THE HEART OF THE ISSUE

ORGAN DONATION IN LONDON'S ETHNIC MINORITY COMMUNITIES

MARCH 2019

LONDONASSEMBLY

Acknowledgments

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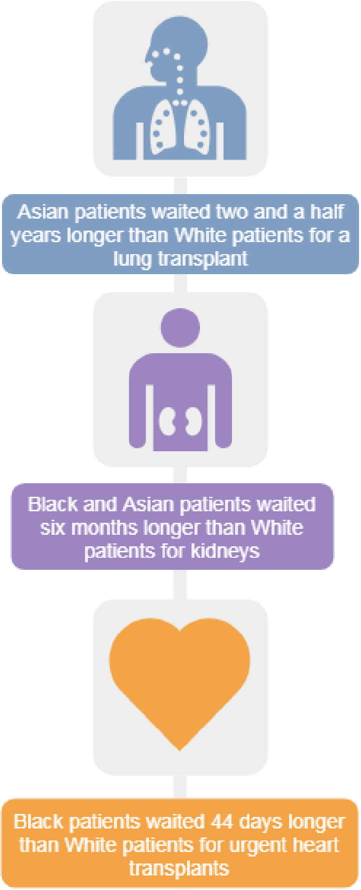
The issue

London’s ethnic minority communities face stark health inequalities when it comes to organ donation. Patients from ethnic minority backgrounds can often wait much longer than white patients to receive vital organ transplants, pitting them against unfair survival odds. National data for 2017-18 illustrates those odds.



Asian patients waited two and a half years longer than White patients for a lung transplant

Black and Asian patients waited six months longer than White patients for kidneys

Black patients waited 44 days longer than White patients for urgent heart transplants

The disparity in waiting times is a direct consequence of a disproportionately high need for organ transplants within ethnic minority communities and disproportionately low consent rates to donation.[2]

The imbalance is a problem because, for a successful transplant, blood and tissue types need to match; and this match is most likely to happen where the donor and the recipient are from the same ethnic background.[3]

21% of people who died waiting for an organ transplant were Black, Asian, or another ethnic minority, despite only making up about 11% of the population

62% of Londoners waiting for an organ transplant were Black or Asian

23% of eligible deceased BAME people became donors
35% of eligible deceased White people became donors

In the case of deceased donors, the big difference in donor rates is down to familial consent.[4]

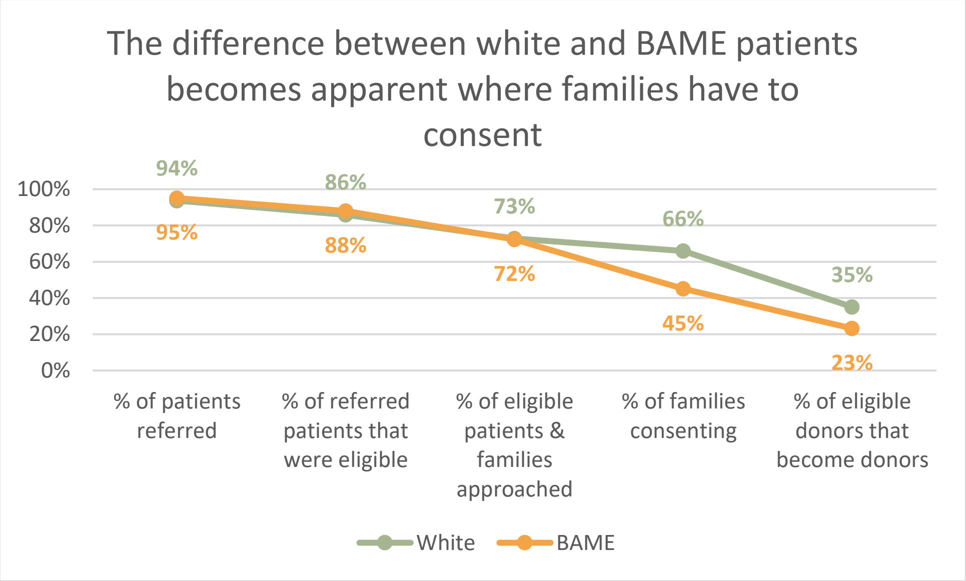
Familial consent

In London, when a deceased person was eligible to donate organs, 66 per cent of White families consented to donation compared to only 45 per cent of ethnic minority families.[5] Under the current donation system, families must consent before a deceased person's organs are donated. Even if the deceased person was on the organ donor register and had a donor card, their family can override the decision after death. The NHS says that family refusal continues to be the biggest obstacle to organ donation. This is unlikely to change without concerted effort, even with proposed changes to the organ donation system.

The Deemed Consent Bill, currently making its way through Parliament, will introduce a system of presumed consent. This means that, unless the deceased has explicitly opted out of the donor register, their consent to organ donation is assumed. Concerns have been raised about the new system. Among other things, some fear that it may encourage more people to explicitly opt-out of the register, and that the trust between doctors and patients' families could break down if families' objections are ignored.

However, it is important to note that, under the current system, people can opt-out, but relatively few do.[6] Most people that become deceased donors now are not on the organ donation register when they pass away. Their families, consenting on their behalf, make the choice to donate.

Furthermore, under the current system, even when there is explicit consent from the deceased, where families object, donation does not go ahead.[7] Nurses and doctors still defer to families to make the ultimate decision. This suggests that, even in an opt-out system, if families raise strong objections, nurses and doctors are unlikely to proceed. So, it is back to the issue of familial consent, and the question of how to help everyone involved understand and be more comfortable with organ donation.[8]



> Ever since I was small, I know my mum and dad had signed up […] when they got their driver's licence. In my house, it was very common, but my mum is one of six and all of her other siblings and their children have never talked about [organ donation].
>
> **Natasha Sandhu**

> My experience has been that families are very secretive about these things. I do not know why, but the awareness raising starts there. It starts with the families – and families really need to talk about this at the earliest possible stage – so that it almost becomes a normal thing to talk about and not taboo.
>
> **Prafula Shah**

Introduction to the committee investigation and #BAMEdonor survey

Considering this inequality, the committee launched an investigation with several key questions in mind:

- Why are family consent rates low in BAME communities?
- What are the barriers that prevent people from signing up to the organ donor register?
- How do interested organisations encourage frank conversations about donation?
- Is the support for donation lower in London's BAME communities than in other communities? And if so, what are the best ways to increase that support?
- What does an effective sustained campaign of engagement with BAME communities on the topic of donation look like?
- Who would need to be involved in such a campaign and what does the Mayor need to do to support it?

