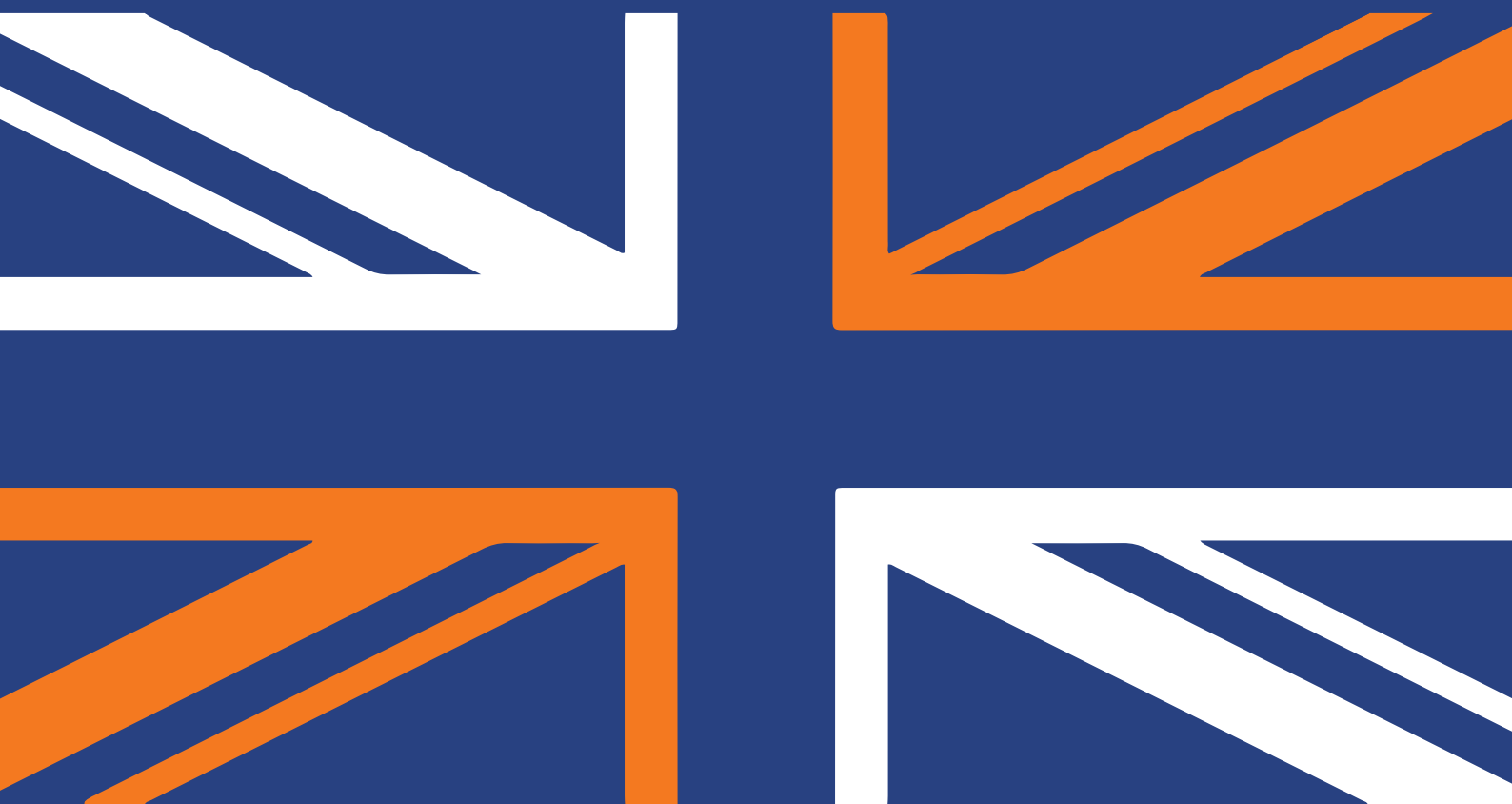


**Organ
Donation
Week
Special**

2020



British Sikh Report 2020

AN INSIGHT INTO THE BRITISH SIKH COMMUNITY

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Introduction

The British Sikh Report (BSR) has been produced every year since 2013. The BSR 2020 will be published in the Autumn of 2020, later than normal, due to delays caused by the Coronavirus pandemic. This short report has been published to coincide with Organ Donation Week, which runs from 7th to 13th September 2020, incorporating data collected through the BSR 2020 survey.

The BSR 2020 survey has been the most successful so far, with around 2,700 responses from Sikhs living in the United Kingdom. 2,500 of these respondents replied to the questions relating to Organ Donation. The responses overall are representative of the known characteristics of the population of British Sikhs. 50.5 per cent of responses were from females, 48.9 per cent from males, and 0.6 per cent preferred not to state their gender. About two thirds of respondents reported that they were born in the United Kingdom. There is also good representation of all age groups, of people with different marital and relationship status, and of the various regions and countries of the UK.

This report provides a summary of respondents' views on organ donation as expressed through the survey, and is accompanied by an article on advocacy of this issue within the Sikh community in the UK.



