

Developing Messages to Promote Organ Donation by Faith among Minority Ethnic Communities Conference Report

4 June 2024



Foreword

This report highlights the outcomes of a vital conference organised by the National Black, Asian, Mixed Race, and Minority Ethnic Transplant Alliance (NBTA) in collaboration with NHS Blood and Transplant (NHSBT). Held on 4 June 2024, the conference was a significant step in addressing the disparities in organ donation awareness and participation among faith-based and minority ethnic communities in the UK. Organ donation is an issue of national importance, yet participation rates from minority ethnic groups remain disproportionately low. This event aimed to tackle these barriers by involving faith leaders, community organisations, and key stakeholders to develop tailored messages that resonate with specific religious and cultural contexts.

Faith and cultural beliefs play an essential role in decision-making about organ donation, and this conference recognised the need for faith-specific engagement strategies. Through interactive presentations, faith group discussions, and collaborative planning, the participants of this event took major strides towards crafting messages that align with religious teachings and cultural values. These messages are critical in promoting greater understanding, reducing misconceptions, and ultimately saving lives by increasing organ donation.

The importance of this conference cannot be overstated. It serves as both a reflective and forward-thinking endeavour that will guide efforts during 2024 and beyond. The work presented here sets the groundwork for ongoing community engagement and evaluation, with the ultimate goal of fostering more equitable healthcare outcomes. As we move forward, the NBTA and NHSBT remain committed to bridging the gap in organ donation rates and providing ongoing support to faith and minority ethnic communities in the future.

The two organisations will continue to work together and have established a Messaging Conference Implementation Group which will take forward the ten Actions arising from the Conference. This group has had its first meeting and will continue working until April 2026. We will of course keep everyone who registered to attend the Conference updated of progress and will reach out to many of you for your support.

Anthony Clarkson (Director of Organ and Tissue Donation and Transplantation, NHSBT)

Orin Lewis OBE (Chief Executive ACLT and Chair NBTA)

Mark Chambers (Director of Donor Experience, NHSBT)

Kirit Modi MBE (Hon President, NBTA and NKF)

Contents

Executive Summary	4
Introduction	6
Programme	8
Actions arising from the Conference	9
Presentations	10
Break out discussion groups to develop messages	15
Muslim group	16
Hindu group	21
Sikh group	25
Jain group	26
Christian group	32
Non-religious group	36
Conclusion	41
Next stage	42
Evaluation	43
Appendix one	44
Appendix two	45

The Conference



Executive Summary

1. The National Black Asian Mixed Race and Minority Ethnic Transplant Alliance (NBTA), in collaboration with NHS Blood and Transplant (NHSBT), organised a conference on 4 June 2024, to promote organ donation within faith and minority ethnic communities. The event focused on developing faith-specific messages to increase organ donation awareness and participation among these communities.

Conference Objectives

1. **Engage Faith Leaders and Organisations:** Involve individuals with expertise in organ donation to develop effective messaging.
2. **Share Data and Research:** Present the latest statistics on organ donation and transplantation by ethnicity and religion.
3. **Develop and Discuss Messaging:** Organise discussion groups by faith to create tailored messages and plans for awareness campaigns.
4. **Resource Development:** Identify and suggest necessary resources such as videos and leaflets to support the new messages.
5. **Implementation and Evaluation:** Publish findings and initiate actions starting with Organ Donation Week 2024.

Key Participants

- **Organisers:** NBTA, NHSBT
- **Key Speakers:** Anthony Clarkson, Orin Lewis, Rachel Johnson, Angelo Lovino, Harpreet Matharu, Lhiza Smith, Dr Leah McLaughlin, Mark Chambers, Kirit Modi
- **Attendees:** 82 delegates from 41 organisations, including healthcare trusts, voluntary and community sector organisations, universities, and faith organisations.

Key Themes

1. Statistics and Research

- **Organ Donation Rates:** Disparities in organ donation and transplantation rates among minority ethnic communities.
- **Attitudes Towards Organ Donation:** Misconceptions, cultural, and religious beliefs affecting decisions on organ donation.
- **Specialist Nurse Experiences:** Challenges faced by nurses in obtaining consent from minority ethnic families.

2. Discussion Groups by Faith

- **Muslim, Hindu, Sikh, Jain, Christian, Non-religious, Buddhism, and Zoroastrianism:** Each group identified specific barriers, enablers, and key messages for their communities.
- **Common Barriers:** Lack of awareness, cultural and religious misconceptions, and generational divides.
- **Enablers:** Trusted messengers, community engagement, and educational initiatives.

3. Action Points and Recommendations

- **Faith-Specific Messaging:** Develop and distribute culturally relevant content.
- **Community Engagement:** Work with faith leaders and community organisations to promote organ donation.
- **Resource Development:** Create and share educational materials tailored to specific communities.
- **Ongoing Evaluation:** Regular updates and follow-up conferences to assess progress.

Conference Outcomes Lovino

- **Commitment to Action:** NHSBT and NBTA to implement the new faith messages and review their national messaging strategy.
- **Partnerships:** Collaborate with community groups to fund and develop awareness assets.
- **Follow-up and Accountability:** Establish a Messaging Conference Implementation Group and provide six monthly progress updates.

Evaluation

- **Participant Feedback:** High satisfaction rates with the conference, presentations, and discussion groups.
- **Future Conferences:** Majority of participants expressed interest in attending follow-up events for ongoing awareness and collaboration.

Conclusion

The conference successfully initiated the development of faith-specific messages to promote organ donation among minority ethnic communities. The collaborative efforts of NHSBT, NBTA, and various faith and community organisations have laid the groundwork for ongoing initiatives to increase awareness and participation in organ donation, ultimately aiming to reduce disparities and save lives.

Introduction

The National Black, Asian, Mixed Race and Minority Ethnic Transplant Alliance (NBTA) is a coalition of organisations which seek to promote awareness of organ, blood and stem cell donation amongst Black, Asian and minority ethnic people and to increase the number of donors from these communities. NBTA together with NHS Blood and Transplant (NHSBT) held a conference on 4 June 2024 working with faith communities to develop messages to promote living and deceased organ donation among Black, Asian and minority ethnic communities. The conference was organised by a joint working group with membership across both organisations (see appendix one).

Key objectives:

1. To have a face-to-face conference in London led jointly by NBTA and NHSBT.
2. To involve key individuals such as faith leaders and organisations with experience and expertise in this area and NHS Blood and Transplant staff to develop new messages.
3. To share the latest information on the impact of the opt-out law in England, as well as data on organ donation and transplantation by ethnicity/religion and attitudes to organ donation by ethnicity and religion.
4. To arrange discussion groups by faith group, to develop messages and to discuss plans to raise awareness about them.
5. To suggest what resources need to be developed by NHSBT and community groups to promote key messages.
6. To publish the findings from the conference so that these can be implemented during Organ Donation Week 2024.

A total of 82 delegates attended the event with 41 organisations being represented consisting of health care trusts, voluntary and community sector organisations, universities, and faith organisations. The full list of organisations is listed in appendix two.

