Improving the recruitment of Black, Asian and Minority Ethnic (BAME) communities in health and social care research: a review of literature

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Abstract

It is suggested that Black, Asian and Minority Ethnic (BAME) communities experience severe health inequalities and poor health outcomes compared to indigenous white groups. However there is a dearth of health-related research undertaken with BAME populations in the UK. Many terms are used to describe this group of people such as 'ethnic minorities', 'racial minorities' 'black and minority ethnic' groups. The aim of this literature review is to identify the barriers and enablers for recruiting people from BAME communities in research. Searches were an iterative process, designed to keep up to date with published material from the year 2000 onwards to 2015. In total, 54 articles were retrieved from which 39 papers were included in this review. A thematic analysis was applied to identify the key issues for consideration when conducting health related research with BAME communities. A number of key themes were identified as potential barriers for conducting research with BAME communities and approaches for improving research participation of Black Asian and Minority Ethnic communities are discussed.

Introduction

This literature review is part of a project funded by the East Midlands Academic Health Science Network and Leicester City Clinical Commissioning Group (CCG) to increase research participation in hard to reach groups starting with South Asian groups living with dementia. It is suggested that Black, Asian and Minority Ethnic (BAME) communities experience severe health inequalities and poor health outcomes compared to indigenous white groups. However there is a dearth of health-related research undertaken with BAME populations in the UK. Many terms are used to describe this group of people such as 'ethnic minorities', 'racial minorities' 'black and minority ethnic' groups. However, we use the term 'Black,

Asian and minority ethnic' communities as the All Party Parliamentary Group (2013) describe this group of people as sharing a similar experience and face particular challenges in getting the support they need.

Our aim is to develop a toolkit to guide and support those wanting to conduct research with BAME populations and consequently increase their representation in UK health-related research. One of the first steps to developing the toolkit has been to conduct a literature review to understand the current evidence base in this area. Though there are very few studies which have evaluated the research experiences of BAME people in the UK, insights can be drawn from US based studies and UK practice based studies.

The aim of this literature review is to identify the barriers and enablers for recruiting people from BAME communities in research. Based on a thematic review of the literature, a number of key themes were identified as potential barriers for conducting research with BAME communities:

1. Language use and ability; participants' English speaking ability, translation and interpretation issues, and illiteracy.

2. Socio-cultural factors that can make it difficult to determine the extent to which problems are concerned with a person's ethnic identity.

3. Participants' lack of knowledge about research, mistrust towards research and health professionals and the stigma associated with certain health conditions.

4. Practical issues such as; the cost implications of research participation and competing priorities for participants.

Our review will discuss each of these four areas. A number of approaches to research with BAME communities are suggested that require the involvement of community members as part of the research team and process. Two models for conducting research with BAME communities are presented with some concluding recommendations based on this review.

Method

A number of strategies were applied to obtain the literature within this body of research:

• Numerous library searches for books and journal articles searching key words such as; ethnicity, culture, BAME, research, research engagement and research participation, health research.
• Electronic database searches (namely the use of Athens) to find electronic journals using the same key words as the search criteria.
• General internet searches (Google and Google Scholar) using the same key words as the search criteria.
• Recommendations of possible useful sources of information (books, journal articles, reports and conference presentations) from colleagues and established networks.

Searches were an iterative process, designed to keep up to date with published material from the year 2000 onwards to 2015. Searches were not limited to the UK in order to maximise the retrieved material. The majority of articles retrieved were based on US studies with some based in European countries however, it is possible to draw parallels with research from different countries. Very few articles were 'research based' with the majority focusing on recruitment and access into services however, the information and guidance provided in these papers can be understood within the context of research and have provided useful insight to help us answer the research question for this literature review. In total, 54 articles were retrieved from which 39 papers were included in this review. A thematic analysis was applied to identify the key issues for consideration when conducting health related research with BAME communities.

Findings

Language

Language has been noted as one of the major barriers for including people from BAME communities in research (Mir and Tovey 2003; Papadopolous 2006; Lloyd et

al 2008; Atkin et al. 2009; Hoopman et al 2009; Rooney et al 2011; De La Nueces et al 2012; Gill et al 2012; Vickers et al 2012). The issue is more complex than one might initially imagine. That is, that the barrier can be overcome by finding a researcher (or interpreter) who can speak the same language as the participants. For example, Hoopman et al (2009) discussed methodological challenges based on their experiences gained in a project with Turkish and Moroccan ethnic minority cancer patients in the Netherlands. Similar to the South Asian community in the UK, five different languages are spoken in Morocco which varied based on participants' educational levels in their country of origin. Finding researchers to accommodate all languages and dialects is not feasible or, even possible in some cases. The authors thus selected the most commonly spoken language amongst Moroccans living in the Netherlands. Once the appropriate researchers were found, an iterative forward-backward translation process was needed which incurred extra costs to the research.

