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BAME Londoners' Views on Organ Donation

Final Report

Agroni Research

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Introduction and background

A number of studies have shown that there is a greater incidence of type 2 diabetes and kidney disease amongst the UK's BAME communities. It is commonly acknowledged that diabetes often leads to organ failure. According to NHS Blood and Transplant (NHSBT) there are 1,300 Londoners currently waiting for an organ transplant and 62 per cent of them are Black or Asian. NHSBT further recorded that this is reflected in the demand for kidneys nationally; in 2017/18, the number of people from BAME communities waiting for kidney transplants in the UK was far greater proportionately than their representation in the UK's population. According to NHSBT, BAME groups made up 35 per cent of the waiting list for kidney transplantation despite representing only 11 per cent of the UK population.

In May 2018 Agroni Research conducted a survey of 1000 participants from England's BAME communities on behalf of NHSBT. The survey showed that only 37 percent of participants said they "definitely would not donate" their organs and 33 percent were opposed or strongly opposed to organ donation. Only 34 per cent of BAME people living in England "supported" or "strongly supported" organ donation. The number of people who said that they would definitely donate some or all of their organs was only 11 per cent. These figures contrast markedly with the picture nationally in which, according to NHSBT, over 80 per cent of the adult population of England stated that they supported organ donation.

Within this context the London Assembly commissioned Agroni Research to conduct a further survey of 400 BAME participants to explore the reasons for and potential solutions

to the health inequalities found amongst London's BAME communities regarding organ donation.

The main purpose of this research was to explore the following issues amongst diverse BAME communities in London:

- Levels of support for organ donation amongst London's ethnic minority communities;
- Reasons why people in these communities would or would not donate their organs;
- Levels of awareness within these communities of current organ donation health inequalities.

Between 22nd November and 3rd December 2018, Agroni Research conducted 459 interviews across the African, Caribbean, Bangladeshi, Pakistani, and Indian communities resident in Greater London. The interviews were conducted in several London boroughs with high density BAME populations, namely Tower Hamlets, Newham, Camden, Croydon, Redbridge, Southwark, Barking and Dagenham, and Hounslow. 459 interviews were initially conducted and responses to 434 were included in the analysis. In total 25 questionnaires were rejected either for minor errors or because they were incomplete.

This report is divided into four main sections:

- Our approach and methodology
- Executive summary (demography and summary findings)

- Key findings (Level of support for organ donation, reasons why people would or not donate their organ and level of awareness)
- Conclusions and recommendations

Our approach and methodology

Upon the commission of the research, Agroni met with the London Assembly research team to agree upon the final design of the project, including sampling points, participants' screening, and the design of the final questionnaire. We agreed to focus on attaining a deep understanding of BAME communities regarding their attitudes towards organ donation as well as identifying the optimum, inclusive approach for future engagement between the London Assembly and London's BAME communities.

It was agreed that Agroni would conduct 400 face-to-face interviews in Greater London. It was also agreed that the survey would be conducted in six inner London and two outer London boroughs using approximately 20 sub-locations. The sampling points and sizes were more or less proportionate to the size of the BAME population for the given sampling point.

Before commencing fieldwork Agroni conducted 20 pilot interviews to test the questionnaire for consistency and user-friendliness. Upon completion of the pilot survey, Agroni provided a face-to-face briefing and training to a team of experienced bilingual interviewers. The languages covered in this survey were Bengali, Gujarati, Hindi, Punjabi and Urdu.

This was a paperless survey. All our interviewers used tablets for conducting the survey and were mostly able to use online facilities to carry out the face-to-face interviews. In order, however, to minimise any interruptions due to the lack of internet access, our interviewers were able to conduct the survey offline when appropriate. As soon as they were able to access the internet, they easily uploaded the survey and use full editing facilities to double check the questionnaires for any errors before submission. It is for this reason that the questionnaire contains instructions for both online and offline users.

The survey was conducted mainly in public spaces including streets, community facilities, cafes, colleges and libraries. Only a small number of interviews (less than 10%) were conducted in people's homes.

Methodological Limitations:

It is important to note the limitations of this study as follows:

- The study was carried out within a very short period. Greater reflection upon the nature of the sample might have been possible and useful within a longer time frame. Educational attainment as well as social class, for example, may have been an important variable. The high proportion of participants who had only arrived in the UK as adults may also have affected the data.
- It was also difficult to ascertain the precise nature and relevance of religious and cultural beliefs and adherence on the basis of the survey questionnaire.

- Undertaking analysis by cross-tabulations and exploring the data in greater depth has meant that many of the figures are small and thus there needs to be some vigilance in reading the following report.
- Nonetheless, the data does reveal notable patterns that may need further exploration as detailed in the Conclusions.