The following table outlines the faiths of delegates where data was provided:

Faith	Number of Delegates
Christian	29
Non-religious	13
Muslim	9
Hindu	5
Sikh	5
Jain	3
Zoroastrian	2
Baha'i	1
Pagan	1
Ravidassia	1
Unknown	1

Key Speakers



Anthony Clarkson



Orin Lewis



Rachel Johnson



Angelo Lovino



Harpreet Matharu



Lhiza Smith



Dr Leah McLaughlin



Mark Chambers



Kirit Modi

Programme

The conference started with presentations which set organ donation within the context of faith and ethnicity considerations. It opened with a presentation from NHS Blood and Transplant giving an overview of the data on organ donation, ethnicity and religion. This was followed by research on communities' attitudes to organ donation including specific research related to Black, Asian, and minority ethnic communities. Highlights into the role of specialist nurses for organ donation then followed and included a description of how they engaged with and addressed challenges from families of different ethnic backgrounds. The presentations closed with messages from specific research on organ donation and Black, Asian and minority ethnic communities.

The Programme For The Day:

9.30 am	Arrival, registration and coffee/tea
10.00 am	Welcome by Anthony Clarkson (NHSBT) and Orin Lewis (NBTA)
10.15 am	Latest statistics on organ donation by ethnicity and religion Rachel Johnson (NHSBT)
10.30 am	A qualitative overview of attitudes to organ donation Angelo Lovino (NHSBT)
10.45 am	Specialist Nurse for Organ Donation perspective Harpreet Matharu (NHSBT) and Lhiza Smith (NHSBT)
11.00 am	Latest statistics on organ donation and transplantation for minority ethnic patients by Dr Leah McLaughlin (Bangor University)
11.15 am	Q&A session
11.40 am	Faith discussion groups
12.30 pm	Lunch
1.30 pm	Discussion groups continue and outcomes finalised
2.30 pm	Report back from discussion groups Chaired by Kirit Modi
3.15 pm	Questions, next stages and conclusion Mark Chambers (NHSBT) and Orin Lewis (NBTA)
3.40 pm	Tea/coffee and depart

Actions Arising From The Conference

1. NHS Blood and Transplant (NHSBT) will consider how to use the conference outputs to review their messaging for faith groups across their communications and engagement channels.
2. NHSBT will work in partnership with NBTA and community groups to develop assets to highlight the new faith specific messages nationally over the next two years.
3. NBTA and community groups, including all successful projects funded through the Community Grants Programme will highlight the new messages in their work with faith groups, starting from September 2024 until August 2025.
4. NHSBT will consider the issues arising from the survey of Specialist Nurses for Organ Donation (SNODs) presented at the Conference and develop an action plan.
5. NHSBT will arrange a meeting by September 2025 of hospital chaplains to review the support they provide in conversations with family members of potential organ donors.
6. NHSBT will review the work done by Organ Donation Committees in raising awareness among local faith groups by September 2025.
7. NHSBT and NBTA will work in partnership to establish easy access to all relevant assets produced by NHSBT and community groups to raise awareness about both living and deceased donation among faith and minority ethnic communities, through their websites and this will happen by September 2025.
8. NHSBT and NBTA will consider options for establishing lead groups or individuals who can co-ordinate activities within specific faith groups to raise awareness about organ donation, similar to the work currently being done by Jain and Hindu Organ Donation Alliance (JHOD) and African Caribbean Leukaemia Trust (ACLT).
9. NHSBT and NBTA will provide six monthly updates on progress to all attendees and arrange a follow up conference in the next two years to review progress.
10. NHSBT and NBTA will establish a Messaging Conference Implementation Group to ensure implementation of these Actions by September 2024.

Presentations

The next section details a summary of the presentations that took place during the conference. The full slide decks for each presentation can be found on the [NBTA website](#).

Latest statistics on organ donation by ethnicity and religion - Rachel Johnson, Assistant Director – Statistics and Clinical Research, NHSBT

Rachel Johnson presented the latest statistics on organ donation and transplantation for Black, Asian and minority ethnic patients.

In addition to the main annual organ donation and transplantation activity report that is published, a report specific to differences relating to ethnicity is also reported. Much of the information presented related to the report for 2022/2023, as the 2023/2024 report is not yet available. Headline (provisional) figures from the main report were presented. The overall data for 2023/24 showed that waiting lists have increased and now exceed those seen 10 years ago, following increases post-pandemic. While organ donor and transplant numbers have increased over the last four years, the numbers have yet to reach pre-pandemic levels.

The 2021 Census data show 18.3% of the England and Wales population are from a minority ethnic group, and this is a useful benchmark for comparison. The data shows that while only 20-30% of new opt-in registrations to the Organ Donor Register (ODR) state their ethnicity, the proportion who are from minority ethnic groups has grown from 5.9% in 2015/16 to 11.7% in 2022/23. While most minority ethnic groups are under-represented in opt-in ODR registrations, more detailed data showed that Asian-Indian, Asian-Chinese and Asian-other people were slightly over-represented. In terms of opt-out registrations, the numbers are falling year-on-year, with only 133,000 opt-outs in 2022/23 of which 32% were from minority ethnic groups.

Family consent rates have changed little in recent years, with 32% of families of potential minority ethnic donors providing consent for donation, compared with 65% of families of potential white donors. There were only 88 deceased organ donors from minority ethnic groups in 2022/23 (21% down over the last five years), with 127 living donors (also 21% down). Despite this and accounted for by transplantation of organs from white donors, the number of organ transplants increased by 2% to 1232 transplants over the last five years. The number of people from minority ethnic groups waiting for an organ transplant increased by 30% with a total of 2365 patients waiting.

In summary, compared with the benchmark of 18.3% of the population being from a minority ethnic group, minority ethnic people are under-represented among ODR opt-ins, eligible and actual deceased donors, and living organ donors. They are over-represented in ODR opt-outs and on the waiting lists for deceased and living donor transplants. The results indicate some progress in ODR opt-ins and living donor transplantation, but the number of people waiting for a transplant continues to grow.

A qualitative overview of attitudes towards organ donation – Angelo Lovino, Market Research Manager, NHSBT

This presentation gave an overview of the attitudes to Organ Donation (OD) among the general public that were gathered over the last seven years through qualitative focus groups.

At the top level, misconceptions and misinformation about the process and eligibility for OD are common to the whole population regardless of ethnicity (slide 1). This leads to lack of understanding of urgency and need. Squeamishness, vanity, and general lack of awareness about the act of organ removal also led to inertia, questioning or disinterest in OD.

The particular concerns are emotional in nature and occur as living people think about their own death. In contrast, engaged and informed OD registrants tend to have a logical, transactional way of thinking about their death

(“My body will only go to waste, why not donate”).

Owing to various faith or cultural reasons, minority ethnic respondents consider the act of donation in a more emotional way: greater importance is attached to giving away “my blood, my organs”; therefore, the motivational threshold is higher, as is the questioning. Added to a possible distrust of institutions among the older generation, this results in a higher feeling of apathy among minority ethnic respondents (slide 3).

