



# Progress Report for BAME Community Investment Scheme Initiative

2020







Department  
of Health &  
Social Care



**NBTA** The coordinating voice for  
Black, Asian and Minority Ethnic  
transplant donation



**Blood and Transplant**

Scheme funded by the Department of Health and Social Care to help communities increase support for organ donation.



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# Foreword by Millie Banerjee, Chair NHS Blood and Transplant and Kirit Modi, National BAME Transplant Alliance

We are delighted to introduce this progress report to you, summarising the activities carried out by the organisations that were successfully awarded a grant in Autumn 2018 through NHS Blood and Transplant's BAME Community Investment Scheme.

This scheme, funded by the Department of Health and Social Care, aims to financially enable black, Asian and minority ethnic cultural or faith-focused organisations to undertake short-term projects in their community to address concerns and questions

about organ donation after death and thereby increase support for organ donation.

This is particularly important as there are stark differences in waiting times for a transplant between black and Asian patients compared to white patients due to the shortage of organ donors from black and Asian communities. The recent law change means that all adults in England will be considered to have agreed to be an organ donor when they die unless they have recorded a decision not to donate or are in one of the excluded groups. Community organisations can play an important role in providing accurate and up to date information to help inform people from their communities about what's happening and to help them make their donation decision.





The BAME Community Investment Scheme set out to address barriers and misconceptions that exist through trusted organisations who are best placed to understand their community's concerns. More recently NHS Blood and Transplant have also been able to use these organisations as our voice to spread the word about the new law and how it might affect them. We know from research into behavioural insights that we are all heavily influenced by the messenger who communicates information to us. Our BAME Community Investment Scheme model was therefore founded on ensuring the right messenger has the right information, relevant support and resources to take the organ donation message to their audiences.

2018 saw NHS Blood and Transplant for the first time put out a call for organisations to apply for funding to specifically focus on sharing information about the importance of organ donation with black, Asian and minority ethnic communities. While promoting organ donation to BAME communities has been a key area of our organ donation promotional activity for many years, NHS Blood and Transplant's efforts had been focused on generating national, regional and community media coverage about the need for more BAME organ donors, the development of real life stories that could be shared on social media and through stakeholders and partners, and working with faith organisations to create and provide faith materials in a range of relevant languages. There has also been a specific initiative with the Muslim community to bring together scholars, imams and umbrella groups to update a fatwa about organ donation as this was one of the recommendations in the Faith Engagement and Organ Donation Action Plan.

There has always been a willingness and drive among community-led organisations and individuals from BAME communities to promote organ donation themselves. Since being established the NBTA has been an important voice and campaigning force on issues relating to donation. We, together with other organisations and individuals have been

doing a great deal to carry out organ donation promotional work, often voluntarily. Wherever possible NHS Blood and Transplant has provided materials or representatives at a national or local level.

Together, NHS Blood and Transplant, the NBTA and the Department of Health and Social Care hoped that the development of the BAME Community Investment Scheme would remove the barriers from organisations that had the commitment, but not necessarily the resources, to promote donation themselves.

The number of applications received demonstrated that there is a lot of desire and drive to deliver work to promote organ donation and we were delighted to fund 25 organisations. We are most grateful to each and every one of them for their efforts: all project leaders and their teams; the specialist nurses; clinicians; surgeons; transplant recipients and donor families who addressed audiences at events, the members of the judging panel and advisory group who reviewed the applications and were on hand throughout to provide a helpful steer to project leads, and the NHS Blood and Transplant staff who administered the initiative.

There are lots of important learnings from the first year of activity which we are pleased to share with you in this progress report.

The BAME Community Investment Scheme is part of a long-term approach to building stronger relationships and trust – not a quick win. It is one of a range of approaches to improving awareness and outcomes in BAME communities

We look forward to all continuing to work together to increase organ donation rates among black, Asian and minority ethnic communities.



# Executive Summary

**NHS Blood and Transplant launched its first grant call for the BAME Community Investment Scheme in September 2018 to financially support community-led organisations to promote organ donation within their own communities.**

Over recent years there have been recommendations made from community organisations, researchers and politicians for the funding of community delivered activity. This approach has also been endorsed by the UK's faith leaders as exemplified with the NHSBT Faith & Organ Donation Action Plan<sup>1</sup>. The funding provided to NHS Blood and Transplant in 2018/19 through the Government's campaign to address the urgent need for black, Asian and ethnic minority organ donors could make it a reality.

NHS Blood and Transplant launched its first funding call for grant applications during Organ Donation Week 2018, having worked collaboratively with the National BAME Transplant Alliance, Department of Health and Social Care and Welsh Government to develop a clear set of criteria for applications. We wanted to receive applications from organisations that would develop and deliver work to break down myths and barriers and increase support for organ donation among black, Asian and minority ethnic communities.

The scheme is part of a long-term strategy to build stronger relationships and trust with local community and faith-based organisations as well as the people they reach. It sits alongside other work to support the BAME community including faith engagement; updating faith materials; creating new resources in a range of languages that can be used to raise awareness about organ donation; inform

people about the change in law; advertising emotive factual storytelling through media; and social media activity to demonstrate the realities of organ donation and transplantation.

## Why the work is needed

Activity focusing on black, Asian and minority ethnic communities by trusted organisations is needed for a number of reasons:

### **Less supportive of donation and lack**

**understanding:** Attitudinal surveys carried out on behalf of NHS Blood and Transplant regularly show that black and Asian people living in England lack some understanding of organ donation, such as that ethnicity matters when it comes to organ matching, and are less supportive of organ donation after death than white people

**Over-representation on waiting lists:** People from black and Asian communities are more likely to develop high blood pressure, diabetes and certain forms of hepatitis than white people. This makes them more likely to need a transplant. 35% of patients waiting for a kidney are from black, Asian and minority ethnic communities, despite representing approximately 11%\* (based on 2011 census) of the population across the UK. Although many black, Asian and ethnic minority patients are able to receive a transplant from a white donor, patients wait longer for an organ and others may die if there is no donor from their own community.

**Lower willingness to donate:** While consent rates among black, Asian and minority ethnic communities for donation after death are increasing, families from these communities are far less likely to support donation going ahead than white families. In 2017/18 there were

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<sup>1</sup> Randhawa G & Neuberger J (2016) The role of religion in organ donation – Development of the UK Faith and Organ Donation Action Plan. Transplantation Proceedings. 48: 3, 689–694. doi:10.1016/j.transproceed.2015.10.074



114 deceased BAME organ donors after death, 7.3% of those donating.

**Deaths on the waiting list:** One in five people who died on the Transplant Waiting List in 2017/18 were from a black, Asian or ethnic minority background.

It was hoped that trusted community-led organisations would be more effective at building support for organ donation amongst their community due to their specialist knowledge, understanding and standing within that community.

## What did the Community Investment Scheme look like?

We were keen to use learnings from other community-led funding initiatives prior to putting out the call for applications focusing on organ donation after death. In particular, the learnings from the NBTA's Living Transplant Initiative<sup>2</sup> and grant schemes run through the Ministry for Housing, Communities and Local Government were particularly helpful.

As this was the first year of activity and as NHS Blood and Transplant secures its funding on an annual basis, the funding call asked for organisations to put in bids for applications for short term projects that would be delivered by the end of June 2019.

- Applicants could apply for up to £2,499 or an amount of £2,500 and above.
- Projects could cover England, Wales or England and Wales.

The focus of the proposed projects needed to be on promoting organ donation after death. Other forms of donation (for example living organ donation, blood donation and stem cell donation) could be included providing the main focus was on donation after death.

## Judging panel

It was important that we had clear criteria in place against which applications could be scored and funding decisions made.

The criteria for awarding the funds was based on:

- how the activity would make a positive impact
- understanding the audience and issues
- experience of previous activity for organ donation or a similar subject
- ability to evaluate activity based on Government Communication Service principles
- value for money

## Appendix 1.1 List of Judges

NHS Blood and Transplant convened a judging panel comprising of key stakeholders in the organ donation and transplant community. This included a family/patient with first-hand experience of organ donation; members of the marketing and communications team at NHS Blood and Transplant; the lead diversity nurse for Organ Donation; clinicians and nurses involved in organ donation and transplantation; a representative from the Department of Health and Social Care; a representative from the Welsh Government; a representative from the National BAME Transplant Alliance; the NHS Blood and Transplant BAME Marketing Manager; and the chair of the Stakeholder 2020 group.

Their knowledge and expertise were vital in ensuring that applications were fairly scrutinised.

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2 Final report <https://www.nbta-uk.org.uk/resources/reports/living-transplant-initiative-final-report-published/>



## Advisory group

The judging panel's support for the initiative continued during the delivery phase too, with members acting as advisors for projects. Many were also invited to speak at events funded through the scheme or carried out media interviews about projects and the need for more donors from black, Asian and minority ethnic communities.

## What we funded

- 25 projects from the 40 applications put forward were funded
- The total investment from the first funding call was £140,977.91.

## Appendix 1.2 List of Advisors / Steering Group Members

NHS Blood and Transplant was able to set up the scheme thanks to funding from the Department of Health and Social Care and a contribution of £2,933 from the Welsh Government to support two projects that would be delivered in both England and Wales.

The funded projects reached people across London, the Midlands and the North West of England, as well as in Cardiff, Bristol, Leeds and Newcastle.

Across the projects a range of approaches were used to raise awareness and increase support for organ donation such as events and workshops, outreach activity at community and faith gatherings, information leaflets, videos and films, and online and social media campaigns.



# Projects funded

## Projects funded up to the value of £2,499:

Organisation	Project name	Faith or community reached	Overall grant
BAPS	Make a gift of life: organ donation and transplantation in Hindus	Hindu	£2,400
Bristol Multifaith Forum	Blood and Organ Donation Champions	Multifaith	£2,299
British Islamic Medical Association	Let's Talk About Organ Donation. Islam, Medicine & Patient Experience	Muslim	£1,900*
British Sikh Nurses	Pass it on	Sikh	£2,499
Centre for the Study of Islam	Understanding Death, Dying & Organ Donation Fatwas in Islam	Muslim	£2,467.07
City Sikhs	Organ Donations Amongst Sikhs	Sikh	£2,499
East Lancashire Community Action Project	Be a Life Saver	Muslim	£2,225
Indian Association Oldham	Indian Association Oldham Organ Donor Awareness Campaign	Indian	£1,900
Mandip Mudhar Memorial Foundation	Positivity out of tragedy – Donating Mandip's Organs	Sikh	£1,390
One Voice Blackburn CIC	Let's Talk About Organ Donation	Multifaith, Muslim	£2,450
One World Foundation	Save a Life	African	£2471.45
Santosh Community Centre CIC	Event to encourage organ donation in the Hindu Community in Belgrave, Leicester	Hindu	£2,450
SEWA Day	SEWA Day Organ Donation Drive	Hindu	£2,490



## Projects funded above the value of £2,500:

Organisation	Project name	Faith or community targeted	Overall grant
ACLT (African Caribbean Leukaemia Trust)	Challenging Black Attitudes About Organ Donation	Black	£11,920
Caribbean & African Health Network Greater Manchester	Precious Life Savers	Caribbean and African	£15,990
Faith's Forum for London	Organ Donation in Muslim Community	Muslim	£9,000*
Global Kidney Foundation	Give Hope, Give Life – London and Birmingham Awareness Project	Multifaith	£10,000*
Karimia Institute	Helping others to survive (HOTS)	Muslim	£6,102
Quran Club	Let's talk organ donation in Islam	Muslim	£9,700
Lancashire BME Network (working in collaboration with Lancashire & South Cumbria KPA)	It Could Be You	Muslim	£11,500
Leeds Cares	Let's Talk	South Asian	£7,200
Lightseekers Ltd	Life Again	Hindu, Sikh	£5,800
RAFFA	Community Health Education	Christian, Black	£6,407.50
Royal Free London NHS Foundation Trust's Kidney Patients Association	The Organ Donation Youth Awareness Project	Black	£6917.89 *
Vanik Council UK	Give a Gift, Give an Organ	Jain	£11,000

Four projects\* were unable to spend their whole grant within the allocated time frame. The remaining funds were recouped from these projects. One project asked for an extension to complete their project in October 2019.