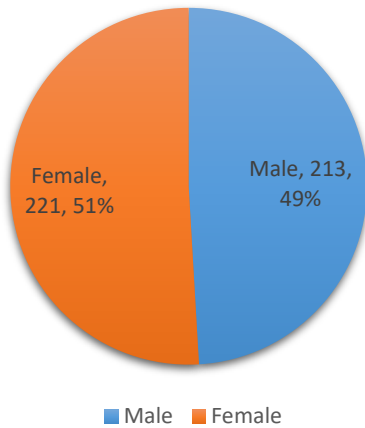
Demographic Breakdown

For this survey Agroni, conducted 459 interviews in total. 59 interviews were over the original target of 400 to allow margin for potential rejections so as to maintain the highest standard of data integrity. 25 questionnaires were nonetheless rejected either for minor errors or for incompleteness. Therefore, the findings are based on 434 complete interviews. The summary of the findings is highlighted below.

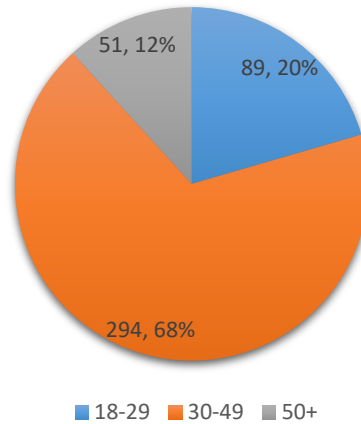
Out of 434 interviews, 213 (49%) participants were male and 221 (51%) were female (Pie 1). 89 (21%) participants were between the ages of 18-29, 294 (67%) were between the ages of 30-49, and 51 (12%) were 50 years of age or older (Pie 2). As can be seen from Pie 3, 84 (20%) participants were from the black African community, 82 (19%) participants each were from the black Caribbean and Indian communities, and 93 (21%) each were from the Pakistani and Bangladeshi communities.

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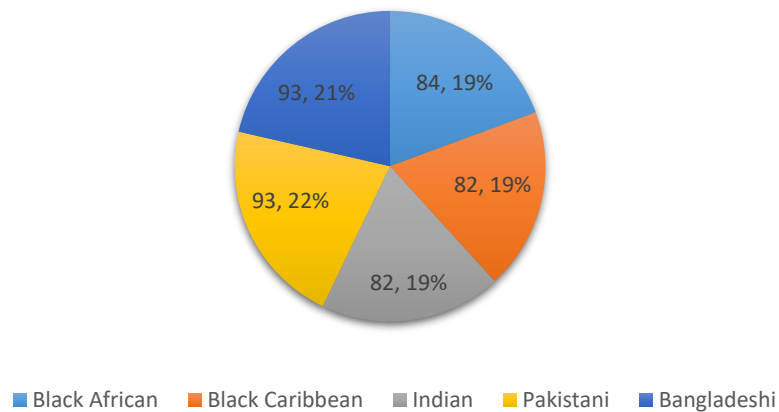
Pie 1 - Gender



Pie 2 - Age Group

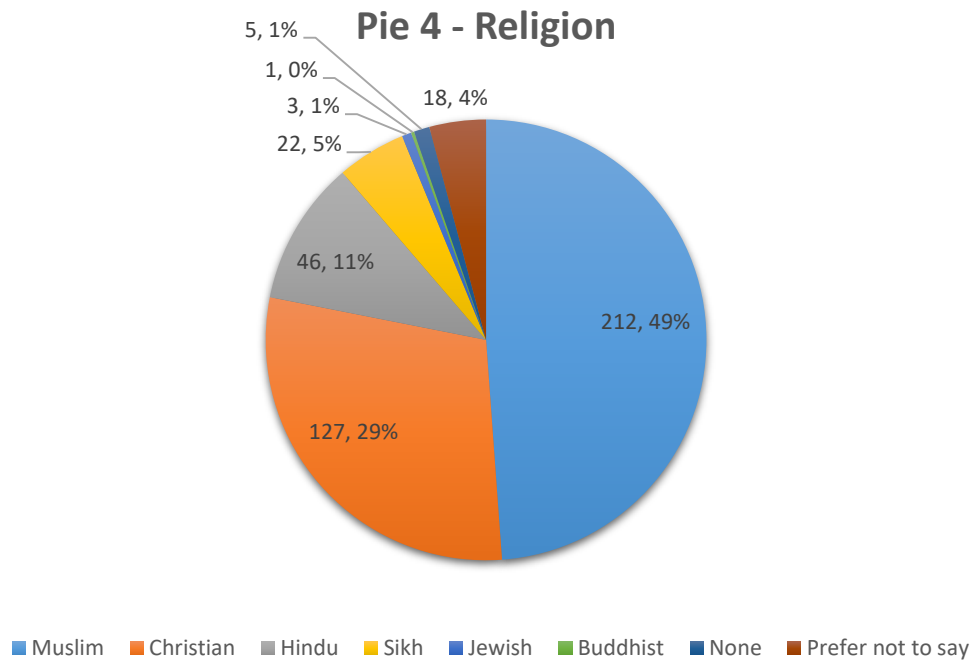


Pie 3 - Ethnicity



In terms of religious affiliation, 95% of participants stated that they adhered to a faith or belief. The detailed breakdown is as follows: 212 (49%) were Muslim, 127 (30%) were Christian, 46 (11%) were Hindu, 22 (5%) were Sikh, 3 (<1%) were Jewish, and 1 (<1%) were Buddhist. There were 5 (1%) participants who self-identified as atheists, and 18 participants (4%) who preferred not to disclose their faith (Pie 4).