Faith/cultural beliefs differ by age and thus create a generational divide, whereby older members of minority ethnic groups are more likely to be wary of or against donation, while the younger, British born, more secular and engaged generations tend to be more in favour. This clash causes a very real conflict among young people, caught between wanting to do something good but not wanting to cause friction among their family/peers. This leads to feelings of guilt or to subterfuge, illustrated by an example of a young Muslim man being frustrated at learning that opt-out has not removed final consent from his family (who were against him registering) or a young Black woman who had registered secretly without telling her mother and had given her supportive aunt’s name as next of kin in an effort to bypass her mother’s lack of consent (slide 4).

Overall, the research highlights the substantial educational groundwork that needs to be conducted among minority ethnic groups, even before more ingrained negative attitudes can be tackled. The examples given illustrate that the current system does not support young minority ethnic people who do want to be donors but are prevented from registering by cultural issues in their communities and unsupportive, older peers who still retain final say.

The Specialist Nurse experience in approaching Minority Ethnic families for Organ Donation: Exploring reasons for the decline and a review of the legislation's impact on consent rates - Harpreet Matharu, Regional Head of Nursing, NHSBT and Lhiza Smith, Specialist Requester, NHSBT

Introduction: Organ donation is not possible without the selfless generosity of donors and families. In the UK organ donation is seen as an altruistic act to save and transform lives. With the [Organ Donation \(Deemed Consent\) Act 2019](#) in place, an increase of donor families consenting to organ donation was expected. However, four years later, Specialist Nurses for Organ Donation have not seen this change, especially in minority ethnic families. In view of this, a survey was conducted among the specialist nurses to explore individual experiences when approaching families for organ donation.

Method: A survey was sent to all the Specialist Nurses, Specialist Requesters, Professional Development Specialists, and the Lead Nurses from 12 different regions in the UK to explore familial perspectives of organ donation. It aims to explore the reasons for decline among the minority ethnic families and to review the impact of the new legislation on consent rates.

Results: A total of 92 responses were received from the team, indicating a common theme amongst the Specialist Nurses. Culture and religion were identified as the top two main reasons why families of minority ethnic backgrounds decline organ donation, but whilst culture remains to be the strongest bond that hinders an open mind to organ donation, religion is often presented as a more acceptable reason to decline. The results also indicated that the legislation had a very low impact on consent rates and families often left more confused and not understanding the implications of the legislation.

Discussion: Despite Specialist Nurse's skill and confidence in approaching and explaining the law, we see more families unaccepting of deemed consent and unsupportive of organ donation. The involvement of decision makers or families abroad provides challenges, as they will adhere to their personal cultural practices and potentially have misconceptions around organ donation that we are unable to myth bust. It is often at odds with families present in the UK or younger generations who have more secular views on organ donation which then often leads to Organ Donation Register overrides. This is where a person's decision to donate their organs can be overridden by their family if the family has compelling reasons to do so. Or the individual 'opts out' of donating by recording a decision not to donate on the NHS Organ Donor Register.

There were also other reasons identified that might affect minority ethnic family's decision to consent:

- family not wanting surgery to the body,
- family wanting more time with their loved ones,

- family wanting their loved ones buried whole and not wanting to delay the funeral.

On further analysis, reasons were noted to stem out from the same cultural and religious reasons. The involvement of community faith leaders however, showed little support especially if families consult their own faith leader. Overall, this survey strongly suggests that the deemed legislation has not increased consent rates for organ donation amongst minority ethnic families. However, it is apparent that irrespective of culture or religion, deemed legislation may not impact families where the reasons above apply.

Recommendations:

- Encourage conversations at home and in the community to diffuse the misconception around organ donation and to advance the positive benefits rather than myths.
- Increase confidence among the specialist nurses through adequate and up to date trainings and exposures regarding culture and religion.
- Continue investing in community engagement to break down barriers and maintain links within the community.
- Review the involvement of faith leaders. How do we get around the negative impact during organ donation conversations?

Latest statistics on organ donation and transplantation for minority ethnic patients: Dr Leah McLaughlin, Research Fellow, School of Medical and Health Sciences, Bangor University

We aimed to learn more about the impact of the law change on attitudes and views likely to be relevant to consent to deceased organ donation between different population subgroups.

We analysed surveys of the public on attitudes towards organ donation undertaken from 2015 to 2021 (19,011), and after the change in law from 2018 to 2022 (45,439). We also interviewed thirty members of the public with a particular focus on minority ethnic and faith perspectives.

We found that changing the law has had little impact on the general public's support for organ donation, which has remained high and stable at around 80% in favour. Furthermore, it does not appear to have influenced people's willingness to become deceased organ donors, but this proportion is lower. Over half (56%) of the population would be prepared to give their organs after death.

- The number of people registering on the organ donor register has stagnated.
- Of those registered, 89% have opted in and are predominately white and around 10% have opted out and are predominately non-white.

- Harmful misinformation campaigns targeted at certain minority ethnic communities encouraged people to opt-out of organ donation.
- The intention of the Act, to allow individuals to make decisions while they are alive, is not straightforward for some minority ethnic families where decisions are shared or delegated in a hierarchy.
- There is a very low level of understanding about what deceased organ donation is, how it comes about, and how this aligns with important end of life rituals and processes in some minority ethnic communities.
- The presumption of consent left gaps in all people's knowledge. They wondered what they needed to do while alive, what would happen if they or their relative who died was eligible for organ donation and, critically, what they would do if they did not know what their relative who died had wanted.

The implementation of the opt-out law seems to have had no effect so far on general public attitudes and consent preferences in England, including within minority ethnic groups.

For further information, you can find the report and updates on the [website](#).



Break Out Discussion Groups To Develop Messages

Break out discussions took place for the following faith groups: Muslim, Hindu, Sikh, Jain, Christian and Zoroastrianism and non-religious.

Discussion groups were asked to consider the following in relation to developing messages on organ donation for their faith:

- To identify key enablers and barriers to deceased and living donation within the faith group.
- To develop key messages to raise awareness/promote organ donation within the faith group.
- To identify how the messages should be developed and shared within the community and the support NHSBT should provide to do so.

The following is a summary of the main discussion and suggested action for each group.

Muslim group



Facilitated by Umar Malik, Community Grants Manager, NHSBT.

Barriers

The group touched upon barriers but largely felt these were similar across most faiths, and in line with some of the presentations in the morning of the conference.

- Lack of understanding of the extent of health issues in relation to organ donation.
- Lack of knowledge around considerations of the clinical process around organ donation and the handling of the deceased which may impact burial or religious considerations around the sanctity of the body.
- Extremely limited awareness in the community, especially led by faith leaders, leading to people taking the safer option of assuming impermissibility, or resulting in the faith leaders considering it impermissible being most visible.
- Lack of education amongst the religious community to consider the Islamic position.
- No socialisation of fatwa produced by Mufti Zubair Butt. In 2019, Mufti Mohammed Zubair Butt, a leading Sunni scholar in Bradford reviewed existing guidance on organ donation within the Muslim community and published a new fatwa to clarify the position on organ donation after death.
- Confusion of law change.

