Harrison, E. K. & Smart, A. (2016). The under-representation of minority ethnic groups in UK medical research. Ethnicity and Health, doi: 10.1080/13557858.2016.1182126

The under-representation of minority ethnic groups in UK medical research

Andrew Smart, Department of Social Sciences, Bath Spa University

Eric Harrison, Department of Sociology, City University London

Abbreviated title: **Under-representation in UK medical research**

Corresponding author (and location of research)

Dr Andrew Smart

Bath Spa University

Department of Social Sciences

Newton Park Campus

Newton St Loe

Bath

BA2 9BN

United Kingdom

+44(0)1225 876193

a.smart@bathspa.ac.uk

The under-representation of minority ethnic groups in UK medical research

Abstract

Objectives. The paper investigates differences in engagement with medical research between White British and Black, Asian and Minority Ethnic (BAME) groups in the UK, using data from the Wellcome Trust Monitor (WTM).

Design. The WTM is nationally representative of the UK population and has collected data over two waves, 2009 and 2012. Data pooled from both waves (n = 2575) were used to examine associations between ethnic group and participation in medical research, and willingness to participate in medical research. Logistic regression analysis used models that controlled for socio-economic and demographic factors, and relevant outlooks and experiences that are, or could reasonably be assumed to be, associated with engagement with medical research.

Results. Respondents from the BAME group were less likely to have participated in medical research compared to those from the White British group, but there was only patchy evidence of small ethnic group differences in willingness to participate. Influences on engagement in medical research varied somewhat between the White British and BAME groups, in particular in relation to occupation, education, health, attitudes to medical science and belief.

Conclusions. These findings consolidate previously context-specific evidence of BAME group under-representation in the UK, and highlight the heterogeneity that exists within the broad BAME group. Efforts to address the under-representation of those from BAME groups might benefit from targeted strategies for recruitment and advocacy, although improved datasets are required to fully understand ethnic differences in engagement with medical research.

Key words: ethnic minorities; participation; willingness to participate; medical research; Wellcome Trust Monitor

The under-representation of minority ethnic groups in UK medical research

Introduction

The UK has long-standing ethnic variations in health outcomes and in the prevalence of some diseases (Bhopal 2014), and ethnic classifications have been embedded in some health intervention guidelines (eg, NICE 2011). It has been argued that the inclusion in medical research of people from Black, Asian and Minority Ethnic (BAME) groups is necessary to avoid unwarranted inequalities and can help guard against an un-representative healthcare evidence-base (Mason et al. 2003). There is, nevertheless, evidence to suggest that people from BAME groups are under-represented in various UK medical research contexts (Mason et al. 2003; Jolly et al. 2005; Ranganathan and Bhopal 2006; Godden et al. 2010). These existing studies, however, do not provide insights into participation in medical research among the general population and give relatively little attention to factors that cut across ethnic groups like socio-economic status, education or engagement with science, or to the role these may have in explaining or mediating any purported ethnic differences in participation. A greater understanding of the general extent of the problem of under-representation and an exploration of potential contributory factors is thus warranted.

In order to do this, we use two waves of the Wellcome Trust Monitor (WTM), 2009 and 2012, to explore ethnic differences in engagement with UK medical research. Specifically we consider if participation in, and willingness to participate in, medical research is lesser among respondents from BAME groups in comparison with White British respondents. Our analysis includes the influences of potential explanatory variables other than ethnicity. The paper begins with an assessment of the evidence that suggests an

under-representation of people from BAME groups in UK medical research, and then reviews explanations about the role that ethnicity, among other factors, may be playing. This is followed by an overview of the data and measures used, a presentation of results and a discussion of the findings. The paper will provide insights into patterns of engagement with medical research, and contribute to discussions about how the medical science community can address the ethical and practical imperatives to encourage ethnic diversity in its research.

Ethnic group differences in participation

There are difficulties in establishing answers to questions surrounding population-level differences in rates of participation in medical research. Medical research covers a range of practices, across the breadth of disease and healthcare contexts, involving people as patients or as healthy volunteers. Participation can be measured in a variety of ways: as eligibility to participate in a study, as participation in a study once an invitation has been made or in surveys that ask potential participants or the general public questions about their 'awareness of opportunities' or their 'willingness to participate'. Even after data has been collected, there remain debates over whether 'representativeness' should be judged based on population proportion, or disease-specific standards (eg, Rathmore and Krumholz 2003).

Concerns that 'minorities' (including ethnic minorities) were under-represented in medical research can be traced to the United States (US), where legislation was introduced in 1993 to encourage greater equality (Epstein 2008). US research continues to suggest ethnic differences in participation rates (eg, Murthy et al. 2004). Various studies show, however, that once people are deemed 'eligible' for research there are not racial/ethnic disparities in rates of participation (eg, Wendler et al. 2006). These findings highlight that under-representation may (in part) be due to eligibility criteria imposed by researchers rather than unwillingness on the part of potential participants. This said, US surveys of people's

'willingness to participate' continue to reveal ethnic differences, with non-Hispanic blacks expressing less interest (Cobb et al. 2014).

Evidence in the UK also suggests ethnic differences in participation. Mason et al. (2003) reported under-representation of 'South Asian' patients in six RCTs covering a range of conditions. Jolly et al. (2005) also found that 'South Asian' patients were more likely to be excluded for recruitment into an RCT for cardiac rehabilitation, but that ethnic differences in rates of participation were not evident among patients deemed eligible. Ranganathan and Bhopal's (2006) review of cardiovascular cohort studies identified research designs that, they argued, were likely to under-represent people from BAME groups. Smart et al. (2008) also found several genetic research studies that restricted recruitment or analysis based on ethnicity. Most recently, Godden et al. (2010: 358) reported that the 'odds of being in a [cancer research] trial were 30% lower for a member of a minority ethnic groups compared to a white cancer patient'. The evidence of under-representation in Jolly et al. (2005) and Godden et al. (2010) remained after they had controlled for other variables (both considered gender, age and diagnosis/ disease, and Jolly et al. (2005) also considered 'deprivation').