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The generational status of these 434 participants was also recorded. 227 (52%) participants were 1st generation migrants (born and brought up overseas). There were 75 (17%) participants who were born overseas but moved to the UK and have been living here since childhood, who we classify as 1.5 generation migrants. The rest of the 132 (31%) participants were 2nd generation, born in the UK to migrant parents. Please note that for the purposes of this study 1.5 generation participants are grouped together with members of the 2nd generation, and represent 48 per cent of our total number of participants.

Summary Findings

- A high proportion of London's BAME population does not appear to be willing to donate their organs, totalling 183 participants (42%, N= 434).

- The number of people willing to donate their organs is roughly the same as the number of people who are unsure about organ donation. 122 participants said they were willing to donate their organs compared to 124 participants who were unsure about donation (both representing 28% of the total sample).
- Only 5 people stated that they had already registered as a donor (1%).
- Of the people who were already donors or were willing to donate their organs, 37 participants (29%) said the main reason why they decided to do so is because they felt a 'social responsibility' to register as a donor. Another group of 35 participants (28%) stated that that they were willing to donate their organs in order to save someone's life.
- Of the participants who were not willing to donate their organs, the majority argued that organ donation was in conflict with their religious belief or faith. This amounted to 93 participants (51%). 35 participants (19%) also said that organ donation conflicted with their cultural beliefs. There is thus substantial evidence to support the argument that many participants considered organ donation to be in conflict with their religious belief or faith.
- Nonetheless, of those who were unsure (N=124), 30 participants (24%) said they did not know whether their religion permitted organ donation and the same percentage felt they did not know enough about the subject. Furthermore, by far the most popular reason given by this group as to why they were uncertain about organ donation was simply that they had not thought about it. This was cited by 42% (N=52) of participants.

- When the 307 participants who were unwilling or unsure about participating in organ donation were asked what would most likely make them decide to donate, responses seemed to be almost evenly spread between their need for more information (21%), being encouraged by someone from their faith/community (22%), or if they knew someone personally who needed or who had an organ donated (26%). Interestingly, only 28% of participants argued that nothing would make them become a donor. Of particular note, only seven participants stated that they would agree to organ donation on the basis of their being a shortage of organs for ethnic minorities. Participants were additionally asked if they had spoken to their families regarding organ donation, but an overwhelming majority – 80% (N=434) – said they had not. By contrast, only 20% said that they had.
- Of those 87 participants who had spoken with family members about organ donation, 48% said they had informed their families about their decision but 52% had not. When asked if their families understood and agreed with their decision, approximately half said 'yes', with only a small number (17%) reporting their family had not either understood or agreed with them. 42 participants (48%) answered 'yes'. Of note, a little over a third of participants (34%) were unsure whether or not their families supported their decision.
- When the 347 participants who had not discussed organ donation with their families were asked for a reason why no conversation had taken place, 24% stated that it simply had not occurred to them to discuss the matter. A further 20% believed that the discussion would upset family members.

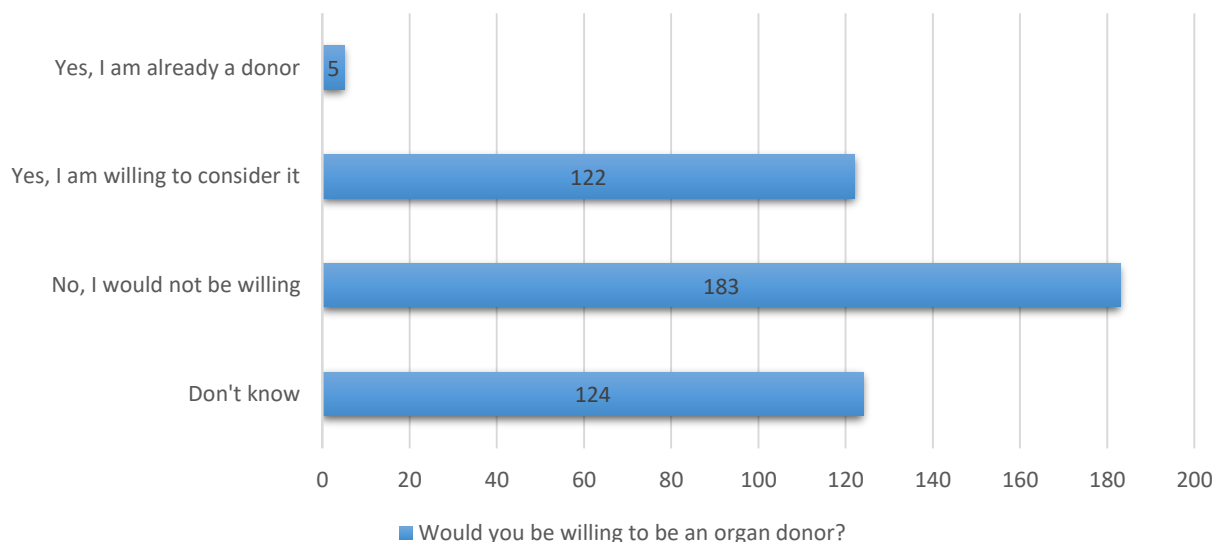
- In responding to the question whether they were aware of the Organ Donation Bill currently going through the parliament that would change the donation system from opt-in to opt-out, an overwhelming majority of 361 participants (83%, N=434)) stated they were not aware. Only 73 (17%, N=434) participants said they knew of the Organ Donation Bill.

