



UNIVERSITY OF LEEDS

This is a repository copy of *Recruiting older people from the Pakistani community in Community Ageing Research 75+*.

White Rose Research Online URL for this paper:  
<http://eprints.whiterose.ac.uk/157485/>

Version: Accepted Version

---

**Article:**

Jacob, I, Mahmood, F, Brown, L et al. (3 more authors) (2020) Recruiting older people from the Pakistani community in *Community Ageing Research 75+*. *British Journal of Community Nursing*, 25 (3). pp. 110-113. ISSN 1462-4753

10.12968/bjcn.2020.25.3.110

---

This document is the Accepted Manuscript version of a Published Work that appeared in final form in *British Journal of Community Nursing*, copyright © MA Healthcare, after peer review and technical editing by the publisher. To access the final edited and published work see <http://doi.org/10.12968/bjcn.2020.25.3.110>."

**Reuse**

Items deposited in White Rose Research Online are protected by copyright, with all rights reserved unless indicated otherwise. They may be downloaded and/or printed for private study, or other acts as permitted by national copyright laws. The publisher or other rights holders may allow further reproduction and re-use of the full text version. This is indicated by the licence information on the White Rose Research Online record for the item.

**Takedown**

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing [eprints@whiterose.ac.uk](mailto:eprints@whiterose.ac.uk) including the URL of the record and the reason for the withdrawal request.



[eprints@whiterose.ac.uk](mailto:eprints@whiterose.ac.uk)  
<https://eprints.whiterose.ac.uk/>

## Abstract

### **Background**

Older people from the South Asian (S.A) population, particularly Pakistani, are under-represented in health research. Language barriers and cultural differences can result in under-recruitment to studies. We report observations by two bilingual researchers (FM and IJ) who have successfully recruited older people ( $\geq 75$  years) from Bradford's South Asian population to the Community Ageing Research 75+ Study (CARE 75+). CARE 75+ is a longitudinal cohort study collecting an extensive range of health, social and economic outcome data.

### **Methods**

Culturally aware bi-cultural and bi-lingual researchers are used to recruit non-English speaking Pakistani participants.

The researchers ensure they are flexible with appointments to facilitate the participant's availability but also to fit in with the family member's wishes. Commonly, family members are present during the consent and assessment visits.

Using a community language is an important facilitator. The bilingual researchers translate questions (and constructs) in the community dialect (Potwari). The CARE 75+ study's information sheet and consent form are in English.

### **Results**

To date, 233 people from the S.A population have been invited to participate in CARE75+, of which 78 have been recruited, giving a recruitment rate of 33%. Of these, 62 are of Pakistani origin. The observed recruitment rate for south Asian participants is comparable to the whole study population (36%).

## **Implications**

Language should not be used as a means of excluding participants from research studies. The Pakistani population is willing to participate with appropriate facilitation which allows them to be included, such as skilled researchers who have knowledge of, and are attuned to, cultural sensitivities of the community.

## **Background**

Many South Asian (S.A) migrants who settled in the UK in the 1950 and 1960s are entering later life. Problems encountered by older people can be magnified in the S.A population, with recognised language barriers and difficulties accessing healthcare<sup>1</sup>. These factors can present a risk of increasing health inequalities in this population. All areas in the north of England are projected to have an increase in the number of people aged 75 and above including those from Black and Minority Ethnic (BAME) backgrounds<sup>2</sup>.

The S.A population have an increased risk of long-term conditions including heart disease<sup>3</sup>, hypertension<sup>4</sup>, asthma<sup>5</sup>, stroke<sup>6</sup> and diabetes<sup>7</sup>. However, older people, particularly those from the S.A population are under-represented in health research<sup>8</sup>.

Increasing the participation of older people from the S.A community in to research is an important first step to investigate health inequalities in this population. The Community Ageing Research 75+ (CARE75+)<sup>9</sup> study is a national, longitudinal cohort study, collecting health and social data, with a focus on frailty, independence and quality of life in older age ( $\geq 75$  years). CARE75+ uses Trials within Cohorts (TwICs) methodology<sup>10</sup>, aligning applied epidemiological research with clinical trial evaluation of interventions. When people consent to participate in CARE75+, they optionally consent to be approached about other studies, thus providing a research recruitment platform for older people.