British Sikh Report data on Organ Donation

Until May 2020, organ donation after death in England was subject to people “opting in” through registering their wishes, or their families giving permission after their death. The [Organ Donation Deemed Consent Act 2019](#) came into effect in England in May 2020, shifting to an “opt-out” system. This assumes that your organs can be donated unless you have positively opted out. Scotland and Wales have also now moved to opt-out systems, while Northern Ireland is planning to consult on this later in 2020.

As the article later in this report discusses, there has been a lot of activity in recent years to increase awareness of the need for organ donation, especially during 2018 and 2019. The BSR 2020 survey sought to assess the level of awareness and acceptability that has been achieved, asking questions on whether people know about the change in law, whether they were happy to be a donor automatically, their attitude towards organ donation being considered a form of *sewa* or selfless service, and whether they have discussed their wishes with family members. The responses to these survey questions are discussed below.

DID YOU KNOW THE ORGAN DONATION LAW WAS CHANGING IN 2020?

To assess awareness of the change in law to “opt-out”, the BSR survey asked people whether they knew that the law was changing in 2020.

51 per cent of respondents said that they did know. However, this varied by age group, with those aged between 50 and 64 showing the highest level of awareness, at 59 per cent, while the level of awareness decreased with younger age groups (Figure 1).

54 per cent of female British Sikhs were aware of the law change, compared with 49 per cent of males (Figure 2).

Figure 1: By Age, Percentage of Age Group

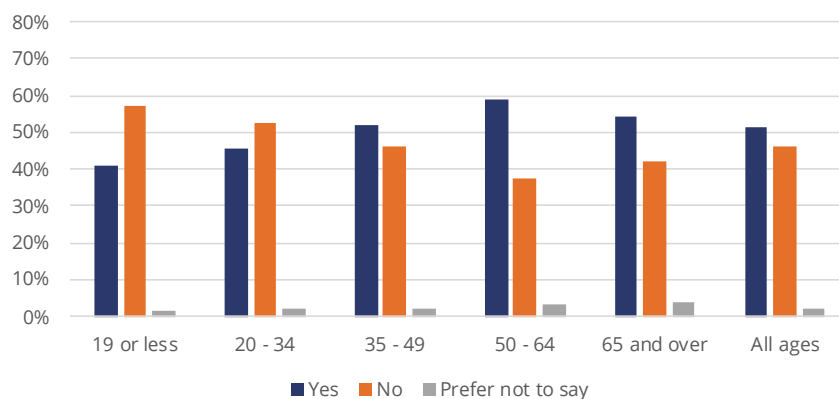
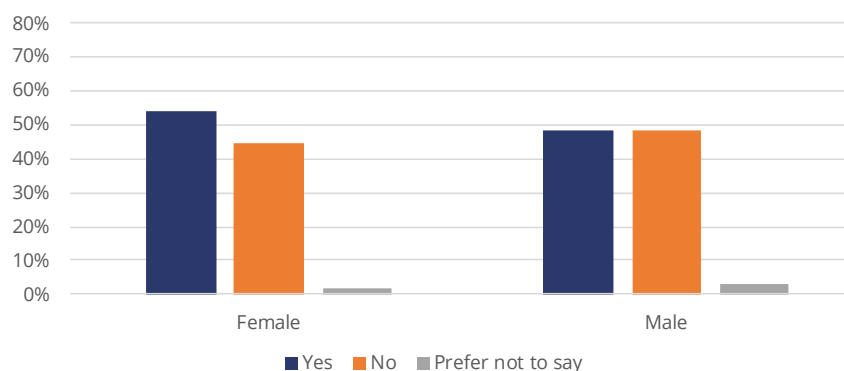


Figure 2: By Gender, Percentage of Total



ARE YOU HAPPY TO STAY ON THE ORGAN DONOR REGISTER AUTOMATICALLY?

Reflecting the change to the “opt-out” system, BSR asked people whether they were happy to be automatically assumed to be on the register. 62 per cent said “Yes”, 17 per cent said “No”, and another 21 per cent said that they either did not know or did not wish to say.

Over 60 per cent of all age groups said “Yes”, except those aged 19 or less, at 54 per cent (Figure 3). There was little difference between males and females, with over 62 per cent of both saying that they were happy to be assumed to be organ donors automatically (Figure 4).

