uptake (49%) than Moslems (34%) or Sikhs (31%), although these differences were, once again, not statistically significant. Only 11% of those posted a leaflet and 5% of those not contacted had a smear test during the same period. The authors conclude that personal visits are most effective, with some evidence that home viewed videos may be particularly effective in one of the most hard to reach groups: Urdu speaking, Pakistani Moslems.

A recent Cochrane review of ‘Interventions targeted at women to encourage the uptake of cervical screening’ includes a small number of non-UK randomised controlled trials of interventions to improve cervical cancer screening uptake by ethnic minorities (Forbes et al 2002). Once again, These are described briefly below, but not included in Table 2.3.4.

Two trial report a minimal effect for a patient reminder letter. In an Australian study, a personal letter written in Vietnamese promoting cervical screening was not associated with any increase in screening uptake (relative rate 0.85, 95% CI 0.55-1.3) (140a). In a second study, file tagging (clinician reminder) and a personal letter (patient reminder) were evaluated in an urban Aboriginal health service and both were found to have minimal effect (284a).

There is some (limited) evidence in these international studies to support the role of linkworkers for ethnic minority populations. Community linkworkers for low-income Latinas have been assessed in the USA with a reported increase in the uptake of cancer-screening tests in the intervention groups in comparison to a community living skills control group (450a). Similarly, Sung (629) has evaluated an in-home educational intervention by lay health workers (LHWs) to increase breast and cervical cancer screening uptake among low-income, inner-city African American women. 321 women were recruited and randomly assigned to LHW intervention and control groups. Linkworkers visited women in their homes on three occasions and provided education on cancer and reproductive health. About 35% of participants aged 35 and older underwent screening within an appropriate interval.

2.7.2 BREAST CANCER SCREENING

A systematic review of interventions to increase breast screening uptake groups interventions into "person directed", "system directed", "social network directed", and "multi-strategy" categories (590). Most of the studies identified were from the UK and evaluated person directed interventions; very few considered ethnic minorities. Although the authors conclude that simple, brief interventions (e.g. a personal letter from the GP) are usually effective, in inner city areas (where ethnic minorities are located) the best approach to raising uptake rates is though to be a multi-strategy one.

2.7.2.1 Person Directed Interventions

Several of the studies identified were evaluations of 'person directed' interventions. These either involved letter/ telephone follow up or a linkworker.

i) GP letter/telephone follow up

Majeed *et al* (367) report an evaluation of the impact of follow up letters to non-attenders for breast screening in 93 South West London general practices. This followed an earlier study of practice uptake levels indicating that the percentage of people in non-white ethnic groups was a factor influencing uptake (368). In the intervention study, 40 practices were offered help from a clerical officer to check names and addresses of non-attenders, and to send them a reminder letter. Breast screening uptake increased by an average of 4.6% in the 40 intervention practices compared with 1.6% in the 53 control practices (difference 3.0%, P < 0.0001). However, the absolute increase in the uptake of screening in the intervention group was small (from 53.8% to 58.5%). The marginal cost for each additional women screened was £7 (compared to an average cost for each women screened of £27). The authors conclude that reminder letters have a limited role in improving the uptake of breast screening in inner city areas, and other methods of increasing uptake need to be developed and evaluated.

Atri *et al* (29) report a similar randomised controlled trial carried out in 37 practices in inner London (Newham) using follow up by telephone contact. Practice reception staff were offered training and they then contacted 2,064 women aged 50-64 years who had failed to attend for breast screening (31% were white, 17% Indian, 10% Pakistani, 14% black, 6% Bangladeshi, 1% Chinese, 4% other ethnic groups, and 16% ethnic group not known). Uptake by non-attenders in the intervention group was significantly better than in the control group (9% v 4%). Impact was highest in Indian women; 19% intervention group vs 5% control. The authors conclude that this simple, low cost intervention is effective in modestly improving breast screening rates, and it could be effective as part of a multifaceted strategy in areas with low uptake rates.

ii) Linkworker

Unlike for cervical cancer screening, there appeared to be no evidence that home visits by a linkworker are effective in improving breast cancer screening uptake by ethnic minority women. Sharp *et al* (582) report the findings of a randomised controlled trial comparing three interventions designed to increase second round breast screening uptake in south east London. 799 women registered with 27 GPs who had not attended for first round screening were randomly allocated to the three groups: nurse visit with health education (group A), nurse visit without health education (group B), and GP letter (group C). In group A, 11.4% of women subsequently attended for screening, compared with 7.8% in group B, and 13.1% in group C. The differences between groups were not statistically significant. The authors conclude that a personal letter from the GP is at least as effective as nurse home visits (with or without a health education intervention). It is also reported that, in general, delivering the nurse-based interventions proved difficult. No separate figures are provided for ethnic sub-groups.

Hoare *et al* (266) report the findings of a randomised controlled trial of a similar linkworker intervention to improve attendance for first round breast screening by Asian (Pakistani and Bangladeshi) women. The control group received no visits. The study population comprised all women with Asian names from a batch of general practices in the north of England (Oldham) where high proportions of patients were Asian. Only 59% of the intervention group could be contacted by the linkworkers. No significant difference in attendance was found between the intervention and control groups (49% and 47%). 25% of women visited were found to be permanently or temporarily not resident at the invitation address. Attendance for screening was related to length of stay in the United Kingdom. The authors conclude that the linkworker intervention was not a successful strategy for promoting uptake by Asian women.

2.7.2.2 Multi-strategy approach

There is some evidence that a multifaceted strategy can have a more significant effect on uptake. Falshaw *et al* (176) report an evaluation of such an approach in east London. Nineteen practices were sent a list of women who had not responded to two invitations to breast screening. Receptionists from 12 of these practices agreed to be trained to enable them to contact these women, and draft letters were provided in English, Cantonese and Bengali. The breast screening mobile unit was left on site for an additional period and health advocates (2 Bengali, Cantonese, Vietnamese and Somali) were made available to accompany women. Ten practices finally participated and 1,038 women were contacted and asked to make appointments to attend. Uptake for practices participating in the scheme was 55%, and 31% for those who did not participate ($p<0.01$). No separate figures are provided for ethnic sub-groups.

Bell *et al* (51) have evaluated a similar multi-strategy in three inner city general practices in Cardiff with a high proportion of ethnic minority women and low uptake in the previous round of breast screening. The strategy included: identification of ethnic language groups; GP endorsement letter; translated literature (including multilingual leaflet, GP letter, screening invitation); free transport to the screening centre; and language support by linkworkers. Of 369 women invited, 50.7% attended for screening compared with an uptake of 35.2% in the previous screening round, a similar sized increase to that reported by Falshaw *et al* (176). The authors conclude that this multi-pronged approach was beneficial, although provision of free transport was under-utilised and therefore appeared ineffective. Uptake figures are broken down by ethnic sub-group; uptake was highest amongst Urdu and Gujarati speaking groups and lowest for Bengali and Somali speakers.

A multi-strategy approach has been evaluated in Bradford by Kernohan (319). This was an educational strategy and included specifically trained Health Promotion Facilitators providing group sessions in both formal and informal settings. Sessions included health education about breast and cervical cancer and the associated screening programmes in the women's preferred languages and use of audio-visual material and a specially designed teaching pack. These sessions were augmented by a local publicity campaign. A stratified sample of 1,000 women (670 South Asian, 163 African-Caribbean, 96 Eastern European and 71 other) was interviewed at the beginning of the project and six months after the health promotion intervention. The authors report significant differences in baseline levels of knowledge about cervical cancer and breast cancer; South Asian women had the lowest levels of knowledge and also showed the most significant improvements. Significant increases in attendance for cervical smear and breast cancer screening were also reported, with breast screening uptake tripling from 22% to 59% over all groups and cervical screening increasing from 67% to 87%.

Finally, an unpublished report by Bradford Community Health (2) provides further confirmation of the effectiveness of such multi-strategies. The author reports the findings of a prospective study targeted at Asian women in a single low uptake Berkshire GP practice. Bus transport was arranged to and from the screening centre and an interpreter greeted women on their arrival. Uptake was increased from 46% before the intervention to 73% afterwards.

2.7.2.3 Economic evaluations

Only two studies were identified that included an economic evaluation, both assessed the same interventions and were carried out by the same research team. Richards *et al* (536) present the results of a cluster randomised controlled trial of a postal intervention (GP letter accompanied by translation sheet), versus an opportunistic intervention (flag in women's notes prompting discussion by health professionals), versus both interventions, or neither intervention (control). The aim was to improve attendance for third round breast screening in 24 general practices with low uptake in the second round of screening (below 60%) in north west London and the West Midlands. A total 6,133 women were included in the trial: 1,721 control; 1,818 letter; 1,232 flag; 1,362 both interventions. Attendance data were obtained for 5,732 (93%) women. The flag was marginally more effective (OR 1.43; 95% CI 1.14-1.79) than the letter (OR 1.31; 95% CI 1.05-1.64). However, estimated cost per additional screening attendance was £26 (letter) and £41 (flag), so the authors conclude that the letter is more cost-effective. Although it is stated that the populations were ethnically diverse, no data are provided on the effect of the intervention on different ethnic minority groups in the sample.

The same team (41) also report the findings of a patient-based, randomised controlled trial of the same primary care based interventions in 13 general practices in the same locations. 1,158 women were randomised: 289 control; 291 letter; 290 flag; 288 both interventions. In this study, the letter ($p=0.04$) was more effective than the flag ($p=0.10$). Health service costs per additional screening attendance were £35 (letter) and £65 (flag), so the authors once again conclude that the letter is more cost-effective in increasing breast screening attendance. No separate results were presented for different ethnic minority groups in the sample.

Although another study (582) that compared a nurse home visit (with and without education) with a GP personal letter for a mixed south east London population concluded that a personal GP letter is at least as effective (13.1% uptake) as a nurse home visit (11.4% with education, 7.8% without), the authors did not consider cost-effectiveness. However, clearly the letter would also be more cost-effective than home visits because it would be far less expensive.

2.8 Conclusions and Recommendations

2.8.1 CONCLUSIONS

The international general literature on cancer screening and ethnic diversity is dominated in this field, as in other clinical arenas, by that from the United States of America. It is quite striking how commonly the matter of ethnic or 'racial' diversity is addressed in US studies, and this has become a routinely collected data item in most studies there. While the ethnic groups of interest are somewhat different in the Americas from the European and

UK settings there are some themes, notably information poverty, socio-economic deprivation, and suspicion of motivation or professional competence, which recur, albeit with differing groups associated with particular issues.
Some interesting points arise in relation to health beliefs and attitudes. Generally, minority groups (certainly in the UK) are seen to be positively oriented to all health-related and 'health-giving' interventions and professions. There is little evidence (although some mention in the USA) of 'fatalism', and no sign that this deters minority respondents from health-promotion-related actions. Minority people are, however, sometimes suspicious of practitioners (and practices) whose role or competence (and authority) are poorly understood, or where ignorance and antipathy is displayed towards cherished cultural practices and symbols. Language is commonly referred to as an issue and appears to be a real barrier in many cases. Similarly, while there is not apathy, there may be disengagement, or at best, lack of positive engagement in health promotion and screening, sometimes arising from fear but more often lack of knowledge or failure of the promoters to explain and target information adequately.

There is a need, agreed by virtually all authorities, for positive, targeted outreach, and also for administrative procedures to take diversity into account: this means recognising religious or cultural festivals, timings of holidays and trips abroad, as well as other religious and cultural sensitivities such as gender-mixing, diet, and naming systems. Furthermore, it is essential that the many projects and initiatives that are created to overcome or address inequalities and perceived problems should be adequately evaluated and publicised, and not simply described as 'desiderata'.

The international literature on CRC screening reviewed in depth, provides consistent evidence of differences in FOBt screening uptake by ethnic group. There is relatively little literature on uptake of subsequent diagnostic procedures e.g. colonoscopy. The available evidence mainly covers US population groups, including African Americans, Chinese Americans, Korean Americans, Hispanics, Filipinos, Japanese Americans, and Hawaiians, although one paper on Swedish immigrants was identified.

Overall, the international evidence indicates that key factors linked to improved CRC screening uptake are younger age and acculturation (including language fluency) or length of residence; for colonoscopy uptake, there is evidence that physician recommendation is also important. Few of the studies have examined uptake corrected for socio-demographic differences, but were this has been considered an 'ethnic' effect remains. There is a large literature on knowledge, attitudes, beliefs, risk perception and their relation to CRC screening practice. The majority of these papers focus on FOB testing, although a significant number also include flexible sigmoidoscopy screening. The literature consistently reports low levels of knowledge of colorectal cancer, poor knowledge and understanding of tests and screening procedures, and low accuracy in terms of risk perception among the ethnic populations studied. In the case of FOBt screening, the only factor identified as a quantitative predictor of planned uptake is age; for flexible sigmoidoscopy, physician recommendation is also related to uptake.

Finally, only 2 studies were identified that actually evaluated an intervention to improve CRC screening uptake. Both are from the USA and neither used a randomised controlled trial design Only one intervention (the Adaptation for Ageing Changes with Practice educational intervention) was found to be effective in improving FOBt uptake in a deprived, mixed-race population; a tailored video, educational intervention was not effective. Neither study considered cost-effectiveness.

The UK literature on cervical and breast cancer screening reviewed in depth, similarly provides consistent evidence of differences in screening uptake by ethnic minority groups, with high uptakes reported for African-Caribbeans but much lower uptakes for Asian women. Language barriers (especially for Asian women); practice characteristics such as absence of female partner and smaller practices; and overcrowding are all identified as factors linked to low uptake at practice level. None of these studies have examined uptake corrected for women’s socio-demographic characteristics; where studies have considered socio-economic indicators this was at a practice level. Papers on breast screening uptake at practice level identify social deprivation and ethnicity as both strongly correlated with uptake, as is list inflation. Breast cancer screening rates seem to be less strongly associated with practice characteristics than cervical screening, as might be expected.

Early articles (1994 and 1996) on cervical cancer screening identify administration, language needs, and poor knowledge of the screening service, as important barriers. A more recent (1999) paper also highlights professional perceptions and poor communication. For breast cancer screening, two early papers (1992 and 1993) identify errors in the screening register, poor health information, and lack of knowledge of screening. Later papers continue to report lack of knowledge and the need for active physician encouragement. More recent research (2001) appears to indicate that the observed early differences in uptake for both cervical and breast cancer screening have not yet been rectified.

The UK literature reports the findings of a number of trials (the majority RCTs) to evaluate interventions to improve uptake of cervical or breast screening. Only one such study has focused on cervical screening, and one on both breast and cervical. The remainder only consider breast screening

There is limited UK research on interventions to improve cervical cancer screening uptake. The only trial identified provides evidence that home visits (with or without a video) are more effective than a postal leaflet. International studies similarly provide evidence of the greater effectiveness of a linkworker versus a patient reminder letter for improving uptake by ethnic minority women.

The majority of intervention trials have focused on improving breast cancer screening uptakes in ethnic minorities (mostly in the meta-category ‘South Asian’) using letter/ telephone follow up, linkworkers or 'multi-strategy' interventions. The use of reminder letters appears to have a limited role in improving uptake. Unlike for cervical cancer screening, there also appears to be no evidence that home visits by a linkworker are effective in improving breast screening uptake. There is some evidence that training practice receptionists to follow up non-attenders can have a significant, but small, effect.

More complex, multi-strategies have been identified as possibly the best approach to improve uptake. These strategies have included practice receptionist training, follow-up letters in various languages, offer of transport, health advocates on site, and screening mobile unit available for longer. Similar levels of increased uptake (ca 50% vs 30%) have been demonstrated in a number of studies. However, the cost-effectiveness of such multi-strategy interventions has not been measured.

Virtually no UK studies have reported the cost-effectiveness of interventions to improve cancer screening uptake by ethnic minority women. The one research team that have examined this report that a GP letter is more cost-effective than a flag in patient notes.

2.8.2 RECOMMENDATIONS

1. Only two studies were identified that have evaluated interventions to increase uptake for CRC screening among ethnic populations (both from the USA). Although this research has demonstrated the potential effectiveness of a particular educational intervention in an African American population, the findings may not be generalisable to the UK. No studies have examined interventions to increase uptake of colonoscopy. In the UK, several RCTs and other studies have evaluated interventions to increase ethnic minority population uptakes for other cancer screening programmes (principally breast screening). These appear to indicate that multi-strategy interventions are required for ethnic populations. The cost-effectiveness of such interventions has not been measured. We would recommend, therefore, that **a robust study be undertaken to evaluate the cost-effectiveness of a multi-strategy intervention to increase ethnic uptake of CRC screening (FOBt and colonoscopy) during the second round of screening in the English Pilot.**

2. Relatively few studies have compared cervical and breast cancer screening uptakes in UK South Asian women. The ones that have demonstrate the importance of practice characteristics as well as those of the women invited for screening. We would recommend, therefore, that **research be undertaken to examine the relationship between ethnic minority CRC screening uptake patterns and those for other established UK cancer screening programmes (i.e. breast and cervical screening)**.

2.9 References - Section 2

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3. Uptake and Acceptability of FOBt Screening by Ethnic Minorities

Chapter Summary

Analysis of routine data

- Although the English Pilot achieved FOBt uptake of 62.2% (above the target of 60%), analysis of population uptake patterns shows that this masks a significantly lower uptake for the South Asian community.
- Of major concern is the particularly low uptake rate in the Muslim community (31.9%), compared to 63.7% for the non-Asian population. Even for the highest uptake Asian group (Hindus) only a 43.7% FOBt screening level was recorded.
- There is no indication of an initial unwillingness to be screened among the Asian community, in fact levels of FOBt refusers were lower than for non-Asians although numbers are small.
- Uptake rates do not demonstrate a pattern of higher uptake by women for Asian sub-groups; uptake is also lower for older invitees. These patterns are different from those observed for the non-Asian population.
- Low uptake rates cannot be explained by differences in factors such as age, gender, date of screening invitation, or deprivation index. FOBt uptake remains two and a half times lower among Muslims and Sikhs, and about twice lower among Hindus even if these other factors are taken into consideration.
- Significantly more individuals in the Asian community had not completed FOBt screening and were recorded as being ‘under process’. Linked to this, a higher proportion of Asians had been sent 4 or more kits. This may indicate problems with understanding how to use the kit, or with other mechanical aspects of the process of testing.
- Screening uptake rates amongst ethnic sub-groups were also related to GP attributes (in terms of religion and language characteristics of the clinician).

Psychosocial factors

- Information about behavioural risk factors indicated that Asians were at lower risk of colorectal cancer than White-Europeans. Asians perceived their susceptibility as lower, although they also appeared to be less aware of bowel cancer.
- Neither perceived susceptibility nor perceived severity of bowel cancer was associated with FOBt uptake amongst Asians, unlike the finding for White-European where non-responders perceived bowel cancer as more severe than responders.
- Although confidence in colorectal cancer screening effectiveness was very high, Asians were less confident than White-Europeans.
- The most important factors affecting FOBt response amongst Asians (as with White-Europeans) related to the ease or difficulty of completing the kit. Muslims reported particularly low self-efficacy with regard to completing the kit.
- Levels of anxiety and depression for all Asian survey participants were higher than population norms. Non-responders to FOBt reported more symptoms of anxiety and depression than those who did complete the kit.

Focus groups

- Focus group discussions in 'safe' environments were conducted for men and women of a number of ethnic/linguistic groups, offering information and support in exchange for participation.

- There was general support and even enthusiasm for the principle of advance warning (screening) for disease, and considerable levels of information sharing took place within the groups.

- Few concerns or reservations relating to cancer or screening were actively expressed, but this must be set against very low levels of professed knowledge or awareness of diseases or relevant procedures.

- The main barriers identified were perceptions of, or ability to cope with, mailed survey-type approaches or postal invitations to participate.

- Suggestions offered to overcome these problems included active awareness raising and community education campaigns, preferably linked to more familiar conditions and processes, such as those associated with diabetes, or 'practice on the sub-continent' ('back home', for older people).

- Responses were clearly linked to personal or family experience, and it can be ascertained that relatively few members of black and minority ethnic groups have experience of colorectal or other cancers.

- Focus groups offered themselves as a way of raising awareness, and following the discussions were keen to take part in screening, and to promote the idea - or suggested that use should be made of television 'soap operas' with which they were familiar.

- Group discussions within the area where screening was piloted detected high proportions of group members who denied receiving the invitation to take part.

- There were no significant religious or cultural difficulties identified (beyond issues of gender and age or household relationships), but there may be culturally specific ways of describing or expressing concerns and accessing information, which need to be responded to 'in kind'.

3.1 Analyses of Routine Data

3.1.1 AIMS AND OBJECTIVES

To analyse routine data downloaded from the pilot data sets to estimate uptake by different ethnic groups and investigate associations of ethnic descriptors with the following aspects of uptake:

- Decision to respond to the offer of screening
- Completion of phase 1 of screening
- Completion of screening
- Completion of screening in responders

3.1.2 METHODS

The stages of screening uptake considered in the ethnicity study were identical to those reported in the main evaluation. In brief these are:

i) *Decision to respond to the offer of screening*: At least one used kit returned (both adequate and inadequate kits included)
ii) *Completion of phase I of screening*: An initial adequate kit returned, giving a result of negative, positive or proceed to phase II (weakly positive)
iii) *Completion of screening*: An overall result of FOB testing available
iv) *Completion of screening in responders*: Definitions as above with denominator restricted to responders.

In addition, the English pilot site also allowed a further outcome to be explored:

v) *Declined screening*: Formal rejection of screening offer by return of refusal letter or telephone call.

3.1.2.1 Data download and preparation of data files for analysis

The data used for the analysis of ethnic uptake rates were extracted from a data download taken from the English Pilot site on 1/6/02; a total of 179,305 records were downloaded. These also formed the basis of the samples drawn for the ethnic psychosocial survey (see section 3.2.2.1). In addition, individuals' names, full postcodes and NHS numbers were separately downloaded to enable a religion and language indicator to be identified based on each individual's name using *Nam Pehchan*. A deprivation indicator (Carstairs index) was also obtained from each subject's full postcode and added to the main file.

