

Briefing Paper - Organ Donation Awareness and Support

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How can Indians, Hindus and Jains help increase organ donation in the UK?

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1. Introduction

I am delighted to provide a Briefing Paper for this important opportunity for Indians, Hindus and Jains to discuss how we can help increase organ donation. This paper has been written in a personal capacity and does not represent views of any organisation. I am most grateful to Lord Jitesh Gadhia for all his help in arranging and chairing this event. I have worked on organ donation with BAPS Swaminarayan Sanstha (Hindu Temple in Neasden) for many years and it is a pleasure to do so again in organising this event. The support of Jackie Doyle-Price, MP, Minister of Health responsible for organ donation in England, is a strong indication of how seriously the Government and many MPs are in tackling this long standing challenge.

This Briefing Paper provides the latest relevant statistics, explains why this is a very good time to address the shortage of organ donors, outlines examples of good practice, suggests some issues for the Minister to consider, invites community groups and others to help and provides information on some resources available.

2. Relevant statistics

The latest statistics published by NHS Blood and Transplant (NHSBT) for 2017/18 shows that:

- 959 Asians were waiting for an organ transplant in March 2018 in the UK. This represents 16% of everyone waiting for an organ transplant. Over 80% of those waiting for an organ transplant are waiting for a kidney. All Asians are grouped together; there is no more specific data available, and no data is collected by religion.
- There were 69 Asians who donated a living kidney. This is 7% of all those who donated a living kidney.
- There were 37 Asians who donated organs after death. This is 2% of all those who donated organs after death.

- The average waiting time for an organ transplant for White people is 2 years; and it is 2.5 years for Asians, highlighting the stark concerns within particular communities.
- 89 people from a Black, Asian and Minority Ethnic (BAME) background died while waiting for an organ transplant. This is 21% of all those who died while waiting.
- 8726 individuals from an Indian background signed the national Organ Donor Register (ODR) to indicate their decision to donate their organs after death. This represents 1.9% of all those signing the register. Census data shows that 2.3% of the overall population is of Indian background. People from Indian background had the highest rate of sign-ups to the ODR compared to other BAME groups listed by NHSBT. It is reasonable to assume that this would be linked to the main religions followed by Indians in the UK; including Hindus, Sikhs and Jains.
- The overall “consent rate”, which is the percentage of family members who consent to the giving of organ donation of a loved one after death at the critical time in hospital, was 66% nationally. It was considerably less for BAME communities at 42%. This highlights the crucial importance of having conversations with our loved ones about organ donation, particularly when we sign the ODR.
- Public opinion on organ donation is positive with 80% saying that they would be willing or would consider organ donation. Again, this figure reduces to 69% for BAME communities.

3. Why this is a good time for taking action to increase organ donation? All of us who have been involved in promoting organ donation for many years know how difficult it is to bring about real change. I think this is a good time to take action because of three main reasons.

Firstly, politicians are responding to the majority public opinion which supports organ donation and wants us to do more to save the lives of those who continue to die while waiting for an organ. Wales took the lead and now England and Scotland have started legislative processes to change the law and introduce “presumed consent”. In England, following a very positive outcome to the consultation which received over 17,000 responses, the Government has announced its intention to support the legislation and this has support among all the main political parties. See the link below. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/731913/govt-response-organ-donation-consent.pdf

This change will mean that over the next year or so, there will be a major communication campaign to explain the changes so that everyone can make an informed decision on organ donation. The plan is to introduce presumed consent from 2020 in England. This is also referred to as an opt out because if someone dies and they have not recorded an express decision, the default decision will be that consent

to donate will be 'deemed.' There will still, however, be a personal discussions with the family at the bedside, and special consideration will be given to a person's faith and the views of loved ones. Clinicians will never proceed if the family objects strongly. That is why the Government is keen to ensure that everyone makes their wishes known to their family to ensure that preferences in life are honoured after death. It should become routine as drawing up a will.