Overall grant	Total spend	Funds returned to NHSBT
£140,977.91	£136,463.70	£4,514.21

Most projects were carried out in a 6-month period between January and June 2019 with some asking for short extensions.



## Evaluating the impact of the projects

It was unrealistic that the impact of any short-term community-led projects focused on promoting organ donation after death could be measured in the same way as the Living Transplant Initiative: through the registration of interest, number of living donor assessments and number of people who went on to donate as a living donors. Someone committing to be an organ donor, may not die for several decades and even then, may not die in circumstances where they could become an organ donor.

Therefore, for this report on the first round of projects, we have looked at what has been achieved, such as the number of events delivered, people reached, and associated activities such as social media and stories in the media.



# Measuring attitudinal change

**Attitudinal surveys carried out over time are a useful way to analyse whether activities developed to drive behaviour change are having the desired impact.**

NHS Blood and Transplant has started to commission an annual survey of black and Asian people living in England (a survey is also being carried out in Wales) to identify signs of any changes in attitudes within specific communities.

A baseline survey<sup>3</sup> of black and Asian adults in England was carried out in May 2018. A follow-up survey was carried out in March 2019. It is not possible from these surveys to determine the relative impact of the community-delivered work compared to other initiatives focused on black, Asian and minority ethnic communities. Nevertheless, they do serve as a useful temperature check.

The second survey showed some movement in understanding about organ donation and attitudes among black and Asian respondents:

- A higher percentage (39%) of respondents in the second survey compared to the baseline survey (22%) correctly answered that you get a better match with a donor from your own ethnicity and 35% (March 2019) stated that black and Asian people are proportionally more likely to need an organ (compared to 11% in May 2018)
- Opposition to organ donation decreased to a more neutral position. 33% of survey respondents in May 2018 told us they oppose organ donation compared to 22% in the March 2019 survey
- The number of those not willing to donate decreased and we saw an increase in consideration of donation. In May 2018, 37% of respondents told us that they definitely wouldn't donate their organs compared to 20% in March 2019. In March 2019, 43% of respondents told us they would consider donating some of their organs compared to 30% in May 2018.

These results may suggest an initial softening of attitudes that, if sustained, may lead to more robust support for organ donation.

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<sup>3</sup> England: <https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/16484/190709-england-summary-bame-organ-donation-attitudinal-survey-wave2.ppt>  
Wales: <https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/16485/190709-wales-summary-bame-organ-donation-attitudinal-survey-wave2.ppt>



# Summary of what was delivered through the BAME community investment scheme

Projects were delivered between November 2018 and end June 2019 with a few projects asking for, and being granted, short extensions.

## Events and materials delivered

**211** events

**46** new videos, education materials, flyers or posters produced.

## People reached

**130,000** Approximate footfall at events where there was an organ donation stand

**4,100** Approximate number of people who engaged in a conversation at a stand or who took away information materials

**7,900** Approximate number of people attending a talk/workshop about donation.

## Associated publicity

**14** Approximate number of press releases issued by projects

**65** Approximate number of broadcast media interviews secured involving people delivering projects

**18** Approximate number of print articles secured involving people delivering projects

**62,000** Approximate number of video views

**244** mentions of organ donation on Twitter from organisations delivering projects, reaching over 750,000 people.

The support of the organisations funded through the first scheme has continued on social media.

There were 97 mentions on social media, reaching over 350,000 people in the four months after the end of the projects

## Actions taken

**371** people pledged to have a conversation with their families about organ donation

**909** people completed organ donor registration forms.

**These figures are approximate and have been collated from the final project evaluation reports provided by the organisations.**

Whilst we tried to encourage consistencies in reporting between projects as part of our evaluation process, not all metrics were provided by all projects. The figures above are therefore an underestimate of what was actually delivered.



# Reflections on the components of successful delivery

**NHS Blood and Transplant recognises that many individuals and organisations deliver activity to promote donation, either voluntarily, as a result of grants, or because promoting donation is part of their own organisational charitable remit.**

This section provides reflections from the first round of BAME Community Investment Scheme activity that we hope will be useful to anyone delivering activity to promote organ donation, particularly within BAME communities, within a faith or cultural context.

## Multi-faceted campaigns

While many of the projects were centred around events, many were able to extend their reach by using other communication channels as part of their promotional and educational efforts. For example, by posting emotive or educational content on social media, and engaging media to carry out interviews on the topic. Implementing a campaign with multiple layers provided projects with a number of touchpoints with their community to share messages about organ donation and help them along the decision-making process. Projects that were most successful in building support for organ donation implemented campaigns through a number of different channels.

## Partnerships and working in collaboration

Collaboration was key to the success of projects, helping organisations to inspire people from their community to attend events and also ensuring that there were appropriate and knowledgeable speakers from local hospitals, religious organisations and patients to deliver the message. We also saw high

levels of collaboration between projects where more than one project was focusing on a specific faith community. This helped to ensure that there was no duplication in effort and that learnings were shared throughout the course of the initiative.

Three organisations from the Sikh community provided a good example of collaboration, coming together at the beginning of their project to ensure synergy and that there were no crossovers within their projects. They also set up a WhatsApp group to encourage collaborative working and to share information about events, used a shared hashtag on social channels and co-created materials such as selfie boards.

Others also established successful partnerships with local organisations or groups including SEWA Day who worked closely with the National Hindu Student's Forum, using their volunteers to spread the word about organ donation at their own events.

## Leaflet distribution

Several projects identified ways to deliver materials to members of their community where there was high footfall. This approach was useful as it took the message out to people and was not reliant on people coming to them.

Materials also provided a conversation starter to open discussions about organ donation. Leeds Cares attended two park run events offering branded water bottles and other promotional items to engage in discussion with the runners and supporters.



## Engaging children and young people

We recognise that many people do not want to talk about donation, but some projects identified ways to engage families and then use the moment to discuss donation in an informal setting. Others directly engaged young people in an education setting and encouraged the young people themselves to take the message home.

ACLT found success in this way by taking their messages to local schools and delivering presentations, talks and discussions to mainly young black audiences and by encouraging the young people to take materials home and use them as a basis for discussion with other family members.

## Use of Donor/Recipient stories

It is clear from registration data to the NHS Organ Donor Register over the last few years as well as from looking at social media engagement on NHS Blood and Transplant's own channels that real people's stories help to educate and emotionally engage people about organ donation and can prompt people to act. We often see spikes in registrations when a donor family, patient waiting, or recipient shares their story. It therefore doesn't come as a surprise that the involvement of donor families and patients was crucial in the delivery of projects as someone who has lived experience can talk knowledgeably and emotively about the impact donation or a transplant has had on them. Experience from year one suggests that every event should involve someone's real story, ideally a donor family story, either in person or through a video as it helps to normalise organ donation within a community.

Vanik Council used real life stories to both normalise and celebrate donation with the presentation of certificates to living donors and the families of deceased donors at an event and show the positive impact it has on people's lives. Other organisations successfully worked with patients on the waiting list,

supporting their appeals and helping them to spread the word in their communities such as Naomi Adams (ACLT) and Hope for Anaya (engagement with the Sikh projects). Others such as the Mandip Mudhar Memorial Foundation shared their own personal experiences as a donor family.

## Use of a Specialist Nurse/Clinician/Transplant Surgeon etc

Many events triggered questions about the donation or transplant process, and it was important that healthcare professionals were on hand to answer these. Indian Association Oldham and Lancashire BME were some of the organisations who worked closely with their local specialist nurse. The latter set up Question Time sessions for the public to ask questions to organ donation experts, medical professionals and the organ donation transplant nurse. This served as an opportunity to break down barriers and dispel any myths.

A challenge for organisations was always being able to identify someone who could attend to educate and inform people about the organ donation process, and many projects were reliant on the same specialist nurse to travel up and down the country. Based on this, NHS Blood and Transplant has been working hard to develop video resources involving black and Asian nurses, and doctors and surgeons involved in the organ donation and transplant process to explain the organ donation processes and address myths or questions that arise in their own community. These are available on our YouTube channel so organisations can share them on their social channels and be less reliant on having to identify healthcare professionals who can attend their face-to-face events.

## Community events

While many of the projects were event-based, there were many different styles. One of the benefits of a community-led approach is that the organisations know what may motivate or inspire people to



attend and participate in their events. They could also be held in accessible places. We saw a mixture of promotional stands at high footfall events, workshops, presentations and debates. Some sessions were delivered in a more relaxed environment (e.g. around yoga sessions given by Lightseekers, and community festivals like Bristol Multifaith Forum) or when delivering a clinical service (e.g. blood pressure checks for people who may be higher risk by Global Kidney Foundation). We would encourage organisations continuing engagement work to always build on learning from previous events, so that they always improve and try to reach new audiences rather than go back to the same group of people with a similar event.

## **Engagement of faith leaders as messengers**

Surveys regularly suggest that concerns about someone's faith or culture not supporting organ donation can act as a barrier to someone deciding to donate, or can lead them to opt out of donation. While all the main religions and beliefs in the UK support donation in principle, in reality the situation can be quite complex.

Organisations, particularly in the Muslim community, recognised it was important to have the right messenger and that in order to engage members of the public, there was a need to engage imams and scholars in advance of the public engagement efforts. If members of the public approach their own faith leader for clarity on whether or not organ donation is permitted, it would be more reassuring to them to receive information from a faith leader who has knowledge of organ donation. There were a number of organisations who held workshop sessions with faith leaders (such as British Islamic Medical Association, Caribbean and African Health Network and RAFFA) prior to commencing activity at places of worship in order to provide them with the relevant information they needed to confidently share their messages.

## **Bespoke materials**

NHS Blood and Transplant makes available for free a range of promotional leaflets, sign-up forms and merchandise for any organisation or individual who wants to promote donation. As such these materials were available to all projects. However, some projects recognised there was an opportunity to use some of their funding to create other materials that linked well with the activity they were undertaking.

One World Africa produced purposely-designed materials for the Swahili-speaking audience aware of the sensitivities in this community around talking about end of life by reframing organ donation as an act of kindness that saves lives every day. The BAPS project also involved creation of bespoke leaflets which inform Hindus of the change in law whilst encouraging them to sign up to the NHS Organ Donor Register.

## **Social media**

Not all projects used social media as part of their delivery. However, those that did used a blend of sharing @NHSOrganDonor content, sharing other content or posting original content. Social media activity was important as it helped to extend the reach of the message beyond any face-to-face activity.

Royal Free Hospital found social media to be the best platform to recruit young black adults to become champions for organ donation, and used this to further boost the reach of their activity throughout the campaign. While Faith Forum for London reached more audiences with their videos through groups such as British Muslim Youth sharing their posts on Facebook.

## **Support from community and regional media**

There were some fantastic examples of projects securing media coverage around their work. Media outlets are keen to cover organ donation



as a subject and to interview community organisations, donor families, patients and healthcare professionals to educate and inform their viewers / listeners / readers. It is important to have a hook, and the activity delivered through these projects often served as a useful 'news' hook for the media to cover donation and the need for more BAME organ donors, as well as provide 'messengers' outside of NHS Blood and Transplant.

British Sikh Nurses took the debate about organ donation to a wider audience via the media, which included a prayer event on the Sikh Channel for Anaya which was widely viewed. This and other content was then boosted further on social platforms. Others, such as Santosh Community and Karimia, used local radio stations to encourage attendance at their events and share messages about organ donation, while East Lancashire Community Action Project organised weekly health shows to cover all aspects of organ donation.