A pilot *Nam Pehchan* run was first carried out on the download, enabling the linkages between the name file and the main screening activity data files to be tested. The language and religion outputs were also checked at a broad level by relating the *Nam Pehchan* output to initial analyses using corrected 1991 Census data for different localities in Coventry and Warwickshire; this provided a form of validation.

Following this, the screening activity data files were checked extensively, and records corrected to remove any inconsistencies e.g. the status of an invitee in the main record might be categorised as 'in progress' even though FOBt results had been entered in the laboratory record. In such cases the main record was corrected; these discrepancies occurred because there could be a considerable time lag (up to 2 weeks) before the main record was updated.

Analyses were undertaken using the same time cut-offs for measuring uptake to those used in the main evaluation. This enabled comparisons to be made. Analysis of response rates and of phase I completion rates were both restricted to individuals who had been sent their initial screening invitation more than three months before the date of the download, to allow sufficient time for kits to be completed and returned. Analyses of screening completion rates only included individuals invited more than four months before the date of download, to allow sufficient time for a final test result to be entered following completion of phase 1.

Table 3.1.1 shows the resulting population coverage at various stages of the colorectal cancer screening process. The Table indicates that screening uptake calculations were based on 139,850 individuals who had been sent their initial screening invitation more than three months before the date of the data download. These included individuals who were subsequently withdrawn for various reasons e.g. due to death, currently under treatment, removed by Health Authorities etc. Once these were removed this left a total of 132,992 individuals *eligible for inclusion* in the final analyses of stage i) uptake - decision to respond to offer of screening - and stage ii) uptake - completion of phase I of screening.

Table 3.1.1: Number of Subjects at Key Stages of CRC Screening Process

	Number
A. Population covered as of June 1, 2002	**179,305**
Individuals with no NHS ID number	359
Individuals for whom ethnic tag placed on record	**178,946**
Number of kit results (more than one kit & result possible for an individual)	103,552
Individuals who sent back kit	95,725
Individuals with Positive FOBt	1,677
B. Individuals with 3 months follow up (i.e. invited to March 1, 2002)	**139,850**
Individuals withdrawn (deceased, currently under treatment, removed by HAs, etc)	6,858
C. Individuals eligible for analysis of Completion of Phase I Screening (i.e. invited to March 1, 2002)	**132,992**
Individuals who returned at least one kit	82,746
Individuals with negative, positive or weakly positive kit results (Completion of Phase I)	82,216
Individuals with Positive FOBt	1,370
D. Individuals eligible for analysis of Completion of Screening (i.e. invited to February 1, 2002)	
Individuals with final FOBt result (Completion of Screening)	**78,206**

The number of individuals with a 4 month cut-off, eligible for inclusion in analyses of stage iii) uptake - completion of screening - and stage iv) uptake - completion of screening in responders - totalled 78,206.

3.1.2.3 Methods of analysis

Logistic regression analysis was used to explore associations between the measures of uptake and various ethnic and demographic attributes of the population; these included gender, age, invitation time, ethnicity and deprivation category. Both univariate and multivariate analyses were undertaken to produce respectively unadjusted and adjusted odds ratios (ORs) with 95% confidence intervals (CIs).

The five distinct religion-language groups identified using *Nam Pehchan* were: Hindu-Gujerati, Hindu-Other, Muslim, Sikh and Other Asian. As discussed in section 1.3.2 (and illustrated in Table 1.3.2) features that distinguish these groups from one another include the nature of their diet (vegetarian, non-vegetarian, consumption of red meat etc.) and their literacy levels, as well as their language and religion. The rest of the population was categorised as ‘non-Asian’.

Data on deprivation (Carstairs index) were obtained from the 1991 Census at disaggregated level and linked to the seven digit postcode of each subject’s residence. In 2.6% of subjects the data could not be matched, due to missing postcodes or formation of new postcodes during the intervening period, and thus the Carstairs index could not be computed for these cases. The cut-off values used for the Carstairs index are shown in Table 3.1.2.

Table 3.1.2: Carstairs Index: Deprivation Cut-Off Values

Deprivation Category	Cut-off Value
1	≤ -3.49
2	≤ -2.34
3	≤ -0.70
4	≤ 2.03
5	≤ 4.24
6	≤ 7.45
7	> 7.45

Interactions between ethnicity and deprivation were carefully investigated. Multivariate analyses were undertaken to include demographic factors; thus, ORs give estimated effects of ethnicity after adjustment for deprivation and other factors (age, gender, date of screening invitation).

The full postcodes provided were also used to link individuals to small geographical areas, thus providing a link to other socio-economic variables that measure the characteristics of the area in which individuals reside and allowing modelling of uptake in other parts of the UK (see section 6).

3.1.3 RESULTS

3.1.3.1 Overall patterns of screening status (see Appendix A5, Table A5.1)

In general, a *lower* proportion of 'Asians[5]' declined the offer of CRC screening (0.53% – 1.13%) than non-Asians (1.43%), except for Hindu-Gujeratis (1.97%). There was therefore no evidence that ethnic groups were less willing to be screened, although numbers were small.

Overall, 62.2% of invitees in the 132,992 individuals eligible for inclusion in the analysis responded positively to the screening invitation by returning at least one test kit (adequate or inadequate). Positive responses to screening were significantly lower among males than females, among younger invitees than those over 60 years, among Asians rather than non-Asians, and among people living in areas of greater deprivation. In particular, significantly lower response rates were recorded for ethnic groups (ranging from 31.9% for Muslims to 43.7% for Hindu-Others); versus 63.7% for non-Asians (see Appendix A5, Table A5.4).

Non-responder rates were, of course, higher in all ethnic groups (ranging from 53% for Muslims to 36.1% for Hindu-Gujerati), compared to 29.1% for non-Asians. However, ethnic groups also all demonstrated a higher percentage of cases still 'under process' (ranging from 27.7% for Other-Asians, 25.4% for Sikhs, to 16.5% for Muslims) compared to 6.6% for non-Asians. Those 'under process' are individuals who have still not produced a final FOBt result 3 months after their screening invitation; their 'current' status may be that they have returned a spoilt kit and been sent another one, that they are undergoing dietary re-tests, or that they have been sent a reminder because they have not yet returned their most recent kit.

3.1.3.2 Kits sent and kits returned (see Appendix A5, Table A5.2)

Linked to the latter finding, the number of kits sent to individuals in different populations (as a proxy indicator of the efficiency of the screening process) varied significantly; as did the number of kits returned by these individuals. A higher proportion of individuals in all ethnic groups were sent more than 1 kit; in particular, more Asians were sent 4 or more kits (between 6.8% and 27.7%) compared with 3.4% for non-Asians. Although the willingness of Asians to return 3 or more kits tails off, it still remains higher than the comparable figure for non-Asian population. These results may be indicative of problems in the Asian community with understanding how to use the kit, or with other aspects of the process of testing, as well as indicating a continued willingness to return FOBt kits.

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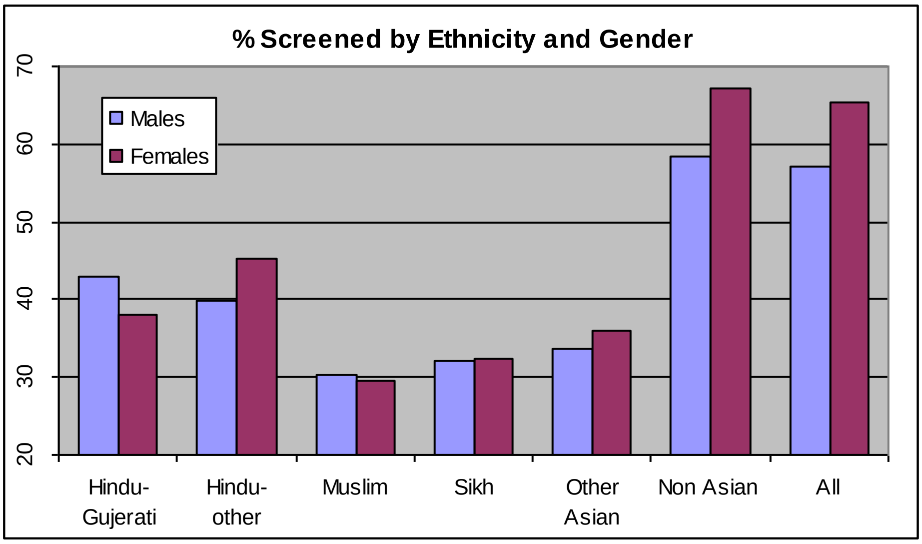
[5] The term 'Asian' is used in this report as a generic description for the *South Asian* groups identified by the *Nam Pehchan* software.

3.1.3.3 Screening status by gender, age and religion/ language group (see Appendix A5, Table A5.3)
Analysis of screening status by gender and religion/language, demonstrates a pattern of higher levels of completed screening for females than males in the whole population and in non-Asians. However, a different gender pattern is observed in some of the Asian religion/ language sub-groups (see Figure 3.1.1). A similar pattern to that for the whole population (i.e. higher female uptake) is only observed in the Hindu-Other population, whereas the reverse trend (i.e. higher male uptake) is observed for the Hindu-Gujerati group; other ethnic groups demonstrate little or no difference between male and female uptake.

Figure 3.1.1: Screening uptake by gender and ethnic group



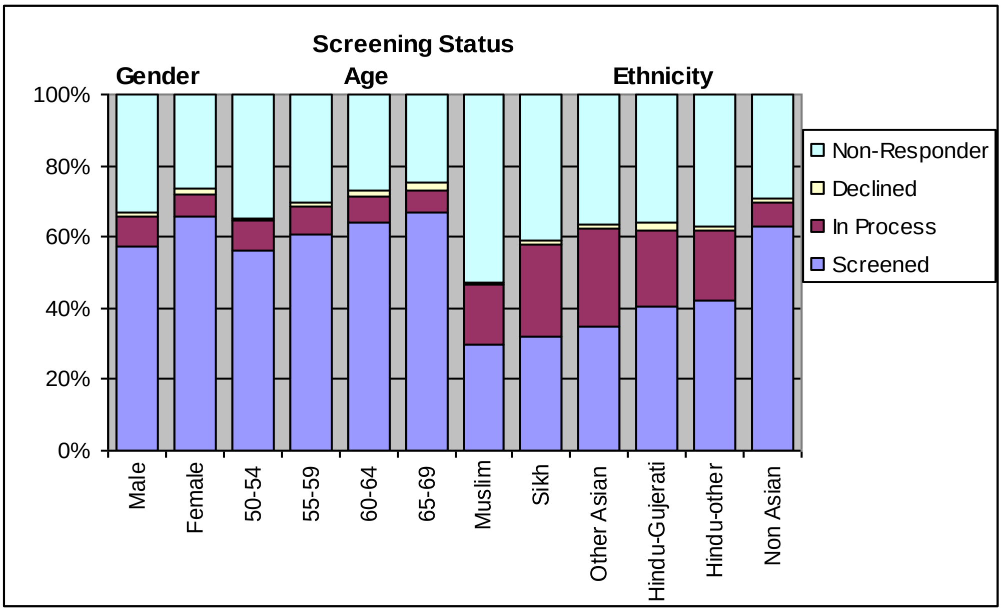
South Asian FOBt kit return rates by gender and age demonstrated different patterns from the majority population. Although for non-south Asians uptake was higher for women than men in all age groups, this was not true for south Asians. Similarly, the higher level of kit returns for older people observed in both male and female non-south Asian populations was not observable for Asian women.

3.1.3.4 Completion of phase 1 screening (see Appendix A5, Table A5.4)
Rates for completion of phase 1 of screening (i.e. return of an adequate kit, giving a result of negative, positive or weakly positive) show much lower levels for South Asian groups (ranging from 30.8% for Muslims to 43.2% for Hindu-Others); versus 63.3% for non-Asians. Multivariate analyses produce adjusted odds ratios that demonstrate a continued significantly lower uptake for all five ethnic groups at the p<0.01 level, even once other factors such as age, sex, invitation time and deprivation (Carstairs Index) are taken into account. These adjusted odds ratios indicate that the likelihood of uptake of screening is two and half times lower among Sikhs and Muslims and about twice lower among Hindus than their non-Asian counterparts; the situation becomes much worse when these communities happen to be living in the most deprived areas. The univariate (unadjusted) analysis shows even larger differentials by ethnic group.

3.1.3.5 Completion of screening (see Appendix A5, Table A5.5)
Completion of screening rates (i.e. production of a final, definitive FOBt result) are also significantly lower for ethnic sub-groups (ranging from 32.1% for Muslims to 45.4% for Hindu-Gujeratis); versus 63.7% for non-Asians. The odds ratios (adjusted and univariate, unadjusted) for completion of screening by gender, age, ethnicity, invitation time and deprivation of area of residence show similar patterns to those calculated above for completion of phase I of screening. Multivariate analysis once again demonstrates a significantly (p<0.01) lower uptake for all ethnic groups, even with these other factors taken into account.

The overall pattern of screening status for different ethnic groups is shown in Figure 3.1.2 below. This clearly demonstrates that although the different ethnic sub-groups vary in their individual profiles, although all sub-groups have a lower percentage of invitees who have completed screening and a higher proportion of cases 'in process' than the non-Asian population. Even were the proportion of 'in process' cases to be similar to those in the non-Asian population, this would not make the uptake for the various Asian sub-groups equal to that of the non-Asian population. For comparison purposes, the variation observed in the whole population for different age groups and for males/females were also displayed. These show far less variation than that observed for different ethnic sub-groups.

Figure 3.1.2: Screening status by gender, age and ethnic group



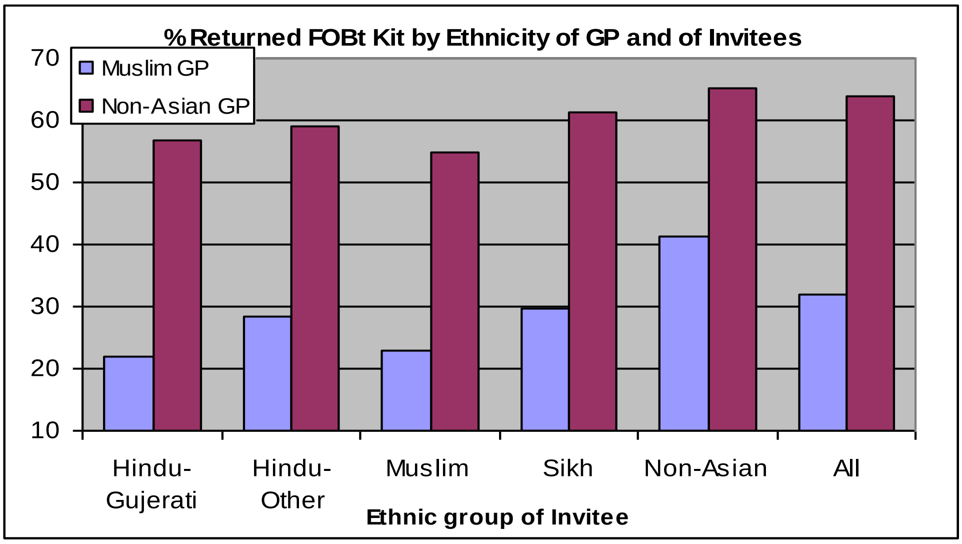
The rate of completion of screening *in responders* (i.e. in those who returned at least one test kit) shows a similar pattern (see Appendix A5, Table A5.5). The overall rate of completion is high for the whole population (99.4%). However, for the Sikh and Muslims populations, responders still demonstrate significantly lower completion rates (adjusted odds ratios 0.22 and 0.31 respectively versus 1.0 for non-Asians; significant at the $p<0.01$ level). For the remaining three ethnic groups the adjusted odds ratios are also lower (0.53 – 0.86), although they do not reach significance at the $p=0.1$ level. These results demonstrate that, even for those who respond by returning an initial FOBt kit, there would appear to be problems in most Asian sub-groups with some aspects of the process of FOB testing.

3.1.3.6 Influence of family physician (see Appendix A5, Table A5.6 and Table A5.7)

There is some evidence from the literature review, although largely from the US literature, that physician recommendation may be a predictor of FOBt screening uptake in ethnic minority groups, and that physicians from ethnic minorities may themselves be less likely to recommend screening. The *Nam Pehchan* software was therefore also used to identify ethnic attributes of GPs. In the pilot site, 99 out of 445 GPs were identified as Asian. When screening uptake behaviour of individuals is related to this GP attribute, some interesting features emerge. Figure 3.1.3 shows that uptake rates are significantly lower for subjects (regardless of ethnicity) registered with an Asian GP, especially when the practitioner is Muslim. The situation is found to be worst for Muslim subjects registered with a Muslim GP (only 22.8% returned a kit and 21.4% completed phase 1 of screening).

Comparison of the geographical location of practices, and CRC screening uptake rates for Asian and non-Asian populations in these locations demonstrates much lower variation between Asian areas. A meaningful number of Asian subjects were found only in six locations (Coventry, Leamington, Rugby, Nuneaton, Bedworth and Warwick) whereas their non-Asian counterparts were from 18 locations. The uptake rate for the Asian population varied from as low as 32.7% in Coventry to 48.3% in Rugby. In contrast, variation in uptake rate for non-Asian subjects by location were far greater (i.e. 55.8% in Kineton to 94.5% in Water Orton).

Figure 3.1.3: FOBt kit return rate by ethnic group of invitee & of GP



3.1.3.7 Influence of population and GP practice attributes (see Appendix A5, Table A5.8)

To explore possible reasons for the lower uptake of screening among the Asian population, multivariate analyses were undertaken that included *both* patient descriptors *and* selected practice attributes (e.g. GP ethnicity, size of partnership, and location of practice).

For the pilot site as a whole, uptake rates were lower for population registered with a single-handed practice (52.9%) as compared to those with a group practice (62.8%). Out of 147 practices, 33 were single-handed practices; of these, 22 (66.7%) were run by an Asian GP. There were also geographical variation in uptake rates (ranging from 58.9% in practices located in Coventry to 67% in Rugby).

The overall pattern of screening uptake for different types of practices is shown in Figure 3.1.4 below for Asian and non-Asian patients attending practices with different characteristics e.g. single-handed vs group practices, or in different locations. This indicates that Asian patients achieve lower rates of return of FOBt kits than non-Asians regardless of the characteristics of the practice.

Figure 3.1.4: FOBt kit return rate by GP practice attributes

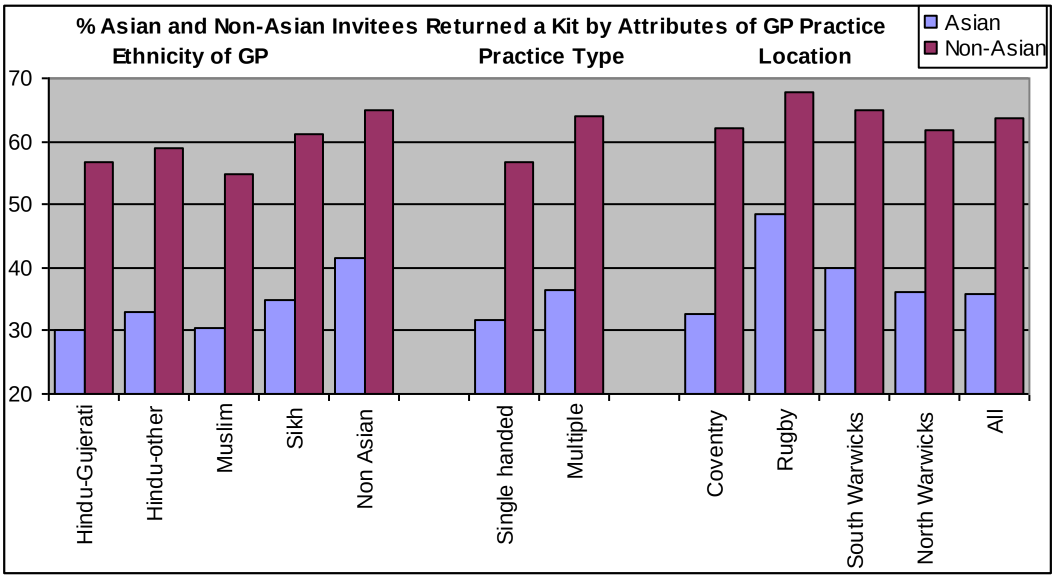


Figure 3.1.5 compares the distribution of Asian GP practices involved in the trial with the detailed geographical distribution of the minority population within Coventry and Warwickshire. Most Asian GP practices are located in the area of largest South Asian population concentration, centred on the Foleshill ward of Coventry.

For the multivariate analysis including *both* patient and GP/practice characteristics, the following patterns emerge when examining uptake rates (i.e. at least one FOBt kit returned):

1. Among the Asian population, unlike the non-Asian population, the uptake rate does not differ between men and women (the reverse of the trend in non-Asians), although it now increases marginally with age in both populations.

2. The likelihood of screening uptake declines with the level of deprivation but much faster among the non-Asian than Asian population.

3. Uptake rates among the Asian population appear to be less likely to be influenced by the type (single handed or group) and location of their GP practice, whereas a significant effect is observed for the non-Asian population.

4. The likelihood of uptake of screening among the different Asian populations is lower if they are registered with an Asian GP as compared to a non-Asian GP, but this only reaches levels of significance ($p<0.01$) for those registered with a Hindu GP. For the non-Asian population uptake levels are significantly lower ($p<0.05$) for those registered with all types of Asian GP, as compared to a non-Asian GP.

In summary, the ability of the population descriptors in the screening dataset (i.e. age, gender, South Asian ethno-religious groups, Carstairs deprivation index) and GP practice attributes (i.e. GP ethnicity, partnership size, practice location) to fully account for the low uptake of screening among different Asian populations appears to be limited. Therefore, one may need to consider other factors, such as cultural or educational differences, in order to explain the observed, significantly lower uptake of CRC screening among the Asian population. Factors such as those that have been reported to influence South Asian women's breast and cervical cancer screening uptake in the UK may be important i.e. poor record keeping; language needs; lack of knowledge of the screening service; extended visits to India; fear and embarrassment; professional perceptions; lack of active physician encouragement; and professional and lay perceptions, and resulting poor communication. Thus, the Asian community may need more targeted educational interventions, including motivation and persuasion from GPs, relatives, friends and their own social networks, in order to achieve equitable CRC screening uptake rates.