- Challenge of family consent when making such a difficult decision that could impact burial timing or be frowned upon by wider family.
- Misinformation – WhatsApp messages being spread during law change leading to people taking direct action to opt-out. Over 200k Pakistanis opted-out in one year which is over 15% of all Pakistanis in the UK (see Black/ Asian Transplant Activity Report).
- A lack of religious leaders speaking about organ donation.
- Lack of a representative body within Muslim community to drive discussion.
- Lack of focused and intense NHSBT driven engagement or activity targeting the Muslim community.
- The community is unaware of successful organ donation practices in their countries of origin.
- Frustration around action that NHSBT take after these types of conferences – with positive conversations not resulting in sustainable action.
- Frustration around response of NHSBT of limited dedicated budgets to tackle this work, outside of the Community Grants Programme.
- SNOD paperwork around the times of potential donation which needs to be reduced and streamlined to give more chance for Muslims to consider donation

To develop key messages to raise awareness/promote organ donation within the faith group.

The group discussed messaging and developed some simple suggestions, but concluded the importance of dedicated messengers rather than the message itself is critical in engaging the Muslim community – with these dedicated messengers also supporting the development of the message using their cultural, faith and community expertise.

- Need to develop bespoke faith and culturally relevant content that is distributed via ethnic media outlets.
- Need to highlight more bespoke case studies of Muslim donors and recipients.
- Highlighting donor stories are key to soften the community rather than the technicalities of Islamic legal permissibility of organ donation.
- Need to focus on celebrating Black and Asian donors, even though few donate, rather than consistent negative messaging.

- 'If you would receive an organ donation, why wouldn't you donate one?' type of messaging.
- Overall messaging still needs to highlight some of the main areas - celebrate stories, highlight the need, provide the statistics and opportunity to understand the clinical process and so on, but needs to be much bolder.
- Messaging needs to be significantly braver and direct. Currently too risk-averse. NHSBT should develop hard-hitting bespoke campaigns which are directly aimed at the relevant communities in partnership with minority ethnic marketing agencies, as opposed to soft prompting messaging that are aimed at the wider public which will not have the level of traction or impact in these nuanced communities that is needed.
- It was discussed whether living kidney should be highlighted as opposed to deceased donation as this has less faith considerations, however it was suggested that we should not focus on this. One of the reasons suggested by medical professionals in the group was due to upcoming advancements in donation which may reduce reliance on living donation.
- 'Fatwa vs TikTok' – the need to develop engaging, human and relevant content to appeal to younger Muslim audiences too, rather than focusing on the technicalities of a religious legal edict.

How the messages should be developed and shared within the community

The group discussed a range of ideas, suggestions and feedback which cut across different areas listed below. The discussion largely focused on the critical role of key Muslim Ambassadors/Champions/Consultants in developing not just messaging, but also leading, developing and driving the activity, and possible effective models of this for NHSBT to consider. The group felt that some extremely positive steps were taken by Amjid Ali who was an extremely important individual in leading and facilitating discussion and activity in this space, but after his unfortunate passing, NHSBT have not sustained this activity.

Ideas, suggestions and feedback:

- Ambassador programme – feedback was shared around the need for us to maximise the Ambassador Programme, hear more about the programme, recruit more Black and Asian Ambassadors, and utilise these key individuals in faith communities.
- Organ Donation Committees (ODC) – the group discussed the important role that ODC's play in collaborating and joining the dots between different organ donation stakeholders internally and within the community. This included a discussion on the important role that Faith Chaplains play in hospitals, and the need for ODC's and SNOD's to be better engaged with Faith Chaplains to develop best practice.

- NHS audience – engage staff members across the NHS on organ donation given the diversity of staff across the NHS, possibly through campaigns, as part of mandatory training, inductions, etc.
- Community Grants Programme – the need for projects to collaborate better with each other in maximising efforts. Also, a suggestion that we should just fund one religious/ethnic faith group per year to allow us to intensify efforts, kick start activity and build foundations per community/faith group.
- Order of St John – better utilising stories as part of the Order of St John, with some events having 30% diversity.
- Recognising Muslim donors – bespoke communications and donor recognition journey for those from diverse communities that do donate. Similar to Ro Blood donors receiving a bespoke journey. Are we utilising the stories of Muslim donors that donate or donor families, or even Muslims that opt-in to the ODR?
- Wall of recognition – some hospitals have this for donors. Can we develop this for Muslim communities and work with Mosques and key faith organisations to display them in their organisations?
- Royal involvement – garden party for Black/Asian organ donors/families.
- Key moments and bespoke campaigns – the need for NHSBT to develop bespoke campaigns with minority ethnic media specialists utilising key moments such as Ramadan. A suggestion around a ‘Citizen Khan’ character too.
- Boroughs – partnerships with key boroughs with high Muslim demographics.

The Importance Of Messengers Vs The Message:

- The group were discussing the key role Amjid Ali played in kick starting activity and discussion on organ donation with key Muslim stakeholders. The group questioned why this work had not continued by NHSBT. NHSBT had a Head of Faith Engagement role where this activity could have sat, but with this role no longer in existence it didn't feel as if there was a natural home to drive this specialist activity within our current PACE/Marketing structure which has a massive gap and oversight.
- The group felt that there was some good work developed by Community Grants Programmes and by Muslim volunteers (clinicians and surgeons etc.) who were doing their best to educate their communities. However, these efforts were too sporadic and not intense. If NHSBT want real change

on a national scale across faith communities, then these efforts need to be intensified with a dedicated team (whether internal or external) which can build stronger foundations with the community, drive new activity, and consolidate existing activity.

Proposed Solution

- NHSBT need to fund a dedicated faith engagement team. This could sit within NHSBT or NHSBT could fund external faith specialists (similar to Amjid Ali) who are responsible for developing plans around engaging their communities on organ donation. However, external faith specialists would be a preference to ensure independence and trust within the community.
- These faith specialists could be responsible for bringing together key faith stakeholders to drive this activity forward and potentially form a working group. This could include working with funded community grants programme projects, and with a network of Muslim volunteers (clinicians and surgeons etc.).
- A faith specialist could have a range of responsibilities aimed at building strong foundations for organ donation and driving intensified awareness in communities. These could include scholar consultations to discuss the fatwa, mosque engagements, developing messaging with the community, identifying funded Faith Ambassadors who have a clear role, developing toolkits and more.
- The faith specialist can recruit a national team of Faith Ambassadors who are carefully mapped out in key locations and responsible for driving activity.
- The faith specialist can advise NHSBT on creating bespoke Muslim focused campaigns and can facilitate dissemination of these through Faith Ambassadors and via ethnic media outlets.

Hindu Group



Facilitated by Kirit Modi, Hon President of NBTA and Chair of JHOD.

There are over 1 million Hindus in the UK according to the 2021 census and they live throughout the UK, mainly in North-West London and the East Midlands.

