

## ORIGINAL ARTICLE

**Faith leaders united in their support for organ donation: findings from the UK organ donation taskforce study**Gurch Randhawa,<sup>1,3</sup> Anna Brocklehurst,<sup>2</sup> Ruth Pateman,<sup>2</sup> Suzannah Kinsella<sup>2</sup> and Vivienne Parry<sup>3</sup>

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**Summary**

This article reports the findings from the one-to-one interviews with the main UK faith and belief leaders, which were commissioned by the Organ Donation Taskforce. Interviews were arranged with the main faith and belief organizations within the UK and covered a range of issues related to organ donation. No faith or belief groups were against organ donation in principle. The interviewees stated that the majority opinion in their faith or belief group is to permit organ donation, with some actively supporting it. Interviewees were keen to stress that there is a broad spectrum of opinions on organ transplantation within each faith and belief group, and that consequently it is difficult to speak on behalf of an entire group. One complication mentioned by interviewees is that as organ transplantation is a relatively new medical procedure, there is no explicit reference to it in many original religious texts. Consequently positions on the receipt and donation of organs are based on interpretation. 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.

**Introduction**

In November 2008, the Organ Donation Taskforce (ODT) published a report 'The potential impact of an opt-out system for organ donation in the UK'. It generated a great deal of debate over several weeks. It is a matter of regret that the position of faith and belief groups on both organ donation and on presumed consent was widely misrepresented in the media. Media reports suggested that Roman Catholics and Muslims were not supportive of organ donation whereas the study interviews illustrated their desire to promote organ donation. This article reports the findings from the one-to-one interviews with the main UK faith- and belief leaders, which were commissioned by the ODT as part of its evidence-gathering exercise. The aim of the interviews was to establish views towards organ donation and opting-in and opting-out among faith and belief leaders (This article focuses on the former issue).

**Background**

The Organ Donation Taskforce was established in 2006 and asked to identify barriers to organ donation and ways to overcome them. Its report 'Organs for Transplant' was published in January 2008 and contained 14 recommendations, which are currently in the process of implementation across the UK. The Taskforce's remit specifically excluded elements of the UK system that would require legislative change and it did not consider the issue of presumed consent. In January 2008, at the request of the Secretary of State for Health, the Rt Hon Alan Johnson MP, the Taskforce was reconvened, with an expanded membership, to consider presumed consent with the following terms of reference:

To establish a special sub-group to examine the potential impact on organ donation of introducing an 'opt-out' or presumed consent system across the UK, having regard to the views of the public and

stakeholders on the clinical, ethical, legal and societal issues, and to publish its findings.

Empirical studies have shown that cultural issues are major influencing factors when making a decision about organ donation [1,2] although the influence of belief and faith systems is less clear [3–8]. This was underlined by a recent study carried out in Birmingham, in which 60% of Muslims, from a wide variety of ethnic backgrounds, said that organ donation was contrary to their faith, when it is not [8]. This situation is not unique to the UK, debates concerning faith and organ donation have been ongoing in many countries within Europe and further afield. Discussion concerning Islamic perspectives has been evolving in recent years in Saudi Arabia and Pakistan [9,10]. Bruzzone [11] provides an eloquent summary of the positive efforts made by His Holiness the Pope in promoting the organ donation debate among Roman Catholics.

There are significant disparities between ethnic groups, which are reflected in the organ waiting lists in the UK. For instance, data from UK Transplant shows that people of South Asian or African-Caribbean descent are three to four times more likely than Caucasian people to develop end-stage renal disease, largely because of the higher prevalence of type 2 diabetes [12–16] and that whilst such groups represent only 8% of the population, they form 23% of the waiting list for kidneys. A further concern is that only 3% of donors are from these communities [17].

Concern about these issues led the Taskforce to include a cultural group amongst the six expert working groups it established to gather evidence and provide advice.

Membership of the Cultural Working Group was drawn from those with expertise in diversity and also organ donation and was chaired by Professor Gurch Randhawa. Its remit was to ‘look at the prevailing attitudes towards organ donation and expression of consent for such organ donation in the many and varied cultural and faith groups in the UK and report on how these could be accommodated in different consent systems’ (www.dh.gov.uk).

## Methodology

### Interviewees

The Taskforce commissioned the Cultural Working Group to gather views on organ donation from a wide range of leading faith and belief organizations. Table 1 presents the list of interviewees, which encompasses a cross-section of the majority of faith and belief groups in the UK.