Figure 3: By Age, Percentage of Age Group

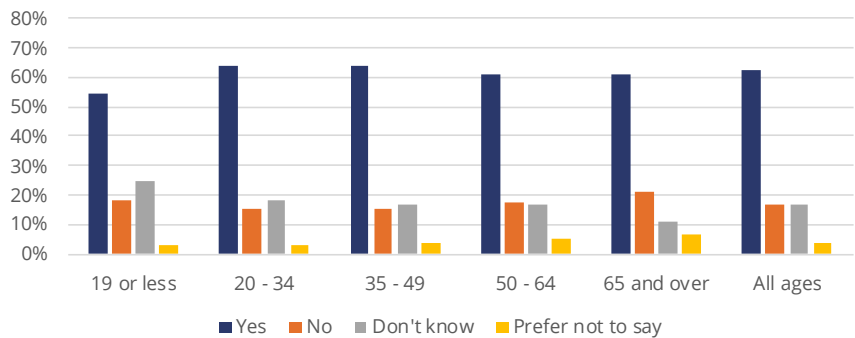
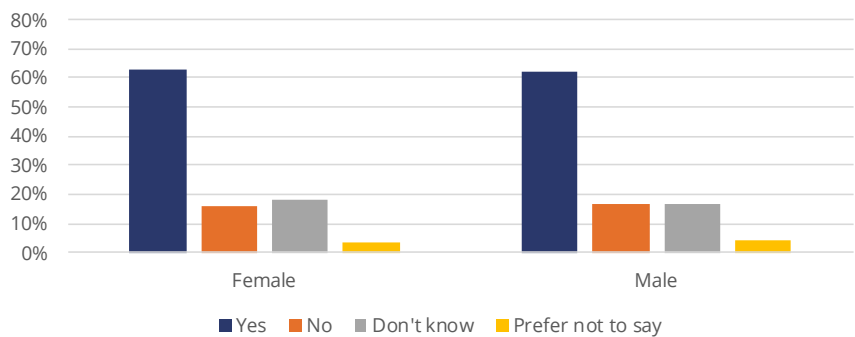


Figure 4: By Gender, Percentage of Total



DO YOU CONSIDER ORGAN DONATION TO BE A FORM OF SEVA AFTER PASSING AWAY?

Some Sikhs consider organ donation to be a form of *seva* (selfless service) after they have passed away. BSR asked British Sikhs if they agree with this definition.

67 per cent said that they did consider organ donation as a form of *seva*, whereas 11 per cent said they did not (Figure 5). 22 per cent said that they either did not know, or did not wish to say.

66 per cent of females and 68 per cent of males agreed with the idea of organ donation being a form of *seva* (Figure 6).

Figure 5: By Age, Percentage of Age Group

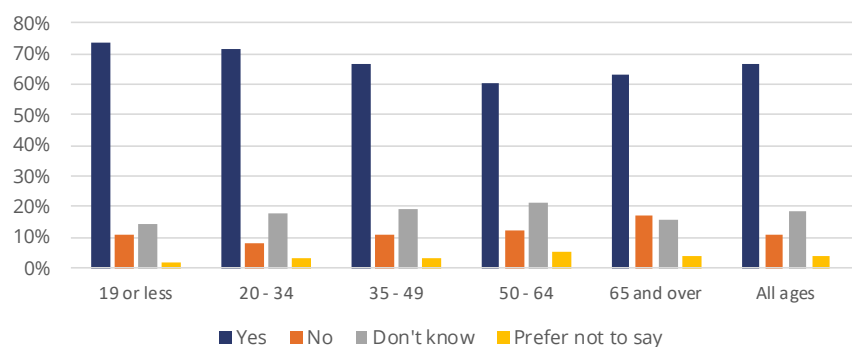
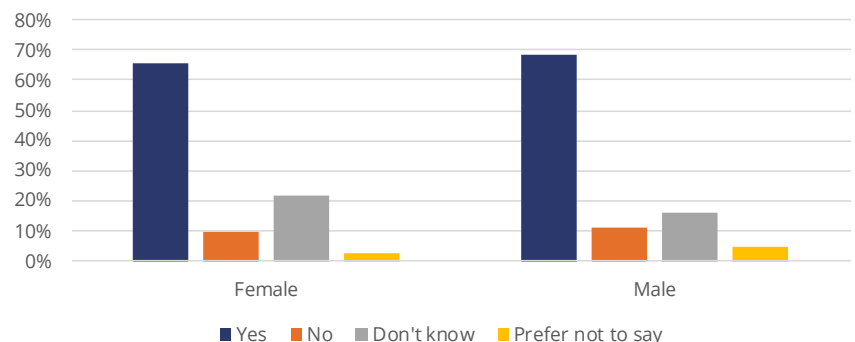


Figure 6: By Gender, Percentage of Total



HAVE YOU DISCUSSED YOUR WISHES REGARDING ORGAN DONATION WITH YOUR FAMILY?

Under the new “opt-out” system, family members of a deceased person can refuse permission for organs to be taken. It is therefore important that families discuss their views and wishes about organ donation, so that they are aware of each other’s opinions if such a situation was to arise. BSR asked British Sikhs whether they had discussed their wishes with their families. 34 per cent of the total said that they had discussed this issue with their families. However, there was variation between age groups, with the percentage increasing with age (Figure 8). While only 27 per cent of those aged 19 or less had discussed within families, this rose to 34 per cent for those aged between 35 and 49 years, and over 40 per cent for those aged 65 and over. There was also a difference between males and females, with 38 per cent of females saying that they had discussed their wishes with family members, whereas only 30 per cent of men said they had done so (Figure 8).