Enablers

The two main enablers to organ donation are:

- Public support for organ donation after death as well as living kidney donation by international Hindu leaders.
- Hindu scriptures support organ donation and details are set out in the Hindu perspective on organ donation which has been updated to cover opt-out and published by NHSBT in partnership with the Jain and Hindu Organ Donation Alliance (JHOD). International Hindu leaders such as Pujya Rameshbhai Oza and Pujya Mahant Swami support organ donation and their messages are available on video from the JHOD [website](#). The core values of “Sewa” (selfless service) and “Daan” (selfless gift) are integral to Hinduism.

The establishment of JHOD

JHOD was established following an initial meeting held in Parliament chaired by Lord Gadhia in 2018. An informal group of 30 volunteers was established to co-ordinate organ donation promotion within the Hindu and Jain communities. JHOD is now

well established as a leading charity promoting organ donation within the Hindu communities in England through partnership working. It has established an excellent reputation of working in partnership with NHSBT and has successfully completed many projects funded by NHSBT, including campaigns during Diwali. JHOD's Strategy over the next four years is available on the JHOD [website](#).

Barriers

The main barriers to organ donation are:

- **Lack of awareness about organ donation.**
Raising awareness among the large Hindu community by the right messengers is challenging because it depends mainly on dedicated volunteers from the community. There is an ongoing need to arrange more events within temples and community groups, increase the use of social and traditional media and highlight more stories from Hindu donors, recipients and individuals waiting for an organ transplant.
- **Confusion about opt-out legislation in England.**
The national messaging about opt-out has been confusing among the Hindu community and made it more difficult to promote organ donation. The confusion is mainly about why one needs to register on the Organ Donation Register within an opt-out system and the role of family members at a critical time in hospital. However, it is important to note that the 2023/24 data on registrations shows that 3.4% of Indians signed up to the Organ Donor Register from a total Indian population in the UK of 3.1% according to the 2021 census data. This is the first time the percentage of Indian registrations was higher than the percentage of Indians in the population.

Develop key messages to raise awareness/promote organ donation within the faith group

The following key messages for organ donation after death are important for the Hindu community:

- Encourage Hindus to register on the Organ Donation Register within an opt-out system, and this decision is underpinned by the Hindu values of “Sewa” and “Daan” and supported by Hindu religious leaders.
- Encourage inter-generation discussion about organ donation within the immediate family, particularly the opt-out system, and highlight that immediate family members will be involved in discussion with nurses at the critical time in hospital.
- Explain the chances of receiving an organ from someone from the same ethnic group are higher because of the need to match blood and tissue type of the donor and the recipient.

- Share that, post-covid, the need for organs has increased and the number of donors has decreased compared to pre-covid numbers.
- Share that patients are dying while waiting for an organ transplant in the UK, and by donating you will save lives.
- Explain that if you are willing to accept an organ transplant if needed, then you should support donating your organs.

The following key messages for living kidney donation are important for the Hindu community:

- A living kidney transplant lasts much longer compared to a kidney transplant from a deceased donor, on average.
- A living kidney transplant can be arranged at a time convenient to the donor and recipient and can also be arranged before dialysis is needed.
- A living kidney can be donated by a member of the family, a friend or a stranger.
- There is a well-run kidney sharing scheme in the UK, if the donor's kidney is not a good match for the recipient.

How the messages should be developed and shared within the community

- A review of existing resources, (videos, leaflets etc), produced by NHSBT, JHOD and others should be undertaken in partnership by NHSBT and JHOD.
- A list of new resources should be developed in partnership by NHSBT and JHOD, followed by a joint Plan of Action. This should include some resources available in the following community languages: Gujarati, Hindi, Bengali and Tamil. Also, resources highlighting new case studies of Hindu donors, recipients and patients waiting for a transplant, as well as intergenerational discussion within families should be developed and published.
- Funding for the new resources should be provided by NHSBT as well as the successful Hindu projects under the 2024/26 Community Grants Programme.
- All resources should be easily accessible from the NHSBT and JHOD websites. Leaflets should be easily accessible from NHSBT.
- Messages to be promoted nationally by JHOD and other community groups through their work in the Hindu community.
- NHSBT and JHOD should work in partnership to publicise these messages through social media as well as traditional media.
- Influencers from the Hindu community as well as the four patrons of JHOD

should be invited to promote the messages, particularly during Diwali and Organ Donation Week.

- Greater partnership working between JHOD, NHSBT Ambassadors and regional SNOD teams should be developed.

Sikh Group



Facilitated by Gurch Randhawa, Professor of Diversity in Public Health & Director, Institute for Health Research University of Bedfordshire.

There was a general discussion of barriers and much focus on how key enablers could be used to develop key messages.

Develop key messages to raise awareness/promote organ donation within the faith group

The group discussed the positive steps taken by Sikh community in promoting dialogue regarding organ donation and ideas as to how the momentum can be increased. Reflection on community dialogue activities to date include:

- Embracing the concept of 'seva' selfless service in relation to organ donation and the idea that the 'soul lives on, the body is a vessel'.
- Reviewing NHSBT resources through proactively developing personalised messengers/messages such as people should look like us and talk like us.
- Promoting health and wellbeing, as well as organ donation – builds trust and reinforces 'seva'.
- Developing a pool of resources, underpinned with 'trusted' messengers and 'tailored' messages in different languages.
- Funding from the NHSBT Community Project has enabled some pioneering resources to be developed.

- Creating a 120 second Sikh Punjabi language film – involving the Harmandhir Sahib (Golden Temple, Amritsar), Sikh donor family, Sikh transplant recipient and Sikh transplant surgeon – prompting thoughts on how this can be shared across the UK and worldwide?
- Finding Sikh arts project resources and questioning how these can be amplified?
- Utilising Sikh media on both television and radio due to their consistent support on donations.
- The only organ donor charity to have received a Queen’s Award for Voluntary Service (QAVS) is the Mandip Mudhar Memorial Foundation – led by a Sikh family – how do we amplify this to raise profile of both the deceased and the living?

How the messages should be developed and shared within the community

- NHSBT should ensure that the impact of the Community Grants Programme is maximised.
- Amplifying existing Sikh resources/assets rather than creating new ones, unless they are complementary.
- Can NHSBT provide an online ‘repository’ of resources that Community Grants Programme have generated?
- Could future Sikh projects focus upon mobilisation of Sikh organ donation resources – e.g. Show 120 second film in GP waiting rooms (in practices with high proportion of Sikh patients)?
- Communities have expressed need to increase visibility of the donor journey – both living donors and deceased donors.

Jain Group



Facilitated by Manhar Mehta, Trustee NBTA and Vanik Council, and Prafula Shah, Trustee JHOD

The 2021 United Kingdom census confirms there are about 65,000 Jains in the UK – they are in the main part of the Indian community, and they live throughout the UK including mainly in North-West London, East and West Midlands, and Manchester. There are also smaller Jain communities in Berkshire, Buckinghamshire and Hertfordshire.

