# An examination of how to engage migrants in the research process: Building trust through an 'insider' perspective

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Ayesha Ahmed[a]*, T. Vandrevala[b], J. Hendy[a], C. Kelly[c] and A. Ala[c,d,e]

[a]Brunel Business School, Brunel University London, UK; [b] Dept. of Psychology, School of Social and Behavioural Sciences, Kingston University, Kingston-Upon-Thames, UK; [c]Dept. of Gastroenterology and Hepatology, The Royal Surrey County Hospital NHS Foundation Trust Guildford, UK; [d]Dept. of Clinical and Experimental Medicine, Faculty of Health and Medical Sciences, University of Surrey, Guildford, UK; [e]Institute of Liver Studies, King's College Hospital London, UK

*Corresponding author
ayesha_ah@hotmail.com
ayesha.ahmed@brunel.ac.uk

Co-authors

t.vandrevala@kingston.ac.uk
jane.hendy@brunel.ac.uk
clairekelly4@nhs.net
aftabala@nhs.net

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# An examination of how to engage migrants in the research process: Building trust through an 'insider' perspective

**Introduction:** Ensuring all members of society can equally participate in research and the provision of services is a challenging goal. Increased migration has been mirrored by media narratives of social threat, leaving many migrants feeling differentiated and distrustful of mainstream society.

**Objectives:** We explore how migrant and ethnic minority populations can be given the opportunity to participate in the research process. In this work, we iteratively and jointly developed a range of engagement strategies that adopt an 'insider' approach; seeking to eliminate feelings of differentiation and 'otherness' by establishing mutual trust.

**Design:** Recruitment activities were carried out with 8 focus groups of first generation South Asian migrants (the largest ethnic minority group in England). Our analysis was grounded in the broad principles of action research with reflective evaluation of our recruitment process using field observations and relevant focus group data; asking whether we tackled barriers to engagement.

**Results:** Our findings show that 'otherness' can be reduced by establishing a trustworthy researcher-community relationship, but also that this relationship is complex, and needs to acknowledge residual mistrust. Alongside, researchers need to enable opportunities for empowered interaction, with flexible strategies to negotiate potential power divides.

**Conclusions**: We can successfully create opportunities for engagement but there is no 'one size fits all'. Engagement requires tailored approaches that embrace flexibility, and position both engagement and non-engagement as positive and empowered choices.

**Keywords**: engaging migrants; engaging ethnic minorities; research; participation; insider perspective; recruitment, trust

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**Introduction**

In the last three decades, the world has seen mass migration on a global scale, with more than two thirds of international migrants settling in high income countries (United Nations 2016). Unsurprisingly, many countries struggle to cope with the demographic, economic and cultural challenges that this brings. Whilst diversity can enrich the host society; infrastructure and public services become stretched often leading to societal tensions (Swinford 2013).

The challenge of providing health care to migrant communities[1] is compounded by health literacy (Zanchetta and Poureslami 2006), health and cultural beliefs, communication difficulties, institutional resource availability and ethical conflicts (Suphanchaimat et al. 2015, Mengesha et al. 2017). To ensure that needs are met and services efficient, adaptable, accessible and equitable; it is imperative that all users are involved in the health care and the health research process (WHO. 2006).

Literature on engaging populations from immigrant and ethnic minority backgrounds reports a lack of participation in research (Redwood and Gill 2013, George, Duran and Norris 2014). Enquiry on this topic (mainly conducted in the United

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[1] Across Europe, there is lack of consensus about who is a migrant and when they make the transition to just being a member of a distinct ethnic group (Mladovsky, P. (2009). "A framework for analysing migrant health policies in Europe." Health Policy **93**(1): 55-63.). Consequently, terms such as 'migrant' and 'ethnic minority' are neither exclusive nor synonymous, nor do they reflect the diverse conditions and needs, some unique some overlapping, of the people they describe. In this article, we use both terms.

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States) presents a conflicting picture. While some research indicates that racial and ethnic minority groups are significantly less interested in participating as a 'diagnosed volunteer' (Cobb, Singer and Davis 2014 p.4), other research suggests that under representation of ethnic minorities in health research is not because of an unwillingness to participate, but a function of access, with researchers failing to invite them (Wendler et al. 2006). Compared to the white majority, minorities may be less aware of clinical trials and less positive about the use of medical information for research (Brown and Moyer 2010). Inclination to participate has also been linked to study type (for example prevention trials versus treatment trials) (Robinson and Trochim 2007) and study characteristics (i.e. site of the study and time commitments) (Wendler et al. 2006). In England, public attitudes to health research report significantly lower levels of confidence in participation among non-white compared to white respondents (Hunn 2013). Other work (Smart and Harrison 2016) finds no clear evidence that Black Asian and Minority Ethnic (BAME) groups residing in the UK are less willing to engage in research than the white majority.

### *Complexities of engaging migrant communities in research*

The domain of health research is traditionally typified by a relational power differential (Karnieli-Miller, Strier and Pessach 2009) resulting from asymmetries in information and perceived expertise (Safo et al. 2016). This differential is expressed in how research is conducted, reported and funded (Sullivan et al. 2001). For participants from minority groups, these power disparities may be superimposed over a legacy of past mistreatment (Brawley 1998) and colonial control (Minkler 2004); and influence the level of trust they can place in researchers (Gollin et al. 2005). Trust is a multidimensional concept based on positive expectations of respect and fidelity, competence and honesty, transparency and confidentiality (Hall et al. 2001). Often within the research processes

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this trust is implicitly assumed, rather than treated as a complex interaction, needing to be earned and reciprocated (McDonald et al. 2008).

Research volunteers express the need to be 'socially comfortable', respected and appreciated (Morris and Balmer 2006 p.1005). This perception of being 'valued' by researchers is especially important for migrant communities who may be rendered a social threat by medial portrayals (Esses, Medianu and Lawson 2013) or feel misidentified (Hendy et al. 2019); and who may already experience feeling of differentiation and 'otherness' when navigating the healthcare system (Szczepura 2005, Fang et al. 2015). Participants from minority groups need to identify with the research process and consider the process is about them, for them and for people like them. Most people feel comfortable in terms of voicing their opinion in groups they feel aligned to (Greenwood, Ellmers and Holley 2014) and in spaces where they feel enabled (de Freitas and Martin 2015). However, creating this shared 'insider' perspective of common knowledge, identity and experiences (Ogilvie, Burgess-Pinto and Caufield 2008) can be challenging particularly if healthcare researchers belong to a majority culture that is unable to interpret minority health behaviors and choices (Sullivan et al. 2001, Hendy et al. 2019).

