

TITLE PAGE

Scarcity of South Asian organ donors, a growing concern in the health care sector!

A survey of attitudes and beliefs regarding organ donation among the South Asians in the UK

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Keywords:

South Asian, knowledge, survey, organ donation, religion

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Abstract

Background

There is an acute shortage of organ donors in the UK, specifically among South Asian communities. This article reports the findings from the largest ever study undertaken among South Asians in the UK that seeks to explore attitudes and beliefs towards organ donation.

Material and Methods

A questionnaire was made available in different South Asian languages and distributed face-to-face and online. The questionnaire had 25 questions divided into three sections to capture knowledge, perceptions and attitudes towards organ donation and demographic details. In total, 907 participants completed a questionnaire.

Results

The results highlight a real concern (40.1% of the total sample) in feelings of mistrust in medical teams, concern about the misuse of organs or the provision of appropriate medical care. Knowledge about registering for organ donation was significantly different between ethnicities, religions and communities.

Conclusion

This article highlights seemingly intractable factors, such as religion and culture, are often tied to more complex issues, such as distrust in the medical system and lack of awareness, that contribute to the shortage of organ donors among South Asian communities in the UK. Tailored community-based engagement is essential to build trust and positive action.

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Introduction

The success of organ transplantation relies on the willingness of the public to donate their organs, either during their lifetime or after death. Globally, over one million people have received organ transplants, having become routine practice and part of the health care system of virtually all countries in the world (1). However, transplantation is limited by the shortage of donated organs (2).

Studies from the 1980s indicate that the South Asian community (those originating from the Indian subcontinent) living in the UK has a diverse and distinctive culture, and the pattern of mortality and morbidity is different from that of the white communities they live in (3,4). In addition to lifestyle factors associated with cultural practices such as diet, racial disadvantage resulting in high levels of unemployment, poor housing and low education achievement may also contribute to differential rates of ill health (5,6,7,8). Moreover, individuals of South Asian heritage living in the UK are three to four times more likely to need a kidney transplant compared to the Caucasian population, as Type 2 Diabetes is up to six times more prevalent in the South Asian community - a major cause of renal failure (9). All these factors contribute to an increased demand for more organ donors from the South Asian community, as the number of patients with organ failure (especially kidney failure) from this community is rising (Table 1). This leads to a disproportionately greater number of South Asians waiting for a transplant with a longer than average waiting time due to the scarcity of South Asian organ donors in the UK – most often, suitable matches are found from individuals of the same ethnic background (9, 10).

| Financial Year | Number of Donors | | Number of Transplants | | Patients on active Transplant waiting list | |
|----------------|------------------|-------|-----------------------|-------|--|-------|
| | White | Asian | White | Asian | White | Asian |
| 2010/2011 | 917 | 12 | 1305 | 230 | 4954 | 1099 |
| 2011/2012 | 988 | 15 | 1425 | 215 | 4673 | 1114 |
| 2012/2013 | 1097 | 19 | 1473 | 260 | 4386 | 1074 |
| 2013/2014 | 1197 | 39 | 2783 | 400 | 4945 | 1123 |
| 2014/2015 | 1092 | 30 | 2614 | 417 | 4852 | 1081 |
| 2015/2016 | 1296 | 27 | 2711 | 469 | 4553 | 1026 |
| 2016/2017 | 1308 | 29 | 2865 | 486 | 4430 | 1009 |
| 2017/2018 | 1441 | 37 | 3097 | 508 | 4130 | 959 |

Table 1: Demographic characteristics (ethnicity) of deceased kidney donors, transplant recipients and active waiting list patients over the past 5 years in the UK (*Data provided by NHSBT Statistics Department*)

Background

In this study, ‘South Asian’ represents the Indian, Pakistani, and Bangladeshi community, considered to be the largest ethnic minority group from South Asia living in urban locations in the UK (11,12).

Historically, South Asians living in Asia and the West have one of the lowest rates of organ donation in the world, a longstanding and disturbing issue internationally (13,14,15). Despite this fact being recognised now for nearly 30 years, little has changed to overcome or address this low organ donation rate; there is also limited understanding as to why South Asian individuals are less likely to register as organ donors (16, 17, 18, 19, 10, 20, 21, 22). On another note, although UK organ allocation is fair and the ethnicity of donors and recipients are of no direct significance in established forms of solid organ transplantation (23), previous reports have suggested there were deep and worrying feelings within the South Asian public that organ allocation was not equal and somehow influenced by ethnicity (24).

This article reports the findings from the largest ever study undertaken among South Asians in the UK that seeks to explore attitudes and beliefs toward organ donation.

Materials and Methods

A questionnaire was used as the instrument of choice for many reasons – it is predetermined, standardised and structured, potentially the quickest and cheapest method of data collection, and a relatively confidential method, not to mention its ability to obtain breadth to the research and a method for collecting large amounts of information from a large sample across a wide geographical area (25). To facilitate comparative analysis with previous studies, it was considered appropriate to use an existing validated tool rather than reinvent and test a new instrument. After reviewing different tools, the questionnaire developed by Morgan et al. (2006) was identified as the most appropriate to use. It concentrated on general attitudes and knowledge of organ donation among ethnic groups in the UK and was not limited to just religious reasoning (16, 20). Using an existing tool increases the reliability and validity of the instrument having been previously used, tested and validated in the same ethnic group in the UK (10). Prior to translation of the English questionnaire into three languages (Urdu, Hindi and Bengali), the content and face validity was discussed with the study group members, including medical professionals, religious and community leaders, patients and families, and lay people from South Asian backgrounds). The group was asked to assess whether questions were socially and culturally valid, wording appropriate, and if other questions needed to be included. The quality of translation was also checked by key language experts within the steering group. In addition, the comprehensibility, reliability, feasibility, acceptability and completeness of the questionnaire content was independently checked by two senior research managers in the Trust and the University. Approval to use the questionnaire from Morgan et al. (2006) saved considerable time as it was already piloted and tested tool in the same ethnic group in the UK.

The questionnaire (Appendix 1) was designed to elicit knowledge and attitudes of the South Asian communities towards organ donation. The questionnaire had 25 items with multiple choice answers, divided into three sections to capture knowledge, perceptions and attitudes towards organ donation and demographic details (10):

1. Knowledge: Asking about knowledge of organ failure and willingness to join the Organ Donor Register (ODR); questions related to willingness to register as a kidney donor.

2. *Perceptions/Attitudes*: Twelve questions reflecting on thoughts and feelings about deceased and live organ donation, along with examining attitudes towards organ donation and transplantation and the reasons behind those specific attitudes which might affect their decision for being a deceased or live donor. Reassurance was provided to participants that there were no right or wrong answers. Questions about the participants' views about deceased organ donation and assessing their willingness to be organ donors after death provided a choice of four options ranging from '*Strongly Agree*' to '*Strongly Disagree*'.

3. *Demographic Details*: Six demographic questions covering age, gender, ethnicity, religion, education level and occupation. The questionnaire was designed to elicit information in the following areas: demographic, social, religious, education and ethnic characteristics of the population, and the known barriers to organ donations.

Previous methods such as distributing questionnaires through General Practitioner practices were not particularly successful in this ethnic group, recruiting only 2.1% of Asian participants (10), whereas distributing questionnaires at community events, was an effective and appropriate method, although time consumed explaining the study face-to-face would be longer but be a more effective method to gaining completed questionnaires.