There are further challenges of assessing the quality of translations and the need for culturally appropriate questions. Hoopman et al (2009) suggest that people from BAME communities frequently have difficulties with long (complex) questions, especially in combination with long or varying response options. Translation of research instruments thus need to consider cultural as well as linguistic aspects. The need for research to be 'culturally competent' is reinforced by the need for meaning to be accurately conveyed from participants to researchers, for participants' wider contexts to be understood, and for researchers to avoid unintentionally causing harm or offence to participants or other members of the target group (Papadopoulos 2006). As suggested by De La Nueces et al (2012) research needs to be "bottom up" incorporating community members from the outset to help formulate appropriate research questions. Such approaches to research are discussed in more detail later in the review.

The use of interpreters has also been debated. Gill et al (2012), argue that the presence of an interpreter can make participants feel uncomfortable and sometimes intimidated. However, South Asian participants in a UK based study reported the

availability of South Asian researchers and the provision of translated study information, and the use of interpreters as appropriate (Rooney et al 2011). There has also been discussion about the use of family members as translators, however, researchers in social care practice, are cautious of using family members as translators because they may not use language in the way that the researcher intends and there is the potential to omit, add, condense or substitute information (Mir and Tovey 2003; Atkin et al 2009). Using interpreters may also undermine the richness of qualitative data unless great care is taken in preparation and training. Hiring bi-lingual researchers for data collection and analysis is thus recommended (Dana-Farber Cancer Institute 2005; Waheed et al 2015).

Furthermore, is the issue of illiteracy, especially amongst BAME older people and migrants (Hoopman et al 2009). Though this may cause difficulties for gaining consent in a traditional research manner, audio-recorded methods of obtaining informed consent have been proven as an acceptable alternative to written consent in study populations where literacy skills are variable (Lloyd et al 2008). Researchers should also consider collecting data in different ways for those who cannot articulate well in a certain language (Gill et al 2012).

It is important to consider potential language barriers and overcoming these barriers. Gill et al (2012) based on their primary research with members of the BAME community, noted the main facilitators and motivations for participation are based on the availability of appropriate language (both for recruitment and during research). P Where research does not address such challenges people from BAME communies was excluded. For example, many studies require participants to have the 'ability to understand and speak English' which excludes many older people from BAME communities and/or migrants – which can be argued as a form of institutionalised racism (Hussain-Gambles et al 2004).

Socio-cultural factors

There are socio-cultural barriers for people from BAME communities as they experience: unfair access and health inequalities; cultural and linguistic barriers and; issues concerning modesty associated with religion and culture (Hussain-Gambles et al 2004). Chahal (2004) found that research on services for BAME communities

generally lacked a comparative component, making it difficult to ascertain whether other service users experienced similar or different problems. It is therefore important to build in considerations of ethnicity alongside other factors, and the potential for comparisons, from the design stage. It is important to consider inter-and intra-group differences; the influence of specific factors such as migrant status, English fluency, educational qualifications, and access to money and resources, which can sometimes be difficult to separate. Research also needs to take into account new migrant communities and 'hidden groups' such as Travellers and Muslim women (Vickers et al 2012). Though an American based study, Sullivan et al (2007) note that BAME men are less likely to participate in research and increased efforts should be made to encourage their participation. BAME men, particularly carers, are similarly under-represented in UK services (APPG 2013). It is well recognised that people from Black and Minority Ethnic (BME) groups are underrepresented in services compared to their white counterparts (Nazroo 1997) and hence they may experience even further isolation, as many of these people face greater inequalities in relation to race, disability and gender and exclusion in employment, education and health (Mir et al. 2001). The nature of experiences such as discrimination and social exclusion of people from BME communities will make a negative impact on their health, wellbeing and the social networks (Raghavan 2009)

Zubair and Norris (2015) argue that there are complexities with definitions of ethnicity in ageing research and the heterogeneity of experiences and cultural diversity. A summary of a number of research projects with various BAME communities within the field of social gerontology (Jutlla 2015; Phillipson 2015; Torres 2015; Zubair and Victor 2015) highlights the need to move away from the idea that ethnicity is 'problematic' and that there are positive or protective aspects of ethnicity that can be a useful resource. The multiple and interconnected dimensions of social inequalities need to be noted in ethnic research projects. A better understanding of the diversity of BAME communities would help to inform more targeted and tailored strategies for engagement (Vickers et al 2012).

Fear of the unknown, mistrust and stigma

A number of authors have highlighted how a lack of understanding of the concept of research and what it involves can result in potential participants refusing to take part (Cronin and Ward 2004; Sheik et al 2009; Rooney et al 2011; Gill et al 2012). Poor understanding of awareness of research coupled with a lack of confidence with people feeling like they don't have anything worth saying creates obstacles (Gill et al 2012). There is also fear or worry, particularly of health related research that may involve diagnosis or hospitals or simply, fear of the unknown and the procedures involved in the research (Gill et al 2012). For example, discussions of hypothetical participation in pharmaceutical trials evoked widespread apprehension among participants (Rooney et al 2011). Hoopman et al (2009) found that some BAME people were reluctant to participate in research due to a concern about their migration status. Lack of knowledge about research processes also leads to a distrust of research and apprehension about participation (Gill et al 2012). This is largely due to the common mistrust of (governmental) services and towards health professionals (Hussain-Gambles et al 2004; Sullivan et al 2007; Gill et al 2012). Though their research was with adolescents, Baxley and Daniels (2014) similarly suggest the need for researchers to obtain trust with open and straightforward communication, assuring confidentiality. Rooney et al (2011) too highlight the importance of fostering and maintaining trusting relationships, as this was noted by participants as crucial for long-term recruitment and retention into clinical studies. Though mistrust towards research and health professionals can lead to a reluctance to participate, Rooney et al (2011) found that their South Asian participants were motivated to take part in their research due to their desire to 'give something back' for the treatment that they have received and a sense of altruism (taking part in something that will benefit others).

