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### Reaching the 'hard to reach': strategies to recruit black and minority ethnic service users with rare long-term neurological conditions

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## Reaching the ‘hard to reach’: strategies to recruit black and minority ethnic service users with rare long-term neurological conditions

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Little is known about health and social care experiences of patients with rare long-term neurological conditions. Furthermore, black and minority ethnic (BME) service users are often perceived to be under-represented in health services research. BME service users have been described as ‘hard to reach’ in the past. However, evidence suggests that a variety of recruitment methods need to be used in order to increase recruitment. We employed a range of recruitment strategies shown to be effective in recruiting BME patients, to recruit patients to participate in one-to-one interviews to establish experiences of health and social care. Strategies included community and clinically based strategies. In total we recruited 15 participants through these recruitment methods, with all recruits ultimately coming from neurology clinics and disease-specific charities. Despite community-based strategies generating interest and a willingness to be involved, the rare nature of these conditions resulted in a lack of recruits from these strategies. Consequently we conclude that researchers need to plan and prioritise strategies carefully in order to maximise recruitment and utilise resources efficiently dependent on the nature of the research.

**Keywords:** black and minority ethnic; hard to reach; long-term neurological conditions; recruitment strategy

### Introduction

The National Service Framework (NSF) for Long Term Neurological Conditions highlights a number of healthcare and social service standards that people with long-term neurological conditions should be entitled to (Department of Health (DoH, 2005). However, little is known about the care received by patients with rare neurological conditions. The RESULT study (Review of Epidemiology and Service Use in Rare Long Term Neurological Conditions) used a survey to identify what health and social care services these patients were accessing in an attempt to gauge whether the NSF recommendations are being met, and to identify any gaps in service provision. The specific conditions covered were Huntington’s disease, motor neuron disease, Charcot Marie Tooth disease, dominantly inherited ataxias, progressive supranuclear palsy, post polio syndrome and multiple system atrophy.

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The Race Relations (Amendment) Act (2000) states that everyone should have equal access to public services. As recognised by Bhopal (2007), providing a blanket service does not mean that everyone is receiving equal services. In order to improve on health inequalities, research needs to include black and minority ethnic (BME) populations to identify where any inequalities lie and how they can be eliminated.

It is often perceived that health inequalities exist for people from the BME community. The BME populations still appear to be under-represented in health services research, not just in the UK, but in the US as well (Sheikh, 2006). Due to the rare nature of the conditions studied, it was anticipated that the number of BME service users would be small. Previous studies indicate the prevalence of these conditions that ranged from 3 to 10/100,000 of the general UK population (Hoppitt et al., 2011). Prevalence figures for the BME population of the UK are not known for these conditions. Existing literature does not suggest that individuals from BME communities are at any greater risk than those from the white British community. Figures from the 2001 Census suggest that BME accounts for 7.9% of the UK population (ONS, 2004) and assuming the disease prevalence rates are generalisable, BME service users in the UK are rare. Consequently, it was decided that interviews with BME service users would be conducted in order to provide in-depth data on a small sample of people.

Historically, people in the BME community were perceived as 'hard to reach' and the low representation of BME groups in research was attributed to this factor. A thematic review of clinical trials revealed a number of factors for low BME representation in clinical trials. Factors included language barriers, increased cost of research, health provider attitudes and suggestions that BME participants may not understand research. Hussain-Gambles et al. (2004) and Sheikh et al. (2009) interviewed researchers and community leaders based in the UK and the US and identified a number of strategies that would help to improve recruitment. They suggested researcher attitudes would make a difference in participation. For example, they found researchers sometimes held stereotypical views about BME communities, and that they perceived BME communities as difficult to engage. In addition, they found that community leaders had little knowledge about research and its aims (Sheikh et al., 2009). These findings suggest that, in order to increase research participation and awareness, researchers need to build relationships with local BME communities, and educate local community leaders about the rationale behind their research. Mohammadi et al. (2008) suggest that multiple recruitment strategies need to be used in order to maximise recruitment. They used a number of different strategies, including snowball sampling and advertising to recruit patients from the Islamic community in Australia, to ascertain experiences of hospitalisation. Snowball sampling proved successful and was responsible for over half the recruited participants, whereas advertising was unsuccessful. Ryan et al. (2011) discussed the use of peer researchers in BME community-based research and how being regarded as an 'insider' can be beneficial for recruiting in some communities where trust may be an issue.