Although the majority of the organizations interviewed represent faith groups, it is important to recognize that some (e.g. Humanism) are not religions, but belief groups. Consequently, the term ‘faith and belief

**Table 1.** List of interviewees.

Name	Organization
Sally Mashedor	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*	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
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†	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‡	Baha’i Community of the UK

\*Attended meeting with Jasdev Singh Rai as an observer.

†In 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.

‡Views submitted in written format rather than via interview.

groups’ is used throughout the article when referring to the groups collectively. Whilst a faith-based approach was taken in selecting and interviewing the individuals listed below, it should be recognized that some of the issues raised within this report relate to both faith and culture. For many faiths, debate on organ donation is at an early stage and their views thus represent preliminary thoughts on what are complex moral and ethical issues.

### Interview process

Following an initial introductory letter, 17 interviews were arranged with 25 of the individuals listed above. Views from the Baha’i community were submitted in a written format.

The majority of the interviews were conducted as one-to-one sessions. However, group meetings were held where this was the advised course of action.

Interviews were led by Gurch Randhawa, the Chair of the Cultural Advisory Sub-Group, and covered the following topic areas using a semi-structured topic guide:

- Their faith (or belief) group's position on the receiving of organs from transplantation.
- Their faith (or belief) group's position on the donating of organs for transplantation.
- Their faith (or belief) group's position on the current legal system for organ donation, opting-in, whereby members of the public volunteer to become an organ donor.
- Their faith (or belief) group'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 during their lifetime.
- Their advice on UK Transplant's current leaflet explaining their faith's position on organ donation.
- Their advice on how in the longer term the Government can engage with their faith at a local level.

A member of the COI team was also present at each interview to observe and record the interview. The interviews were recorded using a digital recording device. Following each interview, a transcript was sent to each interviewee with an invitation to make any amendments. Qualitative analysis was undertaken to highlight the key themes.

### Terminology

The quantification given reflects the number of interviews in which a view was expressed, rather than the number of individuals holding a view. The individual who responded in written format is referred to as an 'interviewee' throughout, and is included in these quantities. The following expressions are used throughout the report:

- The minority of interviewees = views expressed in less than half of the interviews.
- The majority of interviewees = views expressed in more than half of the interviews.
- Some interviewees = views expressed at a small number of interviews (up to five). This is used where interviewees are expressing views which were not explicitly asked for, and therefore not commented on by other interviewees.
- Many interviewees = views expressed in a large number of interviews (six or more). As above, this is used where interviewees are expressing views which were not explicitly asked for, and therefore not commented on by other interviewees, but in higher volumes.

## Findings

### Views on organ donation

No faith or belief groups were against organ donation in principle. The interviewees stated that the majority opinion in their faith or belief group is to permit organ donation, with some actively supporting it.

*There is no objection to Baha'is either donating their organs or receiving donated organs* (Barney Leith, Baha'i Community of the UK)

*Hinduism has always supported organ donation* (Dr H. V. S. Shastry, Hindu Council UK)

*There is no particular Jewish position on receiving organs. The question is whether the procedure has been validated and shown to be worthwhile and useful in terms of saving and preserving life* (David Katz, Board of Deputies of British Jews)

Many also referred to particular principles of their faith or belief that support organ donation.

*The principle of giving and helping others is understood and applauded* (Dr Indarjit Singh, Network of Sikh Organizations UK)

*We have a commission to seek health and healing* (Dr Malcolm Brown, Archbishop's Council of the Church of England)

*The objective for Jains is to live and to help others to live* (Dr Natubhai Shah, Jain Network)

*The Humanist view is that we only have one life, and therefore it should be as good, fulfilling, healthy and happy as possible. Receiving an organ is life-improving and therefore seen as positive* (Naomi Phillips, British Humanist Association)

*Many references support the concept of organ donation in Hindu scriptures. 'Daan' is the original word in Sanskrit for donation meaning selfless giving. In the list of the 10 'Niyamas' (virtuous acts), 'Daan' comes third* (Dr Raj Pandit Sharma, Hindu Priest Association UK and Hindu Council UK)

Interviewees described a divergence of opinion within the Muslim community, with some scholars permitting, and some forbidding, organ donation.

