

Faith leaders united in their support
for organ donation & transplantation

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Findings from the Organ Donation
Taskforce's study of attitudes of UK
faith leaders

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Acknowledgements

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Setting the Context

There are not enough donated organs to save people's lives in the UK. Although over 3,000 people in the UK received an organ transplant in 2007/08, another 1,000 died after having waited in vain on the waiting list, which currently numbers over 8,000 people.

Data relating to organ donor waiting lists and organ donors highlights significant disparities between ethnic groups. For instance, UK Transplant data shows that people of Asian or African-Caribbean descent are three to four times more likely than white people to develop end-stage renal disease, largely because of the higher prevalence of type 2 diabetes

UK Transplant data shows them to make up 23% of the kidney waiting list but 8% of the population. A further concern is that only 3% of donors are from these communities.

Setting the Context

Empirical studies have shown that cultural issues are important influencing factors when making a decision about organ donation. The influence of belief and faith systems is less clear.

Recommendation 13: ‘There is an urgent requirement to identify and implement the most effective methods through which organ donation and the “gift of life” can be promoted to the general public and specifically to the BME population....’ (Organs for Transplants, Organ Donation Taskforce, 2008)

The Organ Donation Taskforce (Presumed Consent) therefore commissioned one-to-one interviews with senior representatives of faith and belief groups.

A total of 17 interviews were conducted by Professor Randhawa (supported by COI).

Faith leaders interviewed

Name	Organisation
Sally Masheder	Network of Buddhist Organisations
Bryan Appleyard	Buddhist Society
Dr Indarjit Singh	Network of Sikh Organisations UK
Jasdev Singh Rai	British Sikh Consultative Forum
Ravinder Singh ¹	British Sikh Consultative Forum
David Katz	Board of Deputies of British Jews
Dr Malcolm Brown	Archbishop's Council of the Church of England
Reverend Debbie Hodge	Churches Together in England
Bishop Joe Aldred	Churches Together in England
Yinka Adeniyi	Freedom's Ark Church
Reverend Katei Kirby	African Caribbean Evangelical Alliance
Reverend Janet Murray	Community Family Challengers Project
Pastor Modupe Afolabi	Redeemed Church of God

Name	Organisation
Sharon Platt-McDonald	Seventh Day Adventist Church
David Jones	Catholic Bishops' Conference of England and Wales
Dr Natubhai Shah	Jain Network
Naomi Phillips	British Humanist Association
Raj Bharkhada	Hindu Forum of Britain
Ramesh Majithia	National Council of Hindu Temples
Ramanbhai Barber	National Council of Hindu Temples
Dr H. V. S. Shastry ²	Hindu Council UK
Malcolm M. Deboo	The Zoroastrian Trust Funds of Europe Incorporated
Mufti Zubair Butt	Muslim Council of Britain
Mohammed Umar	The Ramadhan Foundation
Khurshid Ahmed	British Muslim Forum
Barney Leith ³	Baha'i Community of the UK

¹Attended meeting with Jasdev Singh Rai as an observer

²In addition to attending the interview, Dr Shastry collated responses from other representatives of the Hindu community, which are referenced in this report. These were:

Dr Krishna Mohan Nath Kunzru, Emeritus Consultant Orthopaedic Surgeon, *Whipps Cross University Hospital*

Kishor Ruperalia, World Council Of Hindus

Dr Raj Pandit Sharma, Hindu Priest Association UK and Hindu Council UK

³Views submitted in written format rather than via interview

Key questions asked

- (1) Your faith tradition's position on both donating and receiving of organs.
- (2) Your faith's tradition's position on the current legal system for organ donation - where members of the public need to opt-in, volunteering to become an organ donor;
- (3) Your faith's tradition's position on the proposed legal system for organ donation – opting out, whereby members of the public are assumed to be organ donors unless they have formally opted-out while alive;
- (4) Your advice as to how in the longer term the Organ Donation Taskforce can best engage with your faith community at a local level so that we can ensure grassroots input in the longer term.