It was acknowledged that there is widespread support from the Jain community for both deceased and living donation. Details of the Jain perspective on organ donation is published by NHSBT in partnership with the Jain and Hindu Organ Donation Alliance (JHOD) and available on their [website](#) and on the Vanik Council's [website](#).

The main principle of Jainism is Non-violence. This envelops not only non-killing of living beings but also saving lives. The desire to save lives is “Karuna” i.e. Compassion. The other core values of “Sewa” (selfless service), helping others and giving selflessly “Daan” (selfless gift) are enshrined within Jainism and the support for organ donation largely falls within this value.

Barriers

The main barriers to organ donation are for deceased donation:

- A lack of knowledge about donation.
- Elders of the community influencing decisions who do not have accurate information.

- The lack of conversation about donation with family members.
- The worry about what the deceased donor will look like at open casket funerals.

The main barriers to organ donation for living donation:

- A lack of knowledge about living donation.
- The impact of the family hierarchy and influence of elders/community on the individual making the choice to be a living donor.
- A fear of surgery.
- The lack of support from the family.
- The individual who needs the organ might be concerned about the health of the family member. As a result, this could prevent them from asking about donation.

Enablers

The main enablers in relation to organ donation are:

- Messages delivered to the community via the right messengers such as faith leaders and within community settings.
- NHSBT's Community Grants Programme allowing bespoke community projects.
- Fit for purpose resources including community specific material.
- Support from influencers who are trusted by the community

Develop key messages to raise awareness/promote organ donation within the faith group

Raising Awareness

There is a continued need to raise awareness amongst the Jain community and the need for messages to be delivered by the right messenger on the ground. There is an ongoing need to:

- Arrange more events within Jain temples and community events.
- Increase the use of social and traditional media.
- Highlight more stories from Jain donors, those waiting for transplants, and recipients in national media and within campaigns from NHSBT and others.

Confusion about opt-out legislation in England

It was confirmed that the national opt-out messaging has caused confusion amongst the Jain community, and it has made it more difficult to start conversations about organ donation. The confusion is mainly about why they need to register on the Organ Donation Register within the opt-out system as they are all automatically organ donors and the role of family members at a critical time in hospital.

However, it is important to note that the 2023/24 data on registrations show that 3.4% of Indians signed up to the organ donor register from a total Indian population in the UK of 3.1%.

There is also lack of understanding that only 1% of those on the Organ Donation Register go on to donating their organs because for organs to be retrieved, death has to occur in a hospital setting.

There is a need for new messaging and better engagement.

The following key messages for organ donation after death are important for the Jain community:

- Encourage members of the Jain community to register their decision on the Organ Donation Register despite being automatically on the register within the opt-out system and this decision is underpinned by the Jain values of Compassion and “Sewa” – selfless giving.
- Explain this is highest form of ‘sewa’ and “karuna” (compassion), serving and doing good for others, saving and transforming lives and is supported by their community and religious leaders.
- Encourage inter-generation discussion about organ donation within the immediate family and ensure wishes are known to the family.
- Explain the chances of receiving an organ from someone from the same ethnic group are higher because of the need to match blood and tissue type of the donor and the recipient
- Explain that a large proportion of those waiting for organ transplants (especially kidney) are from the same community.
- Share that post-covid the need for organs has increased and the number of donors has decreased compared to pre-covid numbers.
- Share that patients from their community are dying while waiting for an organ transplant in the UK. Through donating your organs, you can help save lives.
- Explain that if you are willing to accept an organ transplant if needed, then you should support donating your organs.

The following key messages for living kidney donation are important for the Jain community:

- On average, a living kidney transplant lasts much longer compared to a kidney transplant from a deceased donor.
- Explain the benefit of a pre-emptive transplant, a living kidney transplant can be arranged at a time convenient to the donor and recipient and can also be arranged before dialysis is required.
- A living kidney can be donated by a member of the family, a friend or a stranger.
- Explain the benefit of the UK Kidney Sharing Scheme which provides the living donation option if the donor's kidney is not a good match for the recipient and allows more transplants to take place.

How the messages should be developed and shared within the community

Resources

- A review of existing resources, (videos, leaflets etc), produced by NHSBT, JHOD, Vanik Council and others should be undertaken in partnership NHSBT and the producer of the resources.
- Any new resources needed should be developed in partnership by NHSBT and easily available. Any new messaging should be promoted by Jain community groups.
- This should include some resources being available in the following community languages: Gujarati, Hindi, Bengali and Tamil. Also, resources highlighting new case studies of Jain donors (both living and deceased), recipients and patients waiting for a transplant, as well as intergenerational discussion within families should be developed and published.
- Funding for new campaigns and the new resources should be provided by NHSBT and the successful Jain projects under the 2024/26 Community Grants Programme and shared with others.

Publicity

- Better publicity and profiling of Jain donors, those waiting for transplants and recipients by NHSBT, NBTA and other stakeholders on their own channels and through national campaigns.
- NHSBT and JHOD to work together on collaborative campaigns at key annual festivals of Paryushan and Diwali, in partnership with the Jain community.

-
- NHSBT, NBTA, JHOD and Vanik Council to work in partnership with Jain organisations to publicise these messages through social media, traditional media and digital content.
 - Medics, influencers, and others from the Jain community to be encouraged to promote the messages, particularly during Paryushan and Organ Donation Week.
 - Build on partnership working between NHSBT Ambassadors and regional SNOD teams.

Christian Group



Facilitated by Orin Lewis, Co-founder, ACLT and Chair of NBTA and Edith Samambwa, Health Ministries Director, South England Conference of SDAS.

The overall state of active participation in being registered (1.2% or 30,615), opt-in (1.4% or 17,457), opt-out (7%), consent to donate (29%) and donating organs (28 deceased and 19 living donors) is very poor in relation to the UK's Black Christian communities (4%) population (See information in NHSBT [Annual Report on Ethnic Differences](#)). This has created a strong reluctance and some ambivalence towards developing proactive messaging in faith based and secular communities within the Black community.

This group of Christian orientated individuals was a mixture of Church leaders, SNODs', Chaplains, Clinicians and facilitators. We discussed and debated many areas linked towards changing the status quo by coming up with bespoke forms of messaging and communication pathways.

Barriers

The main barriers and hurdles towards organ donation are the following:

- Lack of awareness about deceased and living organ donation.
- Mass confusion about an individual's opt-in status when they are asked to sign a form to confirm their registration. Are they in or out?
- Bad timing, when the Deemed Consent opt-in was launched during the peak of the covid-19 pandemic.

- Driving License does not highlight the Deemed Consent of opt-in or opt-out.
- “What’s the point of having the law?” Was it just activated to cover the covid-19 period?
- Organ donation awareness and messaging is very low on the annual/monthly priority list for the Black church and its leadership.
- Church leaders are unaware of numbers of organ failure individuals within their congregation.
- “The Black Auntie” within our families and communities often dictates the final decision on deemed consent or deciding to donate a loved one’s organs.
- Wealth has an important relevance to decision making.