To answer some of these questions, the committee commissioned Agroni Research to conduct a survey of 400 BAME participants in London. Agroni Research conducted 459 interviews across the African, Caribbean, Bangladeshi, Pakistani, and Indian heritage communities in London.

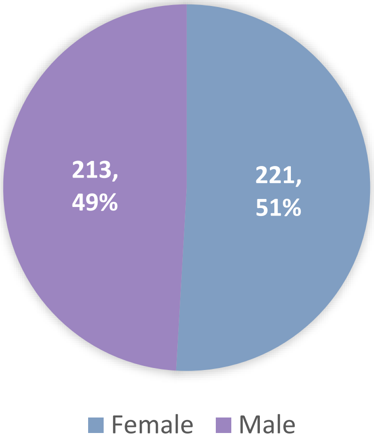
The interviews were conducted in several London boroughs with high-density BAME populations, namely Tower Hamlets, Newham, Camden, Croydon, Redbridge, Southwark, Barking and Dagenham, and Hounslow. 459 interviews were initially conducted and responses to 434 were included in the analysis.

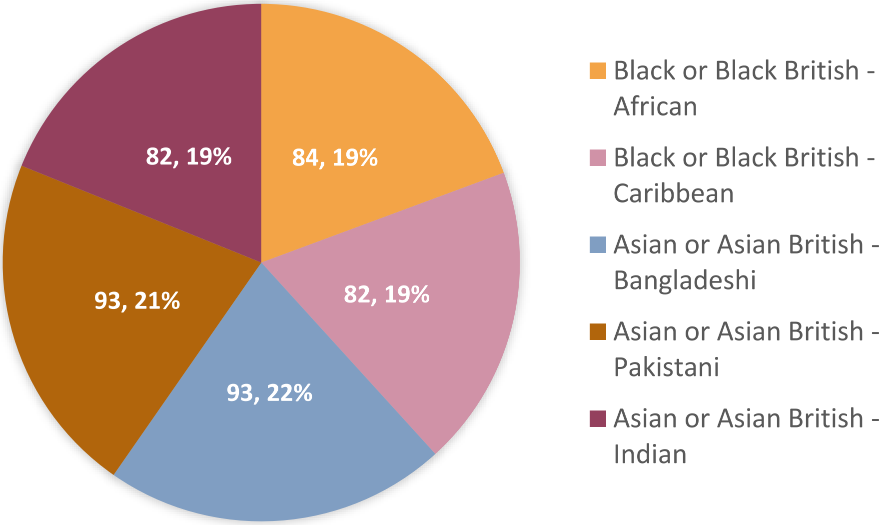
The committee wanted to understand the views of Londoners from the city’s diverse ethnic minority communities. The aim was to explore:

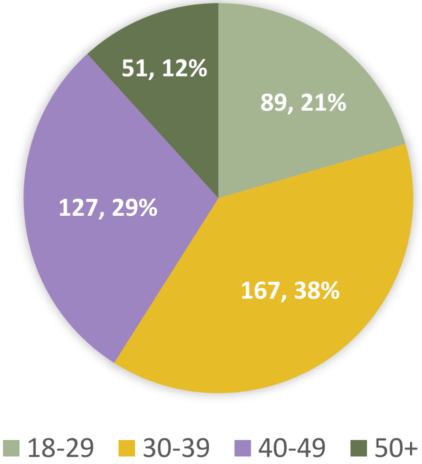
- Levels of support for organ donation among London’s ethnic minority communities.
- Reasons why people in these communities would or would not donate their organs.
- Levels of awareness within these communities of current organ donation health inequalities.

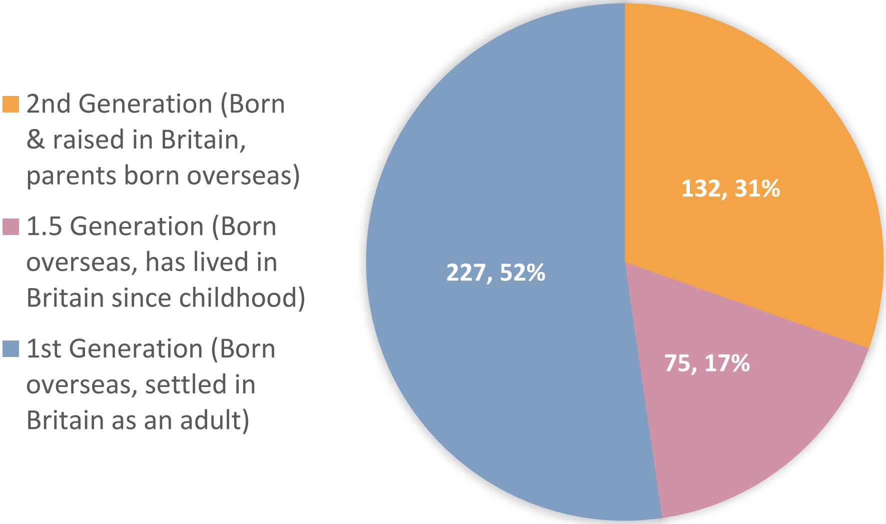
For some context, in May 2018, Agroni Research conducted a survey of 1,000 participants from ethnic minority communities across England on behalf of NHS Blood and Transplant (NHSBT), who are responsible for managing and supplying organs. The survey showed that only 34 per cent of survey participants “supported” or “strongly supported” organ donation. Only 11 per cent said that they “would definitely donate some or all” their organs.[9]

Who were the survey participants?






