

The Mela Study: exploring barriers to diabetes research in black and minority ethnic groups

Gillian A. Hood^{1,2}, Tahseen A. Chowdhury¹, Christopher J. Griffiths², Rosie K.E. Hood¹, Christopher Mathews² and Graham A. Hitman^{1,2}

¹Barts and the London NHS Hospitals Trust, London, UK

²Barts and the London School of Medicine and Dentistry, Queen Mary University of London, London, UK

Background: Black and minority ethnic (BME) groups are particularly susceptible to diabetes and its vascular complications in the United Kingdom and most western societies. To understand potential predisposition and tailor treatments accordingly, there is a real need to engage these groups in diabetes research. Despite this, BME participation in research studies continues to remain low in most countries and this may be a contributory factor to reduced health outcomes and poorer quality of life in these groups. This study explores the barriers BME groups may have towards participation in diabetes research in one area of East London, and includes local recommendations on how to improve this for the future. **Methods:** A questionnaire designed from previously reported exploratory work and piloted in several BME localities was distributed at the East London Bangladeshi Mela and similar cultural and religious events in London, UK. People were asked opportunistically to complete the survey themselves if they understood English, or discuss their responses with an advocate. The purpose of the questionnaire was to understand current local awareness with regards to diabetes, identify specific BME barriers and attitudes towards diabetes research by ethnicity, gender and age, and gain insight into how these barriers may be addressed. **Results:** Of 1682 people surveyed (16–90 years; median age 40 years), 36.4% were South Asian, 25.9% White, and 11.1% Black and other ethnicities; 26.6% withheld their ethnicity. Over half cited language problems generally (54%) and lack of research awareness (56%) as main barriers to engaging in research. South Asian groups were more likely to cite research as too time consuming (42%) whereas Black groups were more concerned with potential drug side effects in research (39%). Participants expressed a general mistrust of research, and the need for researchers to be honest in their approach. Recommendations for increased participation in South Asian groups centred round both helping the community (61%) and improving health (55%). With regards to gender influences, females (34.6%) were significantly more likely to fear drug side effects than males (23.8%), $P < 0.001$. Females were also significantly more likely not to participate in research due to fear of experimentation (25.8%) compared with males (18.9%) $P = < 0.001$. **Conclusion:** Initial findings from the study demonstrate that in East London research barriers are focused on time, drug side effects, lack of awareness and language. There is a perception that research is time consuming even though the majority of those surveyed had not taken part in a research study. Further potential solutions from the survey have suggested that researchers also need to involve BME community leaders in their study strategy and indicate any individual health benefits to participation in research. Accessible studies with regards to time and advocacy provision need to be included in the design.

Key words: BME Groups, UK; diabetes; research barriers

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Correspondence to: Gillian A. Hood, Barts and the London School of Medicine and Dentistry; Queen Mary, University of London QMUL Innovations, 5 Walden St., London E1 2EF, United Kingdom. Email: gillian.hood@bartshealth.nhs.uk

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Introduction

Diabetes incidence in England has been conservatively estimated to accelerate to 4.6 million people by the year 2030, affecting 9.5% of the population (Yorkshire and Humber Public Health Observatory, 2010) with similar predictions for the devolved nations. For some UK Black minority ethnic (BME) groups (definition provided in the appendix), the rate of diabetes occurrence is already disproportionate to these estimates. For example, studies have shown it is up to six times more likely for a person of South Asian origin to develop diabetes than a White European counterpart (Riste *et al.*, 2001). South Asian populations may present with diabetes 10–15 years earlier than White Europeans even though they may have lower body mass indices (BMI) than White Europeans, and this may lead to earlier development of diabetes complications (Ujic-Voortman *et al.*, 2009).

With regards to preventing diabetes in the future, the lifetime risk for Type 2 diabetes (T2D) in South Asians is higher than indigenous populations, around one in three, and in urban India recent surveys indicate that T2D and impaired glucose tolerance are present in one in four of all adults over the age of 20 years (Ramachandran *et al.*, 2001). Other Black African groups, such as the Somali population, also endure the same higher incidence of diabetes and earlier complications (Khan, 2002).