## Spreading the word

Several projects, including Leeds Cares and Lancashire BME, wanted to expand the reach of the message by asking people they engaged with at events to pledge to go home and talk to their family or to engage 'community champions' to take the message wider and further. City Sikhs held an event at the Houses of Parliament and Birmingham City Hall to engage with MPs whose constituencies have large BAME communities; these events also had high profile Sikh business leaders and celebrities attend. The success of the community champion approach varied between projects and demonstrated that it is important that organisations delivering projects are clear about what being a community champion means, how they are recruited, educated and trained and also have the materials for their own outreach efforts.

## Videos

The main focus of some projects was to develop video materials that could be used to educate, inform and inspire members of their community around organ donation. Such assets could also have a lifespan beyond any face-to-face events and could be used /accessed by a wider group of people.

One Voice Blackburn took an insight-driven approach using focus groups to feed into plans for video content and to identify potential speakers for the videos. Short videos were also created by other projects featuring prominent religious leaders (Indian Association Oldham), events and seminars to share on social channels or with delegates for onward dissemination to their community groups/faith communities.

## Using technology to reach an audience

Quran Club's project focused around an app which was already being developed to reach members of the Muslim community on matters relating to their faith. It was also aimed at younger people, raising awareness of the subject and directing people to further materials. Even though the engagement after watching the animation was limited, the survey on the app reached large numbers. Learnings from this trial can be built on for any future work with apps has helped identify scope for using new technologies such as this to reach previously untapped audiences.

## Educating others

Whilst NHSBT provides factual content around organ donation, it is understood that there are many questions that need to be answered with regards to religion and the new law in order for an informed decision to be made. A number of projects identified an opportunity to create useful educational assets for their communities. With the introduction of the new law imminent, a number of organisations produced useful insights. The Centre for the Study of Islam project exclusively targeted the Muslim



community, focusing on giving theological-based talks about the Islamic position on organ donation, while City Sikhs launched the British Sikh Report in Parliament, which focused on organ donation.

## Actions taken

There were at least 909 organ donor registrations resulting from the first wave of activity. Although this may seem low we should not judge success on just these numbers. 371 people were engaged in conversations about organ donation and pledged to talk with their families and friends about it, whilst many more were touched by our messages either at an event or via other channels. It is well recognised that behaviour change can take time. For a subject such as organ donation, where awareness and understanding levels among the BAME community are low, people may need to hear about it, have access to information in a number of different ways and seek further clarification before making a decision. To complement community-delivered activity, NHS Blood and Transplant has been working to ensure that its own advertising and marketing efforts are also reaching black and Asian communities, that there is greater diversity in the content we are sharing on our own social channels and that we are expanding the network of supportive stakeholders who are happy to share organ donation messages.

## Where are we now and what next?

There are positive signs over the last few years that the situation in relation to BAME organ donation has been improving.<sup>4</sup>

- The number of BAME deceased organ donors across the UK has increased by 51% over the last five years, from 80 in 2014/15 to 121 in 2018/19. In 2018/19 they represented 8% of all deceased organ donors. Significantly, there were more Asian deceased donors (56) last year than ever before.
- Consent rates for organ donation amongst BAME families have risen over the last five years, with 42% now saying 'yes' to donation.

Nevertheless, we cannot become complacent while the proportion of black, Asian or minority ethnic families who agree to organ donation going ahead still lags significantly behind the proportion of white families, and 1 in 5 people who die waiting for a transplant are from black, Asian or minority ethnic communities.

Also, with the law changing in England in 2020 and in Scotland in 2021 to an opt out system, there is a huge opportunity to raise awareness of organ donation among the population as a whole and to encourage people to record and share their donation decision with those closest to them.

We cannot ignore the fact that the majority of people who have opted out of organ donation so far have told us they are black, Asian or minority ethnic when registering their decision. We have seen a number of short spikes in opt outs, and these have often occurred as a direct result of misinformation circulating on social media or on private messaging platforms about the upcoming change in the law around organ donation.

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<sup>4</sup> <https://www.organdonation.nhs.uk/helping-you-to-decide/about-organ-donation/statistics-about-organ-donation/>



While it is everybody's right to opt out if they do not wish to be an organ donor, we are concerned that many people are making this decision based on misinformation, because they are worried about the donation process itself or don't think that their faith or beliefs will be respected.

The work of community-led organisations is vital to delivering the facts through trusted messengers and ensuring that people understand that unless more people from their community come forward as organ donors, patients from their own communities will continue to die waiting for an organ transplant.

In October 2019, following another funding call, we were delighted to fund 26 projects focusing on black, Asian and minority ethnic communities. While some of the organisations had carried out work in the first year of the scheme, we were pleased to fund other organisations too, as we were keen to grow the scheme and reach out to new audiences. When we put out the funding call we made it clear that we were keen to receive applications from organisations focused on black communities, organisations who can help us reach younger audiences, and from organisations that were going to try something new, for example by using arts, technology or different community approaches.

The projects will vary in length as applicants were given the choice as to whether they would deliver projects to June 2020, October 2020 or March 2021. Project extensions have been provided to organisations as a result of COVID-19.

We invested over £200,000 in this second funding round across a range of projects that will reach black African, black Caribbean, south Asian, Chinese, Hindu, Jain, Muslim and Sikh communities. While some projects will be national in their reach others have a more specific geographic focus.

All of the projects that will be delivered in England will need to deliver accurate information about the change in the law and people's choices, as well as address concerns or questions within each specific community that may serve as barriers to consent.

This second funding round is an important element of the wider programme of work to increase awareness and understanding and the willingness of black, Asian and minority ethnic communities to become organ donors.

With funding assured until March 2021, we expect to build on the scheme with another funding round in 2020/21.

The BAME Community Investment Scheme is an important element of the wider programme of work to inform, engage and inspire people from black, Asian, mixed race and minority ethnic communities about organ donation. It sits alongside a range of other initiatives. NHS Blood and Transplant is running national advertising to communicate the change in the law and people's choices, working with community and regional media to deliver media stories about donation, and advertising in community publications and radio shows that are read and heard by people from black, Asian and minority ethnic communities. The organisation is engaging at a national level with faith groups to ensure that people can find accurate information on the stance of their faith on organ donation and hear the perspective of faith leaders. It is also working with a range of stakeholder organisations and influencers who can deliver information through their own communication channels, and developing content that tells the stories of BAME donor families and recipients or addresses concerns held within these communities.

We want to normalise organ donation from black, Asian, and minority ethnic communities and to do that we need to ensure that people see and hear about it in the right spaces and that the message resonates with them.

It is going to take time, focus and energy from all of us working together to deliver the lasting change we all want to achieve for patients from black, Asian, mixed race and minority ethnic communities.



# Project summaries



Attendees at Community Investment Scheme Launch Workshop on 20th December 2019 in Birmingham





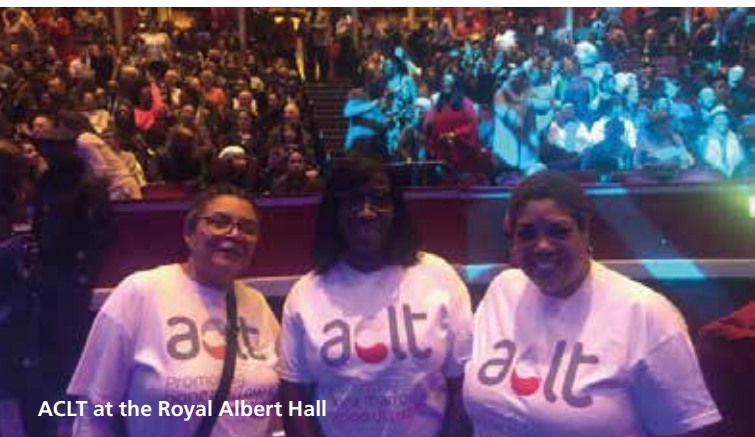




ACLT presentation at American Airlines



ACLT at Woodhouse



ACLT at the Royal Albert Hall



Attendees at an ACLT event



Orin Lewis and David Michael at an event



ACLT at Southfields



# African Caribbean Leukaemia Trust: Challenging Black attitudes about Organ Donation



## Value of grant; £11,920

ACLT was established by Orin Lewis OBE and Beverley De-Gale OBE in 1996 with the aim of saving lives by promoting blood, organ and stem cell donation within black, Asian and minority ethnic communities. This life-saving work started in order to find a matching stem cell donor for their son, Daniel De-Gale, in his on-and-off battle against blood cancer. After a 6-year search a donor was found, but sadly in 2008, at the age of 21, he died from multiple organ failure.

The project was focused on delivering presentations, talks and discussions to mainly young black audiences about the need for more deceased (and living) organ donors, whilst breaking down the cultural/religious beliefs which have historically been linked to poor registration numbers. They presented a mixture of audio, videos and talks by themselves, patients in need and actual living donors. Their activities included stalls at live events and working with local schools.

Real people's stories sat at the heart of the ACLT initiative and they worked hard to support patients from black, Asian and minority ethnic communities who are appealing for donors. Millions of ITV London Today and Tonight viewers for example watched patient Naomi Adams and ACLT's Orin Lewis talk about her need for a donor, and for black people to have a conversation with family members around the fact that an 'opt out' system for organ donation will come into effect in England in 2020.

The charity was able to gain further reach beyond the events themselves by sharing videos on their social channels, including a video of ACLT's Orin Lewis fronting the new London Assembly video on organ donation awareness.

There were nearly 300 sign ups to the NHS Organ Donor Register as a result of this initiative.







Manchester organ donation event 2019



Organ donation stand, Leicester



The BAPS team promote organ donation at an event



Parliamentary event hosted by Lord Gadhia



# BAPS Swaminarayan Sanstha: Making a gift of life: organ donation and transplantation in Hindus

## Value of grant: £2,400

BAPS Swaminarayan Sanstha is a spiritual, volunteer-driven organisation dedicated to improving society through individual growth by fostering the Hindu ideals of faith, unity, and selfless service.

The main focus of the project was to inform Hindus of the change in law and encouraging them to sign up to the NHS Organ Donor Register. They planned to achieve this by creating a leaflet which explained the change in the law, and included real life stories about someone waiting for a transplant, someone who has had a transplant and a donor family – all from the Hindu community, as well as quotes from Hindu scriptures and religious leaders.

The leaflet was created in conjunction with the Jain and Hindu organ donation steering group who developed a supporting video.

Working collaboratively meant that their messages were not only consistent but also more powerful. Both of these were launched at an event in Parliament hosted by Lord Gadhia and attended by the Health Secretary, Rt Hon Matt Hancock.

During the course of the BAPS initiative, they held events all across the South East including at the BAPS centres in Harrow, Finchley, South and South East London, Chigwell, and Luton. BAPS reached approximately 2,000 people through these events.

The new organ donation materials continue to be used on social channels and at awareness events in BAPS centres and Hindu Temples around the country. The next steps for this project would be to translate the materials into more languages to make them more accessible.



Some pages from the new leaflet





The Bristol Multifaith Forum team raise awareness at an organ donation event with Chair, Cllr Tom Aditya



Speakers are thanked at the Bethel Church event



Bristol Multifaith Forum event in a local Gurdwara



# Bristol MultiFaith Forum: Fears and Myths of Organ Donation: Awareness Campaign and Community Champions Enrolment Programme



## Value of grant: £2,299

Bristol Multi-Faith Forum is an organisation which works with Bristol's faith communities and the community sector to encourage cohesion and social harmony. Bristol Multi-Faith Forum is committed to promote and support blood and organ donation campaigns amongst various faith communities.

In the hope of raising awareness of organ donation, Bristol Multi-Faith Forum's blood and organ donation campaign organised four events at four prominent community venues in 2019, including a church, a temple, a gurdwara and a mosque.

The professionals, experts and ambassadors were carefully selected with support from NHS Blood and Transplant, who were able to educate the attendees with their expert knowledge and real-time experience. The religious leaders

who were speakers at the event clarified the myths related to organ donation from a religious perspective and appealed to the audiences to take up the campaign further.