51, 12%
89, 21%
127, 29%
167, 38%
18-29
30-39
40-49
50+


2nd Generation (Born & raised in Britain, parents born overseas)
1.5 Generation (Born overseas, has lived in Britain since childhood)
1st Generation (Born overseas, settled in Britain as an adult)
132, 31%
227, 52%
75, 17%

We asked our respondents if they were willing to become organ donors

In the committee’s survey, support for organ donation (those already registered and those willing to donate) sits at 29 per cent. The NHS puts national support for organ donation at around 80 per cent. This is out of step with this survey’s findings and the 2018 national BAME attitudinal survey.[10] Ethnic minority attitudes are distinct and should be explored as such.

Life on dialysis is very difficult. I cannot overestimate the disadvantages. It has an impact on all areas of my life, on my physical and mental wellbeing, on my family life, on my productivity, on my creativity.

Gillian King

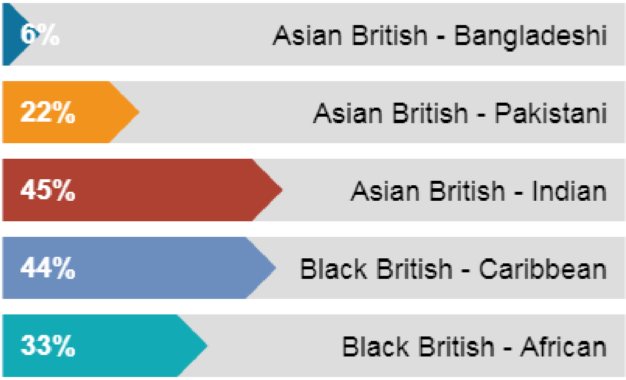
Eight years on [after receiving a transplant from my sister], I can testify that my life has changed. Although I was on dialysis for only a few months, my life has changed from that and I can do 90 per cent of what I used to do as a younger man.

Richard Todd

…if you know anyone in your family or your extended family or a close friend who needs a kidney and is well enough to have a kidney transplant […] then you must do everything you can to try to be a living donor.

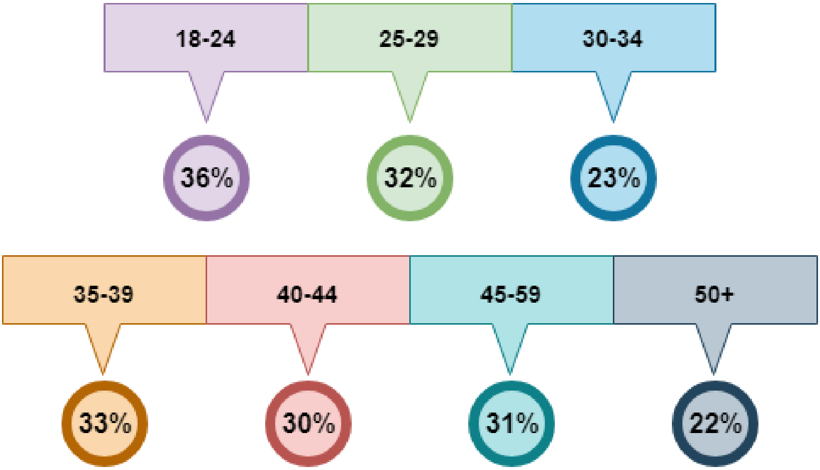
Kirit Mistry

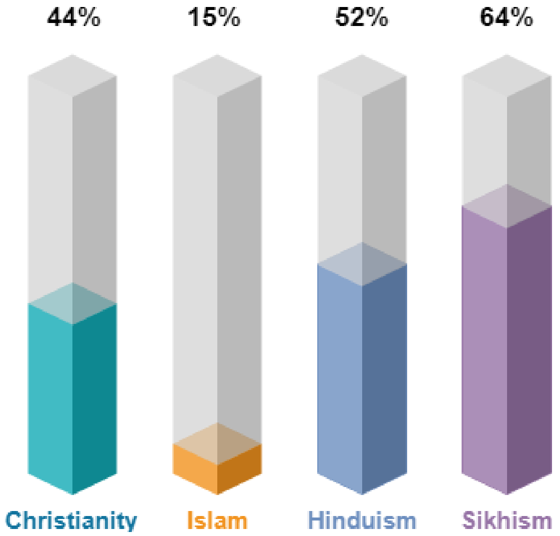
Support for organ donation varies across ethnicities, religions and age groups



Organ donation had the most support from Caribbean- and Indian- heritage Londoners

Organ donation was most popular with the youngest participants, and least popular with the oldest ones





The lowest levels of support came from Muslim participants. This finding appears to be supported by work done nationally on the matter. In the Government's public consultation on the proposed changes to the organ donation system, 79 per cent of Muslim responders felt the change could have a negative impact on those from certain faith groups and ethnic backgrounds.[11]

> *"Muslim respondents commonly cited the lack of consensus amongst religious scholars over the compatibility of their religious views and organ donation as being problematic, arguing that there is a need for better engagement with Islamic communities on the issue."*[12]

Motivations

We asked our participants about their willingness to become donors and why

Why are you willing?

29% Feel a social responsibility

28% It would improve or save a life

24% Someone I know or love could need a transplant one day, or needs one now

19% Feel a moral or religious responsibility

Why are you not willing?

51% Believe it conflicts with religious belief/faith

19% Believe it conflicts with their cultural beliefs

13% Don't know enough about it

8% It may upset my family & friends

Why are you unsure?

42% Have never thought about it

24% Do not know enough about it

24% Believe their religion may not permit it

10% Don't know how my family would feel

You asked, ‘what makes you donate?’ When I found out Tom [my son] had already signed up, it made it very easy for me and my daughter and my family.