'Outsider' researchers with reduced sensitivity to cultural norms and practices, are liable to construct research models on individualistic tendencies that are at odds with the collectivist orientations of the ethnic groups (Marshall and Batten 2004), resulting in inappropriate application of research instruments, methodology and interventions (Sullivan et al. 2001, Mikesell, Bromley and Khodyakov 2013, Bonevski et al. 2014); and in emphasizing the need to fix what may be perceived as incorrect, rather than capitalizing on community strengths and empowering people to come up with their own solutions (Mikesell, Bromley and Khodyakov 2013).

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Moreover, insider-outsider standpoints are not fixed, and researchers can find themselves positioned in multiple ways, based on simultaneous commonalities and differences in personal traits such as ethnicity, gender, age, language, education, social class, religion and experiences (Ryan 2015). Successful engagement demands that researchers negotiate as well as reflect on these standpoints throughout the research process - from conception to recruitment to data collection and interpretation (Kerstetter 2012).

Here, we further our understanding of *how migrant and ethnic minority populations can be given the opportunity to participate in the research process, by developing appropriate engagement strategies that address the potential issues outlined above*. We do this by reporting work done with the South Asian community in England, detailing *how we built trust through an 'insider' perspective.* We *reflect on whether these methods were successful* in providing migrant community members with a context that allows them to freely and comfortably contribute to healthcare research.

**Materials and Methods**

*Study Context*

South Asians are the largest ethnic minority group (>3.5%) in England and Wales (Office for National Statistics 2015). Migrants particularly from Pakistan, India and Bangladesh have a disproportionately high prevalence of Viral Hepatitis B and C (Uddin et al. 2010, Sweeney et al. 2015), contributing to the overall burden of liver related morbidity and mortality in the UK (Williams et al. 2014). However engagement with health services aimed at diagnosing and treating Viral Hepatitis has been less than ideal (Greyson 2012). The wider study in which this work is embedded, funded by the National Institute for Health Research (NIHR), aimed to develop and test a video

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intervention to raise awareness of chronic Viral Hepatitis and promote screening among the South Asian community in England, through participatory research.

Exploration of participation of South Asians in health research has previously identified logistical concerns such as timing and location of research activity, availability of childcare; fears such as trial drug side-effects affecting health; and cultural concerns for e.g. ability to care for family, permissibility of trial drug ingredients and (lack of) respect for cultural/religious sensitivities (particularly regarding female modesty) (Hussain-Gambles, Atkin and Leese 2006, Rooney et al. 2011). An inability to speak and understand English, particularly among women, the older age group and the socioeconomically disadvantaged, is noted to lead to difficulties in comprehending research terms and processes and especially consent forms (Hussain-Gambles, Atkin and Leese 2006). And lack of resources in providing translations of research literature and gender appropriate staffing (Hussain-Gambles, Atkin and Leese 2004, Hussain-Gambles, Atkin and Leese 2006) stymie appropriate opportunities for participation.

Whilst there is no reported ethnic aversion to participating in research among the Indian, Pakistani and Bangladeshi community, and motivations behind research participation are likely to be identical to those of the white majority, mistrust and alienation can arise from negative past experiences of perceived discrimination whilst receiving healthcare (Hussain-Gambles, Atkin and Leese 2006). Researcher behaviour can also be subject to stereotypical views concerning the health beliefs, outlook on preventive health and over-arching male authority of ethnic minorities (Hussain-Gambles, Atkin and Leese 2006), and ethnic groups being 'unreliable' (Sheikh et al. 2009). However, a main hurdle to engagement is thought to be a lack of awareness and

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invitation to take part (Sheikh et al. 2009), particularly among older South Asian

women (Hussain-Gambles, Atkin and Leese 2006).

Keeping these concerns in perspective, we invited the first-generation South

Asian community in Greater London and South-East England to participate in cross

sectional focus groups that would inform the content and the delivery of the educational

video. Focus groups (FGs) do not rely on an ability to read or write, and have been

successfully previously utilized in the UK to assess ethnic minority health needs and

explore issues of a sensitive nature (Culley, Hudson and Rapport 2007).

The research team consisted of two clinicians (C1 an expert hepatologist and C2

a gastroenterology registrar); two health psychologists (HP1 and HP2) and a public

health graduate with a degree in medicine (PM). Three of the five researchers (C1, HP2

and PM) were first generation migrants from the Indian sub-continent.

### *Recruitment and Data Collection*

We employed purposive sampling. Eligibility criteria included being at least 18

years of age; being born in India, Pakistan or Bangladesh and having fluency in English,

Urdu or Hindi. We aimed to include majority faith groups prevalent in South-Asia.

Ethical approval was provided by East of England - Cambridge Central Research Ethics

Committee, HRA, NHS (Reference No. 16/EE/0138).

Recruitment activities were mainly carried out by our three researchers of south

Asian ethnicity (PM, C1 and HP2) and progressed in stages. We initially identified,

through personal contacts and community websites, organizations and figures well

known to the community, who could act as our 'links'. These included primary care

settings e.g. general practitioner (GP) surgeries (n=3); women's centres (n=2); mosque

officials (n=2); leads at the local borough council (n=1) and individuals with established

social outreach (n=2).  They were contacted by phone and email and then in person to explain details of the project and how and why we needed their help. Each of these links was provided with hard and electronic copies of English and/or Urdu versions of participant information sheets[2] as well as flyers for potential focus group dates and a point of contact (PM). Information sheets clearly explained the aims of the study, details of what participation entailed, and assured participants of the voluntary, anonymous and confidential nature of participation.

Community links arranged for us to present the planned research at their associated sites and meet potential members, where we further elaborated on the research process, finalized dates and addressed questions. Researchers proposed that the FGs could be conducted separately for men and women, be run by a researcher of the appropriate gender and could be conducted in an Urdu/Hindi/English/mix[2]. Participants were given a consent form and a demographic questionnaire to complete. For participants not fluent in English, PM provided meaning-based verbal translation and assisted in completing the questionnaire and consent. No payment or re-imbursements were offered except light refreshments and thank-you card.

Based on the literature described, we felt the community would be more familiar and comfortable in talking about health service use and engagement than research participation.  To avoid leading people to create opinion on what research participation

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[2] Hindi and Urdu, although differing in script, share the same basic vocabulary and grammatical principles such that both are widely spoken and understood by people of the Indian subcontinent. Additionally, the majority of Hindi speaking community is fluent in English and so participant information sheets were not translated into Hindi.