CARE75+ recruits participants from across the UK, including from ethnically diverse populations in Bradford, where approximately 20% of the population is of Pakistani origin of which 6.5% are over 75 years<sup>11</sup>.

To date, 233 people from the S.A population have been invited to participate in CARE75+, of which 78 have been recruited, giving a recruitment rate of 33%. Of these, 62 are of Pakistani origin. The observed recruitment rate for South Asian participants is comparable to the whole study population (36%). In total the number of participants involved in CARE 75 from the Bradford district are 560.

We report the experiences of two bi-lingual researchers (FM and IJ) with S.A heritage who have successfully recruited from the S.A population to the CARE75+ study and describe the potential barriers and facilitators to successful study recruitment of this population.

## Potential barriers

### 1) Language and literacy

The main barrier to recruiting older people from the S.A (predominantly Pakistani community) is language. Recruitment to CARE75+ follows defined steps, each of which present language and literacy challenges as a large proportion of Pakistani elders in the Bradford community are not proficient in either written or spoken English. The first step is an invitation letter and brief information sheet sent from the general practice (GPs). The main community dialect (Potwari) is a spoken language with no written form. Therefore, information typically requires translation by a family member who is proficient in written English prior to the initial telephone call by a researcher.

Researchers then call potential participants to arrange home visits to provide comprehensive study information face-to-face. If at this stage no-one has read the brief information sheet to the potential participant, it can mean a lengthy

phone conversation, including discussions with family members and follow-up phone calls.

Sometimes the participant contact number is a family member who undertakes all bi-lingual communication. These ‘gate-keepers’ will either facilitate or refuse a consent visit.

## 2) Consent and assessments

One of the most challenging tasks is the consent process. CARE75+ consent includes mandatory components and optional components (e.g. consent to be approached about other studies and consent to data linkage). When consent visits are arranged, family members usually attend. The consent process is often a ‘shared decision’ with several family members providing considerable input into the process. There is a paucity of literature on this topic; however, evidence suggests the concept of shared family decision making behaviour in S.A communities.<sup>13</sup>

Several family members may be present during consent, interested in the type of questions which will be asked. However, relying on family members to translate is problematic and labour intensive<sup>14</sup> requiring adaptability and sensitivity to cultural norms. Extra time needed for the information to be delivered and scrutinised must be factored in for visits. By contrast, our experience suggests that white English speaking participants have often made the decision to participate, or not, prior to the initial visit; and family members may be present, but usually not.

The majority of participants are able to sign the consent form. However, some S.A participants have reported that they do not know how to hold a pen due to

lack of schooling. In these circumstances a consultee assent form is completed by a family member.

At the baseline assessment the Case Report Form (CRF) is usually translated into Potwari, a dialect spoken by approximately 90% of Bradford's Pakistanis in the home. Bilingual researchers translate questions and constructs into the community dialect. Thus relatively simple tests, such as the Montreal Cognitive Assessment (MoCA) can take much longer to complete. Sometimes the assessment tools can also become a topic for protracted discussion for example participants may question the nature of ageing from a cultural perspective.

### 3) Ensuring confidentiality

Ensuring confidentiality within a close-knit community is paramount but can be challenging. Most CARE75+ Pakistani participants migrated from the Mirpur region<sup>10</sup> and live in a small area within the Bradford district where kinship networks remain strong. Researchers need to be mindful that neighbours tend to know when a non-resident appears on their street. This is especially relevant if the researcher, as a non-resident, is an 'apna' (insider) with a shared language as it can be difficult to disengage from social interactions on the street without appearing disrespectful.