The events were promoted on various local radio channels and media as well as through faith organisations, at the Bradley Stoke Community Festival, and on social media. As a result, all the events were well-attended with over 200 attendees overall and 89 asking for more information. Many stated that they gained valuable knowledge and would consider signing up to the register at their convenience. Participants expressed an interest in volunteering to support the project in future.



Bristol Multifaith Forum event at Greenbank Mosque





Imams engage in discussion at a planning session



The BIMA team and volunteers involved in planning the event: Let's talk about organ donation



Attendees pictured at BIMA's event: Let's talk about organ donation



# British Islamic Medical Association: Let's Talk About Organ Donation



BRITISH ISLAMIC  
MEDICAL ASSOCIATION

## Value of grant: £1,321.20

This was a project carried out by an organisation which supports Muslim healthcare professionals in the UK. Their plan was focused around bringing together 18 imams from across the North East and delivering a presentation to them by local healthcare professionals. The session offered the opportunity for imams to network and those present were encouraged to invite their congregations to a public event. The Let's Talk About Organ Donation event was hosted by BIMA and comprised an open networking session followed by a series of talks by scholars and medical experts and a question and answer session.

Initially, misconceptions about organ donation within the Muslim community acted as a barrier to people committing to attend the public event. Imams promoting it within their community, pre-event media on FastFM and spiceFM radio stations and social posts led to a high number of attendees, 86 of whom completed an attitudinal survey.

Some of the questions asked were 'Do you think organ donation is Halal?' and 'If organ donation is Halal, would you register for it?' the results of which showed a positive shift towards supporting organ donation following the event. The organisation was able to gain further reach by securing coverage on the ITV news.

### – DO YOU THINK ORGAN DONATION IS HALAL?

	Before	After
Yes	25/86 29%	72/86 84%
No	11/86 13%	2/86 2%
Not sure	50/86 58%	12/86 14%

(Positive shift is 55% of the people completed the forms, from 29% → 84% between "before the talks" and "after" of the people who believe that organ donation is permissible)

### – IF ORGAN DONATION IS HALAL, WOULD YOU REGISTER FOR IT?

	Before	After
Yes	56/86 65%	68/86 79%
No	9/86 10%	6/86 7%
Not sure	21/86 24%	12/86 14%

(Positive shift is towards registering for OD card from 65% to 79% if it is Halal)

The approach taken by BIMA – to engage imams and garner their support before arranging a public event – led to a well-attended public event where people were able to engage positively with the subject and have their questions around the permissibility of organ donation in Islam addressed.





Rohit Sagoo with Gurch Randhawa, talking with broadcaster Harjap Banghal



Rohit Sagoo, senior lecturer at Anglia Ruskin University and founder of British Sikh Nurses at the Sikh Temple, Gurdwara Sri Guru Singh Sabha



British Sikh Nurses Founder, Rohit Sagoo, mans an information stand



# British Sikh Nurses: Pass It On

## Value of grant: £2,499

The British Sikh Nurses project focused on taking the organ donation message into gurdwaras, to engage Sikhs on the subject within their familiar faith setting.

During the course of the project, they held 14 events, reaching around 2,000 people and securing around 150 registrations to the NHS Organ Donor Register. The events ranged from an all-day health screening event at Guru Nanak Sikh Temple in Walsall alongside the Hope 4 Anaya campaign, a stand at Vasaikhi Birmingham and an organ donation drive in the Central Gurdwara in London.

British Sikh Nurses carefully considered the type of events they wanted to attend and focused on venues or events with high anticipated numbers of people. They worked very closely with the Hope 4 Anaya campaign, a campaign drawing attention to Anaya, a Sikh toddler who desperately needed an organ transplant. Her story emotionally engaged Sikhs on the subject, demonstrated the shortage of donors within the Asian community and highlighted the plight of patients in need of transplants.

In addition to the events, British Sikh Nurses took the debate about organ donation to a wider audience by engaging the Sikh media. Rohit Sagoo appeared on MATV and Akaal TV alongside Professor Gurch Randhawa and took part in a prayer event on the Sikh Channel for Anaya. British Sikh Nurses also made good use of their social channels during their project, posting nearly 70 times about organ donation. This activity led to around 20,000 video views of organ donation content on their Facebook page and over 1,000 likes on their Facebook page and Twitter feed. The high number of retweets of their Twitter content (c500) showed that they have an engaged community following them and that the content they were posting was of interest.



TV appearances







Pastors and Leaders Workshop



Pastors and Leaders Workshop

CAHN
NHS
Blood and Transplant

# Precious Life Savers

Organ Donation Awareness & Recruitment Project

Around 600 black people are waiting for an organ transplant across the UK

More than 2300 people from the black community are alive today thanks to organ donors

Last year, sadly 31 patients from black backgrounds died waiting for a transplant

Sign up today to the NHS Organ Donation Register  
[www.organdonation.nhs.uk/preciouslifesavers](http://www.organdonation.nhs.uk/preciouslifesavers)

From spring 2020 the law around organ donation in England is changing

*Let's talk about it*

Local Church Leaders supporting Organ Donation as an act of love and giving!

Email: [organdonation@cahn.org.uk](mailto:organdonation@cahn.org.uk) Contact: 07575 579377  
 Spread the word #PreciousLifeSavers #PassionOn #ShareYourWishes  
 Visit [www.cahn.org.uk/organ-donation](http://www.cahn.org.uk/organ-donation) for further information.



Pastors and Leaders Workshop



# Caribbean and African Health Network: Precious Life Savers



## Value of grant: £15,990

The focus of the Precious Life Savers project was to work closely with their existing networks of faith leaders and churches in the Manchester area to explore organ donation from a religious and cultural perspective. The project aimed to train champions with lived experiences of organ donation to raise awareness of the benefits and to help alleviate fear and mistrust of the medical profession.

They organised a successful workshop, which was attended by 23 pastors and church leaders and was promoted prior to the event in churches and on social media using #PreciousLifeSavers. On Twitter these posts spread the word about organ donation to Caribbean and African communities and encouraged attendance to the workshop, gaining over 3,000 impressions and over 37 engagements.

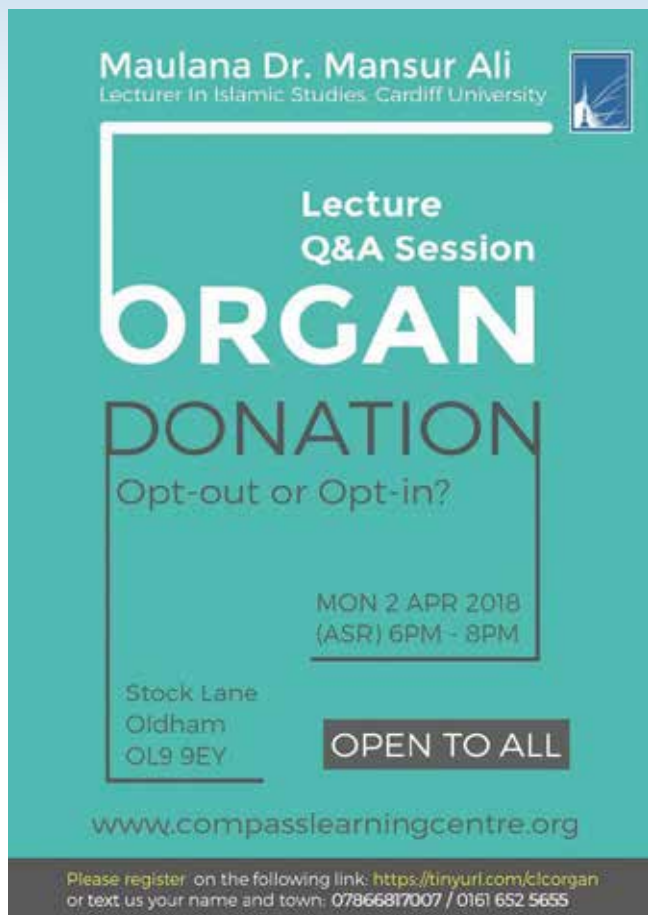
Alongside the workshop, CAHN attended 15 events where they spoke at churches and larger venues, as well as distributing flyers and eflyers with the aim of reaching over 1,000 people by using a diverse range of platforms.

Whilst they had hoped to recruit four champions with lived experiences of organ donation they managed to engage a recipient and a donor family to support the project. These real-life stories gained further coverage on UCB radio and BBC Radio Manchester.

The network was also able to boost their reach by sharing video feedback from participants at the pastors and church leaders' workshop. Three other ministers were also interviewed giving their support to organ donation and clearly confirming that there are no biblical barriers.

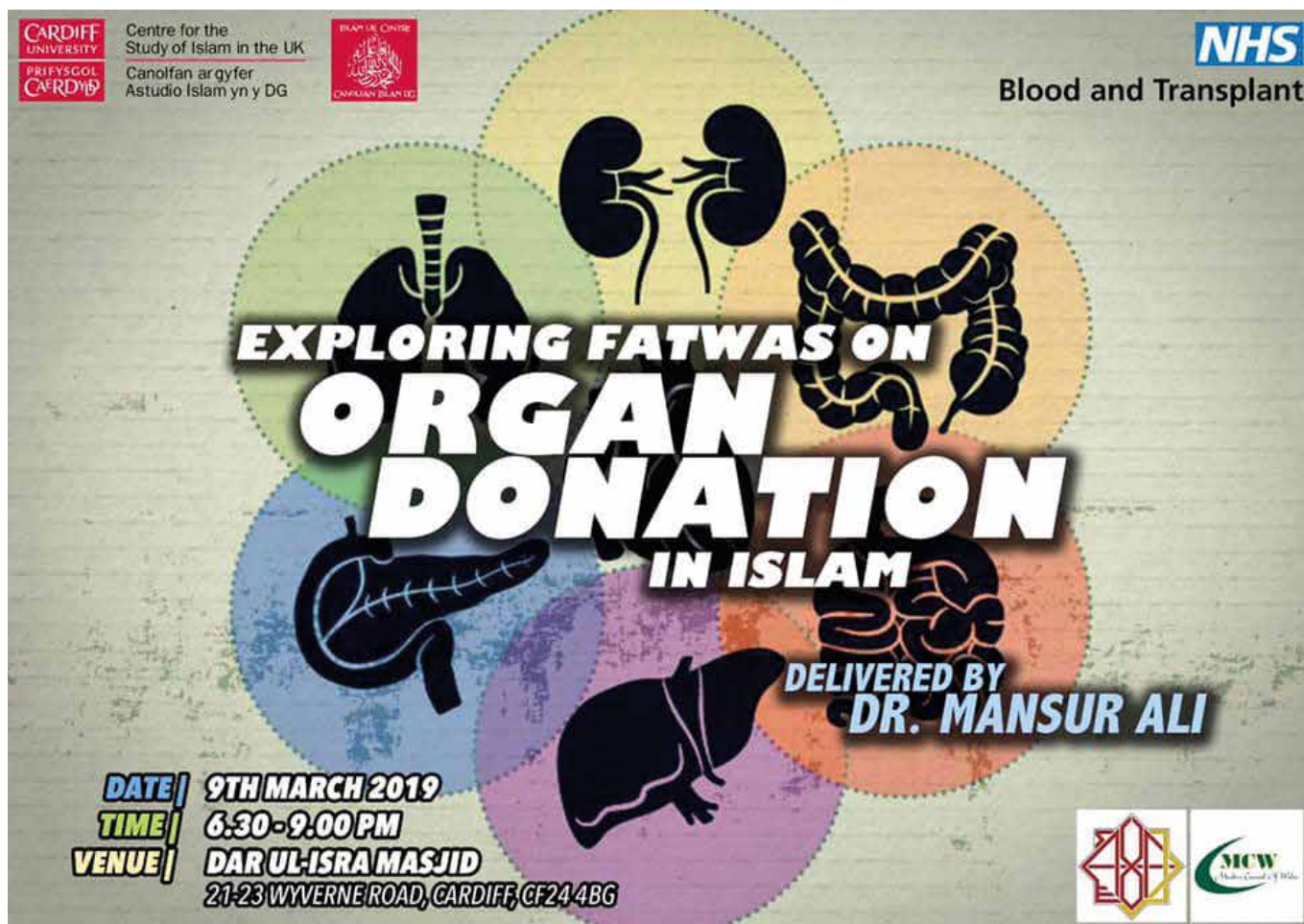
82 people completed pledge forms showing an interest in signing the NHS Organ Donor Register and there were 56 sign ups as a result of this initiative.