Key Findings

Levels of support for organ donation

- Out of the 434 participants, the majority, just over 42% (183 participants) said they were unwilling to donate. On the other hand, over 29% (127 participants) answered that they were either already donors or were willing to donate their organs. Notably, almost the same number i.e.124 participants said they were not sure about whether they would be willing to become organ donors (Bar 1).

Bar 1 - Would you be willing to be an organ donor?



- Of the 122 participants who answered that they were willing to donate their organs, a small majority were female – 53% compared to 47% who were male. On the other hand, males were more certain as to whether they would not be willing to donate; of the 183 participants who said they would not be willing to donate, 54% were male and 46% were female. Of those that were unsure about organ donation, again there was a preponderance of females.
- In terms of age breakdown, there appear to be some interesting trends with uncertainty about organ donation decreasing by age. Nonetheless, of those who were uncertain about organ donation, 27% were in the 18-29 age range, rising to 39% among 30-39-year olds and decreasing to 26% of 40-49-year olds. Notably, in the 50+ age range, although the numbers are small, there was far more certainty with 30 participants out of 51 50+ year olds saying that they would not be willing to donate and only ten participants who were uncertain.

Table 1

Willingness to donate	18-29 years	30-39 years	40-49 years	50+ years	Totals
Yes, I am already a donor/Yes, I am willing to consider it	30 (24%)	47 (37%)	39 (31%)	11 (9%)	127 (100%)
No, I would not be willing	25 (14%)	72 (39%)	56 (31%)	30 (16%)	183(100%)
Don't know	34 (27%)	48 (39%)	32 (26%)	10 (8%)	124 (100%)
Column Totals	89 (21%)	167 (38%)	127 (29%)	51 (12%)	434 (100%)

- It also appears that a reluctance to donate at all follows a similar pattern. 14% of those unwilling to donate were in the 18-29 age range, 39% in 30-39-year olds, but falling to 31% in 40-49-year olds.
- In terms of ethnicity, the highest levels of support towards organ donation came from the Indian and Black Caribbean participants. Almost half (45%, N=82) of Indian participants answered that they were willing to donate and 40%, (N=82) of Black Caribbean participants also said they were willing to donate their organs. In contrast, nearly half (48%, N=84) of Black British Africans were not willing to donate and similar percentages were to be found among Pakistanis (44%, N=93). Among Bangladeshis, however, this figure not to be involved in organ donation rose to 54% (N=93).
- Of particular note, there was almost the same percentage of those who were unwilling as those who were uncertain (i.e. 50%, N=183 and 56%, N=124) respectively) about organ donation who identified as either Bangladeshi or Pakistani. This contrasts with those from the Indian and Black Caribbean communities who together represented only 23% (N=124) of participants who were not certain to donate. Even including those from the Black African community, this figure of participants uncertain to donate only rose to 44% (N=124).