At community gatherings a hard copy questionnaire was provided along with an invitation letter and information sheet. South Asian community gatherings were targeted, including those at community centres and religious places where large numbers of people from the local communities could easily be reached. To gain access to these events, study information was made available to religious and community leaders, and their verbal agreement to allow engagement with the community in this way was gathered prior to attending any event. As a result, the questionnaire survey was conducted at different times on different days. The researcher had a stand at the meeting with information about organ donation and people who approached the stand were invited to take part in the questionnaire, with a verbal explanation by the researcher as to the purpose of the research study. Care was taken to encourage a range of ages, different ethnic backgrounds and religious beliefs to gather a varied representation of perceptions. Participants could either complete the survey at the event or at home. There was no monetary incentive for the voluntary participation, and no names were attached to the questionnaire so anonymity was maintained.

A website (www.southasianorgandonor.org.uk) was made available at the outset of the study and this was advertised at the different community events, giving participants the option to complete the survey online at their leisure and in private if preferred, giving increased data confidentiality and anonymity. Awareness of the study website was promoted using a specially created Facebook group and linked to Asian media outlets, the Trust, University and through the British Renal Society.

Sample

The aim of the survey was to explore perceptions and attitudes towards organ donation, recruiting sufficient people for analysis across the three South Asian groups, rather than providing a representative sample of the target population. In the North West, the target population indicated 293,700 potential South Asian participants (27), but to gain the views of so many would be impossible in the timeframe. It was anticipated that a convenience sample of c.500 would be feasible to recruit given the six month timeframe of the study, similar to Karim et al. (2013). Morgan et al. (2006) targeted the testing towards Black Caribbean's and other ethnic groups, but only actually recruited 33 Asians out of 1536 participants. However, in a smaller Masters level study exploring barriers to organ donation, AP had experience of recruiting 100 people across two community events (24), so 500 responses was considered a realistic target.

Data was collected between April and October 2012. There were 554 completed questionnaires returned, along with another 353 questionnaires completed online, making a total sample of 907 (181.4% of the target). This forms the largest data set of its kind in the UK exploring the opinions and perceptions of the South Asian community towards organ donation, nearly double that of Karim et al. (2013), who recruited 556 Asian people (16).

Ethical Considerations

Due to the sensitivity and complexity of the subject, the ethical and IRB approval process was both a challenge and time consuming. The study obtained ethical approval from different organizations - the National Research Ethics Committee, Central Manchester University Hospitals Foundation Trust (CMFT) Ethical Committee (Employer of the Researcher),

University of Salford Research Ethics Committee (where the Researcher was a PhD student) and NHS Blood and Transplant (to access the statistics of the Organ Donor Register).

Data Analysis

The empirical portion of quantitative studies involves collecting research data and preparing that data for analysis (28). The initial questionnaire survey data was entered into an electronic survey system (BRISTOL) either directly by the respondent using the online questionnaire or by the researcher from the hard copy questionnaires. A professional statistician assisted with analysis using SPSS (version 20).

Initially Chi-squared tests were used to test the existence of associations between outcomes and demographic characteristics, and between attitudes, knowledge and demographic characteristics. The perspectives of the target community (Indian Hindu, Indian Christian, Indian Muslim, Pakistani Muslim, Bangladeshi Muslim and others including Sikh) were examined, and characteristics explored according to age, gender and level of education (see Table 2). A significance level of $p < 0.05$ was used throughout. However, the sample obtained was self-selected and convenient, so it was difficult to identify how representative the respondents were of the communities they came from. The distribution of data across ethnicity, religion, community, age and education groups was considerably different. A large number of tests were carried out to identify the likely barriers to organ donation and to understand the attitudes and devise an intervention, so correcting for multiple testing was not feasible. Therefore, p-values reported are raw results from the tests keeping in mind that, due to multiple testing, there are some chance significances. The distributions among different subgroups were unbalanced and some sub-groups were small. Therefore, tests had limited power to detect differences.

Results

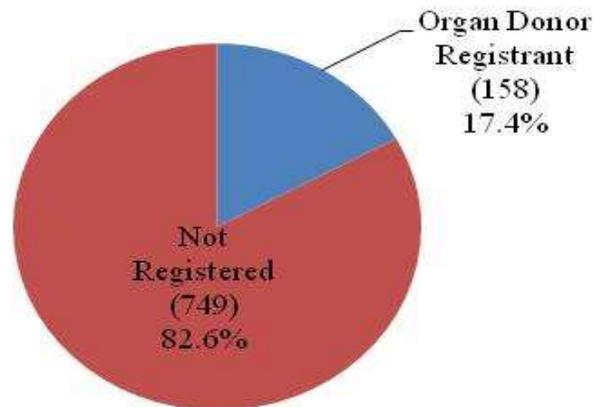
Table 2 - Survey sample demographic characteristics

| Religion/ Ethnicity | Gender | | Education | | Age (yrs) | | |
|--------------------------------|----------------|----------------|----------------|-----------------|----------------|-----------------|----------------|
| | M | F | School | Post school | 18-25 | 25-45 | 45-81 |
| Indian Christian (n=347) | 178 (51.3%) | 169 (48.7%) | 45 (13.0%) | 302 (87.0%) | 44 (12.7%) | 24 (71.2%) | 56 (16.1%) |
| Indian Hindu (n=193) | 118 (61.1%) | 75 (38.9%) | 18 (9.3 %) | 175 (90.7 %) | 20 (10.4%) | 115 (59.6 %) | 58 (30.1%) |
| Indian Muslim (n=53) | 26 (49.1%) | 27 (50.9%) | 6 (11.3 %) | 47 (88.7%) | 11 (20.8 %) | 35 (66.0 %) | 7 (13.2 %) |
| Bangladesh Muslim (n=72) | 44 (61.1 %) | 28 (38.9%) | 7 (9.7 %) | 65 (90.3 %) | 21 (29.2 %) | 37 (51.4 %) | 14 (19.4 %) |
| Pakistani Muslim (n=171) | 83 (48.5 %) | 88 (51.5 %) | 23 (13.5%) | 148 (86.5%) | 38 (22.2 %) | 108 (63.2 %) | 25 (14.6%) |
| Sikh (n=25) | 7 (28.0 %) | 18 (72.0%) | 3 (12.0%) | 22 (88.0%) | 9 (36.0%) | 13 (52%) | 3 (12%) |
| Other (n=46) | 23 (50.0 %) | 23 (50.0%) | 3 (6.50%) | 43 (93.5%) | 4 (8.7%) | 28 (60.9%) | 14 (30.4%) |
| Total | 479 (52.8%) | 428 (47.2%) | 105 (11.6%) | 802 (88.4%) | 147 (16.2%) | 583 (64.3%) | 177 (19.5%) |

Organ Donor Registration

The most notable finding from this study was that, out of 907 South Asian respondents, only 17.4% were actually registered as potential organ donors (Figure 1).

Figure 1 - Number of ODR registrants



Indeed, the sample characteristics of those people registered and those who were not were explored further, which identified no significant difference in answers between males and females, or at education level (see Table 3).