Enablers

- Education is key to understanding organ donation.
- Understand the different cultural traditions that fuel religious beliefs.
- Understand and appreciate that there are significant differences between SNOD messaging and public messaging with consent to donate.

Develop key messages to raise awareness/promote organ donation within the faith group.

There is the potential for new understanding and messaging for Black Christian communities. The main organ donation understanding, perceptions and messaging examples are:

- There needs to be more positive activity by the church in relation to organ donation, in the same way that many do in relation to hosting Food Banks, etc.
- Utilise other forms of donation awareness messaging like blood and stem cell before focusing on deceased or living organ donation.
- Integrate the message of all forms of donation: stem cell, blood and organ.
- Church testimony is key and vital in messaging to show the before and after, in relation to organ donation success.
- The following question needs to be asked: “Would you be happy to receive an organ donation? If so, why would you not want to donate an organ to someone else?”
- Utilise “The Texas Model” of utilising the first Ladies of the community who are key to creating new messaging.

- Make organ donation messaging a priority in Black Christian churches.
- Utilise well known public figures/Influencers such as DJ ACE and Steve O The MadMan, to deliver strong messaging.
- Use mediums such as podcasts, webinars to plant the “seed of organ donation” by “gate keepers” such as Pastors and Church leadership.
- Utilise “The Texas Model of Pastor Toolkits” for UK based Black preachers.
- Promote the importance of blood group “B” to well matched organ donation. This blood group is found in many Black and Asian people.
- Utilise religious phrases such as “Dust to Dust, Ashes to Ashes”, Loving Thy Neighbour” and “giving the Gift of a Lifetime” as new organ donation messaging to saving lives alongside their theologian usage.
- Use messaging that highlights the chances of receiving an organ from someone from the same ethnic group being higher if the donor is also from the same ethnic background.
- Use messaging that highlights that Black patients are dying while waiting for an organ transplant (deceased and living) in the UK. By donating, you will save lives.
- Get Black Churches to create new visually stimulating leaflets and posters depicting the positivity of religion and medical science working together on organ donation awareness.
- Utilise living organ donation awareness messaging as a prelude to rolling out deceased organ awareness, as it is clear that the former is more easily digestible to open debate rather than the “elephant in the room” which is deceased donation.
- On average, a living kidney transplant lasts much longer than a kidney transplant from a deceased donor and can be donated by a member of the family, a friend or a stranger.
- Use new messaging to highlight the UK’s kidney sharing scheme, which is utilised if the donor’s kidney is not a good match for the recipient and paired couples are linked so that all waiting patients find a matching donor.

How the messages should be developed and shared within the community

- Review all the existing Black Christian organ related resources (videos, leaflets, posters, social media postings etc) produced by NHSBT, Seven Day Adventists, GOLD, ACLT and others in partnership with NHSBT and NBTA.

-
- A list of new resources containing some or all of the above including developing new Christian and cultural related messaging in partnership with NHSBT and NBTA, followed by a joint Strategy Plan to flesh out the potential of new initiatives like researching and undertaking the potential objectives of the Texas Pastor Kits. In addition, collaborating with key organisations such as ACLT and Gift of Living Donation (GOLD) to showcase new Black living and deceased donor/patient case studies which could be developed and published for future usage in new campaigns and mainstream news/social media platforms.

The above proposals should be funded by NHSBT as part of the existing 2024/25 Community Grants Programme, or for the 2025/26 version. The ultimate outcomes will be the following:

- New leaflets, posters will be planned, created by verified organisations and deposited into the NHBST Hub, with the capability of rolling these resources out to the community gatekeepers.
- During key organ related days and weeks such as Black History Month, the new bespoke messaging will be led by the verified organisations and their associated spokespersons and influencer friends.
- Closer working relationships between the verified NHSBT associated organisations and well known Black Christian churches and key health professionals such SNOD's and Retrievers.

Non-Religious Group



Facilitated by John Richardson, Assistant Director – Organ & Tissue Donation, NHSBT.

Barriers

- Apathy was noted as a major barrier. This was linked to a lack of understanding of the scarcity and rarity of donation, and the individuals thinking they need to die in a certain way to donate.
- There is not always the reach into and across communities, alongside differences in intergenerational understanding.
- Inconsistency in raising awareness and education about donation in schools particularly who want to inform students about organ donation as part of the social curriculum. But, often delivering education on organ donation is dependent on interest from schools, age of students and nursing staff capacity and availability.

Enablers

- Engagement through a trusted individual or organisation such as the role and benefit of peer educators.
- Positive messages / discussion in advance of an organ donation decision.
- Strong messaging that certain ethnic groups are much more likely to need a transplant, 430 people die a year etc.

- Using experience of a group in a peer educator role, asking questions such as ‘how many of you know someone who has had a transplant?’
- Healthcare practitioners offering education to schools during donation week or generally increasing health literacy on this. Building relationships within education is key. An example in point is the work of some schools in Glasgow who have prioritised requests from the health sector to talk to pupils about organ donation.
- Importance of highlighting the inequalities in donation and transplantation to aid discussion.
- New generation may be driven or motivated by inequity, equity and fairness.
- Getting the information out in digestible and accessible ways e.g. use of QR codes or phone numbers to call and have the conversation.
- Need for law change to require registration and prevent next of kin from over-ruling an individual’s decision.
- Positive use of donor family stories from different ethnicities and faiths.

Develop key messages to raise awareness/promote organ donation within the faith group

- Changes to the legislation and mandatory registration (as in the Netherlands experience).
- Redesign the registration process so it is simplified. The simplification to include prompts such as ‘Do you want to donate organs?’ ‘Do you want to donate tissues?’ ‘Is there anything you don’t want to donate?’
- Wider integration of donation requests in other area such as railcards, bus passes, Amazon, major life events, or at a GP practice.
- Provide more information when opting out to get people to reconsider.
- Prompts from NHS App to ‘renew’ or validate wishes.
- Letters to those coming of age – 16 or 18.
- Making the process to over rule more ‘official’ e.g. In Scotland family members who want to opt-out are asked to sign a form and this then acts as an aid to open a discussion, consideration and answer any questions they might have.
- Learn from the Mohan Foundation who do not see ‘no’ as ‘really a no’ by family members. But enable a ‘cool-off period’ of 10 minutes before checking again with family members.

-
- Factoring donation into the endoflife discussion earlier (opportunities such as the NHSBT Specialist Early Exploration of Donation trial).
 - COMFORT tool in Glasgow, Scotland is part of the end of life care and a prompt for clinicians to consider organ donation.
 - ICU death debriefs for staff.
 - Connecting with public health messages e.g. hypertension, renal failure, diabetes with health inequalities and potential need for organ donation.
 - Local education and promotion modelling the Northern Ireland experience.
 - Peer educator network.
 - Need to work on addressing trust, perceptions and experiences of institutional racism which might impact on people's willingness to donate.
 - Give the donor the ability to leave a letter, message or video alongside the organ donation registration to family members.