It remains an open question, however, whether people from BAME groups are generally under-represented in UK medical research. Each of the studies outlined above reflects specific contexts (for example healthcare or geographical setting, disease focus or forms of research study). Furthermore, most of these studies report having to confront and address as best they can a long-standing barrier to understanding the nature and scale of this problem: non-existent, unreliable or inconsistent data on the ethnicity of study subjects (Sheikh et al. 2004). Our analysis of the WTM contributes to the field of study because it is based on a representative sample of the general population and thus offers a viewpoint that spans the different contexts of medical research. Furthermore, problems relating to the recording of ethnicity are, to some extent, circumscribed as respondents' self-reported ethnicity.

The WTM asks whether people (or their family) have participated in medical research and their willingness to take part in medical research (specifically, that which allows access to personal health information on an anonymous basis). Based on the available evidence above, we propose the following hypothesis:

Compared to people from the White British group, people from the BAME group will be less likely to have taken part in medical research and less likely to express a willingness to participate in medical research.

Reasons for under-representation

A range of factors influences engagement with medical research. In US survey research, awareness of opportunities for participation has been associated with income, age, chronic ill-health, education and family history of disease (Davis et al. 2013; Brown and Moyer 2010). Willingness to participate in hypothetical medical research in the US has been associated with having a friend or relative with an illness, age, previous participation in medical research, attitudes toward medical research, education and gender (Trauth et al. 2000; Cobb et al. 2014; Ding et al. 2004). In the UK, willingness to participate has also been associated with gender, age and previous experience of medical research (Jenkins et al. 2010) and participants in clinical studies are motivated, in part, by a supportive attitude toward the work of medical researchers (eg, Gabbay and Thomas 2004).

Explanations for ethnic disparities in engagement with medical research relate to the practices/ outlooks of the medical research community, and/or the experiences/ outlooks of potential research subjects (Hussain-Gambles et al. 2004; Sheikh 2006; Robinson and Trochim 2007). Hussain-Gambles et al.'s (2004) review of the mainly US literature found evidence suggesting investigator bias (including stereotypes and cultural myths about people from minority ethnic groups); trials with exclusionary designs (eg, language restrictions); and concerns among researchers about additional costs, including those

relating to interpretation/ translation. They also found evidence suggesting fear and mistrust on the part of potential research subjects (including experiences of discrimination within the healthcare system); difficulties in access (relating to low socio-economic status and language differences); and potentially conflicting socio-cultural beliefs (eg, modesty/gender roles, and the use of alternative medicines). The small amount of UK research that has explored the issue largely concurs with this range of potential explanations, with issues relating to language differences being highly prominent (Hussain-Gambles et al. 2004; Jolly et al. 2005; Sheikh et al. 2009; Gill et al. 2013).

Sheikh et al. (2009) also underline the importance of national contexts and histories of migration, demographic profiles and linguistic and religious variation for understanding disparities in participation in medical research. For example, Jolly et al. (2005) found stark variations between the groups compressed into the 'South Asian' classification, and noted variations within ethnic groups (as age and gender played important roles in relation to the potential to be excluded based on language). Similarly, Hussain-Gambles et al.'s (2004) work focused on 'South Asian' groups in particular, and reported on the influences of various socio-economic, demographic and cultural differences. Mason et al. (2003) highlight the importance of age, as the proportionately smaller number of elderly 'South Asian' people in the UK would necessarily influence their representation in trials that recruit older patients. Furthermore, being 'available' to be involved in some research medical research may differ between ethnic groups in relation to differences in disease prevalence (Godden et al. 2010).

Our analysis of the WTM will control for socio-economic and demographic factors and for a range of relevant outlooks and experiences. Based on the available evidence and theories that explain ethnic disparities in relation to trust, access and socio-cultural difference, we propose the following hypotheses:

Rates of participation in medical research and expressions of willingness to participate in medical research will be higher among those that a) have generally positive attitudes toward

medical science (indicating trust) b) have higher levels of occupational status (indicating access) and c) have less religious outlooks (indicating socio-cultural beliefs). We expect these effects to be stronger among people from the BAME group compared to people from the White British group (as this would show that these factors were having a greater impact on the outcomes for those in minority ethnic groups).

Methods

Data

The hypotheses outlined above are tested using data from the Wellcome Trust Monitor (WTM). The WTM focuses on questions about science education, engagement with medical research and public attitudes toward biotechnologies. It is conducted on a representative, randomly selected, sample of the UK population. The WTM first wave was conducted in 2009 and a second wave followed in 2012, with many of the original questions repeated. Each WTM survey had two sets of respondents: adults and young people, aged 14-18 years. The analysis in this paper relies on data collected from adults over the two waves (n = 1179 in 2009; n = 1396 in 2012; total n = 2575). Further details of the findings, design and methodology are available in two research reports (Butt et al. 2009; Ipsos MORI 2013a).

Measures

The WTM captured respondents' ethnicity by asking: 'to which of these ethnic groups do you consider you belong?' and offering a show card of options (which used the ethnic group categories from the Census of England and Wales). The Census categories were adjusted in 2011, and data collection practices in Wave 2 were changed to reflect this. The ethnic composition of the samples in Waves 1 and 2, reported in the WTM Research Report Wave 2 (Ipsos MORI 2013a: 16), shows an approximate match in the *proportions* of the various

ethnic groups in both waves of the survey compared with population estimates from the 2011 Census of England and Wales. Despite this proportionality, using the WTM to address questions about ethnic difference raises a problem in relation to sample size. Where a sample contains relatively small numbers of respondents from BAME groups it can be difficult to robustly disaggregate study finding by ethnicity. Indeed, the WTM Research Reports do not disaggregate findings by ethnic group for this reason.

Given our primary interest in ethnic variation we have created a meaningful sub-group analysis by 'pooling' the datasets from the 2009 and 2012 surveys. There is a precedent for aggregating waves of survey data in this manner to address the problem of low numbers of respondents from minority ethnic groups (Campbell and Troyer 2011). Of the adult participants in Wave 1 (2009), 14.1% self-reported their ethnicity in categories other than White: English/Welsh/Scottish/Northern Irish/British and in Round 2 (2012) this rose to 18.4%. Even after pooling two datasets there remained limited potential to disaggregate findings *within* and *between* BAME groups, and so in this paper the only specific ethnic group label used alone is White: English/Welsh/Scottish/Northern Irish/British (from here on, for simplicity, 'White British'). Against this 'White British' group all other ethnicities (including White minority ethnic groups) were grouped into the reference category: an aggregated 'BAME group'.