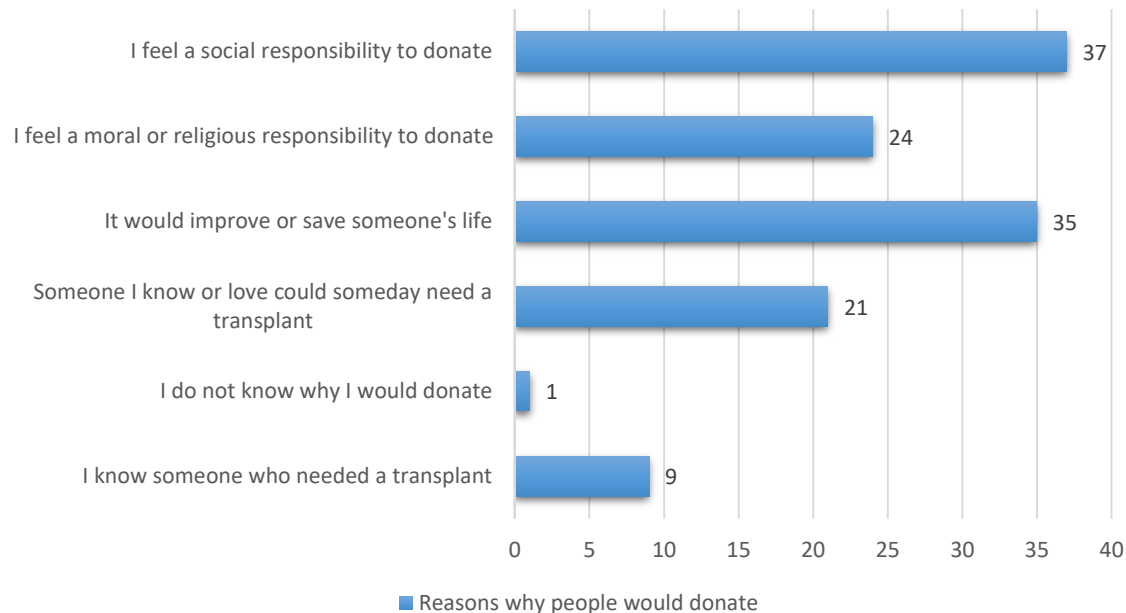
- This analysis seems to correlate with participant's religion or faith. It appeared, for example, that Muslim participants were overwhelmingly against organ donation. Indeed, 51% of Muslim participants answered that they were not willing to donate their organs out of a total of 212 interviewed i.e. accounting for 59% (N=183) of all those who were not willing to be donors. Furthermore, of those who were not certain whether they might donate a similar percentage (58%, N=124) identified as Muslim i.e. just over a third of all those who identified as Muslim (34%, N=212). The greatest support for organ donation came from Hindu and Sikh participants. Just over half (52%) of 46 Hindu participants, and nearly two-thirds (64%) of 22 Sikh participants interviewed answered that they were willing to donate their organs. Christian participants also displayed a favourable opinion towards organ donation, though not only marginally. Out of a total of 127 Christian participants interviewed, 41% said that they were willing to donate their organs. A slightly lower figure of 37% Christian participants said they were not willing to donate.

Reasons why people would donate

- The 127 participants (29%) who answered that they were already donors or were willing to donate their organs were asked to give a reason as to why they would do so. Although opinion was roughly spread over the available options, the three most popular reasons were as follows: "I feel a social responsibility to be a donor" (29%), "It would improve or save someone's life" (28%) and "I feel a moral

or religious responsibility to be a donor" (19%) (Bar 2). Furthermore, of the 37 participants who chose the reason identifying social responsibility, the majority were Muslim (N=10) or Christian (N=16).

Bar 2 - Reasons why people would donate



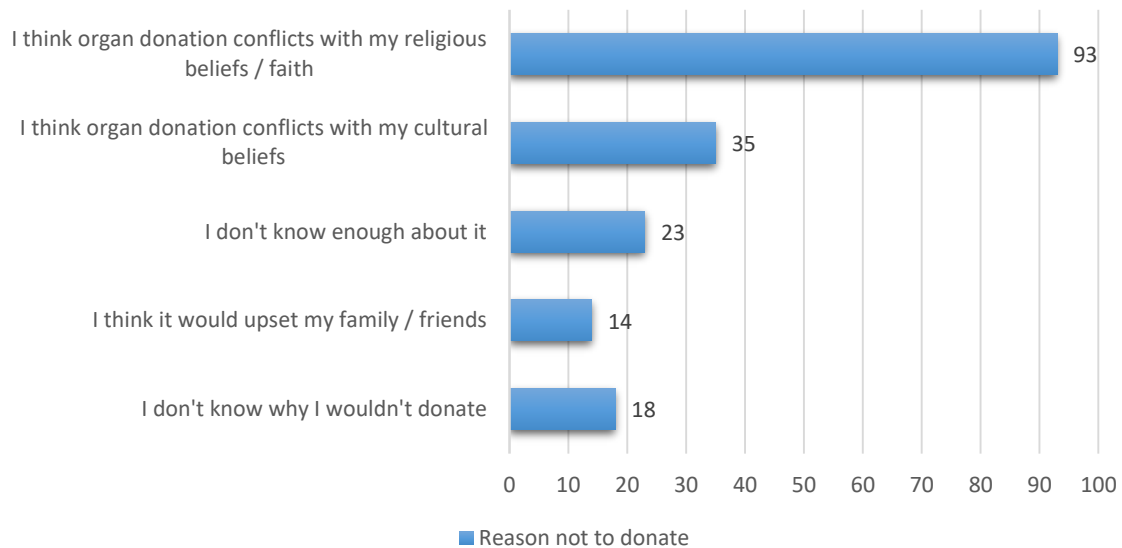
- Breaking these figures down by gender revealed a slightly different picture and drew attention to the variation in male/female perceptions. For males there were two clear reasons i.e. "It would improve or save someone's life", and that "I feel a social responsibility to be a donor", being chosen by 19 and 18 of the 59 male participants respectively. For females, on the other hand, although both these reasons were popular (19 and 16 participants respectively out of 68 females), there was also almost equal support (16 participants) for, "I feel a moral or religious responsibility to be a donor".