Figure 7: By Age, Percentage of Age Group

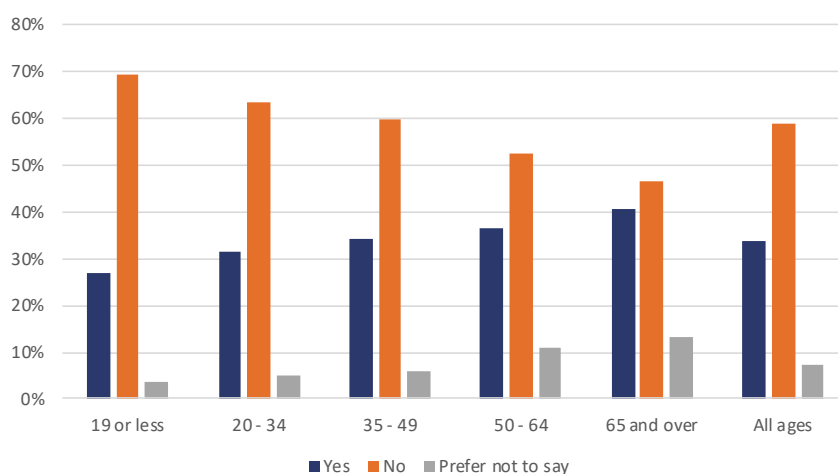
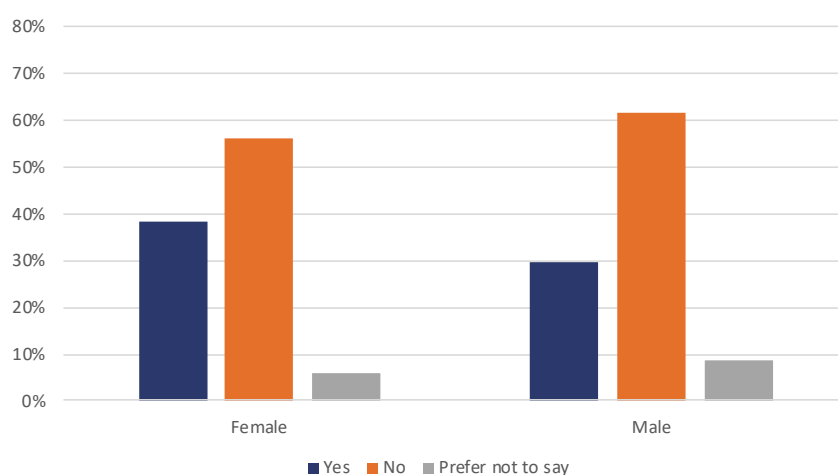


Figure 8: By Gender, Percentage of Total



Last year, BSR 2019 had asked British Sikhs whether they had registered for organ donation or carried an organ donor card. Overall, 40 per cent had said yes. The difference between males and females was similar to that for those who said for BSR 2020 that they had discussed the issue with family members. 44 per cent of females said that they had registered or carried a donor card, whereas 35 per cent of men said they did so. It would appear that women are more likely to discuss the issue with family members, and actually act on it by registering their wish to donate organs, compared with men.

The BSR 2019 survey had also asked whether people would respect a relative’s wishes if they had registered to donate their organs. 94 per cent had said that they would respect their relative’s wishes. This reinforces the need to have open discussion of this topic, so that family members are aware of each other’s views.

Organ donation and advocacy in the Sikh Community

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Until recently in the United Kingdom organ donation relied on donors opting in by joining the donor register, or a family consenting to donation when a loved one had died. The Organ Donation Deemed Consent Act 2019 approved by Parliament, which received royal assent on 15th March 2019 and came into effect in Englandⁱⁱ in May 2020 changes that, and organ donation in England moved to an 'opt-out' system referred to as 'Max and Keira's Law' named after Keira Ball and Max Johnson. Keira Ball, 9, was killed in a road traffic accident in the summer of 2017. Keira's organs helped four people, her kidneys went to two adults, her liver went to a baby and her heart went to nine year old Max Johnson who had heart failure caused by a viral infection. Max and his family campaigned in favour of an opt-out system for organ donation.ⁱⁱⁱ

This new system moves away from an 'opt-in' system of consent to donating organs to a 'soft opt-out' system, which means that all adults in England are considered to have agreed to be an organ donor when they die unless they have recorded a decision not to donate. It is hoped that this new legislation will increase and improve the organ donation process so that more lives are benefitted and saved.^{iv} Importantly, England will retain both the opt-in and opt-out register, thereby enabling the public to still register their opt-in organ donation wishes if they so wish.

Following the publication of the NHS Blood & Transplant – Faith & Organ Donation Action Plan, there has been recognition of the important role that faith-based organisations can play in raising awareness and stimulating debate regarding organ donation.^v Consequently, in recent years, a number of Sikh faith-based public education campaigns and donor registration initiatives have played a vital role in trying to improve the uptake of registering for organ donation in the Sikh community. As Sikhs celebrated the 550th birth anniversary of Guru Nanak, the founder of the Sikh Dharam, in 2019 it coincided with a remarkable year of activism promoting organ donation within the Sikh community.

Guru Nanak's teachings which emphasize spiritual wisdom, righteous living, and responsibility towards God and its creation have been embraced to advocate for organ donation. Guru Nanak advocated for a sense of 'duty' and 'way of life' achieved through practicing three core principles: *naam japna* (recitation of God's name), *kirat karna* (earning an honest living) and *vand chakana*



NHS Organ Donation Posterⁱ



The Anaya campaign at Guru Nanak Darbar Gurdwara Gravesend.