Table 3 - Demographic relationship and ODR registration

| Are you registered | | NO | YES | p Value |
|--------------------|-------------|--------------------|--------------------|----------|
| Total Sample | | 749 (82.6%) | 158 (17.4%) | |
| Gender | Female | 347 (81.1%) | 81 (18.9%) | p=0.29 |
| | Male | 402 (83.9%) | 77 (16.1%) | |
| Ethnicity | Bangladeshi | 67 (88.2 %) | 9 (11.8 %) | p=0.046 |
| | Indian | 502 (80.4 %) | 123 (19.6 %) | |
| | Pakistani | 164 (88.2 %) | 22 (11.8 %) | |
| | Other | 16 (78.9 %) | 4 (21.1 %) | |
| Religion | Christian | 295 (81.9 %) | 65 (18.1 %) | p<0.0001 |
| | Hindu | 154 (76.2 %) | 48 (23.8 %) | |
| | Muslim | 271 (88.9 %) | 34 (11.1 %) | |
| | Sikh | 22 (88 %) | 3 (12 %) | |
| | Other | 7 (46.7 %) | 8 (53.3 %) | |

| | | | | |
|-----------|--------------------|-------------|-------------|----------|
| Education | University | 473 (80%) | 116 (19.7%) | p=0.11 |
| | Further | 183 (85.9%) | 30 (14.1%) | |
| | Secondary | 77 (89.5%) | 9 (10.5%) | |
| | Primary | 12 (80%) | 3 (20%) | |
| | No school | 4 (100%) | 0 | |
| Age (yrs) | 18-25 | 126 (85.7%) | 21 (14.3%) | p=0.49 |
| | 26-45 | 474 (81.3%) | 109 (18.7%) | |
| | 46-65 | 129 (83.2%) | 26 (16.8%) | |
| | 66-81 | 20 (90.9%) | 2 (9.1%) | |
| Community | Indian Christian | 288 (83%) | 59 (17%) | p=0.0053 |
| | Indian Hindu | 146 (75.6%) | 47 (24.4%) | |
| | Indian Muslim | 49 (92.5%) | 4 (7.5%) | |
| | Bangladeshi Muslim | 64 (88.9%) | 8 (11.1%) | |
| | Pakistani Muslim | 151 (88.3%) | 20 (11.7%) | |
| | Sikh | 22 (88%) | 3 (12%) | |

Respondents from Muslim and Sikh religions were less likely to be registered on the ODR. Although ‘being registered’ was not significantly different between ethnicities ($p=0.046$), it was highly significant across different religions ($p<0.0001$) (Figure 2) and different communities ($p=0.005$) (Figure 3).

Figure 2 - ODR and religion

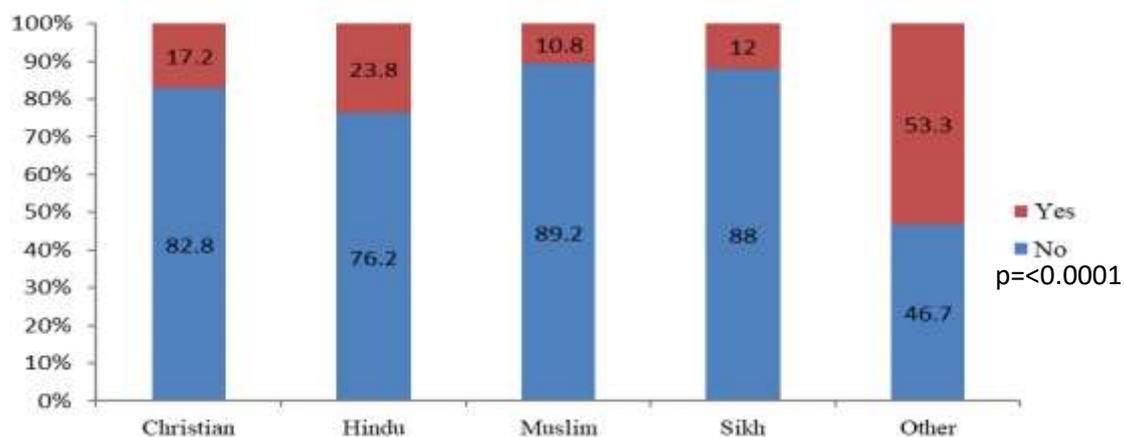
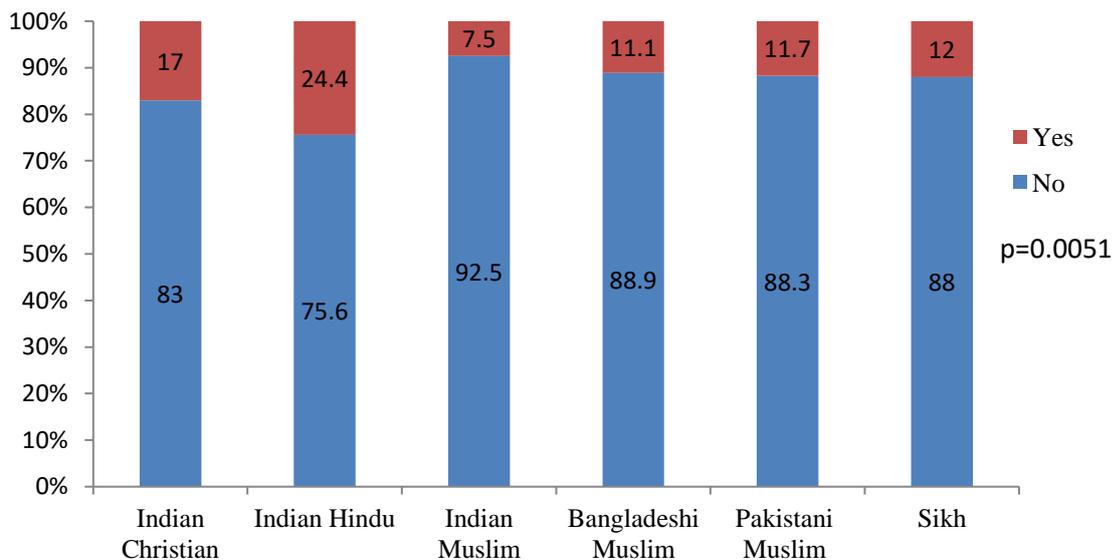


Figure 3 - ODR religion and community



1.1 Attitudes and Beliefs Influencing Donation

A series of eight questions comprised statements about previously identified cultural, religious and personal barriers to registration, with responses on a five point scale (strongly agree, agree (combined as agree), disagree, strongly disagree (combined as disagree) and don't know). The responses to these statements were explored, examining the significant differences in perceptions which, on closer examination, appeared to exist across different ethnic community groups, rather than sensitive to a particular religion.

The results to the questions are summarised in Table 4, exploring attitudes towards a willingness to register against the different statements. Table 5 summarises attitudes of those not registered, compared by community group. The findings and interpretation of the whole data set indicate the willingness to register was significantly associated with attitude. Responses highlighted concerns shared across groups that exposed the need for health professionals to establish a more trusting relationship with South Asian communities to alleviate the strongest and widespread attitude and misconception of mistrust associated with medical staff and the retrieval of organs within the UK.

The use of odds ratios as summaries became difficult to interpret with three optional responses (No, Yes, Not Sure) for *willingness to register*, so the percentages for each response are presented (Table 4 and 5).