*I must stress that there is a difference of opinion amongst scholars on this issue* (Mohammed Umar, Ramadhan Foundation)

*There are different views, a wide diversity, within Islam on these issues* (Khurshid Ahmed, British Muslim Forum)

One interviewee stated that where organ donation is forbidden, this is for the following reasons:

*(It is forbidden) first because when an organ has been removed from the body it is deemed to be impure. Second, because of the honor and dignity that belongs*

to man (Mufti Zubair Butt, Muslim Council of Britain)

Another interviewee said that he was unaware of any religious objections to organ donation, but emphasized that he was not an expert on Islamic law.

*I would think that preservation of life is just as important in the Islamic faith as it is in other faiths, therefore donation and receipt would be perfectly permissible... (I am) not aware of anything in Islam which would prohibit the donation of organs (Khurshid Ahmed, British Muslim Forum)*

### Organ donation is a complex issue for many faith and belief groups

Interviewees were keen to stress that there is a broad spectrum of opinions on organ transplantation within each of the faith and belief groups, and that consequently it is difficult to speak on behalf of an entire group.

One complication mentioned by interviewees is that as organ transplantation is a relatively new medical procedure, there is no explicit reference to it in many original religious texts. Consequently, positions on the receipt and donation of organs are based on interpretation.

*The texts were written at the time of the gurus... there was not any discussion about it in those times (Dr Indarjit Singh, Network of Sikh Organisations UK)*  
*There are no explicit references to organ donation in the texts (Malcolm M. Deboo, The Zoroastrian Trust Funds of Europe Incorporated)*

Furthermore, it was highlighted that some objections to organ donation for particular faith and belief groups may not arise from the religion itself, but from cultural beliefs.

It seems that knowledge of organ donation, and the position of one's own faith or belief group towards it, is low in some communities, and extends even to religious leaders, possibly because it is currently not high on the agenda for many groups.

*If you spoke to Sikhs on the street, you would get a whole mix of responses, because there is quite a lot of ignorance about the religion itself (Dr Indarjit Singh, Network of Sikh Organisations UK)*

*Generally the Hindus do not know all the doctrines of the Hindu Dharma, the spiritual core of their religious contents. If you asked a common Hindu about any specific issue like the present one, they might want you to check with professionals (Dr H. V. S. Shastry, Hindu Council UK)*

*If they (consult a priest), the priest would probably not be that familiar with the issue (organ donation)*

(David Jones, Catholic Bishops' Conference of England and Wales)

Finally, it was mentioned that views on organ donation can change when people are confronted with death. *The default option moves to the 'religious right' close to death. People who may not be that observant will suddenly become very observant (David Katz, Board of Deputies of British Jews)*

### Opting-in or opting-out

The majority view amongst interviewees was against a change in legislation (see Table 2). Some were only slightly opposed, whereas some expressed strong opposition to the opt-out system.

### Suggested approaches to long-term engagement on organ donation with faith and belief groups

*More engagement is needed*

Many interviewees said that the organizations they were representing had had little or no contact with the authorities about organ donation before this interview, but all are open to future engagement.

It was mentioned that organ donation is currently not a priority for some groups, and it is felt that the debate needs to be initiated.

It was also felt that that any engagement needs to be ongoing if it is to be effective.

*Like any learning, it is not enough to hear a lecture once... You can be inspired by one talk, but you will lose the inspiration over time (Dr Indarjit Singh, Network of Sikh Organisations UK)*

*Need to take two or three steps back. Rather than saying – this is what we want to do, this is the opinion we want you to have, and can you support us – instead, we need to ask them what they think, and have a drawn-out conversation. Then I think there would be movement (Mufti Zubair Butt, Muslim Council of Britain)*

One interviewee suggested that a variety of types of communication would be needed to convey the message effectively.

*It is also very difficult to reach all Hindus across the country; hence we would have to try many means and measures. No one source would be enough to reach all Hindus (Dr H. V. S. Shastry, Hindu Council UK)*

*There is a need to engage at a local level*

It was felt that engaging with people at a local level via events and meetings would be most effective. It was suggested that religious centers such as churches and gurdwaras would be a good route for engagement.

