

RESEARCH PAPER

Recruitment of South Asians into asthma research:
qualitative study of UK and US researchersLucy Stirland^a, Laila Halani^b, Bhopal Raj^c, Gopalakrishnan Netuveli^d, Martyn Partridge^e,
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Originally received 4th December 2010; revised 22nd January 2011; accepted 27th January 2011; online 20th April 2011

Abstract**Background:** There is increasing international concern about the persistent under-representation of ethnic minority patients in research.**Aims:** We aimed to explore strategies being employed by US and UK researchers when attempting to recruit minority ethnic participants into research with a view to increasing participation by South Asians in UK asthma research.**Methods:** Qualitative interviews with 36 asthma-interested researchers.**Results:** Key themes were: the need to build long-term trusting relationships; ensuring that the procedures and practices used were respectful; paying attention to logistic considerations with respect to funding, the location of the research and taking proactive steps to overcome language-related barriers; and the importance of effective dissemination of results to, amongst others, the minority ethnic groups under study. The use of financial incentives or "co-payments" was reported as being a successfully-employed strategy in the US context, which could be considered for use in the UK.**Conclusions:** There is a need for funders and researchers to take proactive steps to develop longer-term relationships built on trust and respect with the populations they wish to study. Attention to the location of research, language considerations, financial reimbursement and appropriate dissemination of results are all likely to translate into improved recruitment of these "hard-to-reach" populations.

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L Stirland *et al.* *Prim Care Respir J* 2011; 20(3): 282-290<http://dx.doi.org/10.4104/pcrj.2011.00032>**Keywords** asthma, ethnic minorities, recruitment, research participation

See linked editorial by Johnson on pg 229

The full version of this paper, with online Appendices,
is available at www.thepcrj.org**Introduction**People from minority ethnic groups are under-represented in United Kingdom (UK) research, and this problem is particularly prevalent in the field of asthma where health inequalities between ethnic groups are striking.¹ This under-representationof ethnic minorities may be due to a range of practical difficulties encountered by researchers and/or may be a consequence of their deliberate exclusion.² As well as carrying ethical and legal implications – as per the Race Relations (Amendment) Act 2000³ and Equality Act 2010⁴ – a discrepancy is likely to affect adversely the external validity of study findings. Previous work has found that United States of America (US) studies are considerably more likely to report the ethnicity of candidates than European ones (62.9% versus 2.9%; $p < 0.0001$),⁵ these differences being even more striking* **Corresponding author:** Professor Aziz Sheikh, University of Edinburgh, Centre for Population Health Sciences, Teviot Place, Edinburgh, Scotland, EH8 9AG, United Kingdom. Tel: +44 (0)131 651 4151 E-mail: aziz.sheikh@ed.ac.uk

in the context of asthma trials.⁶ A key factor contributing to these differences is the impact of the 1993 National Institutes of Health (NIH) policy stating that clinical research funded by the NIH must include a representative proportion of people from minority ethnic backgrounds; we have reported on the importance of this policy difference elsewhere.^{7,8} Whilst undoubtedly important, this is unlikely to be the only factor explaining these differences, as suggested by our study comparing the impact on ethnicity reporting in studies funded by the NIH and other US funders which are not bound by the same regulations on recruiting women and minority ethnic groups.⁹

In order to progress understanding on this issue, there is a need to understand more fully the experiences, views and concerns of researchers and patients. In this paper, we focus on the perspectives of academics with an interest in asthma drawn from both the US and UK. We enquired about the barriers they face in recruitment and the strategies they have (successfully or otherwise) employed in overcoming these. This study focuses on South Asians as the largest minority ethnic group in the UK, accounting for approximately 50% of the UK's minority ethnic population and 4% of the total UK population.¹⁰ In contrast, approximately 3% of the minority ethnic population of the US is of South Asian origin, making up 0.7% of the total population.¹¹ This paper builds on earlier reports from our study focusing on the policy level differences between the US and UK,⁸ and the perspectives of UK South Asian patient/carer perspectives on barriers and facilitators to asthma research.¹²

Methods

Study design

In-depth interviews were conducted with asthma researchers from the UK and the US. Multi-centre research ethics committee and local research governance approvals were obtained, and all participants gave their informed consent to participate.

Sampling and recruitment procedures

A database of researchers was compiled by contacting experts and conducting a search of principal investigators on asthma projects undertaken or funded between 2001-2006 listed in Medline, the NIH database, the UK National Research Register, Asthma UK, and the Cochrane Airways Group. US and UK researchers were purposefully selected to identify researchers from diverse but relevant disciplinary backgrounds: i.e. genetics, basic sciences, epidemiology, statistics, primary and secondary care, and quantitative and qualitative research. When sampling, we also considered researchers' likely experiences of recruiting and working with minority ethnic people, based on published reports, to ensure that we recruited at least some participants who could draw on their previous experiences.

Data generation

Interviews with researchers were conducted either face-to-face or by telephone by a social anthropologist with considerable experience of conducting qualitative field work. Interviews lasted 15-60 minutes and a topic guide derived from key findings in the literature (Appendix 1, available online at www.thepcrj.org) was used as a prompt, if necessary. Interviews were digitally recorded and transcribed in full; interviewees were offered a copy of the transcript to check. Participants were assured anonymity in order to encourage them to speak freely on a potentially sensitive subject.

Data analysis

Data analysis occurred as an ongoing process throughout data generation thereby allowing issues raised by participants to be fed into future interviews and continued until after data collection had ceased.¹³ The study researcher and principal investigator met weekly to discuss the findings from interviews and considered the data and our evolving interpretations of these at regular intervals with members of the wider multi-disciplinary project steering group. We attempted to remain abreast of key developments in the literature, thereby allowing these issues to be discussed and also to allow our findings to be understood in the context of this broader literature.¹⁴

Data were analysed using the Framework approach, a method developed for social policy research and particularly suited to large data sets.¹⁵ This involved the following key stages:

- i. familiarisation with the data
- ii. identification of a thematic framework
- iii. indexing and annotating of transcripts with a set of descriptors
- iv. charting, and where necessary, rearranging the data according to category (see Appendices 2 and 3, available online at www.thepcrj.org), and
- v. mapping and interpretation thereby allowing the linking of themes and analysing their possible explanations.

We actively sought out alternative explanations and remained aware of the need to be reflexive with respect to our own backgrounds and experiences when analysing and interpreting these data.¹⁶ Data collection continued until saturation, i.e. the point at which no major new ideas were emerging.