Key findings (1)

Views on organ donation

- Diverse views on organ donation exist even within faith groups
- According to interviewees, the majority of faith and belief groups covered tend to allow organ donation
- Whilst the majority of faith and belief groups permit organ donation, and some even have core beliefs which support it, religion was not described as a key influence for people opting in
- The definition of death as brain stem death is an issue in some quarters across a range of faith and belief groups
- Small numbers within different faith and belief groups may have specific objections to the receiving or donating of organs
- Many expressed the view that the decision to donate is a choice for the individual to make, and some felt that it is important to ensure that organs are donated under conditions of informed consent, and not received through trafficking from less developed countries, or from those who have been exploited
- There was recognition that the feelings and wishes of the families must be taken into account

Key findings (2)

Views on the current opt-in system

- The majority of interviewees were positive towards the current opt-in system
- Its key advantage was considered to be that it allows for free choice, and ensures that organs have been donated under conditions of informed consent
- There was recognition that the current system is currently not providing enough organ donors to meet demand, because organ donation is not a priority for most people
- It was also mentioned that there is a reluctance to opt in within some communities, due to a fear that they may receive inferior medical treatment as a result of being on the register
- A further complication raised is that donors do not always inform their families of their wish to donate organs, which can lead to difficult discussions at death
- The majority of interviewees felt that increasing awareness of organ donation and the opt-in scheme will have a positive impact
- Some suggested that there is a need to make opting in simpler and to provide more information about the ways that people can join the register
- One interviewee mentioned a need to increase the transplant coordinator network and for the medical parties involved to be 'in sync' with one another
- Whilst recognising the shortcomings of the opt-in system, the majority of interviewees felt that there is scope to increase the number of donations without a change in legislation

Key findings (3)

Views on the idea of an opt-out system

- The majority of interviewees are opposed to the introduction of an opt-out system. Only three are in favour of a change in legislation (British Humanist Association, Zoroastrians Trust Funds of Europe, Hindu Council UK)
- One key concern expressed by interviewees is that the opt-out system would not allow for personal choice. Whilst some felt that allowing people to opt out does provide a choice, many others were concerned about the difficulty in establishing whether the donor has made an informed decision to donate
- There was particular concern that certain 'hard-to-reach' audiences would not have the information needed to opt out, or that people would simply forget
- There was also a view that introducing the opt-out system is a lazy way to get more organs, and that it may make people feel uncomfortable about opting out
- Many interviewees felt that the opt-out system would alter the relationship between state and individual, and expressed unease about this. It is felt that this system would give the government a level of control which could be abused
- Some also felt that assuming that organs can be used when they have not actively been donated is dehumanising
- Some suggested that introducing opt-out could trigger a backlash in communities

Summary

- The importance of making an informed, personal choice was a strong theme, raised in many interviews. No interviewees described donating, or refusing to donate, as a fundamental condition of their faith or belief. Instead, it was considered that donating is a decision for the individual to make.
- Most interviewees recommended creating an awareness and engagement campaign to encourage people to opt in.
- It was felt that a much greater level of engagement is needed, as organ donation is currently not a priority for many faith and belief groups. There is a need for engagement at local levels in particular, and the route to these communities is often, although not exclusively, via the organisations represented here. It is important to note that there are likely resource implications for this
- Interviewees stressed that ongoing debate was required, and all welcomed the opportunity for ongoing discussion about organ donation

The way forward

- There was widespread recognition of the extent of work required at grass roots level within their communities to encourage donation and a willingness to engage with the Government in this work.
- There was little prior awareness among the interviewees of the leaflets published some years ago setting out the views of some prominent faiths on organ donation. This suggests that written leaflets alone may be ineffective and that other methods of engagement need to be found.
- In order to achieve better engagement on organ donation with members of faith and belief groups in the future, it will be important to continue the dialogue that has begun with these interviews.
- A multifaceted communications strategy is essential which promotes debate concerning organ donation in all faith and belief groups at national and local level.

All the evidence we collected is now available to everyone

400+ pages of supporting evidence, including the systematic literature review and reports of expert working groups is available alongside the main report at

www.dh.gov.uk/organdonationtaskforce

The **KEY MESSAGES**

Faith leaders are united in their support for organ donation

Organ donation could be promoted at national and local level
via faith communities

We must all talk to our family and friends about whether or
not we would wish to donate so that, if asked, they are
clear about our wishes

Visit <http://www.organdonation.nhs.uk>

Or call 0845 60 60 400