As highlighted by Hoppitt et al (2012) there are further complexities where stigma is attached with certain conditions. This is not just with mental health conditions as Rooney et al (2011) found this with asthma. According to Waheed et al (2015) the possible stigma for family, family perspectives and the influence of the spouse can encourage the decision for non-participation in research.

Practical issues

A well noted barrier for conducting research with participants from BAME communities is the additional costs (Cronin and Ward 2004; Hussain-Gambles et al 2004; Vickers et al 2012; Brown et al 2014). Costs have been reported as a major barrier due to the analysis of extra variables for quantitative data, translation and interpretation costs and sometimes, the additional costs associated with ethics requirements (Hussain-Gambles et al 2004).

Hussain-Gambles et al (2004) suggest that where these costs have not been covered, it can be argued as a form of institutionalised racism in the same way as that of research projects that have not taken the necessary steps to overcome language barriers. The decision on whether to include people from BAME groups must firstly involve a judgement of cost and benefit (Allmark 2009), and additional costs will need to demonstrate value for money (Sheik et al 2009). It is here that we observe the distinction between US and UK studies. The dearth of research with BAME communities in the UK is a reflection of the lack of influential policy requiring information about the experiences of BAME populations. The National Institute of Health (NIH) in the US have a requirement to include BAME people in research and hence, the large number of studies in this area from the US. Such drivers will support and provide funding opportunities for such research studies currently missing in the UK.

There are other practical issues concerned with researching migrants especially with regard to recruitment such as inaccurate or unregistered home addresses and extended stays in their country of origin (Hoopman et al 2009). Where potential participants were accessible, participation was dependent upon: timing and location of the research (long-time commitments or substantial travel distances), availability of child care and, competing priorities such as education, employment, family commitments (Cronin and Ward 2014; Waheed et al 2015). Though such issues are universal regardless of ethnic background, they still need to be considered for the successful recruitment and retention of research participants. Gill et al (2012) reported that generally, participants are willing to give up 30-60minutes of their time for research however; do not feel comfortable travelling to unfamiliar areas and locating unfamiliar places.

Ethnic Identity Matching

Some authors argue that having the researcher from the same background as the participants will improve recruitment and the overall research experience (sheikh et al 2006; Hoopman et al 2009; Brown et al 2014). However; Cronin and Ward (2004) argue that researchers should be culturally competent despite their ethnic identity. Cultural competence is defined as having the necessary self-awareness, cultural knowledge, and skills to foster culturally effective and ethical communications, interactions, and relationships with people of various cultural backgrounds (Cronin and Ward 2004). Though one may argue that researcher-participant ethnic identity matching will overcome language and cultural barriers, Burlew et al (2011) highlight the need for further research to see if this approach actually improves outcomes. Furthermore, Gill et al (2012) in their primary research with members of the BAME community argue that the profession, age and ethnicity of the researcher was unimportant to the research participants though same sex was appreciated. Similarly, Hoopman et al (2009) found that the gender of the researcher is important and argue that women are generally more acceptable because in many cultures (as is the case for Moroccan people), it is more acceptable for a woman to interview a man than the other way around. The authors also suggest employing older and mature researchers due to the sensitivities and complexities of health research. Overall, as highlighted by their research, the personal qualities of the researcher outweigh these attributes (Gill et al 2012). A culturally competent researcher will actively develop and practice appropriate, relevant, and sensitive strategies/skills in working with individuals from different cultures (Cronin and Ward 2014). Using modalities that are consistent with the life experiences and cultural values of the participants will build trust and rapport which is an important component for research with BAME communities.

McDonald (2009) also highlights the need for cultural self-awareness for researchers as stereotypes and beliefs/pre-dispositions about certain communities create barriers in research. For example, assumptions that particular groups will be 'difficult' or 'hard to reach' create obstacles for recruitment and research participation. Hussain-Gambles et al (2004) emphasise the importance of researcher attitudes by

highlighting how prejudicial biases and stereotypes towards BAME groups create obstacles for not only in relation to recruitment but also for building trust and rapport. McDonald (2009) based on his experience of cancer research, highlight that greater awareness of one's own culture's pre-judgements would have helped the researchers to understand the differences of the BAME groups and deal with them in a more culturally sensitive manner. McDonald also points out that researchers should be aware of their own occupational culture and how members of the public may not share this. It could be argued that the mistrust towards health professionals as highlighted earlier could be the result of differing beliefs and perspectives towards health based on an individual's professional background (e.g. eastern vs. western ideologies). It is therefore important to not see all differences through the lens of culture (such as wealth, social status, or education). As pointed out by Torres (2015) those with a minority ethnic background should not be assumed to entail disadvantage. Equally, data analyses must be developed to recognise the interaction between ethnicity and other key social statuses – notably age, class, gender and sexuality (Phillipson 2015).