The palpable need to maintain and raise the momentum to address the increasing problem of diabetes in the UK generally, is now evident. Research into effective prevention methods, screening tools, new diabetes treatments, and innovative self management techniques remains a priority for the government, for our health service, and most importantly from people who have the disease. Additionally, there is a need to focus this research on certain population groups who appear to be at even greater risk of developing the condition, who tend to develop diabetes at a younger age, and have more complications. To this end it is essential to explore current barriers BME groups may have with regards to diabetes research in anticipation that they can become more included in tailored treatments.

It is generally accepted that BME groups in the United Kingdom, especially South Asians, do not usually engage in research as much as their

indigenous White European counterparts and have poorer health outcomes (Hussain-Gambles *et al.*, 2004; Hussain-Gambles, 2004). This is a common problem with all types of health research, and efforts have been made to address possible under representation in research studies (Harden and McFarland, 2000). Applications for ethics approval or research funding will usually involve addressing the needs of local ethnic minority populations. Justification now has to be made if these groups are not to be included in the intended research.

Despite these efforts, participation remains low and many studies have attempted to identify the barriers for continued low uptake in general health research participation. Some studies among both African Americans and Indians (Shah *et al.*, 2010) indicate these barriers are perhaps historic in nature, with past treatment of some BME groups feeding into a culture of mistrust which is perpetuated by present inequities in socio-economic status and education (Branson *et al.*, 2007). This mistrust may also stretch to a fear of research generally; a fear of losing control over one's health; or being coerced by health professionals. Others have attempted to highlight the practical aspects of research participation which may involve travelling to research sites; lack of child care support; taking time from work; and, lack of support from family members (Yancey *et al.*, 2006; Robiner *et al.*, 2009). People may also be wary of complying with, or understanding fully, research protocols which might require specific documentation, completion of diaries, etc. Conventional methods of recruitment into studies from written invitations via general practitioners have also been found to be problematic in South Asians (Douglas *et al.*, 2011). Although other recruitment methods exist, accessing people with diabetes now managed in primary care usually involves the general practice. This can be problematic with some GPs not having the time or interest for research or refusing access to researchers.

Studies involving barriers to participation in cancer research have also cited language and communication barriers, less access to health services, and the perception of the risks of being in a clinical trial, or with experimentation (Mills *et al.*, 2006). The latter is also cited as a main cause of low ethnic minority participation in US studies (Hussain-Gambles *et al.*, 2004). Religion has also been referred to as a barrier, in that God

(not research) will determine the nature and progression of disease. It has also been noted that barriers to research participation in BME groups may lie outside their own control. Such groups may be as willing to participate and are no more likely to decline than indigenous populations, but it may be that they are less likely to be approached, usually due to language problems and the additional cost of advocacy (Okamoto *et al.*, 2010).

The numerous general barriers to research outlined above may all be relevant to BME groups with diabetes, or barriers may vary within certain groups, within certain disease conditions, and even by age and gender. At present there is very little work which seeks to identify local (East London) research barriers specific to diabetes although some other UK centres have begun to explore these themes (Lloyd *et al.*, 2008). If studies are to be designed to target diabetes in BME groups, it is imperative that we understand the attitudes towards diabetes and the barriers which may prevent local research participation.

Study aims

The main aim of the study was to identify, by questionnaire, the barriers BME groups may have towards participation in diabetes research in one area of East London, and find local recommendations on how to improve this for the future.

Methods

A questionnaire was designed by members of the diabetes research team based on previous outreach pilot work and then peer reviewed by two consultant diabetologists and one Professor of Primary Care. The study was also peer reviewed by the adoption panel of the Diabetes Research Network (DRN). Members of the panel are health professionals with research expertise who advise on study suitability and delivery. After some modifications the questionnaire was piloted in one general practice having a diabetes awareness day for the public, and final changes were made in light of feedback received.