Results

A total of 43 (21 UK, 22 US) invitations were sent out to asthma researchers. Four (2 UK, 2 US) of those invited failed to respond and a further three (US) declined. We therefore had a total of 36 (19 UK, 17 US) participants. Eleven (9 UK, 2 US) interviews were conducted face-to-face, the remainder being conducted by telephone. Researchers were recruited from a range of

Table 1. Disciplines of asthma researchers

Researcher No.	Discipline
R01	Sociologist
R02	Respiratory consultant
R03	Social scientist
R04	Primary care
R05	Environmental and occupational medicine
R06	Primary care
R07	Basic scientist, immunologist
R08	Respiratory consultant and journal editor
R09	Allergy and immunology physician
R11	Primary care
R12	Primary care
R13	Primary care
R14	Primary care
R15	Epidemiologist
R16	Respiratory physician and journal editor
R17	Health policy and health education
R18	Social scientist
R19	Epidemiologist
R20	Epidemiologist, basic scientist, geneticist
R21	Social scientist
R22	Basic scientist
R23	Epidemiologist
R24	Geneticist
R27	Basic scientist, epidemiologist
R29	Statistician
R30	Primary care
R35	Epidemiologist, health educationist
R37	Sociologist, behavioural scientist
R38	Epidemiologist, statistician
R39	Translational scientist
R40	Clinical professor
R41	Basic scientist
R42	Pharmacist, health economist, editor
R43	Health educationist, qualitative researcher
R44	Basic scientist
R45	Psychologist, educationist

Apart from the three social scientists (who were chosen due to their interest and works on ethnicity and health research), all the interviewees have worked and published on asthma.

Identifiers have been kept to a minimum to avoid the risk of inadvertent disclosure of identity.

disciplinary backgrounds (see Table 1).

Interviewees discussed their views on recruiting people from ethnic minority backgrounds into research studies and the barriers they believed are contributing to this under-representation of minority ethnic groups. They shared their experiences of effective strategies for increasing participation

Box 1: Key findings

- The need to build long-term trusting relationships
- Ensuring that the approaches and procedures used are, and are seen to be, respectful of the community's and individuals' values
- Careful attention to a number of key logistic considerations during study planning and execution – including the location of the research, securing funding for translation, interpretation and reimbursing gatekeepers and participants, flexibility and persistence.
- Effective dissemination of findings to peers, but crucially also to the minority ethnic populations themselves.

amongst ethnic minority communities and their ideas for potential future methods of overcoming barriers to inclusion. Some of these methods reinforced recruitment strategies that have been identified in studies conducted in other disease contexts,¹⁷⁻²⁴ whereas others have not, as far as we are aware, been previously reported. There was a marked difference between researchers' experiences in the two countries: in the US far more interviewees had worked with people from ethnic minorities and had developed strategies to do so effectively and efficiently, whereas in the UK there was a marked lack of exposure to, and hence engagement, with the issue. Box 1 summarises the key themes identified, which are then discussed in more depth below.

1. Trusting relationships**a) Community organisations and leaders**

A frequently recommended strategy for earning the trust of potential study participants was ongoing involvement with community groups, community leaders and faith organisations. Researchers who had previously liaised with organisations, whether in the context of research or indeed in any other context, found it relatively easy to know both who to approach and also how to forge an effective relationship with these communities. Involving groups early on in the research process also helped to cultivate a sense of ownership of the project. One researcher reported employing community leaders as research personnel, whilst others described communicating through a link person who acted as an ambassador between the community and investigators:

"Because I myself am not an African-American person... I have co-investigators and colleagues who know the community well and who are trusted in the community"
R02, US

Most researchers thought this person should be from the

community in question, but this could and at times did raise potentially important issues in relation to ensuring confidentiality; this needed to be taken into account:

"That might put them off because the other thing with a lot of Asian people, if they know you're from the community they're going to say "Oh you're going to gossip"... it is a social thing but I think it's more of a cultural thing... "but what would the neighbours say?" You know that kind of thing." R03, UK

Personal contact with community leaders and/or elders was described as essential by those with positive previous experiences of recruiting minority participants. Such a personal relationship, if cultivated, could be an antidote to the problem of possible "research fatigue" experienced by some members of their community or faith groups. Penetration of collaborations of community groups and/or national organisations was also raised as being potentially important – since this could facilitate entry into related organisations and hence participants in other geographical regions or age groups. Finding mutually beneficial arrangements for researchers and community/faith groups was advocated; suggested examples included buying advertisements in community newsletters/publications and hiring rooms in community/religious centres in which to hold meetings and/or assess research participants. More direct approaches were also cited. For example, one US researcher reported giving a financial gift to a church in return for help with recruitment.

Conversely, participants also reported instances where consultation with or work on minority ethnic communities was perceived by the communities themselves as being conducted in a tokenistic fashion, these adverse experiences having a negative impact on relationships with the research community with knock-on implications for future studies.

b) Schools and family involvement

Schools can be a helpful and trusted link in areas with large numbers of ethnic minority people, especially where health services are already present in schools. Researchers reported that teachers and school staff (including nurses) were often willing to help recruit their students for studies if approached sensitively. Staff were also cited as a valuable resource for not only understanding how best to approach the target age group, but for practical issues such as translation. However, one participant reported that when a school nurse was the sole representative of a study in a school, recruitment was lower than when research staff were also physically present.

Incentives for participation could be aimed not only at students for responding to invitations, but also towards the school – such as small gifts of classroom materials for a poorly resourced school. However, there were potential concerns raised about the giving of gifts directly to students, since unless chosen carefully these could promote rivalry and peer pressure to participate. Whilst the importance of adequate consent

procedures was taken 'as read', some researchers noted the particular importance of involving other family members in the consent process when recruiting minority ethnic children:

"In some cultures... if I want to do something I'm part of a family group and I maybe need to get at least the tacit approval of the group." R04, UK

c) Communication and transparency

Effective communication was another suggested attribute of a successful recruitment programme. A recurring theme in the interviews was that when potential participants fully understand the work being carried out they engage better to, and are more likely to respond positively to, invitations. Some distrust towards researchers, especially in the US, appeared to be tied-up with a suspicion that research professionals are in some way linked to either the authorities or hospital debt collectors. If these fears are dispelled and the need for more inclusive representation and the benefits of participation for both individuals and society at large explained, then people were more likely to be willing to take part:

"Maybe if you could explain that it's an asthma trial, asthma outcomes are poor in your population group and yes, one of the reasons maybe is because people from your ethnic group haven't taken part in the research, so we haven't come to understand the particular needs..."