A flyer for the Centre's lecture on organ donation

A flyer for the Centre's organ donation event





# Centre for the study of Islam in the UK, Cardiff University: Understanding Death, Dying and Organ Donation Fatwas in Islam

## Value of grant: £2,467.07

The project exclusively targeted the Muslim community, focusing on giving practical theology talks in four mosques and providing people with an alternative understanding of the Islamic positions on organ donation so that they can make religiously informed decisions.

The project planned to address theological anxiety and assure people that deceased organ donation is neither an assault on scripture nor a violation of the dignity of their deceased loved ones. There were nearly 200 attendees for these events.

Due to the success of these presentations and the experience and knowledge of Dr Muhammad Mansur Ali, he was asked to provide support for a number of other organ donation projects. These included those who received funding from the Community Investment Scheme and NHS Blood and Transplant and centred upon the publication and contextualisation of Mufti Zubair Butt's fatwa. Dr Ali had originally planned to carry out an in-depth interview with Dr Rifaqat Rashid, a GP and trained Muslim scholar, but as a result of these additional activities some of the original plans were left uncompleted.



Centre for the  
Study of Islam in the UK  
Canolfan ar gyfer  
Astudio Islam yn y DG



The project empowered members of the Muslim community and helped them to make a decision regarding organ donation through theologically informed presentations.







An article on the British Sikh Report published in Punjabi newspaper, Ajit

A copy of the British Sikh Report 2019 was presented to the then Prime Minister Theresa May



The British Sikh Report launch event



# City Sikhs: Organ donation amongst Sikhs

CITYSIKHS  
www.citysikhs.org.uk

## Value of grant: £2,499

When they embarked on their project, organ donation amongst Sikhs, City Sikhs aimed to hold three events to engage Sikhs with organ donation. They exceeded this target by arranging four events. They had a promotional stand at Vaisakhi in the Square (a huge annual event in Trafalgar Square), an event in Parliament, an event in Birmingham and an event in Manchester. City Sikhs directly spoke to around 430 British Sikhs across their events, including parliamentarians and key stakeholders, and influential people within the Sikh community.

While not an original objective of the project, a significant achievement of the City Sikh project was the focus on organ donation within the British Sikh Report 2019, which was officially launched at their event in Parliament in April, and subsequently shared at their other regional events. Importantly, the report included the results of a survey investigating Sikh attitudes to organ donation. This survey found that 9 out of 10 Sikhs would respect the wishes of a family member who wants to donate their organs after they die.

The British Sikh Report 2019 was downloaded almost 1,000 times from the website, with a further 400 hard copies being distributed at events.

The launch of the report served as a strong news hook to generate stories in the media which would hopefully trigger conversations among Sikhs about organ donation. Coverage included the Chair of City Sikhs, Jasvir Singh talking about organ donation amongst Sikhs on BBC Radio 4's Thought for the Day on the eve of the event in Birmingham.

City Sikhs also secured coverage in Ajit Newspaper and 'TV Punjab', expanding awareness about organ donation among the Sikh community further than the events themselves.

City Sikhs used the hashtag #OrganSewa on social media, a hashtag they carefully selected as it linked organ donation with the concept of selfless service. To encourage social sharing they worked with NHS Blood and Transplant to develop selfie boards. Their social media efforts achieved over 95,000 impressions.

City Sikhs took a collaborative approach from the start, working closely with British Sikh Nurses and the Mandip Mudhar Memorial Foundation to ensure that each other's work complemented rather than replicated efforts.





Taken at the Pendle Community Radio Studios – Presenter Shakil Salam interviews donor family member, Tim Rogers, and Angie Ditchfield, Diversity Lead Nurse for Organ Donation



Taken at the Pendle Community Radio Studios – Presenter Shakil Salam (standing) with Tim Rogers (left) a donor family member & Angela Ditchfield (right) who is the Diversity Lead Nurse for Organ Donation



Mufti Usman Maravia, an Islamic Scholar & Faizan Awan, a patient who has had a double kidney transplant, are interviewed



Mufti Usman Maravia, an Islamic Scholar & Faizan Awan, a patient who has had a double kidney transplant



Presenter Shakil Salam with guests Mufti Usman Maravia, an Islamic Scholar & Faizan Awan, a patient who has had a double kidney transplant



## East Lancashire Community Action Project: Be a Life Saver



### Value of grant: £2,225

This project aimed to raise awareness and generate discussions about organ donation within East Lancashire's Muslim community through community radio.

Over the course of the project, six of Pendle Radio's weekly health shows, presented by Shakil Salam, focused on organ donation. Health professionals, scholars, transplant patients and donor families were invited onto the show, with the aim of educating listeners about the subject. Listeners were able to hear more about the organ donation process from a Muslim transplant retrieval surgeon; from a Muslim man about what it's like waiting for an organ transplant; from someone who agreed to donate a relative's organs; and from Amjid Ali about the fatwa issued by Mufti Muhammed Zubair Butt. Pendle Radio estimates reaching around 2500 radio listeners with these shows. In addition to these programmes, English and Urdu ads about organ donation, created by the station, aired.

The project wasn't just delivered through radio activity. Pendle Radio presenter, Shakil Salam, also made a number of reports on Dunya News UK (Sky Channel 850) reaching around 6,000 people with stories about organ donation. The Pendle Community Radio social media pages also regularly mentioned their organ donation campaign too.

This project reached members of the Muslim community with information about organ donation, but as it was a local initiative focused on raising awareness and educating listeners, viewers and followers, it is difficult to measure any direct link/impact on registrations within the Muslim community as a whole.





A photo from one of Faith's Forum's community discussions



An individual reading NHSBT materials at a Faith's Forum event



The Mosques and Imams National Advisory Board



# Faiths Forum for London: Faith Forum Muslim Organ Donation

**Value of grant: £9000,  
actual spend £6,581.50**

Faiths Forum were keen to raise awareness of organ donation after death, having had much discussion about it amongst their members. They planned a number of activities including conferences, videos and smaller regional events.

The project came up against a number of barriers in gaining support from the local community and in persuading local community centres to host the discussions, as most institutions had to get the buy-in from their trustees and management who were worried about the response from their members. Despite these initial issues the organisation carried out four community discussions with around 140 attendees from the local community. These events involved a panel of faith leaders and health experts. The hope was to get the community centres to understand the need to engage in the topic of organ donation and to consider hosting their own sessions.

Two videos were produced as part of this project, each about two minutes 30 seconds long to explain why more Muslims and diverse communities need to support organ donation; why it's important to inform family and friends on decision regarding organ donation and how imams and faith leaders can support this. These were shared by the British Muslim Youth Facebook page.



The project also gained further reach by organising an interview with Dr Majid Muhammad, a transplant surgeon and an imam on Asian Fever Radio in Leeds, as part of their community health slot, whose listeners are particularly from the Asian community.

Whilst registering people proved difficult, at events people were asked to give a show of hands around their views, and 70% of attendees responded with a more favourable opinion of organ donation compared to their views before attending the session. These events also gave a greater awareness of the need for organ donation. Through the community discussions they were able to tackle many of the common misconceptions associated with organ donation.



Poll done during the Dar Al Had Discussion





The team at Guru Nanak Gurdwara Smethwick, Birmingham



A nurse completes a health check



Nurses running one of Global Kidney Foundation's health check stands



Nurses run a health check stand



A nurse completes a health check



## Global Kidney Foundation: "Give Hope, Give Life!" London & Birmingham Awareness Project

**Value of grant: £10,000,  
actual spend £9,416**

Global Kidney Foundation's project was focused on piloting a new approach to sharing messages about organ donation by linking it with health checks. This involved recruiting and training nurses to provide free health checks and to use the time during the health check to engage individuals in a conversation about organ donation.

They hoped to do this amongst BAME communities in London and Birmingham in a number of ways including one-to-one conversations at local churches, educational bodies and GP surgeries as well as talks and workshops during events..

Out of five events hosted, the University of Birmingham proved one of the most successful. This was due to support from the University in promoting the event. People were queueing to have a health check done so staff and volunteers were able to talk to those waiting with the nurse reinforcing these messages during the health check.

Key learnings from these events highlighted how crucial it was to carefully plan the event and venue to accommodate both the health checks and conversations around organ donation, to balance the need for privacy with the need for maximum exposure of the stall and work with the venue/ organisation to promote the event beforehand.



This project facilitated more than 400 conversations with a wide range of people in Birmingham from all ages and different faiths and with 35 new registrations (out of 101 completed registration forms) this suggest that it targeted people who previously hadn't been reached by organ donation messages. There were also 211 people who promised to talk to their families.

This pilot served to show that health checks aid the initiation of conversations about organ donation, getting people to start considering it while thinking about their health. Based on this, it merits further investigation.





Only Women presentation session



Indian Association Oldham & NHS  
**Organ Donation Awareness Campaign**  
Organ donation within the Indian Community.  
The difference you can make.

**FIND OUT:**

- What is organ donation?
- What is tissue donation?
- What can I donate?
- Living donation
- What are the restrictions?
- Organ donation and my beliefs
- Organ donation and ethnicity
- Why you should share your decision
- Myth busting
- Is organ donation for me?

Current UK statistics for organ donations and transplants as on 22nd February 2019

6015 - people are waiting for a transplant in the UK

3541 - people have received a transplant since April 2018

Anaya, is in desperate need of a kidney transplant. Anaya was born prematurely with a disease that led to her having two enlarged kidneys, an abnormal liver, underdeveloped lungs and damage to her heart.

Faizan is currently waiting for a third kidney transplant after being born with renal failure.

A couple of weeks after Prem's passing, I received a letter from the organ donation team informing me that five different lives had been saved from Prem's organ donation.

**Please join us on Ramnavmi**  
Sunday 14th April, 7.00pm - 8.00pm

If you are interested in becoming an organ donor, you will be able to register on the day.

Indian Association Oldham, Schofield Street, Oldham, OL8 1QJ  
For more information please contact  
Shashibhai Mohandas 07784 512847 Ravjibhai Gorasia 07767 404624

Indian Association Oldham & NHS  
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A couple of weeks after Prem's passing, I received a letter from the organ donation team informing me that five different lives had been saved from Prem's organ donation.

**Please join us after Shiv Puja on**  
Monday 4th March, 7.00pm - 8.00pm

If you are interested in becoming an organ donor, you will be able to register on the day.

Indian Association Oldham, Schofield Street, Oldham, OL8 1QJ  
For more information please contact  
Shashibhai Mohandas 07784 512847 Ravjibhai Gorasia 07767 404624

Flyers created by Indian Association Oldham to advertise their events





## Indian Association Oldham: Indian Association Oldham Organ Donor Awareness Campaign

### Value of grant: £1,900

The Indian Association Oldham has groups that hold regular activities each week, which include religious and non-religious events over the year. Their members travel from across Greater Manchester.

The organisation planned to deliver six sessions targeting the Asian and black communities of Oldham and surrounding districts where community members could gather and participate in the organ donation presentations. Local doctors and specialist nurses for organ donation (SNODs) attended to answer queries as well as join in the presentation. Statistics and video clips were used to emphasise religious beliefs.

Indian Association Oldham were able to gain further reach beyond the events themselves with a story in the Oldham Times and by creating a video which they shared on their social channels.