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was likely to mean for them, the FGs were aligned to our main topic of hepatitis and testing. A focus group guide was used. The opening question enquired about general health issues of importance in their community. The discussion was then moderated towards viral hepatitis and the community's knowledge about spread, treatment, prevention, screening and associated dis/benefits. We avoided response and social bias by not directly asking members about their opinions and attitude to research. Participants were asked for suggestions that address the challenges associated with testing. Iterative modifications to the guide were made as the work progressed. Following the first FG, a Question & Answer session was included after each group, so participants could raise queries.

Field observations of the interactions between researchers, community-link workers and (potential) participants; were collected ethnographically, mainly by PM (first author) who was of South Asian descent. There was no tool or pre-determined format for recording instant physical notes because we thought this could indicate a distance and a 'data collection-oriented formality' which could undermine the trust which we needed to create. Hence the aim was to note sensitivities, keenness and skepticism in conversations and interactions that could indicate a readiness or reluctance to offer help or participate.

This was noted mentally and intuitively as the first author was embedded as part of the cultural community of the sample, was aware of the context in which responses were given, could identify with emotion and sentiment expressed, but at the same time did not wish to influence responses and interactions. Observations and reflections were later jotted as personal notes and memos – tempered with an analysis of potential themes and sources of (dis)engagement (including at times exact phrases and tones of conversation and at others brief impressions) for discussion with research team.

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*Analysis*

Our analysis, grounded in the principles of action research (McNiff 2002), is mainly a reflective evaluation of our recruitment process and whether we tackled barriers to engaging migrant communities as highlighted in literature. The research team was de-briefed after each field visit-both by email and through face-to-face meetings. Concerns and interactions from the field experiences were raised and strategies for adapting a methodology aimed at recruitment and engagement explored. For example, considerable discussion time was given to the idea of how to provide (expected) benefit to participants without altering the staged design of the project and resulted in offering the Question and Answer sessions at the end of each FG. This formed the basis of our research reflection exercise, when we revisited first author experiences in interacting with people and clarified and queried research and recruitment decisions.

The team reviewed field experiences and FG data in tandem. FGs were audio recorded digitally and transcribed verbatim. Transcripts were analyzed using NVivo 11, progressing from a detailed, empirical reading of the data towards greater abstraction. FG transcripts were read with the aim of picking out information that conveyed points on engagement and disengagement as lower order themes. These were grouped together to signify higher order themes summarising engagement behaviour. We followed an interpretative textual strategy as evident from our combining findings from field observations and FGs into one smooth thematically focused text.

Our processes were aligned to Lincoln and Guba's (1985) criteria for demonstrating rigour in qualitative research. The research team had native and migrant members so personal biases could be kept to minimum, discussions could be challenged and consensus reached. We included in our FG a later sample of younger south Asian men to broaden representation. We carried out triangulation by supporting field

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observations with relevant FG data and the researchers' own knowledge of migration

linked issues, including verbatim text where possible, and a comprehensive literature

review of the topic (Kelly et al. 2018). Further, we formed a patient and public

involvement panel with whom we shared theme development and received feedback.

**Results**

We ran 8 FGs, (min n=3, max n=11). A total of 26 men and 27 women in the age range

25 – 61+ years took part (see Table 1 & Table 2). Participants were of mainly Pakistani

and Indian origin, from different faiths, education and socioeconomic backgrounds; and

living in the UK for a number of years ranging from 1 to more than 50 years. Focus

groups ran for 40 to 75 minutes. Recruitment and focus groups spanned a period of 10-

12 weeks, except the final focus group which was arranged later after review of

collected data.

*Insert Table 1 and Table 2 here*

Based on our field observations and supplemented by relevant FG data, we

outline seven themes that address potential engagement/ disengagement issues and

facilitate an insider approach to participation (Table 3).  For ease of understanding we

have presented themes sequentially, although many findings were iterative, overlapping,

and recursive.

*Insert Table 3 here*

***Initial engagement strategies for building trust***

*Enlisting support from Community Links*

Our first point of engagement was with individuals from a South Asian migrant

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background, who were embedded, respected and trusted within the community. These included health support workers, language teachers, religious figures, general practitioners and social contacts of the recruiting researchers. We hoped an approach mediated by these links, though time consuming would add to our credibility.

The community links had a wealth of service experience and community 'know how'. These 'gatekeepers' can be protective, selective and potentially wary of researchers (Sanghera and Thapar-Björkert 2008). In our study some gatekeepers had been approached before by researchers asking for access to the community. This had resulted in both positive and negative experiences. The two women's support workers complained about the 'attitude' and pre-supposed ideas researchers had previously expressed.

In the hope of dispelling residual negativity, we used the preliminary meetings to explain the project and provide our motivations. We hoped that the presence of researchers of similar migrant backgrounds would help break down barriers and power differentials. We attempted to remain open to queries and clearly convey our scientific and social premise for involving the local South Asian population; speaking to community members in their preferred language and emphasizing that we were asking for help in raising awareness of Viral Hepatitis for 'their-our' people. Community links helped to either arrange focus groups at their sites, referred us to other sites or helped publicise the study.

*Getting to know the community in a non-research environment*

Community links were willing to introduce us to prospective participants and provided a useful context on how to establish trust but were cautious about giving guarantees. It was suggested that we get to know people less formally at first, in a non-research

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environment through community events. We needed to be open and flexible, and share

our personal background, our ethnic origin and motivations. In deciding to employ

South Asian researchers with cultural and linguistic proficiency, we aimed to enable

engagement on informal 'familiar' terms and create 'oneness'; a social concordance that

put potential participants at ease.

One support worker was particularly keen on having service users from the

organisation meet with all female members of the research team together, irrespective of

their ethnic origin. PM (South Asian) and C2 (White British) attended a local English

language lesson, getting to know women practising their conversation skills. At the end

of the session we explained the research project and handed out information sheets. We

noted that the women expressed feeling positive about seeing female researchers from

different ethnicities working together.

### Reducing fears connected to participation

*Explaining research process/consent to new participants*

Early interactions highlighted that for many research participation was new, and they

had concerns regarding consent and the use of collected data. It was important that

ample time was taken to explain, in person, not just the study and its commitments, but

the research process as well as aims of consent. We encouraged people to take the time

to really consider participation, to discuss this with fellow community and family

members, and raise any queries for clarification. We aimed not to pressurize but to

actively encourage people to explore turning us down.