**Table 2.** Summary of positions on opt-in and opt-out systems.

	Opt-in			Opt-out			Remarks
	Supportive	No issue	Concerns	Supportive	No issue	Concerns	
B. Appleyard, Buddhist Society	X					X	In favour of retaining opt in
Dr M. Brown, Archbishop's Council of the Church of England*	X					X	
Mufti Z. Butt, Muslim Council of Britain	X					X	
D. Jones, Catholic Bishops' Conference of England and Wales	X					X	
D. Katz, Board of Deputies of British Jews	X					X	
S. Mashedier, Network of Buddhist Organisations	X					X	
British Sikh Consultative Forum	X					X	
Dr I. Singh, Network of Sikh Organisations UK	X					X	
M. Umar, The Ramadhan Foundation	X					X	
Black Majority Churches†	X					X	
Hindu Forum of Britain and National Council of Hindu Temples	X					X	
B. Leith, Baha'i Community of the UK		X			X		No issues with either system
Dr N. Shah, Jain Network		X			X		
K. Ahmed, Muslim Forum of Britian		X			X		
Rev. D. Hodge (DH), Churches Together in England			X			X	Concerns about both systems
N. Phillips, British Humanist Association			X	X			In favour of introducing opt out
M. M. Deboo, The Zoroastrian Trust Funds of Europe Incorporated	X			X			
Dr H. V. S. Shastry, Hindu Council UK	X			X			

\*It should be noted that whilst the representative of the Archbishop's Council of the Church of England interviewed tended towards retaining the existing system, the submission to the House of Lords inquiry states that:

*"Whether organ donation should be arranged through an 'opt-in' or an 'opt-out' system is not a question on which Christians hold a single set of views"*

†This was a group meeting. One person was in favour of opt-out, with the other attendees in favour of continuing with the existing system.

We would need to arrange local events with national support and coordination. We would need to engage with regional gurdwaras, or clusters of gurdwaras (Dr Indarjit Singh, Network of Sikh Organisations UK)

In order to engage the Sikh community, it was also recommended that local statutory and nonstatutory bodies be encouraged to work together.

Engagement via community leaders, schools, Connexions centres and Sure Start centres were also suggested.

One interviewee felt that it would be useful for Department of Health representatives to be present at these meetings, whilst another suggested that the initial approach would be best made by a faith figure.

#### *Greater resources will be needed to achieve greater engagement*

Some organizations said that they do not currently have enough funding, and that financial support from the Government would enable them to communicate more effectively with their respective communities. Additional

resources would be used to employ more part-time staff, to respond to consultations and to produce materials.

Organizations like the Network of Sikh Organisations UK, which were set up voluntarily to look across the whole range of inter-faith life in the UK, are being run on a shoe string (Dr Indarjit Singh, Network of Sikh Organisations UK)

If the Government were asking churches to engage communities, finance and resources would be helpful (Reverend Janet Murray, Community Family Challengers Project)

I think if the objections are more likely to come from a religious context, then faith communities should be encouraged to campaign and should be supported financially to campaign (Khurshid Ahmed, British Muslim Forum)

## Discussion

No faith or belief groups were against organ donation in principle. 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. 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 organizations represented in these interviews. 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.

## Conclusion

For many faiths the one-to-one interviews, which were conducted at times and in places convenient to them, were the first opportunity that they had had to engage with the issue of organ donation. 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 was underlined by a recent study carried out in Birmingham, in which 60% of Muslims, from a wide variety of ethnic backgrounds, said that organ donation was contrary to their faith, when it is not [8]. When the low level of donations from within certain groups was outlined, it came as a surprise to some of the interviewees who had not been aware of this. It was a concern for all, given the higher level of need in particular ethnic groups. In all of the interviews, 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. It was recognized that leaflets alone would not be an effective solution.

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 engagement that has begun with these interviews. This process has already begun with the Department of Health commissioning the lead author (GR) to build upon the initial meetings and scope out precisely the manner in which the faith organizations can assist in promoting organ donation at national and local level. A multifaceted communications strategy is essential. It is important not only for the public to be aware of the position faith and belief leaders take in wishing to support organ donation, but also just as important for the medical profession and policy makers to recognize that all UK faith and belief

leaders interviewed wish organ donation and transplantation to be a success.

## Authorship

GR: designed the study, co-developed the interview schedule; conducted the interviews; assisted with writing up of results. AB, RP, SK: co-developed the interview schedule; assisted with the interviews; analysed findings; wrote up results. VP: assisted with design of study, assisted with writing up of results.

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