We aimed to recruit BME service users to participate in semi-structured qualitative interviews to establish their views and experiences of health and social care. Due to the low prevalence of these conditions, we were aware that potential participants would be limited and consequently proposed a number of recruitment strategies that have been successfully used in previous studies (Grewal & Ritchie, 2006; Mohammadi et al., 2008; Ryan et al., 2011; Sheikh et al., 2009).

## Methods and recruitment success

### *The interviewer*

The interviewer in qualitative research plays an important role in obtaining accurate and complete information from an interviewee. A number of studies have considered power differentials that may play a role, and may therefore have an impact on the type of interview data that are collected. For example Carter (2004) described potential difficulties encountered when he, as a white male researcher, interviewed African-Caribbean nurses about issues relating to work and ethnicity. In addition, Ryan et al. discussed the issue of gaining the trust of communities in order to gain access to them to conduct research. Particularly in the current political climate, the authors suggest the need to eliminate suspicion surrounding research motives in certain communities. The authors discuss the concept of position to analyse ‘insider/outsider’ status of researchers and how this can affect the research process Ryan et al. (2011).

The interviewer in this study was responsible for engaging with and recruiting participants from the BME community. Although of Indian origin, the interviewer did not fall into the main religious groups of Hindu, Sikh or Muslim. Grewal and Ritchie (2006) state that a shared language and ethnicity is helpful for data collection in a qualitative interview. In addition, Ryan et al. (2011) discuss the merits of using peer researchers in community-based research, due to their ‘insider’ status which is assumed to derive from ethnic, religious and linguistic backgrounds, or networks within specific neighbourhoods. Consequently, the interviewer was keen to immerse myself in other cultures in order to build rapport with local communities.

### *Recruitment journey*

The researchers anticipated that the most successful method in terms of the numbers recruited for interview would be by attending neurology clinics to identify eligible participants. However, in order to conduct research using NHS patients it is a requirement to obtain ethical approval from the NHS National Research Ethics Service. In addition, the DoH who commissioned the programme of research, of which this study was a component, requested that we adopted strategies to target BME populations to ensure this community was represented in the research and had sufficient opportunity to be involved.

Consequently, during the timeframe of the ethical application procedure which was 8 months, we employed additional strategies in an attempt to recruit patients with long-term neurological conditions from the BME community, which had proven successful in previous studies (Grewal & Ritchie, 2006; Mohammadi et al., 2008; Ryan et al., 2011; Sheikh et al., 2009).

### *Visits to places of worship*

Initially the interviewer visited places of worship in order to get to know different BME communities and provide an opportunity to meet with community leaders. One study found that community leaders had poor understanding of the importance of research, especially BME research, and therefore needed to be involved more (Sheikh et al., 2009). Another major factor reported to lead to lack of participation in clinical trials was lack of cultural understanding, and researchers holding certain stereotypes about various cultures (Hussain-Gambles et al., 2004). A study

involving African Americans achieved a high participation rate from this community when researchers were trained on how to approach people appropriately (Thompson et al., 1996). These studies suggest understanding prospective participants may influence recruitment rates. In order to familiarise with local communities and breakdown cultural barriers, a number of visits were made to places of worship in the West Midlands area. This geographical area was convenient due to both its proximity to the University of Birmingham and ethnic diversity. Estimated figures of the population of Birmingham in 2007 suggest that just over a third (37.9%) of the population are from an ethnic minority (ONS, 2007). A number of repeated visits were made in order to build relationships with community leaders and members of the community. Visits were made during weekdays when lunch was provided, so it attracted many of the older community members who were retired. The majority of these conditions affect adults in middle to old age. An initial observational visit to a Hindu temple was made. The interviewer spoke to the temple leader and was invited to stay for lunch and the different activities. This gave the opportunity to see what kinds of things people were involved with, and it acted as a learning experience for how the interviewer, as a British Indian female, should behave in that environment. As a new face in the community attending places of worship, community members were interested to know who the interviewer was and what the purpose of their visit was. Egharevba (2001) stated from her own experience how offering information about oneself helped to build rapport and break down any hierarchies. Therefore, the interviewer offered information about herself such as information about her family and origins. Community members reciprocated and were keen to learn more about the study. Many of them had not heard of any of the conditions. However, the interviewer was given the opportunity to explain in more detail the kinds of conditions and symptoms. These repeated visits resulted in building relationships with members of the community and community leaders. Community leaders at key Hindu and Sikh temples agreed to try and identify people living with these conditions within the community, and enabled the interviewer to continue integration with community members. On one occasion, the interviewer was asked to speak to the whole group and explain what the study was about, how it was beneficial, and how the researchers would be willing to make home visits. Study leaflets available in English and Gujarati were also left at the places of worship. One home visit was made as a result of a leaflet. However, unfortunately, it transpired that this person did not have any of the conditions being researched. Despite generating a great deal of interest in the study amongst many community members, no one who attended these places of worship had, nor were aware of anyone with the conditions and no participants were recruited through this strategy.