(selfless service).^{vi} These core practices are both internal and external practices that enable spiritual growth and facilitate moral and ethical living. They emphasize an individual's social responsibility to ensure the well-being of society. As discussed in the [British Sikh Report 2019](#) the last core teaching, *vand chakana*, is most pertinent here to highlight how the Sikh teachings should be seen as a strong advocate for organ donation because Sikhs fundamentally believe that the body and organs are simply mechanisms to allow the eternal soul to experience life during this stage of existence

ਵਿਚਿ ਦੁਨੀਆ ਸੇਵ ਕਮਾਈਐ

In the midst of this world, do seva,

ਤਾ ਦਰਗਹ ਬੈਸਣੁ ਪਾਈਐ ॥

and you shall be given a place of honour in the Court of the Lord.

(Guru Nanak, GGS, ANG 26)^{vii}

Sikh teachings place great emphasis on *seva* and altruism and Sikhs engage in three forms of *seva* (selfless service): "*seva* rendered through one's body (*tan*), *seva* rendered through one's mind (*man*), and *seva* rendered through giving of one's material wealth (*dhan*). While all three forms of *seva* are considered equally important, the Sikh Gurus stressed that all *seva* should be a labour of love performed without desire (*nishkam*), without intention (*nishkapat*), and with humility (*nimarta*)."^{viii}

In 2019 to mark the 550th birth anniversary of Guru Nanak, and most recently in 2020 during the COVID-19 Pandemic we have countless Sikhs all over the world carrying out volunteer charity work with their ethos firmly embedded within Sikh philosophy and entirely consistent with the service of donating organs to give life to others and alleviate suffering.

Individual Focus Campaigns

As mentioned earlier, the opt-out law is referred to as 'Max & Keira's Law' in England. This is because research has shown that for organ donation rates to increase in any country, there has to be tailored messaging regarding the experiences and impact of organ donation. There have been a number of campaigns on social media, like @AKidney4Simran;^{ix} Meena^x @Match4meena; Swab4Harj^{xi} @Swab4H. These families who require transplants have put themselves in the public eye to raise their profiles in the hope that they will find a donor, but most importantly they aim to educate the public and provide individuals access to information so that they can make better informed decisions.

The most influential and successful campaign on social media and in the gurdwaras that we have seen has been Hope4Anaya^{xii} @Hope4Anaya.

Below is a personal reflection on the Anaya Kaur Kandola campaign from her parents and Sandie Shokhar. They highlight the family's experiences of running a campaign and helping to inform members of the community about organ donation, and the lived experience of a family running a family-led campaign to find a living donor:

"To us, Anaya is a gift from God. Without Anaya, there is so much we would not have learnt." Amrik Kandola.

Anaya Kaur Kandola was born with a rare and complex condition called Autosomal Recessive Polycystic Kidney Disease (ARPKD), a condition that was identified just two days before she was born. Joety and Amrik were told to brace themselves for the worst, that the baby may not survive birth, or at best would be with them for just a matter of days. The first nine months of her life were spent within the confines of hospital and during this time, Anaya had seen both kidneys removed, endured daily dialysis and tragically suffered a stroke. The family themselves had decided, that should the situation arise, Anaya herself would be a donor.

With many health complications to contend with, Anaya's family witnessed her determination; despite the never-ending complications of such a condition,

somehow Anaya fought off every single battle and defied the odds.

Given that dialysis, although a punishing regime that does not always go to plan, was the only bridge to transplant, it was accepted that either Joety or Amrik would be Anaya's kidney donor with transplant due to take place as soon as Anaya was of appropriate height and weight.

It came as a shock therefore when continued testing determined that Anaya was no longer compatible with her parents; having undergone almost twenty blood transfusions, Anaya's tissue type had changed and there was more chance of a match being found outside of the family. For Anaya to survive, the best opportunity lay in an altruistic donor coming forward to share their spare kidney.

This raised some serious issues; Joety and Amrik had never had to consider the possibility of having to find a donor for Anaya. It also highlighted the challenges within the community. Anaya's best match would come from someone of a similar ethnicity. This in turn brought focus on the challenges of Organ Donation within the BAME community, something that would need to be addressed.

Naturally the Kandolas had been focused on Anaya's survival, yet it was apparent that to help Anaya survive, serious consideration had to be given as to how to share Anaya's story and to encourage fellow Punjabi Sikhs to consider their opportunity to be a lifesaver. The Sikh faith is known for their selfless seva, performing noble deeds to all human kind. This is highlighted in the Guru Granth Sahib - the teachings of Sikhism.

With this in mind, Hope4Anaya was launched with help from friends and extended family, an initiative conducted on social media platforms, TV, radio (both mainstream and the Sikh-faith channels), gurdwaras, football tournaments, nagar kirtans, sufi concerts, wedding fayres, school fayres and beyond. Naturally the campaign needed to raise awareness of living donation. However it was Amrik and Joety's wish that the primary message would be that of

post-life Organ Donation in order that it would benefit all those awaiting a lifesaving transplant.