R06, UK

d) Personal touch

A personal approach, including face-to-face contact, was seen as instrumental to building relationships between research staff and members of ethnic minority communities. Some researchers reported this process taking several years and that telephone contacts were the best method of maintaining a rapport once a relationship had been forged. One recommended giving participants the researcher's personal phone number so they could be contacted with any queries. The involvement of clinicians whom patients already know, particularly family doctors, was repeatedly commended as this too could help develop trust. This long-term personalised relationship building allowed a tacit understanding of community values and orientation to emerge, which in turn gave the researchers greater licence and confidence to engage with the communities in an organic, mutually enriching way:

"I think that if... you recognise what you don't know, you're respectful of the community, you're comfortable in the community and you're actually doing research in the community, we always did pretty well recruiting patients." R43, US

However, a topic that frequently arose was the difficulty in accessing the potentially valuable support of primary care providers. Interviewees felt that, in particular, UK GPs often did not have the time, training or financial incentives to support recruitment. It was also mentioned that in some minority ethnic

communities where the population is transient, GPs are not a practical gateway to patients. One UK researcher described several GP practices joining together to employ a research assistant who could then personally support the recruitment effort.

2. Respect

a) Incentives and reimbursement

The most commonly mentioned strategy for improving recruitment rates was financial reimbursement for participants' time, this being raised in almost half of the interviews. This is an area where marked differences between the US and UK were apparent; for example, US researchers described the appropriateness of "co-payment" for patients' medications in return for their taking part in a study, giving free general health screenings or offering services such as spirometry to clinics that might not otherwise have the opportunity to use them. US researchers reported the use of vouchers that could be used to purchase food or other essentials, but they also reported instances in which they had paid subjects by cheque (which was acceptable to the funding bodies sponsoring the research); these payments, whether in kind or in cash, were regarded as important as these served as a practical demonstration that people's time was valued.

Problems raised with such incentives included the exclusion of those with higher incomes for whom a financial incentive was less attractive, and the acceptance of an incentive, but then a reluctance to participate meaningfully (for example, in a focus group discussion). Abuses of these incentives were also reported – for example, people lying about their condition in order to meet the eligibility criteria and then using the payments to buy large amounts of alcohol.

There was more convergence between the US and UK when it came to reimbursing patients for travel expenses and offering snacks or a meal if the intervention took place over a meal time, both of which were common practices. Covering child care costs or providing on-site activities for children was reported as effective when working with families.

One US researcher discussed the value of holding community events such as barbecues or family activity days to publicise the work being carried out. Another interviewee with particular experience working in schools threw pizza parties for the class that had the highest response rate to invitations to participate (whether positive or negative). American hospitals or health centres were willing to be approached to fund these sorts of initiatives, but local businesses had also agreed to contribute, this latter approach perhaps being more applicable within a UK context. US funding bodies (including the NIH) were willing to allow budgeting for these "extra costs" of recruiting people from ethnic minorities, including reimbursement for their time; a willingness to cover the more traditional costs such as for translation was reported as being more broadly acceptable to both UK and US funders.

b) Cultural and religious sensitivity

The broad, but vital issue of cultural and religious sensitivity was broached in many of the interviews. Attention to detail can help promote trust and generate respect for researchers as well as facilitating a smooth study experience. Examples mentioned included holding gender-specific interviews and focus groups where appropriate, being prepared to accept and document verbal consent, and only entering a participant's home when accompanied by a community member. Some researchers highlighted attention to specific religious norms – for example not sending male staff to interview unaccompanied young Muslim women. One strategy mentioned which worked around this was a researcher taking his wife with him on field visits. It was advised that information material be clear and comprehensive to minimise the impact of studying possibly stigmatising conditions (including asthma). Careful communication was hailed as a key approach to fostering good relations, which would allow understanding between researchers and study participants of issues where important cultural differences might exist:

"And you explain to them why and then you say "can you help me now? I don't know a lot about Sri Lanka. I've never been there, I don't know anybody from Sri Lanka.

Could you help me understand?" R12, US

This was seen as working best when techniques were employed to help staff appreciate and understand principles of engagement rather than a set of rules. Flexibility was important so that different communities' needs could be catered for without the use of stereotypes; the sometimes unfamiliar health beliefs of people from different communities could then be respected.

3. Logistic considerations

a) Language

Language issues were a major contributor to difficulties faced by researchers, both in the US and UK. A lack of time and resources for translating material was widely recognised as a reason for excluding minority people. Conversely, simply translating the invitation letter into several languages dramatically increased one researcher's response rate:

"People were quite happy filling in the English instrument but they wanted a letter in there in their own language. And it was interesting as all we did... was just literally put several versions of the same letter in the envelope." R11, UK

The importance of questionnaires ideally being validated in other languages or at least trialled by some members of the community was emphasised. The difficulties posed by not having suitably validated instruments in the required language(s) were also highlighted, since this could in effect bar use of these questionnaires and by extension their enrolment in the study. Some researchers proposed the idea that a national resource

bank should be formed, allowing researchers to share translation materials and contacts and encouraging the improvement of translation facilities. A database of asthma patients including their ethnicity would, it was suggested, also be useful for recruiting into large-scale studies. On a more individual level, a technique that many researchers used was to employ a member of research staff who could speak the language of the community in question and could help not only with direct translation but also in building trust:

"As long as there is someone around that speaks their language and they feel comfortable, that spreads beyond, the rest of us get extra credit – they're more comfortable with us because they see that we've taken the effort" R41, US

It was also noted that ideally the researcher should be fluent in the language and have specialist knowledge so that they could explain technical details of the trial – for example, how to use equipment/inhalers.

b) Advertising

The use of appropriate languages was recommended for advertising – for example, using multilingual posters or providing spoken study information on CD or DVD – which would also be suitable for use in communities with predominantly oral cultures. The use of symbols was suggested to ensure the inclusion of people who are functionally illiterate. It was emphasised that translations should be thorough and culturally appropriate, and that interpreters may need specialist skills to clearly explain complex clinical procedures.

