Visualizing community networks to recruit South Asian participants for interviews about bowel cancer screening

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Abstract

Background

South Asians make up the largest ethnic minority group in England and Wales. Yet this group is underrepresented in some programmes to promote health, such as cancer screening. A challenge to addressing such health disparities is the difficulty of recruiting South Asian communities to health research. Effective recruitment requires the development of participants' knowledge about research and their trust. Researchers also need to increase their cultural understanding and to think about how they will communicate information despite language barriers. This article describes the use of an organogram, informed by social network analysis, to identify the community contacts likely to encourage participation of South Asian adults (aged 50 to 75 years) in interviews to identify the facilitators of home bowel cancer screening.

Methods

We developed an organogram which represented the directional relationships between organizations and key informants against the level of recruitment success to visualize where networking engaged participants. Primary data were recruitment records (February 2019-March 2020).

Results

The majority of participants were recruited from faith centres. The topic of bowel cancer was a barrier for some, but recruitment was more successful with the advocacy of leaders within the South Asian communities. Visualizing community networks helped the research team to understand where to concentrate time and resources for recruitment.

Conclusions

The organizational chart was easy to maintain and demonstrated useful patterns in recruitment successes.

Policy summary

An organogram can provide a practical tool to identify the best strategies and community contacts to engage South Asian participants in studies to inform policy on health promotion activities such as cancer screening.

Keywords

Ethnic minorities, Asian, Bowel cancer, Screening, Recruitment, Network analysis, health inequalities

1. Introduction

South Asian communities include the largest minority ethnic groups in England and Wales with 5.3% of the population identifying as Indian, Pakistani, or Bangladeshi in the last Census [1]. There are disparities in terms of these ethnic groups' participation in health promotion programmes such as cancer screening. For example, the uptake of bowel cancer screening by South Asian adults is approximately half that of non-Asian adults [2]. Yet, a challenge for addressing such disparities is the underrepresentation of South Asian communities in health research because the specific needs of these communities are not well understood [3].

The barriers to research participation by people of South Asian ethnicity are participants' limited knowledge and understanding of research, mistrust, conflicts with faith and cultural beliefs, and the costs of participation in terms of time away from work and family responsibilities [4]. For researchers, barriers to recruitment are false assumptions about South Asian communities, language barriers and logistical issues such as the need to travel to meet communities [4,5].

Studies on methods to increase the recruitment of South Asian adults to research have largely focused on recruitment to clinical trials [6] but there are some themes in the findings which appear applicable to other study designs. Limited knowledge about the value of research could be addressed by clearer communication about the benefit of participation to the individual [7] and particularly to the community [8] since altruism is typically powerful in South Asian cultures [9]. A further theme in the literature on increasing recruitment is the need for researchers to build trust with South Asian communities. Some studies have suggested that association of the research with official bodies could be helpful, but some communities have linked organizations such as the National Health Service with poor treatment of South Asian groups. Therefore, using branding by official bodies may have mixed success [9] and it may be more beneficial to increase trust with potential participants and gatekeepers through frequent visits to communities by the researchers [10]. Visits to South Asian groups and working with insider informants could also improve researchers' knowledge of cultural practices to improve their sensitivity to the needs of different communities. For example, through community contacts, researchers may improve their understanding of religious calendars, daily routines, and family expectations [11]. Language has frequently been cited as a barrier to recruitment of South Asian groups. Consequently, it is important to diversify communication methods to allow information to be shared with as many participants as possible. It may be beneficial to produce materials in pictorial or video form to reduce the reliance on reading [12] or to engage younger community members to talk to older adults [13]. Despite the value of having researchers who can communicate in South Asian languages, it is not necessarily essential for researchers to be of South Asian ethnicity because other differences relating to age, gender, education, and perceived social status also create barriers [7]. Differences between researchers and participants can be advantageous and lead to richer data as participants explain cultural differences to the researchers [13].

Therefore, to increase the recruitment of South Asian people, it appears valuable to increase knowledge (for both researchers and participants) and to cultivate interpersonal relationships with key individuals and community groups. Yet achieving these things take time [14] and such investment of time and staff resources may mean studies are not feasible if relationships need to be built for each and every study with South Asian participants. Moreover, studies with South Asian groups could also become less attractive for research teams due to the challenges of recruitment, perpetuating health disparities [5].

This paper describes the development of an organogram to visualize the relationships between key groups and individuals within the local South Asian community. This process involved extensive network and relationship building. Our original study aimed to develop an intervention to increase bowel cancer screening in South Asian populations using the Theoretical Domains Framework [15]. However, we report the process of engaging with the local South Asian communities to outline how the organogram supported the recruitment for our study but also to discuss the use of this visualization tool to facilitate multiple studies through the development of a community network.