The Hope4Anaya team attended events from Glasgow to Gravesend, and it was apparent from these interactions that organ donation presented a challenge to those within the Sikh Community and wider communities. There were many conversations that supported the principle of organ donation; however, there were clearly those for whom organ donation was a taboo and unwelcome discussion.

Amrik and Joety shared the need for a living kidney donor for Anaya. Over 35 unknown people came forward to be tested as living kidney donors for Anaya. In May 2019, just six months after the launch of their desperate campaign, Joety and Amrik released the news that out of 35 willing donors, one had been found to be a match for Anaya. Anaya's transplant took place on 19th September 2019, and in October 2019, Amrik and Joety met the person whose actions made Anaya's transplant possible. 36-year-old Surinder Sapal from Leeds was the kind hearted benefactor who, following an online appeal, put herself forward to be tested as a match for Anaya. Surinder's determination saw her convince her husband and two young daughters that it was her duty as a Sikh, and as a Mum, to help save the life of someone else's child.

Surinder's generosity and selflessness captured the hearts of mainstream media in December 2019, when the wider press and TV channels took the story of Anaya's campaign to the masses. That someone would respond to a Facebook appeal and give the unequivocal gift of a kidney has brought about great admiration from the Sikh community, but also from other communities who appreciate the impact of a donor on the life of an innocent child.

For the family though, they recognise the significant challenges of finding an Asian donor, and continue to use the Hope4Anaya platforms to support others in need of a donor. As a direct result of Anaya's campaign it is known that one other person was blessed to receive an altruistic kidney donation from Azeem Ahmed, who failed as a match

for Anaya, but who was convinced of the impact he could have on someone in need.

It is intended that Anaya's campaign and existing platforms will focus on continuing to raise awareness of organ donation within the Sikh community, using Anaya's story as a case study.^{xiii}



Anaya's visit to Gurdwara Sri Guru Singh Sabha, Newcastle after her transplant.

Charities and wider campaigns

Alongside the aforementioned individual campaigns that have focused on the need for organ donation, there have been remarkable efforts to promote awareness of the experiences of organ donation. This has only been achieved through the courage of donor families who have bravely shared their stories of experiencing the loss of a loved one, and their reasoning and experience of organ donation. A number of foundations have been set up to promote organ donation among Sikh and other minority communities. One that stands out for the Sikh community is the Mandip Mudhar Memorial Foundation who received the Queen's Award for Voluntary Service in recognition of their efforts to promote community conversations regarding organ donation.^{xiv} Bobby Mudhar, the Chair of the Foundation and brother of Mandip Mudhar, whose organs were donated by the family after his sudden and tragic death, said:

"One of the core elements of the Sikh Faith is selfless service (help others) known as SEVA. At the time of making our decision to donate we were comforted knowing that we would be able to help others through this selfless act of donation. For us it was the ultimate act of seva and not only was it a human decision to donate but the values of Sikhism supported this. Furthermore, it helped us to deal with the tragedy of losing Mandip in a positive way. Since 2001, our family ethos has been "Positivity out of Tragedy" and it is the basis of the foundation we set up in Mandip's memory and how we promote awareness around organ donation."^{xv}

Bobby highlighted how in the 550th birth anniversary year of Guru Nanak the Foundation had been very active in raising awareness:

"The NHSBT Community Investment Scheme has been a great opportunity to raise awareness of organ donation in the Sikh community. We know that concerns about the organ donation process can act as a barrier to people deciding to donate their organs, so having the opportunity to share Mandip's story from a family's perspective played an important part in normalising donation and demonstrating that families can take a positive out of loss through donation. In this important year The Mandip Mudhar Memorial Foundation hosted and attended numerous events from January to June 2019 to encourage organ donation awareness and registration. The Foundation was visible at events where there was a high proportion of the South Asian/Sikh Community and also supported campaigns such as DKMS and Hope4Anaya partnering with various charities such as the Sikh Arts & Cultural Association, Khalsa Football Federation Bedford, City Sikhs and British Sikh Nurses.

The foundation also shared 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 Channel TV station, and by using the hashtags #organsewa and #positivityoutoftragedy.'



Bobby Mudhar raising awareness about organ donation.



Bobby Mudhar raising awareness about organ donation.

Rohit Sagoo from British Sikh Nurses has been very active in driving awareness of organ donation in the Sikh community through dialogue and conversations to bridge the gap in knowledge between the NHS and the Sikh Community about organ donation. Rohit notes:

“I have focused on increasing the up take of BAME organ donor registrations to address the growing disparity between supply and demand for organs amongst the South Asian community.

Although government strategies have targeted religious perspectives and published informational resources in the Punjabi language, there is so much more that we, as a collective community can do to generate greater awareness of organ donation.

Having worked with Sikh media it is obvious that dialogue with the Sikh community members of all ages has concurred that what happens to our bodies after life, can be a positive discussion. Many acknowledge the need for education and awareness and welcome the opportunity to share their own thoughts on how they wish to serve others. The concept of saving a life as the highest form of Sewa has been echoed many times over.