- There did not appear to be any discernible patterns in terms of either age or ethnicity, possibly, in part, due to the small number of participants
- More interesting were these figures when broken down by religion. 29% out of the 56 Christian participants who had become or were willing to become donors chose again, "I feel a social responsibility to be a donor". Among the Muslim population, however, even though a majority of those interviewed were against organ donation, they still formed a high proportion of those who were willing to become or had become donors and they, too, cited the same reason as those Christian participants who were favourably inclined.

Reasons why people would not donate

- A total of 183 participants who answered that they were not willing to donate were then asked to give a reason. By far the most popular statement selected among all participants was, "I think organ donation conflicts with my religious beliefs / faith". (51%) (Bar 3). Nearly two thirds of this group were male (56 participants) and just over a third were female (37 participants).

Bar 3 - Reasons why people would not to donate



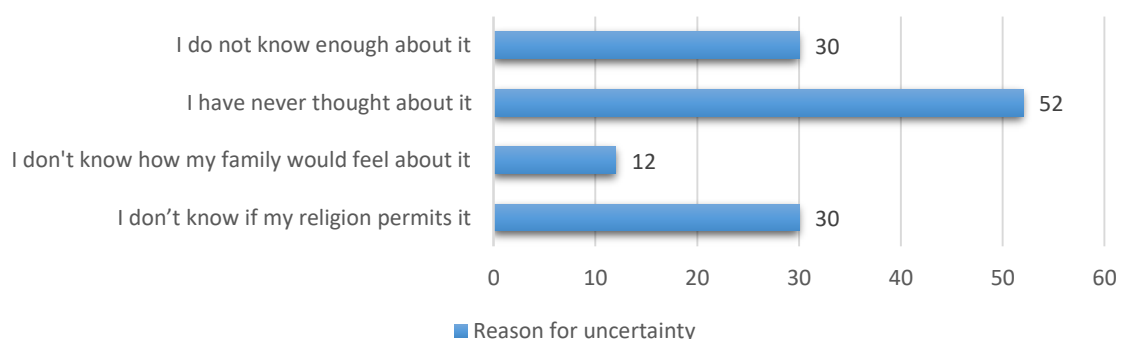
- The reason was also the most popular for dissent among all age groups as well as across ethnicities, in particular among Bangladeshis with 40 out of 50 participants citing this reason. Only Indian participants picked a different reason why they would not donate their organs: 9 out of 23 Indian participants agreed with the statement “I think organ donation conflicts with my cultural beliefs”.
- By far the majority of those who also chose this reason were Muslim at 81% (N=93) compared to the 14% who identified as Christian. Within the group of Muslims who would not be willing to donate their organs, almost 70% chose this reason (N=108). On the other hand, the most popular response from the Christian participants was, “I think organ donation conflicts with my cultural beliefs”. This statement was chosen by 18 of the 47 (38%) Christian participants.

- Notably, whereas only one participant did not know why they would donate, substantially more were unclear why they would not donate i.e. almost 10% of those who would not donate (N=183). This, perhaps, indicates that there is greater certainty among those who would donate as to their decision but far less clarity among those who would not.

Reasons why people are unsure

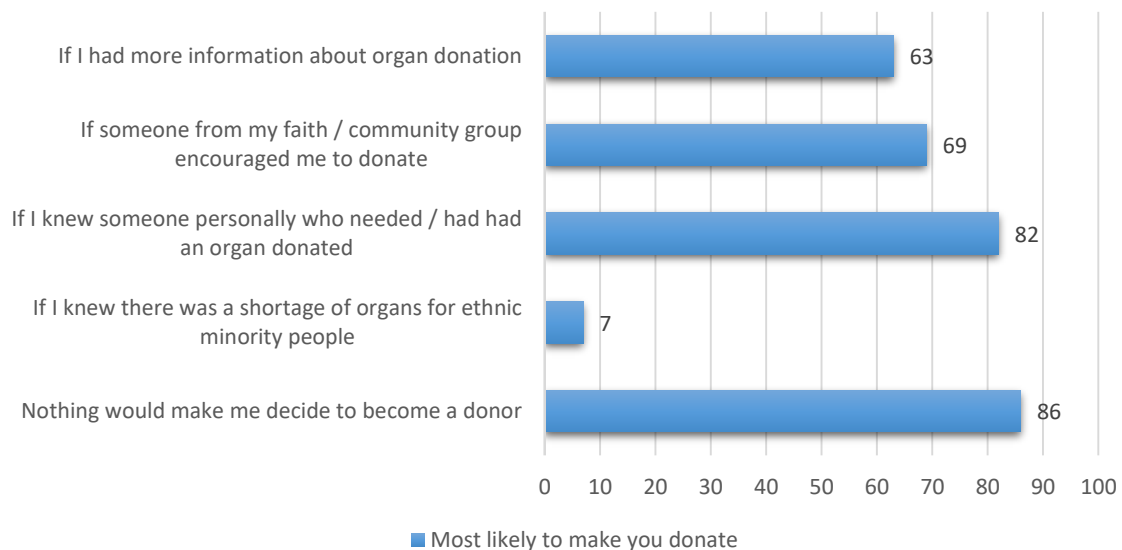
- Nonetheless for the substantial group of participants (N=124) who were unsure about organ donation, it was uncertainty both as to whether it was allowed by their religion as well as the lack of available information, amounting to 25% in each case. For the majority of participants (42%, N=52), however, the most significant reason cited was that they simply had not thought about it (Bar 4). It was evident, too, that this was the case for all ethnic groupings as well those who were Muslim (49%, N=72). For Christians, however, the lack of information and awareness tended to be marginally more important than whether they had thought about it.