1.1.1 Chance of life – Gift of Life

Those who believed that ‘*It is important to give a chance of life*’ were more likely to be registered than those who didn’t agree (Odds ratio=10.71, 95% Confidence interval (CI) (2.61, 43.94), $P<0.0001$), suggesting this attitude of helping others to live or the ‘Gift of life’ theory may be a useful way to encourage people to register as organ donors. Apart from the Indian Muslim community, willingness to register was significantly different between those who thought ‘*It is important to give a chance of life to somebody else*’, and those who did not - $p=0.039$ for Bangladeshis and $p<0.0005$ for all other communities (see Table 4).

Table 4 - Summary of attitudes towards willingness to register

| Statement/ attitudes towards willingness to register as organ donor | Agree/ Disagree | No | Not Sure | Yes | Test of Association |
|---|-----------------|-------------|-------------|-------------|---------------------|
| I don’t mind who will receive my organ | Agree | 89(11.3 %) | 317(40.2 %) | 382(48.5 %) | $P<0.0001$ |
| | Disagree | 68 (57.1 %) | 34 (28.6 %) | 17 (14.3 %) | |
| It is important to give chance of life. | Agree | 101 (12.4%) | 320(39.4 %) | 391(48.2 %) | $P<0.0001$ |
| | Disagree | 56 (58.9 %) | 31 (32.6 %) | 8 (8.4 %) | |
| I worry medical team won’t try as hard to save me | Agree | 73 (18.3 %) | 173(43.5 %) | 152(38.2 %) | |
| | Disagree | 84(16.5 %) | 178(35 %) | 247(48.5 %) | |
| I worry they use my organ without consent for other purposes | Agree | 80 (22 %) | 157(43.1 %) | 127(34.9 %) | |
| | Disagree | 77 (14.2 %) | 194(35.7 %) | 272(50.1 %) | |
| It is important to have intact body hereafter | Agree | 80 (24.5 %) | 142(43.6 %) | 104(31.9 %) | $P<0.0001$ |
| | Disagree | 77 (13.3 %) | 209(36 %) | 295(50.8 %) | |
| I feel uneasy of the thought my body being cut up. | Agree | 101 (25.1%) | 176(43.7 %) | 126(31.3 %) | |
| | Disagree | 56 (11.1%) | 175(34.7 %) | 273(54.2 %) | |
| Registering is tempting my own death | Agree | 47 (24.2 %) | 79 (40.7 %) | 68 (35.1 %) | $P=0.0033$ |
| | Disagree | 110 (15.4%) | 272(38.1 %) | 331(46.4 %) | |
| Donating is a way of serving God. | Agree | 35 (6.2 %) | 26 (40.4 %) | 299(53.4 %) | $P<0.0001$ |
| | Disagree | 122(35.2%) | 125(36 %) | 100(28.8 %) | |

Table 5 - Summary of attitudes agreed of those not registered compared by ethnic community

| Attitudes/justification of those not registered on ODR | Indian Christian (288) | Indian Hindu (146) | Indian Muslim (49) | Bangladeshi Muslim (64) | Pakistani Muslim (151) | Sikh (22) |
|---|---------------------------|-----------------------|-----------------------|----------------------------|---------------------------|---------------|
| An intact body is needed hereafter | 96 (33.3%) | 50 (34.2%) | 22 (44.9%) | 27 (42.2%) | 83 (55.0%) | 11 (50.0%) |
| Registering is tempting my own death | 72 (25.0%) | 25 (17.1%) | 9 (18.4%) | 15 (23.4%) | 38 (25.2%) | 6 (27.3 %) |
| I worry medical team will not try to save me | 140 (48.6%) | 62 (42.5%) | 17 (34.7%) | 25 (39.1%) | 77 (51.0%) | 16 (72.7%) |
| I worry my organ will be used for other purposes without my consent | 101 (35.1%) | 56 (38.4%) | 19 (38.8%) | 23 (35.9%) | 89 (58.9%) | 14 (63.6%) |
| I feel uneasy of the thought of my body being cut | 122 (42.4%) | 52 (35.6%) | 24 (49%) | 31 (48.4%) | 99 (65.6%) | 8 (36.4%) |
| It is not important to give a chance of life to somebody after my death | 23 (8.0%) | 14 (9.6%) | 6 (12.2%) | 10 (15.6%) | 32 (21.2%) | 6 (27.3%) |
| I do mind who will receive my organs | 23 (8.0%) | 10 (6.8%) | 8 (16.3%) | 18 (28.1%) | 44 (29.1%) | 6 (27.3%) |
| Donation is not a way of serving God | 65 (22.6%) | 58 (39.7%) | 28 (57.1%) | 31 (48.4%) | 84 (55.6%) | 14 (63.6%) |

In all communities, except for the Indian Hindu community ($p=0.1410$), willingness to register was significantly different between those who ‘*Do not mind who receives the organ*’ and those who do mind - $p=0.028$ for Bangladeshi, $p=0.031$ for Indian Muslims, $p=0.02$ for others, and $p<0.0002$ for all other communities (see Table 4).

1.1.2 Reincarnation, Tempting Fate and Intact Body

People who believed ‘*An intact body is needed after death*’ were less likely to be registered than those who did not believe (Odds ratio= 0.41; 95% CI= (0.27, 0.62), $P<0.0001$) (Table 3).

In particular, among the Pakistani Muslim community, a willingness to register was

significantly different between those who held the belief '*needing an intact body after death*' and those who did not ($p < 0.0001$), compared to the majority of other communities where no significant difference was noted (see Table 4).

1.1.3 Religious Uncertainty and Lack of Consensus

In all communities, the belief that '*Donation is a way of serving God*' made a significant difference to their willingness to register - $p = 0.0142$ for Indian Muslims, $p = 0.038$ for Sikhs and $p < 0.0032$ for all other communities. Indeed, those who thought '*Donation is a way of serving God*' were more likely to be registered than those who didn't agree (Odds ratio = 1.51, 95% CI (1.05, 2.2), $P < 0.036$) (see Table 4).

1.1.4 Mistrust in the Medical Team

The results highlighted a real concern that 40.1% of the total sample (the majority of whom were higher educated - see Table 2) expressed a feeling of mistrust in medical teams, mentioning concern about the misuse of organs or not receiving the appropriate medical care.

It was evident that those who worried '*The Medical team will not try hard to save me*' were less likely to be registered than those who didn't agree (Odds ratio = 0.57; 95% CI = (0.4, 0.82), $P = 0.002$). There was no statistical significant difference in being registered between people who worried '*organs will be used without their consent*' and those who were not of this opinion (Odds ratio = 0.79; 95% CI = (0.55, 1.12), $P = 0.24$) (see Table 4).

Among Indian Hindus, a willingness to register was significantly different between those who were concerned '*The organ will be used for other purposes without their consent*' and those who didn't ($p = 0.036$), compared to other communities where no significant difference was noted. A willingness to register was significantly different when participants in Indian Christians ($p = 0.028$) and others ($p = 0.006$) were asked if they were concerned '*medical teams will not try hard to save the person in order to use the organ*', compared to other communities where no significant difference was noted (see Table 4).

