



Messaging guidance for Jain audiences

Themes to support promoting
organ donation by faith among
minority ethnic communities

Introduction

A key aim of the National Black, Asian, Mixed Race and Minority Ethnic Transplant Alliance (NBTA) and NHS Blood and Transplant (NHSBT) conference on 4 June 2024 was to identify faith-specific message themes to increase organ donation awareness and participation.

Delegates from 41 organisations, including healthcare trusts, voluntary and community sector organisations, universities and faith organisations, collaborated to identify opportunities and barriers to communicating around faith.

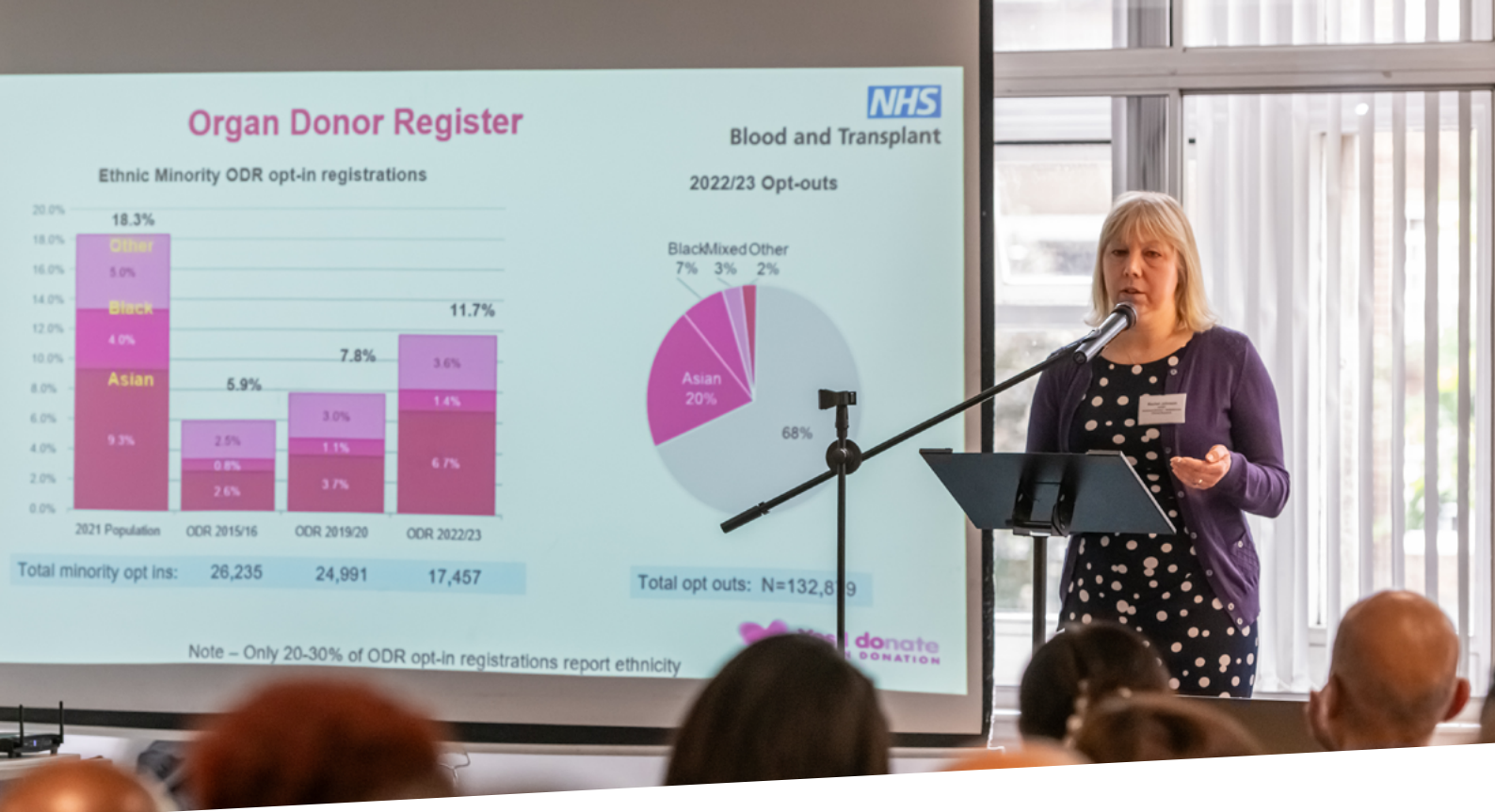
This conference considered the confusion caused by the publicity related to the change in law to opt out in England in May 2020, as well as the limited impact of this change. A report from the conference has been published by [NHSBT](#) and [NBTA](#) and is available on their websites. This document sets out the messaging themes from the conference and provides guidance which we hope will be helpful. Both NBTA and NHSBT will promote the guidance extensively.

NHSBT will refer to the guidance for its campaign work and ensure that it is shared with its Community Grants Programme organisations to highlight organ donation to their communities through their work. Please note that these themes and any guided messaging represent the views of many leading individuals and groups involved in working with ethnic and religious communities in England.

NBTA and NHSBT are working jointly to implement the ten actions which emerged from the conference. One of these relates to producing and publicising a range of assets to support the message themes set out in this guidance.