Approaches to research with BAME communities

There a number of approaches to research with BAME communities that have proven effective, and helped to overcome some of the issues highlighted above. Community Based Participatory Research (CBPR), Participatory Learning and Action (PLA) and, Participatory Action Research (PAR) are all terms used to describe an approach that involves community members, or the target group, as part of the research team and process.

Following their systematic review of 19 peer reviewed articles, De La Nueces et al (2012) suggest the use of what they term Community Based Participatory Research (CBPR) which involves community members as partners of research as opposed to participants, at every stage of the research process including the formulation of the research question(s). Their findings suggest that CBPR improves recruitment and retention of BAME populations and the effectiveness of health interventions geared towards these communities. Such an approach is supported by those who have increased participation of service use by working collaboratively with key local influential leaders. For example, Markham et al (2014) improved access to hospice

services by engaging with cultural and religious leaders who served as a point of information for community members and consequently encouraged the uptake of services. Gregory et al (2005) developed an educational intervention for BAME women and noted the benefits of involving students during the planning stages resulting in a course that was more appropriate to participants expressed needs. Rooney et al (2011) also suggest that collaboration between researchers and respected individuals within BAME communities is an approach which allows researchers to earn trust and increase positive awareness of their research. Williams (2005) argue that community members are becoming more educated consumers of research and this presents an opportunity for collaboration between researchers, community agencies and community representatives to advocate for the time, space and resources to create mutually beneficial research.

Lane and Tribe (2010) suggest recommendations based on an iterative and critical learning process through their experiences of consulting with a range of BAME groups over many years. They note the effectiveness of encouraging participation in the planning and provision of health and social care services. Though this is not about research per se, similarities can be drawn as the authors use what is termed the Participatory Learning and Action (PLA) approach to community consultations. Using a range of methods from visualisation to interviewing and group work, PLA increases consultations and dialogue between health and social care providers and BAME communities thus ensuring that they play a larger role in the development and delivery of services. The authors also stress the importance of feedback and follow up with those providing advice and guidance. Such advice is also true to that of research involvement, seeing community members as 'consultants of research' and ensuring an equal two-way dialogue. This is even more so important where particular questions of research ethics arise where findings may have implications for members of marginal, disempowered or stigmatised groups (Temple and Moran 2006; Vickers et al 2012).

While the cost implications of best practice in translating research tools often lead to compromises, such as contracting out translation of questionnaires (McManus et al. 2006), active participation of the research team in translation may have scientific and

ethical benefits. These may range from involvement of members of the target group in the research design, to ensuring a sufficiently shared understanding as a basis for genuinely informed consent, interpretation of data, accessible dissemination products and implementation of findings.

However, it has been suggested that where stigma is attached to a condition, community-based strategies for recruitment will not always be effective. Hoppitt et al (2012) discuss strategies to recruit service users from BAME communities with rare long term neurological conditions. The authors recruited 15 participants using community and clinically based strategies. Recruiting through neurology clinics was the most successful recruitment strategy. The authors highlight the impact that the target group can have on recruitment. For example, for their study, due to the rare nature of neurological conditions, a clinic targeted towards these patients presented opportunity to approach patients that would not have been possible through the community-based strategies that were employed. For Hoppitt et al (2012) community-based methods were essentially ineffective in recruiting participants as community members many not have heard of certain neurological conditions, and the low prevalence of conditions meant that it was unlikely that the potential participants would be found at various community events or centres. Thus there is a need to 'plan ahead' and steps should be taken to understand where participants are likely to be accessible (Hoppitt et al 2012; Dana-Farber Cancer Institute 2005).

Participatory Action Research (PAR) has been suggested as an effective means to enhance community development and research endeavours, whilst empowering marginalised groups (Oden et al 2011). Similar to that of CBPR, PAR is an approach to research which involves both researchers and participants as stakeholders invested in the social impact of research projects, with participants demonstrating varying degrees of influence in determining research agendas and processes. For example, BAME older people have also expressed their frustration that researchers wanted to do yet more research, rather than making a difference in services with what was already known. They suggested that researchers were either trying to answer questions that had been answered years ago, or were looking at research that did not reflect the lives of older people (Butt and O'Neil 2004).

According to Oden et al (2011) benefits of the PAR approach are both at an individual and a community level including an; increased knowledge of the research topic area, increased sense of independence (empowerment) and, increased desire to advocate. The PAR approach is thus particularly useful for research projects where stigma may be an issue as it presents an opportunity to educate the community and raise awareness of stigmatising illnesses using research as the vehicle. Arguably, PARs can serve as gatekeepers who have the potential to boost response rates due to their shared vision for the research and persuasive skills to recruit participants (Mier et al 2006). Raghavan and Pawson (2011) in their work with improving access to leisure services by disabled young people from South Asian communities in Bradford involved disabled young people from South Asian community as co-researchers to improve access to leisure services.