Lisa Wilson

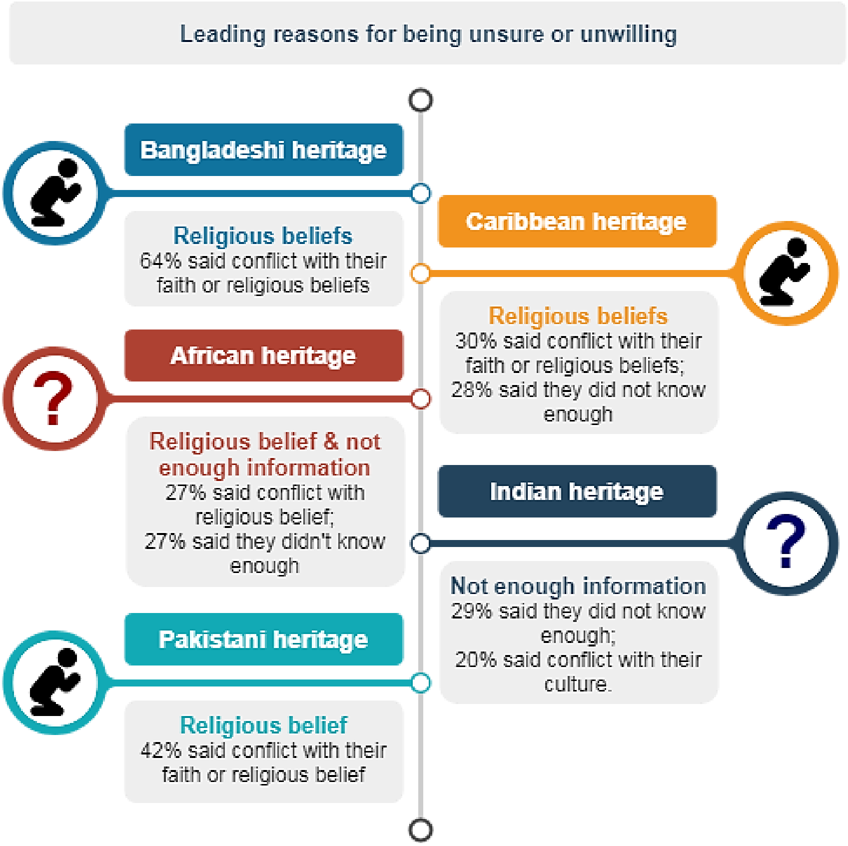
To me, it is about giving an opportunity for someone to prolong their life. That is like another year of experiences. Some more birthdays, weddings, some more experiences, and that has to be the right thing to do.

It is our Sikh faith. One of the pillars of the Sikh faith is selfless service and I always knew that in the back of my mind and so we were always going to make the human decision at that point.

Bobby Mudhar

[donating my kidney to my father] only happened because of the support from the healthcare community that I could reach out to. It only happened because I could have conversations early on. They took place at home. They took place with friends and with family over a period of time. It was in our own setting in our own time.

Sheena Visram



Leading reasons for being unsure or unwilling

Bangladeshi heritage

Religious beliefs
64% said conflict with their faith or religious beliefs

Caribbean heritage

Religious beliefs
30% said conflict with their faith or religious beliefs;
28% said they did not know enough

African heritage

Religious belief & not enough information
27% said conflict with religious belief;
27% said they didn't know enough

Indian heritage

Not enough information
29% said they did not know enough;
20% said conflict with their culture.

Pakistani heritage

Religious belief
42% said conflict with their faith or religious belief

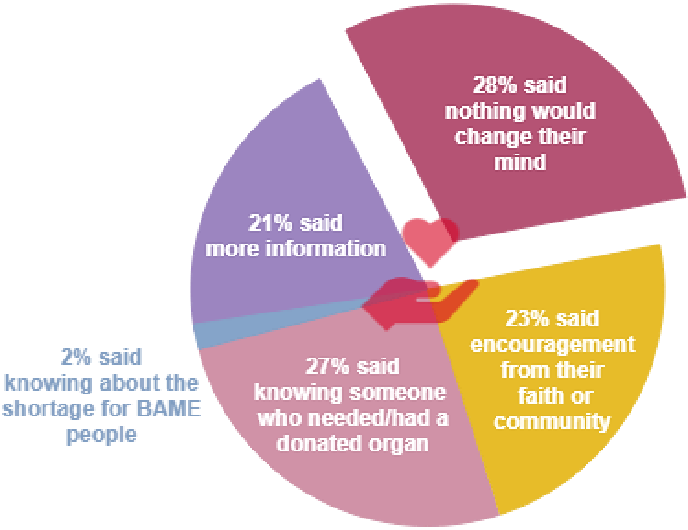
Conversations about organ donation and ethnic minority communities often center on religion and culture as the keys to understanding why there is a reluctance to donate. However, these are two separate issues. When the NHS collects data, religious and cultural beliefs are grouped together as a single reason why a family might deny consent. NHSBT's survey into BAME attitudes on organ donation took the same approach.[13]

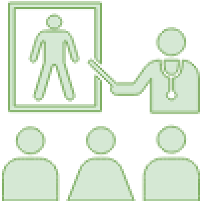
However, culture cuts across nationalities and ethnicites in different ways to religion; and grouping the two masks important nuances that could help inform strategies to engage BAME communities on the topic of organ donation.

In the committee's survey, religious beliefs and cultural beliefs were different options participants could choose, to help explore their different influences. 20 per cent of the participants who were unwilling to donate felt organ donation conflicted with their cultural beliefs. While participants of Indian heritage were the most supportive of organ donation, they were also the most likely to be unwilling to donate because of conflicts with culture.[14] For the other ethnic groups, conflict with religious belief was the leading reason why people were unwilling to donate or unsure about organ donation.

Even where the committee has tried to consider religious and cultural beliefs separately, cultural beliefs and religious beliefs can bleed into each other, making them hard to extricate. The survey may reflect this in the following way. 100 per cent of all the Bangladeshi-heritage and Pakistani-heritage participants unsure or unwilling to donate were Muslim. Yet, a much larger share of Bangladeshi-heritage participants (64 per cent) said conflict with faith or religious belief was the leading reason they were unsure or unwilling, compared to Pakistani-heritage participants (42 per cent).

We asked our respondents what would be most likely to make them decide to donate





44% of the under-25s said more information would make them more likely to decide to donate

Almost 40% of 50+ participants said nothing would make them decide to donate

For those who were unsure or unwilling to donate due to conflict with religious beliefs, 30 per cent said encouragement from their faith or community could make them decide to donate.

Participants of Bangladeshi and Pakistani heritage were least likely to change their minds on organ donation: 39 per cent and 34 per cent, respectively, said that nothing would make them decide to donate.