### ***Health fair***

A health event in a temple organised by a sizeable Hindu temple and Sandwell PCT took place in 2009. A similar event held in a mosque, where attendants were able to have their blood pressure measured, was well received and people took an interest in their health (Ghoury, 2005). Consequently, we used the opportunity to set up a stall to promote our study in an attempt to identify and recruit patients with the conditions of interest. Leaflets and study information packs were available in English and Gujarati which were spoken by the interviewer in our study. Unfortunately, no patients with long-term neurological conditions were identified.

### **Media**

In order to promote the study to as wide an audience as possible, we approached a radio station which broadcasts across the West Midlands and has a large Muslim community audience. The aim of the show is to inform listeners of any changes to the health services, and to encourage people to get involved in health consultations. This particular programme is listened to widely in the Muslim community and it was anticipated that it may reach a wider variety of people not visible in other areas of the community. It was thought that a radio slot would offer an alternative to only having written materials to promote the study, and that it would attract people who understood a different language but could not read or write in that language. The programme was conducted in both English and Urdu. The study received a 45 min slot on a community radio station in an information-specific slot. The interviewer in our study was interviewed by the regular radio presenter and explained what the conditions were and the kinds of symptoms that people may experience. This was done because some people may have been unaware of their own diagnosis. A study in Italy reported how a number of carers asked for their relatives not to be fully informed of their Alzheimer's (Pucci et al., 2003). Although there is no evidence to suggest that diagnoses of these neurological conditions are concealed from those with it, there may have been cases where people knew their condition by a different name, but may have recognised the symptoms. The programme did not result in any contacts or enquiries.

Following this, we contacted newspapers targeting Asian and the black communities to promote the study further. Although previous studies reported a lack of recruitment by this method (Mohammadi et al., 2008), we decided it was justified based on having identified no participants by other methods so far. However, despite emailing and writing to editors or health editors, the study was not featured, and consequently this strategy was unsuccessful in recruiting any participants.

### **Voluntary sector**

So far, despite generating interest in the communities, the recruitment strategies had proved unsuccessful yielding no participants. Our next step was to approach condition-specific charities and locally based BME charities, who were informed of the aims of the study and how they could be involved and assist us with recruitment. The locally based BME charities that were contacted were quite unresponsive despite repeated requests for help. They cited that they did not have time to help with research, but this also meant that as gate-keepers to potential participants, there was a group of people we would not be able to access. Rugkåsa and Canvin (2010) highlighted how they also had similar problems when recruiting participants into their study, with some organisations stating that they would not undertake research for 'free'. The charities contacted in our study did not request payment, however they appeared to lose interest as soon as the conditions were mentioned, suggesting that they may not have come across anyone with those conditions.

Condition-specific charities raised awareness of the study. The charities had study information and contact details on their websites, sometimes on the front page, and they also had details of the study in their newsletters. One charity had a register of members who were notified of research, and each member was approached by email or letter informing them of the study. This generated a great deal of interest, with

many people enquiring about the study. Two different approaches were used to recruit BME participants specifically.

Name searching has been successfully used in other areas of research. This method involves searching name lists to identify patients who are potentially eligible for the research in question. Potential participants are then followed up to confirm eligibility and ascertain willingness to participate. Hughes et al. (1995) used the electoral register to identify participants from a BME background. In our study, we used name lists provided by charities to identify potentially eligible patients.

In another part of our research we recruited participants to complete a survey of health-resource use. We also used this opportunity to identify potentially eligible individuals for the BME interviews based on their names. Those who enquired whose name did not appear to be typically white British were asked directly to confirm their ethnicity. Eligible patients were invited to participate in an interview.

Where it was not clear if participants were white British, an email was sent specifically detailing the option of interview if someone was in a different ethnic group from white British. This did not result in any interviews. Some people questioned (by email) the motives for interviewing BME and not white British service users suggesting preferential treatment for non-white British participants. Email responses explaining the reasons for interviewing BME service users were sent. A number of these people replied thanking us for the explanation and confirmed understanding of the strategy.

Information sheets outlining the background and aims of the study, and what participation would entail were provided to individuals identified from name searches, who indicated an interest in participating. No financial incentives were offered. Five interviews were conducted as a direct result of this recruitment strategy.