The utility of face-to-face explanations over lengthy study information sheets, in

recruiting ethnic minority groups has been acknowledged (MacNeill et al. 2013),

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although this may be more a function of socioeconomic status than ethnicity (Rugkasa and Canvin 2011). In our experience, information leaflets, even the translated ones were only a supportive resource – to reinforce credibility. Most people were reliant on verbal interaction with the research team.

I am not in favour of pamphlets (referring to information sheets) as some people can read and write while others can't. If I receive a pamphlet, I will not show it to anyone and put it in the bin right away. [Male, retired]

*Reassuring data confidentiality*

Similar to previous researchers working with BAME groups (Rugkasa and Canvin 2011), our community links pointed out that some women felt uneasy about being recorded, based on a mistrust of authority and institutions. This appeared more salient for those not fluent in English. We strongly emphasised that our recordings would only use first names, that transcripts would be anonymised, recordings would remain with research institutions and only be heard by the study team, some of whom they had met. We stressed the voluntary nature of participation and encouraged people to withdraw (now or at any point) if they felt uncomfortable. Although some women chose not to participate, others were reassured:

I see, yes okay…its fine. Now that you are talking to us it feels right, I like it. You are asking about the illness, nothing wrong that you are discussing…I find it very right. The questions that you have asked me I find them correct. [Female, 40s]

*Countering stigma linked to participation in disease specific research*

Migrant and ethnic minority groups can experience higher disease related social stigma (Loutfy et al. 2012, Sweeney et al. 2015) and many within the South Asian community

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may choose not to share disease diagnosis; as this can have negative implications for the wider family, and reduce marital prospects, particularly for women (Rooney et al. 2011). A surprising finding we had not anticipated, was that illness related stigma could also hinder people from participating, or even consider participating in disease-specific research (Rooney et al. 2011). As one senior female community figure commented:

…you know how one thing leads to another in the community…oh so and so is going for the test, maybe she has this illness. So if you can keep it on a very low level so that not many people get to know. [Female, 60+yrs]

We actively addressed these concerns as they arose and highlighted the confidential nature of screening. The focus groups discussed the illness largely in a non-judgemental way and explored perceptions of burden and how these could be addressed in a culturally considerate manner. Many participants noted feeling empowered by knowledge of the illness. Some people shared their experiences of knowing someone in the community with Viral Hepatitis and three participants gave a personal history of having a hepatitis-like-illness.

*Local endorsement and insider context*

Local endorsement as opposed to passive recruitment are effective in increasing research participation in collective communities (McLean and Campbell 2003). In our experience, many participants were invited by someone known to and trusted by them. Many participants encouraged other family and friends to participate, with this context being reported as a significant reason they agreed to attend and subsequently found participation to be useful:

This discussion that we're having…If we'd have been invited by you, I wouldn't have

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come…Only, only because, say, for example, it's a close friend associated with this I have

come. Otherwise I don't care about this discussion to be honest…Definitely it was a very good

discussion actually, enjoyable discussion! [Male, 30s]


### *Facilitating participation from all*

#### *Overcoming opportunity costs*

As outlined, family commitments and economic reasons are conflicts to research

participation among South Asian migrants. To mitigate this, we arranged focus group

sessions at times suited to people and at places familiar and convenient for them. For

example, we arranged sessions during school hours for mothers, or weekends for

working members; and in local community centres or at a local residence. On other

occasions, we ran sessions at times when people were already visiting recruiting sites

for social or religious purposes.


#### *Addressing communication*

Participants suggested that for those not fluent in their host country's language, health

interactions and research participation are challenging with communication difficulties

more acutely experienced by recently arrived migrants

> …lots of people feel shy because of the language. Yes, they feel shy and they don't try
> to get information because they are not understood at the surgeries or not explained. Language
> is a very important factor. [Female, 30s]

Additionally, if serious illness is not openly talked about, migrants may find it

challenging to participate in research exploring it (Lee, Sulaiman-Hill and Thompson

2014). Providing 'cultural safety' in language (Ogilvie, Burgess-Pinto and Caufield

2008), ensures minorities are not excluded and reduces feeling of otherness. The

expertise in Urdu and Hindi within the research team enabled us to recruit and conduct

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focus groups in these native languages, which was particularly salient while engaging

with women and older migrants:

> Particularly those women who come from the villages…are extremely shy. Let alone
> English, they hesitate in getting information even if it is given in their own language. [Female,
> 30s]

> … And the very important thing that when you arrange a meeting with the older people,
> make sure it is in Urdu and Punjabi…Sometimes, they feel hesitant that if they aren't fluent in
> English, they would not speak. If you talk to people in their language, you will get more
> information. [Male, 50s]

Participants stressed the importance of using accessible language and removing

medical jargon.

> You have to go slow and steady. If you are a doctor, then you must have the skill to be
> able to explain things to common man…Praise be to God, doctors are very learned, but many a
> times they don't come down to a level to which general public has knowledge or ability to
> think, or to absorb. So, it's not just enough to say to them…they have to absorb it and to be able
> to explain its main points at home to family and children, or friends. [Female, 60+yrs]

Therefore, our FGs began with general questions and we kept the discussion as

non-medical as possible, at a pace that was easy for participants. For some women, this

was the first opportunity to comfortably speak to a medically trained professional (PM)

in the community and was positively appreciated:

> …Like in the community people like you can come and help us. [Female, 40s]

### *Making research culturally compatible*

Recruitment activities were carried out by researchers of a South Asian background and

we remained cognizant of cultural values and customs. This included gestures such as

greeting/addressing older members, and members of the opposite gender in a culturally

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appropriate way, suitably acknowledging the role and contribution of respected

community figures and presenting the work in a relevant manner. A few of our FGs

were held in the Islamic month of Ramadan and we made sure FG timings did not

interfere with worship routines.

Trust begins with familiarity (Dwyer and Buckle 2009), and having an 'insider'

researcher was important. All groups except one (with younger more educated men-see

below) were moderated by culturally matched researchers. This allowed participants to

raise and discuss culture-linked issues with a common reference point.  For instance,

during a discussion around raising awareness of disease transmission, a female

participant shared the frustration she experienced when trying to educate members of

the community

In our... in our ethnicity, if you try and explain to them...they are so strict to it. Oh, I

don't want to listen. You might be wrong. I'm always right. That's fine, but people are trying to

say something, that this is the right thing to do. They don't listen. They think, oh, well, I know

everything. [Female, 30s]

We noted participants felt reassured that their encounters were shared and

provided supporting comments such as "as you know". This kinship and joint cultural

knowledge was important in creating a relaxed atmosphere and the 'insider' context we

were aiming for.