Questionnaire design

The questionnaire consisted of a one page survey capturing non-identifiable data from the general public (>age of 16 years) on age, gender

and ethnicity. Diabetes status was asked together with awareness of diabetes risk. There were questions on awareness of medical research and of diabetes research in particular. Willing participants could choose reasons why they might not become involved in research but what also might make them change their mind in the future. Opinion was elicited on the methods which could be employed to improve BME participation in research.

Procedure

Members of the public were invited opportunistically from a diabetes research network promotion stall to complete the questionnaire at 14 important cultural, religious or other events locally over the course of 20 months; starting in May 2010 and ending in July 2012. The biggest and first event was the Brick Lane Mela from which the study takes its name. This primary event celebrates the Bangladeshi New Year in the heart of the largest Bangladeshi community in East London and in the past has drawn an audience of 90 000 people. Other events were cultural or health promotion events in the surrounding area.

Data analysis processes

The questionnaire comprised of mainly yes/no answers for responses regarding diabetes awareness and risk, and was analysed using percentages. The questionnaire had three main semi-closed questions regarding research with a range of responses and this was analysed using χ^2 (SPSS version 18). An open ended question at the end invited individual comments with regards to increasing research participation and comments were applied using contextual analyses.

Ethical considerations

As the questionnaire was anonymous, for the general public, and not directed specifically at patients, ethics permission to use it was advised as not being required. Verbal consent to complete the questionnaire was accepted as consent to participate. Permission to distribute the questionnaire was given by all event organisers.

Results

From the 14 events attended by the diabetes research team, a total of 1682 questionnaires were

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completed, 45% male, 51% female and 4% did not complete the answer for gender. The age range of the people completing the question was 16–90 years, median age 40 years (for both males and females). About 16% of the people completing the questionnaire were already diagnosed with diabetes. Ethnic breakdown using the standard definition derived from the 2001 census was 36.4% Asian, 25.9% White, 11.1% Black and other ethnicities; 26.6% withheld their ethnicity/did not respond to this question. Of the 1161 people who responded to information on their primary language 58% cited English and 42% other languages.

Diabetes and research awareness

Awareness of the effects on health from having diabetes was generally very high with a mean of 77% for all events. Of the samples, 65% were also aware that ethnic minority groups are at a higher risk of developing diabetes. For all events 78% of those surveyed wanted more to be done to include ethnic minorities in research and 15% had taken part in some medical research before.

Barriers to research participation

In the first of three open-ended questions, participants were asked to select the main reason which might prevent them from taking part in medical research. Overall participants suggested that research was too time consuming (36%), in particular those of an Asian ethnicity (42%). Participants were also fearful of drug side effects (31%) and experimentation (23%). Black and other ethnicities stated drug side effects as the largest barrier (39%) as did those of a White ethnicity (32.6%). Previous results which indicate amount of blood taken to be a barrier was less selected by this sample (2%) although there were worries over DNA sampling (15%). Whites were more likely to cite lack of incentive to participate in research (11.2%) compared with other groups. Of the entire sample, 11% also selected their own reasons. These responses were largely concerned with, as one respondent cited 'The Unknown' – which included: not knowing enough about research; not being given research results; worry over the quality of research; disagreements with research treatments; not having self-confidence to participate; completing too many

forms; and generally not having enough time from work.

Reasons to participate in research

In response to the second question on what would help a participant to decide to take part in medical research 55% were altruistic selecting research which would benefit the community, especially those of Asian ethnicity (60.6%) and also Black and other ethnicities (50%). Overall 54% of the entire group thought that a study with clear health benefits might help them to participate and 41% thought that taking part in a medical research project might get them better treatment. In all, 19% of Whites agreed that financial rewards might encourage them to participate more in research.

In addition, 4% selected their own reasons and revealed a range of inducements from having: research conducted by 'nice people'; robust safety regulations; safety concerns answered; opportunities for full discussion and explanation; employers who allowed time off; and, not losing money as a result of being in a research project.