### ***Recruitment through the NHS***

Other than name searching from disease-specific charity directories, recruitment strategies had generally been unsuccessful. Having exhausted all the methods suggested, and attempted those which have proven successful in the literature; we attempted to recruit participants via the NHS. By this stage, we had received favourable ethical opinion from South Staffordshire Research Ethics Committee. We received permissions to conduct the research from The University Hospital Birmingham NHS Trust Research and Development department.

In addition, the study was adopted onto the NIHR Clinical Research Network portfolio, specifically the Dementias and Neurodegenerative Diseases Research Network (DeNDRoN). This enabled us to identify further sites across the UK where it was thought we may be able to recruit patients through NHS neurology clinics.

### ***BME health link workers***

A number of NHS trusts have policies in place to monitor ethnicity data and have developed strategies to overcome inequalities. Sandwell PCT employed link workers as part of their strategy. The main objective of their role was to raise awareness about health issues that may affect minority groups and to provide information about the types of services that were available. Following favourable ethical approval, we were able to approach link workers to identify patients from the BME community with long-term neurological conditions. Link workers attended

community events and promoted well-being classes and were not in a position to directly identify people with these conditions. Consequently, no one with these conditions was identified using this strategy.

### ***Neurology and condition-specific clinics***

Having been largely unsuccessful in the strategies described previously, we then commenced a more conventional method of recruiting through neurology and condition-specific clinics at the Queen Elizabeth Hospital in Birmingham. It was anticipated that this strategy would yield the greatest number of participants as it enabled us to target condition-specific clinics, somewhat overcoming the barrier of the low prevalence of the conditions being studied. Neurologists based in Birmingham who specialise in some of the conditions, helped to recruit participants into the study. A research nurse attended neurology clinics and neurologists directed eligible participants to the research nurse. The research nurse explained the nature of the study in more detail and provided patient information sheets. Information sheets outlined the background and aims of the study, and what participation would entail. No financial incentives were offered. Participants who were interested in participating were given details of a researcher whom they could contact to ask more questions about the study, and to arrange an interview. As anticipated, this strategy was the most successful strategy in recruiting BME participants into the study and resulted in 10 interviews.

### ***Snowball sampling***

Snowball sampling involves tapping into existing participants' networks in order to identify links with other potential participants. It can be a useful strategy with hidden or hard-to-reach populations, and has been used to investigate drug use, sexuality and HIV (Browne, 2005; Carlson et al., 1994; Ekstrand et al., 1999). Snowball sampling is particularly useful where the characteristics being researched (such as drug use) have a stigma attached and it is effective if participants are part of a network including links to other potential participants (Faugier and Sargeant, 1997). It was anticipated that snowball sampling may be effective in recruiting service users into this study. However, due to the lack of participants recruited in the community, and the extreme rare nature of these conditions, no apparent links materialised over the duration of the study.

### **Discussion**

As anticipated, recruiting through neurology clinics was the most successful recruitment strategy in terms of the numbers recruited. Due to the rare nature of these conditions, a clinic targeted towards these patients presented opportunity to approach patients that is not possible through the community-based strategies employed. This strategy showed high consent rates which suggest that BME service users with these conditions were willing and interested in participating in research. This finding is consistent with Wendler et al. (2006) who looked at all trials that reported invitation rates and consent rates for BME. They found that consent rates in studies was slightly higher in the BME population, and that figures were low because less BME people were invited to participate in research. Voluntary and

community service name searching was also a relatively successful strategy and has been successfully used in other studies (Hughes et al., 1995; Mason et al., 2003). The successful response from the name searching may be seen as surprising as it was anticipated that people from the BME community would be less likely to use these services. However, charities work increasingly closely with health and social care to provide a complete package of care so BME service users may be more inclined to use these services. As early as 2004, a strategic agreement between the voluntary sector and the NHS was developed so that charities would be providing services alongside the NHS to enhance service provision and patient choice (DH, 2004). BME service users could therefore be targeted through mainstream charities in the future.

Other strategies employed were not as successful in terms of participant recruitment for interviews. Although steps were taken to promote understanding in the different communities as suggested by the literature (Mohammadi et al., 2008; Sheikh et al., 2009), no one had heard of the conditions or knew anyone with them. A number of participants mentioned that they had become withdrawn from community events since diagnosis, as had their carers. In many cases this is probably through necessity rather than voluntarily and as such may partially explain the lack of eligible participants identified in the community across a number of our adopted strategies.