#### Potential facilitators

The CARE75+ study has been guided by lay representative involvement from the Frailty Oversight Group (FOG).<sup>12</sup> FOG members were instrumental in signposting to specific general practices with an interest in research and large S.A populations. This provided researchers with the best possible sampling frame for the cohort and ensured that the study was well supported by practice

staff, most of whom are bi-lingual. Additionally, the FOG had representation from Meri Yaadain (My Memories), a Social Services (Adult Social Care) led partnership initiative which aims to increase dementia awareness amongst S.A elders. The Meri Yaadain representative was able to provide advice on the engagement, consent and assessment study protocol.

Language barriers and cultural differences have been identified as key factors that can result in under-recruitment to research studies<sup>3</sup>. One potential solution is to use bi-lingual researchers to recruit ethnic minorities to research<sup>7</sup>. Being an “apna” brings a shared background and awareness of cultural norms which build trust between the researcher, the participant and their family. One is expected to know how to greet the participant; names are rarely used, instead elders are addressed as ‘uncle’ or ‘auntie’. Being mindful of seating positions, for example, one should keep an appropriate distance from the opposite sex and never make physical contact except where necessary (e.g. taking blood pressure assessments). As a male researcher, IJ is often seated in the more formal lounge of the home whereas FM, as a female, is usually invited to sit in the more private and informal areas such as the kitchen or dining area. The timing of contact is important; for example, prayer times, the month of fasting and celebratory Eid days are best avoided.

‘Outsiders’ need to ensure that they understand the social nuances of S.A culture. Face-to-face contact allows trust and rapport to build. Researchers should be prepared to answer personal questions; for example, about marital status, children, parents and where their relatives originated from. These conversations may appear intrusive but are part of trust-building demonstrating the ‘emotional understanding’ of the researchers which will facilitate the assessments.



Researchers are mindful about the ‘footprint’ left in the community; the aim is to engage and show empathy with the lives of individuals who have historically been excluded from research. This is especially important for the CARE75+ study, designed as a platform for future nested studies. Evidence suggests that participation is determined by the attitude of a potential participant towards research and the benefits arising from participation.<sup>15</sup> Retention rates of S.A participants are higher than the cohort with a 99% retention rate to date. However the S.A participants have a significantly lower rate of consent (25%) when it comes to being approached about further research compared to their white counterparts who have a consent rate of approximately 76%.

## **Conclusion**

There are a range of potential barriers and facilitators that should be considered when planning any research study that will potentially involve recruiting participants from the S.A population. Key potential barriers include language of participants who may speak verbal dialects with no written form, literacy of participants who may have had no formal schooling, and the consent process as a shared family decision. Family members often act as ‘gatekeepers’ and will play a major role in important decisions such as consenting to participate and being approached about future research. They are an important facilitator as well as barrier to recruitment and further work to increase awareness and engagement of the wider S.A. community will be important to maximise participation of S.A elders in research studies.

Potential facilitators include researchers having a detailed understanding of cultural norms, which also recognise the residence of participants within close-knit communities. Recruitment should be undertaken by skilled bi-lingual researchers who have knowledge of, and are attuned to, cultural sensitivities of

a particular community. Allowing extra time for visits and being willing to share personal information in order to build trust.

We recommend that researchers who are planning studies that may involve participants from the S.A population should incorporate methods to facilitate participation as part of study set up, with a particular focus on the initial approach, the consent process and relevant social considerations that may support ongoing study engagement.

In the CARE75+ study we have demonstrated that, with appropriate facilitation Pakistani participants are enthusiastic about participation in research, report enjoying study participation and maintain engagement across longer periods of study follow-up, with low drop-out rates.