2. Methods

Eligible participants for the bowel cancer screening study were South Asian adults (from India, Pakistan, Bangladesh, Nepal or the Maldives) who were aged between 50 and 75 years of age. Recruitment started in February 2019 and interviews occurred between May 2019 and March 2020. The research was approved by [Ethics panel/number anonymised]. No sample size was pre-determined. The sociodemographic characteristics and previous use of screening tests of the interview participants were monitored. Recruitment approaches were adapted to reach a wide range of ethnic identities, first languages and faith groups. This purposive sampling approach was adopted to ensure that the research recognised the heterogeneity of the South Asian community. The team also wanted to reach people who had opted to do and not to do the home-screening test, as well as people who were about to receive the invitation.

Initially, we approached local businesses, faith centres and health organizations to recruit. During these earlier attempts, a small number of local organizations were mentioned by multiple stakeholders. Consequently, we created a working document within an online flowchart program called Lucidchart (www.lucidchart.com). This document was updated regularly during the study. The organogram was based on the principles of a directed sociogram used in social network analysis [16]. Arrows showed the direction of the relationship between organizations so that the flow of information sharing could be visualized. The number of arrows pointing to a setting and the number of participants by their sociodemographic characteristics recruited from each organization informed the research team about which organizations should be prioritised for engagement activities and relationship building. This visualization method helped us to understand whether we were reaching a broad range of subgroups within the South Asian communities. The chart also informed decisions about where and when to stop approaches to key informants and how to divide recruitment activities between members of the team. For example, where multiple contacts led to one organization, more visits and contacts were planned to that setting to maximise recruitment; where no response was received after multiple attempts, the contact was ended.

3. Results

Participants in the bowel cancer screening study

Twenty-five participants were recruited (14 women; 11 men). Twenty participants were engaged through faith centres: five from social groups. Participants were primarily Pakistani (48%) and Indian (40%). The majority were Muslim (56%) but Hindus (28%) and Sikhs (16%) were also interviewed. First languages included English, Punjabi, Urdu, Hindi, Bengali and Pashtun. Participants were aged between 50 and 74 years (mean 62 years, SD 7.8). Eight of the 15 participants over the age of 60 years, who were eligible for the screening, had not returned a test.

The organogram is presented in Figure 1. The specific names of organizations and individuals have been removed to protect identities but information about the number of contacts and interviews and the best mode of contact between the researchers and the organization are represented. At the top of the figure is the university which was geographically closest to the area selected for recruitment. The chart shows the initial contacts the research team made with local groups known to them, such as the local health authority and contacts from previous public engagement work. Where attempts to make contact or recruit participants were unsuccessful, the reasons were recorded so that the team could learn from these experiences. For example, some contacts were lost when the topic of the research (bowel cancer) was known, and this occurred in places where we contacted eligible participants without the advocacy of community leaders. Also, we attempted to speak to a faith leader directly before we had established links with community informants. When we were later advised that we should have approached the committee responsible for running the faith centre first, we were able to speak with the faith leader, through the committee’s advocacy, and to recruit for the study. This learning meant that we spoke to the right people more quickly at other faith centres. Reviewing this chart also suggested that the local Asian Community Centre (ACC) was a useful place to concentrate efforts to build relationships because several arrows linked the centre to other sources of contact. Subsequently, the team visited this centre regularly to provide health information about bowel cancer screening. The ACC and interfaith groups connected with it endorsed the research with local faith groups and they also invited the team to community events to talk to participants directly. The chart also showed us contacts which were less effective, and we reduced our attempts to network with these groups. These groups included pre-existing public engagement volunteer lists, family physician (General Practitioner) patient liaison groups and some local businesses (e.g. shops and taxi companies).