3.1.4 DISCUSSION

Data from the English pilot confirm that it is possible to achieve uptake of FOBt that exceeds the target of 60% achieved in the Nottingham trial; with a similar uptake figure for different age- and sex- groups (see Appendix A5, Table A5.9). However, there should be concern that the overall uptake figure masks a significantly lower uptake for the South Asian community, without any indication of an initial unwillingness to be screened. More detailed analyses indicate that:

- in general, lower levels of Asians declined screening than did Non-Asians, providing no evidence of an initial unwillingness to be screened in the Asian community (although it should be borne in mind that absolute numbers are small);

- of major concern are the numbers of Asians who did not complete screening, with completion figures up to half as low in Asians as among non-Asians. There are particularly low completion rates in the Muslim (32%) and Sikh (35%) communities;

- gender- and age-related uptake patterns appear to differ from those observed in the non-Asian population. A higher female uptake rate is observed only in the Hindu-Other population; higher male uptake is observed for the Hindu-Gujerati group; other populations demonstrate little or no difference between male and female uptake. Asian uptake also appears to be generally higher among younger invitees (the reverse of the pattern observed for non-Asians);

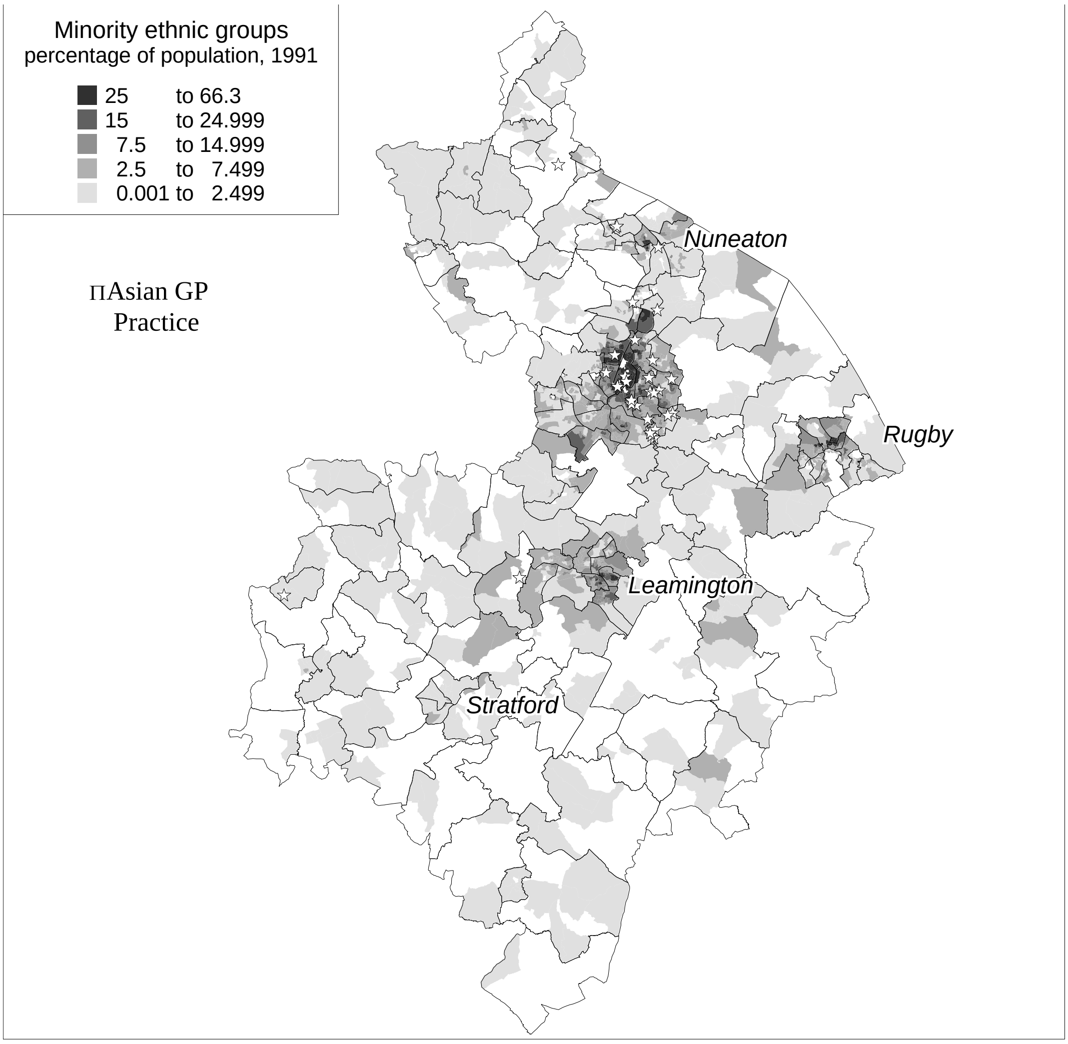
- the observed lower levels of uptake of FOBt screening in the Asian community cannot be explained by age- or gender- differences or other factors such as deprivation (Carstairs index). Multivariate analyses produce adjusted odds ratios showing that the likelihood of uptake of screening is still two and half times lower among Sikhs and Muslims and about twice lower among Hindus than their non-Asian counterparts even allowing for differences factors such as deprivation; the situation becomes much worse when these individuals happen to be living in the most deprived areas;

- significantly more individuals in the Asian community are also recorded as being ‘under process’; highest for Sikhs (25%) and lowest for Muslims (15.7%) than are non-Asians (5.8%). Linked to this, a higher proportion of all ethnic groups are being sent several kits, with the figure for 4 or more kits ranging from 6.8% to 27.7%, compared with 3.4% for non-Asians. These figures may be indicative of problems in the Asian community with understanding how to use the kit, or with other mechanical aspects of the process of testing (reinforced by responses to the psychosocial survey; see section 3.2.5). Even if the ‘under process’ figures were to be similar to that for non-Asians, the various ethnic sub-groups would still exhibit a lower FOBt uptake figure.

- there is some evidence that uptake rates are significantly lower for individuals (regardless of ethnicity) registered with an Asian GP. The situation is found to be worst for Muslim subjects registered with a Muslim GP (only 22.8% returned a kit);

From these analyses, we conclude that people in the Asian community are currently less likely to accept the offer of CRC screening by returning a test kit and, perhaps more importantly, even if they do accept it they are less likely to complete the testing protocol required. If multivariate analyses are undertaken that include *both* patient descriptors *and* selected GP practice attributes (i.e. ethnicity, type of practice and location of practice), the results indicate that the influence of patient demographic factors and practice attributes cannot fully explain the uptake of FOBt screening among the Asian population. Therefore, other factors (including cultural and educational ones) need to be considered to explain the low uptakes observed. It would appear also that interventions to increase uptake by South Asians will need to be targeted at GP practices as well as individual invitees.

Figure 3.1.5: GP practices and the minority share of ward populations



3.2 Psychosocial Surveys

3.2.1 AIMS AND OBJECTIVES

To conduct a retrospective survey of Asian invitees to FOBt utilising appropriate theoretical models and standard instruments with the objectives of:

1. Understanding beliefs and attitudes concerning response to FOBt versus non-response
2. Evaluating psychological distress following FOBt invitation
3. Comparing Asian versus White-European responses to FOBt.

3.2.2 METHODS

The preliminary analysis using Census data, carried out at the outset of the study to estimate the approximate total number of each ethnic minority group available for survey in the English Pilot site area (see section 1.3.1), indicated that the figures for all but one of the main Asian groups (Sikh) were approximately equal to (or less than in the case of Bengalis) the total number required for the psychosocial survey sample for that group. This preliminary analysis therefore demonstrated that those who had already been invited to screening by the time the ethnicity study started would also need to be included in the psychosocial survey in order to generate a large enough sample. This necessitated a *change of design to a retrospective survey* rather than the prospective approach initially planned.

The pilot *Nam Pehchan* runs confirmed that all the main ethnic minority groups (except the Sikh group) would need to be sampled in their entirety for the psychosocial survey, because they were relatively small.

3.2.2.1 Sampling

1. Samples have been drawn with the aim of achieving 250 survey participants amongst each of (a) Hindu-Gujerati (b) Hindu-other (c) Muslim (d) Sikh-Punjabi with the aim of including equal numbers of FOBt responders and non-responders. Ethnicity was determined by applying the *Nam-Pehchan* programme to patient surnames.
2. Sufficient numbers were only available for the Sikh-Punjabi group. A random sample was drawn from this population. For all other groups, a 100% sample was surveyed.

3.2.2.2 Protocol

The survey protocol recommended by Dillman (1983) was utilised to maximise participation rates. Those sampled are sent a) a questionnaire booklet and letter b) a reminder letter two weeks later c) a second booklet and reminder letter three weeks later. Participants to the survey were offered the opportunity to be entered into a prize lottery draw for a £50 voucher. The letter accompanying the questionnaire booklet contained a passage translated into 5 languages inviting people to seek the assistance of an English speaker if they required this in order to complete the booklet.

3.2.2.3 Questionnaire

The questionnaire booklet was a shortened version of that utilised for the main study. The questionnaire was scrutinised by specialist members of the ethnicity evaluation team and discussed with community centre attendees. Some changes to specific wordings were made following this pilot..

3.2.2.4 Participation.

Completed questionnaires were obtained from a total sample of N = 783. (87 Hindu-other, 194 Hindu-Gujerati, 191 Muslim and 311 Sikh-Punjabi).

The questionnaire participation rate varied considerably across responder groups. After adjusting the denominator for numbers of people who were unavailable or refused to participate and returned a blank questionnaire, participation rates were (a) Phase 1 non-responders 6% (b) Phase 1 negatives 48.8%. Participation also varied by ethnicity. Hindus were more likely to participate (Hindu-other = 35.5%, Hindu-Gujerati = 26.8%) than either Muslims (18.3%) or Sikhs (16.7%) (see Tables 3.2.1 and 3.2.2).

Comparison of questionnaire participants and non-participants showed that non-participants had higher deprivation category scores (see Table 3.2.3). There were no associations with age or gender.

3.2.3 RESULTS; UPTAKE OF FOBT: COMPARISON OF NON-RESPONDERS AND RESPONDERS.

3.2.3.1 Behavioural risk and uptake (see Appendix A6, Tables A6.1 and A6.2)

Approximately forty per cent of all survey participants reported never or rarely engaging in physical activity and about 10% were current smokers. Sikh- Punjabis were less likely to smoke than other groups (3.3%). Between 44 % and 55% of all participants were obese/overweight according to the BMI and between forty and fifty per cent of Hindus and Muslims reported a low fibre intake. Sikh-Punjabis were less likely to report a low fibre intake (33%). Hindu-Gujeratis, Muslims and Sikh-Punjabis were also less likely to report a blood relative with bowel cancer than White-Europeans. All risk indicators were lower for Asians than has been found amongst the main sample of White-Europeans.

FOBt non-responders were less likely to engage in regular exercise and were less likely to report knowing someone with bowel cancer or a family history of bowel cancer.

3.2.3.2 Perceived susceptibility to bowel cancer (see Appendix A6, Tables A6.3 and A6.4)

Approximately forty percent considered themselves to be at personal risk of developing bowel cancer. Levels of age specific optimism were quite high; just 47% of Hindu-others and 44% of Hindu-Gujeratis % perceived themselves at higher risk of bowel cancer than other people of their own age compared with 59% of Muslims. Perceived susceptibility was not associated with uptake of the test.

3.2.3.3 Perceived severity of bowel cancer (see Appendix A6, Tables A6.5 and A6.6)

We assessed both perceived physical severity and perceived psychosocial severity. Approximately two thirds of the sample considered bowel cancer painful and likely to cause physical sickness. Perceived severity was not associated with uptake of FOBt, although a significant association with uptake has been obtained for the White-European sample.

3.2.3.4 Perceived efficacy of FOBt in reducing cancer risk (see Appendix A6, Table A6.7 and A6.8)

Public confidence in the effectiveness of FOBt was very high across all groups. FOBt was viewed by over ninety percent of participants as likely to lead to earlier treatment, and by over eighty percent of participants as likely to detect abnormalities, prevent drastic treatment and reduce worry about bowel cancer. However, we did obtain significant differences between non-responders and responders. Non-responders were less likely to believe that taking part in FOBt would give them peace of mind and less likely to believe that FOBt would prevent the need for drastic treatment.

3.2.3.5 Perceived self-efficacy and barriers to completing FOBt (see Appendix A6, Tables A6.9, A6.10, A6.11 and A6.12)

Self-efficacy was an important determinant of FOBt uptake. Nearly 90% of responders perceived the FOBt kit as easy to complete and were confident in their ability to do so. However, non-responders were significantly less confident, with only 60% reporting that it would be easy for them to do the kit. Muslims were least confident of their ability to complete the kit. Table A6.11 shows specific difficulties in completing the kit. Difficulties related to constipation, irregular bowel movements, illness and lack of time distinguished non-responders from responders. No specific barrier explained the lower self-efficacy of Muslims.

3.2.3.6 Perceived psychological costs of completing FOBt (see Appendix A6, Tables A6.13 and A6.14)

Psychological barriers to completing an FOBt were important discriminators of non-respondents. Non-responders to FOBt were more likely to view completing the kit as an invasion of privacy (54%), embarrassing (67%), disgusting (58%) or unhygienic (56%). Hindu-Gujeratis also perceived the test as more disgusting and more unhygienic than all other groups.

3.2.3.7 Perceived social encouragement for performing an FOBt (Tables A6.15 and A6.16)

People often take the opinions of others into account when deciding whether to perform a behaviour. We included all the sources of social influence previously investigated amongst White-Europeans but also included ‘community leaders’ in the ethnicity survey. FOBt non-responders were less likely than responders to perceive encouragement from their partners or children. Perceived support from community leaders was low for both groups (64% and 69%). Hindu-Gujeratis reported the lowest levels of support and Sikhs the highest levels of social support for completing an FOBt.

3.2.3.8 Comparison of Asians and White-Europeans (see Appendix A6, Tables A6.17, A6.18, A6.19, A6.20, A6.21, A6.22 and A6.23)

Asians as a whole were less likely to take up FOBt than White-Europeans (section 3.1.3) so we examined absolute differences between the two populations. White-Europeans were more likely to be smokers, obese, have a higher fat intake and a lower fibre intake than Asians. They were also more likely to know someone with bowel cancer and have a family history of the disease. Interestingly these findings were paralleled by a lower perceived susceptibility amongst Asians. Asians and White-Europeans did not view bowel cancer differently, except in terms of pain. Whilst perceived severity was associated with uptake amongst White-Europeans, it was not associated with uptake amongst Asians.

Perceived efficacy of screening, self-efficacy and barriers, costs and social influence were significant discriminators of screening for both Asian and White-European samples. Asians also perceived screening as less efficacious, were less confident of their ability to complete the FOBt kit and perceived more barriers to screening. Asians also found the test more unpleasant to complete and some groups reported high levels of disgust and concerns about hygiene. Perceived social support was also lower amongst Asians. Support from community leaders was perceived as low, whereas support from GPs was perceived as high.

3.2.3.9 Future intentions and thoughts about roll-out (see Appendix A6, Tables A6.24 and A6.25)

Over 70% of FOBt non-responders and over 90% of responders stated an intention to complete an FOBt if they were offered one in the future. Asians were slightly less likely to agree that screening should be rolled out, particularly Muslims and Hindu-Gujeratis.

3.2.4 RESULTS: PSYCHOLOGICAL DISTRESS AFTER FOBT (SEE APPENDIX A6, TABLE A6.26)

Psychological distress was assessed using standard validated measures of anxiety, depression and anger, which have been used in previous studies of colorectal cancer, breast and cervical cancer screening impact. It should be noted that these measures have not been validated on minority ethnic groups, for whom specific norms are not available.

Levels of anxiety and depression for all Asian survey participants were higher than available population norms and higher than White-Europeans. Sikh-Punjabis reported the highest levels of depression and anger.

Non-responders to FOBt reported more symptoms of anxiety and depression than those who did complete the kit.

3.2.5 DISCUSSION

Although FOBt uptake was reasonable overall, there is clearly room for improvement. Moreover, uptake was substantially lower amongst Asians than amongst White-Europeans. The psychosocial survey may provide information which could assist in addressing inequality in uptake, and promote uptake generally.

The protocol followed standard practice to maximise survey returns; the instrument was scrutinised by ethnic minority members, a foreign language letter was included in the packages and 2 reminders and a lottery prize inducement were utilised. Nonetheless, the response rate to the questionnaire was less than optimal, and considerably lower than that obtained amongst the white-European sample. The lowest response rates were obtained amongst those groups with the lowest known levels of literacy. Notwithstanding this limitation, data were obtained from over 700 members of ethnic minorities, and provide data suitable for drawing comparisons with white-European respondents. It would have been inappropriate to utilise an instrument or approach that did not permit such direct comparison.

Information about behavioural risk factors indicated that Asians were at lower risk than White-Europeans and this was reflected in lower perceived susceptibility. It should also be noted that Asians may be less aware of bowel cancer, being less likely to report either knowing someone with the disease or having a blood relative with the disease. Notably, however, neither perceived susceptibility nor perceived severity of bowel cancer was associated with FOBt uptake amongst Asians. This is in contrast to the finding that White-European non-responders perceived bowel cancer as more severe than responders.

Public confidence in bowel cancer screening effectiveness was very high. However, doubts about its effectiveness in preventing death from bowel cancer and in providing peace of mind about bowel cancer did explain a proportion of variance in non-response. Moreover, Asians were less confident of the effectiveness of screening than White-Europeans. Maintaining confidence in screening will be an important consideration for a mass-screening programme.

The most important factors affecting FOBt response amongst both Asians and White-Europeans are those relating to the ease or difficulty of completing the kit. Muslims reported particularly low self-efficacy with regard to completing the kit. Constipation, irregular bowel movements and lack of time distinguished Asian non-responders from responders. Non-response was also associated with finding the process of completing the kit disgusting or embarrassing or having concerns about hygiene. Asians were almost twice as likely to report these concerns compared with White-Europeans. These emotional reactions may be linked to complaints of constipation or diarrhoea. It may be possible to address these barriers in communications sent to people with their kits.

We obtained no evidence of psychological distress following FOBt. Non-responders were more distressed than responders generally. However, Asians as a whole and Sikh-Punjabis in particular were significantly more distressed than White-Europeans irrespective of their responder status.

Table 3.2.1. Overall response rate to the ethnic psychosocial questionnaire.

		No response		**Returned Complete**		**Returned Blank**		**Unavailable**		**Total**
		N	%	N	%	N	%	N	%	
Hindu-Gujerati	Phase I Non-Responder	378	88.9	36	8.5	6	1.4	5	1.2	425
	Phase I Negative	152	47.	158	49.7	3	0.9	5	1.6	318
	Overall	530	71.3	194	26.1	9	1.2	10	1.3	743
Hindu-Other	Phase I Non-Responder	112	84.2	14	10.5	3	2.3	4	3.0	133
	Phase I Negative	46	837.7	73	59.8	2	1.6	1	0.8	122
	Overall	158	62.0	87	34.1	5	2.0	5	2.0	255
Muslim	Phase I Non-Responder	704	91.4	48	6.2	7	0.9	11	1.4	770
	Phase I Negative	148	48.5	143	46.9	9	3.0	5	1.6	305
	Overall	852	79.3	191	17.8	16	1.5	16	1.5	1075
Sikh-Punjabi	Phase I Non-Responder	1240	93.4	57	4.3	16	1.2	14	1.1	1327
	Phase I Negative	314	52.3	254	42.3	15	2.5	17	2.8	600
	Overall	1554	80.6	311	16.1	31	1.6	31	1.6	1927
	Overall Response	3094	77.4	783	19.6	61	1.5	62	1.6	4000

Table 3.2.2. Response rate to the ethnic psychosocial questionnaire– returned blank and unavailable removed.

		No Response		Returned Complete		Total
		N	%	N	%	
Hindu-Gujerati	Phase I Non-Responder	378	71.3	36	8.7	414
	Phase I Negative	152	49.0	158	51.0	310
	Overall	530	73.2	194	26.8	724
Hindu-Other	Phase I Non-Responder	112	88.9	14	11.1	126
	Phase I Negative	46	38.7	73	61.3	119
	Overall	158	64.5	87	35.5	245
Muslim	Phase I Non-Responder	704	93.6	48	6.4	752
	Phase I Negative	148	50.9	143	49.1	291
	Overall	852	72.1	191	27.9	1043
Sikh-Punjabi	Phase I Non-Responder	1240	95.6	57	4.4	1297
	Phase I Negative	314	55.3	254	44.7	568
	Overall	1554	83.3	311	16.7	1865
	Overall	3094	79.8	783	20.2	3877

Table 3.2.3 Overall comparison of survey participants and survey non-participants.