The WTM contained a block of questions addressing respondents' involvement in medical research, including questions about willingness to participate in different types of study. As a measure of previous participation respondents were asked:

Q: Have you or a member of your family ever taken part in a medical research project. This might have involved testing a new drug as part of a clinical trial, providing samples of blood or tissue for a project tracking the development of a particular illness, or completing a survey about your experiences of a particular illness or drug [*1. Yes, respondent; 2. Yes, member of*

respondent's family; 3. Both respondent and member of respondent's family; 4. No, neither; 9. Don't know]

The data show that only 12.1% of respondents have ever participated in medical research. This is 13.4% among those in the White British group and 5.7% among those in the BAME group. With respect to respondents' willingness to participate in medical research, the only item included in both waves makes specific reference to allowing access to anonymised medical records:

Q. How willing or unwilling would you be to take part [AGAIN] in a medical research project which involved allowing access to your personal health information, that is, your medical records, on an anonymous basis [*1. Very willing; 2. Fairly willing; 3. Fairly unwilling; 4. Very unwilling; 9. Don't know*]

In contrast to the small proportion of respondents who had taken part in research, two thirds (66.7%) of respondents were fairly or very willing to participate in the form of medical research specified in the question. There were small differences between ethnic groups in willingness to participate but the association was very weak (Chi-Squared 21.637, Cramer's V .092, p .000). For our multivariate analysis we derived dichotomous outcome variables for participation ('Yes, respondent' and 'Both respondent and family member' versus all other responses) and willingness to participate ('Very willing' and 'Fairly willing' versus all other responses).

As noted above, a range of factors has been associated with participation in, or willingness to participate in, medical research including some specifically relating to ethnic difference. Our analysis will control for socio-economic and demographic factors (age, gender, education and occupation). Gender (male versus female) is dichotomous. Age in

years was coded into four groups (18-34, 35-49, 50-64, 65 and over). Education was coded into four categories by highest qualification (None, Secondary education, Further education, Degree). Occupation was coded using NS-SEC 5 classes (Routine, Supervisory/technical, Self-employed, Intermediate, Managerial/professional). In order to retain the maximum number of cases and guard against item non-response bias, dummy variables were included for respondents whose education and/or occupation was not reported.

Our analysis will also include variables for a range of outlooks and experiences that relate to (or can reasonably be assumed to relate to) likelihood of participation, including engagement with science, socio-cultural beliefs and health. Indicators of engagement with science included dichotomous variables for: having a science qualification; whether they had sought information about medical research; confidence in medical science to improve quality of life; and, whether a family and/or household worked in medical science. Other variables for engagement with science were interest in science at school and interest in medical research (both coded as Very interested, Fairly interested, Not interested); and 'scientific literacy' based on a score in a science-based quiz (grouped into High, Medium and Low scores). We also included indicators of socio-cultural beliefs using two dichotomous variables: holding a religious belief and holding creationist beliefs. Measures of health included self-rated subjective health coded into three categories (Poor health, Fairly good heath, Very good health), and a dichotomous variable for the respondent or a relative having a genetic condition.

Statistical Analysis

Regression models were constructed to assess ethnic group differences in relation to two outcome variables: 1) participation in medical research and 2) willingness to participate in medical research. For each outcome, results are presented for two models that test for the effect of ethnic group while controlling for a range of other characteristics. Model A contains ethnic group and other selected socio-economic and demographic factors. In Model B,

socio-economic and demographic factors are supplemented with measures of outlooks and experiences that specifically related to likelihood of participation or willingness to participate. In order to unpack the relationship between ethnic group and the rest of the predictors, we undertook the analysis on (i) all respondents and on separate samples of respondents from (ii) the White British group and (iii) the BAME group.

Findings

Multivariate models are presented in Tables 1 and 2. Table 1 assesses ethnic group differences in participation in medical research using both models among all respondents (Models 1Ai and 1Bi), and among the White British (Models 1Aii and 1Bii) and BAME groups (Models 1Aiii and 1Biii). Table 2 assesses ethnic differences in willingness to participate using both models among all respondents (Models 2Ai and 2Bi), and among the White British (Models 2Aii and 2Bii) and BAME groups (Models 2Aiii and 2Biii). We use the results to address in sequence the hypotheses set out earlier in the paper.

Compared to people from the White British group, people from the BAME group will be: less likely to have taken part in medical research; *less likely to express a willingness to participate (WP) in medical research.*

The analysis supports the hypothesis of lower participation: people from the White British group were 87% more likely than those from the BAME group to have participated in medical research when controlling for socio-economic and demographic factors. This difference fell to 64% when also controlling for other relevant outlooks and experiences. The analysis weakly supports the hypothesis of less WP: at lower levels of statistical significance, people from the White British group were 27% more likely than those from the BAME group to express WP when controlling for socio-economic and demographic factors. However, the

difference in WP loses its statistical significance when other relevant outlooks and experiences are controlled. The analysis below will consider further the various control variables to highlight which ones are most relevant to understanding ethnic group variation in engagement with medical research.

Rates of participation in medical research and expressions of willingness to participate (WP) in medical research will be higher among those that that have generally positive attitudes toward medical science (indicating trust). We expect these effects to be stronger among people from the BAME group compared to people from the White British group.

The analysis does not support the hypothesis of greater participation among those with more 'confidence in medical science to improve quality of life'. There was no association between these variables in assessments of ethnic differences that controlled for socio-economic and demographic factors and relevant outlooks and experiences, or in the White British and BAME sub-group analyses. In contrast, the equivalent analyses for WP do support both parts of the hypothesis. Those who had 'confidence in medical science to improve quality of life' were 80% more likely than those without 'confidence' to express WP. In the White British sub-group analysis the association between WP and confidence was weaker than the same association in the BAME sub-group analysis (WB OR = 1.74 versus BAME OR = 2.89). This suggests that confidence in medical science to improve quality of life is a stronger influence on WP for people in the BAME group than it is for those in the White British group.