In many Asian communities, single gender gatherings are more likely to lead to

comfortable interaction, forming and sharing opinions and debate, particularly when it

comes to socially sensitive topics (Culley, Hudson and Rapport 2007). Where

appropriate, we provided gender separation especially respecting the older Muslim

participants. We anticipated that women would be more inclined towards interactions

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with female researchers

> Some ladies should be coming, because we cannot tell the men…so better to talk to ladies…However much we can share with you, we cannot share with a male…there should be ladies for ladies. [Female, 40s]

South Asian women do not always feel that they have a voice in their community, so the presence of women (PM, HP2) from their ethnic migrant background, who also needed to 'negotiate' British society was imperative in bringing familiarity to an otherwise odd and rather formal social situation.  We made an exception to building this rapport within our final focus group. We realised we needed to capture the views of younger, educated first-generation men - whose contribution had thus far been scarce. This group was acculturated to Western norms so although recruitment was done through Indian 'links', the group was run by a white British researcher. Our awareness of the lack of input from this group came late in the project work, and team member availabilities meant we had to use a white British researcher or risk the work not being done. On reflection, we felt this was the correct decision as the interactions were open and went well.

### *Reciprocating participation*

*Stressing all/any contribution will be of value*

At times community members can refrain from coming forward thinking they have nothing significant to offer to a research discussion (de Freitas and Martin 2015). In our introductory meetings, some people expressed the concern that due to their limited knowledge of hepatitis, their participation would be 'of little use'.

> I don't have any understanding…That what is it. [Female, 30s]

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We gave constant feedback that 'correct' answers or 'knowledge' was not needed or expected. All and any contribution would be of value. We reiterated our commitment to highlighting due credit and acknowledging all forms of contribution in any publications and disseminations.

*Requiting participation*

 Reciprocity is imperative, and the team supported the community in running a health session on a topic unrelated to viral hepatitis, demonstrating our commitment to partnering with the community and increasing knowledge. It brought in a significantly larger number of the local community and provided new contacts for recruitment in later phases of the project.

Some community members expected that participation would aid and educate them about Viral Hepatitis and they would be immediately tested for the disease.

Do you do the testings, or we have to make an appointment? [Male, 60+yrs]

Although we had clearly communicated that this was not part of the current phase of the study, we felt that it was crucial for participants to feel they had gained by participating. To meet these expectations, we offered participants informal question and answers sessions at the end of the focus groups, and signposted websites providing further information.

**Giving accurate representation and voice to participants**

*Conveying meaning-based translations in transcripts*

Focus groups were translated and transcribed into English through professional companies. PM verified the transcripts against audio recordings, to check meanings

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were context based rather than literal translations. This was done to ensure participant

comments were represented as they had intended them to be understood.

*Empowering participants to share perceptions on engagement in health based
interactions*

Research has shown that socioeconomic status and life struggles can influence

awareness of and participation in research (van der Velde, Williamson and Ogilvie

2009). Our recruitment activities aimed to benefit people from varying educational

backgrounds and length of residency in the UK.

30,40,50 years we have been living here. I think, like you said before that the NHS has

funds, but those funds aren't spent on our community. [Male, 50s]

Some suggested that racism and discrimination were factors that undermined

their inclination to engage.

Yeah, but the only thing, in the British society, the discrimination - the Asian got it,

don't worry about it. [Male, 60+yrs]

Others suggested that lack of participation in research stemmed from fear within

the community and reluctance to think about health issues.

I don't know there is some kind of fear, I think, we have as a community, we don't go

into these things. we are just so busy with our own lives…And we are just gonna be thinking it

is the end of the world if we do something else. You are lucky that we have 9-10 people sitting

here today. [Male, 50s]

These voices affirm that attitudes to engagement are complex and influenced by

multiple lived (healthcare) experiences. They reflect the success of our trust building in

helping community members to speak about these concerns.

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*Aiming for long-term relationships*

Community members suggested that previous researchers had failed to acknowledge community participation and failed to provide an update on project outcomes. To avoid this 'in and out' approach we invited community links to project meetings and to a patient and public involvement panel to discuss progress, to obtain input on further phases of the study and to create a long-term relationship. We aimed to build a sense of positive engagement, personal investment and empowerment. Focus group discussions informed the content of the research instruments for the following phases. We have since returned to the community with the completed educational film (the wider aim of the work) to collect insight and feedback on whether our intervention is 'fit for purpose'.

**Discussion**

This study furthers our understanding of how migrant and ethnic minority populations can be offered the opportunity to participate in the research process, by developing appropriate engagement strategies through building an 'insider' perspective. Here, we discuss how successful these 'insider' methods were in providing a context that allows migrants to freely and comfortably contribute to healthcare research.

Firstly, our findings highlight that a fundamental step in reducing feelings of otherness within minority groups is establishing a trustworthy researcher-community relationship. This is a complex and progressive endeavour, facilitated not just by the support of trusted community link-figures but by researcher attitudes, integrity, congruence and responsiveness to community needs and preferences, all of which help achieve a connectedness above and beyond tokenistic racial matching (Fryer et al. 2016). Shared experiences provide an 'acceptance' and gateway that would otherwise

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be less likely (Dwyer and Buckle 2009). As others note, commitment is reliant on informal referrals (Rugkasa and Canvin 2011) and public interaction by researchers, the endorsement of which goes some way in reducing power differentials, particularly around sensitive health concerns (Waheed et al. 2015). The importance of remaining non-judgmental while engaging with sensitive issues is key to creating trust. The position of our recruiting researchers in being 'inside enough' (due to common ethnicity, gender and more importantly shared immigrant background) and yet having some professional distance allowed participants to share views frankly. This combination of a connection combined with professionalism, creates less fear of judgement or gossip, issues associated with totally immersed community insiders (Ryan, Kofman and Aaron 2011). Having insider knowledge of the cultural context of the research cannot be underestimated, nevertheless, having non-South Asian White British members on the team brought outsider 'objectivity' to the research process, and particularly the analysis which was continually overseen by HP1.

Secondly, our findings illustrate how trust alone is not sufficient. Residual discrimination and misgivings need to be acknowledged and tackled if researchers want to truly engage, particularly when researching a condition that may be stigmatized in the community and carries negative social consequences. Researchers must provide suitable opportunities for participation and ensure that participants feel empowered. To mitigate this, our encounters re-affirm the importance of the boundary-spanning role played by bicultural researchers (Ogilvie, Burgess-Pinto and Caufield 2008, Lee, Sulaiman-Hill and Thompson 2014). Boundary –spanning, in terms of belonging to host country but also in sharing cultural and migrant backgrounds makes communication less intimidating and more empathetic, particularly for women participants. Bicultural researchers consequently aid potential participants to negotiate power divides, raise

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queries and understand the premise of the research.