## References

1. Rait, G., & Burns, A. (1997). Appreciating background and culture: the South Asian elderly and mental health. *Int J Geriatr Psychiatry*, 12(10), 973-977.
2. Buckner, L., Croucher, K., Fry, G. & Jasinska, M. (2011). The impact of demographic change on the infrastructure for housing, health and social care in the functional economies of the North of England. Demographic Change Project, Strand 4 Report: N8 Research Partnership
3. Rankin, J., & Bhopal, R. (2001). Understanding of heart disease and diabetes in a South Asian community: cross-sectional study testing the 'snowball' sample method. *Public Health*, 115(4), 253-260. doi: 10.1038/sj.ph.1900777
4. . Bhopal, Raj, & Sengupta-Wiebe, Sushmita. (2000). Cardiovascular risks and outcomes: Ethnic variations in hypertensive patients. *Heart (British Cardiac Society)*, 83, 495-496. doi: 10.1136/heart.83.5.495
5. Netuveli, G., Hurwitz, B., Levy, M., Fletcher, M., Barnes, G., Durham, S. R., & Sheikh, A. (2005). Ethnic variations in UK asthma frequency, morbidity, and health-service use: a systematic review and meta-analysis. *Lancet*, 365(9456), 312-317. doi: 10.1016/s0140-6736(05)17785-x
6. Patel, Mahendra G., Wright, David J., Gill, Paramjit S., Jerwood, David, Silcock, Jonathan, & Chrystyn, Henry. (2002). Prescribing of lipid lowering drugs to South Asian patients: ecological study. *BMJ (Clinical research ed.)*, 325(7354), 25-26. doi: 10.1136/bmj.325.7354.25
7. Greenhalgh, P. M. (1997). Diabetes in British south Asians: nature, nurture, and culture. *Diabet Med*, 14(1), 10-18. doi: 10.1002/(sici)1096-9136(199701)14:1<10::aid-dia282>3.0.co;2-
8. Hussain-Gambles, M., Leese, B., Atkin, K., Brown, J., Mason, S., & Tovey, P. (2004). Involving South Asian patients in clinical trials. *Health Technol Assess*, 8(42), iii, 1-109.
9. Heaven A, Brown L, Young J, Teale E, Hawkins R, Spilsbury K, Mountain G, Young T, Goodwin V, Hanratty B, Chew-Graham C, Brundle C, Mahmood F, Jacob I, Daffu-O'Reilly A, Clegg A. Community ageing research 75+ study (CARE75+): an experimental ageing and frailty research cohort. *BMJ Open* 2019;9(3):e026744. doi: 10.1136/bmjopen-2018-026744
10. Clegg, Andrew, Relton, Clare, Young, John, & Witham, Miles. (2015). Improving recruitment of older people to clinical trials: use of the cohort multiple randomised controlled trial design. *Age and Ageing*, 44(4), 547-550. doi: 10.1093/ageing/afv044
11. Department for Communities and Local Government. "The Pakistani Muslim Community in England". Department for Communities and Local Government. pp. 5–11 (6), 36–41. <https://webarchive.nationalarchives.gov.uk/20120920001118/http://www.communities.gov.uk/documents/communities/pdf/1170952.pdf>
12. Heaven, Anne, Brown, Lesley, Foster, Marilyn, & Clegg, Andrew. (2016). Keeping it credible in cohort multiple Randomised Controlled Trials: the Community Ageing Research 75+ (CARE 75+) study model of patient and public involvement and engagement. *Research Involvement and Engagement*, 2(1), 30. doi: 10.1186/s40900-016-0044-9
13. Zubair, M., Martin, W. and Victor, C. (2009b) Exploring Gender, Age, Time and Space when Researching Older People living in Pakistani Muslim Communities in the UK: Reflections from the 'Field', Paper presented at British Society of Gerontology (BSG) 38th Annual Conference, Bristol. <https://www.britishgerontology.org/DB/gr-issues-2007-to-present/generations-review/researching-ethnicity-critical-reflections-on-cond>
14. Hilder, Jo, Gray, Ben, Dowell, Anthony, Macdonald, Lindsay, Tester, Rachel, & Stubbe, Maria. (2017). 'It depends on the consultation': revisiting use of family members as interpreters for general practice consultations – when and why? *Australian Journal of Primary Health*, 23(3), 257-262. doi: <https://doi.org/10.1071/PY16053>
15. Frew, P. M., Hou, S. I., Davis, M., Chan, K., Horton, T., Shuster, J., . . . del Rio, C. (2010). The likelihood of participation in clinical trials can be measured: the Clinical Research Involvement Scales. *J Clin Epidemiol*, 63(10), 1110-1117. doi: 10.1016/j.jclinepi.2009.12.002