Differences were identified between age groups in regards a belief of mistrust in medical teams; these responses were explored further and relationships between age and community group responses compared (Figures 6-11). Older participants were more likely to disagree with the

statement 'I worry organs will be used without consent', particularly those from the Sikh community. The most significant difference was in the Indian Christian community, from which the 18-25 age group was less likely to disagree, compared to the >25-45 age group (Odds ratio=0.28, P=0.0002). In the Pakistani community, the odds of disagreement in the >45-81 age group was greater, compared to that in the >25-45 age group (Odds ratio=3.02, P=0.02). The same trend was seen in the responses to 'Worry medical team will not try to save...', except in the Indian Hindu community in which odds of agreement in the >45-81 age group was greater, compared to that in the >25-45 age group (Odds ratio=4.68, P=0.22). In Indian Christian, Indian Hindu and Pakistani communities, the 18-25 age group was significantly more likely to agree (Odds ratio= 3.019, 4.24 and 2.23, P= 0.002,0.005 and 0.041 respectively) (see Table 4, Figures 4-9).

Figures 4-9: Worry organs will be used without your consent: Community relationship across different age groups

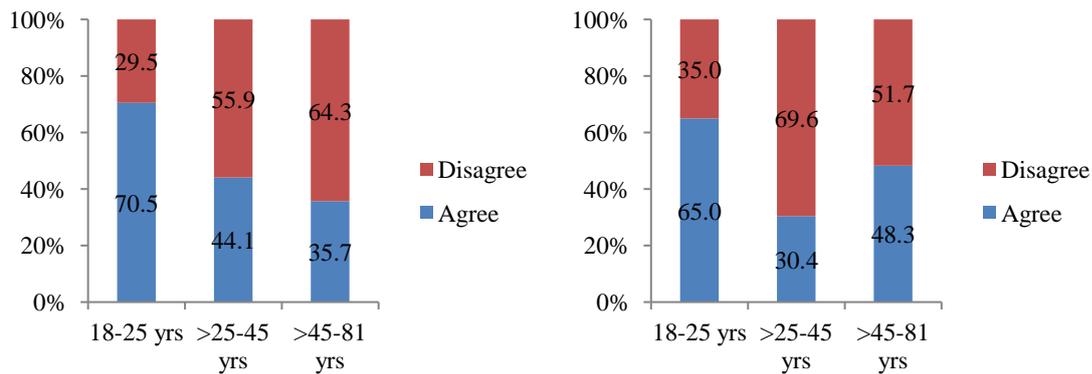


Figure 4 Indian Christian community

Figure 5 Indian Hindu community

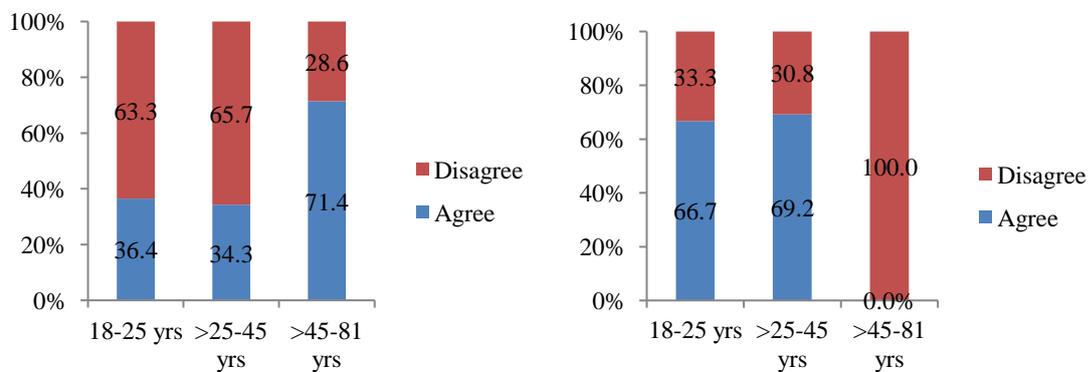


Figure 6 Indian Muslim community

Figure 7 Sikh community

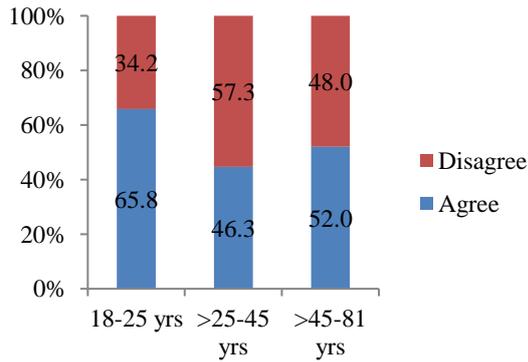


Figure 8 Pakistani community

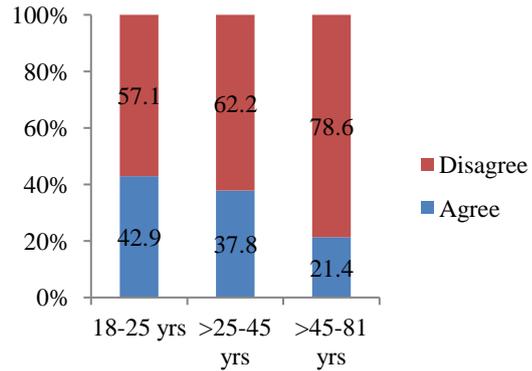


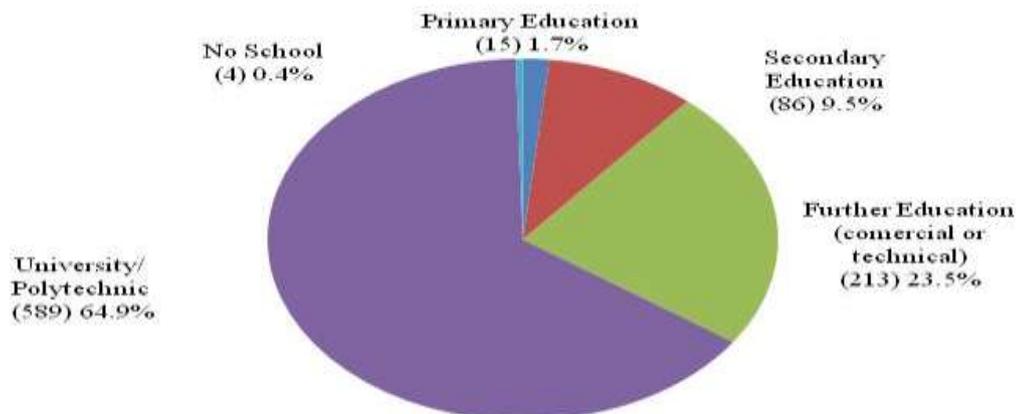
Figure 9 Bangladeshi community

It is important to note that mistrust in the medical team is present in every community compared to other attitude questions; concern among participants on this particular aspect represents the highest percentage with more than 35% in every community. Interestingly, the Sikh community had more than 63% who expressed concern about the medical care and misuse of organs (Figure 7, Table 4).

1.2 Highly Educated Lacking Awareness

The majority of respondents (64.9%) had university or higher education qualifications and 33% had secondary school or above education; only 2.1% had primary or no education (Figure 10). Participants from this highly educated sample - over 54% - did not feel well informed about registering as a kidney donor. Even though translated questionnaires were readily available, they were only requested by six individuals.