Rates of participation in medical research and expressions of willingness to participate (WP) in medical research will be higher among those that that have higher levels of occupational status (indicating access). We expect these effects to be stronger among people from the BAME group compared to people from the White British group.

The analysis does not support the hypothesis. There was no association between these variables in assessments of ethnic differences that controlled for socio-economic and demographic factors and relevant outlooks and experiences. There was some evidence of occupational differences in participation, but only *within* one arm of the sub-group analysis. The BAME sub-group analysis that controlled for socio-economic and demographic factors only revealed that those who held managerial/ professional occupations were over eight times more likely to have participated than those in routine employment. Some patterns of association emerged in the analyses between occupational status and WP. In assessments of ethnic differences in WP that controlled for socio-economic and demographic factors alone, willingness was higher among those in managerial/ professional roles (OR = 1.45) and those who were self-employed (OR = 1.46) when compared to those in routine employment. The sub-group analysis suggests differences in this occupational influence, with WP significantly associated with managerial/professional roles in the WB sub-group analysis (OR = 1.54) and self-employment in the BAME sub-group analysis (OR = 2.84).

Rates of participation in medical research and expressions of willingness to participate (WP) in medical research will be higher among those that that have less religious outlooks (indicating socio-cultural beliefs). We expect these effects to be stronger among people from the BAME group compared to people from the White British group.

There is some evidence to support the hypothesis of higher rates of participation among those with less religious outlooks. There was no association between holding 'religious beliefs' and participation in assessments of ethnic differences that controlled for socio-economic and demographic factors and relevant outlooks and experiences, or in the White British and BAME sub-group analyses. However, those holding 'creationist beliefs' were 34% less likely to participate in medical research than those not holding such beliefs. While there was no such association in the White British sub-group analysis, in the BAME sub-group those who held 'creationist beliefs' were 87% less likely to participate in medical research

than those not holding such beliefs. This suggests that, in the general population, beliefs in creationism reduce the likelihood of participation in medical research; but while those in the White British group with creationist beliefs are no more or less likely to participate, those within the BAME group who hold creationist beliefs are less likely to participate than those who do not. The only association between religious outlooks and WP was in the White British sub-group analyses, where those holding 'religious beliefs' were 20% less likely to express WP than those that did not.

Other notable variations: health and education

In assessments of ethnic differences in participation that controlled for socio-economic and demographic factors and relevant outlooks and experiences, higher levels of participation were associated with being older, having poorer health and greater engagement with medical science. Of these variables in the BAME sub-group analysis, however, only poorer health remained clearly associated with participation (with a stronger level of influence). In assessments of ethnic differences in WP that controlled for socio-economic and demographic factors and relevant outlooks and experiences, higher levels of WP were associated with better health (i.e. the inverse of the relationship with actual participation). In the White British sub-group analysis the association between WP and being in fairly good health (compared to being in poor health) was weaker than the same association in the BAME sub-group analysis (WB OR = 1.43 versus BAME OR = 2.26).

With respect to education, the White British sub-group analysis that controlled for socio-economic and demographic factors alone showed those with a degree level qualification had double the likelihood of participation of those with no qualification (OR = 2.16). In contrast, in the BAME sub-group analysis, some increases in educational level were associated with lower likelihoods of participation: compared to those with no qualification, those with secondary educational qualifications were 86% less likely to have

participated and those with qualifications from further education were 78% less likely to have participated, but at lower levels of statistical significance. A pattern was also evident in relation to willingness to participate. In the WB sub-group analysis that controlled for socio-economic and demographic factors only, those with a degree level qualification were 59% more likely to express WP in comparison with those with no qualification. In contrast, in the BAME sub-group analysis that controlled for socio-economic and demographic factors and relevant outlooks and experiences, those qualified to degree level were 66% less likely to express WP in comparison to those without educational qualifications.

Discussion

This analysis of the WTM has shown a broad ethnic difference in rates of participation in medical research. Respondents in the White British group were more likely to report participation in medical research than those in the BAME group; a difference that exists after controlling for socio-economic and demographic factors, and relevant outlooks and experiences. These findings correspond with the above-mentioned research suggesting an under-representation of participants from BAME groups in UK medical research in specific settings. They are particularly important because they help to join up evidence from those other studies that might otherwise be considered piecemeal and context specific.

It was less clear whether respondents in the BAME group were less likely than those in the White British group to express willingness to participate in medical research. The weak evidence in support of this hypothesis that existed when controlling for socio-economic and demographic factors lost its statistical significance after controlling for outlooks and experiences. Previous surveys demonstrating ethnic variation in hypothetical decisions about willingness to participate in the US (eg, Cobb et al. 2014) sit against evidence of equal consent to participate once invitations have been made in the US (eg, Wendler et al. 2006) and in the UK (Jolly et al. 2005). Our analysis of the WTM dataset suggests only patchy

evidence that those in the BAME group were slightly less willing to participate; the evidence that those in the BAME group were less likely to have participated was greater, stronger and more consistent. This evidence suggests that the problem of under-representation is not primarily about willingness to participate, which support arguments against blaming 'marginalised people' for patterns of unequal participation (Sheikh 2006).

It is, however, difficult for us to make larger claims about where causes for the different rates of engagement lie using the WTM. As discussed earlier, three broad explanations have been advanced for differential rates of participation. While the WTM data do not allow us systematically to address explanations relating to the practices of the medical research community or factors relating to demographic differences, we made use of the available variables to test hypotheses that focused on factors relating to potential medical research participants. We are mindful that discussions of 'participants' characteristics' in isolation from socio-structural barriers could appear to 'blame' those identified characteristics. Nevertheless our analysis reveals interesting and important differences that warrant discussion as they could help to inform the strategies of those in the medical research community who are attempting to address under-representation.

Our analysis did not reveal consistent associations between ethnic group, occupational status and engagement with medical research. However, we did find higher participation rates among those in the BAME group that were in managerial/ professional roles and higher willingness to participate among the self-employed. In the UK, self-employment has been linked to higher socio-economic status for some ethnic minority groups (Mason 2006). The findings support previous evidence of socio-economic status differences in engagement in medical research within BAME groups (Hussain-Gambles et al. 2004). This highlights that occupational status is an important driver of engagement with medical research and underlines the importance of recognizing variability within and between BAME groups.