There were approximately 300 attendees across the sessions with 35 people signing up to the NHS Organ Donor Register and over 50 people stating in a post-event survey that they were likely to sign up.







# Karimia Institute: Helping Others to Survive



## Value of grant: £6,102

Karimia Institute had raised awareness of organ donation in the past during Jumma congregational prayers as well as on the radio. Drawing on experience from this, the focus of this project was to organise three workshops for local imams and community leaders, community workers/ volunteers and others who run community organisations. At these workshops they talked about organ donation and asked attendees in turn to talk about organ donation to their congregations, families, friends, colleagues and neighbours. These conversations were supported by once-a-month displays of leaflets at six mosques around the Nottingham and Walsall area on Fridays during congregational prayers.

Alongside this work there were weekly live programmes for 20 weeks on the community radio station, Radio Dawn 107.6 FM. The project coordinator, imams, community leaders and NHS Blood and Transplant worked together to develop a monthly radio programme plan which encouraged people to call and share their thoughts, views, concerns etc. Audience figures for Radio Dawn 107.6FM are over 10,000 when a program or event like this is live-streamed.

As a result of this project a lot of awareness was raised. Support from imams in speaking about the subject of organ donation in Friday prayers helped to inform congregations and address barriers and misconceptions. Many said they were not against organ donation but needed more time to think or consult with families and friends.



Specialist Nurse for Organ Donation, Angie Ditchfield, speaks to attendees at the launch event



Lancashire BME – Burnley Question Time on Dunya TV



Lancashire BME – Question Time event



An image taken at the Imam Forum



Blackburn Imams' forum in partnership with Lancashire Council of Mosques with Dr Mansur Ali, Imam Ajmal Masroor and Mr Majid Mukadam



Members of the Lancashire BME team at an organ donation event



# Lancashire BME Network (in collaboration with Lancashire and South Cumbria KPA): 'It could be You!'



## Value of grant: £11,500

Lancashire BME Network joined forces with the Lancashire and South Cumbria Kidney Patients Association – to engage the local BAME community to learn more about organ donation whilst sharing real life stories.

As part of the project they recruited nine volunteer champions who undertook a 2-hour training session with NHS Blood and Transplant. Between them, these champions delivered 14 workshops engaging with a total of 251 people from across Lancashire, each of whom completed an evaluation form pledging to cascade the information they gained about organ donation to ten other people.

Three of these events were “Question Time” sessions which were held for the public to have dialogue with organ donation experts from across the UK including faith leaders, academics, medical professionals, specialist nurses and organ donors/recipients. These were designed to dispel myths and break down barriers about organ donation. The events were well-attended and gained considerable national and international media interest.

In order to engage faith leaders, two Imam Forums were held in Blackburn and Preston. These sessions were attended by 45 imams from across Lancashire, during which they were able to engage with medical and theological experts and academics to ask questions in order to dispel myths and break down the stigma attached to organ donation. This allowed them to have an open dialogue around organ donation from a faith perspective.

The imams that attended reported that following the sessions they felt more informed about the ‘opt out’ system, and more confident about having discussions in their mosque with their congregation around organ donation – especially during Friday prayers. Based on feedback from the imams, it is estimated that they were able to share information about organ donation with approximately 13,500 members of their congregation during Friday prayers.

The imams felt that the forums were an effective opportunity for them to learn about organ donation and they have suggested that the forums be continued and expanded in order to reach other imams across Lancashire. This will ensure that they all have a factual understanding of the changes to the law about organ donation and its implications.







Leeds Adult Transplant Team Football event



Members of the team pose for a photo



Leeds Cares, TV appearance



# The Leeds Teaching Hospitals in collaboration with Leeds Cares: Let's Talk – Open Dialogue about organ donation in South Asian Communities in Leeds

## Value of grant: £7,200

Using experience from previous BAME projects carried out in relation to organ donation, the liver and renal transplant team at Leeds Teaching Hospitals planned to share messages around the importance of healthy lives and healthy organs. This tied in with encouraging people from local schools and community groups to participate in two local park runs in Leeds and Bradford with over 800 participants attending over the two events.

The team had a stand at these events offering 'Yes I Donate' branded merchandise such as mini-footballs, mini-frisbees and reusable water bottles which reflected their commitment to health and wellbeing. The events were supported by transplant recipients and donor families who shared their personal stories with the park run attendees.

The team also hosted a Community Faith and Belief Engagement Day where there were 13 speakers, including two patients who spoke of their illness and wait for a transplant. This enabled organ donation to be looked at through a variety of perspectives. Surveys and short videos by some of the keynote speakers were shared with delegates following the meeting for onward dissemination to their community and faith groups. This provided a useful opportunity to encourage members to use these films to open conversations with people and encourage discussions about organ donation in the BAME communities.

leeds cares

The activity also generated a wide range of spin-off opportunities and activities, predominantly community-focused, that developed and expanded as the project progressed.

A staff member and a patient, both from ethnic minority backgrounds, were invited to appear on a regional news programme at prime time to discuss organ donation and transplantation across BAME groups, achieving viewing figures of over 790,000 people. This was a great reflection of the interest in this topic across the region.





Aari (donor) with friends (recipients)



Phir Zindagi (Life Continues) film screening





## Lightseekers: Life Again

### Value of grant: £5,800

Lightseekers is an organisation, led by a yoga instructor, that delivers creative projects to underrepresented communities. The idea was to raise awareness of the shortage of organ donors within the BAME community and link it to aspects of Hindu “dharma”, which highlights the importance of helping others. This was carried out in the relaxed atmosphere of yoga classes, discussing important issues in an informal yet structured way.

This activity was supported by two screenings of a short film about a Hindu family’s decision to donate their son’s organs to audiences of more than 500 people, many of them of the older generation. There was a lot of positive feedback from this event, which inspired the audience to consider donation and find out more.

The organisation was able to gain further reach beyond the lessons and screening by securing media coverage in a BBC Asian Network interview and on social media, reaching 5,872 followers.





MMMF Gurdwara event



Gurdwara event



Photo taken at the annual MMMF charity football tournament



Bobby Mudhar and Jasvir Singh OBE



Sikh Arts & Cultural Association Charity Bikeride



Professor Gurch Randhawa with cricketer Monty Panesar



# Mandip Mudhar Memorial Foundation: Positivity out of Tragedy: Donating Mandip's organs



## Value of grant; £1,390

The Mandip Mudhar Memorial Foundation was established by Bobby Mudhar after the death of his brother from a tragic accident in 2001. Mandip became an organ donor after he died, and one of the main aims of the Foundation set up in his memory is to educate and promote the importance of organ donation within black, Asian and minority ethnic groups.

Initially, this project set out to hold events in Hitchin, Luton, Bedford and Southall Gurdwaras. However, during the course of the project they changed strategy to focus on events with a higher footfall, such as the Southall Nagar Kirtan and Southall Smagem, where they were likely to engage a higher number of people and hopefully generate a larger number of sign-ups to the NHS Organ Donor Register.

What was special about this project was that the story of an organ donor sat at the heart of it. We know that concerns about the organ donation process can act as a barrier to people deciding to donate their organs, so hearing the story from a family's perspective plays an important

part in normalising donation and demonstrating that families can take a positive out of loss through donation.

The Mandip Mudhar Memorial Foundation hosted and attended a total of seven events from January to June 2019 to encourage organ donation awareness and registration. The charity was visible at numerous events where there was a high proportion of the South Asian / Sikh Community and also supported campaigns such as DKMS, Hope4Anaya (partnering with various charities such as the Sikh Arts & Cultural Association), Khalsa Football Federation Bedford, City Sikhs and British Sikh Nurses. These included sharing Mandip's story at the launch of the British Sikh Report 2019 in Parliament and at the London Health Committee BAME organ donation awareness event.

The charity was able to gain further reach beyond the events themselves by securing media coverage in Eastern Eye and the Sikh TV channel and by using the hashtags #organsewa and #positivityoutoftragedy.



Event attendee signs up at the Gurdwara



Event attendee signs up at the Gurdwara





Stills taken from the videos produced by One Voice Blackburn





## One Voice Blackburn CIC: Let's talk about organ donation



### Value of grant: £2,450

One Voice Blackburn CIC has worked over the years to engage with residents of Blackburn and Darwen, and East Lancashire on the issue of organ donation and transplants by organising events and creating videos for BAME communities. Using this experience One Voice planned to produce a series of short videos on why organ donation is needed. These videos used information gained in six focus groups which gauged people's opinions of the issue of organ donation. A total of 84 individuals engaged in the focus groups, out of which ten agreed to take part in videos promoting or speaking about organ donation.

Four videos were formally launched at an event on 22nd February 2019 with over 300 attendees and generating more than 5,200 views on various platforms. A second set of four were produced and promoted shortly after. All videos were sent to community groups, health centres and relevant schools for use.

The set of videos have reached over 14,000 people in total, including 34 shares, 147 likes, and numerous comments, some of which asked direct questions relating to organ donation. NHS Blood and Transplant, and other organisations working within the BAME community to raise awareness of organ donation, have also used the resources.



A discussion at a One Voice event







Attendees at an event



# One World Foundation Africa: Save a life



## Value of grant: £2,471.45

One World Foundation Africa work to support the Swahili-speaking community in the UK and their plan was to raise awareness of organ donation within these communities, engaging particularly with the African communities living in East London.

One World Foundation Africa were acutely aware of the challenge they faced due to the possibility of being stigmatised or rejected and because of traditional beliefs that when you talk about death, death itself follows you. They targeted Christian churches, and other places of worship, using their charity networks, to address taboos and sensitise people on the importance of organ donation by focusing on how lives are being saved every day by loving and kind people, both individuals and families, who donate organs. 173 members of the Swahili-speaking community participated in these six organised events.

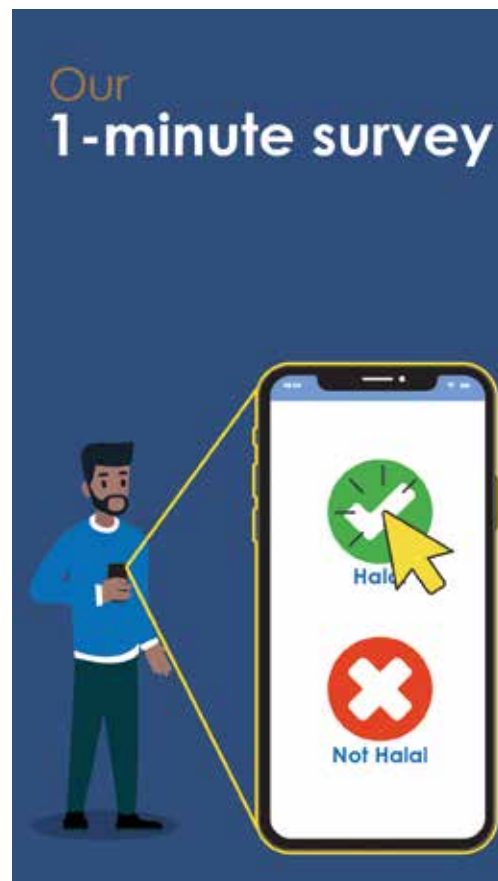
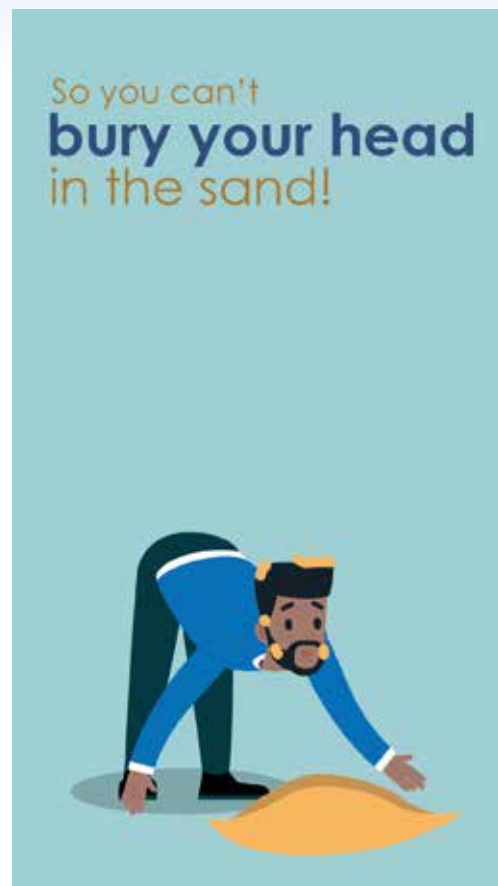
Bespoke resources were produced, purposely designed for the Swahili-speaking audience from the Great Lakes region of East Africa. Posters and leaflets were left in accessible community places and over 1,000 flyers were distributed, together with other resources sharing messages on organ donation.