Figure 10 Education status



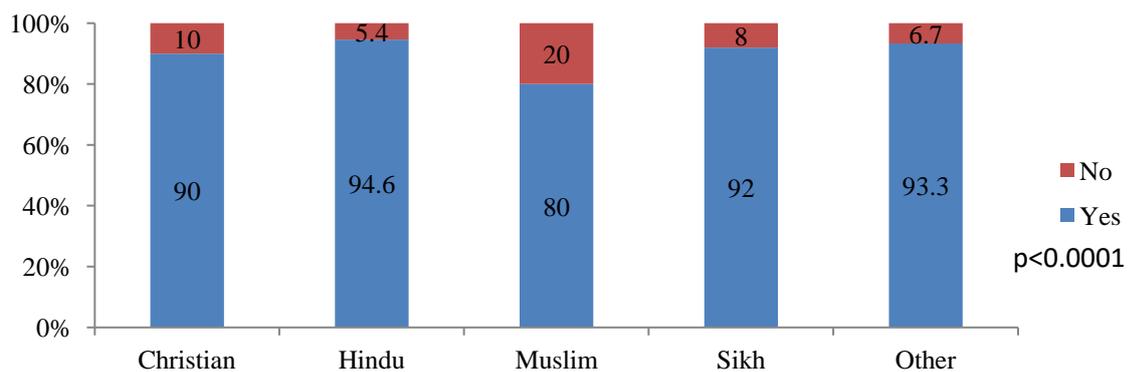
Knowledge about registering for organ donation was significantly different between ethnicities, religions and between communities ($p < 0.0001$ in all cases) (see Table 6). Respondents from Muslim religions were less likely to be registered on the ODR and less likely to be aware it was possible to leave your kidneys for transplant and/or how to register.

Table 6 - Informed or not about organ donation

| Community | Not informed | Little informed | Well informed | Test Association |
|--------------------|--------------|-----------------|---------------|------------------|
| Indian Christian | 29 (8.4%) | 135 (38.9%) | 183 (52.7%) | p<0.0001 |
| Indian Hindu | 13 (6.7%) | 82 (42.5%) | 98 (50.8%) | |
| Indian Muslim | 11 (20.8%) | 24 (45.3%) | 18 (34%) | |
| Bangladeshi Muslim | 23 (31.9%) | 34 (47.2%) | 15 (20.8%) | |
| Pakistani Muslim | 23 (13.5%) | 84 (49.1%) | 64 (37.4%) | |
| Sikh | 4 (16%) | 11 (44%) | 10 (40%) | |

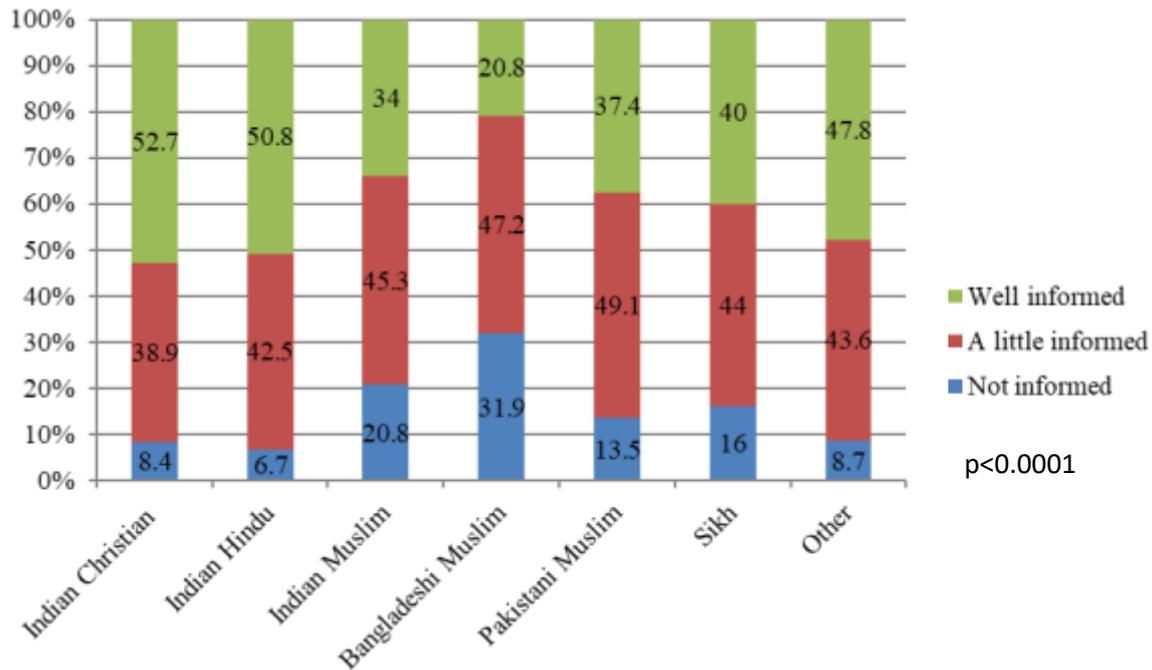
Even though more than 90% of the Indian Hindu community knew it is possible to leave kidneys for transplant after death, when considering how to register and how to become an organ donor, it was identified that all religious groups felt poorly informed (see Figure 11).

Figure 11 - Aware you can donate your organs?



Among the surveyed communities, Bangladeshi Muslims were the least informed group about organ donation (31.9% unaware) (Table 6). Knowledge about donation was significantly different between ethnicities, religions and between communities ($p < 0.0001$ in all cases) (Figure 12).

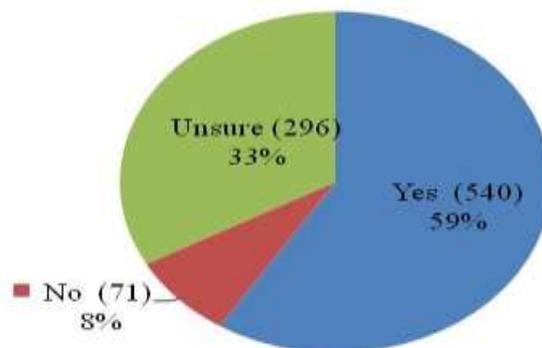
Figure 12 - Community levels of awareness of organ donation