Bar 4 - Reason why people are unsure



- The importance of information was also clear when those who were either not willing or were unsure as to whether they were willing (71%, N=307) were asked what might make them decide to become a donor with 21% (N= 63) believing they would need more information. 27% (N=82) of participants said they might consider organ donation if they knew someone who needed or who had benefited from a donated organ, and 22% (N=69) might agree if someone from their faith or community group encouraged them to donate. However, the largest proportion (28%, N=86) declared that nothing would make them become a donor (Bar 5). Almost half (42.5%, N=68) of both Bangladeshi and Pakistani participants who answered this question, believed that nothing would encourage them to donate. On the other hand, only 38% (N=70) of those participants who were Muslim said nothing would make them decide to become a donor, pointing again to the complexity of the relationship between ethnicity and faith.

Bar 5 - Most likely to make people donate



- This complexity is again reflected through looking at the cross-tabulation between those who would not be willing to donate and reasons that would prompt participants to change their minds, because 27% of the 93 participants who believed that organ donation conflicted with their religious belief also thought that they might assent if someone from their faith or community group encouraged them to do so. This was also the case for over half (51%, N=35) of participants who believed that organ donation conflicted with their cultural beliefs.

Discussions with Families

- Participants were also asked if they had spoken with their family regarding organ donation. The vast majority (80%, N=434) said they had not. There did not appear to be any evident demographic pattern in this response.
- Despite the small number, of those (N=87) who had talked about organ donation with their families, participants were roughly split between those who had told their families and those that had not (48% and 52% respectively). However, it was notable that fewer males appeared to have told family members their actual decision than females. On the other hand, within this group of male and female participants, a relatively higher proportion believed that their families agreed with their decision than those who did not (48% and 17% respectively) with more

males supporting this assertion than females. It is also notable that just over a third (34%) of this group didn't know how members of their family would respond.

- A larger proportion of participants who had spoken with their families were also willing to donate their organs, compared with those who were not willing. A quarter (25%) of the 122 participants who were willing to donate their organs had spoken to their families about organ donation, compared to just over a fifth (21%) of the 183 participants who said they were unwilling to donate their organs.
- More revealing, perhaps, is that for the majority of participants (52%) i.e. those who had not talked about their decision with their families, although there seems to be little difference in behaviour between males and females, the most common reason was that it simply had not occurred to them to discuss it. Nearly a quarter (24%) of the 347 participants who had not discussed it with their families. 45% of these (N=82) were male and 55% were. Females, however, were also more likely not to know why they had not discussed it with their family. 20% of those who had not discussed it with their families (N=347) also believed it would upset them to embark on such a discussion.
- The reasons why participants did not discuss organ donation with family members also tended to vary by age. For those over 45 years, the proportions of those who said it would upset their family and those for whom it had not occurred

to them to discuss it were the same (25%). A roughly similar pattern can be noted for the 25-29 year age group.

- Uncertainty remains, nonetheless. Nearly 30% of all participants were unsure as to whether they would consent to a family member's organs being donated if they knew what their wishes were, while nearly 40% were unsure as to whether they would consent when then they did not know what the wishes of the family member were. In both scenarios, females appear to be more uncertain than males.
- On the other hand, whereas the majority (43%) of all participants would agree to donating a family member's organs if they knew they were on the donor list (this may well include either those who were not willing to a be donor or were not sure if they would themselves donate), well over half (56%) of participants were emphatic that they would not agree if they did not know their relative's wishes. The majority of participants in this group were male (53%, N=241)

Awareness of Organ Donation

a) General

- The following table details the answers to Question 18 which asked participants to state whether they believed certain statements were either true or false (Table

2). Breaking down the figures by gender, religion or ethnicity did not reveal any particular patterns.