Gill et al (2012) asked 91 people from BAME communities what would encourage them to participate in research. They noted that researchers should go to religious and community organisations to talk directly to people about the research. This would encourage leaders to be involved and would also start the process of snowballing. Based on their experience of conducting research with Hispanics and African Americans, Polanco et al (2011) highlight the importance of having an effective research team for increased recruitment through a cohesive, empowered team.

Hoppitt et al (2012) highlights that the aim of the research and the target group need to be taken into consideration for not making assumptions about commonly used methods to recruit BAME participants will work for every study. Taking this into consideration, for people with dementia specialist clinics (e.g. memory clinics) would be the best place to recruit as opposed to community-based strategies. Based on their experience, Hoppitt et al (2012) argue that BAME participants are not 'hard to reach' but rather, researchers need to look in the right places to enhance recruitment. NBCWN (2008) suggest that groups commonly characterised as 'hard-to-reach' may be more accurately understood as 'easy-to-ignore', and that accessing

ethnic minorities is not difficult, but rather a matter of assessing and committing the necessary time and resources. Brown and Scullion (2010) suggest a designation of 'hard to reach' may also reflect 'a lack of knowledge on behalf of the researcher about how, who, and where to contact certain groups or individuals.

Conducting research with BAME communities

Based on their experiences, a number of researchers have sought to provide a framework for conducting research with BAME populations. Rooney et al (2011) have attempted to capture the considerations needed when planning research targeting BAME communities (see Figure 1) whilst Cronin and Ward (2004) present a cultural competence model for design and conduct for of clinical trials (see Figure 2). Both these frameworks highlight the need for collaborative work with community members/target group at the outset of the research.
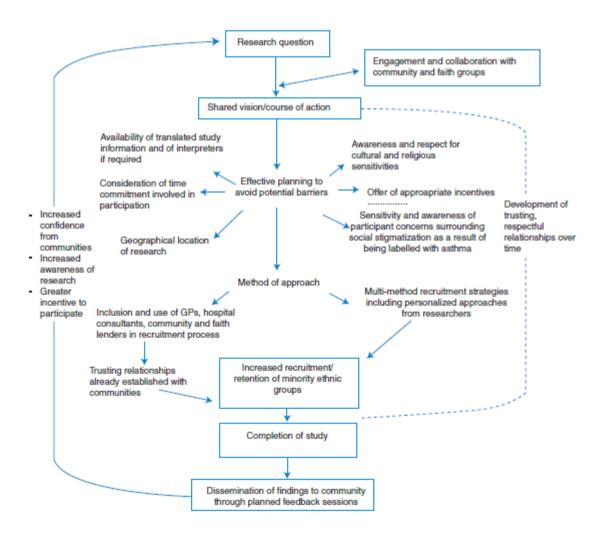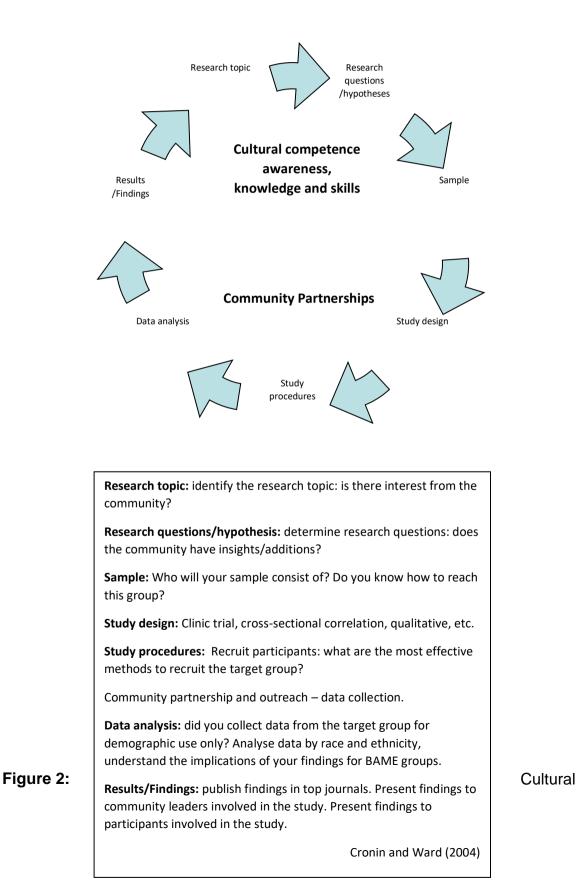
Figure 1: Considerations when planning research targeting minority ethnic communities (Rooney et al 2011: 613).