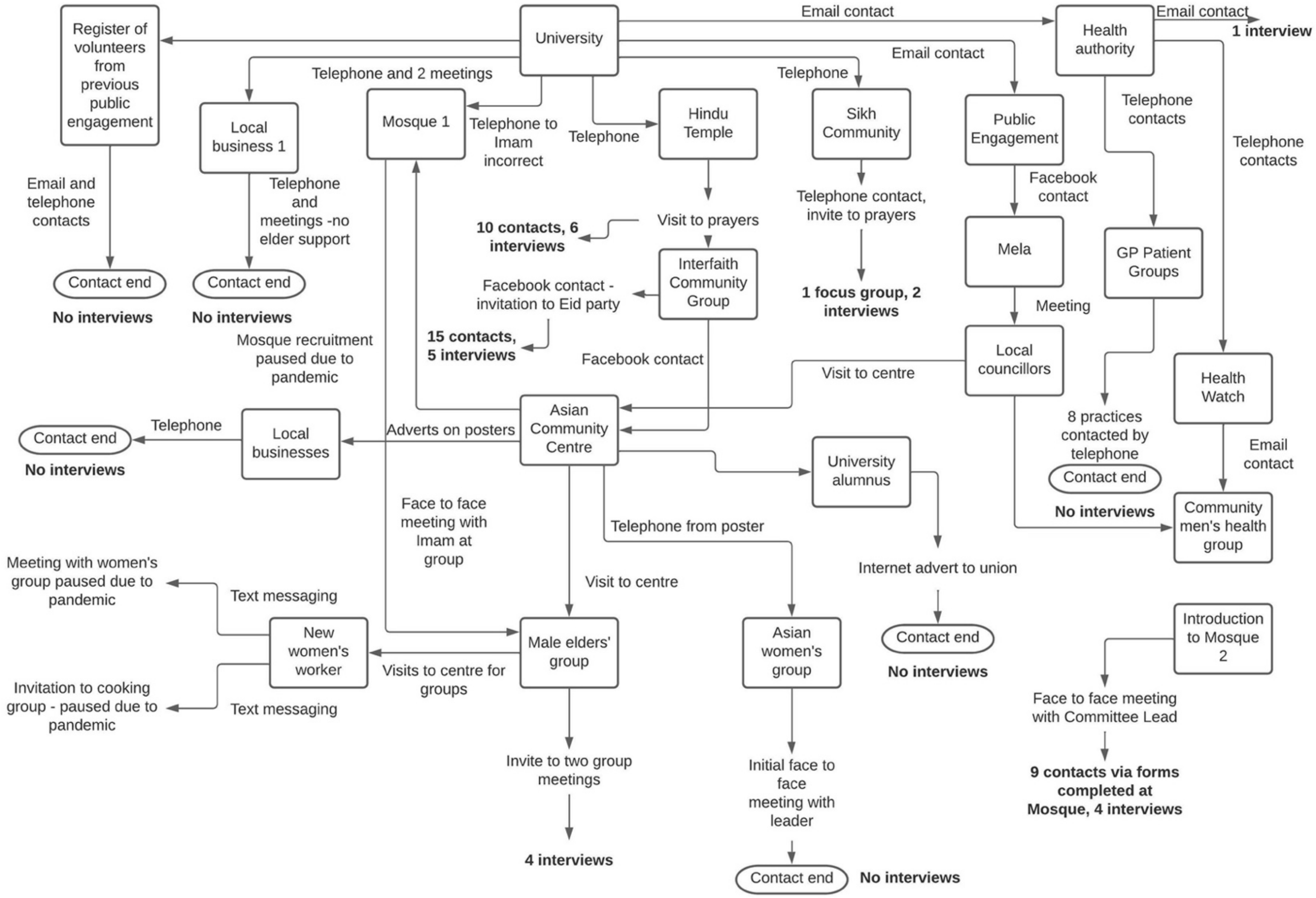

Figure 1: Organizational chart developed for the bowel cancer screening research (organizations anonymised

4. Discussion

This organogram was helpful to helpful to visualize the relationships between organizations so that a research team, unfamiliar with the South Asian community, could learn about the complex inter-connections between groups and individuals. Organizations which initially appeared promising proved to be less fruitful than expected. Time spent building relationships with interfaith and faith groups was more valuable, but in the end participant recruitment was only possible through the advocacy of key individuals. At times these individuals were identified only after a series of other organizations or people had passed on the information about our study, which increased the time needed for recruitment. The visualization in the organogram revealed these pathways so that researchers could recognise each organization's contributions.

There is a drive to empower communities to work in partnership with researchers, practitioners and policy makers [17]. Yet, such initiatives can be time-consuming for teams who have limited funding to complete projects. Our own recruitment efforts took three months before any interviews took place and we needed to continue efforts to reach new communities throughout the data collection period. The amount of work needed to identify key partners may deter some researchers from undertaking studies with South Asian communities, slowing the development of effective interventions. However, once networks are established, it could become possible for research teams to conduct multiple studies more efficiently. Researchers also need to know more about how to work with communities to encourage trust in research and participation[18]. This knowledge could be enhanced by tools which are flexible enough to shape to diverse needs and which are simple enough that they can be used by a wide range of stakeholders.

Moreover, the learning from this organogram could be transferable to future studies with the same community groups so that research teams can save time by working immediately with the right community advocates or gatekeepers to achieve their goals. For example, the methods of communication recorded in our organogram demonstrate how telephone and face to face meetings/visits are more useful than email contacts. Some community groups were lost due to the topic of the study while others remained. By sharing such learning about recruitment between project teams, pre-planned recruitment strategies may become more efficiently focused on parts of the network more likely to respond and how best to make contacts. Improved efficiency afforded by such knowledge could therefore reduce the temptation, noted in previous research, to focus on easier to reach ethnic groups to complete health research [5].

Our network visualization allowed us to refocus our activities quickly to reach and engage groups which would add particular value to our study, an ability which has been previously highlighted as important for research with South Asian communities. A possible critique of the organogram is that there are statistical methods to conduct a social network analysis. Measures which denote the relative importance of each connection in the network, could be useful for providing objective data to generate theory about how recruitment could work in underrepresented populations. However, statistical models require specific skillsets and software to generate and interpret them. Consequently, they may not be available to all research teams. This visual organogram can be used to communicate information and learning in a way which is easy to maintain, share and interpret even without access to sophisticated software and statistical expertise.

5. Conclusions

The organogram was valuable for suggesting where resources and time should be invested to enhance relationships with key members who could advocate for the research. This tool was simpler than statistical methods of network analysis, making the method accessible for a range of stakeholders to create, maintain, interpret, and share. The flexibility of this tool makes it adaptable to a range of community groups and purposes to facilitate information sharing to make recruitment to future studies more efficient.

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