	Survey Participants		**Survey Non-Participants**		**Chi-square**
	N = 783		**N = 3094**		
	N	**%**	**N**	**%**	**χ^2, p**
Phase I Non-Responder	155	19.8	2434	78.7	976.244, p < .000
Phase I Negative	628	80.2	660	21.3	
Men	396	50.6	1538	49.7	0.187, ns
Women	387	49.4	1556	50.3	
Hindu-Gujerati	194	24.8	530	17.1	71.852, p < .000
Hindu-Other	87	11.1	158	5.1	
Muslim	191	24.4	852	27.5	
Sikh-Punjabi	311	39.7	1554	50.2	
Age 50-54	250	31.9	1077	34.8	6.946, ns
Age 55-59	177	22.6	737	23.8	
Age 60-64	204	26.1	674	21.8	
Age 65-69	152	19.4	606	19.6	
Depcat ½	97	12.6	244	8.0	81.314, p < .000
Depcat 3	89	11.6	204	6.7	
Depcat 4	198	25.7	561	18.4	
Depcat 5	123	16.0	552	18.1	
Depcat 6/7	263	34.2	1495	48.9	
Depcat1/2/3	186	24.2	448	14.7	40.117, p < .000
Depcat 4/5/6/7	584	75.8	2608	85.3	

3.3 Focus Group Studies

3.3.1 AIMS AND OBJECTIVES

The aims of the focus group discussions were to supplement the quantitative data obtained through routine monitoring and the questionnaire survey, and to obtain some insight into the possibly differing rationalisations of behaviour and motivation among members of minority ethnic groups whose cultural background was likely to differ from the majority white population. In particular, we sought to gain understanding of:

- Knowledge of, and attitudes towards, cancer (including bowel cancer)
- Attitudes towards the concept of screening
- Issues associated with participation in the FOBt screening process
- Suggestions as to how to increase or assure uptake of the screening

3.3.2 METHODS

Following previous experience and the evidence of research into sensitive issues such as cancer, addiction and sexual health among minority groups, the decision was taken to use a suitably modified form of the focus-group approach (Basch 1987; Johnson & Verma 1998; Hankinson *et al* 2002; Williams *et al* 1997). Locally recruited and normally bilingual fieldworkers were recruited, usually from among community or health promotion workers and provided with brief additional training in focus group methodology, use of tape-recording and transcribing, and information about colorectal cancer and the screening process. A similar approach was adopted in the USA for studies investigating ethnically diverse high risk groups for colorectal cancer screening (Bastani *et al* 2001; Beeker *et al* 2000).

Tape-recording of the proceedings assisted in the production of an edited and translated transcript covering the key points raised, verbatim reportage of clear statements, and commentary on the proceedings by the moderator. These were then reviewed by the analysis team and the ‘findings’ report fed back to the fieldworkers for their comment on the interpretation made of their work. The analysis procedure followed the approach of Glaser & Strauss’s ‘grounded theory’ methodology, building on iterative review of the texts and annotation of ‘emergent themes’. Themes were constrained within the framework of a topic guide agreed with the researchers conducting the psychosocial survey element of the study (see Table 3.3.1). This ensured consistency and comparability with the analysis of the main study, and allowed reporting largely in terms of the key issues explored in the Main Evaluation, of awareness and understanding of (bowel) cancer; acceptability of (FOBt) screening as an approach to health management; and responses to adverse outcomes and the need for further investigation such as colonoscopy. Groups in each case also made suggestions for future improvements to the management of screening programmes.

The focus group section represents a compilation and analysis of the data from transcripts of groups conducted with members of minority ethnic communities in the East and West Midlands (and, for Vietnamese/Chinese, South London) using the agreed Topic Guide.

Responses are condensed and summarised following the main emergent themes elicited in the focus group discussions, informed by experience in pilot discussions and debriefing of the facilitators of the groups.

3.3.2.1 Sampling

The selection of focus groups was purposive and opportunistic, in that we sought to cover the range of the major identified minority ethnic groups known to be likely to demonstrate distinctive cultural (and/or linguistic) patterns in health (Modood *et al* 1997; Johnson *et al* 2000), within the constraints of the budget and the availability of communities accessible to our methodology. In total, around 150 men and women were included in our 21 discussion groups (some arriving late or leaving early).

Table 3.3.1: Ethnic Minority Focus Groups –Topic Guide.

Offer short briefing: the research is helping the Health Service to develop its screening services. Screening is a way of helping people to find out if they are at risk of developing a disease, before it becomes obvious. If signs are found, they can be treated earlier, and this may help to stop the disease from developing. In particular, we are looking at something called Colorectal cancer, which affects people's bowels.

Explain that: there will be an opportunity for them to ask questions, and to be given a leaflet and information about the disease at the end, and contact details for other help.

1: Knowledge (and fear) of cancer and bowel disease in general

☐ What do people know, or feel about cancer, in general?
☐ Do people know anything about 'bowel disease' – does this worry them?
☐ Some diseases are more common as people get older – what is this group most concerned about?

2: Attitude towards screening/ learning about disease risks and personal health status

☐ Is it better to know about your risk of developing a disease?
Would you prefer not to know until it happens? ('Don't ask, Don't tell'?)

☐ If there was a test for (any) disease, would you try to take it, or would it depend on how afraid you are of that disease

☐ Or are there some diseases you would be too worried about to ask for a test?

3: Specific knowledge of Bowel Cancer – term 'Colorectal'; implications.

☐ Have people heard of Bowel Cancer or 'Colorectal cancer' before?
☐ What do you know about it – or think these might be like

(If possible, explore their feelings about:
Symptoms; Prognosis/Risk; Cause; Avoidance; Treatment – effects.)

4: Knowledge about possibility of screening for Bowel cancer – FOBt, Colonoscopy

☐ Does anyone know about screening for bowel cancer – explain if not, the difference between FOBt (looking for invisible blood in the faeces/ 'poo') and colonoscopy – putting a tube with a camera inside you to see if there are any growths. Reactions?

Brief group about the Screening Programme (see handbook) as much as needed…..
(this may include showing diagram of the bowel, explaining the procedure of being sent a card to put a sample on, and posting it back to the hospital).

NOTE: The screening has so far ONLY been done in Warwickshire and Coventry, to see whether people support it.

5: Possible reasons for avoiding/ not taking part in screening:

☐ How do people feel about the procedure as we have described it?
☐ Any reasons why they might not respond to a letter inviting them to take part?

* Fear / denial of severity of disease/ level of threat & impact on social life
* Distaste over notion of (FOBt) testing,
* Religious scruples over (dealing with) waste matter
* Other worries about hygiene ('it is dirty')
* Avoidance (rather not know - ? is this general for all screening?)
* Lack of confidence in the screening test (it would make no difference)
* Belief that disease itself cannot be prevented/ cured/ treated (it is of no value)
* Fear of follow-up investigations (e.g. Colonoscopy) or of Treatment
* Practical problems of conducting test – storage, timing, bowel habits

Table 3.3.1 (contd): Ethnic Minority Focus Groups –Topic Guide.

6: Explore possible reactions to getting test results (How might you feel…)

☐ Fear that it may be too late to do anything
☐ Relief that it might have been caught in time
☐ Shame
☐ Worry that next test might be painful, or lead to bad result
☐ Concern that the test result might be wrong

7: Do you know anyone who has had / done test; had positive result;
☐ (or indeed, anyone they know who may have had cancer of bowel);

(we don't want to know their names etc, but to see how widely this sort of experience is shared among the community) (This may have been answered: don't repeat).

8: General question on fears and information needs

☐ Ask if there are any questions that we have not yet answered, anything they have heard people talking about that might need to be explained….

9: General question on how to get people to take part in screening programmes dealing with difficult subjects like this.

☐ If you had to try and get people from (your community) to take part in (any) screening, what do you think would be the best way to encourage them to do it?

FOR COVENTRY/WARWICKSHIRE/LEAMINGTON ONLY: Has anyone on the group had one of these invitations? What did they think about it then? (What did they do – if they'd like to tell the interviewer afterwards!!)

10: Offer of further help/ information and assurance of confidentiality, offer to see people afterwards to discuss any problems, or any 'after thoughts' they'd not been able to say at the time. Explain they can send anything to us they think about later.

While we have taken into account the Asian category groups which emerge from the use of the *Nam Pehchan* programme (i.e. Muslim, Sikh-Punjabi; Hindu Gujerati; Hindu-Other) we were unable to identify a specific 'Hindu-Other community (i.e., principally, members of Non-Sikh Punjabi-speaking and possibly South Indian groups). Furthermore, the Muslim group is primarily drawn from two distinctive national origins speaking very differing languages: the Pakistani/Kashmiri group speaking Urdu or a closely-related dialectal variant of Punjabi (including Pahari, Kashmiri etc), and the Bangladeshi-origin group, who predominantly speak the Sylhetti dialect. We were also able to interview Muslim Gujerati speakers and a minority group of Muslim Khatri women.

The 'Black/Black-British' group identified in Census returns and other studies of minorities in the UK were represented by groups of African-Caribbean ('West Indian') origin. We did not explore the specific dimensions of African-origin communities, who are largely to be found in South London. Similarly, the 'far-Eastern' societies were represented by members of the communities of Vietnamese origin, which include almost equal numbers of speakers of Chinese (Cantonese/ Mandarin/ Han/ Hakka), and Vietnamese.

The project protocol did not allow for consideration of minority groups of European origin such as the Irish, Italian and Polish communities, or those of Traveller / Gypsy background.

An overview of groups convened (with ID labels) is provided in Table 3.3.2 below.

Table 3.3.2: Groups Covered, and Numbers of Participants

Bangladeshi (Bengali):
- Men – two groups of 26 in total, all aged over 50, **(BBM a and b)** Birmingham
- Women – two groups of 18 in total **(BBF)** Birmingham

Vietnamese/Cantonese: – two mixed groups of about 10, Lewisham **(LVC)**

Punjabi Sikh:
- Men (**CPM** - 7, **SPM** – 12, **LPM** - 8) Leamington Spa, Coventry, Leicester
- Women (**LPF – 8**) Leicester

Gujerati
- Men (**LGM** – 7 men, **CGM** – 7, **LHM** - 5) Leicester, Coventry
- Women (**LGF** – 6 women, **LMF, LHF** - 6) Leicester
- Muslim Khatri Women (**LMF**) - Leicester

Pakistani/Urdu (Kashmiri):
- Men (This group had to be abandoned following several meetings re-arranged around Ramadan, following illness in the facilitator's family).
- Women (**LUF1** - 6, **LUF2** - 7) Leicester

African-Caribbean
- Men (2 groups - **CAM**) Coventry
- Women (2 groups - **CAF**) Coventry

3.3.2.2 Topic Guide

The Topic Guide (see Table 3.3.1) was developed by discussion within the 'ethnicity' team and piloted with staff and friends from minority ethnic backgrounds prior to recruiting fieldworkers who were to conduct the focus groups. We were also able to draw upon discussions with Punjabi Asian and African-Caribbean elders when piloting the psychosocial survey questionnaire in Leicester. Copies of the Topic Guide were circulated to all members of the evaluation team. A few minor modifications were made following the training session held with the first field-workers.

The guide was intended to be used as a prompt checklist, rather than as a set-down script for the discussions, and fieldworkers made adaptations as required including additional questions and prompts, and translation into the language(s) of their groups. Presentations of information about colorectal cancer and the screening process were incorporated into most of these events, drawing on the pack circulated by the Screening Pilot team at Rugby to all health care professionals in the screening area, Asian-language information leaflets on bowel disease prepared by workers in Leicester in the stoma-care team (translations from Pullen M [no date]) and the Beating Bowel Cancer leaflet 'Don't Sit on your Symptoms'.

3.3.2.3 Conduct of Focus Groups

Focus group discussions were held, where possible, with members of existing social networks (natural groupings), and if possible within the frame and format of 'normal' meetings of the group e.g. at a West Indian Domino club; Vietnamese lunch-club for elders, etc) and moderated by the trained fieldworker who was normally already known to the group. The focus group was usually conducted in the normal ‘home’ language of group members (which may have been a mixture of English and another tongue). Groups were generally gender-segregated to facilitate easier discussion of sensitive topics.

Examples of the circulated FOB test kit were used in these groups and information given about the disease and screening process, as part of the stimuli for the discussions. These were phased to ensure that un-forced comments were recorded first, and that subsequent discussion could be based on some knowledge – especially as many of the discussion groups had to be held in locations outside the screening pilot, where communities had not been sent postal materials. Where focus group interviews were held with groups within Warwickshire /Coventry, enquiries were made as to receipt of the formal invitations to participate. It appeared that some at least of the eligible participants reported that they had not yet seen the postal invitation. One (African-Caribbean female) reported that the invitation arrived while she was abroad, and this was why she had not taken part. Three members of the Sikh community in Coventry asked us to follow up their non-receipt of test kits, but the pilot project was unable to provide further mail-outs of kits by that time. Explanatory letters were written, and respondents advised to attend their GP for tests, if they were still concerned.

3.3.3 RESPONSES

As a general rule, there was (at least theoretical) support and even enthusiasm for the principle of screening among most minority ethnic communities. Few people, once the principle had been explained, thought that there was, or should be, a problem with completing the test. Many suggested that ‘doing it at home’ was a more convenient and acceptable method than having to report to a hospital. However, at the same time, it was clear that many members of minority groups would not respond to postal invitations unless prior warning had been given and community-relevant sources had alerted them to the value of the activity. Low levels of literacy meant low awareness or reliance on others (such as children) to advise about postal material, and some said that their children protected them against intrusive surveys and the like. We did not find the anticipated level of resistance to FOBt screening on the grounds of hygiene or religion, although there were some questions about ‘storage’.

It became apparent during the course of reviewing the focus group transcripts that, in general, there were fewer differences between the ‘ethnic groups’ involved than between groups which contained someone who was relatively well-educated or had been affected by a family member (or personal) experience of cancer, and those which were less well informed. Clearly, there were points at which ‘ethnic-specific’ culturally linked responses were made, but as a general rule, there was a considerable degree of consistency between the groups in the way they discussed the issues. We have therefore presented the results according to the themes of the discussions. More detailed text (including quotations) is presented in Appendix A7 for certain themes. Where this is the case, this is indicated at the beginning of the discussion theme section.

3.3.3.1 Knowledge (and fear) of cancer and bowel disease in general (see Appendix A7 for more details)

In nearly every community there was some prior knowledge about ‘cancer’, and agreement that this was a fearsome and probably inexorable disease with fatal consequences, which had many forms and could attack different parts of the body. An early reaction was that the patient with cancer was in God’s hands, and that death was possibly inevitable. However, a few people were able in some of our groups to challenge the consensus, and it is evident that knowledge is spreading and attitudes changing.

That said, it was clear that the majority were aware that there is a natural history of cancer, which implies at least that an early recognition and detection may lead to better outcomes. There was also clearly a consensus that cancer was a hard thing to discuss, and some discussion as to whether there was a word for it in their own languages. The English word was probably at least as familiar, although there was much less awareness of other technical terms.

3.3.3.2 Attitude towards screening/ learning about disease risks and personal health status (see Appendix A7 for more details)

As began to emerge during the earlier discussion of broad prompts regarding general levels of knowledge and fears about cancer and other bowel disease, the notion of preventability and early intervention was certainly known and approved of in all groups. There was, despite some reference to the hand or will of God, no belief that ‘fate’ was inexorable or should not be changed by personal action.

There was also, clearly, some sophistication in understanding that screening was not a ‘once for all’ event, but only part of a longer-term health maintenance plan, and with its own shortcomings as well as the potential to avert future disaster. Even among the men, it was clear that knowledge of their wives’ experiences (and opportunities) affected their attitude towards the possibilities of screening.

Overall, we may see that screening and advance information about health risks was regarded as a helpful aid to personal health maintenance, and that a positive attitude to participation was expressed by virtually all groups (with individuals inevitably differing), although this could be affected by levels of awareness of risk or, perhaps more importantly, the possibility of successful intervention.

3.3.3.3 Specific knowledge of Bowel Cancer – term ‘Colorectal’; implications (see Appendix A7 for more details)

Although a few people had indeed themselves had, or been screened for, bowel cancer there was almost no knowledge about the disease or its implications, although some ‘guessing’ and as the discussion developed, rather more people did refer to bowel or colorectal cancer. However, at the start, virtually no-one recognised the term ‘colorectal’ and bowel or intestinal cancer was one of the least-commonly mentioned in the early discussions about the nature of cancer.

Levels of knowledge were, however, slightly higher in Coventry/Warwickshire, where it was apparent that several people had received information connected to the national FOBt screening programme.

3.3.3.4 Knowledge about possibility of screening for Bowel cancer – FOBt, Colonoscopy (see Appendix A7 for more details)

With the exception of the one woman in Leicester, knowledge of any means of screening or examining for signs of bowel disease was confined to discussion of individuals who had had a ‘camera’ introduced into their anus or mouth, or a barium test, to look for causes of disease once they had been referred with other symptoms. Most groups, eventually, turned out to know of one such example, although this was not always associated with Bowel disease, or indeed, necessarily with cancer, and certainly was not a form of pro-active symptom-less screening. That said, there was in our discussion groups a full and apparently relaxed discussion about some of the investigations which individuals had undergone.

At the end of nearly all the sessions held in Leicester and Birmingham there was a significant demand, or at least enthusiasm, to take part in future trials.

3.3.3.5 Possible reasons for avoiding/ not taking part in screening (see Appendix A7 for more details)

Once the FOBt procedure had been described to the members of the focus groups, they were asked explicitly whether there were any aspects of the process which might lead them to refuse to take part, or why else they ‘might not respond to a letter inviting them to take part’. Interestingly, the general response seemed to be that while they might not have done so, before having had the explanation and learning about the disease through the earlier discussion, the members were more inclined to respond positively after the description of the process, than hitherto. That said, there were members of the groups who expressed some worries, and one or two who had aesthetic concerns, as well as a few who if not fatalistic, were unconcerned about their health, having experienced few if any scares. Others regarded the taking part in such a communal activity as mass screening as part of their duty to the community as a whole – a very distinctive reaction, which resonates with certain core values among most of the minority ethnic groups.

Others, however (perhaps the majority) suggested that they would not be interested in taking part unless they had some idea of the overall or personal importance and value of taking part – reinforcing the need for a general awareness-raising programme before any future screening. Most, including the men, were not worried about the possibility of having to handle their waste matter. A major problem expressed by many group members, however, was about literacy: while some could read Asian languages, and it was felt important that letters and leaflets be translated, the impact of written communications even among those who could read, was said to be low. Post was clearly an issue in some Asian households – where children and husbands may also exercise some control or protect their family from unwanted mail, particularly if literacy is an issue.

3.3.3.6 Explore possible reactions to getting test results (How might you feel…) (see Appendix A7 for more details)

A concern explored in some detail in the main survey psychosocial questionnaire was the possible reaction of participants to receiving adverse diagnoses. This could affect the likelihood of completing the tests, if fear of knowing was too great. The general view among minority ethnic participants was that this was only to be expected, and it was better to know, and to face up to fears, than to live in ignorance. The most important factor was the availability of some form of treatment, and a belief that earlier intervention would raise chances. This did, however, depend on the confidence that people had in their doctors or local hospitals – and this was not universal.

There was general agreement that waiting for, and receiving, test results could be stressful, but equally, this was not thought to be a reason to avoid taking part.

See Appendix A7 also for responses on 'General question on fears and information needs' and 'Other issues' (e.g. gender and religion).

3.3.3.7 Experience of Participation in the Coventry/Warwickshire Pilot

For the focus groups which were conducted in areas where CRC FOBt screening invitations had been sent out, and where at least in theory all our respondents should have been screened, we asked the groups if they recalled receiving the invitation or test kit, and if so, what their reaction had been. (It was made clear that we did not wish to know their outcomes, and they could share this information with the facilitator after the meeting, in order to preserve confidentiality). The timing of the discussions was such that we did not start the focus group programme until after the completion of all primary invitations and most of the reminder and recall letters had also been sent out, in order to avoid creating any possible bias or affecting the response rate for the main study through changing the level of awareness and knowledge among minority communities, as compared to the white majority population.

Most of the members of the groups were clearly aware of the programme and either had themselves received a kit, or know of others who had done so. However, a significant number denied ever having personally received one. In one group of 11 men, four reported that they had not been sent a kit or invitation, and three of these asked the facilitator to expedite the process, leaving him their names and addresses. We were able to follow these names and addresses up with the screening co-ordinator, who identified that none of the names were recognised on the project database as having been sent invitations, but that one of the addresses was recognised and the (apparent) wife of the man had been sent an invitation. Without more detail on their precise ages, any house moves, and possibly asking about alternative spellings or presentations of their names (a significant problem for the NHS among many Asian communities) we were unable to resolve this further. As by this stage the screening programme was winding up, and had no spare kits (‘in date’) to send out, letters were sent to all these men, explaining that the current phase of the screening programme had ended, but that if they were concerned, they could visit their GP and ask for a test.

For those who had been invited (or remembered this) the experience was generally stated to have been positive. Indeed, the enthusiasm expressed seems greater than might be attributed to courtesy bias, and most groups then went on to suggest ways in which the efficacy of the screening programme could be improved. None felt that it was a bad idea, and there was general agreement that the procedure had been relatively simple (in their view) and that the outcomes had not been as bad as might have been feared:

> Almost all of the (12) participants were aware that the screening programme was taking place and all confirmed receipt of the kits. 4 out of 10 said that they had completed the test … all said ‘they felt obliged to carry out the test’. Of the ones that did not complete the test, explanations ranged from ‘did not feel a need’ to ‘fear of discovering cancer’. (SPM)
>
> Of the 4 that did complete the test, they felt extremely happy when their results indicated no sign of cancer. (All) confirmed that they found the test quite simple to do (SPM)
>
> Me and the old man got involved in the test and sent it back – both of us are well, tank goodness (CAF)
>
> Three participants indicated that they had personally read the leaflet (sent with the invitation) and that they were far too long … The four that did complete the test (out of 7) and had received feedback said they felt extremely fearful between the period of sending in the samples and receiving the results. All felt very happy on finding out their results indicated no sign of cancer. One was still awaiting feedback.

> All felt that the procedure was very easy to follow, although two did have the assistance of their children (CPM).
>
> ‘Yes! I did – and I did it –
>
> (*What did you think of the process?*) I thought it was brilliant /
> I received a form through the post, filled in the form, and then was summoned for a test in Rugby /
> I ignored the first time but took it up the second because it was explained to me and its my body, my health (*general noises of agreement*). (CAM)
>
> It’s a frightening thing to do because you might have to change your life, but I feel better for doing it (CAF)
>
> At first we find it funny but we know it’s important because of our age. It wasn’t too bad if you didn’t think about it too much. I think he felt more uncomfortable really, but I think he felt better ‘cause I was doing it too (CAF)

3.3.3.8 How to get people to take part in screening programmes.

At the end of the discussion groups, we asked group members to reflect on the best way to make such screening programmes and other health promotion more effective. Most were very positive about the role played by the facilitators and the focus group process itself, and others made highly practical suggestions. In general, these reflected advice given in earlier studies about health promotion with minority communities, focusing especially on the role of the (‘ethnic’) media, the greater immediacy and accessibility of oral and visual messages over the written word; the essential importance of using translation and scripts that signalled relevance to specific language communities, and the need to work through family members and to educate the whole community. Bilingualism, and recognition of the ‘home’ language were both important, as was choice of the style of language. Community centres and community-based activities remained central to communication with individuals. It was also clear that, especially among the older generation, letters and written communications (including leaflets) were often ignored or at least only accessed through younger members of the family – who would need to be alerted to their importance or else they may ‘protect’ their elders by putting the mail in the bin. Endorsement of the validity and significance of the message (such as by local respected medical practitioners) might also be needed in some cases.