How the messages should be developed and shared within the community

- Better use of networks such as staff networks, NHS networks, Black, Asian and minority ethnic networks, local authorities, companies etc.
- Promoting donation across NHSBT during organ donation week.
- Building donation into end of life care planning discussions with patients – look to collaborate with the Royal College of GPs on the use of Advance Care Plans.
- Expelling the myth that you can't donate organs if you're deferred for blood donation and enable promotion of organ donation with other registries.

Zoroastrianism Group



Facilitated by Fatim Kesvani, Head of Organ Donation Marketing, NHSBT

Due to the small number of participants, discussion across these faiths took place in one group. The importance of the 'body' and its interpretation was noted. There are multiple perspectives within the 'single' faiths.

Enablers

Reciprocity in terms of doing good for others (donation) correlates with doing good to oneself (receiving an organ).

Barriers

- Lack of expertise/skills amongst the chaplaincy in hospitals.
- Delay in administering last rights.
- Concerns that need to be addressed such as inconsistency in health sector consideration for after death (speed of paperwork that needs to be done for donation).

Develop key messages to raise awareness/promote organ donation within the faith group.

- There needs to be different levels of messaging to bridge generational gaps.

How the messages should be developed and shared within the community

- Highlight the law change on the organ donation registrar status as appropriate for the different faith groups.
- Manage expectations about containing family involvement.
- Appeal to the 'human element' e.g. reciprocity of good – 'would you be prepared to give if you receive', is an appealing message.
- Raising awareness locally.
- Community outreach.
- Information endorsed by faith leaders and work with them to take action.
- Understand differences in 'single' faith/ethnic groups.
- Understanding living donation as an option.
- Positive stories.
- Drip feed information – constant messaging.

Conclusion

The conference concluded with a summary from Mark Chambers from NHSBT who thanked participants for their contributions. The conference discussions and the issues raised have provided a challenge to NHSBT in how they work with others to shape meaningful messages relevant to the faith communities about organ donation.

Next Stage

The event was closed by Orin Lewis, Chair of NBTA who thanked all the presenters and contributions from participants. There is an opportunity to now move forward to develop appropriate messages that enable more uptake on the donation registers and transplantation. NBTA will continue to work with NHSBT Department for Health and Social Care and the government to move forward in reducing inequalities in organ donation.

Feedback from the Conference

June 2024

There was a total of 82 attendees, and we received 60 survey responses. The average ratings of the responses and the key themes/comments are shown below.

How satisfied were you with the conference overall?

4.49
OUT OF 5

How satisfied were you with the speakers/ presentations?

4.69
OUT OF 5

How satisfied were you with the discussion groups?

4.36
OUT OF 5

How satisfied were you with the arrangements for the conference?

4.33
OUT OF 5

In your opinion, did the conference meet its objectives?

"I thought this was a fascinating learning opportunity and it was a real privilege to attend, and take insights away to my research on organ recipient experiences and outcomes."

"Process has started. Need to see how it develops and more importantly what concrete, effective and sustainable actions and messages are made."

"Yes, it did. However, will be helpful to have a follow up on progress."

"It got a conversation going, but sceptical if anything will change."

"Yes, I had the opportunity of meeting other possible competitors for the Community grant programme and also the SNOD."

Which elements of the conference did you like the most/were the most helpful?

"Group discussions, Research, SNOD questionnaire."

"Understanding the Angelo's research on behaviour, SNODS and how the law isn't/is supporting donation."

"The presentations were very informative. Good to meet/network."

"I really appreciated the stats and SNOD presentation and networking."

"Group discussions was very good."

Which elements of the conference did you like the least/were the least helpful?

"All was helpful but we have had many of these discussions before."

"Feedback sessions needed to be more summarised."

Any other comments and feedback:

"Bigger venue, more speakers from the community."

"More faith leader involvement."

"Should continue every year for awareness."

"It was striking to see the commonality between the groups and comments about the importance of the messenger as well as the message. But we have to be careful to not duplicate effort."

Appendix One

NBTA/NHSBT Conference Planning Team

Dr Daniel McCloskey – Team Margot

Fatim Kesvani – Head of Organ Donation Marketing, NHSBT

John Richardson – Assistant Director – Organ & Tissue Donation, NHSBT

Kirit Mistry – Founder and lead for health inequalities, South Asian Health Action UK

Kirit Modi (Chair) – Hon President NBTA and Chair, JHOD

Lisa Burnapp – Associate Medical Director – Living Donation and Transplantation, NHSBT

Manhar Mehta – Trustee (NBTA), Chair (Vanik Council)

Nadia Martini – Trustee, Team Margot

Orin Lewis – Co-founder and Chief Executive of ACLT, Chair of NBTA

Stephanie Norris – NHS Graduate Management Trainee, NHSBT

Tracey Bignall – Director of Policy and Engagement, Race Equality Foundation

Umar Malik – Community Grants Manager, NHSBT

Winnie Andango – Lead Practitioner - Equality, Diversity, and Inclusion OTDT, NHSBT

Yaser Martini – Trustee, Team Margot

Zulekha Mirza Butt – Research Assistant, Race Equality Foundation

Appendix Two

Organisations represented at the event

1. African Caribbean Leukaemia Trust
2. Bangor University
3. BAPS Swaminarayan Sanstha (Neasden Temple)
4. British Islamic Medical Association
5. British Sikh Nurses
6. British Union Conference
7. Chelsea and Westminster Hospital
8. Donor Family Network
9. EAVA FM
10. COLAB2
11. Guy's and St Thomas' NHS Foundation
12. Jain and Hindu Organ Donation Alliance
13. Kenyan Nurses and Midwives Association
14. Kidney Care UK
15. Kidney Research UK
16. Kingston Hospital NHS Foundation Trust & Hounslow & Richmond Community NHS Trust
17. London Kidney Network
18. London School of Hygiene & Tropical Medicine
19. National Black, Asian, Mixed Race, and Minority Ethnic (BAME) Transplant Alliance (NBTA)
20. Newcastle University
21. NHS Lothian
22. NHS Scotland
23. NHS Blood and Transplant
24. National Kidney Federation
25. Queen Elizabeth Hospitals NHS Trust
26. Race Equality Foundation
27. Royal Brompton & Harefield OD Chair
28. Royal Free Hospital
29. Royal Free Hospital Kidney Patients Association
30. Sickle Cell Society
31. Shade 7 Limited
32. Shrewsbury and Telford acute hospital NHS Trust
33. South Asian health action
34. South England Conference of Seventh-day Adventists
35. South Tyneside and Sunderland NHS Foundation Trust
36. Team Margot
37. The Rebel With A Cause (TRWAC) CIC
38. University Hospital Coventry & Warwickshire NHS Trust
39. University Hospital Birmingham
40. University Hospitals Plymouth NHS Trust
41. University of Bedfordshire
42. Vanik Council
43. Your Blood Helps
44. Zoroastrian Trust Funds of Europe

nbta@racefound.org.uk
<https://www.nbta-uk.org.uk/contact-us/>