Other suggested methods to make advertising more effective included targeting the adverts at certain communities – for example, advertising on a radio station aimed at Asian listeners. Posters featuring photos of minority ethnic people placed in community centres or places of worship had proven effective, and one researcher suggested asking well-known people from the South Asian community to endorse studies.

c) Geographical location and convenience

A potentially important and effective method of increasing recruitment that has not yet really been discussed in the published literature was targeting a geographical area with a high concentration of people from ethnic minorities. Holding studies in these areas and ensuring easy accessibility would (it was suggested) improve response rates. A number of US (but not UK) researchers were factoring such deliberations into their funding proposals:

"We make sure that access to the study clinic is very easy so don't put it in the middle of a big hospital complex where they have to pay for parking and... the bus stop is 4 blocks away and everything. Put it in a suburban shopping mall or some place that's right next to the bus stop or tube stop... [so] they can just walk right in." R38, US

Some interviewees emphasised that meeting patients in a place where they feel safe and confident such as hired rooms in a community centre or working alongside a local GP in their practice building can help foster trust as well as providing easy access. Researchers said that if the study centre could not be moved to a convenient place then they arranged transport or reimbursement for travel costs. Offering to work with patients at a time that suits them, such as evenings or weekends, also increased recruitment and retention.

d) Persistence

The importance of persistence was another effective technique highlighted by US researchers that has again not previously been discussed in the literature. Examples cited included repeated phone calls to remind participating clinicians to ask their patients to consider enrolling in a study and, more commonly, direct contact with potential subjects. This included telephone contact and visiting them at home. Researchers reported that in some communities it can be hard to reach patients by telephone, especially if they are frequently relocating. One suggested approach to this problem was to ask for multiple telephone numbers, but clearly this was only really appropriate after a certain degree of trust has already been established:

"We have learned after our first couple of studies we get no fewer than 10 phone numbers from these patients, including relatives, places they might [be]... we ask about pagers, cell phones... We just say, you know, "We want to be able to contact you no matter where you go." R37, US

4. Recommendations throughout the research process, and dissemination

Some researchers suggested that the involvement of people from ethnic minority backgrounds should be considered right from the outset of the research process. The design stage was mentioned as a key point at which to begin engaging with community groups and developing a sense of shared ownership of the project. Some reported that US funding bodies accepted the extra costs involved in recruiting people from ethnic minorities, such as for translation and employing specific members of staff. The recruitment stage was seen as the time when researchers can draw on relationships already forged with local communities to work with them and through so doing gain respect and trust. Some US researchers also reported addressing logistical issues such as translating materials and considering oral consent at an early stage in the project's gestation. It was noted that a well-developed understanding of the community allows staff to be culturally sensitive throughout the data collection process. There was a need expressed throughout the research process for researchers to challenge existing negative stereotypes and misconceptions so as not to derail efforts at trying to engage with these communities. Active and open discussion and debate were seen as important in this respect:

"We had small group discussions and you could see, sort of having the debate that happens in small groups and then start letting people open it up... but then after that you could have people giving ... 20 minute presentations on how they work with a specific minority in a specific area and they try to take those and generalise them to broad concepts." R12, US

Once completed, the sharing of results back to participants was also seen as demonstrating the value of their contribution, which could in turn lay the foundation for future collaborative ventures. Researchers recommended publishing work on recruitment and ethnic minorities in widely-read journals to raise awareness of these issues among the research community. The importance of training the research fraternity in diversity considerations was also emphasised.

Discussion

This study has uncovered a wealth of techniques already in place or being considered for promoting more representative recruiting into asthma studies.^{8,12} Of particular interest is the range of (as yet) untried approaches in the UK being employed in the US, perhaps most important of all in the short-term being the issue of reimbursing participants for their time. However, concerns have been raised about this method since potentially it could lead to the exploitation of those on lower incomes;²⁵ so such an approach, if considered appropriate to use in the UK, would need to be implemented with considerable care.

Some of the techniques mentioned in interviews have also been described in relation to the literature in other disease areas. A UK study exploring the views of South Asians about research recommended providing translated study information or audio or video recordings, as well as advertising on Asian radio stations or with posters in community centres, GP surgeries or cultural events (Melas).¹⁷ Similarly, a large Department of Health drug misuse project advertised in the local and national press, and by sending flyers to minority ethnic community centres; they also tried to cultivate a sense of ownership of the project among people from the communities being studied by recruiting community representatives to carry out the work and hold local events.²¹ One study's method for trying to formulate a shared vision was to involve the community at an early stage and then to share the results with participants when the study concluded.²² Involvement with community groups, faith organisations and community leaders is also seen as an important method for trying to improve recruitment,^{18,19,26} as is community outreach.²³ This could perhaps be extended to the involvement of people from relevant minority ethnic communities in ethics committee deliberations so that a culturally-sensitive approach could be introduced from the design stage.

Strengths and limitations of this work

The inclusion of researchers from the US and the UK coming from disparate backgrounds was an important strength of our approach. The findings generated built on and extended the findings of previous work in this area, thereby suggesting novel approaches that could be employed, particularly in the UK, to try and bolster researchers' experience and in due course expertise in working with relatively unfamiliar population groups and also to make research more acceptable to the minority communities themselves. That the findings from this work resonate with other key developments in the broader ethnicity literature, such as the need for proactive consultation with minority groups, the importance of effective inter-cultural communication,^{27,28} staff receiving cultural awareness and sensitivity training,²⁰ and the involvement of community groups and link workers, are additional strengths of this work.²⁹ Any changes in legislation should be consistent with current policy to maximise efficacy, particularly with the Race Relations Amendment Act and Equality Act.³⁰

Qualitative work always raises the issue of generalisability beyond the participants involved. In this case, due to the differing proportions and composition of ethnic minorities in US and UK populations – for example, the researchers' work with African American and Hispanic people – it may not be possible to apply some of the US-based approaches to South Asians in the UK. The clear differences between the US and UK health services also limits the extent to which US techniques may be effective in the UK. For example, healthcare-based incentives can have a considerable benefit to a US patient who does not have health insurance, whereas in the UK, where healthcare is free at the point of delivery, patients may not see the direct advantages. Not all recruitment methods mentioned allow for representative samples, such as working with young people in schools (who often have different language and cultural experiences from older generations, especially if they were born in the US or UK) and therefore they may not be representative of their ethnic group as a whole.