A lack of trust in medical professionals has been linked with ethnic minority under-representation in the US (Shavers-Hornaday et al. 1997), but the evidence supporting this in the UK is more contested (Hussain-Gambles et al. 2004; Jolly et al. 2005). In our analysis, less 'confidence in medical science to improve quality of life' was not associated with participation in medical research, including in the ethnic sub-group analyses. Having positive attitudes toward medical research has been associated with willingness to participate (eg, Trauth et al. 2000), and we also found evidence that having less confidence in medical science to improve quality of life reduced expressions of the willingness to participate. Notably this relationship was stronger among those in the BAME group. This suggests that the medical science community could encourage greater engagement by communicating its vision of the benefits of research, including in ways that were inclusive to those in BAME groups.

We found those with religious belief in the White British group expressed less willingness to participate in medical research. We also found that belief in creationism lessened the likelihood of participation in medical research, and did so more strongly among people in the BAME group. This suggests that a belief in creationism is a marker for a set of ideas or practice that are part of the explanation for lower rates of participation and that this influence is stronger among people from BAME groups. This could, in part, be about strength of belief; Allum et al. (2014) show that people who are 'more religious' may be less persuaded by claims about the benefits of biomedical research. It could also, in part, mark stricter adherence to particular ethno-cultural practices, including gendered issues about modesty that commonly feature in explanations of BAME group under-representation (Hussain-Gambles et al. 2004). What these findings suggest is that the attempts by the medical science community to address BAME under-representation should carefully avoid conflating ethnicity, faith and creationist beliefs.

Our sub-group analysis also adds some new dimensions to the existing debate. In the WTM dataset, being in poorer health increased everyone's likelihood of participation in

medical research. However, it had a stronger effect among people in the BAME group. Similarly, being in fairly good health lessened everyone's likelihood of expressing a willingness to participate, but again with a stronger effect among people in the BAME group. In other words, those from the BAME group in poorer health are – relative to those of a similar health status in the WB group - more likely to get involved in medical research, and less likely to express a willingness to participate. The sub-group analysis also revealed differences in relation to level of education. In contrast to what might be expected (eg, Trauth et al. 2000), and what was seen in the White British sub-group analysis, the BAME sub-group analysis showed some evidence of lower rates of participation and willingness to participate associated with increases in the level of education. Should these patterns be confirmed in other research there would be a need to develop explanations as to why being in a minoritised ethnic group can magnify the influence of health status and reverse the usual relationship with educational level.

How does our analysis contribute to addressing problems of under-representation? It has been argued that the onus should be on the medical research community to encourage equal access for all (Mason et al. 2003; Wendler et al. 2006; Sheikh 2006). Ethics committees and research funders have been urged to remove barriers to inclusivity, and medical researchers have been encouraged to improve access to research sites and information about opportunities. It is in this light that practices for addressing under-representation have been developing (eg, Nazroo 2006; Lloyd et al. 2008; Samsudeen et al. 2011). Our analysis identified variations in a broadly constituted BAME group; factors that were either a stronger influence in the BAME group compared to the White British group, or unique to the BAME group. While the existence of difference was expected, the nature and direction of some of these associations are notable. If further research were able to replicate these findings and to more fully identify inter-group and intra-group differences, those who are developing solutions to under-representation might usefully employ information about variability to develop targeted strategies for recruitment and advocacy.

Several limitations should be noted. We recognise that aggregating waves of survey data is not an ideal way to gain a sample for analysis, although it is a recognised solution for research about ethnic difference in contexts where respondents from BAME groups are under-represented in survey sampling practices (Saperstein 2013). It is also unfortunate that even this pooled data did not yield sufficient *n* to facilitate analysis within and between BAME groups. We also note the need for better measures of key variables. The outcome of willingness to participate in medical research was specifically tied to access to anonymised health records. The variable 'confidence in medical science to improve quality of life' cannot wholly capture the ways in which historical and contemporary discrimination may impact on trust in medical science. The variables 'belief in religion' and 'belief in creationism' are only partial markers of socio-cultural belief, and we recognise that a wider range of socio-cultural factors have been suggested to explain ethnic differences in participation.

Nevertheless, our analysis suggests ethnic differences in engagement with medical research that warrant further investigation in an improved dataset with larger numbers of participants from BAME groups. We thus echo calls for better quality information about patterns of participation (eg, Mason et al. 2003; Sheikh et al. 2004). In particular, we recommend that future rounds of the WTM should sample the UK population in such a way as to allow a finer-grained analysis of difference within and between BAME groups, which have been shown to be important in other studies (Hussain-Gambles et al. 2004; Jolly et al. 2005; Godden et al. 2010; Gill et al. 2013).

In conclusion, we found ethnic group differences in engagement with medical research in the UK, with those from BAME groups less likely to participate than those in the White British group but without being clearly less 'willing to participate'. This inequality has implications for the equitable and effective delivery of healthcare to Britain's increasingly multi-ethnic population. Engagement with medical research is subject to many influences and thus we must resist exaggerations about the role of ethnicity. Indeed, our findings highlight the importance of variation within our (by necessity) broadly conceived BAME

group. After controlling for socio-economic and demographic difference and relevant outlooks and experiences, engagement with medical research within the BAME group varied in relation to occupation, education, attitudes to medical science, socio-cultural beliefs and health, and varied in ways that were different to the White British group. It follows therefore that improved knowledge about the causes of differential engagement should be encouraged and potentially used to inform more targeted interventions to reduce ethnic inequalities.

References

Allum, N., E. Sibley, P. Sturgis, and P. Stoneman. 2014. "Religious Beliefs, Knowledge about Science and Attitudes towards Medical Genetics." *Public Understanding of Science* 23 (7): 833–49. doi:10.1177/0963662513492485.

Bhopal, R. 2014. *Migration, Ethnicity, Race, and Health in Multicultural Societies*. Second. Oxford: Oxford University Press.