Main BME barriers to research participation

Respondents were finally asked in the third question to select the factors which they thought were the main barriers for BMEs participating in medical research. Again many selected more than one answer: a general lack of awareness about research (56%) was cited as the main barrier especially among those of Asian (59.3%), Black and other ethnicities (60.2%). Language was also stated as a main factor (54%), principally by those of Asian ethnicity (62.3%). Black people were more likely to select religion (25%), culture (39.2%) and family influences (19.4%) as barriers to research and they were also more likely to mistrust health care generally (24%). Comparison to responses by ethnicity is given in Table 1.

Individual comments for other BME barriers included 'vegetarianism'; 'lack of understanding' and 'misunderstanding' about research; 'people think it's a waste of time'; lack of ethnic integration and 'mixing'; 'historical perspectives'; 'ignorance'; and, 'apathy'.

Lastly 78% stated they would like more to be done to include South Asian and African groups in research, with a response rate of 48% for opinions

Table 1 Comparison of ethnicity responses for the three questions

		White (%)	Asian (%)	Black and others (%)	Total (%)	P-value
Factors perceived as preventing research participation	Too time consuming	28.0	41.8	34.6	35.8	<0.001**
	Giving blood (DNA)	12.4	16.2	16.1	14.8	0.203
	Too much blood	2.1	2.3	2.2	2.2	0.319
	Drug side effects	32.6	26.6	38.7	30.6	0.004*
	Fear of experimentation	23.6	21.1	28.0	23.0	0.139
	Lack of incentive	11.2	8.8	8.1	9.6	0.319
Factors that might encourage research participation	Helps the community	47.7	60.6	50.0	54.5	<0.001**
	Improves my health	53.7	54.7	49.5	53.6	0.449
	To get better treatment	39.4	43.1	39.2	41.2	0.409
	Financial reward	18.6	13.2	14.5	15.3	0.058
Main barriers for BME groups taking part in research	Language	48.4	62.3	41.9	54.3	<0.001**
	Lack of awareness	50.0	59.3	60.2	56.2	0.005*
	Culture	36.5	28.6	39.2	33.0	0.004*
	Social class	10.3	9.8	15.1	10.8	0.121
	Mistrust of healthcare	15.6	16.2	23.7	17.1	0.035
	Family influence	17.4	15.2	19.4	16.6	0.349
	Religion	25.7	16.5	26.3	21.2	<0.001**

*Statistically significant at 0.05; **statistically significant at 0.001.

P-value at 5% significance.

BME = Black and minority ethnic.

on how to increase BME participation in research. Many responses centred on continuing outreach events but there was a general theme of trust which was needed with researchers having not only a 'straight approach' but also 'the right approach'. Researchers needed to be more flexible, offer health checks and find ambassadors in the community.

Gender differences in research barriers

A comparison of male and female responses to barriers in research participation found no significant differences with regards to the categories 'too time consuming' ($P = 0.240$); giving blood sample/DNA ($P = 0.403$); or lack of incentive ($P = 0.167$). Females (34.6%) were, however, significantly more likely to fear drug side effects than males (23.8%), $P < 0.001$. Females were also significantly more likely not to participate in research due to fear of experimentation (25.8%) compared with males (18.9%), $P = < 0.001$.

Age differences in research barriers

Older people (>60 years) were less likely to be concerned with the time taken to participate in research (22.7%) compared with young adults

(16–24 years) (36.6%), $P = 0.001$. The latter group also perceived giving blood as a distinct factor in preventing research participation (23.6%), in contrast to older people (11.7%), $P < 0.001$. Young adults also strongly believed that research which might help their community would be an encouragement to participate (63%) and they were also more likely to be encouraged by financial incentives (19.9%) compared with older people (45.0% and 8.2% respectively, $P < 0.001$).

Discussion

The Mela Survey was a simple but effective way of engaging a large number of BME groups in London, England to elicit reasons why research participation continues to be low. People appeared to enjoy the relaxed atmosphere of the cultural event as a way of finding out health information/ completing questionnaires at their own pace and level. This is in comparison to cited studies that have tended to work with a smaller sample group and have used interviews and focus groups (Mills *et al.*, 2006; Branson *et al.*, 2007; Robiner *et al.*, 2009). Although the sampling was opportunistic,

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the survey was equally completed by males and females with a representative age range, and 16% of responders included people with diabetes.