Stigma associated with some of the conditions, especially those with a genetic element may also have contributed to difficulties in identifying suitable participants. Historically Huntington's disease was stigmatised with compulsory sterilisation advocated in the US and in Germany (Wexler, 2010). Although the focus has now changed, it is conceivable that the stigma remains in some communities. Stigma may be problematic in cultures where arranged marriages are common, or where religious beliefs lead to service users and carers thinking that the condition is some kind of punishment. A study exploring religious beliefs about epilepsy found that Muslims believed the cause to be 'God's will' and Hindus and Sikhs believed it to be fate (Ismail et al., 2005). Another study found that people sometimes concealed a diagnosis of dementia so that marriage arrangements would not be compromised (Mackenzie, 2006). The contact details for our study were for someone of Indian origin. It is plausible that this may have acted as a barrier to initial contact if stigma was a factor. In one instance, a carer who was recruited through a neurology clinic was initially suspicious of the study. It later emerged that they had concealed their partner's diagnosis from everyone they knew and did not want it revealed to anyone. Although this carer did agree to participate initially, and assurances were given that confidentiality would be maintained at all times, they ultimately cancelled and were not willing to rearrange.

One could argue we were naïve to attempt community-based strategies to recruit patients who in addition to being incredibly rare, are most probably withdrawn from community events through necessity as a result of their condition. We were aware at the outset of our research that we may not be successful in recruiting patients using these methods. However, the DoH who commissioned the study encouraged us to adopt a variety of strategies in order to ensure BME communities were involved in the research. Despite the fact that fewer number of participants were recruited via these strategies, it was felt that immersing in the community enabled the interviewer to obtain an understanding of the communities and enabled familiarity when conducting the interviews with people from similar communities, recruited through more conventional avenues. Furthermore, these methods have been shown

to be effective in other studies, albeit in more prevalent conditions, and the research team felt it was important to test such proven strategies in this disease population.

Snowball sampling did not work primarily because the participants that were interviewed did not have links to other service users with the conditions being researched and therefore a snowballing effect did not materialise. For snowball sampling to be effective, the sample being researched have to have some common link (Faugier & Sargeant, 1997).

Despite us being unsuccessful in recruiting BME service users from many of these strategies, the issue here does not appear to be that BME service users were hard to reach. We suggest that the low prevalence of these conditions, and withdrawal from the community through necessity, resulted in little identification of eligible participants.

We argue this as, although only the more conventional methods of recruiting participants were directly successful in recruiting, the community-based methods were successful in generating interest in our research and consequently argue we were successful in reaching the 'hard to reach'. Based on the responses we received from the community we believe that had individuals been eligible then they would have been willing and interested to take part. For instance, had we been conducting a study into a more common condition such as diabetes, we feel the community-based methods employed in this study would have resulted in successful recruitment. Despite not leading directly to recruitment, there were some benefits in carrying out these methods. For example, evidence has shown that learning to behave appropriately can improve recruitment (Thompson et al., 1996). In our opinion, strategies such as attending places of worship, meeting community leaders and meeting members of different communities, all helped to understand different cultures, how they vary, and how to behave differently depending on an individual's ethnic group and cultural background. This understanding was ultimately valuable when consenting and interviewing participants recruited using the more successful non-community methods.

## **Conclusions**

We conclude that BME participants are not 'hard to reach' but that researchers need to look in the right places to enhance recruitment. The majority of people from BME communities approached were responsive to research and showed an interest. Community-based methods were essentially ineffective in recruiting participants as community members had generally not heard of any of the conditions, and the low prevalence of the conditions meant that it was unlikely that potential participants would be found at various community events or centres.

Future studies should plan ahead and steps should be taken to understand where potential participants are likely to be accessible. Researchers should avoid falling into the trap of automatically assuming commonly used methods to recruit participants from BME backgrounds will be successful in all studies regardless of the aim of the research and the disease group being studied. We used a lot of resource employing the community-based strategies. Researchers need to assess the likelihood of recruitment success from various strategies, taking into account aspects such as disease prevalence and characteristics. For highly prevalent conditions such as hypertension and diabetes, where patients are more likely to remain active in the community, alternative methods of recruitment such as those used here may prove

successful. A more time- and resource-efficient method in a study of very rare conditions would have been solely to concentrate recruitment on specialist neurology clinics in large metropolitan areas with ethnic diversity, which was ultimately where we were successful in recruiting participants to our study.

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### Notes on contributors

Thomas Hoppitt was involved in writing and preparing the article for publication.

Sonal Shah was responsible for carrying out the recruitment strategies and interviews mentioned.

Paramjit Gill, Melanie Calvert, Mel Stewart, Qulsom Fazil, Hardev Pall and Cath Sackley provided input and comment on drafts of the article.

Hardev Pall and Peter Bradburn were responsible for recruiting patients from neurology clinics.

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