Brown, M., and A. Moyer. 2010. "Predictors of Awareness of Clinical Trials and Feelings about the Use of Medical Information for Research in a Nationally Representative US Sample." *Ethnicity & Health* 15 (3): 223–36. doi:10.1080/13557851003624281.

Campbell, M. E., and L. Troyer. 2011. "Further Data on Misclassification A Reply to Cheng and Powell." *American Sociological Review* 76 (2): 356–64. doi:10.1177/0003122411401251.

Cobb, E. M., D. C. Singer, and M. M. Davis. 2014. "Public Interest in Medical Research Participation: Differences by Volunteer Status and Study Type." *Clinical and Translational Science*, January. doi:10.1111/cts.12142.

Cooper, H., H. Lester, S. Wilson, N. Freemantle, and H. Riley. 2003. “Representation of South Asian People in Randomised Trials.” *BMJ : British Medical Journal* 327 (7411): 394–95.

Davis, M. M., S. J. Clark, A. T. Butchart, D. C. Singer, T. P. Shanley, and D. S. Gipson. 2013. “Public Participation In, and Awareness About, Medical Research Opportunities in the Era of Clinical and Translational Research.” *Clinical and Translational Science* 6 (2): 88–93. doi:10.1111/cts.12019.

Ding, E.l., N. R. Powe, and J.B. Braunstein. 2004. “Women and Willingness to Participate in Clinical Trials: Results from a Hypothetical Randomized Control Trial.” *Annals of Epidemiology* 14 (8): 610–610. doi:10.1016/j.annepidem.2004.07.051.

Epstein, S. 2008. *Inclusion: The Politics of Difference in Medical Research*. Chicago: University of Chicago.

Gabbay, J., and J. Thomas. 2004. “When Free Condoms and Spermicide Are Not Enough: Barriers and Solutions to Participant Recruitment to Community-Based Trials.” *Controlled Clinical Trials* 25 (4): 388–99. doi:10.1016/j.cct.2004.06.004.

Gill, P. S., G. Plumridge, K. Khunti, and S. Greenfield. 2013. “Under-Representation of Minority Ethnic Groups in Cardiovascular Research: A Semi-Structured Interview Study.” *Family Practice* 30 (2): 233–41. doi:10.1093/fampra/cms054.

Godden, S., G. Ambler, and A. M. Pollock. 2010. “Recruitment of Minority Ethnic Groups into Clinical Cancer Research Trials to Assess Adherence to the Principles of the Department of Health Research Governance Framework: National Sources of Data and General Issues Arising from a Study in One Hospital Trust in England.” *Journal of Medical Ethics* 36 (6): 358–62. doi:10.1136/jme.2009.033845.

Hussain-Gambles, M., B. Leese, K. Atkin, J. Brown, S. Mason, and P. Tovey. 2004. "Involving South Asian Patients in Clinical Trials." *Health Technology Assessment (Winchester, England)* 8 (42): iii, 1–109.

Ipsos MORI. 2013a. *Wellcome Trust Monitor Report Wave 2. Tracking Public Views on Science, Research and Science Education*. London: Wellcome Trust.

Jenkins, V, D Farewell, L Batt, T Maughan, L Branston, C Langridge, L Parlour, V Farewell, and L Fallowfield. 2010. "The Attitudes of 1066 Patients with Cancer towards Participation in Randomised Clinical Trials." *British Journal of Cancer* 103 (12): 1801–7. doi:10.1038/sj.bjc.6606004.

Jolly, K., G. Y. Lip, R. S. Taylor, J. W. Mant, D. A. Lane, K. W. Lee, and A. J. Stevens. 2005. "Recruitment of Ethnic Minority Patients to a Cardiac Rehabilitation Trial: The Birmingham Rehabilitation Uptake Maximisation (BRUM) Study [ISRCTN72884263]." *BMC Medical Research Methodology* 5 (1): 18.

Lloyd, C. E., M. R. D. Johnson, S. Mughal, J. A. Sturt, G. S. Collins, T. Roy, R. Bibi, and A. H. Barnett. 2008. "Securing Recruitment and Obtaining Informed Consent in Minority Ethnic Groups in the UK." *BMC Health Services Research* 8: 68. doi:10.1186/1472-6963-8-68.

Mason, D. 2006. "Ethnicity." In *Social Divisions*, by G Payne, Second, 102–30. Basingstoke: Palgrave Macmillian.

Mason, S., M. Hussain-Gambles, B. Leese, K. Atkin, and J. Brown. 2003. "Representation of South Asian People in Randomised Clinical Trials: Analysis of Trials' Data." *British Medical Journal* 326 (7401): 1244–45.

Murthy, V. H., H. M. Krumholz, and C. P. Gross. 2004. "Participation in Cancer Clinical Trials: Race-, Sex-, and Age-Based Disparities." *JAMA: The Journal of the American Medical Association* 291 (22): 2720–26. doi:10.1001/jama.291.22.2720.

Nazroo, J. Y., ed. 2006. *Health and Social Research in Multiethnic Societies.* London: Routledge.

NICE. 2011. *Hypertension: Clinical Management of Primary Hypertension in Adults*. London.

Rathore, S. S., and H. M. Krumholz. 2003. “Race, Ethnic Group, and Clinical Research.” *British Medical Journal* 327 (7418): 763–64.

Robinson, J. M., and W. M. K. Trochim. 2007. “An Examination of Community Members’, Researchers’ and Health Professionals’ Perceptions of Barriers to Minority Participation in Medical Research: An Application of Concept Mapping.” *Ethnicity & Health* 12 (5): 521–39. doi:10.1080/13557850701616987.

Samsudeen, B. S., A. Douglas, and R. S. Bhopal. 2011. “Challenges in Recruiting South Asians into Prevention Trials: Health Professional and Community Recruiters’ Perceptions on the PODOSA Trial.” *Public Health* 125 (4): 201–9. doi:10.1016/j.puhe.2011.01.013.

Saperstein, A. 2013. “Representing the Multidimensionality of Race.” In *Mapping “Race”. Critical Approaches to Health Disparities Research.*, by L. E. Gomez and N Lopez, 133–45. New Brunswick: Rutgers University Press.