The awareness of diabetes seemed to be higher than previously reported and this would be in keeping with many local campaigns to raise awareness of diabetes (Jama, 2006). The message that London BME groups are at higher risk of diabetes, and that diabetes is a threat to health and well-being, now appears to be more commonly known. Research remains a more difficult concept for these populations, although a high percentage of responders in the Mela Survey wanted more to be done to encourage BMEs to engage in research.

As with previously cited papers, BME populations fear the experimental side of research and this is especially true of women. Women defined being 'experimented' on with invasive clinical techniques and the taking of unlicensed drugs. Targeting specific BME women's groups to disseminate information about research may be a future recommendation to engage more women with diabetes. This may help them to understand the condition and participate more in local studies.

As 82% of responders had not participated in research before the main finding that research is 'too time consuming' may be a *perception* of research rather than the experience of it. If researchers are to plan diabetes prevention studies for the future it may therefore be crucial to accurately record the time and number of visits as well as giving the flexibility of patients to be seen outside normal hours. As one respondent suggested 'we need to smash this 9–5 regime'. It may also be necessary to produce a further information leaflet with any prevention study which explains the nature of the research or experiment, and gives more information on drugs and their uses than is currently the practice.

Individual responses to increasing research also centred on flexibility and trust. Many citations were about the actual researcher as the 'right researcher'. According to responses the 'right researcher' is someone who can be mobile with his/her research; talk to participants in a social context; have a straight approach and practise at a more 'grassroots level'. It may also be helpful if this researcher had contacts in the community – a kind of community champion, or as one respondent

suggested, researchers need to 'find a spokesman they [the community] trust'.

Researchers should also work on projects where the benefit to the community is obvious. This was a very clear finding from the selection made by respondents and also from free text comments. Research involving BME groups needs to have an apparent and relatively immediate benefit, such as including a free health check for people; it should have an educational component to 'reduce misconception' and 'develop a better image'; and most importantly, it needs to be conducted by a trusted researcher who can engage and involve the community appropriately.

As research may be influenced by both culture and religion it would seem appropriate that local community leaders and religious authorities should be consulted about likely projects and be part of any steering group. Health advocates would also need to be trained in research so that they do not convey their own biases when providing linguistic services. This would be a particular recommendation when engaging women in research.

Raising awareness of diabetes and diabetes research through outreach events was overwhelmingly welcomed by all the different communities served and there were several comments about improving BME uptake in research by having 'more stalls like this'. The events did snowball and more were undertaken through direct invitation from other religious groups and their organisers. Outreach events would appear to help research in 'developing a better image' and there may be a need to develop an even more robust strategy to demystify research through a number of workshop events. As one respondent suggested: 'We must get away from disease as fate or God's will, and more that it's God's will that you look after yourself'. As young BME groups appear to have some negative attitudes towards research it may be productive to aim these workshops at colleges and schools. As one participant commented – 'attract the younger generation to influence their elders'.

Opportunistic sampling at such outreach events can be a beneficial method of promoting diabetes research locally. This study has indicated the need to move from solely approaching people in health-related environments and to move instead into areas which are less formal and perhaps where people feel more in control. There is of course a resourcing implication in conducting such events

and outreach work should be part of any patient and public strategy or public health initiative which desires to recruit more BME groups into research. Hopefully, once the main barriers have been identified it will be possible to design studies which are more accessible/acceptable for all ethnicities giving a broader coverage and a better, more balanced understanding of medical research.

Limitations

There are several limitations to the study which are noted here. Some BME groups had no understanding of the phrase 'medical research' which sometimes made translations difficult and may indicate a need for more basic educational work to be undertaken. The use of some phrases such as 'primary language' and even 'ethnicity' was not understood by some participants. This was an opportunistic way of sampling and may therefore not be indicative of certain ethnic groups

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Appendix

* The term ‘Black and Minority Ethnic’ (BME) is defined here as referring to ‘all people of minority ethnic status in England. It does not only refer to skin colour but to people of all groups who have a shared race, nationality or language and culture.