Many of the approaches we have been able to identify may be extrapolated to minority ethnic groups other than South Asians because the data from US researchers drew on experiences with Hispanic and African American populations that shared many of the same problems in recruitment as identified by UK researchers. Research involving other minority ethnic groups in the UK is likely to encounter common barriers to that with South Asian people; for example language issues. The researchers interviewed all had an interest in asthma and their comments reflected the need for sensitivity in what could potentially be a stigmatising condition. However, most of the techniques in use were not

specific to asthma research and could (we believe) probably be employed in other disease areas.

Implications of this work

The importance of forming long-term relationships built on trust and mutual respect is fundamental to ensuring progress in trying to recruit more inclusively into studies, and this is likely to be most effectively and efficiently achieved in the UK by funders investing in regional specialist ethnicity hubs, which can then act as a resource to the entire research fraternity.

Our work has also identified the need to consider a range of important logistical considerations which should really be considered at the planning stage and then be costed into the study right from the outset; whilst some of these costs such as those relating to translation and interpretation services are likely to prove acceptable to UK funders, others relating to the provision of community events and funding for link workers are likely to be less familiar to reviewers and grant awarding panels and may therefore be looked at with a degree of suspicion. More controversially perhaps, this work has identified the need to consider co-payment for researcher time: the failure to offer to reimburse in this respect may be seen by the individuals concerned and their communities as in some way failing to appreciate their input; conversely, even token "payments" may be seen as valuing individual's time and input and may thus serve as a useful bridge to establishing more meaningful long-term relationships. However, such an approach is not without a number of important ethical challenges as well as obvious short- and possibly long-term funding implications for research funding bodies. Therefore, we believe it should not be extended to the UK in the absence of a more secure evidence base.

Acknowledgements

We are very grateful to the participants for sparing the time to share their views on this subject and also for their frankness in discussing a potentially sensitive subject.

Conflicts of interest

Aziz Sheikh is Joint Editor-in-Chief, Mark Levy is Emeritus Editor, Chris Griffiths is an Assistant Editor and Gopalakrishnan Netuveli is Statistical Editor of the *PCRS*. None of these authors were involved in the editorial review of, nor the decision to publish, this paper.

Contributorship

AS conceived and was PI of this study supervising all aspects of project management, analysis and writing up. LS undertook data analysis and drafted the manuscript. LH undertook data collection and contributed to analysis. RB, GN, MP, JC, CG and ML were grant-holders and contributed to designing and interpreting data; they furthermore commented on drafts of the manuscript.

Funding

Asthma UK.

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Appendix 1: Topic guide for interviews.

Introductions

- Particular interest or area of asthma research? (basic sciences, epidemiology, translational work, clinical/applied research)
- Experience of clinical/research work in US? UK? Elsewhere?

Subject under study

- Understanding of rationale for study
- Is the subject important? Why/why not?
- In what contexts might ethnicity considerations be most relevant?

Experiences of recruiting minority ethnic people with asthma into studies

- Ever considered the question of ethnicity of recruits into studies?
- Experiences of attempting to engage with minority ethnic communities, in particular South Asians.
- Are there barriers to recruiting South Asians that you have personally experienced or you are aware that other researchers have experienced? (Prompts: linguistic, cultural, religious, fear of falling foul, lack of interest, research fatigue, gatekeeper fatigue, obtaining informed consent, time, costs, irritated by political correctness)
- Are there strategies that you/others have successfully used in recruiting South Asians? (Prompts: location of study, minority ethnic co-researcher/research fellow, support of national/local community/religious organisations, financial)

Reporting of data

- When might ethnic specific reporting of data be relevant?
- Have you done this with previous studies? Why/why not?
- Are funders/journals interested?

Next steps

- Is more discussion, debate and consensus still needed?
- Response to recent research showing that minority ethnic people are equally likely to participate as Whites if invited to do so
- Is the US model of target setting a useful way forward?
- National initiatives that might help facilitate greater recruitment of South Asians?
- Actions that funding bodies/ethics committees/journals/researchers/ minority ethnic groups need to take?
- Anything else?

Demographic characteristics of participant

- Age
- Ethnicity
- Position
- Geographical location

Appendix 2: Coding framework with topics arranged in order of frequency.

Topic	Mentioned in interview
Recompense participants with money, gift certificates	R02, R07, R09, R14, R16, R27, R35, R37, R38, R40, R41, R42, R43, R45
Research colleagues from community being studied act as trusted link	R02, R06, R09, R11, R12, R16, R27, R29, R35, R38, R39, R41
Target people through relevant community groups	R01, R04, R06, R12, R16, R27, R29, R35, R43, R03
NIH makes it compulsory to recruit ethnic minorities	R01, R02, R12, R16, R17, R27, R38, R41, R42
Be flexible and tailor needs to individual communities	R02, R05, R07, R08, R16, R27, R29, R43
Reimburse participants for travel expenses	R09, R16, R27, R37, R39, R41, R43, R45
Recruit participants through faith organisations	R11, R16, R27, R29, R35, R37, R41, R43
Long-term relationship building	R02, R09, R27, R29, R35, R37
NIH demands relevant representative samples from communities	R02, R29, R37, R41, R42, R44
Translate information material	R04, R06, R07, R18, R20, R42
Approach community leaders to help with recruitment	R04, R05, R12, R27, R29, R37
Approach patients through their GPs	R03, R08, R11, R17, R23, R37,
Provide childcare while patients are taking part in the study	R27, R35, R37, R38, R39, R45
Ensure translations are culturally appropriate	R06, R16, R19, R38, R42
Develop understanding of cultural differences between researchers and community by communication	R11, R12, R18, R27, R35
Employ fluent speakers who can understand and explain complex issues	R09, R11, R16, R38, R41
Advertise in community-specific media	R01, R03, R07, R11, R35
Specialised research employees who focus on recruitment	R02, R07, R20, R27, R41
Fully explain what to expect from the study	R02, R06, R07, R12, R29
Explain the benefits of participation	R02, R06, R29, R35
Find and use a link person within community	R06, R09, R12, R35
Meet people in their community's geographical area	R01, R35, R41, R43
Translate questionnaires	R02, R04, R06, R45
Rely on "snowballing"	R05, R12, R27, R37
Speak personally to invitees	R08, R15, R41, R45
Coordinator gets to know the participants personally	R27, R38, R39, R43
Provide services not otherwise available, eg bronchoscopy	R09, R27, R37, R38
Provide personal support in the language required, even if the participant speaks English	R02, R04, R09, R16
Translate consent form	R04, R20, R38, R45
Invite participants by telephone	R04, R08, R11, R15
Be culturally sensitive in recruitment	R01, R04, R16, R42
Combine data from different sites	R29, R39, R41
NIH may withdraw funding if targets are not met	R02, R39, R41
Explain the need for proportional representation	R05, R06, R12
Provide incentives to subjects for participating	R02, R09, R35
Consider involving other family members in consent process	R03, R04, R12
Provide facilities for speakers of languages other than English	R29, R43, R45
Validate questionnaires and documents	R02, R06, R19
Explain the benefits of participation for the subjects' community	R02, R06, R12
Persistence: repeated phone calls	R02, R27, R45
It is difficult to get away from representing minorities	R02, R12, R16
Private funding bodies may also penalise for excluding ethnic minorities	R02, R12, R16
NIH guidelines on recruitment and representation work	R02, R17, R37
Involve participants and community leaders at the design stage	R04, R27, R35
Oral consent in the patient's language	R03, R09, R41
NIH accepts provision for incentives within grant budgets	R02, R09, R35
Recruit current participants for a subsequent study	R09, R27, R37
Provide a meal for participants if they are needed for over an hour	R27, R37, R39
Provide patients with their medication	R27, R37, R43
Target younger members of a community	R03, R05