Thirdly, our results show that engagement strategies need to be premediated (considered prior to the research process), reactive (considered during the research and on completion of the study) and adaptable. The importance of remaining flexible and nimble by adapting research to the community's wishes when engaging with minority groups is highly relevant (Shelton and Rianon 2004). Each of the outlined themes is a crucial ingredient in achieving the goal of engagement. The specifics of the approach taken will depend on the context of the research question and its target community.

Efforts were made to keep consent as informed and unhurried as possible, but we are limited in saying if the presence of an 'insider' researcher proved to be a facilitator of informed decision making or whether it harnessed a 'blind trust', causing a level of obligation (Hussain-Gambles 2004). Reassuringly, not everyone we approached participated. Further research needs to be done to explore the role that elaborate study materials and written versus verbal consent play in encouraging or discouraging research participation among minority ethnic groups.

While we were successful in getting women to participate and articulate opinions, we were unable to recruit a large number of participants giving a personal history of hepatitis. This only points out the extra work that even 'insiders' would be required to do to combat participation related stigma and persuade people to come forward.

Additionally, we must point out that engaging participants in a longer clinical trial, with multiple follow ups, would require more intensive and ongoing groundwork. We would further caution researchers not to use our findings as a recipe for success or to assume minority groups are a single broad ethnic group. There is no one size fits all,

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the research needs to consider the country of origin, migration status, acculturation into the host society, religion, educational levels, socio-economic position and the cultural values and norms that exists within differential groups.  There is diversity of interest both within and between ethnic communities, and it is likely that other BAME groups and those with immigrant parents but themselves born and raised in the UK may view research participation differently and so require very different and tailored approaches (Waheed et al. 2015).

## *Conclusion*

The openness and flexibility of the research team, paying careful attention to community priorities and sensitivities, to acknowledge differences and positively address these was vital to engagement. We remained transparent in our communication (McLean and Campbell 2003) particularly about exactly what participants were not signing up for and offered suitable return on participant contribution. We stressed our main goal of raising awareness within the wider community through participant suggestions. Overall, the feedback from participants and the community leaders was unanimously positive.

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## Declaration of interest

The authors declare that there is no conflict of interest.

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**References**

Bonevski, B., M. Randell, C. Paul, K. Chapman, L. Twyman, J. Bryant, I. Brozek and C. Hughes (2014). "Reaching the hard-to-reach: a systematic review of strategies for improving health and medical research with socially disadvantaged groups." <u>BMC Medical Research Methodology</u> **14**(1): 42.

Brawley, O. W. (1998). "The study of untreated syphilis in the negro male." <u>Int J Radiat Oncol Biol Phys</u> **40**(1): 5-8.

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." <u>Ethn Health</u> **15**(3): 223-236.

Cobb, E. M., D. C. Singer and M. M. Davis (2014). "Public interest in medical research participation: differences by volunteer status and study type." <u>Clin Transl Sci</u> **7**(2): 145-149.

Culley, L., N. Hudson and F. Rapport (2007). "Using focus groups with minority ethnic communities: Researching infertility in British South Asian communities." <u>Qual Health Res</u> **17**(1): 102-112.

de Freitas, C. and G. Martin (2015). "Inclusive public participation in health: Policy, practice and theoretical contributions to promote the involvement of marginalised groups in healthcare." <u>Soc Sci Med</u> **135**: 31-39.

Dwyer, S. C. and J. L. Buckle (2009). "The Space Between: On Being an Insider-Outsider in Qualitative Research." <u>International Journal of Qualitative Methods</u> **8**(1): 54-63.

Esses, V. M., S. Medianu and A. S. Lawson (2013). "Uncertainty, Threat, and the Role of the Media in Promoting the Dehumanization of Immigrants and Refugees." <u>Journal of Social Issues</u> **69**(3): 518-536.

Fang, M. L., J. Sixsmith, R. Lawthom, I. Mountian and A. Shahrin (2015). "Experiencing 'pathologized presence and normalized absence'; understanding health related experiences and access to health care among Iraqi and Somali asylum seekers, refugees and persons without legal status." <u>BMC Public Health</u> **15**: 923.

Fryer, C. S., S. R. Passmore, R. C. Maietta, J. Petruzzelli, E. Casper, N. A. Brown, J. Butler, M. A. Garza, S. B. Thomas and S. C. Quinn (2016). "The Symbolic Value and Limitations of Racial Concordance in Minority Research Engagement." <u>Qualitative health research</u> **26**(6): 830-841.

George, S., N. Duran and K. Norris (2014). "A systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders." <u>Am J Public Health</u> **104**(2): e16-31.

Gollin, L. X., R. C. Harrigan, J. Perez, D. Easa and J. L. Calderón (2005). "Improving Hawaiian and Filipino Involvement in Clinical Research Opportunities: Qualitative

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Findings from Hawai'i." Ethnicity & disease **15**(4 Suppl 5): S5-111-119.

Greenwood, N., T. Ellmers and J. Holley (2014). "The influence of ethnic group composition on focus group discussions." BMC Medical Research Methodology **14**(1): 107.

Greyson, O. (2012) "Hepatitis C awareness among South Asians." Nursing Times.

Hall, M. A., E. Dugan, B. Zheng and A. K. Mishra (2001). "Trust in physicians and medical institutions: what is it, can it be measured, and does it matter?" Milbank Q **79**(4): 613-639, v.

Hendy, J., T. Vandrevala, A. Ahmed, C. Kelly, L. Gray and A. Ala (2019). "Feeling misidentified: Understanding migrant's readiness to engage in health care screening." Social Science & Medicine **237**: 112481.

Hunn, A. (2013). Survey of the general public: attitudes towards health research, HRA, NHS.

Hussain-Gambles, M. (2004). "South Asian patients' views and experiences of clinical trial participation." Fam Pract **21**(6): 636-642.

Hussain-Gambles, M., K. Atkin and B. Leese (2004). "Why ethnic minority groups are under-represented in clinical trials: a review of the literature." Health Soc Care Community **12**(5): 382-388.

Hussain-Gambles, M., K. Atkin and B. Leese (2006). "South Asian participation in clinical trials: the views of lay people and health professionals." Health Policy **77**(2): 149-165.

Karnieli-Miller, O., R. Strier and L. Pessach (2009). "Power relations in qualitative research." Qual Health Res **19**(2): 279-289.