Research topic

Research questions /hypotheses

Cultural competence awareness, knowledge and skills

Sample

Results /Findings

Community Partnerships

Study design

Data analysis

Study procedures

Figure 2:

Cultural

> **Research topic:** identify the research topic: is there interest from the community?
>
> **Research questions/hypothesis:** determine research questions: does the community have insights/additions?
>
> **Sample:** Who will your sample consist of? Do you know how to reach this group?
>
> **Study design:** Clinic trial, cross-sectional correlation, qualitative, etc.
>
> **Study procedures:** Recruit participants: what are the most effective methods to recruit the target group?
>
> Community partnership and outreach – data collection.
>
> **Data analysis:** did you collect data from the target group for demographic use only? Analyse data by race and ethnicity, understand the implications of your findings for BAME groups.
>
> **Results/Findings:** publish findings in top journals. Present findings to community leaders involved in the study. Present findings to participants involved in the study.
>
> Cronin and Ward (2004)

competence model for design and conduct of clinical research (Cronin and Ward 2004)

Though both these frameworks encourage and emphasise the need for community collaboration, there are a number of suggestions that also need to be taken into consideration to improve the recruitment and retention of BAME groups in health research. These include:

- Careful consideration at research planning and design stage
- Strategies to reduce fear and mistrust (e.g. via health professional's education, and researcher education)
- Special advocacy or community link workers, independent of the medical profession.
- Outreach strategies need to be sensitive to different cultural understandings of health and healthcare.
- Targeting high BAME populated practices for recruitment
- Greater cultural sensitivity
- The use of focus groups to understand potential barriers and find ways to overcome them
- Minimize need for transportation
- Help with child care arrangements
- Hire bi-lingual staff
- Use multiple recruitment strategies
- Understand and incorporate individual's cultures, traditions, beliefs, practices, lifestyle onto promotional materials
- Pilot test recruitment strategies

(Dana-Farber Cancer Institute 2005; Hussain-Gambles et al 2004; Waheed et al 2015)

Conclusion

The aim of this literature review was to identify the barriers and enablers for recruiting people from BAME communities in research. A thematic review of 39 papers highlighted a number of issues worthy of consideration for conducting

research with BAME communities. These include; language issues namely, participant's inability to speak, understand, read and write English and the consequent translation and interpretation issues. Socio-cultural factors such as language, education and social status make it difficult to determine the extent to which problems are concerned with a person's ethnic identity. The lack of knowledge about what constitutes research; mistrust towards research and health professionals and the stigma associated with certain health conditions cause further complexities for recruiting people from BAME communities. There are also cost implications of research and other practical issues such as time and competing priorities for participants that can cause further difficulties.

There are mixed feelings about the idea of researcher-participant ethnic identity matching with some authors suggesting that researchers should be culturally competent regardless of ethnic background. Resources thus need to be invested in cultural competency training for the research team, ensuring they have the necessary skills in place to be able to work respectfully and confidently with people from diverse cultures. The use of community members/target group as partners of the research is highly valued and almost all research papers recommended this. However, further complexities may arise where research is concerned with health issues that carry stigma (e.g. mental ill-health). The methods for recruitment will thus be dependent upon the target group in question with scoping exercises to determine where to target potential participants. It is also advised that suggested methods (both from the community and or, the research team) are firstly piloted to test their effectiveness. As noted by Vickers et al (2012) detailed accounts are available of creative strategies developed in work with particular populations, many of which emphasise the importance of pilot studies and built in measures for verification in order to develop research tools and practices tailored to the specific research question and population.

Though we have some information to help guide us with research with BAME communities, there is still a need for further research in this area. Very little work has been undertaken on BAME populations in the UK. Brown et al (2014) conducted a systematic review and found no trials that tested interventions for enhancing recruitment of BAME groups, that there is still a need to test different recruitment strategies and evaluate their effectiveness. Similarly, Burlew et al (2011) suggest

that more research on effective strategies to promote inclusion in clinical trials and research more broadly is needed. More research is thus needed to develop culturally appropriate research methods, materials and data collection instruments. Current research methods and designs means that BAME groups are not given a choice to participate (Hussain-Gambles et al 2004), meaning that they have unfair access to research for almost the same reasons as why they may have unfair access to services (e.g. due to language and cultural barriers).

In Sheik et al's (2009) study US researchers were considerably more positive than their UK counterparts about the importance and logistics of including BAME communities, which appeared to a large extent to reflect the longer-term impact the National Institute of Health's (NIH) requirement in the US to include BAME people in research. The UK funding bodies should follow the lead of the US NIH requiring the recruitment of people from BAME communities. Furthermore, the body of research evidence available to policy makers should reflect the diversity of the population (Allmark 2009). Inclusion and involvement of people from diverse ethnic and cultural communities is captured by Vickers et al (2012:18):

> 'at every stage of the research process, from commissioning to dissemination, we need to be alert to the ways in which a diversity of relationships – around 'race', culture, religion, language, nationality, class, gender, disability, life history, age, mental health, and sexuality – connect individuals, as part of groups, to wider contexts and processes up to an international level, in a two way, dialectical process. This is in addition to reflecting this in outcomes and a commitment to tackling disadvantage and discrimination.'