Despite the sensitivities around talking about end of life, they managed to engage ten volunteers to support the campaign. These spread the word via information handouts and organised presentations using small community-based discussion forums, and open stalls at public events.

30 people attended an end project evaluation workshop and recorded considerable change of attitude as a result of the campaign.



Screen grabs from the Quran Club app







## Quran Club: Let's talk: organ donation in Islam

### Value of grant: £9,700

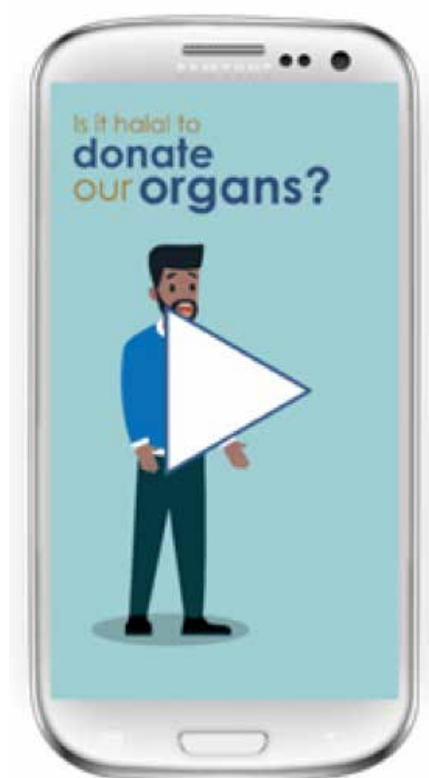
The Quran Club's initiative aimed to use the Quran Club App to help address a question that is commonly asked and is important to Muslims thinking about organ donation: is it halal to donate my organs?

The idea was to present a short animated video to users of the App, explaining why Muslims can't bury their heads in the sand and need to make a decision about organ donation. Users were then asked to complete a short survey, and depending on their answers were either directed to information about organ donation and Islam on the [organdonation.nhs.uk](http://organdonation.nhs.uk) website or to an online sign-up form.

As the App is global and this initiative was focusing on people living in the UK, the Quran Club needed to carefully consider how they would navigate users to content relevant to them. For example, it wouldn't be appropriate to navigate someone living outside of the UK to register on the NHS Organ Donor Register.

The Quran Club ran their campaign with the animation and survey during Ramadan and while this did help them reach a large number of people, the campaign was somewhat drowned out by the many other Islamic campaigns running. Despite this, over 5,000 users of the App viewed the video and over 750 people completed the survey. Nearly 7 out of 10 completing the survey were under 35, showing that an App approach could be a useful way to reach younger people. 113 respondents clicked through to read more about organ donation in Islam.

Given the concerns and doubts that are known to exist among Muslims around organ donation, the main focus of the campaign was to raise awareness and create conversation within the community about whether organ donation is permissible. As such, whilst the sign ups to register were expectedly small, there was a high level of interest amongst the survey respondents in both attending information sessions to find out more about organ donation and Islam, and to read more about what Muslim scholars have to say about organ donation. It is hoped, therefore, that this campaign has helped to start getting Muslims thinking about organ donation in advance of the law change in England and getting them to seek out further information that will help them to make a donation decision. This lays foundations that the Quran Club can build on in the future.







An image from the Metro Wednesbury Birmingham Campaign



The event at Park Lane Christian Centre, Birmingham



Michael and Patricia Willis with Sup Karen Geddes



An image from the Metro Wednesbury Birmingham Campaign



NHSBT Convocation



# RAFFA: Community Health Education (Proverbs 3:27)

## Value of grant: £6,407.50

RAFFA work in partnership with the Church of God of Prophecy corporate office and their 64 churches located in England. Their project aimed to work with these black-led Christian churches as well as elderly homes and community centres within the Birmingham area. The plan was to use their network of Voluntary Christian Nurses to share health talks in a spiritual setting and address the concerns, biblical beliefs and misconceptions that prevent people making informed decisions about organ donation.

A resource manual was produced for use by churches, including an adult sermon and bible study resources. Unfortunately, many Church Leaders weren't confident that they had enough information to deliver them to congregations. The onus therefore fell on eight volunteer nurses to do this on their behalf. Nonetheless, there were 32 events/sessions on organ donation over the length of the project and the team spoke to at least 5,000 people of which over 50% agreed to talk about it with their family or visit the website to learn more/register.

As a result of this, many younger members of the congregation signed up to the NHS Organ Donor Register or said that they would sign up later. However, the seniors remained wary and were not ready to engage. Therefore, RAFFA adapted their plans to work more closely with the church leadership team first before talking to the congregation.



Michael Willis, a double lung transplant recipient, and his wife Patricia were the face of this campaign and their story was shared as part of the presentations to churches and in the media – including The Express, The Star, The Phoenix and The Voice – who followed their journey in reaching out to black/Asian community. RAFFA also worked closely with the Michael Willis Foundation to raise awareness of organ donation at their gala dinner and metro campaign.



The Voice newspaper coverage





Organ donation event, Tottenham



Royal Free Hospital Committee meeting



cap down awareness



# Royal Free London NHS Foundation Trust: The Young People's Community Engagement Project (YPCE)/Organ Donation Youth Awareness Project



## Value of grant: £6,917.89, actual spend £5,985.18

The aim of this project was to engage young adults from black African and Caribbean minority ethnic groups in the local community served by the Royal Free London NHS Foundation Trust to become ambassadors in raising awareness, improving education and attitudes towards – and dispelling myths and hearsay about – deceased organ donation. They planned to host an awareness-raising event for local young adults and their families and friends, at which they hoped to enlist young adults willing to take this message further via a creative art form (e.g. a music video, film etc.). Any assets produced would be disseminated as part of an ongoing social media campaign.

Targeted adverts appealing for individuals interested in designing creative material and becoming Organ Donor Champions, were designed by young creatives and posted on targeted social media platforms (e.g Facebook, SocialFix, Instagram) along with 'Job Descriptions' and application forms.

All videos and content produced served as social media promotion both for an awareness-raising event, and for the post-event distribution.

The awareness-raising event (Organ Donation: A Conversation Black People NEED To Have), was successfully delivered by the YPCE project team with around 50 attendees. Seven Organ Donor Champions attended and were on site to facilitate the smooth running of the event.

Results from post-event surveys, through limited, were promising.

- 85% thought organ donation was a good idea
- 66% would consider donating organs after death
- 77% think it is important to talk to family about deceased organ donation
- 85% of respondents reported being very or quite likely to have a discussion about deceased organ donation with friends or family
- 93% of respondents reported being very or quite likely to sign up on the NHS Organ Donor Register (including one person who is already on the register).

The project also attracted widespread interest from the Royal Free Hospital NHS Foundation Trust Communication Department, the BBC, The South West Londoner newspaper and a freelance blogger.







Photo by Abhishek Upadhyay on Unsplash



# Santosh Community: Event to Encourage Organ Donation in the Hindu Community in Belgrave, Leicester



## Value of grant: £2,450

Santosh Community Centre CIC are a day care centre providing a service to the elderly and vulnerable BAME communities by offering meals, health-related activities and support to family members. Their plan was to hold a large-scale event for their service users and their friends and family to encourage discussions amongst Hindu families about organ donation and to break down religious challenges and taboos.

At the event a Hindu priest gave a speech which clarified how, according to the teachings of Hinduism, organ donation could be deemed as one of the greatest selfless acts. He dispelled any religious misinformation and provided followers with confirmation and comfort that the decision to become an organ donor was supported by religious teachings.

Other guests included organ recipients and donors: Dr Shroff, an experienced Consultant Urologist, Kidney Transplant Surgeon; Mr Rajesh Sivaprakasam, Consultant Transplant and Access Surgeon; and Dr Sunil Daga. The doctors were able to answer any medical question and give professional advice in culturally appropriate language to amplify understanding.

This event was advertised on Sanskar Radio Station to encourage attendance and highlight the upcoming changes in legislation surrounding organ donation.

Based on a post-event evaluation over 90% of the attendees (13 out of the potential 14) who had not registered as organ donors prior to this event would consider or strongly consider registering as an organ donor at the end of the session. The event also encouraged 14 people to start a dialogue with family and close friends about organ donation.



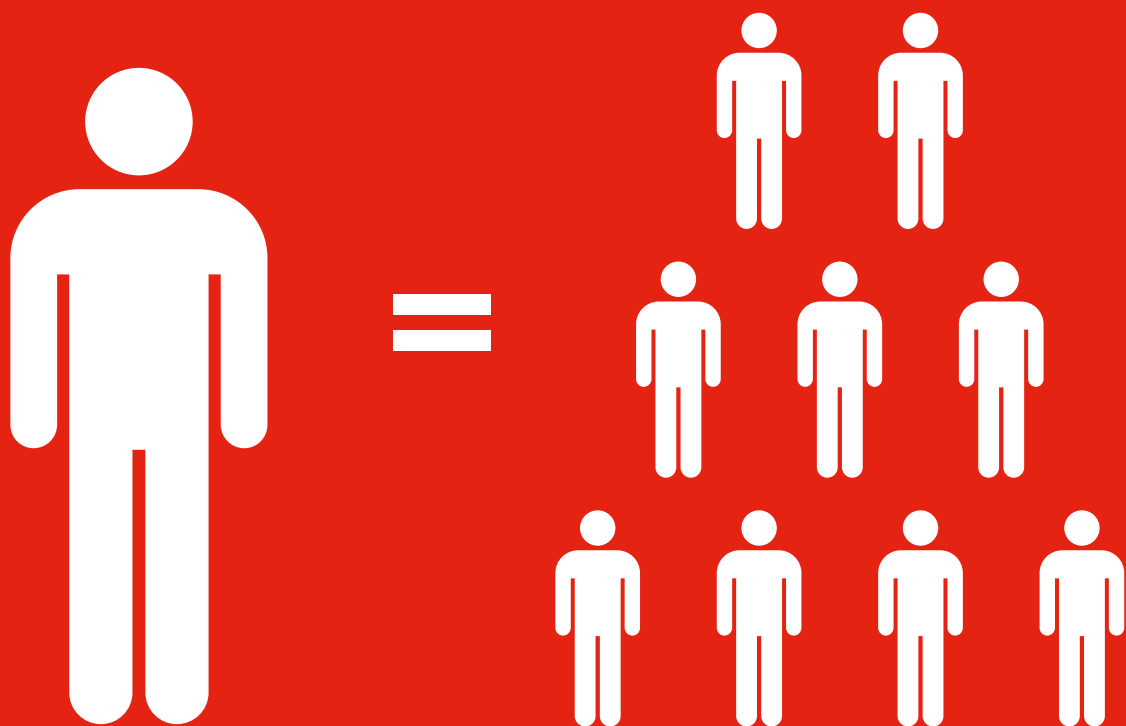
Organ Donation in the Hindu Community event in Belgrave, Leicester



**BE A THINKER.**

**BE A DO-ER.**

**BE A DONOR.**



**YOU COULD CHANGE 9 LIVES**

A poster used by Sewa Day to raise awareness of organ donation



## SEWA day: SEWA Day Organ Donation Drive



### Value of fund: £2,490

Sewa Day are a community organisation who work in Asian communities to provide information, general awareness, facilitated discussions and workshops to get people involved and engaged in registering to become blood donors. Their plan was to host information sessions, conduct talks and work with the National Hindu Students' Forum within universities in areas with high concentrations of BAME population, (Bradford, Manchester, Nottingham, Birmingham and Leicester).