Shavers-Hornaday, V. L., C. F. Lynch, L. F. Burmeister, and J. C. Torner. 1997. “Why Are African Americans under-Represented in Medical Research Studies? Impediments to Participation.” *Ethnicity & Health* 2 (1-2): 31–45. doi:10.1080/13557858.1997.9961813.

Sheikh, A., G. Netuveli, J. Kai, and S. S. Panesar. 2004. “Comparison of Reporting of Ethnicity in US and European Randomised Controlled Trials.” *British Medical Journal* 329: 87–88.

Sheikh, A. 2006. “Why Are Ethnic Minorities under-Represented in US Research Studies?” *PLoS Medicine* 3 (2): e49.

Sheikh, A., L. Halani, R. Bhopal, G. Netuveli, M. R. Partridge, J. Car, C. Griffiths, and M. Levy. 2009. “Facilitating the Recruitment of Minority Ethnic People into Research: Qualitative Case Study of South Asians and Asthma.” Edited by K. Daniels. *PLoS Medicine* 6 (10): e1000148. doi:10.1371/journal.pmed.1000148.

Smart, A., R. Tutton, P. Martin, G. T. H. Ellison, and R. Ashcroft. 2008. “The Standardization of Race and Ethnicity in Biomedical Science Editorials and UK Biobanks.” *Social Studies of Science* 38 (3): 407–23. doi:10.1177/0306312707083759.

Trauth, J. M., D. Musa, L. Siminoff, I. K. Jewell, and E. Ricci. 2000. “Public Attitudes Regarding Willingness to Participate in Medical Research Studies.” *Journal of Health & Social Policy* 12 (2): 23–43. doi:10.1300/J045v12n02_02.

Wendler, D., R. Kington, J. Madans, G. Van Wye, H. Christ-Schmidt, L. A. Pratt, O. W. Brawley, C. P. Gross, and E. Emanuel. 2006. “Are Racial and Ethnic Minorities Less Willing to Participate in Health Research?” *PLoS Medicine* 3 (2): e19. doi:10.1371/journal.pmed.0030019.

List of Tables

Table 1: Logistic Regression predicting Participation in Medical Research: Odds Ratios (Standard Error)

Table 2: Logistic Regression predicting Willingness to Participate in Medical Research: Odds Ratios (Standard Error)

Table 1: Logistic Regression predicting Participation in Medical Research: Odds Ratios (Standard Error)

	All		White British		BAME	
	Model 1Ai OR (SE)	**Model 1Bi OR (SE)**	**Model 1Aii OR (SE)**	**Model 1Bii OR (SE)**	**Model 1Aiii OR (SE)**	**Model 1Biii OR (SE)**
Ethnic Group:						
White British	1.87** (0.23)	1.64* (0.24)	-	-	-	-
Ref=All others	-	-	-	-	-	-
Gender:						
Male	0.93 (0.13)	1.02 (0.14)	0.90 (0.13)	0.98 (0.14)	2.01 (0.46)	2.01 (0.57)
Ref=Female	-	-	-	-	-	-
Age:						
65 and over	4.04*** (0.21)	3.99*** (0.24)	4.52*** (0.23)	4.43*** (0.25)	0.28 (1.33)	0.30 (1.46)
50-64	2.86*** (0.21)	2.37*** (0.22)	3.24*** (0.22)	2.76*** (0.24)	0.42 (0.95)	0.10^ (1.22)
35-49	2.14*** (0.20)	2.09*** (0.21)	2.20*** (0.23)	2.17*** (0.23)	1.94 (0.49)	2.53 (0.65)
Ref=18-34	-	-	-	-	-	-
Educational Qualification:						
Has degree	1.99** (0.25)	1.49 (0.28)	2.16** (0.27)	1.62 (0.3)	0.28 (0.92)	0.27 (1.2)
Further education	1.24 (0.24)	0.97 (0.25)	1.35 (0.25)	1.08 (0.27)	0.22^ (0.89)	0.20 (1.14)
Secondary education	1.16 (0.23)	1.13 (0.24)	1.25 (0.23)	1.24 (0.25)	0.14* (1.04)	0.15 (1.26)
Missing data	0.68 (0.26)	0.91 (0.27)	0.70 (0.27)	0.94 (0.29)	0.18 (1.04)	0.45 (1.4)
Ref=None	-	-	-	-	-	-

Occupation:						
Managerial/professional	1.38 (0.18)	1.11 (0.19)	1.22 (0.19)	1.00 (0.20)	8.32** (0.77)	4.72 (0.93)
Intermediate	1.11 (0.25)	1.01 (0.26)	1.07 (0.25)	0.98 (0.27)	0.00 (9954.84)	0.00 (9156.59)
Self-employed	1.26 (0.24)	1.07 (0.25)	1.26 (0.25)	1.10 (0.25)	0.00 (7492.12)	0.00 (6085.37)
Supervisory/technical	0.90 (0.27)	0.82 (0.28)	0.90 (0.28)	0.85 (0.29)	0.00 (8398.06)	0.00 (6823.37)
Missing data	1.09 (0.27)	1.09 (0.28)	1.05 (0.30)	1.08 (0.31)	2.78 (0.80)	0.97 (0.99)
Ref=Routine	-	-	-	-	-	-
Has science qualification		1.00 (0.15)		1.06 (0.16)		0.97 (0.65)
Interest in science at school:						
Very interested		1.02 (0.18)		0.99 (0.19)		0.60 (0.98)
Fairly interested		1.03 (0.16)		1.01 (0.17)		1.20 (0.86)
Ref=Not interested		-		-		-
Interest in medical research:						
Very interested		2.89*** (0.28)		2.80*** (0.28)		59005393.83 (3621.84)
Fairly interested		2.11** (0.26)		1.92* (0.27)		82239995.44 (3621.84)
Ref=Not interested		-		-		-
Sought info medical research		1.69*** (0.14)		1.68*** (0.15)		2.81^ (0.61)
Subjective health:						
Very good		0.66* (0.18)		0.70* (0.18)		0.09** (0.87)
Fairly good		0.66* (0.17)		0.69* (0.17)		0.12* (0.17)