> Leaflets do not tell us what we want to know – this sort of setting is much better. Television is nice also (LGF)
> The Punjabi leaflets are too difficult to understand, they are written in a very complicated Punjabi and need to adopt a simpler style (SPM)
>
> Individuals like you explaining to groups like us are more effective than just sending letters in different languages (LUF)
>
> It will go straight in the bin. We would know more about it from people at BNC (the neighbourhood community centre) verbally. We would inform the neighbours because we have heard about this but the rest would not know. Our children would think it is junk mail and would put it straight in the bin (LGF)
>
> Most of our older children are at home before we are and so if they see the post when they come home from school they can alert us to this mail. The older children can be very persuasive to get their parents to have this test. They could be very influential and can act as mediators for education of the elders. This can be useful also if the information is in English. (LGF)
>
> Children/Carers need to be educated (SPM)
>
> Having members of the same sex to explain about the sensitive issue is essential, as even within the family, women do not discuss personal women’s issues with their sons, fathers … If they were to provide with explanations via community workers, nurses within GP settings, health promotion workers within local settings in appropriate language (LMF)
>
> Some members will not participate if not well informed. Especially if they do not read or write in any language and rely on others to pass information on to them (LUF)

> If you do a thing on the TV at the end (of) a high profile programme that a test will be sent through the post, and repeat it several times – I think the message will get through. It will need to be after a very important programme, after the news or something. All our people watch the news, whether in English or Gujerati (LGF)
>
> Target MATV, SABRAS, BBC Asian Network, community newsletter … (LUF)
>
> To tell you the absolute truth it needs to be in Gujerati. A verbal message for about 2-3 minutes on the media such as MATV in Gujerati or Hindi would be helpful for most of our community, Most of our people watch MATV. (LGM)
>
> Asian media (TV radio and press) was an excellent means of communicating information … they were more likely to respond positively if the message was delivered by bilingual Asian health professionals (CPM)
>
> If the doctor does not tell them about it also, they may not do it. So it will need some kind of local endorsement from the local hospitals for them to trust the test (LGF)
>
> Peer education and people coming to talk will also help, not just leaflets. Most people come here (Neighbourhood Centre) for their meals and to learn things. Many do not read so leaflets alone will not help. They are elderly. (LGM)
>
> Radio and TV in Hindi and Punjabi. Explain that the test will arrive in the post and encourage participation – Awareness should be raised first before the screening is carried out otherwise the test will be thrown in the bin (LPM).
>
> But most important is having verbal explanations about the reason/benefit for the test. Local information programmes (are) more likely to work than a blanket approach (LMF).

3.3.4 DISCUSSION

While the above transcripts and discussion illustrate a number of themes, such as fear of knowing about health outcomes, hygiene and contamination, and self-efficacy, which are common to all populations and societies, it is clear that these are often expressed in very culturally specific ways. There are certain issues which may be true for ‘white’ majority populations (such as literacy and access to incoming post) which have emerged as if they were specific to groups where family dynamics and literacy are apparently distinctive. In this, we may simply have highlighted issues which are not discussed in the majority community, or which will become less significant as migrant populations take on the characteristics of a ‘modern’ society. Nevertheless, certain themes which were elicited in our reading of the academic and practice-based research literature from America recur here, and in general across the minority ethnic groups of our sample. In particular, low levels of knowledge and awareness are commonplace, and there is a strong requirement for intensive community-based education to raise awareness and salience before embarking on any future screening activity. This needs to be conducted through ‘peer’ or ‘role-model’ structures, and many very practical pieces of advice were presented to our facilitators. For each cultural community, this will need to be tailored, and reassurance provided that health professionals will be aware of, and competent to handle, the needs of individuals from those backgrounds. While there is strong general faith in the validity of the health professions, there is also strong awareness of individual practitioners’ weaknesses, so prior educational preparation will also be required (and know to have been provided) for them too.

Although we have attempted to cover a variety of religious and linguistic/cultural groups in separate discussion groups, the overwhelming impression is that the majority of their concerns were shared, albeit framed in distinctive ways, and by reference to different sources of legitimacy (Koran, Temple, family, homeland). The relative salience of particular issues (e.g. gender) may vary slightly between groups, but in all cases there was a concern that their particular and specific identity should be recognised and respected. It is also fairly clear that while their concerns may be shared, a single ‘one size fits all’ response would not be reassuring, and that these concerns will need to be addressed explicitly for each.

Overall, the minority communities surveyed, while having individual concerns about the `practicalities of the screening programme, were highly positive about the value of being involved in it, and enthusiastic about helping to promote it in future. Any future programmes should build upon that sort of local support, which can undoubtedly be elicited in other locations, by drawing upon narratives which are grounded in the culture of each community. Any approach which simply replicates a 'scientific' and impersonal approach without prior preparation risks being ignored, and if adequate preparation of support services (and sensitivity to specific cultural needs, especially around gender) is lacking, then adverse messages will be quickly transmitted throughout communities which are clearly very cohesive and possess their own mechanisms for internal communication. Without strong and positive messages supported by valued and appropriate sponsors, rumours and uncertainty can flourish and will have an adverse influence on the outcome of future health-related initiatives.

3.4 Conclusions and Recommendations

3.4.1 CONCLUSIONS

Although data from the English pilot confirms that an overall FOBt uptake above the target of 60% can be achieved, this masks a significantly lower uptake for the South Asian community. There is no indication of an initial unwillingness by Asians to be screened from analysis of the screening Pilot data, and this is confirmed by focus group findings. However, calculated uptake figures demonstrate that people in the Asian community are both less likely to return a screening test kit and, even if they do return one, less likely to be able to complete the testing protocol. FOBt uptake figures are up to half as low in Asians as among non-Asians, being particularly low in the Muslim (31.9%) community, compared to 63.7% for the non-Asian population. Even for the highest uptake Asian group (Hindus) only a 43.7% level was recorded.

If multivariate analyses are undertaken that include *both* patient descriptors *and* selected GP practice attributes (i.e. GP ethnicity, size of partnership, and location of practice), the results indicate that the ability of these factors to account for the low uptake of screening in different Asian populations appears to be limited. Therefore, there is a need to explore other factors, such as cultural and educational ones (for patients) and administrative and organisational ones (for practices), in order to explain the observed, significantly lower uptake of CRC screening among the Asian population. It would appear that in order to achieve equitable uptake rates the Asian community needs interventions targeted both at ethnic minority individuals and their GP practices.

The psychosocial survey indicates that Asians are less aware of bowel cancer, and less likely to know someone with the disease. Also, neither perceived susceptibility nor perceived severity of bowel cancer are associated with FOBt uptake amongst Asians, in contrast to the White-European population. This mirrors findings from the USA on risk perception and the lack of any relationship to FOBt uptake in ethnic minorities (321, 482, 359). Asians in the Pilot site are also less confident of the effectiveness of screening than White-Europeans. Therefore, establishing and maintaining confidence in screening must be an important consideration for any mass-screening programme. However, difficulties completing the kit were the most important factors affecting FOBt response. Muslims reported particular problems.

The focus groups similarly highlight low levels of knowledge and awareness, and a strong requirement for intensive community-based education (using 'peer' or 'role-model' structures) to raise awareness before any future mass-screening activity. While common themes such as fear of knowing about health outcomes, hygiene and contamination, and self-efficacy emerged, these are often expressed in very culturally specific ways. Others such as family dynamics and literacy are apparently distinctive. Also, while there is strong general faith in the health professions, there is awareness of individual practitioners' weaknesses. For each cultural community, interventions will need to be tailored, and reassurance provided that health professionals will be aware of, and competent to handle, the needs of individuals from those backgrounds. Overall, the minority communities are highly positive about the value of CRC screening, once this is explained, and enthusiastic about helping to promote it in future. Any future programmes should build upon that sort of local support.

3.4.2 RECOMMENDATIONS

1. Our analyses clearly demonstrate significantly lower uptake of CRC screening among Asians versus non-Asian populations. Factors such as differences in age, gender or deprivation index do not appear to explain the differences observed. The psychosocial survey demonstrates poor knowledge and perceptions of risk, and highlights problems with performing the FOB test for Asian populations. Analyses of the Pilot data also indicate that GP practice characteristics appear to influence uptake significantly. We would recommend, therefore, that **a robust study be undertaken to evaluate a multi-strategy intervention (targeted at individuals and practices) to improve FOBt uptake for ethnic minorities to an acceptable level in the second round of colorectal cancer screening in the English Pilot site**.

3.5 References - Section 3

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4. Uptake and Acceptability of Colonoscopy by Ethnic Minorities

Chapter Summary

- Large variations in uptake of colonoscopy amongst FOBt positives were observed for different ethnic groups, with an overall uptake of 54.9% for Asians vs 74.4% for non-Asians.

- This effect remains after adjusting for potential confounding factors such as differences in age, gender, and deprivation patterns. Colonoscopy uptake by Asians is still half that of non-Asians ($p<0.01$).

- Within the Asian population, Hindu-Gujerati and Muslim groups demonstrate significantly ($p<0.05$) lower uptake levels.

- A much higher proportion of Asian patients refused to continue (19.6% vs 8.3% for non-Asians). Further research may be required to understand specific reasons associated with non-uptake.

- A higher percentage of FOBt positive Asian patients were still ‘under process’ (i.e. had not reached a firm decision 3 months after receipt of a positive FOBt result). Part of the lower uptake may be due to a longer period needed to make a decision about colonoscopy.

- The psychosocial survey of different ethnic groups, received responses from too few FOBt positives to be able to examine factors influencing colonoscopy uptake.

- The focus groups also offered few clues that might explain the apparently higher rates of refusal, and lower uptake, of colonoscopy. Clearly there was very little knowledge about the procedure, but equally, when it was explained to the groups, the general response was positive.

- Other factors that might have impacted on uptake include – as for FOBt screening - lack of literacy, reliance on family members to read (and relate) postal communications, and mobility (absences during critical periods, for family visits or religious trips) affecting availability.

4.1 Analyses of Routine Data

4.1.1 AIMS AND OBJECTIVES

To analyse routine data downloaded from the pilot data sets to investigate colonoscopy uptake by different ethnic groups among FOBt positives and investigate associations of ethnic descriptors with the following aspects of uptake:

- Decision to respond to the offer of colonoscopy
- Completion of colonoscopy
- Reasons for failure to undergo colonoscopy

4.1.2 METHODS

4.1.2.1 Data download and preparation of data files for analysis

Data used for the analysis of ethnic colonoscopy uptake rates were extracted from a data download taken from the English Pilot site on 1/6/02 (see Table 4.1.1). A total of 179,305 records were downloaded. As explained (see section 3.1.2), individuals were tagged with a language/ religion 'ethnicity' indicator using the *Nam Pehchan* software applied to a separate download of individuals' names. A total of 178,946 records had ethnic indicators attached. In addition, a deprivation indicator (Carstairs index) was similarly attached to each individual's record based on their full postcode.

The resulting data file was checked extensively, and records corrected to remove any inconsistencies (see section 3.1.2.2). A total of 1,285 individuals had a positive FOBt result that was recorded at least 3 months before the date of the data download and were therefore eligible for examination of colonoscopy uptake rate (see Table 4.1.1).

Table 4.1.1: Number of Subjects at Key Stages of CRC Colonoscopy Process

	Number
A. Population covered as of June 1, 2002	**179,305**
Individuals for whom ethnic tag placed on record	178,946
B. Individuals eligible for analysis of Completion of Screening (i.e. invited to February 1, 2002)	**78,206**
C. Individuals with Positive FOBt result with at least 3 months follow-up time since test (i.e. eligible for colonoscopy uptake analysis)	**1,285**
Individuals appearing in any nurse appointment/ colonoscopy/ histopathology/ surgery/ oncology/ radiology datasets	936

The tracking of colonoscopy and other investigations/ interventions following a positive FOBt result was problematic. This is because, once a subject was identified as FOBt positive, their willingness to continue with the process initiated by the FOBt screening test might be recorded in a number of different ways in the data files. We therefore identified any evidence of a willingness to undergo further examinations or interventions. Thus, if the subject was found in any data file to have attended a nurse pre- and post-colonoscopy appointment, undergone colonoscopy, had a histopathology test result recorded, undergone surgery, or attended for oncological or radiological treatment, then this was taken as an indication that s/he had expressed a *willingness to take up further CRC procedures* (diagnostic and/or therapeutic).

In addition, the English pilot site's computerised nurse data sets were examined. They were also used to determine whether failure to perform colonoscopy was due to the subject's medical unfitness or other reasons.

Patients were recorded as non-compliant only if other alternative routes (e.g. patient referred direct to imaging and surgery) were not recorded in the main data files downloaded and there was no indication in the nurses' data set of contra-indications for colonoscopy.

Logistic regression was used to investigate associations between uptake of colonoscopy or other investigations and ethnic and other demographic variables. Univariate analyses were used to produce unadjusted odds ratios (point estimate and 95% CI) for each demographic factor. Multivariate analyses with all demographic variables included in the model were used to produce adjusted odds ratios.

4.1.3 RESULTS

Table 4.1.2 shows that 936 subjects (72.8% out of the 1,285 FOBt positives) had undergone a further investigations or procedures allowing a period of at lest 3 months from the FOBt positive result.

The uptake rate in Table 4.1.2 does not vary significantly by age, gender or deprivation category. However, large variations are observed for different ethnic groups with overall uptake of further investigations of 54.9% for Asians vs 74.4% for non-Asians. Furthermore, multivariate analysis produces an adjusted odds ratio which demonstrates that the colonoscopy uptake rate for the combined Asian group, once factors such as age, gender, deprivation index are taken into account, is half that of non-Asians ($p<0.01$). Within the Asian population also, Hindu-Gujerati and Muslim groups demonstrate significantly ($p<0.05$) lower uptake levels, with adjusted odds ratios of 0.31 and 0.37 respectively versus 1.0 for non-Asians. For other ethnic groups, uptake rates were also lower (0.27 – 0.82 adjusted odds ratios), although these differences were not significant at the $p=0.1$ level.

Colonoscopy uptake rates were found to be significantly lower in the 154 invitees with a more recent positive FOBt result (screening invitation issued post October 2001). 48 of the more recent cases, still ongoing or being followed up (including 4 Asian subjects), were contacted by the English pilot site nurse when they did not accept colonoscopy referral; 23 stated that they needed more time to think about it; 12 wanted to discuss it with family members; 8 needed a consultant review due to other health problems; and another 5 wanted to discuss this with their GP. However, when contacted again after more than a month, 14/48 subjects had agreed to take up an appointment for colonoscopy. It may be, therefore, that the low level of colonoscopy uptake in the Asian population is *partly* due to longer delays in making a firm decision about colonoscopy.

However, Table 4.1.3 indicates that although a higher percentage of FOBt positive Asian patients are still ‘under process’ (i.e. including individuals who still have to make a firm decision) there is nevertheless a much higher proportion of Asian patients who have refused to continue (19.6% vs 8.3% for non-Asians).

Figure 4.1.4 shows the overall pattern of throughput for the different FOBt screening and colonoscopy phases (with figures for South Asian subjects in parentheses).

4.1.4 DISCUSSION

Following a positive FOBt result, uptake of colonoscopy is disappointingly low for ethnic minority groups. Even once other factors such as deprivation are taken into account, analysis shows an uptake rate for the whole Asian group half that of non-Asians. Particular sub-groups such as the Hindu-Gujeratis and Muslims have colonoscopy uptake rates one third of the non-Asian population.

The fact that colonoscopy uptake rates are significantly lower in those with a more recent positive FOBt result may be partly due to delays in making a firm decision about further investigative procedures; and this process may be more extended in the Asian population. However, there is also evidence that a much higher proportion of Asian FOBt positives are refusing to continue (reason unknown).

Table 4.1.2: Uptake of Colonoscopy (allowing at least three months from FOBt positive test result) by Demographic and Ethnic Factors

Demographic/ Ethnic Factor		Number	Uptake (%)	Unadjusted OR (95% CI)	Adjusted OR (95% CI)	Adjusted OR (95% CI)
Gender	Male	584	74.02	1 (-)	1 (-)	1 (-)
	Female	352	70.97	0.858 (0.668 - 1.103)@	0.905 (0.697 - 1.175)@	0.905 (0.698 - 1.175)@
Age	50-54	182	70.82	1 (-)	1 (-)	1 (-)
	55-59	207	75.00	1.236 (0.843 - 1.813)@	1.205 (0.810 - 1.794)@	1.169 (0.787 - 1.736)@
	60-64	263	72.85	1.106 (0.775 - 1.578)@	1.095 (0.756 - 1.585)@	1.059 (0.733 - 1.530)@
	65-69	284	72.63	1.094 (0.772 - 1.551)@	1.011 (0.704 - 1.453)@	0.991 (0.690 - 1.424)@
Invitation Time	July-Sept 2000	34	87.18	1 (-)	1 (-)	1 (-)
	Oct-Dec 2000	148	75.90	0.464 (0.172 - 1.253)@	0.481 (0.176 - 1.313)@	0.475 (0.175 - 1.293)@
	Jan-Mar 2001	183	73.49	0.408 (0.153 - 1.087)**	0.407 (0.151 - 1.096)**	0.408 (0.152 - 1.097)**
	Apr-June 2001	191	80.59	0.611 (0.227 - 1.649)@	0.646 (0.237 - 1.761)@	0.638 (0.235 - 1.731)@
	July-Sept 2001	226	71.75	0.374 (0.142 - 0.986)*	0.398 (0.149 - 1.061)**	0.398 (0.149 - 1.061)@
	Oct-Dec 2001	150	62.24	0.243 (0.092 - 0.643)	0.274 (0.102 - 0.735)	0.284 (0.106 - 0.760)
	Jan-Mar 2002	4	44.44	0.118 (0.023 - 0.592)	0.141 (0.027 - 0.734)*	0.139 (0.027 - 0.716)*
Religion	Hindu-Gujerati	7	46.67	0.301 (0.108 - 0.838)*	0.307 (0.108 - 0.872)*	
	Hindu-other	2	50.00	0.344 (0.048 - 2.455)@	0.266 (0.036 - 1.964)@	
	Muslim	10	43.48	0.265 (0.115 - 0.610)	0.374 (0.155 - 0.901)*	
	Sikh	33	64.71	0.631 (0.350 - 1.138)@	0.820 (0.439 - 1.532)@	
	Other Asian	4	44.44	0.276 (0.074 - 1.032)*	0.336 (0.080 - 1.404)@	
	Non Asian	880	74.39	1 (-)	1 (-)	1 (-)
	Asian Total	56	54.90	0.419 (0.278 - 0.632)		0.517 (0.332 - 0.807)
Deprivation	1 & 2	289	73.72	1 (-)	1 (-)	1 (-)
	3	270	75.84	1.119 (0.804 - 1.558)@	1.115 (0.796 - 1.563)@	1.113 (0.795 - 1.558)@
	4	256	72.11	0.922 (0.667 - 1.273)@	1.023 (0.733 - 1.428)@	1.008 (0.723 - 1.405)@
	5	67	68.37	0.770 (0.476 - 1.247)@	0.908 (0.551 - 1.498)@	0.880 (0.535 - 1.445)@
	6 & 7	35	60.34	0.542 (0.306 - 0.961)*	0.846 (0.450 - 1.591)@	0.835 (0.449 - 1.554)@
	Total	936	72.84			

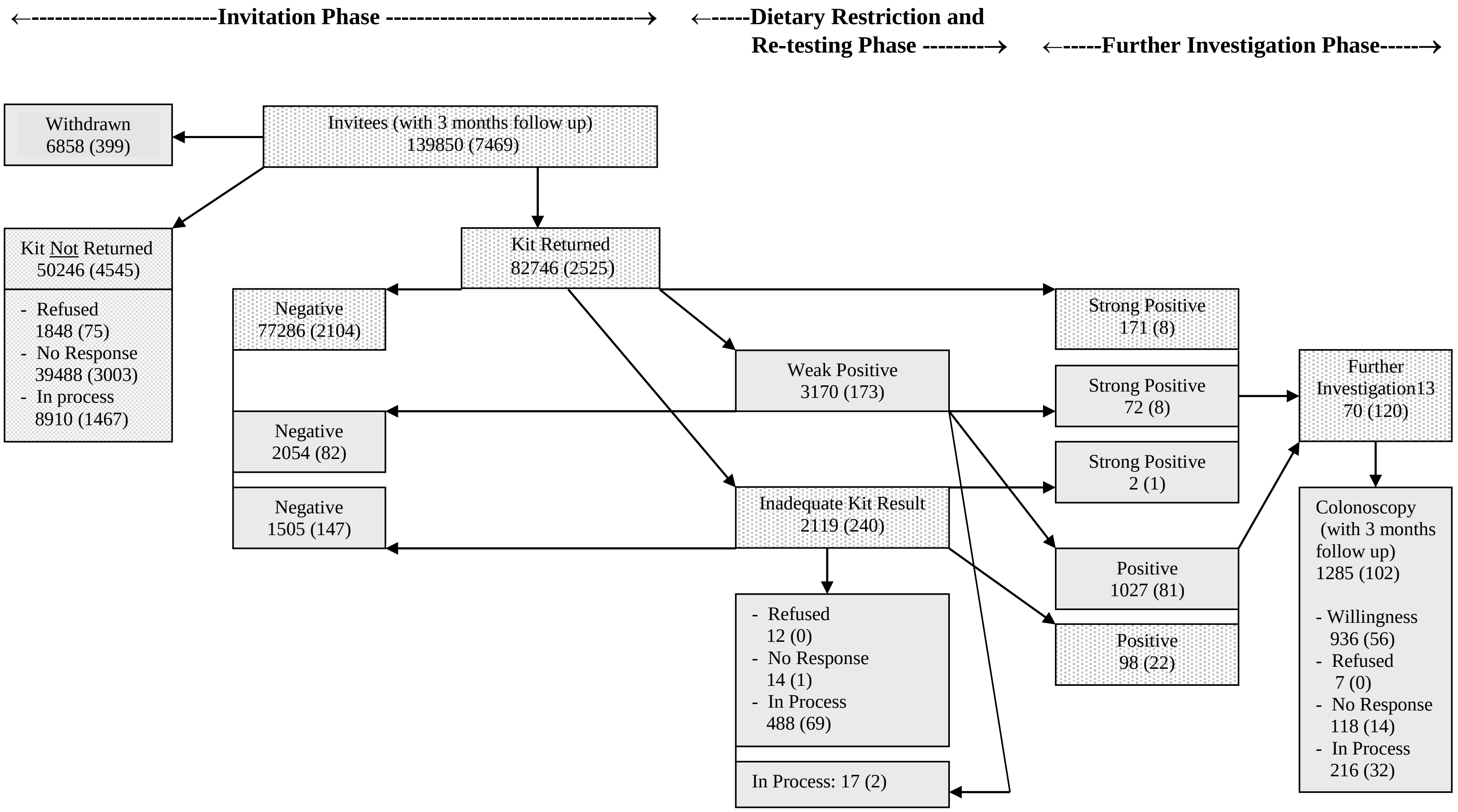
Note:* indicates p<.05; ** indicates p<0.10; @ indicates not significant; all the remaining coefficients are significant at p<.01 level.