Kelly, C., M. Pericleous, J. Hendy, S. de Lusignan, A. Ahmed, T. Vandrevala and A. Ala (2018). "Interventions to improve the uptake of screening across a range of conditions in Ethnic Minority Groups: a systematic review." International Journal of Clinical Practice **72**(8): e13202.

Kerstetter, K. (2012). "Insider, Outsider, Or Somewhere In Between: The Impact Of Researchers' Identities On The Community-Based Research Process." Journal of Rural Social Sciences **27**(2): 99-117.

Lee, S. K., C. R. Sulaiman-Hill and S. C. Thompson (2014). "Overcoming language barriers in community-based research with refugee and migrant populations: options for using bilingual workers." BMC International Health and Human Rights **14**(1): 11.

Lincoln, Y. S. and E. G. Guba (1985). Naturalistic Inquiry. Beverly Hils, CA, SAGE.

Loutfy, M. R., C. H. Logie, Y. Zhang, S. L. Blitz, S. L. Margolese, W. E. Tharao, S. B. Rourke, S. Rueda and J. M. Raboud (2012). "Gender and Ethnicity Differences in HIV-related Stigma Experienced by People Living with HIV in Ontario, Canada." PLoS ONE **7**(12): e48168.

28

MacNeill, V., C. Nwokoro, C. Griffiths, J. Grigg and C. Seale (2013). "Recruiting ethnic minority participants to a clinical trial: a qualitative study." <u>BMJ Open</u> **3**(4).

Marshall, A. and S. Batten (2004) "Researching Across Cultures: Issues of Ethics and Power." <u>Forum Qualitative Sozialforschung / Forum: Qualitative Social Research</u> **5**, Art 39.

McDonald, M., A. Townsend, S. M. Cox, N. D. Paterson and D. Lafreniere (2008). "Trust in health research relationships: accounts of human subjects." <u>J Empir Res Hum Res Ethics</u> **3**(4): 35-47.

McLean, C. A. and C. M. Campbell (2003). "Locating research informants in a multi-ethnic community: ethnic identities, social networks and recruitment methods." <u>Ethn Health</u> **8**(1): 41-61.

McNiff, J. (2002). Action research for professional development: Concise advice for new action researchers.

Mengesha, Z. B., J. Perz, T. Dune and J. Ussher (2017). "Refugee and migrant women's engagement with sexual and reproductive health care in Australia: A socio-ecological analysis of health care professional perspectives." <u>PLoS One</u> **12**(7): e0181421.

Mikesell, L., E. Bromley and D. Khodyakov (2013). "Ethical Community-Engaged Research: A Literature Review." <u>American journal of public health</u> **103**(12): e7-e14.

Minkler, M. (2004). "Ethical challenges for the "outside" researcher in community-based participatory research." <u>Health Educ Behav</u> **31**(6): 684-697.

Mladovsky, P. (2009). "A framework for analysing migrant health policies in Europe." <u>Health Policy</u> **93**(1): 55-63.

Morris, N. and B. Balmer (2006). "Volunteer human subjects' understandings of their participation in a biomedical research experiment." <u>Soc Sci Med</u> **62**(4): 998-1008.

Office for National Statistics (2015). 2011 Census Analysis: Ethnicity and Religion of the Non-UK Born Population in England and Wales, Home Office.

Ogilvie, L. D., E. Burgess-Pinto and C. Caufield (2008). "Challenges and approaches to newcomer health research." <u>J Transcult Nurs</u> **19**(1): 64-73.

Redwood, S. and P. S. Gill (2013). "Under-representation of minority ethnic groups in research — call for action." <u>The British Journal of General Practice</u> **63**(612): 342-343.

Robinson, J. M. and W. M. 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." <u>Ethn Health</u> **12**(5): 521-539.

Rooney, L. K., R. Bhopal, L. Halani, M. L. Levy, M. R. Partridge, G. Netuveli, J. Car, C. Griffiths, J. Atkinson, G. Lindsay and A. Sheikh (2011). "Promoting recruitment of minority ethnic groups into research: qualitative study exploring the views of South Asian people with asthma." <u>J Public Health (Oxf)</u> **33**(4): 604-615.

29

Rugkasa, J. and K. Canvin (2011). "Researching mental health in minority ethnic communities: reflections on recruitment." Qual Health Res **21**(1): 132-143.

Ryan, L. (2015). ""Inside" and "Outside" of What or Where? Researching Migration Through Multi-Positionalities." 2015 **16**(2).

Ryan, L., E. Kofman and P. Aaron (2011). "Insiders and outsiders: working with peer researchers in researching Muslim communities." Int J Soc Res Methodol **14**.

Safo, S., C. Cunningham, A. Beckman, L. Haughton and J. L. Starrels (2016). ""A place at the table:" a qualitative analysis of community board members' experiences with academic HIV/AIDS research." BMC Med Res Methodol **16**: 80.

Sanghera, G. S. and S. Thapar-Björkert (2008). "Methodological dilemmas: gatekeepers and positionality in Bradford." Ethnic and Racial Studies **31**(3): 543-562.

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." PLoS Med **6**(10): e1000148.

Shelton, A. J. and N. J. Rianon (2004). "Recruiting participants from a community of Bangladeshi immigrants for a study of spousal abuse: an appropriate cultural approach." Qual Health Res **14**(3): 369-380.

Smart, A. and E. Harrison (2016). "The under-representation of minority ethnic groups in UK medical research." Ethn Health: 1-18.

Sullivan, M., A. Kone, K. D. Senturia, N. J. Chrisman, S. J. Ciske and J. W. Krieger (2001). "Researcher and researched--community perspectives: toward bridging the gap." Health Educ Behav **28**(2): 130-149.

Suphanchaimat, R., K. Kantamaturapoj, W. Putthasri and P. Prakongsai (2015). "Challenges in the provision of healthcare services for migrants: a systematic review through providers' lens." BMC Health Services Research **15**(1): 390.

Sweeney, L., J. A. Owiti, A. Beharry, K. Bhui, J. Gomes, G. R. Foster and T. Greenhalgh (2015). "Informing the design of a national screening and treatment programme for chronic viral hepatitis in primary care: qualitative study of at-risk immigrant communities and healthcare professionals." BMC Health Services Research **15**(1): 97.

Swinford, S. (2013) "Immigrants create overcrowding and fuel tensions, report finds." The Telegraph.

Szczepura, A. (2005). "Access to health care for ethnic minority populations." Postgraduate Medical Journal **81**(953): 141-147.