Appendix 2: Coding framework with topics arranged in order of frequency continued.

Topic	Mentioned in interview
Clinics geographically situated in minority ethnic areas	R09, R41
Thorough use of translators, e.g. for advising on equipment technique	R05, R41
Provide incentives for clinics to participate	R09, R37
Publish in widely read journals to raise awareness	R18, R39
Make it clear that researchers are not coming from the authorities	R35, R37
Give inconvenience payments in instalments	R41, R43
Provide entertainment or gifts for children	R02, R35
Persistence: visiting homes	R02, R03
Use interviewers who can speak the relevant language	R02, R11
Translate invitation letter	R04, R11
Verbal consent if participants illiterate	R05, R09
Use young researchers to target young subjects	R05, R45
Ethics committees require translations to be available	R08, R18
Contribute towards cost of patients' medication	R09, R27
Offer to meet patients at times convenient to them – evenings etc	R09, R35
Telephone participants during study	R09, R35
Check questionnaires with people in the community	R12, R19
Invite patients by letter through their GP	R15, R19
Ensure translator is from the minority group being studied	R16, R23
Include diversity training in qualitative research programmes	R01, R18
Treat ethnic minority patients the same as everybody else	R19, R27
Approach people who are already working in the communities	R29, R41
Raise awareness of the importance of including ethnic minorities	R29, R39
Work with school principals	R37, R45
Provide health education to potential participants	R37, R45
Do not be judgemental about participants' health beliefs or practices	R38, R39
Male interviewer took his wife with him to people's homes	R01
Use techniques to understand cultural differences rather than rules	R01
Department of Health is encouraging people to gain skills in recruiting ethnic minorities	R01
Dept of Health is publicising the benefits of recruiting ethnic minorities	R01
Textbook published to encourage researchers to include ethnic minorities	R01
NIH demands regular reporting on recruitment	R02
Persistence despite cost	R02
Explain the benefits of participation e.g. children who join studies do better at school	R02
Work with schoolteachers to enrol their students	R02
Give participants credit for their contribution	R02
Use interpreters in focus groups	R04
Work with national collaborations of community groups	R04
Approach community elders to build trust	R05
Careful and appropriate use of focus groups	R05
Explain the personal benefits of participation	R06
Be culturally sensitive in focus groups	R06
Be prepared to hold separate male and female focus groups where appropriate	R06
Be aware of the impact of cultural sub-groups on focus group dynamics	R06
Ensure ethics committees have a representative from communities involved	R06
Including ethnicity in a large database of asthma patients	R07
Use existing language resources	R07
Provide better facilities for translation	R07
Ethnicity recorded in hospital notes so readily available	R07
Work unobtrusively with allied professionals	R09
GP practices employ research assistant to phone participants	R11
Explain the benefits of participation for society at large	R12
Explain that researcher's role is not part of the government	R12
Funding boards have a minority health representative	R12
Advertise using multi-lingual posters	R13
Use symbols in advertisements to suit those who are functionally illiterate	R13
Involve GPs in the development of the study	R15

Appendix 2: Coding framework with topics arranged in order of frequency continued.

Topic	Mentioned in interview
Give participants researcher's personal phone number	R15
Advertise in the language relevant to a community	R16
Include photographs of people from relevant community in advertising media	R16
Funding organisations allow for translation costs	R16
Hold focus groups to find out which advertising strategies work	R16
Include awareness of diversity in medical school teaching	R18
Provide spoken study information in DVD or CD format	R18
Include awareness of diversity in NHS training	R18
Ethics committees quote the Amendment of the Race Relations Act	R18
Journal referees expect to see figures for ethnicity of participants	R18
Clinicians phone their patients to invite them personally	R19
Be aware of the content of information material when recruiting for a potentially stigmatising condition	R23
FDA states that a drug must be tested on Afro-American populations before being administered to them	R23
Employ community leaders as study personnel	R29
Personal contact with community leaders	R29
Advertise with posters in places frequented by members of certain community	R29
Broaden the area in which recruitment is taking place	R29
Recruit in a variety of physical locations	R29
Involve people coordinating government aid systems	R29
Rely on enrolment of ethnic minorities working in health service	R29
Combine results from different studies by meta-analysis	R29
Conduct study in area where many people speak the language in question	R29
Ethics committees have question on ethnic minorities	R30
Approach local hospitals or businesses to fund community events	R35
Provide transport to take people from their homes to research centres	R35
Allow for incentives in project budget	R35
Provide incentives for participation even to control subjects	R35
Hold free community events eg. barbecues	R35
Community events are acceptable to funding organisations if they are kept fully informed	R35
Spend time building relationships with community organisations	R35
Pay to advertise in community groups' publications	R35
Only enter people's homes accompanied by a community member	R35
Work with respected local hospitals	R35
Work with other researchers focusing on similar recruitment areas	R37
Approach school administration	R37
Give presentations to school PTAs	R37
Approach community through health professionals already trusted there	R37
Work in GP surgeries	R37
Feed study results back to communities	R37
Persistence: ask for several phone numbers from each participant	R37
Make it clear that researchers are not coming from hospital debt collectors	R37
Employ project staff who are neither doctors nor nurses	R38
Allow easy access to the study clinic	R38
Display photos of the doctors involved in the study clinic	R38
Give participants the option of bringing family members or friends	R38
Provide inexpensive activities for accompanying friends or family	R38
Provide simplified versions of consent forms	R38
Patients attracted to study by opportunity to try expensive drugs	R38
Funding organisations allow for the extra cost of recruiting minorities	R42
Offer incentives to faith organisations for their involvement	R43
Employ people who feel comfortable working in the relevant community	R43
Employ nurses as research personnel	R43
Employ female personnel to promote trust	R43
Advertise in clinical research section of free newspapers	R43
Provide free health screenings	R43

Appendix 2: Coding framework with topics arranged in order of frequency continued.