Table 4.1.3: Distribution of FOBt Positives Considered to be Defaulters by Reason (Based on English Pilot Site Nurse Records)

Current Status	Reason for defaulting	Asian		Non-Asian		All	
		Number	%	Number	%	Number	%
Gone for Colonoscopy		56	54.90	880	68.30	936	72.84
Under Process		24	23.53	168	14.20	192	14.94
Defaulters		22	21.57	135	11.41	157	12.22
	Currently under treatment	0	0.00	12	1.01	12	0.93
	Refused to continue	20	19.61	98	8.28	118	9.18
	Going for private treatment	1	0.98	21	1.78	22	1.71
	Other reasons*	1	0.98	4	0.34	5	0.39
All		102	100.00	1183	100.00	1285	100.00

Note: * Five cases against 'Other reasons' include: no polyp surveillance (1), recently screened (3) and patient unfit (1).

Figure 4.1.4 Throughput for Screening Phases (South Asian Subjects in Parentheses)



4.2 Psychosocial surveys

4.2.1 METHODS

The methods and response rates to the psychosocial survey are reported in section 3.2.2. The questionnaire sent to FOBt positives and cancer positives included additional questions concerning the meaning of their abnormal result, their experience of colonoscopy and psychological distress.

4.2.2 RESULTS

In the surveys of different ethnic groups, data were only obtained from a total of 8 FOBt positives and no cancer positives. It was not possible, therefore, to consider colonoscopy uptake using this approach.

4.3 Focus Group Studies

4.3.1 METHODS

The methods used for the focus groups are reported in section 3.3.2. The topic guide explored issues of follow-up to the FOBt procedure in terms of learning about adverse outcomes and attitudes towards further investigations. Group members were also asked if they knew anyone (else) who had such experiences.

4.3.2 RESULTS

It became very clear at an early stage that there were low levels of knowledge about cancer, and a high level of fear of the disease. Very few people had any understanding of the implications and sequelae of being diagnosed with colon disease (such as radical surgery) – only one respondent mentioned ‘stoma’ care. This meant that it was sometimes hard to ask detailed questions in respect of the implications such as colonoscopy.

There were few clues in the discussions groups transcripts that might explain the apparently higher rates of refusal and lower uptake, of colonoscopy. Clearly there was very little knowledge about the procedure, but equally, some familial or anecdotal experiences were shared and none of these seemed to reflect adversely on colonoscopy. It became apparent that in many groups there was one (or sometimes more) person who had personal – or close indirect – experience of at least colonoscopy (‘a camera put inside you’). When such testimony was presented to the groups, a lively discussion ensued. The general response to the anecdotes revealed to the groups in our discussions was positive, however, reflecting the outcomes for the patients discussed.

Other problems which might have impacted on uptake were also present – as for the FOBt screening - such as the lack of literacy, reliance on family members to read (and relate) postal communications dealing with matters of some sensitivity to their elders, and mobility (absences during critical periods, for family visits or religious trips) affecting availability. As with other intimate or controversial examinations, shy or naïve (uninformed) people may require more assertive outreach and personal intervention (preferably via GP or practice nurse) to ensure compliance. CRC screening and health promotion/ preventive work could also be built on the use of personalised narratives which raise the salience and accessibility of the issue.

4.3.3 DISCUSSION

It might be argued that people – since those with links to an experience were few - were unlikely to have any exposure to the subject of colonoscopy and were therefore refusing out of fear of the unknown. In such a case, wider dissemination or publicity relating to the procedure might raise uptake - while running the risk of a more complex effect. For example, a study of vaccination in Glasgow found that lack of knowledge of adverse side-effects (widely discussed among the White population) was a possible reason for the much higher level of compliance with invitations to vaccination among Asian mothers. Higher knowledge of the potential adverse effects of colonoscopy might therefore reduce uptake by as much as higher awareness of the procedure in general raises it.

The whole question of uptake of colonoscopy requires more exploration with relevant informants. This may require support with information-giving through the use of diagrams, models, and question-answering. Some personal testimony might help overcome reticence in focus groups, although running the risk of technical contamination of the data. It would be particularly desirable to obtain Caldicott clearance to form discussion groups from Asian people who had been invited to perform the procedure, and explore their fears and concerns or (lack of) knowledge.

4.4 Conclusions and Recommendations

4.4.1 CONCLUSIONS

Uptake of colonoscopy has been found to be significantly lower among Asians with a positive FOB test result (54.9% vs 74.4% for non-Asians). Even once other factors such as deprivation are taken into account, the colonoscopy uptake rate for the whole Asian group is half that of non-Asians. Particular groups such as the Hindu-Gujeratis and Muslims have colonoscopy uptakes one third of the non-Asian population.

Although colonoscopy uptake rates were significantly lower in those invitees with a more recent positive FOBt result, fewer than 10% of these were Asian subjects and so this cannot be a major factor. There is some indication that the low level of colonoscopy uptake by Asians may be *partly* due to delays in making a firm decision about colonoscopy. It may be that the 3 month post positive FOBt cut-off adopted for the main evaluation is too short for the Asian community, and longer term follow up of these individuals is required to assess true uptake. However, even allowing for this factor, there would appear to be evidence that a much higher proportion of Asian FOBt positives than non-Asians (19.6% vs 8.3%) are refusing to continue to colonoscopy (reason unknown) and this requires further investigation.

The low response rates to the psychosocial survey questionnaire sent to FOBt positives and cancer positives meant that it was not possible to consider colonoscopy uptake using this approach. Similarly, there was little information in the discussion group transcripts that might explain the apparently higher rates of refusal and lower uptake of colonoscopy.

It has been suggested by the Main Evaluation that the problem of low uptake of colonoscopy more generally in the Pilot (ca 80%) could be addressed by more comprehensive informed consent procedures, ideally at the outset, making participants aware of the procedure and its potential adverse effects[6]. If this is implemented, very careful thought and sensitive testing will be needed, if it is not to further adversely affect uptake in the Asian community.

4.4.2 RECOMMENDATIONS

1. The Pilot has clearly demonstrated significantly lower uptake of colonoscopy following positive FOBt among Asians versus non-Asians. This may partly be an artefact due to a longer time period required to make a firm decision about colonoscopy for the Asian population. We would recommend, therefore, that further analyses be undertaken comparing longer term colonoscopy status (i.e. 6 months following positive FOBt) for Asian and non-Asian groups in the first round of screening.

2. It remains likely, however, that a higher proportion of Asian FOBt positives than non-Asians are refusing colonoscopy (reason unknown). We would recommend, therefore, that focus groups be used to explore and compare reasons for non-uptake of colonoscopy in Asian and non-Asian groups.

3. Linked to 2 above, we would recommend that a study be undertaken to evaluate the effectiveness and cost-effectiveness of targeted interventions to increase colonoscopy uptake in ethnic minority invitees who screen FOBt positive.

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[6] Evaluation of the UK Colorectal Cancer Screening Pilot: Final Report. February 2003. p54.

5. Screening Outcomes for South Asians

Chapter Summary

- Overall, the neoplasia rate per 1,000 subjects testing positive (Positive Predictive Value or PPV) was 407 per 1,000. Within the Asian community this figure was much lower (PPV 157 per 1,000 FOBt positives), although the statistic is based on a very small number of cases.

- However, recorded PPV rates may be significantly lower that potential rates, because colonoscopy uptake rates are significantly lower for Asian subjects with a positive FOBt result (50% lower), especially for higher risk groups (e.g. Muslim red meat eaters).

- Diagnosed malignancy (polyp cancer) was also very low (1 case) among the Asian community, as was invasive CRC (1 case).

- Our analysis shows higher PPV with increasing age, lower values for females, and no relationship with deprivation (Carstairs index).

- For ethnic sub-groups, the only significantly lower positive predictive value was observed for Sikhs (p<0.01).

5.1 Analyses of Routine Data

5.1.1 AIMS AND OBJECTIVES

To analyse routine data downloaded from the pilot data sets to investigate adenoma and cancer detection rates by different ethnic groups among FOBt positives, and to investigate associations of ethnic descriptors with these.

5.1.2 METHODS

5.1.2.1 Definitions

Abnormalities were classified as follows:

- ***invasive colorectal cancer (CRC)***
  all cancers with Dukes stage identified from histopathology data

- ***malignancy: polyp cancer (sometimes called malignant polyp or malignant adenoma)***
  all other cancers (identified through resection and histopathology data)

- ***non-malignant adenoma (sometimes called adenoma)***
  polyp where lack of malignancy is confirmed by histopathology data

- ***neoplasia***
  all abnormalities that are classified as either invasive colorectal cancer, polyp cancer, or non-malignant adenoma (i.e. sum of three categories above)

Subjects with more than one polyp and/or cancer were classified according to their most severe condition. All other individuals who were FOBt positive were classified as not having neoplasia. These fell into four distinct types:

- no neoplasia (confirmed by pathology)
- no neoplasia reported at colonoscopy (not confirmed by pathology)

- neoplasia status not known (including non-malignant polyp of unknown type, malignancy status not known, malignancy suspected at colonoscopy but no pathology)
- colonoscopy not performed

5.1.2.2 Data download and preparation of data files

Data used for the analysis of ethnic colonoscopy uptake rates were extracted from the data download taken from the English Pilot site on 1/6/02 (see Table 5.1.1).

Table 5.1.1: Number of Subjects at Key Stages of Cancer Detection Process

	Number
Individuals with Positive FOBt result with at least 3 months follow-up time test (i.e. eligible for colonoscopy uptake analysis)	**1,285**
Individuals appearing in any nurse appointment/ colonoscopy/ histopathology/ surgery/ oncology/ radiology datasets	936
Neoplasia cases	523

A total of 1,285 records had a positive FOBt result recorded 3 months or longer before the date of the data download. For analyses of detection rates for neoplasia, malignancy, and invasive CRC, a restriction of 3 months between the FOBt positive result date and the download was applied. The tracking of polyp cancers and invasive colorectal cancers using the data files downloaded was difficult. This was because all subjects identified as FOBt positive did not necessarily have a definitive cancer diagnosis entered into their files by the cut-off time point.

Therefore, once again, we made use of the English pilot site’s nurse data sets to identify the final status of some individuals. The rates of malignancy and invasive colorectal cancer calculated from the data download were compared with the list maintained by the English pilot site in order to resolve any inconclusive cases. This enabled a final status to be obtained for all but one patient (status ‘currently ongoing’).

5.2 Neoplasia and Cancer Detection Rates

The detection rates for neoplasia, malignancy, and invasive CRC are shown in Table 5.1.2; these cancer and adenoma rate figures are based on a relatively small numbers of cases.

Out of 1,285 FOBt positives with 3 months follow up, 523 were recorded as having neoplasia; this is equivalent to an overall neoplasia rate per 1,000 subjects testing positive (Positive Predictive Value or PPV) of 407 per 1,000. Within the Asian community this figure was much lower (PPV 157 per 1,000 FOBt positives). Diagnosed malignancy (polyp cancer) was also very low (1 case) among the Asian community, as was invasive CRC (1 case). However, it should be borne in mind that colonoscopy uptake rates were also significantly lower for Asian subjects with a positive FOBt result (50% lower), with higher risk groups (e.g. Muslim red meat eaters) least likely to undergo colonoscopy. Therefore detection rates may be significantly lower that actual rates, were a similar colonoscopy uptake rate to be achieved to that observed for non-Asians.

Table 5.1.2: Invasive Cancer, Polyp Cancer and Neoplasia Detection Rates

		Number Cases	Rate per 1,000 Subjects Completing FOB Testing	Rate per 1,000 Subjects Testing Positive (Positive Predictive Value)
Invasive CRC	**All**	**85**	**1.09**	**66.15**
	Asian	1	0.48	9.80
	Non-Asian	84	1.10	71.01
Malignancy	**All**	**16**	**0.20**	**12.45**
	Asian	1	0.48	9.80
	Non-Asian	15	0.20	12.68
Neoplasia	**All**	**523**	**6.69**	**407.00**
	Asian	16	7.73	156.86
	Non-Asian	507	6.66	428.57

The association between neoplasia detection rates among FOBt positives by demographic and ethnic factors is presented in Table 5.1.3. There is a strong association in both univariate and multivariate analyses between neoplasia detection rates and increasing age. The detection rate is lower among females, in those with a positive FOBt result in the recent past, and among the Asian community as a whole. The influence of deprivation category was found to be insignificant on neoplasia detection rate among FOBt positives. Three out of the five Asian ethnic subgroups demonstrated a lower detection rate – Sikh (p<0.01), and Hindu-Gujerati and Muslim groups (only at p<0.10 level).

5.3 Conclusions and Recommendations

5.3.1 CONCLUSIONS

The overall neoplasia detection rate calculated for the data download taken from the English Pilot site on 1/6/02 was 407 per 1,000 FOBt positives (Positive Predictive Value or PPV). The overall neoplasia detection rate among Asians was much lower (157 per 1,000), although colonoscopy uptake rates were also significantly lower for the Asian population and therefore detection rates may be reduced by up to 50%.

Our analysis also shows higher PPV with increasing age, lower values for females, and no relationship with deprivation (Carstairs index). These trends mirror those reported by the main Evaluation Group (see Main Report Table 4.2.4). For ethnic sub-groups, the only significantly lower positive predictive value was observed for Sikhs (p<0.01).

5.3.2 RECOMMENDATIONS

1. Due to the small number of cancer cases detected among Asians it is difficult to be confident that differences with their non-Asian counterparts are 'real'. Differences may partly be due to lower colonoscopy uptake rates among Asians at 3 months, with a longer period of follow up being required for Asian invitees post positive FOBt. Therefore, we would recommend that **the analysis of Asian neoplasia detection rates be repeated for the complete data download from the first round of screening and include a 6 month follow up period.**

Table 5.1.3: Neoplasia Among FOBt positives (allowing at least 3 months from FOBt result) by Demographic and Ethnic Factors

Demographic/ Ethnic Factor		Number	Uptake (%)	Unadjusted OR (95% CI)	Adjusted OR (95% CI)	Adjusted OR (95% CI)
Gender	Male	349	44.23	1 (-)	1 (-)	1 (-)
	Female	174	35.08	0.674 (0.534 - 0.850)	0.715 (0.562 - 0.910)	0.714 (0.561 - 0.909)
Age	50-54	87	33.85	1 (-)	1 (-)	1 (-)
	55-59	105	38.04	1.223 (0.857 - 1.747)@	1.171 (0.815 - 1.691)@	1.169 (0.810 - 1.687)@
	60-64	151	41.83	1.438 (1.030 - 2.008)*	1.391 (0.985 - 1.964)**	1.390(0.985 - 1.961)**
	65-69	180	46.04	1.691 (1.219 - 2.346)	1.586 (1.131 - 2.225)	1.582 (1.128 - 2.218)
Invitation Time	July-Sept 2000	22	56.41	1 (-)	1 (-)	1 (-)
	Oct-Dec 2000	87	44.62	0.622 (0.311 - 1.245)@	0.562 (0.274 - 1.155)@	0.566 (0.276 - 1.160)@
	Jan-Mar 2001	111	44.58	0.622 (0.315 - 1.227)@	0.549 (0.270 - 1.116)**	0.556 (0.275 - 1.126)**
	Apr-June 2001	100	42.19	0.564 (0.285 - 1.117)**	0.522 (0.257 - 1.062)**	0.528 (0.261 - 1.071)**
	July-Sept 2001	137	43.49	0.595 (0.304 - 1.163)@	0.573 (0.285 - 1.154)@	0.582 (0.290 - 1.167)@
	Oct-Dec 2001	64	26.56	0.279 (0.140 - 0.560)	0.296 (0.143 - 0.613)	0.302 (0.147 - 0.622)
	Jan-Mar 2002	2	22.22	0.221 (0.041 - 1.201)**	0.225 (0.040 - 1.272)**	0.228 (0.040 - 1.293)**
Religion	Hindu-Gujerati	2	13.33	0.205 (0.046 - 0.913)*	0.231 (0.051 - 1.046)**	
	Hindu-other	1	25.00	0.444 (0.046 - 4.285)@	0.442 (0.045 - 4.377)@	
	Muslim	4	17.39	0.281 (0.095 - 0.830)*	0.393 (0.128 - 1.207)**	
	Sikh	8	15.69	0.248 (0.116 - 0.532)	0.356 (0.161 - 0.784)	
	Other Asian	1	11.11	0.167 (0.021 - 1.338)**	0.182 (0.021 - 1.551)@	
	Non Asian	507	42.86	1 (-)	1 (-)	1 (-)
	Asian Total	16	15.69	0.248 (0.144 - 0.428)		0.327 (0.185 - 0.576)
Deprivation	1 & 2	166	42.35	1 (-)	1 (-)	1 (-)
	3	155	43.54	1.050 (0.786 - 1.403)@	1.043 (0.775 - 1.405)@	1.043 (0.775 - 1.404)@
	4	137	38.59	0.856 (0.638 - 1.147)@	0.966 (0.713 - 1.308)@	0.965 (0.713 - 1.306)@
	5	38	38.78	0.862 (0.548 - 1.356)@	1.035 (0.646 - 1.658)@	1.036 (0.647 - 1.658)@
	6 & 7	15	25.86	0.476 (0.256 - 0.885)*	0.763 (0.391 - 1.487)@	0.774 (0.398 - 1.503)@
	Total	523	40.59			

Note: * indicates p<0.05; ** indicates p<0.10; @ indicates not significant; all the remaining coefficients are significant at p<0.01 level.

6. Extrapolation of English Pilot Site Ethnic Uptakes to UK Population

Chapter summary

- The aim of this part of the analysis was to identify a method of estimating the likely geographical pattern of uptake of colorectal screening across the UK, based on the results of the English Pilot.
- The limited amount of data available from the Pilot constrained the type of analysis that could be undertaken.
- A simple model which could be generalised across the whole UK was identified. Sophisticated estimation procedures were avoided in order to emphasise the exploratory nature of the exercise and the fact that only tentative associations could be established from the available data.
- The model was limited to the initial decision to respond to the offer of screening i.e. return at least one FOBt kit (adequate or inadequate).
- Based on this model, predicted CRC screening uptake rates for unitary authorities in England range from 45.5% to 62.5%, with a powerful association between indicators of socio-economic deprivation and, to a somewhat lesser extent, with the percentage of the population from South Asian ethnic groups in these areas.
- The overall pattern is of higher predicted rates in suburban and rural areas and lower predicted rates in the inner cities, especially in Inner London, Leicester and Birmingham. Areas with large South Asian (especially Muslim) populations have the lowest uptake rates, reflecting the lower uptake by people from these ethnic groups in the English Pilot.
- The patterns predicted for England are repeated in other parts of the United Kingdom, although a narrower range is predicted in the three other countries; Scotland (56.2% - 60.6%), Wales (56.7% - 60.0%) and Northern Ireland (54.8% - 60.4%). Ethnicity does not influence the geographical pattern of uptake in these countries.

6.1 Aims and Methods

6.1.1 AIMS AND OBJECTIVES

To extrapolate the Coventry and Warwickshire pilot site findings to populations in various geographical locations in the UK with the objectives of:

1. Identifying the composition of ethnic minority groups in different geographical areas that might form the basis of any national roll-out
2. Estimating the likely colorectal cancer screening uptake rates for the ethnic and socio-economic mix of populations in these areas, based on the English pilot data
3. Providing a map of England with indicative colorectal cancer screening uptakes to inform any national roll-out.

6.1.2 DATA USED

Data used for the extrapolations were taken from the 1991 and 2001 Census. These were supplemented by information extracted from a routine data download taken from the English Pilot site on 1/6/02; a total of 179,305 records were downloaded. The latter formed the basis of the main screening and colonoscopy uptake analyses (see sections 3.1 and 4.1). As part of the main uptake analyses, a database was constructed that included an individual's NHS number, age, sex, a religion and language indicator (identified using *Nam Pehchan*), a deprivation indicator (Carstairs index), and the screening history of the individual. This database contained the full (7 character, or ‘unit’) postcode for each person used to calculate the Carstairs index. This also enabled each person to be allocated to the 1991 Census Enumeration District (ED) in which they live, using the “All Fields Postcode Directory” (a small percentage could not be matched because recently created postcodes were not in this lookup file). These EDs typically contain about 200 households, and are often regarded as representing reasonably socially homogeneous 'neighbourhoods', because of the tendency of people of similar types to live in similar areas (Timms, 1971). This formed the first stage in developing a dataset for extrapolation to other geographical areas in the UK.