I have been reaching out to the Sikh Community across different areas of the UK, and have attended religious events and functions to spread the word of healthy living and organ donation to the Sikh Community, especially when working directly with the family of @Hope4an-aya. I have also worked with Gurdwaras and Sikh TV channels to raise awareness, and have also used social media to raise awareness. My long term campaign for raising awareness for organ donation in the Sikh community has led to winning funding from NHSBT to drive my campaign forward.”

Through the support of the NHSBT Community Investment Scheme, the Mandip Mudhar Memorial Foundation, British Sikh Nurses and City Sikhs in 2019 were able to work together successfully to bring the issue to the forefront of the community's attention and promote organ donation. They developed and used a hashtag #OrganSewa to support Sikhs in exploring the Seva aspect of organ donation. Organ donation was a significant part of the British Sikh Report launch events in London, Birmingham and Manchester.

Gurdwaras

In 2019 Sri Guru Singh Sabha Southall (SGSSS) and Sikh Welfare & Research Trust (SWRT) engaged in an Organ Donation campaign with NHS Blood and Transplant support.^{xvi}

Harmeet Gill, a trustee at the Sri Guru Singh Sabha Southall Gurdwara described how on 12th November, to mark the 550th birth anniversary of Guru Nanak, the founder of the Sikh Faith, his gurdwara decided to do something different in the UK, which would have an everlasting legacy. Taking on board the legacy of Guru Nanak and all the Sikh Gurus who devoted their lives to humanity and sacrificed their lives for the welfare of others, they decided to start a conversation amongst the community to dispel the fears, myths and misinformation that surrounds organ donation. They

also launched Project 550, a campaign to register at least 550 Sikh organ donors before the end of 2019. With just two weekends of campaigning, they exceeded their target.^{xvii}

Harmeet noted “We were always confident of signing up 550 donors, what surprised us the most was that it took only 2 days!”

As part of the project they held lectures and talks conducted by Sikh doctors, surgeons, recipients and existing living donors. “Our small little project that started in West London, has helped raise a significant amount of awareness across our community internationally, with gurdwaras across the world beginning to do similar drives to sign up Sikh donors.”



The Anaya campaign at Guru Nanak Darbar Gurdwara Gravesend.

Whether individual, community or gurdwara initiatives, what is clear is that they have all raised awareness of the organ donation issue among Sikhs. As a community, we now need to build on this work in 2020, especially disseminating information about the change in law to opt out because consent will be presumed unless people have opted out. We need to ask each other, as to how many know about the change of law, how many had already signed up for organ donation and how many had discussed the subject of organ donation with their families. To ensure that information is disseminated correctly and effectively members of the Sikh community need to work with gurdwara leadership, community groups, NHSBT and the National BAME Transplant Alliance (NBTA).

Guru Nanak Darbar Gurdwara Gravesend created a “Community Engagement & Wellbeing Team” in November 2017, with a view to increasing activities related to improvement of the health and wellbeing of the *sangat* (congregation), and the local community at large. The team has organised activities related to mental health, healthy diets and eating habits, screening and checking for certain conditions such as diabetes and heart disease, guidance for healthy living, and sporting activities.

Since 2018 they have actively promoted organ donation. At *Vaisakhi* in April 2018, various organisations set up stalls at the gurdwara and among these was the “Sikhs Embrace Organ Donation Campaign.” This helped to raise awareness amongst both the public and the gurdwara *sewadars* involved with the work on wellbeing. The gurdwara also has a very active Guru Nanak Sports Club, which became aware of the Swab4Harj campaign. Harj, a fellow sports enthusiast, needed a stem cell match to save his life. As a result, a session was held for recruiting potential donors, with supporters of the campaign attending and taking swabs for a whole day. Hundreds of members of the Sports Club and others were encouraged to register on a busy day at the gurdwara. He found a match and on 26 April 2019 he had his stem cell transplant.

Later in 2018, the Gurdwara was approached by supporters of the Hope4Anaya campaign, and asked to display posters. Anaya’s picture touched many hearts and interest in supporting the campaign increased. Jagdev Singh Virdee, now General Secretary of Guru Nanak Darbar Gurdwara, and at the time head of the Community Engagement and Wellbeing Team, explained how they managed to highlight the Hope4Anaya campaign at their annual *Diwali/Bandi Chhor* celebrations:

“Bandi Chhor is one of the busiest days of the year at the Gurdwara, finishing with a huge fireworks display in the grounds, and anywhere between 2,500 and 3,500 people attending. A stall was set up in the foyer with several volunteers ready to sign up potential donors. The evening programme included Katha^{xviii} in English by Basics of Sikhi, which particularly attracts young people, as well as traditional Kirtan and Katha in Punjabi. We decided to get a slot on the stage for Anaya’s campaign just before the English Katha, when Anaya’s Masi (aunt) Sharan Kaur Chahal spoke passionately about Anaya and the family. Sharan also introduced Dr Kiran Kaur Sanghera, who has been a keen campaigner for organ donation since her father spent years waiting for a transplant. The speakers won many hearts, I think, because they said they signed up more people in a couple of hours that evening than whole days in other locations.”