Topic	Mentioned in interview
Hire community centre's rooms	R43
Remember personal details about patients between visits to build rapport	R43
Government policies affect research practices	R44
Involve parents in study, not just giving their consent	R45
Physical presence of researchers	R45
Provide incentives for parents	R45
Meet with children in their schools	R45
Work alongside school health services	R45
School doctors can provide services to even those who do not have insurance	R45
Ask school students to fill in a survey about asthma whether they have it or not, then recruit those who do	R45
Use "passive consent" in high schools	R45
Offer incentives for the class with the highest return of surveys	R45
Work with schoolteachers to understand how best to recruit children	R45
Anonymise survey returns to minimise peer pressure	R45
Ask parents about child recruitment techniques	R45
Provide fun incentives that would not encourage rivalry	R45
Approach high school students first, then check with their parents	R45
Ensure privacy when recruiting in school setting	R45
Employ researchers that teenagers can relate to	R45
Employ research assistant from same ethnic group as community	R45
Students keen to participate if they are allowed to miss lessons	R45
Ask a member of school staff to translate	R45
Provide small gifts for teachers for use in the classroom	R45
Use current school staff or volunteers to recruit students	R45
Persistence: repeated phone calls to GPs	R45
Work at doctor's clinic and mention the doctor's backing	R45
Give small gifts to school nurses who help with recruitment	R45
Ask school nurses to give surveys out to students with asthma	R45
Target schools made up predominantly of ethnic minority students	R45
Play games during interventions	R45

Appendix 3: List of descriptors from coding, organised in categories.

Trusting Relationships

- **Community groups**

Target people through relevant community groups
Work with national collaborations of community groups
Spend time building relationships with community organisations
Pay to advertise in community groups' publications
Hire community centre's rooms

- **Community leaders**

Approach community leaders to help with recruitment
Involve participants and community leaders at the design stage
Approach community elders to build trust
Employ community leaders as study personnel
Personal contact with community leaders

- **Faith organisations**

Recruit participants through faith organisations
Offer incentives to faith organisations for their involvement

- **Schools**

Work with schoolteachers to enrol their students
Approach school administration
Work with school principals
Meet with children in their schools
Work alongside school health services
School doctors can provide services to even those who do not have insurance
Ask school students to fill in a survey about asthma whether they have it or not, then recruit those who do
Use "passive consent" in high schools
Offer incentives for the class with the highest return of surveys
Work with schoolteachers to understand how best to recruit children
Ask parents about child recruitment techniques
Provide fun incentives that would not encourage rivalry
Approach high school students first, then check with their parents
Ensure privacy when recruiting in school setting
Students keen to participate if they are allowed to miss lessons
Ask a member of school staff to translate
Provide small gifts for teachers for use in the classroom
Use current school staff or volunteers to recruit students
Give small gifts to school nurses who help with recruitment
Ask school nurses to give surveys out to students with asthma
Target schools made up predominantly of ethnic minority students
Anonymise survey returns to minimise peer pressure

- **Incentives and reimbursement**

Provide entertainment or gifts for children
Provide incentives to subjects for participating
Recompense participants with money, gift certificates
Provide services not otherwise available, eg bronchoscopy
Reimburse participants for travel expenses
Contribute towards cost of patients' medication
Provide incentives for clinics to participate
Provide a meal for participants if they are needed for over an hour

Provide childcare while patients are taking part in the study
Provide patients with their medication
Provide incentives for participation even to control subjects
Hold free community events e.g. Barbecues
Allow for incentives in project budget
Approach local hospitals or businesses to fund community events
Provide health education to potential participants
Provide inexpensive activities for accompanying friends or family
Patients attracted to study by opportunity to try expensive drugs
Give inconvenience payments in instalments
Offer incentives to faith organisations for their involvement
Provide free health screenings
Offer incentives for the class with the highest return of surveys
Provide fun incentives that would not encourage rivalry
Provide small gifts for teachers for use in the classroom
Provide incentives for parents
Give small gifts to school nurses who help with recruitment

- **Family involvement**

Consider involving other family members in consent process
Give participants the option of bringing family members or friends
Provide inexpensive activities for accompanying friends or family
Involve parents in study, not just giving their consent
Ask parents about child recruitment techniques
Approach high school students first, then check with their parents

- **Clear explanations**

Fully explain what to expect from the study
Explain the need for proportional representation
Explain that researcher's role is not part of the government
Make it clear that researchers are not coming from the authorities
Make it clear that researchers are not coming from hospital debt collectors

- **Explain benefits**

Explain the benefits of participation
- for example, children who join studies do better at school
- for example, for the subjects' community
Explain the need for proportional representation
Explain the personal benefits of participation
Explain the benefits of participation for society at large
Feed study results back to communities

- **Personal approach**

Long-term relationship building
Provide personal support in the language required, even if the participant speaks English
Invite participants by telephone
Speak personally to invitees
Telephone participants during study
GP practices employ research assistant to phone participants
Give participants researcher's personal phone number
Clinicians phone their patients to invite them personally
Coordinator gets to know the participants personally
Personal contact with community leaders

Spend time building relationships with community organisations
Remember personal details about patients between visits to build rapport
Physical presence of researchers