Analysis of 1991 Census data reveals that people from South Asian ethnic groups have a very strong tendency to cluster together, with marked geographical separation from other ethnic groups (Peach, 1996). Other minority ethnic groups also tend to cluster together, but tend to exhibit a lesser degree of geographical concentration. Black-Caribbean people display a higher degree of inter-ethnic partnership than South Asian people and are more likely to live in social rented accommodation, and hence display a lower degree of spatial segregation from other ethnic groups. The consequence of a high degree of segregation is that the Census data for the ED or neighbourhood in which the person invited to take part in the screening Pilot resides is quite likely to describe their socio-economic and other characteristics; conversely, for less segregated ethnic groups it is much less accurate to make this inference.

Thus, the Census data can be seen as representing a ‘proxy’ for individual characteristics when analysing, on a geographical basis, the behaviour of people invited to participate in the Pilot. The types of indicators of prosperity which can be used in such geographical analyses include the unemployment rate and the percentage of households with two or more cars within the ED. Similar variables are used in the DETR’s Index of Local Conditions, which aims to summarise the deprivation of neighbourhoods using Census data, and in the Townsend and Carstairs indices of deprivation (though these indicators use the percentage of households without cars, thus measuring deprivation rather than prosperity). Though it was recognised that 1991 Census data may no longer adequately represent the characteristics of populations for areas in which migration or social change has been rapid during the 1990s, a full set of data from the 2001 Census will not become available until mid-2003, and therefore for some indicators no more up-to-date information on neighbourhoods was available at the time of writing this report (February 2003).

6.1.3 METHODS

The method used to develop a simple model of uptake within the English Pilot area, that could be generalised to the whole UK, had to be based on the available data. The screening data set contained a limited number of variables that could be used to "explain" the probability of different types of individual accepting the CRC screening invitation and returning an FOBt kit; these included age, gender, religion/language group, and deprivation (Carstairs) index. There was no information on education level, psychosocial factors (e.g. beliefs and attitudes), or previous screening behaviour (e.g. cervical and breast for women) to use as explanatory variables.

The method chosen to address extrapolation to other areas in the UK was to aggregate the individual Pilot responses to EDs, for which Census data measuring the characteristics of the population in the Pilot EDs and other EDs was available; and then to make the assumption that the population of the Pilot EDs was sufficiently homogeneous that the average population characteristics for the area fairly accurately represent those of the persons living there who were invited to participate in the Pilot. However, only a limited range of Census variables are cross tabulated by ethnic group, limiting the range of explanatory variables which could be incorporated for minority ethnic groups. Moreover, because of confidentiality restrictions, Census data is extremely limited at this spatial scale. For example, the age breakdown of ethnic groups from the Census is such that the population aged over 50 in 2001 has to be estimated, and detailed information on many socio-economic variables by ethnic group is not available.

Some of these constraints would be relaxed by undertaking the analysis for electoral wards. However, this approach was not adopted because there were only 125 electoral wards in Coventry and Warwickshire in the 1991 Census data (with much larger populations than EDs) and working at this scale would therefore seriously dilute the association between the characteristics of the area and the characteristics of people involved in the Pilot.

Regression models were then estimated, in which the probability of being invited for CRC screening was related to the socio-economic characteristics of the area in which the individual lived. The parameters of these models were then used to estimate the probability of screening uptake in local authority districts, using district-level Census data for the explanatory variables in the model. The choice of explanatory variables was thus further constrained by the need to match variables available at both the local scale in 1991 and the district scale in 2001.

6.2 Extrapolations

6.2.1 DEVELOPING A MODEL

In order to develop a model that could be used to predict likely uptake levels in different geographical locations in the UK, the data available for the English Pilot site was first examined on a small area basis. In order to do this, individual-level data from the screening Pilot was aggregated to 1991 Census Enumeration Districts, using the ONS All Fields Postcode Directory (accessed via MIMAS). Next, the uptake rate for each neighbourhood was calculated as the percentage of persons contacted who returned a kit. In other words, the uptake analyses used in all the extrapolation models focus on the *decision to respond to the offer of screening* signalled by at least one FOBt kit being returned, either adequate or inadequate kits included; other indicators of uptake such as *completion of phase I of screening* or the *completion of screening* were not considered (see section 3.1.2 for definitions).

There are 1,718 EDs in the English Pilot area, and the distribution of male and female uptake rates in these enumeration districts is shown in Figures 6.2.1 and 6.2.2. The barcharts show the number of EDs with particular uptake rates (presented in 5% bands) for males and a similar distribution by ED for females. These indicate the wide range of uptakes in different neighbourhoods, ranging from 0% to 100%, with much higher uptakes evident for women in these neighbourhoods (57.6 per cent, compared with 48.1 per cent for males).

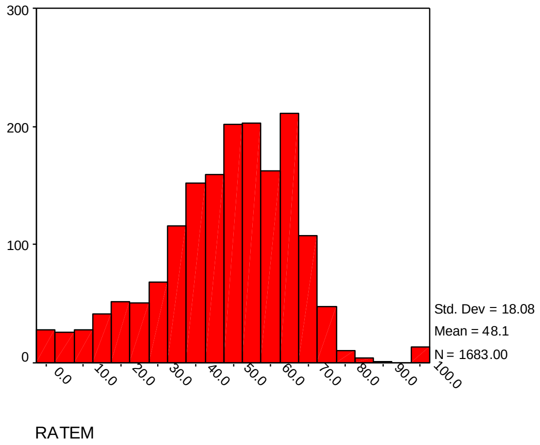


Figure 6.2.1: Male

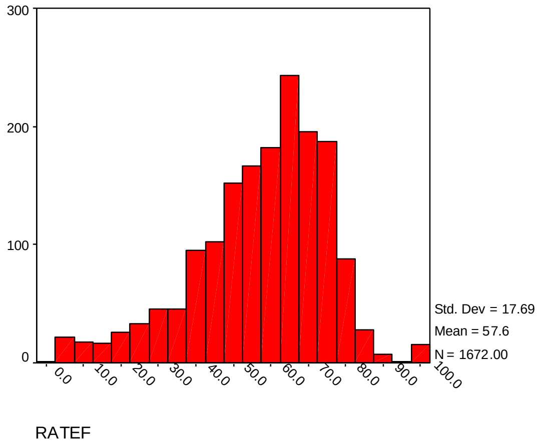


Figure 6.2.2: Female

Similar distributions for uptake rates at ED level for the whole population (men and women) in different ethnic groups are shown in Figures 6.2.3 to 6.2.5. Data are presented for different population groups based on the *Nam Pehchan* classification; for this analysis individuals in the five distinct religion-language groups identified by the software were aggregated into meta-categories (broad level of aggregation) and classified as either Muslim, 'non-Muslim South Asians', or 'non-Asians' (the latter including white, Chinese and African-Caribbean people).

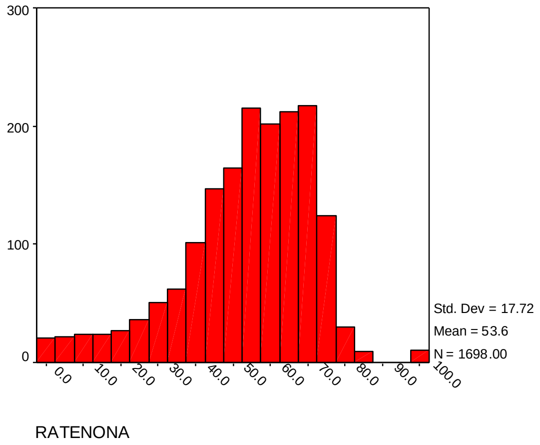


Figure 6.2.3: Non-Asian CRC screening uptake rates by ED

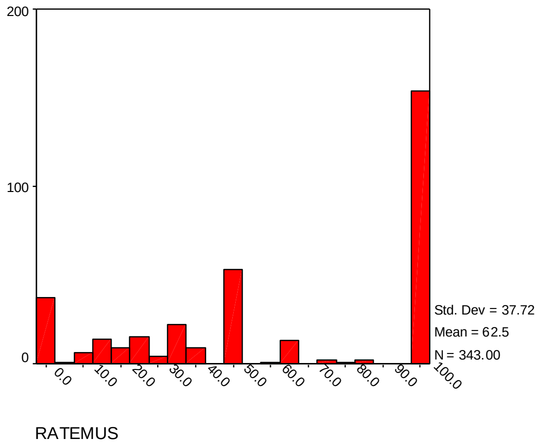


Figure 6.2.4: Muslim uptake rates by ED

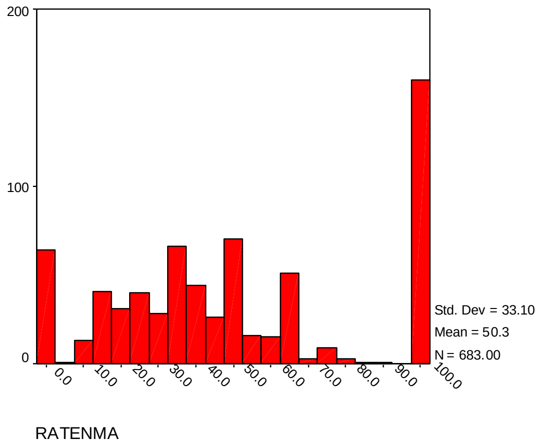


Figure 6.2.5: Non-Muslim South Asian uptake rates by ED

Uptake rates for non-Asians by enumeration district average 53.6%, with the distribution slightly skewed, so that low neighbourhood uptake rates are much more common than high uptake rates. The mean uptake rates by ED for Muslims is 62.5% and that for non-Muslim South Asians 50.3%. This is the reverse of the pattern observed for individual uptakes (see section 3.1.3.3 and Figure 3.1.1).

For these two groups, small numbers in many EDs mean that it is more likely that some neighbourhood Asian uptake rates will lie at the extremes; in an ED with a small number of Asian people, it is highly likely that either everybody or nobody living in that ED will return a kit, giving uptake rates of either 0 or 100 per cent. This is apparent in Figures 6.2.4 and 6.2.5, in which the largest bars are at the extremes, and at 50 per cent (where one person out of a population of 2 returns a kit). A better estimate of the mean uptake rate would therefore exclude small populations from the calculation.

Mean uptake rates by Enumeration District for non-South Asians, Muslim and non-Muslin South Asians were therefore calculated by first excluding EDs with 3 or fewer persons from the sub-group in the list of invitees. This calculation yields the mean uptake rates by ED shown in Table 6.2.1. The mean ED uptake rates are now much closer to the pattern observed over the whole Pilot area; uptakes 31.9% Muslims, 34.6% - 43.7% other Asian groups, and 63.7% Non-Asians (see Table A5.4: Appendix A5).

Table 6.2.1: Mean ED uptake rates with low ethnic minority population areas removed

Ethnic group	Mean ED uptake rate	Standard error	Standard deviation	No. of EDs in calculation
Non-South Asians	53.44	0.43	17.58	1688
Non-Muslim South Asians	36.82	1.05	21.49	416
Muslim South Asians	32.25	1.05	22.43	100

6.2.2 MODELLING UPTAKE RATES

Figures 6.2.6 and 6.2.7 depict the weakly negative relationships between area uptake rates at ED level and the percentage of people invited to take part in the screening Pilot in each of the 1,718 neighbourhoods who are Muslim or non-Muslim South Asian.

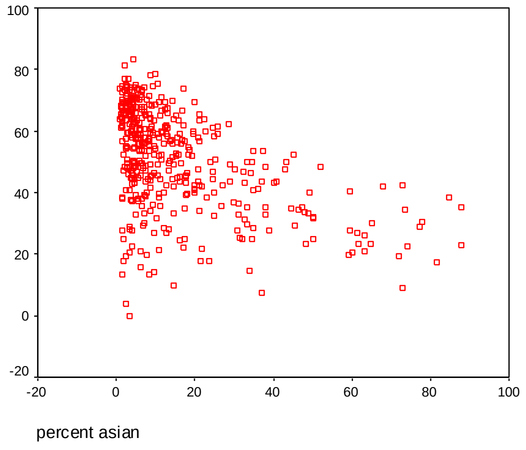


Figure 6.2.6: Relationship of uptake rate to % non-Muslim South Asians among invitees

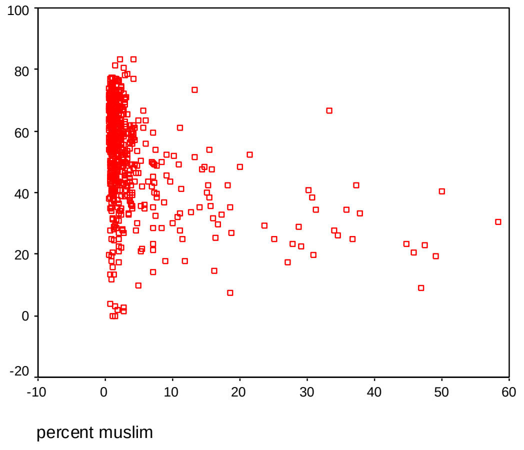


Figure 6.2.7: Relationship of uptake rate to % Muslims among invitees

Since there was no clear relationship with these single variables, various approaches were then adopted to try to model the observed geographical CRC screening uptake patterns in the English Pilot site.

6.2.2.1 Using 1991 Census data

In order to model uptake rates by enumeration district, a number of explanatory variables were first derived from 1991 Census of Population data, adjusted for the "under-count" using factors calculated by the ESRC-sponsored "Estimating With Confidence" project. Two approaches were then adopted to model uptake. The first approach (Model 1) utilised data on the unemployment rate in EDs, the percentage of the population born abroad in parts of South Asia and the Caribbean, and the calculated Carstairs index of deprivation. The results are shown in Table 6.2.2. A second approach (Model 2) utilised 1991 Census data on the percentage of different ethnic groups in EDs; the results of this are shown in Table 6.2.3.

Table 6.2.2: Model 1 – Deprivation and country of birth

Independent variables (derived from 1991 Census of Population)	Unstand-ardized Coefficients	Std. Error	Standard-ized Coefficients	t	Sig.
(Constant)	60.337	.665		90.673	.000
Unemployment rate	-.700	.050	-.358	-13.966	.000
Carstairs index	.373	.103	.085	3.622	.000
% born in India	-.273	.145	-.053	-1.880	.060
% born in Pakistan and Bangladesh	-.538	.298	-.051	-1.803	.072
% Caribbean born	.163	.579	.007	.281	.779

Adjusted R^2 = 0.176, F=67.925, standard error=15.87

Table 6.2.3: Model 2- Deprivation and ethnic group

Independent variables (derived from 1991 Census of Population)	Unstand-ardized Coefficients	Std. Error	Standard-ized Coefficients	t	Sig.
(Constant)	60.339	.663		90.959	.000
Unemployment rate	-.707	.053	-.362	-13.273	.000
Carstairs index	.374	.103	.085	3.628	.000
% from Indian ethnic group	-.125	.061	-.058	-2.041	.041
% from Pakistani and Bangladeshi ethnic groups	-.239	.144	-.046	-1.654	.098
% from Black ethnic groups	.128	.285	.012	.448	.654

Adjusted R^2 = 0.175, F=67.83, standard error=15.88

Tables 6.2.2 and 6.2.3 illustrate that there is little difference in the explanatory power of the two models, which in both cases is very low (R^2 = 0.176/ 0.175). In terms of ethnicity, Table 6.2.2 indicates that none of the country of birth variables are statistically significant at the 5 per cent level, and that there is a negative sign only for the two measures of South Asian population (i.e. not for those born in the Caribbean). In Table 6.2.3, a similar pattern emerges; the adjusted 1991 ethnicity variables are now statistically significant at the 5 per cent level for the Indian ethnic group, and again there is a negative sign only for the two South Asian ethnic groups (and not for the Black ethnic group). Both models exhibit a positive sign for African Caribbean/ Black ethnic groups and estimate a mean uptake rate of around 60%, keeping other variables constant. The most powerful influence on variations in uptake is the unemployment rate, indicating that the higher the level of unemployment, the lower the level of uptake. The coefficients on the Carstairs index reinforce the association of low uptake with deprivation.

6.2.2.2 Using population characteristics recorded in the Pilot

In a third approach the observed uptake rates by enumeration district were regressed against various characteristics of the population invited to participate in screening as shown in Table 6.2.4. The independent variables used in this model were the percentage of all invitees aged 60 and over, the percentage female, the percentage classified by their name as Muslim, the percentage classified as falling within other South Asian religious groups, and the 1991 unemployment rate (as an indicator of deprivation; no local data were available from the 2001 Census of Population at the time the analysis was undertaken).

Table 6.2.4 shows, once again, that the unemployment rate is the most important influence on uptake in a neighbourhood; that the uptake rate declines as the percentage of invitees from Asian ethnic groups increases; and that the uptake rate increases as the percentage of females and older people amongst those invited increases. The explanatory power of this model is somewhat higher than the two models discussed above, although still low (R^2 = 0.396).

Table 6.2.4: Relationship of uptake rate to characteristics of invited persons

Independent variables	Unstandardized Coefficients	Std. Error	Standardized Coefficients	t	Sig.
(Constant)	35.905	6.325		5.677	.000
Unemployment rate[1]	-.672	.085	-.387	-7.882	.000
Percent Muslim[2]	-.265	.090	-.143	-2.941	.003
Percent non-Muslim South Asians[2]	-.266	.061	-.189	-4.367	.000
Percent aged 60 plus[2]	.217	.102	.084	2.132	.034
Percent female[2]	.414	.113	.147	3.679	.000

[1] Based on 1991 Census data [2] From analysis of English Pilot data

Adjusted $R^2 = 0.396$, F=56.16, standard error=12.56

The coefficients from this geographical model were next used to model likely uptake by different areas across the UK.

6.2.2 NATIONAL ROLL-OUT: LIKELY CRC SCREENING UPTAKES

The first breakdowns of 2001 Census data were published for local authorities on February 13th 2003. These data include a table on the religious breakdown of the population. We have used this to make very tentative estimates of CRC screening uptake rates, by applying the regression coefficients presented in Table 6.2.4 to population data for 2001. Preliminary results are shown in Tables 6.2.5 – 6.2.9, including predictions for all unitary and shire authorities and Government Office Regions in England, together with unitary authorities and local authority districts in Scotland, Wales and Northern Ireland.

Table 6.2.5 shows that the overall predicted uptake rate for England is 58.1%. Regional rates within England vary from a high of 60.1% (South West) to a low of 54.7% (London), followed by 56.9% (West Midlands). Table 6.2.6 presents the uptake rates for the top 20 unitary authorities in England with the highest predicted CRC screening uptakes, and for the 20 likely to have the lowest uptakes (see Appendix A10 for predicted uptake rates for all unitary authorities in England).

Tables 6.2.7, 6.2.8 and 6.2.9 present the predicted uptake rates for Wales, Scotland and Northern Ireland respectively. For Wales the overall predicted uptake is 58.8%; for Scotland 58.9%; and for Northern Ireland 58.7%. The range of predicted uptakes is smaller in these three countries. In Wales, uptake is predicted to be highest in Powys (60 per cent) and lowest in Blaenau Gwent (56.7 per cent). In Scotland, the highest uptakes are predicted in East Lothian, Mid Lothian and East Dunbartonshire (60.6 per cent each) and the lowest in Glasgow (56.2 per cent). In Northern Ireland, predicted uptake is highest in Castlereagh (61.5 per cent) and lowest in Derry (54.8 per cent).

Finally, Figure 6.2.8 provides a map of the UK with indicative uptake rates for colorectal cancer screening in the event of any national roll-out.