However, for Bangladeshi and Pakistani heritage participants that would be open to changing their minds, having a personal relationship with someone who needed an organ, or who'd had an organ transplant, was most likely to make them decide to donate.

> The thing is that people do not know what the process is after organ donation and sometimes they will say, "Religiously, we are not allowed", and at that time I will say, "Can you point to me in the religious scripture where it says you cannot donate your organs?" They do think about it [...] A lot of people have said to me, "It is so refreshing, an Asian woman from our background talking about this", and they want to question you. If you do question the religious arguments that they give [...] it makes them think and reconsider, because you are from that community and that helped a lot.
>
> **Surma Begum**

Our story: Jay and Sina Patel

Sina and I, unfortunately, two years ago on 23 November 2016, lost our son. He was three and a half years old. Aari had a fantastic three and a half years with us and we are blessed to have had those three and a half years with him.

I remember four days of intensive care. On the second day, Sina asked if I would consider organ donation to which I firmly said “Yes”, but straight away, we said to ourselves: ‘Aari will be fine and back home soon, so we don’t need to think about it’. At the time, I remembered that when I met Sina 23 years prior, when we were dating, she got her driving licence and she told me she wanted to be an organ donor. We spoke about it for literally about 10 seconds and that was it.

When we were told at 2.00am that [Aari] would not survive another 72 hours, instantly we told the consultants to donate every single organ they could and to save other children because, if we were in the same situation, we would like to receive an organ. We met consultants and Specialist Nurses for Organ Donation within five hours of that decision being made and Aari’s PICU consultant said, “Aari’s heart is a diamond”. It is very rare for a child of such a young age to be a donor; though it does happen. Our decision was not faith-based. It was just based on human nature. We made the right decision for our son and I think, if Aari was here today, he would say, “Dad, you have done the right thing”.

I am a Hindu by background, but I have never been religious to an extreme extent. I remember having a conversation my mum at 9.00am that morning, because I did not know her thoughts or what she would say to me.

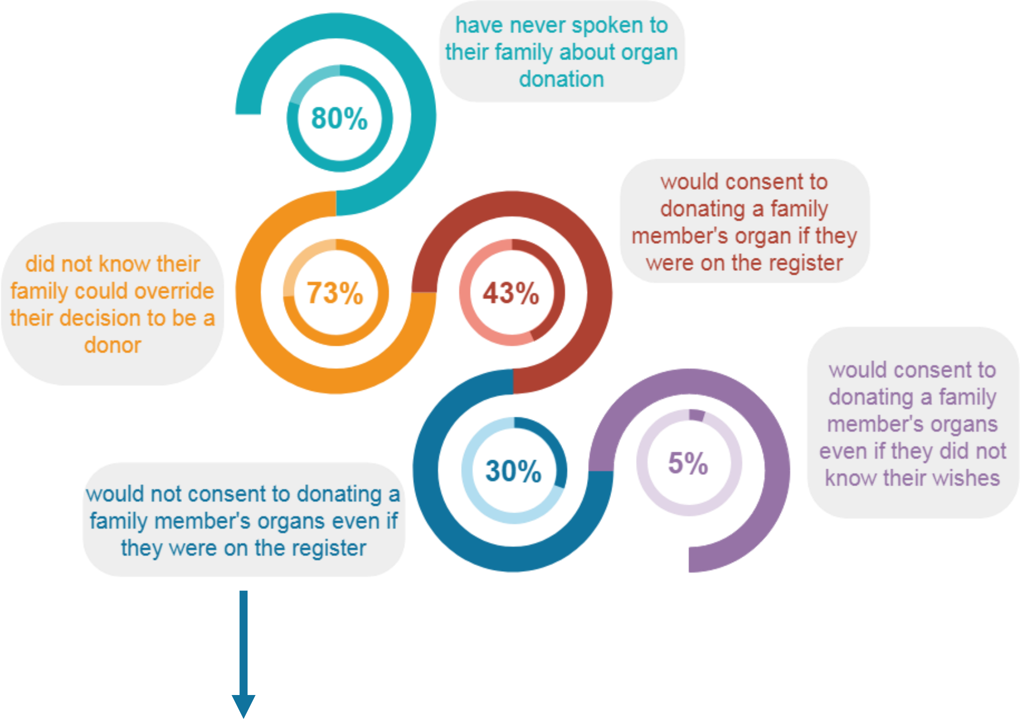
Her view was, “You have made me proud, and you have made Aari proud, and you have made the best decision of your life”.

We agreed to donate seven organs. Unfortunately, a match could not be found for Aari’s kidneys, but the children who received Aari’s other organs are alive. There were respectively two children, one of two and one of three. Those children, at the ages of five and four, are alive today.

Aari’s twin sisters are now three and a half, coming up to four. At the age of two, straight after Aari passed away, we signed up his sisters to the organ donor register. [What] people may or may not know is that there is no age limit on being an organ donor. There is consent required for minors under the age of 16, but you can sign up at any age. One of the things that I know his sisters will do is they will educate others in all communities because they talk today every day about their brother. They just think of him as being in the sky. They do not fully understand where he is, but there will be a day that they will understand that he gave the ultimate gift of life. Reaching out to those communities at a younger age and across functions and communities is actually important.

One of the things that is important for Sina and I is that we work alongside NHS Blood & Transplant, as well as being NHS Organ Donation Ambassadors. As part of this, we talk to all communities. Aari’s story touches a lot of people because of his age. We will never stop talking about Aari and we will continue to campaign on the positives of organ donation for all of us. We do not know what religious background or what ethnicity the recipients are, but I am sure that they are doing well wherever they are.

Families



Even if the deceased were a registered organ donor, 30 per cent of survey respondents said they would not consent to organ donation. This is something that we know happens. Last year, there were three cases in London where BAME families overuled the explicit wishes of the deceased and denied donation.[15] Families' rights to make difficult decisions in such times should be respected but it is important that when a person decides to become a donor, families respect and understand the decision.

Many who become living donors do so because a family member or close friend requires a kidney or some other organ tissue. It was very clear from the committee’s open-mic event that family was one of the strongest motivating factors for people that became living donors. A fifth of the survey participants that support organ donation said people they knew or loved ones needing organs was the reason why. However, for far too many of those surveyed, family has been excluded from their thoughts about organ donation, with very few having had as much as a conversation. Almost three quarters knew nothing about the significant role families play in the organ donation process.