Using their partnership with the National Hindu Students' Forum key individuals based at five different universities were briefed and trained on organ donation drives and events which they subsequently held. These events in Swindon, Wembley, Bradford, Birmingham and Coventry were held, with over 1,000 people attending in total.

A social media campaign was carried out in support of this activity using #SewaDay, urging students to pass on their messages around organ donation.



An example from the student-organised event in Coventry





# A Jain Initiative

**'Give a Gift, Give an Organ'**  
- Pass it On



Following the death of 19-year-old Kurran Mehta in a car crash in Sept 2018, his mother chose to donate most of his organs to give the chance of life to other people.

**“Out of this unfathomable tragedy something very positive has happened, there is no better way to remember Kurran's short but beautiful life.”**  
- Kurran's Mother



A page from the leaflet created as part of the project

## VANIK COUNCIL UK

Invites you to a  
**Day of Celebration**  
For all Jain and Vaishnav Vaniks

### Entertainment For the Family

**Delicious Lunch Included**  
**9th Jun 2019**  
**Registration and Refreshments 10:00 to 11:00**  
**Programme Starts 11am to 2pm (Lunch)**  
**Navnat Centre, Printing House Lane, Hayes, UB3 1AR**

Register by 2nd Jun 2019 Limited Availability; First come first basis.  
Tickets £5, refunded on attendance at the event  
For tickets contact your organisation or register at  
<https://vcccelebration.eventbrite.co.uk>  
For more information contact  
Manhar Mehta 07775523233 or Mahesh Gandhi on 07801718293

**Organ Donation**  
**Plus lots more**

**Raas Garba**  
**Dances**  
**Raffles**

**NHS Blood and Transplant**  
<http://www.nhs.uk>

**Yes I donate ORGAN DONATION**  
<https://www.organdonation.nhs.uk/>

A flyer for an event held by the Vanik Council



Manhar Mehta speaks at the launch of the Jain leaflet at the Houses of Parliament



This is the page that was published in 'Gujarat Samachar', a Gujarati newspaper about an event of 9th June, this newspaper has circulation throughout the UK



## Vanik Council UK: Give a Gift, Give an Organ



### Value of grant: £11,000

The aim of Vanik Council's project was to target the Jain Community in North West London to raise awareness of organ donation by designing and producing materials relevant to their community, including stories from donor families and recipients. This was printed as a leaflet and 5,000 copies were distributed via Jain organisations.

Vanik Council, as a member of the Jain and Hindu Organ Donation (JHOD) steering group, also produced a video of donors, recipients, Jain spiritual and community leaders to talk about organ donation and the changes to the law. This was made available on their website for members and affiliated organisations to promote.

Organ donation was promoted at four events organised by Vanik Council: in North West London, Crawley, Leicester and Hayes. A total of 850 people attended, of whom 119 completed the organ donation registration forms.

At each of the conferences, evaluation was carried out prior to the conferences to give an indication of how many people are aware of the new legislation. During the June event, at the beginning, only a small number of the 450 attendees raised their hands, with a full house raising hands by the end of the session.

The event in June at Hayes used the concept of celebration, both in terms of celebrating culture through dance performances to engage attendees, and in terms of celebrating donors through the public presentation of certificates to living donors and the families of deceased donors at the event. This type of recognition helped to normalise donation and show the positive impact donation has on both living donors and the families of deceased donors. A video of this event was produced and was distributed to all Vanik Council's members and affiliated organisations.

A reporter for Zee TV was present at the conference and it was shown as part of their "Out & About" programme.



### Celebrating Organ Donation



- 450+ attendees – inclusion of refreshments and entertainment helps participation
- 55+ Registered on Organ Donor Register
- Lord Gadhia, Mayor of Harrow, NHSBT and Faith Leaders participated





# Case Studies

## **Shivum Kakkad agreed to organ donation after his father Bharat died following a cardiac arrest**

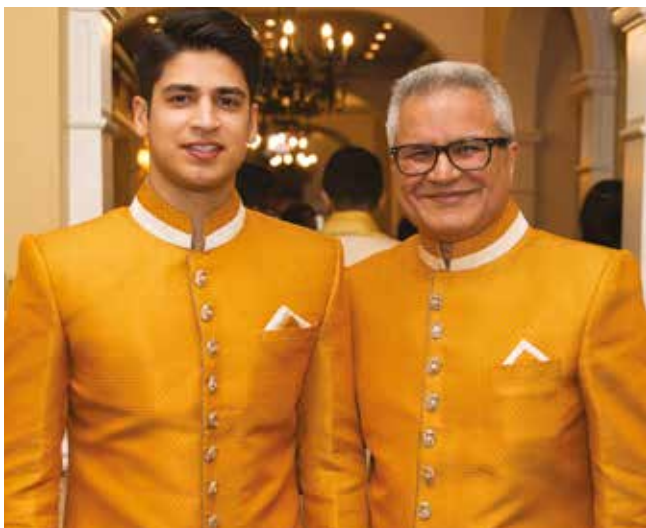
Bharat fell ill suddenly one morning in May 2019 at the family home in Middlesex. He sadly never regained consciousness and died just a few days later in hospital. He was 63.

“My father was a very giving person. He did charity work and the Hindu act of Sewa, of service to god, was very important to him.

“When the specialist nurse approached us about organ donation, we had already made our decision. There was no hesitation. We knew that helping others in need was exactly what my father would have wanted.”

Shivum was told that his father would be able to donate his kidneys and liver. The family also agreed to tissue donation including corneas.

Shivum added: “My father was a vegetarian, he went to the gym, and was a non-smoker and didn’t drink. There was no logic to his death. But we knew he would not have wanted his organs to go to waste, and as a family we take comfort from knowing he helped others. One day I hope to hear from those people who have benefited from his donation.”

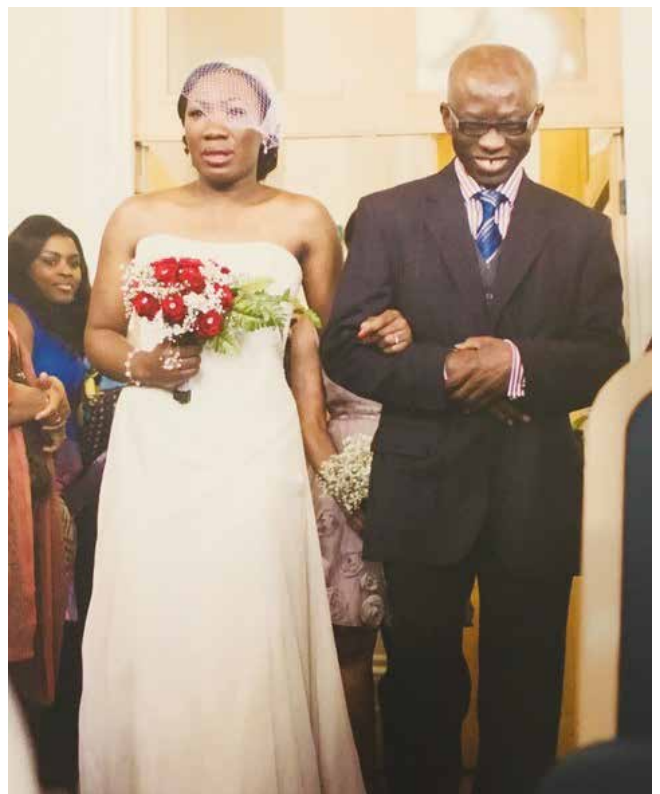


## **When Henry Ihezue suffered a stroke in his late 50s his family did not hesitate in agreeing to donate his organs to help others even though he was not on the organ donor register**

His daughter Ebuzo described how Henry was a very calm good-natured man who always wanted to help people.

“Organ donation has given us a great sense of pride that family has been able to help so many people in need.”

Ebuzo who works as a sonographer in London added: “ Whilst I was on a placement at Great Ormond Street Hospital, I saw children of a similar age to my own daughter waiting for the same organs my father donated. At this moment I knew we had made the right decision as it has brought something positive out of a sad situation.”





## Faizan – Patient waiting for a kidney

Faizan was born with renal failure and is waiting for his third kidney transplant. Fez had his first organ transplant at the age of just three from an anonymous donor. When that failed at the age of 14, he was on dialysis for 18 months and in 2000, he received a kidney from his father, who is still fit and well following the operation. That kidney worked until Fez was in his second year at university and it then started to fail again. He is now 33 and back on the organ transplant list and has been waiting for a kidney for the last two-and-a-half years. He is managing his condition using nocturnal dialysis where he is hooked up to the machine at night.

Fez said: “It feels like my life is on hold. I can’t hold down a proper job as one week I am great and then next I am ill. People don’t realise how many young people are on the organ transplant list – it is not just older people. It can happen to anyone at any age. My third donation will be more complicated than the previous two and it will need to be a really good match – which means it needs to come from my own community. I am not hopeful I’m afraid as the Asian community has the lowest number of donors on the register.”



## Hilaria – Recipient of a kidney

Hilaria became unwell at the age of 35 after suffering a miscarriage. Her condition quickly deteriorated to septicaemia, then multiple organ failure. Remarkably the same circumstances occurred again two years later. She was later diagnosed with kidney disease. She was told that a kidney transplant was the only way her condition would improve, though a shortage of donors from the black community meant that she had a long wait. She was advised she could be on the transplant list for up to ten years.

Hilaria received a transplant after a six year wait. She said: “I look back at the kind of person I was and I look at what I became afterwards. I was a shadow of myself. When I got the call it was like a miracle. I could not believe I’d got the kidney. I just wanted to burst into song, and sing!”





# Appendix 1

## Appendix 1.1 List of Judges

**Agimol Pradeep** – *Liver Transplant Coordinator*

**Amjid Ali** – *Organ recipient and NHSBT Project Lead, Transplantation in Islam*

**Angela Ditchfield** – *NHSBT Diversity Lead Nurse*

**Bimbi Fernando** – *Consultant Transplant Surgeon*

**Doug Nichols** – *Communications Officer, Welsh Government*

**Emma Avery** – *NHSBT Senior Marketing and Campaigns Officer & Project lead*

**Geraldine Parker-Smith** – *NHSBT National BAME Marketing Manager*

**Gurch Randhawa** – *Professor of Diversity in Public Health*

**Jay Patel** – *Donor parent*

**Kay Ellis** – *Department of Health and Social Care*

**Kirit Modi** – *Organ Recipient and Honorary President of National BAME Transplant Alliance*

**Majid Mukadam** – *Lead Retrieval Surgeon & Transplant Specialist – Heart and Lung Transplantation*

**Shibu Chacko** – *Specialist Nurse for Organ Donation*

**Sina Patel** – *Donor parent*

## Appendix 1.2 List of Advisors / Steering Group Members

**Agimol Pradeep** – *Liver Transplant Coordinator*

**Amjid Ali** – *Organ recipient and NHSBT Project Lead, Transplantation in Islam*

**Angela Ditchfield** – *NHSBT Diversity Lead Nurse*

**Emma Avery** – *NHSBT Senior Marketing and Campaigns Officer & Project lead*

**Hazel Preece** – *NHSBT Senior Marketing and Campaigns Officer*

**Geraldine Parker-Smith** – *NHSBT National BAME Marketing Manager*

**Gurch Randhawa** – *Professor of Diversity in Public Health*

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**Sina Patel** – *Donor parent*