Table 6.2.5: Predicted uptake rates in England

Unitary Authority	Unemployment rate	Percent Muslim	Percent non-Muslim Asian	% 50-64 year olds female	% 50-64 year olds aged 60-64	Predicted uptake rate
ENGLAND	5.0	3.4	2.2	50.6	27.9	58.1
North East	7.4	1.2	0.5	50.6	29.2	57.8
North West	5.7	3.3	0.7	50.5	28.6	58.1
Yorkshire and the Humber	5.7	4.1	0.9	50.5	28.4	57.8
East Midlands	4.9	1.8	2.8	50.1	27.4	58.1
West Midlands	5.7	4.4	3.5	50.1	28.4	56.9
East	3.8	1.6	1.1	50.5	27.4	59.5
London	6.5	9.3	6.9	51.6	27.8	54.7
Inner London	*8.4*	*12.9*	*3.8*	*51.8*	*28.6*	*53.4*
Outer London	*5.2*	*7.0*	*8.8*	*51.5*	*27.4*	*55.5*
South East	3.3	1.5	1.4	50.5	27.1	59.7
South West	3.8	0.5	0.5	50.7	28.1	60.1

Table 6.2.6: Highest and lowest predicted uptake rates by Unitary Authority in England

Unitary Authority	Unemployment rate	Percent Muslim	Percent non-Muslim Asian	% 50-64 year olds female	% 50-64 year olds aged 60-64	Predicted uptake rate
Highest 20						
19UC Christchurch	3.5	0.2	0.3	53.3	32.4	62.5
19UD East Dorset	2.6	0.2	0.3	52.6	29.0	62.2
18UB East Devon	3.2	0.1	0.2	52.2	31.1	62.0
45UD Chichester	2.8	0.3	0.4	52.3	29.4	61.9
19UH West Dorset	3.0	0.2	0.4	52.0	29.8	61.7
21UG Rother	3.9	0.7	0.4	52.8	31.0	61.6
45UC Arun	3.4	0.4	0.3	51.9	30.7	61.6
21UH Wealden	2.5	0.4	0.3	51.8	27.8	61.5
24UJ New Forest	2.9	0.2	0.2	51.7	28.8	61.5
46UD Salisbury	2.5	0.3	0.4	51.2	28.5	61.4
19UE North Dorset	2.7	0.2	0.5	51.6	28.3	61.4
32UF South Holland	3.4	0.2	0.3	51.5	30.3	61.4
45UB Adur	3.0	0.8	0.6	52.2	28.8	61.4
30UF Fylde	3.1	0.3	0.3	51.4	29.5	61.3
30UQ Wyre	4.1	0.2	0.4	51.8	31.5	61.3
24UE Fareham	2.4	0.4	0.4	51.1	27.6	61.2
38UF West Oxfordshire	2.0	0.2	0.3	50.6	26.7	61.1
19UG Purbeck	2.9	0.2	0.4	51.3	27.9	61.1
33UC Broadland	2.8	0.2	0.3	50.7	28.8	61.1
36UD Harrogate	2.6	0.2	0.3	50.5	28.4	61.1
Lowest 20						
00CW Wolverhampton	8.6	1.9	12.9	50.3	30.3	53.6
00AP Haringey	8.9	12.8	3.9	52.7	28.8	53.6
00AG Camden	7.6	12.9	3.4	51.7	26.2	53.5
00CS Sandwell	8.5	5.0	9.7	49.7	30.5	53.5
00KA Luton UA	5.7	15.8	4.1	49.2	28.7	53.4
00BH Waltham Forest	7.3	16.5	3.1	51.7	28.5	53.4
00CX Bradford	6.9	17.5	2.3	50.5	28.7	53.2
00AQ Harrow	4.5	7.7	22.8	52.3	27.9	52.5
00AT Hounslow	4.7	9.9	18.2	50.8	27.9	52.4
00EX Blackburn with Darwen	6.7	21.2	0.6	49.7	27.8	52.2
00AA City of London	4.8	6.1	2.6	40.8	21.0	51.8
00BC Redbridge	5.5	12.9	14.8	50.9	26.2	51.6
00AJ Ealing	5.8	11.1	18.6	50.7	28.8	51.4
00CN Birmingham	9.5	15.6	5.7	50.5	29.8	51.3
00AM Hackney	11.2	15.6	3.2	51.3	28.8	50.9
00MD Slough UA	4.8	14.5	15.0	47.6	26.7	50.4
00AE Brent	7.6	13.3	20.3	51.8	30.6	49.9
00FN Leicester UA	7.9	11.9	20.6	50.9	29.3	49.4
00BB Newham	11.4	26.7	11.4	50.9	29.8	45.6
00BG Tower Hamlets	11.2	39.3	2.3	50.8	32.5	45.5

Table 6.2.7: Predicted uptake rates by Unitary Authority in Wales

Unitary Authority	Unemployment rate	Percent Muslim	Percent non-Muslim Asian	% 50-64 year olds female	%50-64 year olds aged 60-64	Predicted uptake rate
220 WALES/CYMRU	5.7	0.8	0.5	50.6	28.4	58.8
00PL Blaenau Gwent/Blaenau Gwent	8.4	0.2	0.3	49.3	28.4	56.7
00PB Bridgend/Pen-y-bont ar Ogwr	5.7	0.2	0.4	50.9	28.8	59.2
00PK Caerphilly/Caerffili	6.0	0.1	0.2	50.4	27.9	58.6
00PT Cardiff/Caerdydd	4.9	4.0	1.5	50.8	27.6	58.1
00NU Carmarthenshire/Sir Gaerfyrddin	5.7	0.2	0.3	50.4	28.5	58.9
00NQ Ceredigion/Sir Ceredigion	5.0	0.4	0.5	50.3	28.8	59.4
00NE Conwy/Conwy	6.1	0.3	0.3	51.8	31.0	59.8
00NG Denbighshire/Sir Ddinbych	5.5	0.3	0.4	50.7	29.3	59.4
00NJ Flintshire/Sir y Fflint	4.4	0.1	0.2	50.5	27.9	59.8
00NC Gwynedd/Gwynedd	6.8	0.3	0.4	50.7	29.5	58.5
00NA Isle of Anglesey/Sir Ynys Mon	7.9	0.1	0.2	51.2	29.0	58.0
00PH Merthyr Tydfil/Merthyr Tudful	7.4	0.3	0.4	50.2	29.0	57.8
00PP Monmouthshire/Sir Fynwy	4.0	0.2	0.4	50.4	27.3	59.9
00NZ Neath Port Talbot/Castell-nedd Port Talbot	7.0	0.3	0.3	50.7	28.7	58.3
00PR Newport/Casnewydd	6.2	2.8	0.4	50.5	28.3	57.9
00NS Pembrokeshire/Sir Benfro	6.5	0.2	0.3	51.1	29.6	59.0
00NN Powys/Powys	4.0	0.1	0.5	50.4	28.0	60.0
00PF Rhondda; Cynon; Taff/Rhondda; Cynon; Taf	6.2	0.3	0.3	50.0	28.0	58.3
00NX Swansea/Abertawe	6.2	1.0	0.5	51.7	28.9	59.0
00PM Torfaen/Tor-faen	5.6	0.2	0.3	49.9	27.4	58.6
00PD The Vale of Glamorgan/Bro Morgannwg	5.0	0.4	0.5	50.6	27.6	59.2
00NL Wrexham/Wrecsam	5.1	0.3	0.3	49.6	27.2	58.8

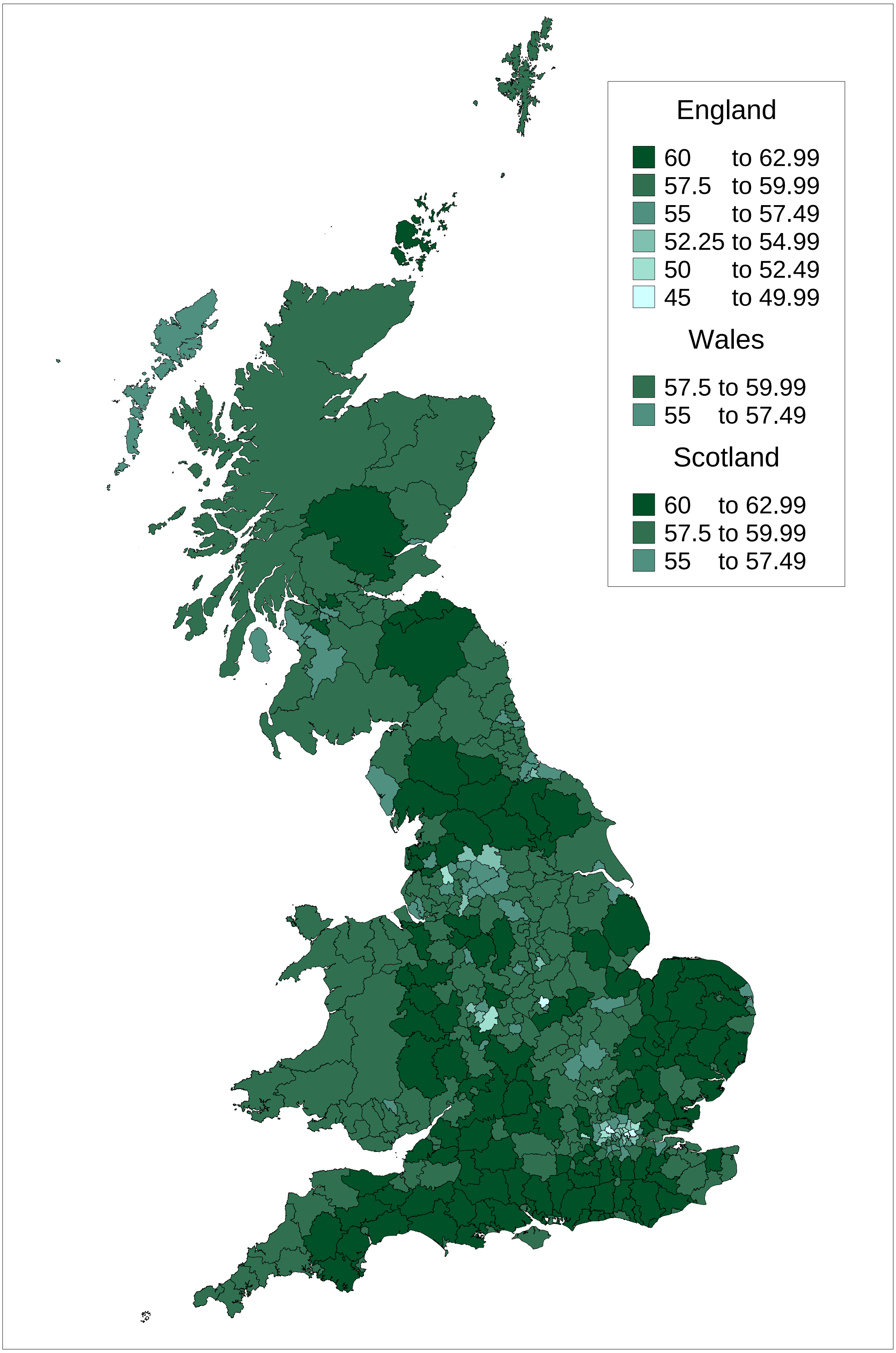
Table 6.2.8: Predicted uptake rates by Unitary Authority in Scotland

Unitary Authority	Unemployment rate	Percent Muslim	Percent non-Muslim Asian	% 50-64 year olds female	% 50-64 year olds aged 60-64	Predicted uptake rate
SCOTLAND	6.1	0.9	0.4	51.2	29.0	58.9
Aberdeen City	4.0	0.9	0.6	50.1	28.2	59.7
Aberdeenshire	3.6	0.1	0.2	49.0	26.3	59.4
Angus	5.7	0.2	0.1	51.0	28.2	59.2
Argyll & Bute	6.0	0.1	0.2	51.1	30.3	59.5
Clackmannanshire	6.6	0.4	0.1	51.1	27.0	58.4
Dumfries & Galloway	6.5	0.1	0.3	50.9	30.2	59.0
Dundee City	8.9	2.1	0.6	51.1	31.0	57.1
East Ayrshire	8.6	0.2	0.1	51.1	28.8	57.4
East Dunbartonshire	4.0	0.7	1.4	52.3	29.2	60.6
East Lothian	4.0	0.2	0.1	51.2	28.8	60.6
East Renfrewshire	3.7	2.3	0.9	52.1	28.4	60.3
Edinburgh, City of	4.3	1.6	0.8	51.8	28.2	60.0
Eilean Siar	7.7	0.2	0.2	48.2	30.8	57.3
Falkirk	5.7	0.6	0.1	51.2	29.3	59.4
Fife	6.8	0.5	0.2	51.4	27.9	58.5
Glasgow City	9.8	3.3	0.9	51.2	31.5	56.2
Highland	6.3	0.2	0.2	50.4	28.5	58.6
Inverclyde	7.5	0.2	0.2	51.4	29.4	58.4
Midlothian	3.7	0.4	0.1	51.6	27.6	60.6
Moray	5.1	0.2	0.2	50.8	29.2	59.7
North Ayrshire	9.3	0.1	0.3	51.5	29.3	57.3
North Lanarkshire	7.2	0.6	0.2	51.9	29.5	58.8
Orkney Islands	4.3	0.0	0.2	50.1	29.6	60.1
Perth & Kinross	4.1	0.2	0.2	51.2	28.6	60.4
Renfrewshire	5.7	0.4	0.3	51.9	29.1	59.7
Scottish Borders	4.5	0.1	0.2	51.3	29.2	60.4
Shetland Islands	3.2	0.3	0.3	47.2	26.0	58.8
South Ayrshire	6.9	0.1	0.2	51.5	29.3	58.9
South Lanarkshire	5.9	0.4	0.2	51.9	29.5	59.7
Stirling	4.6	0.4	0.3	51.1	28.7	60.0
West Dunbartonshire	8.6	0.2	0.2	51.9	28.6	57.7
West Lothian	5.1	0.6	0.2	51.0	27.4	59.3

Table 6.2.9: Predicted uptake rates by Unitary Authority in Northern Ireland

Unitary Authority	Unemployment rate	Percent Muslim	Percent non-Muslim Asian	% 50-64 year olds female	% 50-64 year olds aged 60-64	Predicted uptake rate
Northern Ireland	6.6	0.1	0.1	51.1	28.2	58.7
Antrim	4.4	0.1	0.1	50.6	26.7	59.6
Ards	4.8	0.1	0.0	50.7	25.9	59.3
Armagh	5.8	0.0	0.0	50.3	27.9	58.9
Ballymena	4.6	0.1	0.1	51.2	28.4	60.1
Ballymoney	5.8	0.0	0.1	50.3	28.8	59.1
Banbridge	4.2	0.0	0.0	51.2	27.9	60.3
Belfast	9.5	0.1	0.2	52.3	30.3	57.7
Carrickfergus	5.1	0.1	0.1	51.0	28.1	59.7
Castlereagh	3.8	0.1	0.1	52.5	30.0	61.5
Coleraine	6.7	0.0	0.2	51.6	30.3	59.3
Cookstown	5.9	0.0	0.0	50.8	27.3	58.9
Craigavon	5.6	0.2	0.1	51.5	28.3	59.5
Derry	11.9	0.0	0.2	50.7	27.6	54.8
Down	5.7	0.0	0.0	50.0	27.7	58.8
Dungannon	5.9	0.0	0.1	50.7	28.4	59.1
Fermanagh	8.2	0.0	0.0	49.2	27.2	56.6
Larne	5.7	0.0	0.0	50.6	28.4	59.1
Limavady	8.2	0.0	0.0	49.9	27.3	57.0
Lisburn	4.9	0.0	0.1	51.5	27.3	59.8
Magherafelt	5.0	0.0	0.1	50.8	27.3	59.5
Moyle	8.2	0.0	0.0	50.1	29.9	57.7
Newry and Mourne	8.1	0.0	0.0	50.4	28.1	57.4
Newtownabbey	4.6	0.1	0.1	51.7	28.8	60.4
North Down	4.7	0.1	0.0	51.5	25.3	59.5
Omagh	7.6	0.0	0.1	49.8	27.7	57.4
Strabane	10.1	0.0	0.1	50.1	28.5	56.0

Figure 6.2.8: Map of predicted uptake across local authorities in England, Scotland and Wales



6.3 Conclusions and Recommendations

6.3.1 CONCLUSIONS

The analysis presented here is based on the limited amount of ethnic-specific data that can be derived for 1991 Census Enumeration Districts (EDs), which approximate to neighbourhoods, and it should therefore be treated with some caution. Furthermore, in terms of ethnic minority groups only South Asian uptake by neighbourhood has been considered because the very dispersed geographical distribution of African Caribbean people means that the use of geographical correlates to identify neighbourhood uptake rates for these ethnic groups was not feasible. Finally, the model for CRC screening uptake rates is limited to the initial *decision to respond to the offer of screening* i.e. the percentage of persons invited for screening who return at least one used kit (adequate or inadequate). Other indicators of uptake such as *completion of phase I of screening* or the *completion of screening* are not considered. For the modelling exercise, the five distinct religion-language groups identified by the *Nam Pehchan* software and used to calculate uptake rates (see section 3.1.2.3) were aggregated into three broader categories; Muslim, ‘non-Muslim South Asians’, or ‘non-Asians’ (the latter including white, Chinese and African-Caribbean people).

The results of the regression analyses indicate a strong negative relationship in the English Pilot site between uptake rates at enumeration district level and indicators of socio-economic deprivation and, to a somewhat lesser extent, with the percentage of the population from South Asian ethnic groups in these areas. There was relatively little difference observable in neighbourhood uptake rates between Muslim and non-Muslim South Asians based on these models, unlike the overall pattern based on individuals' responses observed in the Pilot area. Furthermore, the explanatory power of all the regression models was relatively low (Adjusted $R^2 = 0.175 - 0.396$). The spatial predictions of uptake rates in other parts of the UK using 2001 Census data are also necessarily limited. These were restricted by the socio-economic detail so far available from the Census, and thus had to use the unemployment rate as an indicator of deprivation.

The resulting colorectal cancer screening uptake predictions are for higher uptake rates in more prosperous areas and low uptake rates in poorer areas. In England, the unitary authorities with the lowest uptake rates (<50%) are those with the largest percentages of their populations from minority ethnic groups; Newham, Tower Hamlets Leicester, and Brent (Table 6.2.6). While the highest uptakes are predicted to occur in the retirement areas of the south coast. The overall pattern is of higher predicted rates in suburban and rural areas and lower predicted rates in the inner cities, especially in Inner London, Leicester and Birmingham. Areas with large South Asian (especially Muslim) populations have lower uptake rates, reflecting the lower uptake by people from these ethnic groups in the English Pilot. When the proportion of the population that is Muslim rises above 10%, the CRC uptake rate drops to 55% or lower; none of the EDs with over 5% Muslim population are predicted to have uptake rates of 60%.

Less diverse uptake rate are repeated in the other three countries within the United Kingdom, compared with the range in England (62.5% to 45.5%). In Scotland, uptake is predicted to be highest in East and Mid Lothian and East Dunbartonshire (60.6 per cent) and lowest in Glasgow (56.2 per cent). In Wales, predicted uptake is highest in Powys (60 per cent) and lowest in Blaenau Gwent (56.7 per cent). In Northern Ireland, the highest predicted uptake is in Newtownabbey (60.4 per cent) and the lowest in Derry (54.8 per cent). These countries all contain much smaller minority populations, their composition is different, and local concentrations of minority ethnic groups are much less marked than in England.

Though more sophisticated estimation techniques could have been used (e.g. weighted regression or Poisson regression), it is likely that a similar pattern of estimates would have been yielded.

This analysis has been largely based on 1991 Census of Population data, since detailed data from the 2001 Census is not yet available. Repeating the analysis with 2001 data should yield more accurate results, since it is clear that minority population growth has been substantial during the 1990s. Additionally, 2001 Census “Output Areas” are designed to be homogeneous in socio-economic characteristics and will therefore represent neighbourhoods better than 1991 Census Enumeration Districts. However, there are still problems involved in using these data, since ethnically-classified neighbourhood level data from the 2001 Census are again limited for reasons of confidentiality, not available at all in areas of small minority populations, and use different ethnic group classifications in Scotland and Northern Ireland to England and Wales.

6.3.2 RECOMMENDATIONS

1. The prediction of uptake rates in other parts of the UK has been largely based on 1991 Census of Population data, since detailed data from the 2001 Census was not available at the time of writing this report (February 2003). **Repeating the analysis with 2001 Census data would yield more accurate results**, since it is clear that minority population growth has been substantial during the 1990s.

6.4 References - Section 6

Peach, G.C.K. (1996) ‘Does Britain have ghettos?’, *Transactions of the Institute of British Geographers (new series)*, 21, 216-235.

Timms, D. (1971) *The Urban Mosaic: towards a theory of residential differentiation* (Cambridge: CUP).

7. Summary and Future Directions

Following the implementation of the Race Relations Amendment Act 2000, there has been a statutory duty laid upon all NHS agencies to ‘have due regard to the need to eliminate unlawful discrimination’, and to make explicit consideration of the implications for racial equality of every action or policy. Our study has highlighted a range of issues which will be relevant to planning for potential roll-out of colorectal cancer (CRC) screening. Clearly one of the aspects which will influence the success of any national CRC screening policy will be its success in addressing the question of improved access and service provision for ethnic minorities.

The Pilot has been able to achieve overall FOBt uptakes rates of 60%, and values for overall rates of neoplasia detection i.e. cancers and potentially pre-malignant lesions (e.g. adenomas) similar to those achieved in the Nottingham and other trials. However, the overall FOBt uptake figure for the English site (63.3%) masks a significantly lower screening uptake for the South Asian community, without any indication of an initial unwillingness to be screened. There are particularly low completion screening rates in the Muslim (32%) and Sikh (35%) communities. Multivariate analysis demonstrates that low uptake rates by individuals cannot be explained by other factors such as deprivation. Similarly, although the overall uptake rate for colonoscopy is 82% for individuals with a positive FOBt, colonoscopy uptake rates are significantly lower among Asians (55%), even once other factors such as deprivation are taken into account.

The observed outcomes of screening in the UK Pilot have led the main Evaluation Group to conclude that the benefits observed in the randomised trials of FOBt screening (including CRC-specific mortality reductions) should be repeated in a national roll-out (see Main Evaluation Report, February 2003). However, our extrapolation of the Coventry and Warwickshire pilot site findings to populations in various geographical locations in the UK suggests that roll-out is unlikely to achieve these uptake levels in many areas. In particular, there are predictions of very low FOBt uptake rates in the inner cities, especially in parts of Inner London (Tower Hamlets and Newham; 45.5% and 45.6% uptakes predicted). Although ethnicity influences predicted screening uptake in England, with the areas of lowest uptake having largest Asian minority populations, ethnic origin has a much smaller effect in Wales, Scotland and Northern Ireland.

In summary, although the UK Pilot has demonstrated that key parameters observed in randomised studies of FOBt screening can be repeated in a pilot programme, these parameters are not achieved in ethnic minority populations. As part of any consideration of full implementation therefore, the implications of ethnicity for roll-out will need to be carefully considered, and a strategic plan developed on how best to address the differences highlighted in this report.

We consider there are a number of areas which would benefit from further research and evaluation:

- follow-up of individuals who are invited to second round screening in the English Pilot, and examination of uptake versus ethnic and socio-economic population characteristics, and GP/ practice characteristics. Comparison of individuals' responses to CRC screening (women only) with uptake of other screening programmes (i.e. breast and cervical) through matching with existing databases;

- analysis of longer-term colonoscopy uptake rates for individuals invited to first round screening: examination of colonoscopy status 6 months following positive FOBt to identify whether Asian uptake remains substantially lower than that of non-Asians;

- the advent of a second round of screening also raises the prospect of evaluating the effectiveness and cost-effectiveness of a multi-strategy intervention to increase ethnic uptake of CRC screening, based on available research evidence;

- if significant colonoscopy uptake differences remain after completion of 2 above, strategies for improving colonoscopy uptake in ethnic minority invitees who screen FOBt positive also need to be developed and evaluated.

The strong evidence provided by our study on variations in uptake linked to ethnicity will inevitably require further research and concerted action. Ideally, research should be integrated into the second round screening currently being undertaken in the English Pilot site, while planning and decision-making are underway over a possible national programme.