1.3 Support for Live Donation

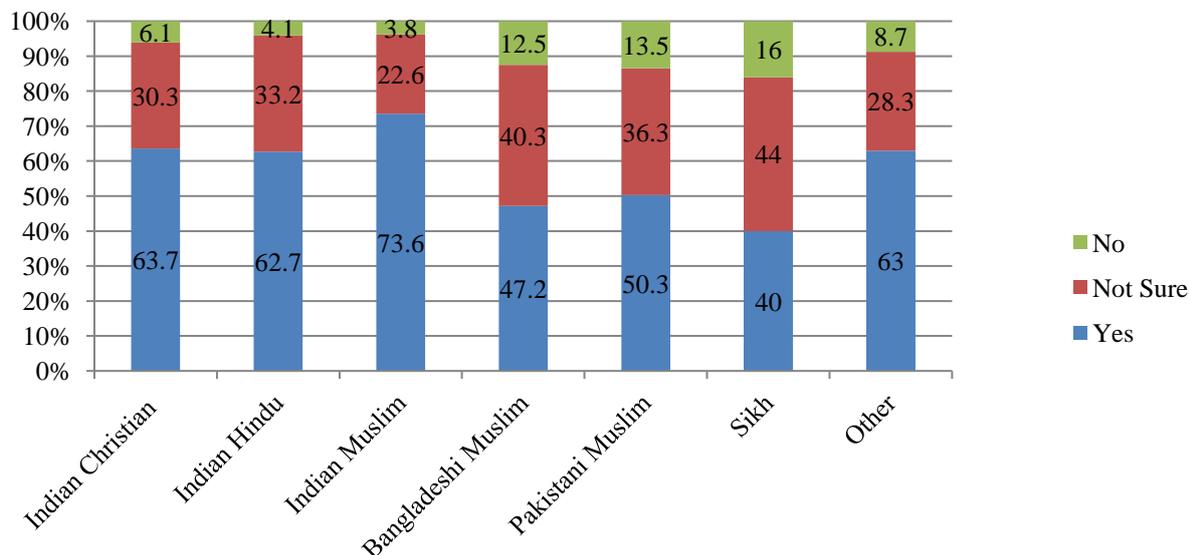
Within the questionnaire, respondents were informed that it is possible to donate a kidney to a close relative or friend whilst still alive. Respondents were then asked ‘If a close relative or friend of yours needed a kidney transplant, would you be willing to consider becoming a live donor?’. Compared to all other questions, the live donor option received the most positive replies, as only 8% answered no and 33% indicated they were unsure about this approach (Figure 13).

Figure 13 Would you be willing to consider becoming a live donor?



In the Muslim community (Figure 14), live donation was more accepted by Indian Muslims (73.6%); the Sikh community (16%) were more unwilling to consider live donation compared to other communities.

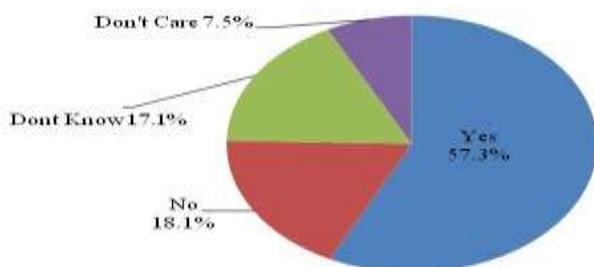
Figure 14 Willingness to be a live donor and ethnic community perception



1.4 Perceptions of an Opt Out System

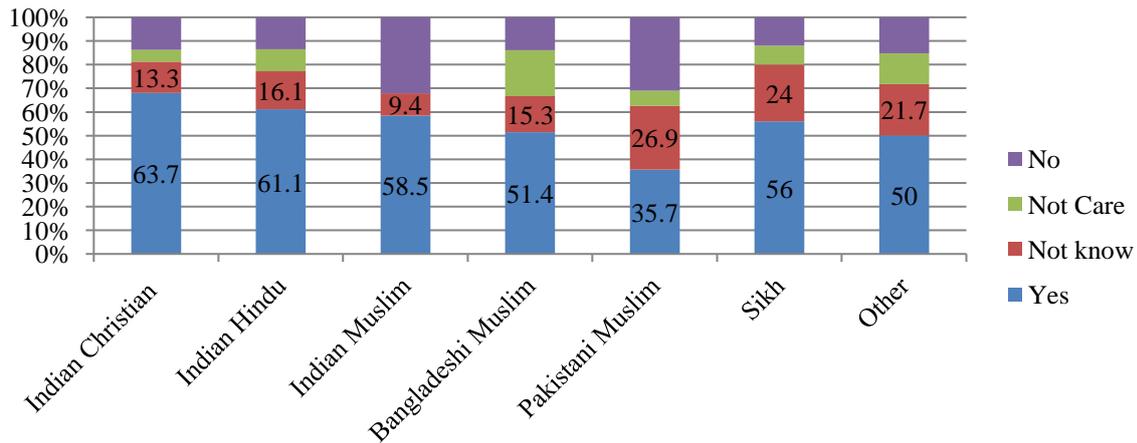
To ensure responses to questions were reliable and participants understood the meaning of the questions, clarification was offered in the questionnaire. Respondents were informed that ‘In some countries it is lawful to take kidneys from any adult who has just died, unless that person has specifically forbidden it while they were alive’; participants were then asked whether they would oppose such a system in the UK. Only 18.1% opposed the idea and 57.3% were in favour of an opt out approach; a further 24.6% were unsure or had no opinion (Figure 15).

Figure 15 Do you support an Opt Out system in the UK?



The Muslim ethnic communities appeared less in favour of such an approach when compared to other groups (Figure 16), particularly the Pakistani Muslim community. Analysis of the different ethnic communities rather than simple religious groups identifies differences that create barriers for some cultural groups and not others of the same religion – an important factor when providing pertinent education.

Figure 16 Community perceptions



Discussion

The primary aim of this study was to identify the perceptions and beliefs of South Asian people and to gain an understanding of the barriers towards organ donation. The findings and interpretation of the study indicated a willingness to register was significantly associated with attitude. Responses highlighted concerns shared across groups that exposed the need for health professionals to establish a more trusting relationship with the South Asian people to alleviate the strongest and widespread attitude and misconception of mistrust, associated with the medical profession and retrieval of organs within the UK.

This article highlights that seemingly intractable factors, such as religion and culture, are often tied to more complex issues such as distrust in the medical system, misunderstandings about religious stances/grey areas, lack of awareness, media misinterpretation, myths and knowledge from their home countries and ethnic roots as reasons behind the scarcity of organ donors from South Asian communities. So, it is obvious that potential targeted educational approaches must include culturally appropriate strategies to engage minority groups, especially through religious or cultural leaders, and make information about the donation process and its positive

outcomes more widely available. It was interesting to note that gender and education status did not affect the view of individuals, but their lack of awareness of the organ donation topic directly influenced the individual's decision to join the Organ Donor Register.

Kidney transplantation is highly cost-effective, particularly in relation to the National Health Service (NHS) expenditure, and is the treatment of choice for many patients with Chronic Kidney Disease (CKD) as opposed to dialysis therapy. The UK National Transplantation 2020 Strategy is a call to action directed at four key groups and seeks to increase organ donation and transplantation (29). If transplant rates increase, it will have a beneficial impact on resources and enable patients currently on dialysis to enjoy an increased quality of life. The results of this study have the potential to make a more modest impact in society and will be a long-term benefit to both the NHS and the people it serves, particularly those with CKD from a South Asian background. Through increased transplantation, the NHS is able to provide cost effective and gold standard treatment for patients with organ failure who are on the transplant waiting list. The outcomes demonstrated in this study provide an insight to understanding why organ donation within the South Asian community in the North West of England is much lower than that of other ethnic groups, as well as identify the perceptions of presumed consent and the cultural/religious influences on this topic.

Indeed, this article highlights how living donation could be increased and encouraged as an alternative way to increase donated organs to enable individuals to observe the tangible benefits of 'gift of life' as compatible to their underpinning beliefs of helping and giving a chance of life. It also explains that apprehension and mistrust around organ and tissue donation needs to be continually addressed, and health professionals' role in educating the South Asian community to alleviate such fears. Also, the importance of talking about opt out implementation was highlighted, as this idea was opposed by less than 20% of participants.