Table 2

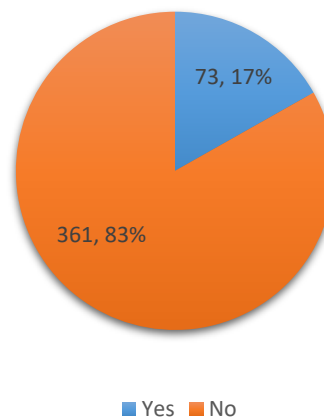
Thinking about organ donation, do you think these statements are TRUE or FALSE?			
	TRUE	FALSE	Response Total
White patients are more likely to need organ donations than ethnic minority patients	24.4% (106)	75.6% (328)	434
Once you are on the organ donor list, you can't change your mind	21.9% (95)	78.1% (339)	434
Having a donor from a similar ethnic background increases the chances of a transplant being successful	57.1% (248)	42.9% (186)	434
A family member can choose to override a person's wish to donate their organs	47.7% (207)	52.3% (227)	434
You can decide which organs you want to donate	82.0% (356)	18.0% (78)	434
You have to be dead to donate any organs	32.5% (141)	67.5% (293)	434
Being an organ donor will negatively affect the quality of end of life treatment I receive	30.0% (130)	70.0% (304)	434
Diabetes is one of the leading reasons why people need to have an organ transplant	47.7% (207)	52.3% (227)	434
		answered	434

b) Awareness of Organ Donation Bill:

- When participants were asked if they were aware of the Organ Donation Bill that is going through parliament, changing the opt-in system to an opt-out, an

overwhelming majority said that they were not aware of such a bill. Only 73 (17%) participants answered that they were aware of the bill, compared to 361 (83%) who answered that they were not (Pie 5).

Pie 5 - Are you aware of the Organ Donation Bill going through Parliament, which changes the current donation system from opt-in to opt-out?



- The awareness of the Organ Donation Bill was higher among male participants. 59% (N=73) of those who were aware were male compared to 41% who were female.
- Despite the small numbers, in terms of age, awareness regarding organ donation appeared to increase with age until the age of 40 after which awareness declined. Pakistani participants appeared to be marginally more aware of the Organ Donation Bill than any other ethnic group. Indeed, a quarter (25%) of Pakistani participants (N=93) were aware of the Organ Donation Bill. Black Caribbean participants appeared to be the least aware, with only 6 (7%) out of a total of 82 participants aware of the bill.

- When it comes to religion, Muslims had the highest level of awareness of all participants of the Organ Donation Bill. 63% of those who were aware identified as Muslim (N=212), accounting for around two thirds of those who were aware (N=73).

Conclusion and recommendations

- This project aimed to look at the levels of support for organ donation among London's BAME communities, exploring participants' level of awareness and reasons for and against organ donation.
- Despite a majority of participants who reported being unwilling to donate organs, it was also clear that a substantial proportion of the sample remained unclear about their strength of feeling regarding such decision-making. It was also evident that information or a raised level of awareness through knowing somebody who needed or had had an organ donation might encourage them to consider donation. It is additionally possible that many people might be persuaded about the plausibility of organ donation through the intervention of someone from their faith or community group.
- Based on these findings, it appears that there are three substantive groupings – that is, those who will willingly donate; those that will not; and those who may be

encouraged by a greater level of information and/or awareness of the experience or knowledge of others to become involved in organ donation

- Nonetheless, this analysis was made more complex by the links between 'faith' and 'ethnicity' and between 'community' and 'faith', especially how these factors might impact on a willingness to donate. In the first place, there remained little scope within the survey to explore the precise (or imprecise) nature of an individual's faith and thus questions regarding faith may well have been interpreted differently by individual participants. Secondly, the relationship between 'faith' and 'community' was also somewhat cloudy. Thus, although the majority of Muslim participants were not willing to donate organs, as they reported on the basis of their religion, they also formed a substantial proportion of those who were 'uncertain' about the merits of organ donation. Findings show, too, that ethnicity may be more important than faith, particularly considering that nearly a third of those who believed that organ donation conflicted with the religious belief also thought they might assent if someone from their community group or faith encouraged them to become involved. Added to this mix, was the notion of 'social responsibility', a concept supported by many even though the term remained undefined.
- To understand additional facilitators and barriers to organ donation, it is recommended that a more in-depth exploration is needed. A qualitative study would allow an unpacking of the relevant factors relevant to organ donation and

explore the links between them. It would also enable a more informed discussion on the factors that would encourage and, conversely, discourage organ donation. On the basis of the findings of this survey, qualitative studies with an appropriate and purposive sample would enable a greater understanding of:

- How people from diverse BAME communities conceptualise 'organ donation';
- The relevance of age and gender;
- The influence and impact of the views of family/community/faith and the balance and interaction between them;
- The relationship and interdependence between 'ethnicity' and 'faith' and how these variables impact on people's willingness to participate in organ donation;
- How 'cultural values' influence organ donation;
- Perceptions of the relationship between 'health' and organ donation; how participants presently access information about health, how they might access information and how they would prefer to access information, and so on;
- The notion of 'social responsibility' and how this might and does impact on willingness to donate'.

END