Gravesend Gurdwara has maintained interest in organ donation amongst the *sangat* (congregation), and a seminar was held on the occasion of Guru Nanak’s 550th birth anniversary celebrations in November 2019 which was also broadcast on a Sikh TV channel. The seminar focused on the changes in the law that were coming in 2020 leading to opt-out, and encouraged people to have open discussions about their views on organ donation. It also highlighted how although we may be moving to ‘deemed consent’, individuals still needed to tell their family what they would want because if they do not have that conversation then family can object to organ donation.

Conclusion

Guided by a wish to relieve suffering, a sense of altruism and love for social action, younger members of the community have become very proactive in their advocacy for organ donation. They have recognised the role that the gurdwara can play in educating the community on important issues, and this is their *seva* through *man* (mind).

ਅਕਲੀ ਸਾਹਬੁ ਸੇਵੀਐ ਅਕਲੀ ਪਾਈਐ ਮਾਨੁ ॥

Wisdom leads us to serve our Lord and Master; through wisdom, honour is obtained.

ਅਕਲੀ ਪੜ੍ਹਿਹ ਕੈ ਬੁਝੀਐ ਅਕਲੀ ਕੀਚੈ ਦਾਨੁ ॥

Wisdom does not come by reading textbooks; wisdom inspires us to give in charity.

(Guru Nanak, GGS, ANG 1245)^{xx}

Such action and activity benefits the whole community:

ਵਿਦਿਆ ਵੀਚਾਰੀ ਤਾਂ ਪਰਉਪਕਾਰੀ ॥

Contemplate and reflect upon knowledge, and you will become a benefactor to others.

(Guru Nanak, GGS, ANG 356)^{xx}

Providing such knowledge and education is altruistic and selfless because it benefits the whole community:

ਓਇ ਪੁਰਖ ਪ੍ਰਾਣੀ ਧੰਨਿ ਜਨ ਹਹਿ ਉਪਦੇਸੁ ਕਰਹਿ ਪਰਉਪਕਾਰਿਆ ॥

Blessed is that mortal being, who shares the Teachings for the good of others.

(Guru Ram Das, GGS, ANG 311)^{xxi}

As the young take up leadership positions within their gurdwaras they will become important influencers in this debate because they recognise the impact of chronic conditions such as diabetes, heart disease, and hypertension, which may result in a need for a transplant. *Granthis* (religious priests) can also play an important role in disseminating Sikh teachings that may be applicable to organ donation, provide information on organ donation to dispel any myths and in turn provide guidance and encouragement to the community.

It is clear that health service providers have recognised the important role of local faith communities in supporting health education and are ensuring that their voices are heard and their contribution maximised. NHS Blood and Transplant has done this successfully with reference to organ donation via the Community Investment Scheme. They have developed successful health dissemination partnerships with all faith communities.

The above Sikh campaigns highlight the positive outcome of collaborating with community and religious leaders and their organisations to influence and educate a community about organ donation. It is clear that religious initiatives, especially when facilitated by religious organisations can really add value in raising the community's understanding of the life-giving benefits of organ, blood and tissue donation, especially when this is done utilizing Sikh values, such as *seva* and *daya* (compassion),^{xxii} and in turn improving the health outcomes of the community. Importantly, these examples provide a template for developing trust between the government and the local communities, which is even more important in the context of Black Lives Matters, and the current COVID-19 Pandemic. All of the Sikh initiatives have been underpinned by building trust, using a trusted community space, working with trusted messengers such as Sikh donor families, health professionals, Sikh researchers and religious and community leaders. For Sikhs some of these conversations on organ donation have taken place in gurdwaras and in homes via the Sikh TV Channels. On a final note, it is important to also note how these conversations on organ donation have led to follow up conversations on other health conditions that may lead to the need for organ donation in the future, i.e. heart disease, obesity and diabetes. In light of this, maybe it is time for gurdwaras to reflect on how they can help improve their congregations' health, i.e. help reduce people's cholesterol and blood pressure levels through reducing sugar and salt in food and increasing fruit/vegetable consumption in the *langar* provided.^{xxiii} Whilst these are difficult conversations it is clear that there is a growing advocacy within the community for change when it comes to health matters, and this can be harnessed by the NHS.

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- xxii. "Make compassion the cotton, contentment the thread, modesty the knot, and truth the twist. This is the sacred thread of the soul." *Guru Granth Sahib*, Ang 471. Similarly, there are many references in the *Guru Granth Sahib* that emphasize the power of love and compassion over rituals. "Upon this plate, three things have been placed: Truth, Contentment and Contemplation. The Ambrosial Nectar of the Naam – the Name of God our Master, has been placed upon it as well; it is the support of all. One who eats it and enjoys it shall be saved." *Guru Granth Sahib*, Ang 1429. Also, "Please bless me with the rice of truth and self-restraint, the wheat of compassion, and the leaf-plate of meditation. Bless me with the milk of good karma, the ghee, of compassion. Such are the gifts I beg of You, Lord. Let forgiveness and patience be my milk-cows, and the let the calf of my mind intuitively drink in this milk. I beg for the clothes of modesty and the Lord's Praise; Nanak chants the Glorious Praises of God." *Guru Granth Sahib*, Ang 1329.
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