- **Work with trusted professionals**
Work with schoolteachers to enrol their students
Approach patients through their GPs
Work unobtrusively with allied professionals
Involve GPs in the development of the study
Invite patients by letter through their GP
Clinicians phone their patients to invite them personally
Approach people who are already working in the communities
Work with school principals
Approach community through health professionals already trusted there
Work in GP surgeries
Display photos of the doctors involved in the study clinic
Employ nurses as research personnel
Persistence: repeated phone calls to GPs
Work at doctor's clinic and mention the doctor's backing
- **Work with professionals already working in the area**
Work with schoolteachers to enrol their students
Work unobtrusively with allied professionals
Involve people coordinating government aid systems
Approach people who are already working in the communities
Work with respected local hospitals
Work with other researchers focusing on similar recruitment areas
Work alongside school health services
Work with schoolteachers to understand how best to recruit children
Ask a member of school staff to translate
Use current school staff or volunteers to recruit students
Give small gifts to school nurses who help with recruitment
Ask school nurses to give surveys out to students with asthma
- **Research staff**
Specialised research employees who focus on recruitment
Research colleagues from community being studied act as trusted link
Use interviewers who can speak the relevant language
Use young researchers to target young subjects
Find and use a link person within community
Employ fluent speakers who can understand and explain complex issues
GP practices employ research assistant to phone participants
Ensure translator is from the minority group being studied
Employ community leaders as study personnel
Employ project staff who are neither doctors nor nurses
Employ nurses as research personnel
Employ people who feel comfortable working in the relevant community
Employ female personnel to promote trust
Employ researchers that teenagers can relate to
Employ research assistant from same ethnic group as community

Respect

- **Incentives and reimbursement**
(see Trusting relationships)
- **Cultural sensitivity**
Validate questionnaires and documents
Be flexible and tailor needs to individual communities
Be culturally sensitive in recruitment
Verbal consent if participants illiterate
Careful and appropriate use of focus groups
Ensure translations are culturally appropriate
Be culturally sensitive in focus groups
Be prepared to hold separate male and female focus groups where appropriate
Be aware of the impact of cultural sub-groups on focus group dynamics
Oral consent in the patient's language
Develop understanding of cultural differences between researchers and community by communication
Be aware of the content of information material when recruiting for a potentially stigmatising condition
Only enter people's homes accompanied by a community member
Do not be judgemental about participants' health beliefs or practices
Male interviewer took his wife with him to people's homes
Use techniques to understand cultural differences rather than rules
- **Raising awareness**
Publish in widely read journals to raise awareness
Include awareness of diversity in NHS training
Include diversity training in qualitative research programmes
Include awareness of diversity in medical school teaching
Raise awareness of the importance of including ethnic minorities
Use techniques to understand cultural differences rather than rules
Department of Health is encouraging people to gain skills in recruiting ethnic minorities
Dept of Health is publicising the benefits of recruiting ethnic minorities
Textbook published to encourage researchers to include ethnic minorities

Logistics

- **Advertising**
Advertise in community-specific media
Advertise using multi-lingual posters
Use symbols in advertisements to suit those who are functionally illiterate
Advertise in the language relevant to a community
Include photographs of people from relevant community in advertising media
Hold focus groups to find out what advertising strategies work
Advertise with posters in places frequented by members of certain community
Pay to advertise in community groups' publications
Advertise in clinical research section of free newspapers

- **Language**
 - Translate consent form
 - Translate information material
 - Translate invitation letter
 - Translate questionnaires
 - Use interviewers who can speak the relevant language
 - Provide personal support in the language required, even if the participant speaks English
 - Validate questionnaires and documents
 - Thorough use of translators, eg for advising on equipment technique
 - Verbal consent if participants illiterate
 - Ensure translations are culturally appropriate
 - Use existing language resources
 - Provide better facilities for translation
 - Ethics committees require translations to be available
 - Oral consent in the patient's language
 - Employ fluent speakers who can understand and explain complex issues
 - Check questionnaires with people in the community
 - Advertise using multi-lingual posters
 - Use symbols in advertisements to suit those who are functionally illiterate
 - Advertise in the language relevant to a community
 - Ensure translator is from the minority group being studied
 - Funding organisations allow for translation costs
 - Provide spoken study information in DVD or CD format
 - Provide facilities for speakers of languages other than English
 - Conduct study in area where lots of people speak the language in question
 - Provide simplified versions of consent forms
 - Ask a member of school staff to translate
 - **Geographical location**
 - Clinics geographically situated in minority ethnic areas
 - Advertise with posters in places frequented by members of certain community
 - Broaden the area in which recruitment is taking place
 - Recruit in a variety of physical locations
 - Conduct study in area where lots of people speak the language in question
 - Meet people in their community's geographical area
 - Provide transport to take people from their homes to research centres
 - Work in GP surgeries
 - Allow easy access to the study clinic
 - Hire community centre's rooms
 - Meet with children in their schools
 - Work at doctor's clinic and mention the doctor's backing
 - Target schools made up predominantly of ethnic minority students
 - **Incentives and reimbursement (see also Trusting relationships)**
 - **Budgeting**
 - NIH accepts provision for incentives within grant budgets
 - Funding organisations allow for translation costs
 - Allow for incentives in project budget
 - Approach local hospitals or businesses to fund community events
 - Funding organisations allow for the extra cost of recruiting minorities
 - **Funding bodies**
 - NIH may withdraw funding if targets are not met
 - Private funding bodies may also penalise for excluding ethnic minorities
 - Funding boards have a minority health representative
 - Funding organisations allow for translation costs
 - Community events are acceptable to funding organisations if they are kept fully informed
 - Funding organisations allow for the extra cost of recruiting minorities
 - **Pooling**
 - Including ethnicity in a large database of asthma patients
 - Combine data from different sites
 - Combine results from different studies by meta-analysis
 - **Persistence**
 - Persistence: repeated phone calls
 - Persistence: visiting homes
 - Persistence despite cost
 - Telephone participants during study
 - Persistence: ask for several phone numbers from each participant
 - Persistence: repeated phone calls to GPs
- Policy**
- **Government policies**
 - NIH accepts provision for incentives within grant budgets
 - NIH demands regular reporting on recruitment
 - NIH makes it compulsory to recruit ethnic minorities
 - NIH may withdraw funding if targets are not met
 - NIH demands relevant representative samples from communities
 - It is difficult to get away from representing minorities
 - NIH guidelines on recruitment and representation work
 - Ethics committees quote the Amendment of the Race Relations Act
 - FDA states that a drug must be tested on Afro-American populations before being administered to them
 - Government policies affect research practices
 - Department of Health is encouraging people to gain skills in recruiting ethnic minorities
 - Department of Health is publicising the benefits of recruiting ethnic minorities
 - **Ethics committees**
 - Ethics committees have question on ethnic minorities
 - Ensure ethics committees have a representative from communities involved
 - Ethics committees quote the Amendment of the Race Relations Act
 - Ethics committees require translations to be available