Studies by Conesa et al. (2003), Haustein et al. (2004), Bracellos et al. (2005) among the general population in the UK explains that higher levels of educated participants were more supportive of deceased organ donation because of their greater knowledge and awareness of the importance of the topic (30,31,32). But, worryingly what is clear from this study is that highly educated South Asian people are not knowledgeable about organ donation. This finding is supported by Gaugher et al. (2013) study among the Asian University students in the UK,

identified the lack of awareness and little knowledge about the organ donation topic (33). Indeed, the sample size demonstrated that young people growing up in the UK had limited knowledge and lacked awareness, often influenced by family beliefs and community elders. This reinforced the need for education in schools and universities, using South Asian social and digital media, with educational techniques that target the whole family, particularly to influence and support the next of kin's decision for deceased organ donation.

Weakness of the study was the composition and failure to recruit a representative sample from different communities and education status. Even though AP attempted to obtain the equal sample from different religious and ethnic groups, they were unsuccessful in reaching the Bangladeshi and Sikh communities. Also, despite of the researcher's best effort of getting a balanced sample with different education status by providing translated questionnaires and attending events in different settings, achieved only 2.1% of sample with low or nil education status. Therefore, the sample provided is not representative of the population of interest in different aspects, such as community (ethnicity and religion), age and education. The authors also acknowledge there is a small risk for the potential of data duplication, as participant identifier data was not collected.

Conclusions

New knowledge generated from the study (see Table 7) includes the confirmation or identification of new or persistent barriers, changing or new perceptions and attitudes within the South Asian migrant population in the UK, and the intelligence of what educational approach may work and for whom. This knowledge will contribute significantly to moving this significantly important topic forward.

Table 7 Summary of Key Findings

Key Barriers

- Lack of knowledge and awareness
- Misinterpretation/guidance of religion/not clear, grey area/worry about tempting fate
- Lack of knowledge from home country
- Mistrust in the medical system/worry about misuse of organs, including organs giving to patients who are non-compliant with post-transplant care, e.g. alcoholic

- Negative influence of media

Key Findings

- Provides an evidence base as one of the largest data sets of South Asian perspectives in respect to organ donation in the UK
- Higher education level does not provide increased knowledge on organ donation topic
- Lack of knowledge and awareness of organ donation whilst growing up in school and organ donation topic is not reflected as important in health education, such as no smoking, cancer awareness campaigns, etc.
- It is important to concentrate on communities rather than religion and ethnicity, as there is a difference in their beliefs and attitudes. From the literature review it was evident that this is the first study which looked at different community perceptions in detail, with a sample size of 907 in the UK.
- Need to concentrate on the younger generation to clarify their mistrust in medical care/misuse of organs, and the secondary effect of social and digital media input
- Lack of knowledge among elders reflecting negative on youngsters' decision making

Policy considerations

- Presumed consent (opt –out) as a possible future option
- Living related donation as a favorable option
- Education in the community is crucial to move forward and facilitate organ donation from South Asian people.

Disclosures:

The authors declare no conflicts of interest

Funding:

The British Renal Society and NOVARTIS Pharmaceuticals have provided some research funding to complete the study.

Appendix-1

QUESTIONNAIRE

(Questionnaire used by Morgan et al. 2006)

Research code:

Identification number:

This Questionnaire asks your views on kidney donation.

Everything you tell us will be treated as strictly confidential.

Please tick the box in answer to each of the following questions

Section A

1. Did you know that it is possible to leave your kidneys for transplant in somebody else after your death?

Yes

No

2. Do you know someone who has received, or is waiting to receive a kidney?

Yes

No

3. Have you ever thought about donating your kidneys after your death?

Yes, I have thought about it seriously

Yes, but not very seriously

Not sure

No, I have never thought about it

4. Have you ever discussed donating your kidneys with a partner, family member, or friend?

Yes

No

5. Are you registered on the NHS organ donor register and/ or do you carry a donor card?

Yes (please go to question 7)

No

6. Would you be willing to register as a kidney donor, and donate a kidney for transplant after your death?

Yes, definitely

Yes

Not sure

No

No, never

In some countries there is an ‘opt-out system’ which means it is lawful to take the kidneys from any adult who has just died, unless that person had specifically forbidden it while they were alive.

7. How would you feel if this kind of system was introduced in the UK?

I would strongly support it

I would support it

I would not care either way

I do not know how I would feel about it

I would oppose it

I would strongly oppose it

Section B: Below are statements that reflect what people think and feel about organ donation. Please read each statement and decide how much you agree or disagree with it. There are no right or wrong answers. Your opinion is valued.

8. If I were a kidney donor, I would not mind who received my kidney after my death.

Strongly agree

Agree

Disagree

Strongly disagree

9. It is important to me to know that I could give someone else a chance of life after my death.

Strongly agree

Agree

Disagree

Strongly disagree

10. I worry that medical teams may not try as hard to save the life of a person they know has agreed to donate their organs.

Strongly agree

Agree

Disagree

Strongly disagree

11. I am uneasy with the thought of my body being cut up after my death.

Strongly agree

Agree

Disagree

Strongly disagree

12. Donating my organs is a way of serving God.

Strongly agree

Agree

Disagree

Strongly disagree

13. I worry that if I agree to donate my organs for transplant, they might be used without my consent for other purposes like medical research.

Strongly agree

Disagree

Agree

Strongly disagree

14. Registering to be a donor or carrying a donor card is like tempting my own death.

Strongly agree

Agree

Disagree

Strongly disagree

15. Donating your organs when you die is a good thing to do.

Strongly agree

Agree

Disagree

Strongly disagree

16. An intact body is needed for the life hereafter.

Strongly agree
Disagree

Agree
Strongly disagree

17. There is currently an urgent need for more kidney donors. Have you seen, read, or heard about this need from any of the following sources:

| | |
|------------------|----------|
| Television | Radio |
| Newspaper | Magazine |
| Leaflet | Poster |
| Religious leader | |

18. How well informed do you feel about registering as a kidney donor?

| | |
|-----------------------|------------------------|
| Very well informed | Fairly well informed |
| A little informed | Not very well informed |
| Know nothing about it | |

19. It is becoming increasingly possible to donate one of your kidneys while you are still alive to a close relative. If a close relative of yours needed a kidney transplant, would you be willing to consider becoming a live donor?

| | | |
|-----------------|-----|-----------|
| Yes, definitely | Yes | |
| Not sure | No | No, never |

Some information about you

20. What is your ethnic group? **Asian or Asian British**

| | | |
|----------------------------|-------------------------|-------------|
| Indian | Pakistani | Bangladeshi |
| Any other Asian background | (please describe) _____ | |

21. What kind of education did you receive?

| | |
|-------------------------------------|---|
| Primary education | |
| Secondary education | Further education – commercial or technical |
| University or polytechnic education | No school education |

22. Are you?

| | |
|------|--------|
| Male | Female |
|------|--------|

23. What is your religion?

| | |
|-----------|-------|
| Muslim | Hindu |
| Christian | Sikh |
| Other | |

24. What is your age? _____

25. Are you?

| | |
|----------------------|--|
| In paid employment | (please state occupation) _____ |
| Student | |
| Retired/ Not working | (please state previous occupation) _____ |

Thank you

Date: Research code:

Identification number:

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