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Table 1: Publications chosen for the review

Authors	Year	Title	Country	Barriers	Enablers/ Strategies
					Main theme(s) highlighted
Allmark, P.	2009	Should research samples reflect the diversity of the population?	UK	Costs	Influential research for policy makers that is representative of different ethnic groups (to encourage funding).
Atkin, K. Ali, N. and Chu, C.E.	2009	The politics of difference? Providing a cancer genetics service in a culturally and linguistically diverse society	UK	Language	Professionally trained interpreters (to not use family members).
Baxley, S.M. and Daniels, G.	2014	Adolescent Participation in Research: A Model of Ethnic/Minority Recruitment and Retention	US	Mistrust	Open and straight forward communication.
Brown, G. Marshall, M. Bower, P. Woodham, A. and Waheed, W.	2014	Barriers to recruiting ethnic minorities to mental health research: a systematic review	UK Systematic review of US studies	Costs	Ethnic identity matching.
Brown, P. and Scullion, L. (2010).	2010	'Doing research' with Gypsy-Travellers in England: reflections on experience and practice.	UK	Assuming groups to be 'hard to reach'	Gain knowledge about where to access community members/target group.
Burlew, A. K. Weekes, J.C. Montogomery, L. T. Feaster, D.J. Robbins, M.S. Rosa, CL. Ruglass, L.M Venner, K.Land Wu, L.	2011	Conducting Research with Racial/Ethnic Minorities: Methodological Lessons from the NIDA Clinical Trials Network	US	Lack of research of effective strategies	Community/target group collaborations.
Butt, J. and O'Neil, A.	2004	Black and minority ethnic older people's views on research findings:	UK	Not asking the right questions/ addressing the	Community/target group collaborations to understand their

		An exploration of how research can bring about change in the lives of black and minority ethnic older people.		needs of the target group	needs/how the research will help them.
Chahal, K. (2004).	2004	Experiencing Ethnicity: Discrimination and service provision. Foundations: Analysis informing change.	UK	Lack of a comparative component Cost Competing priorities	Address socio-cultural factors so that findings may be applied to other groups.
Cronin, K. and Ward, E.	2004	Recruiting Racial and Ethnic Minority Participants for Clinical Research.	US	Lack of understanding about research Mistrust Stigma (e.g. of mental health)	Involve culturally competent staff – training and education. Community/target group collaborations.
Dana-Farber Cancer Institute.	2005	Recruiting Diverse Populations in Clinical and Community Research Trials: Guidelines and Recommendations.	Boston	Language	Bi-lingual staff. 'Plan ahead' knowing where to access potential participants. Greater cultural sensitivity. Utilise focus groups to assess barriers prior to data collection. Use multiple strategies and pilot test them.
De La Nueces, D. Hacker, K. DiGirilamo, A. and Hicks, L.S.	2012	A Systematic Review of Community-Based Participatory Research to Enhance Clinical Trials in Racial and Ethnic Minority Groups.	North America	Language	Community/target group collaborations from the outset via Community Based Participatory Research Approach.
Gill, P.S. Plumridge, G. Khunti, K. and Greenfield, S.	2012	Under-representation of minority groups in cardiovascular research: a semi-structured interview study.	UK	Language Costs Lack of knowledge of research Lack of confidence	Collect data in different ways for those who can't articulate well in a certain language. 30-60minutes for data collection.

					from participants Mistrust Competing priorities Time	Familiar and local places to travel to Gender matched researchers. Culturally competent researchers. Community/target group collaborations.
Gregory, P. Lester, C. O'Neil, M. and Gray, L.	2005	Widening participation of black and ethnic minority women: A pilot educational intervention using action research.	UK			Community/target group collaborations.
Hoopman, R. Terwee, C.B. Muller, M.J. Ory, F.G. and Aaronson, N.K.	2009	Methodological challenges in quality of life research among Turkish and Moroccan ethnic minority cancer patients: translation, recruitment and ethical issues.	Netherlands	Language Illiteracy Mistrust Costs Migrants – inaccurate home addresses and extended stays in country of origin		Bi-lingual staff. Ethnic Identity Matching. Gender matched researchers.
Hoppitt, T. Sha, S. Bradburn, P. Gill, P. Calvert, M. Pall, H. Stewart, M. Fazil, Q. and Sackley, C.	2012	Reaching the 'hard to reach': strategies to recruit black and minority ethnic service users with rare long-term neurological conditions.	UK	Stigma		Focus on the target group. If it is people with rare or stigmatising conditions, community-based strategies will not always work.
Hussain-Gambles, M. Atkin, K. and Leese, B.	2004	Why ethnic minority groups are under-represented in clinical trials: a review of the literature.	UK	Language Socio-cultural factors (e.g. unfair access to services) Mistrust Costs Institutional racism		Culturally competent researchers. Self-awareness. Multiple strategies. Pilot test ideas.
Jutlla, K.	2015	The impact of migration	UK	Mistrust Stigma		Migrants possess resiliency and self-

		experiences and migration identities on the experiences of services and caring for a family member with dementia for Sikhs living in Wolverhampton, UK.			efficacy skills that are a useful resource.
Lane, P. and Tribe, R.	2010	Following NICE 2008: a practical guide for health professionals on community engagement with black and minority ethnic (BME) community groups.	UK		Community/target group collaborations via the Participatory Learning and Action (PLA) approach
Lloyd, C.E. Johnson, M.R.D, Mughal, S. Sturt, J.A. Collins, G.S. Roy, T. Bibi, R. and Bernett, A.H.	2008	Securing recruitment and obtaining informed consent in minority ethnic groups in the UK.	UK	Language Illiteracy	Audio-recorded methods of obtaining informed consent have
Markham, S. Islam, Z. and Faull, C.	2004	I never knew that! Why do people from Black and Asian Minority Ethnic groups in Leicester access hospice services less than other groups? A discussion with community groups.	UK		Community/target group collaborations
McDonald, M.	2009	Medical Research and Ethnic Minorities.	US	Mistrust	Cultural self-awareness for researchers. Build trust and rapport. Cultural sensitivity.
McManus, S. Erens, B. Bajekal, M.	2006	Conducting surveys among ethnic minority groups in Britain.	UK	Costs	Contracting out translation of questionnaires.