Ref=Poor		-		-		-
Science literacy:						
High score		2.08** (0.25)		2.00** (0.26)		2.57 (1.33)
Mid score		2.20*** (0.22)		2.12** (0.23)		3.31 (1.29)
Ref=Low score		-		-		-
Family genetic disorder		1.70** (0.17)		1.54* (0.18)		3.70^ (1.33)
Believe leads to improvement		1.18 (0.27)		1.05 (0.28)		51650739.15 (4745.65)
Religious beliefs		1.18 (1.40)		1.16 (0.15)		1.00 (0.62)
Creationist beliefs		0.66* (0.20)		0.85 (0.21)		0.13* (0.78)
Household member science job		1.51** (0.15)		1.47* (0.15)		3.35^ (0.71)
Constant	0.03*** (0.32)	0.01*** (0.52)	0.04 (0.29)	0.01*** (0.50)	0.05 (0.89)	0.00 (5969.83)
n	2575		2231		344	
-2 Log likelihood	1799.31	1690.98	1618.12	1527.08	152.95	108.9
Nagelkerke R2	0.08	0.15	0.06	0.14	0.06	0.48

^ .10>p>.05; * .05>p>.01; ** .01>p>.001; *** .001>

Table 2: Logistic Regression predicting Willingness to Participate in Medical Research: Odds Ratios (Standard Error)

	All		White British		BAME	
	Model 2Ai OR (SE)	**Model 2Bi OR (SE)**	**Model 2Aii OR (SE)**	**Model 2Bii OR (SE)**	**Model 2Aiii OR (SE)**	**Model 2Biii OR (SE)**
Ethnic Group:						
White British	1.27^ (0.12)	1.18 (0.13)	-	-	-	-
Ref= all others	-	-	-	-	-	-
Gender:						
Male	1.18^ (0.09)	1.17 (0.10)	1.13 (0.10)	1.08 (0.11)	1.28 (0.22)	1.33 (0.25)
Ref=female	-	-	-	-	-	-
Age:						
65 and over	0.94^ (0.14)	0.95 (0.16)	1.09 (0.15)	1.16 (0.17)	0.44^ (0.44)	0.51 (0.49)
50-64	1.27 (0.13)	1.09 (0.14)	1.43* (0.15)	1.28 (0.16)	0.85 (0.36)	0.67 (0.40)
35-49	0.90 (0.12)	0.83 (0.13)	1.02 (0.14)	0.97 (0.14)	0.67 (0.25)	0.48* (0.30)
Ref=18-34	-	-	-	-	-	-
Educational qualification:						
Has degree	1.28 (0.10)	0.85 (0.20)	1.59* (0.21)	1.17 (0.23)	0.64 (0.43)	0.34* (0.51)
Further education	1.27 (0.16)	0.98 (0.18)	1.23 (0.18)	1.01 (0.20)	1.46 (0.40)	0.98 (0.47)
Secondary education	1.26 (0.15)	1.15 (0.16)	1.32 (0.17)	1.27 (0.18)	1.10 (0.41)	0.96 (0.46)
Missing data	0.39*** (0.16)	0.5*** (0.17)	0.43*** (0.18)	0.58** (0.19)	0.24*** (0.41)	0.27** (0.45)
Ref= None	-	-	-	-	-	-

Occupation:						
Managerial/professional	1.45** (0.13)	1.18 (0.13)	1.54** (0.14)	1.27^ (0.15)	1.17 (0.32)	0.97 (0.36)
Intermediate	1.19 (0.17)	1.04 (0.17)	1.18 (0.17)	1.01 (0.18)	1.43 (0.62)	1.80 (0.65)
Self-employed	1.46* (0.18)	1.40^ (0.18)	1.36 (0.19)	1.24 (0.19)	2.84* (0.53)	4.08* (0.57)
Supervisory/technical	1.02 (0.17)	1.02 (0.18)	1.03 (0.18)	1.02 (0.19)	0.99 (0.53)	1.55 (0.60)
Missing data	0.87 (0.15)	0.80 (0.16)	0.82 (0.19)	0.77 (0.20)	0.91 (0.30)	0.82 (0.33)
Ref=Routine	-	-	-	-	-	-
Has science qualification		1.04 (0.10)		0.97 (0.12)		1.48 (0.28)
Interest in science at school:						
Very interested		1.18 (0.13)		1.16 (0.15)		1.42 (0.35)
Fairly interested		1.08 (0.11)		1.13 (0.12)		0.93 (0.30)
Ref=not interested		-		-		-
Interest in medical research:						
Very interested		3.18*** (0.15)		3.16*** (0.17)		3.44** (0.41)
Fairly interested		2.06*** (0.12)		2.05*** (0.13)		2.06** (0.32)
Ref=not interested		-		-		-
Sought info medical research		1.37** (0.11)		1.39** (0.12)		1.30 (0.27)
Subjective health:						
Very good		1.33* (0.13)		1.23 (0.14)		2.22* (0.36)
Fairly good		1.49** (0.13)		1.43** (0.14)		2.36* (0.36)
Ref=poor		-		-		-

Science literacy:						
High score		2.16*** (0.16)		2.17*** (0.17)		2.56* (0.42)
Mid score		1.49** (0.12)		1.72*** (0.13)		0.88 (0.30)
Ref= low score		-		-		-
Family genetic disorder		1.17 (0.14)		1.11 (0.15)		2.11 (0.47)
Believe leads to improvement		1.8*** (0.16)		1.74** (0.18)		2.89** (0.38)
Religious beliefs		0.87 (0.10)		0.80* (011)		1.10 (0.32)
Creationist beliefs		0.94 (0.12)		0.99 (0.14)		0.74 (0.27)
Household member science job		1.07 (0.12)		1.06 (0.13)		0.89 (0.36)
Constant	1.27 (0.18)	0.24*** (0.28)	1.40 (0.18)	0.24*** (0.30)	1.94 (0.38)	0.16** (0.71)
n	2575		2231		344	
-2 Log likelihood	3110.20	2932.28	2563.39	2416.7	519.98	463.51
Nagelkerke R2	0.09	0.17	0.08	0.17	0.15	0.3

^ .10>p>.05; * .05>p>.01; ** .01>p>.001; *** .001>