A view is that overall this process will have a significant impact on the number of people from BAME background who sign –up to the ODR. In particular, I anticipate that those from Indian, Hindu and Jain background will sign up in significant numbers.

Secondly, the specific challenges facing BAME communities in relation to organ donation is rightly getting more attention. The Government has recently announced a new campaign to increase Black and Asian organ donors. I am very pleased that it includes funding to support a "community investment scheme" so that community organisation can access funding to engage local communities in organ donation. The invitation to bid for funding was announced on 5 September 2018 and bids have to be submitted by 24 September 2018. Details are available at:

<https://www.nhsbt.nhs.uk/get-involved/promoting-donation-hub/bame-funding-call/>

This greater recognition of the challenges facing BAME communities is most welcome, particularly by those of us who have been advocating this approach through the National BAME Transplant Alliance (NBTA), www.nbta-uk.org.uk for some time.

Finally, we now have examples of excellent practice in promoting organ donation among BAME groups. I want to highlight two of these; one led by Professor Sejal Saglani from BAPS Swaminarayan Sanstha and the other by Mr Manharbhai Mehta from the Vanik Council UK. In both cases we have had major projects led by well-established groups, with clear aims and objectives, working in partnership with local hospitals, with detailed project plans and rigorous evaluation. I am very pleased that representatives from both these groups will be sharing their experience with us at today's meeting. A report on the first year's work done by both groups, as part of the Living Transplant Initiative (managed by NBTA and funded by NHSBT) is available at <https://nhsbt.dbe.blob.core.windows.net/umbraco-assets/1837/interim-report-of-living-transplant-initiative.pdf>

4. Some issues for the Minister to consider

I am most grateful to Jackie Doyle-Price MP for taking the lead in moving this agenda forward, by securing the Government's support for the Bill on presumed consent in England and by publishing a refreshed campaign to increase organ donation among

BAME communities. I would like to request the Minister to consider four issues to further support both these initiatives.

Firstly, there were 101 responses to the consultation on presumed consent from Hindus, 34 from Sikhs and none recorded from Jains. I think it is not unreasonable to assume that the majority of the responses from Hindus and Sikhs were in support of presumed consent. There were more responses from people of other faiths. The decision by the Government to introduce a **faith specific donor card** is most welcome. It would be most helpful if the Minister would ensure that representatives of Hindu, Sikh and Jain communities are fully involved in the development of these new donor cards. This is important because there was poor attendance from these communities at the faith meeting on organ donation organised by the Department Of Health in May 2018.

Secondly, living kidney donation do not seem to have been given sufficient importance by hospitals and NHSBT; although there are signs that this is beginning to change, following the publication of the Manifesto on Living Donation by the All Party Parliamentary Kidney Group earlier this year. The manifesto is available from the NKF website at:

<https://www.kidney.org.uk/assets/Uploads/documents/All-Party-Parliamentary-Kidney-Group/NKF-manifesto.pdf>

As shown above, living kidney donation is more common among Asian communities. In 2017/18, there were overall 1574 donors after death in the UK and 1051 living kidney donors; so living kidney donors constitute 40% of all organ donors. Also, a living kidney transplant lasts, on average, longer than a kidney transplant from a deceased donor for a variety of reasons and this needs to be highlighted more nationally. It would be most helpful if the Minister would ensure that living kidney donation is given appropriate importance as we introduce presumed consent in England.

Thirdly, the categories we use for collecting of data on ethnicity related to organ donation are inconsistent and not satisfactory, as can be seen from paragraph 3 above. Some data is only collected by using broad categories such as Asian or Black (which is of limited use). Also there is no data collected by religion, as mentioned above. Better data collection has been raised with NHSBT by a number of us for some time without any progress. It would be very helpful if the Minister could consider this, particularly in the context of the development of the faith specific donor card.