For further information about this guidance, please contact marketing.comms@nhsbt.nhs.uk or Kirit Modi, MBE, Hon President from NBTA kiritmodi1@hotmail.com.





Statistics

Latest figures from the Annual Report on Ethnicity Differences in Organ Donation and Transplantation

(1 April 2023 – 31 March 2024)

Statistics can powerfully convey the need for opt-in registrations from ethnic minority communities and can be used to highlight key messages.

Further information can be found at [Five year high on number of ethnic minority patients receiving a lifesaving organ transplant - but there's a significant drop in the number of donations - NHS Organ Donation](#)

Key findings, which you may wish to highlight, include the following:

- The number of ethnic minority deceased organ donors has fallen by 19% from 108 in 2022/23 to 88 in 2023/24.
- The number of ethnic minority living organ donors has fallen by 8% from 138 in 2022/23 to 127 in 2023/24.
- The number of transplants in people from ethnic minority backgrounds increased from 1,129 in 2022/23 to 1,232 in 2023/24.

- There were 2,365 people from ethnic minority backgrounds on the active organ transplant list at 31 March 2024, an increase from 2,237 as at 31 March 2023. This is mostly due to increases in the kidney and liver transplant lists, where non-urgent patients have been reactivated after being suspended during the height of the pandemic.
- Median waiting times to transplant show that, generally, white patients wait less time than patients from ethnic minority backgrounds. Black patients often wait the longest.
- Family consent/authorisation is much lower for ethnic minority potential donors than for white potential donors. Overall, consent rates were 32% for ethnic minority and 65% for white potential donors last year, lower than the previous year.

The main reasons families from ethnic minority backgrounds gave for declining consent/authorisation for organ donation were that they felt it was against their religious or cultural beliefs, or they were unsure whether the patient would have agreed to donation.



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Highlight the principle of Jainism

- The main principle of Jainism is non-violence, which implies not only a refusal to harm living beings but also the need to save lives. The desire to save lives is known as 'Karuna' - compassion. This view is supported by Jain faith and community leaders.
- Other core values of 'Sewa' (selfless service) and 'Daan' (selfless gift), which encourage helping others and giving selflessly, are enshrined within Jainism. The support for organ donation largely falls within these values.

Understand the importance of family and customs

- Develop messaging to reach elders of the community. They may be influencing decisions without accurate information.
- Increase support by encouraging families to have conversations about donation, providing the information and signposts to facilitate discussion.
- Address the worry about deceased donor appearance at open casket funerals.

Increase knowledge of living donation

- A third of all kidney transplants are from a living donor. A kidney from a living donor offers the best chance of a successful transplant.
- Anyone can be a living donor- family member, friend or even someone who has never met the person but volunteers to donate to someone in need of a kidney.
- A living donor transplant can be planned in advance, avoiding the need for dialysis and making sure that it happens at the best time for recipient and donor.
- Donating and receiving a kidney through the UK Living Kidney Sharing Scheme, increases transplant opportunities for everyone, especially for long-waiting patients and people on the transplant list without a living donor of their own.
- Donating a kidney is a big operation so, anyone who volunteers to donate is carefully assessed to make sure that it is as safe as possible for them to donate.
- Living donation isn't for everyone and a person should only donate if it is the right decision for them. There are dedicated teams who assess people volunteering to donate and their [details can be found here](#)



Consider living donation

A kidney transplant can transform the life of someone with kidney disease

1 in 3 of all kidney transplants carried out in the UK are from living donors.

A living kidney donor is a person who gives one of their healthy kidneys to someone who needs a transplant. This could be a friend or family member, or even someone they do not know.

The UK Living Kidney Sharing Scheme is an important part of the living donor programme and about 1 in 4 (a quarter) of people who receive a living donor kidney transplant do so through this successful scheme.

'Kidney swaps' allow donor-recipient pairs who may not be a match for each other to exchange kidneys with other pairs in transplant cycles. Transplant chains, triggered by non-directed altruistic donors (people who simply want to donate a kidney to someone in need) are also part of the scheme. Together, these offer people the chance of a transplant they otherwise may not have had.

The scheme benefits all, adults and children, including long-waiting patients and people from ethnically diverse backgrounds.

A kidney donated by a living donor offers the best long-term outcome for the recipient and the opportunity for a planned transplant. Studies have shown that the average patient survival at 10 years is 90% with a living donor transplant.

Source: Annual Report on Ethnicity Differences in Organ Donation and Transplantation Report for 2023/2024

As this is a complex area, we suggest referring to the website before pulling together messaging

[Donating your kidney - NHS Organ Donation](#)

Key guidance is below:

- Anyone can volunteer to be considered as a living kidney donor - family member, friend (directed donor) or someone who does not know the recipient (non-directed donor).
- The UK living kidney sharing scheme is the largest of its kind in comparison with European countries and offers people the opportunity of a transplant they may otherwise not have had.
- Non-directed altruistic donors are the 'game-changers' in the UK living kidney sharing scheme by increasing transplant opportunities for everyone.
- A living donor kidney transplant tends to last longer compared to a kidney transplant from a deceased donor.
- A living donor kidney transplant offers the best chance of success and an opportunity for a planned transplant to avoid dialysis.

Useful links

- [Organ donation and your beliefs](#)
- [For more information](#)
- [Become a living donor](#)