Families need to be encouraged to have these conversations, armed with facts about the process and stories of people’s experiences. The National BAME Transplant Alliance (NBTA) has many resources available on their website, targeted at different ethnic minorities.[16] NHSBT also has various myth-busting tools available.[17]

> “I am a live kidney donor. I [wanted] to donate my kidney to my niece but was not a direct match. Through the National Kidney Sharing Scheme, luckily [for my niece] […] in the first run of that scheme, a match was found […] and someone needed my kidney as well. It was a match that they needed and so I donated my kidney last March [2018].
>
> **Prafula Shah**”

Our story: Polly and Richard Todd

Hi, I'm Polly – a live kidney donor.

As a child my brother Richard had a kidney problem, and this was something he grew up with; but let us fast-forward to 2007 when my brother was told that his kidney was deteriorating, and he should look within the family to see whether we could donate. We had discussions with Richard and I said I would donate to him if necessary. In 2009 it became necessary, and without hesitation and behind the scenes I discovered that I wanted -- well, I wanted to make sure I was able to donate to him, so behind the scenes I had all the tests and then in 2010 I donated to Richard once I got the all-clear.

Initially, Richard did not want me to do this, but it was my choice and I decided that it was what I wanted to do for him. On 12 January 2011 I donated my right kidney to Richard and this was called a 'hand-assisted nephrectomy'. The operation went really well and recovery for me as a live kidney donor was about eight weeks before I was able to return to work.

I would say to anyone thinking of donation to really think about it. It is a risk to the donor and a lesser risk to the receiver. Consider the risks and speak to family. Ensure that you have family support and friends who can support you. My health now is really good. I drink lots of water. I stay away from alcohol sometimes. It has been eight years now and Richard is doing really well, and so I am an advocate of live kidney donation.

Hi, I’m Richard – the recipient of my sister’s kidney.

I have always appreciated what my sister did, but at that time I felt that I didn’t because when you are told that your kidney is deteriorating and there needs to be some interaction from the medical profession, you sink into a state of almost darkness. You do not know what you are going to do, and I did not want to put that type of pressure on my family.

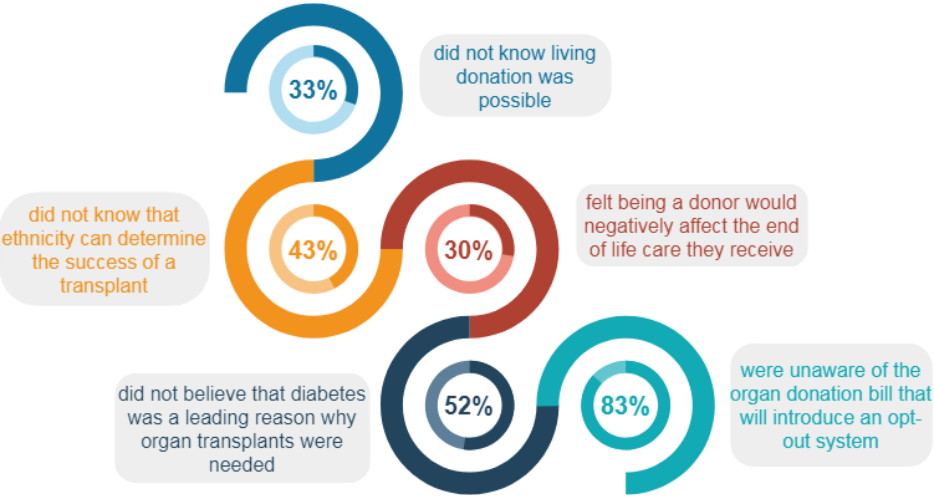
I was told to take home videos and pass them on to family and extended family, but I took them home and just put them down because I felt “everyone has their own lives to lead, we are all adults, we all have families”. It was something that I felt was my problem and I felt that, somehow, I had to deal with it; but my sister went [to be tested for a match] without my knowledge.

I think my wife phoned around my family without my knowledge. This was going on behind me, really. I did not know for about a year, and then all of a sudden, my sister said she was a donor and she had gone through all the tests. My mum - my late mother - called me and she said, “Richard, you really ought to take that kidney your sister is offering you. It is a blessed thing she is doing for you and we all want you to have it”, and so at that point I decided to take it.

Eight years on, I can testify that my life has changed. Although I was on dialysis for only a few months, my life has changed from that and I can do 90 per cent of what I used to do as a younger man. That is it. That is our testimony.

The importance of community

Communities are an important source of information; and where people feel disenfranchised or disillusioned with healthcare institutions, their immediate communities can be their primary source of information.



The survey shows that there is a general lack of understanding about issues relating to organ donation. NHS and public health messaging is not getting through. These messages must reach people where they are. Effective campaigning and marketing has the power to make a real difference by planting the right seeds in people's minds. The Mayor has the power to take advantage of London's vast advertising space and has the market intelligence to target that advertising well.

The committee calls on the Mayor to reach out to NHSBT and the NBTA to design a targeted publicity campaign, to raise awareness and encourage organ donation in London’s ethnic minority communities.

Just over half of participants did not see the link between diabetes and organ transplants. The most common transplants are for kidneys – 35 per cent of donors waiting for kidney transplants are from Black, Asian or another ethnic minority.[18] Chronic kidney disease, often caused by diabetes or high blood pressure, is the leading cause of organ failure. Diabetes has a particularly high incidence in people of South Asian, African and Afro-Caribbean descent.[19] Being able to make the link between diabetes, organ failure, and organ donation may help bring the idea of organ donation closer to home for some.

A significant minority of participants did not know that living donation was an option. Latest statistics show that 40 per cent of all organ donors are living donors, and that living donor kidney transplantation accounts for 97 per cent of kidney transplant activity.[20] Many believe organ donation is reserved for when a person passes away – that association with death may be an obstacle to conversations. Introducing people to the possibilities of living donations may encourage them because then, organ donation is not a decision relegated to the end of one’s life.