Uddin, G., D. Shoeb, S. Solaiman, R. Marley, C. Gore, M. Ramsay, R. Harris, I. Ushiro-Lumb, S. Moreea, S. Alam, H. C. Thomas, S. Khan, B. Watt, R. N. Pugh, S. Ramaiah, R. Jervis, A. Hughes, S. Singhal, S. Cameron, W. F. Carman and G. R. Foster (2010). "Prevalence of chronic viral hepatitis in people of south Asian ethnicity living in England: the prevalence cannot necessarily be predicted from the prevalence in the

country of origin." <u>J Viral Hepat</u> **17**(5): 327-335.

United Nations (2016). *International Migration Report 2015: Highlights (ST/ESA/SER.A/375)*.

van der Velde, J., D. L. Williamson and L. D. Ogilvie (2009). "Participatory action research: practical strategies for actively engaging and maintaining participation in immigrant and refugee communities." <u>Qual Health Res</u> **19**(9): 1293-1302.

Waheed, W., A. Hughes-Morley, A. Woodham, G. Allen and P. Bower (2015). "Overcoming barriers to recruiting ethnic minorities to mental health research: a typology of recruitment strategies." <u>BMC Psychiatry</u> **15**(1): 101.

Wendler, D., R. Kington, J. Madans, G. V. 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?" <u>PLoS Medicine</u> **3**(2): e19.

WHO. (2006). Ninth futures forum on health systems governance and public participation. Copenhagen, WHO.

Williams, R., R. Aspinall, M. Bellis, G. Camps-Walsh, M. Cramp, A. Dhawan, J. Ferguson, D. Forton, G. Foster, I. Gilmore, M. Hickman, M. Hudson, D. Kelly, A. Langford, M. Lombard, L. Longworth, N. Martin, K. Moriarty, P. Newsome, J. O'Grady, R. Pryke, H. Rutter, S. Ryder, N. Sheron and T. Smith (2014). "Addressing liver disease in the UK: a blueprint for attaining excellence in health care and reducing premature mortality from lifestyle issues of excess consumption of alcohol, obesity, and viral hepatitis." <u>Lancet</u> **384**(9958): 1953-1997.

Zanchetta, M. S. and I. M. Poureslami (2006). "Health literacy within the reality of immigrants' culture and language." <u>Can J Public Health</u> **97 Suppl 2**: S26-30.

Table 1. Details of focus groups (n=8)

| Focus Groups | Women | | | | Men | | | Mixed |
|---|---|---|---|---|---|---|---|---|
| Recruited from | Women's Support Centre 1 | Community Centre & Mosque | Social Networks | Social Networks & Women's Support Centre 2 | Mosque | Mosque | Social Networks | GP Surgery |
| Location | Support Centre | Mosque | Local Residence | Support Centre | Mosque | Mosque | Local Residence | GP Surgery |
| Participant numbers | 3 | 4 | 8 | 11 | 9 | 4 | 7 | 7 |
| Length of stay in UK (years) Min Max Average | 1 10 4.67 | 26 47 38.5 | 5 13 9.875 | 4 48 30.73 | 12 50 37.125 | 50 54 51 | 7.75 13.5 11.04 | 20 50 38.93 |
| Predominant Faith | Islam | Islam | Hinduism | Islam | Islam | Islam | Hinduism | Sikhism |
| Language | Urdu | Predominantly Urdu | Predominantly English | Urdu-English | Urdu-English | Urdu-English | English | Hindi-English |

Table 2. Sample characteristics of focus group participants

| | Women (n=27) | Men (n=26) |
|---|---|---|
| **Age (yrs.)** | | |
| 18-24 | 0 | 0 |
| 25-40 | 12 | 5 |
| 41-50 | 4 | 3 |
| 51-60 | 2 | 5 |
| ≥61 | 9 | 13 |
| **Birth place** | | |
| Pakistan | 12 | 13 |
| India | 12 | 10 |
| Bangladesh | 0 | 1 |
| Other | 3 | 2 |
| **Education** | | |
| No formal education | 1 | 0 |
| School | 5 | 7 |
| College | 2 | 7 |
| University | 12 | 5 |
| Professional | 5 | 3 |
| Not disclosed | 2 | 4 |
| **Faith** | | |
| Islam | 17 | 13 |
| Hinduism | 7 | 6 |
| Sikhism | 1 | 4 |
| R. Catholic | 1 | 0 |
| Jainism | 0 | 1 |
| Buddhism | 1 | 0 |
| Not disclosed | 0 | 2 |

Table 3. Themes addressing sources of engagement and disengagement in research participation for migrant groups

| Themes | | Process for eliminating 'otherness' and building trust | Research Awareness | Trust | Power Differentials | Social Ease | Cultural Alignment | Appropriate Opportunity |
|---|---|---|---|---|---|---|---|---|
| 1. Engagement strategies for building trust | i. | Enlisting support from community links | ✓ | ✓ | | | | |
| | ii. | Getting to know community in a non-research environment | | ✓ | ✓ | ✓ | | |
| 2. Reducing fears connected to participation | iii. | Explaining research process/consent to new participants | ✓ | ✓ | ✓ | | | |
| | iv. | Reassuring data confidentiality | ✓ | ✓ | | ✓ | | |
| | v. | Countering stigma linked to participation in disease specific research | | | | ✓ | | |
| | vi. | Local endorsement | | ✓ | | ✓ | | |
| 3. Facilitating participation for all | vii. | Overcoming opportunity costs | | ✓ | | ✓ | | ✓ |
| | viii. | Addressing communication | | ✓ | ✓ | ✓ | | ✓ |
| 4. Making research culturally compatible | ix. | Recruiters and Researchers who the community could identify with | | ✓ | ✓ | ✓ | ✓ | |
| | x. | Gender based groups | | ✓ | | ✓ | ✓ | ✓ |
| | xi. | Gender matched researchers | | ✓ | ✓ | ✓ | ✓ | ✓ |
| | xii. | Respecting religious and cultural norms | | ✓ | | ✓ | ✓ | ✓ |
| 5. Reciprocating participation | xiii. | Stressing and appreciating any/all contribution | | ✓ | ✓ | ✓ | | |
| | xiv. | Requiting participation | | ✓ | | | | |
| 6. Giving accurate representation and voice | xv. | Conveying meaning-based translations in transcripts | | ✓ | | | ✓ | |
| | xvi. | Empowering participants to share perceptions on engagement in health-based interactions | | ✓ | ✓ | | | ✓ |
| 7. Aiming for long term relationships | xvii. | Ongoing community feedback/advice | ✓ | ✓ | ✓ | | ✓ | |