Mier, N. Medina, A.A. Bocanegra-Alonso, A. Castillo-Ruiz, O. Acosta-Gonzalez, R. I. and Ramirez, J.A.	2006	Finding Respondents from Minority Groups.	US		Use of gatekeepers who have the potential to boost response rates due to their shared vision for the research and persuasive skills to recruit participants.
Mir, G. and Tovey, P.	2003	Asian carers' experiences of medical and social care: the case of cerebral palsy.	UK	Language	Professional interpreters.
NBCWN (National Black Carers and Workers Network).	2008	Beyond We Care Too: Putting Black Carers in the Picture	UK	Time Resources Stereotypes that certain communities are 'hard to reach.'	Assessing and committing the necessary time and resources.
Oden, K. Hernandez, B. and Hildalgo, M.A.	2011	Payoffs of Participatory Action Research: Racial and Ethnic Minorities with Disabilities Reflect on their Research Experiences.	Chicago		Community collaborations via Participatory Action Research.
Papadopoulos, I.	2006	Culturally competent research: a model for its development	UK		Culturally appropriate questions. Culturally competent research – understand findings within participant's wider context.
Phillipson, C.	2015	Placing ethnicity at the centre of studies of later life: theoretical perspectives and empirical challenges	UK	To move away from the idea that ethnicity is 'problematic'	Address cultural diversity.
Polanco, F.R. Dominguez, D.C. Grady, C. Stoll, P. Ramos, C. Mican, J.M. Miranda-	2011	Conducting HIV Research in Racial and Ethnic Minority Communities: Building a	US		An effective research team.

Acevedo, R. Morgan, M. Aizvera, J. Purdie, L. Koziol, D. and Rivera-Goba, M.V.		Successful Interdisciplinary Research Team.			
Rooney, L.K. Bhopal, R. Halani, L. Levy, M.L. Partridge, M.R. Netuveli, G. Car, J. Griffiths, C. Atkinson, J. Lindsay, G. and Sheikh, A.	2011	Promoting recruitment of minority ethnic groups into research: qualitative study exploring the views of South Asian people with asthma.	UK	Language Lack of knowledge of research Mistrust Stigma	Use of interpreters. Building trusting relationships. Community/target group collaborations.
Sheikh, A. Halani, L. Bhopal, R. Netuveli, G. Partridge, M. R. Car, J. Griffiths, C. and Levy, M.	2009	Facilitating the recruitment of minority ethnic people into research: Qualitative case study of south Asians and asthma.	UK with a US comparison		Ethnic identity matching.
Sullivan, P. S. McNaghten, A. D. Begley, E. Hutchinson, A. and Cargill, V. A.	2007	Enrolment of racial/ethnic minorities and women with HIV in clinical research studies of HIV medicines.	US	Gender – BAME Men less likely participate.	Make an extra effort to reach out to men and encourage them to participate.
Temple, B. and Moran, R. (eds).	2006	Doing Research with Refugees: Issues and Guidelines.	UK	Stigma	Community/target group collaborations
Torres, S.	2015	Expanding the gerontological imagination on ethnicity: conceptual and theoretical perspectives.	UK		Ethnic minority background should not be assumed to entail disadvantage.
Vickers, T. Craig, G. and Atkin, K.	2012	Research with black and minority ethnic people using social care services.	UK	Language Socio-cultural factors Costs Stigma	Include new migrant populations. Use multiple strategies. Pilot test strategies. Community/target group

					collaborations.
Waheed, W. Hughes-Morely, A. Woodham, A, Allen, G. and Bower, P.	2015	Overcoming barriers to recruiting ethnic minorities to mental health research: a typology of recruitment strategies.	UK review of US studies	Language Trust Stigma Gender Mistrust Location Time Travel Competing priorities Family's influence Lack of culturally competent staff	Outreach strategies. Culturally competent researchers. Bi-lingual staff. Gender matched staff. Flexibility and choice of location.
Williams, C.	2005	Ethical Considerations in Mental Health Research with Racial and Ethnic Minority Communities.	US		Community members are becoming more educated consumers of research and this presents an opportunity for community/target group collaborations.
Zubair, M. and Norris, M.	2015	Perspectives on ageing, later life and ethnicity: ageing research in ethnic minority contexts.	UK	Heterogeneity of experiences and cultural diversity Ethnicity seen as problematic	Focus on positive aspects. Address social inequalities.
Zubair, M. and Victor, C.	2015	Exploring gender, age, time and space in research with older Pakistani Muslims in the United Kingdom: formalised research 'ethics' and performances of the public/private divide in 'the field.'	UK	Formal procedures reinforce hierarchal research relationships. Over -emphasised social and cultural differences of ethnic minority older participants.	Research frameworks and procedures should empower participants, not make them feel vulnerable.