Having the right messengers, as well the right message, is essential to engaging communities. When having, what can be, difficult conversations about death and health, speaking to a person who understands your faith, culture and circumstances can make that conversation easier. The message, the messenger, and the time and place matter.

Community organisations play a key role bridging the gaps between people and formal institutions, even in the realm of healthcare. 30 per cent of those surveyed felt that their end of life care would suffer if they were on the organ donor register. That is a substantial minority of BAME Londoners who may not fully trust the commitment of health services to look after them equally, no matter what. It is important for the NHS and other policymakers not to label BAME communities "hard to reach". Instead, the committee believes there is a duty on public bodies to listen, learn and adapt to all communities.

> "We are all different. We have different cultures. We have different beliefs and different faiths and different fears as well. If you want to talk to the black community, you have to divide them into the different places or areas they come from.
>
> Hilaria Asumu"

My story: Dela Idowu

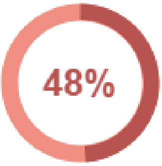
My name is Dela Idowu, the founder of an organisation called Gift of Living Donation (GOLD). We raise awareness of living donation in the African Caribbean community. I also came forward as a living donor for my brother.

To see an increase in organ donation in BAME communities, it's very important that people from those communities take a lead role in raising awareness and promoting its benefits. GOLD is currently working in partnership with Guy’s Hospital on a project funded by the National BAME Transplant Alliance (NBTA) on a living transplant initiative. The initiative is a home-based educational programme led by trained African and Caribbean peer volunteers to support African Caribbean renal patients on the active transplant waiting list.

Peer volunteers support and encourage patients to have the conversation about living donation within their homes with their families. This type of engagement, where volunteers talk about their experiences of living donation from a black perspective with patients and family members, can help loved ones make better decisions about living donation allowing more black patients to have access to transplantation.

As part of the initiative, GOLD is also working with Guy's Hospital looking at areas and identifying gaps where they can improve support to their large cohort of black renal patients.

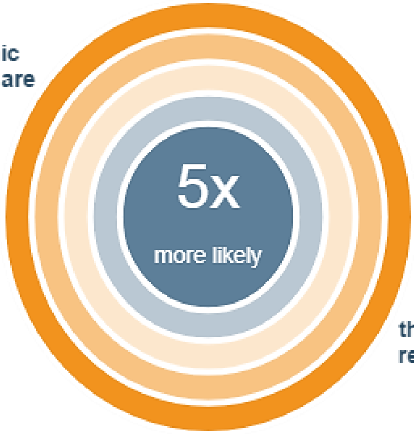
Faith communities



of participants who were unsure or unwilling to donate due to their religious beliefs, said 'nothing would change their mind'

of participants unwilling to donate due to religious beliefs were Muslim

In London, ethnic minority families are



than White families to refuse consent due to religion or culture

Faith and religious beliefs have featured significantly in the survey findings. Engaging with communities on matters of faith and organ donation will be vital to changing attitudes and starting conversations. Therefore, it is important for faith leaders to encourage dialogue about organ donation, especially where matters are open to interpretation with no prevailing consensus.[21]

The committee calls on London's political leaders to work with faith leaders to increase support and awareness of organ donation.

Eleven projects in London have received money from the Government to increase the number of BAME donors. Eight of these projects will explicitly target some of London's faith communities, including Sikhs, Hindus, Jains and Muslims. Faith organisations are playing an important role in educating and encouraging Londoners about organ donation; and their work should be supported.

> "Let us not be afraid to handle those taboos and cultural differences. People do have a lot of cultural differences and a lot of faith communities have very different views, but we should know about those and should not be afraid to have that conversation.
>
> **Prafula Shah**"

Schools

> our [NHSBT organ donation] ambassadors have found great engagement in schools. In fact, every time I have gone into a school, every time I have ever been stumped by a question on organ donation, it has always been [from] a child, because children have such a fascinating desire to learn, it is a fascinating subject to them...
>
> My donor was a child. He died at eight and a half years old, but he made his donation decision when he was five or six years old when they had a family discussion after a news story on the telly, and he told his mum, “Well, I want to donate a kidney, because I only need one”. He was fascinated by it. If he had not said that, I would not be alive today. Children have this incredible curiosity and if we are looking at changing the culture, it has to start young.
>
> **Katy Portell**

Schools are an excellent place to educate and engage children and young people on organ donation. Reaching people early means preventing misconceptions and myths taking root in the first place.

The NHS has produced resources and lesson plans for schools on organ donation, and on the last count, they had been accessed 10,000 times.[22] However, because organ donation is not a compulsory part of the national curriculum, schools are not required to cover it. The Government has made a commitment to increase BAME donors.

To fulfil their commitment to increase BAME donors and ensure the success of the opt-out system, the committee calls on Government to consider making organ donation part of the national curriculum.

At the London-level, the Mayor has no statutory powers in education, but he already has an avenue into London's 3,000+ schools through his Healthy Schools programme. Knowledge about organ and blood donation, and the reasons why people require them is the sort of health and scientific education that should be promoted in London's schools.

The committee calls on the Mayor to make organ and blood donation awareness part of his Healthy Schools Programme criteria.

At a local level, charities are working with schools to raise awareness. In 2015, the Gift of Living Donation charity (GOLD), partnered with Capital City Academy in Brent to "encourage people – particularly those in the Black and Asian communities – to learn about the life-changing potential of kidney donation."[23] GOLD launched a poster competition for pupils from Years Eight, Nine and Ten. The best posters were displayed at Brent Civic Centre Library. More than 60 students were involved, with the community invited to vote online. The winning poster design was displayed in public spaces in the borough.[24]

Speaking to Dela Idowu, the founder of GOLD, she said she was especially keen to engage with students in creative and dynamic ways, and that this project really involved the whole community. Idowu made the point that what really helped this project was the initiative and enthusiasm of the school's headteacher.

Coordinating efforts

Representatives from several community and charitable organisations attended the committee's open-mic session at City Hall. From their testimonies, it was apparent that these organisations are doing innovative, varied and vital work, providing services such as counselling. However, it also became clear that it was difficult to find the information, services, and support networks all these organisations provide.