Finally, the inclusion of funding (£115K for England and £20k for Wales 2018/19) to support community groups through the Community Investment Scheme in the new campaign published recently by the Minister is most welcome. This will provide an opportunity to build on the experience within the Living Transplant Initiative which

uses a similar approach. At present, this new funding is on a pilot basis. We know that changing behaviour regarding organ donation takes time and there is a need to continue this work on an ongoing basis. It would be helpful for the Minister to consider funding for supporting community groups as part of the overall campaigning budget on a **longer term** basis. Also, it is important that local BAME community groups who submit good bids are able to access this funding and that large amounts of this funding are not allocated to national charities which may not have effective links with local communities.

5. How can Indian, Hindu and Jain community groups help?

We have some excellent examples of work led by Hindu and Jain groups on organ donation. This is the time for all community leaders to step up and build on what we have done so far. We are in a very good position to do so because:

- Hinduism and Jainism support organ donation and our faith leaders have publicly stated this on many occasions.
- Hindus and Jains are generally positive about organ donation.
- We have examples of excellent practice led by community groups, and these are published so that everyone can learn from them.
- We can now access some funding from the Government to support this work.
- We have excellent resources (videos and leaflets) on organ donation specifically aimed at the Hindu and Jain communities. These have been produced by the community groups, working in partnerships with hospitals and NHSBT, and are available freely (see below).
- We have donor families, living donors and recipients from our communities who are keen to share their stories. I am very pleased that Jay and Sina Patel and Swati Bhagat will be doing so at this meeting.
- Our communities have extended families and hence there are more opportunities for us to find a living kidney donor.

I have been thinking about how ambitious we can be in increasing organ donors from our communities. Clearly, our long term aim should be that no one dies in the UK while waiting for an organ transplant. I wonder if we should consider setting a five year aspirational targets of having 101 living kidney donors and 101 organ donors after death from the Hindu and Jain communities? This would probably more than double the 2017/18 figures. I would urge all Hindu and Jain community leaders to step-up and do all we can to achieve this. We will set aside time towards the end of this event for everyone to make a pledge of what they will do in their community.

6. List of helpful resources

The list below consists of resources I know of and am happy to recommend for use nationally.

BAPS Swaminarayan Sanstha has produced a number of resources aimed at the Hindu community on organ donation.

1. Video on organ donation after death
<https://www.kidney.org.uk/help-and-info/videos/making-a-gift-of-life-possible-organ-donation-and-transplantation-for-hindus/>
2. Leaflet on organ donation after death
<https://www.kidney.org.uk/assets/Uploads/hindu-donor-english-leaflet.pdf>
3. Video on living kidney donation:
<https://www.nhsbt.nhs.uk/get-involved/promoting-donation-hub/download-digital-materials/black-asian-and-minority-ethnic-living-organ-donors/>
4. Leaflet on living kidney donation:
http://londonmandir.baps.org/images/2017/10/LivingOrganDonation_leaflet.pdf

Vanik Council UK has produced a number of resources aimed at the Jain

Community on organ donation.

1. Video on living kidney donation
https://drive.google.com/file/d/1_E8icJGg6f-YsdTEptLhqMzqbPFbemQ/view?ts=5b44cd89
2. Leaflet on living kidney donation:
<https://nhsbt.dbe.blob.core.windows.net/umbraco-assets-corp/6562/living-organ-donation-give-a-gift-donate-a-kidney.pdf>

The **National Kidney Federation** has published a Jain perspective on organ donation after death, following a meeting held at the **Manchester Jain Samaj**.

<http://www.jainology.org/wp-content/uploads/2013/11/Jain-Perspective.pdf>

Jay and Sina Patel have shared their story about donating the organs of their son Aari at

<https://www.youtube.com/watch?v=zYaQVk3levU&feature=youtu.be>

NHSBT has a wide range of very useful resources available from its hub

<https://www.nhsbt.nhs.uk/get-involved/promoting-donation-hub/>