Structured methods of referring people to the charities and organisations in London that educate and support people touched by these issues would improve the situation. Furthermore, the services offered by community organisations need to be better coordinated.

The committee calls on the Department for Health and Social Care to take a more active role in helping people navigate the services and support available, through coordination.

The committee also heard from these organisations that a lack of funding creates barriers. Community organisations are working with schools, producing accessible content, and providing support to families and individuals – all these activities require money.

In 2018-19, about £141,000 was awarded by the Government as part of a nation-wide funding call for community organisations. Just 25 organisations received funding (including eleven in London). The entire pot of £250,000 available is to be spent by June 2019. This is an inadequate level of support, considering the work required to engage with communities in meaningful and sustained ways. NHSBT are in talks to secure funding for an annual grant funding pot for future years, but it is unclear how much will be available.

Along with the Department for Health and Social Care, the Mayor also has the resources to support these community organisations, having made grants available to many types of small, local organisations during this mayoralty.

The committee calls on the Department for Health and Social Care to increase funding available to BAME community organisations across England and Wales; and increase their efforts to encourage the work of small, local organisations.

The committee calls on the Mayor to provide funding for community organisations committed to promoting organ donation in London’s ethnic minority communities.

This committee believes that much more needs to be done to support the efforts of London’s BAME organisations and the NHSBT in promoting and encouraging organ donation. We call on the Mayor and the Government to exercise greater leadership to address this critical health inequality.

CALL TO ACTION

- The Department for Health and Social Care should increase funding for, and coordinate efforts to, encourage organ donation in the nation’s ethnic minority communities.
- The Government should consider including organ and blood donation in the national curriculum.
- London’s political leaders should work with faith leaders to increase support and awareness of organ donation.
- The Mayor should provide funding for community organisations committed to promoting organ donation in London’s ethnic minority communities.
- The Mayor should reach out to NHS Blood & Transplant and the National BAME Transplant Alliance to design a targeted publicity campaign, to raise awareness and encourage organ donation in London’s ethnic minority communities.
- In his next review, the Mayor should include organ and blood donation awareness as part of his Healthy Schools Programme criteria. In the meantime, education leaders should seek to increase awareness of organ donation in our city’s schools.

… I have been fortunate to have some literature and things like that, but that is solely because Kidney Research UK have sent it to me, Kirit [Mistry] has sent some to me. It is great stuff, it is out there as well, the leaflets that are in different languages and they talk about different faiths. That is great, but it is not easily accessible for everyone.

Natasha Sandhu

[…] but as someone who is recently diagnosed, no information was given to me to go and have the discussion with my family […] If you are looking for information on organ donation and how to have the discussion, you cannot find it.

Naomi Adams

One way that this area could improve both in information to people who are going to donate and receive and people on the list is for this information to be more organised and disseminated within the communities so that people in the communities are speaking to people in their communities about what is needed.

Gillian King

About the London Assembly Health Committee

The London Assembly holds the Mayor and Mayoral advisers to account by publicly examining policies and programmes through committee meetings, plenary sessions, site visits and investigations. The Health Committee reviews health and wellbeing across London, with a particular focus on public health issues and reviewing progress of the Mayor's Health Inequalities Strategy.

The committee's meetings are open to the public and are broadcast on our website at www.london.gov.uk. The committee also regularly seeks views from the public through calls for evidence, events and meetings in public.

If you would like to be kept informed about our work on organ donation or other projects, or have a question or suggestion about the Assembly's work on health and wellbeing, please contact healthcommittee@london.gov.uk. We would love to hear from you.

You can also follow us on Twitter via #AssemblyHealth

Endnotes

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[1] Various icons made by Freepik from www.flaticon.com

[2] Organ Donation and Transplantation data for Black, Asian and Minority Ethnic (BAME) communities Report for 2017/18 Statistics use the median number of days waited: Asian patients waited 1,191 days (just over 3 years) compared to white patients who waited 261 days (about 8 and a half months). White patients waited 723 days (about 2 years) for a kidney transplant; Black and Asian patients waited 985 days and 891 days, respectively (about 2 and a half years). Black patients waited 44 days longer than White patients for urgent heart transplants.

[3] Organ donation and ethnicity, NHSBT

[4] Gov.uk News story, Campaign to increase BAME donors; ODT Statistics, London team – key statistics by ethnicity for 2017/18

[5] Organ Donation and Transplantation data for Black, Asian and Minority Ethnic (BAME) communities Report for 2017/18

[6] At the end of March 2018, there were 24.9 million people had opt-in registrations to the organ donor register, compared to 517,124 opt-out registrants.

[7] BBC News, Hundreds of families block organ donation, 19 October 2017

[8] ODT Statistics, London team – key statistics by ethnicity for 2017/18

[9] NHSBT 2018 Attitudinal survey of Black and Asian adults in England (May 2018)

[10] NHSBT 2018 Attitudinal survey of Black and Asian adults in England (May 2018)

[11] The New Approach to Organ and Tissue Donation in England, Government response to public consultation

[12] The New Approach to Organ and Tissue Donation in England, Government response to public consultation

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[13] NHSBT 2018 Attitudinal survey of Black and Asian adults in England (May 2018)

[14] 39 per cent of unwilling Indian-heritage participants identified cultural conflict as the reason why – significantly more than Caribbean-heritage (28 per cent), African-heritage (25 per cent), and Bangladeshi-heritage (14 per cent).

[15] ODT Statistics for London 2017/18 (unpublished)

[16] NBTA Resources

[17] NHSBT Myth-busting page

[18] https://www.organdonation.nhs.uk/faq/organ-donation-and-transplantation/

[19] Type 2 diabetes is more than six times more common in people of South Asian descent and up to three times more common among people of African and African-Caribbean origin. Diabetes Facts & Stats 2016

[20] ODT Clinical Living Donation statistics

[21] Source for Graphics: ODT Statistics, London team – key statistics by ethnicity for 2017/18

[22] Launch of schools' pack from NHSBT, February 2016

[23] Kilburn Times, Pupils at Willesden school pen posters for living organ donation, April 2015

[24] Kilburn Times, Talented students win awards for organ donation awareness posters

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