The potential impact of an opt out system for organ donation in the UK
A report from the Organ Donation Taskforce

SUPPORTING INFORMATION

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(Cultural Working Group Report)
Including
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Appendix A : Membership
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ANNEX M

REPORT OF THE ‘CULTURAL’ WORKING GROUP OF THE ORGAN DONATION TASKFORCE ON PRESUMED CONSENT

1. INTRODUCTION

1.1 The Terms of Reference of the Cultural Working Group of the Organ Donation Taskforce were to look at prevailing attitudes to organ donation and consent in the many and varied cultural and faith groups within the UK and report on how these could be accommodated in different consent systems, including “hard” and “soft” opt out systems, and other alternative approaches to consent that might be achieved without a change to the legal basis.

1.2 In doing so, the group would:
   - identify key concerns of different groups and ethnic backgrounds and whether these could be met by appropriate safeguards in legislation or codes of practice
   - evaluate the level of acceptance and/or resistance amongst various groups and ethnic backgrounds within society across the UK
   - advise on whether an opt out system would need to include the capability for “presumed opt out” for certain groups (e.g. religious faiths known to object to removal of organs)
   - consider what stops people “opting in” at the moment and whether these barriers could be addressed by an “opt out” system.

2. MEMBERSHIP

2.1 A list of the membership is at Appendix A.

3. METHODOLOGY

3.1 The work of the Group was organised as follows:

   - assembling a membership with the range of specialist knowledge and skills necessary to provide sound advice on these complex questions
   - formal meetings of the Group. The Group met four times.
   - structured interviews with representatives of a number of faith and belief groups.
4. **The Group’s Focus**

4.1 At its first meeting, the Group agreed that a significant body of empirical evidence had already been compiled about the views of the public towards organ donation. This had been submitted to the Taskforce in 2007 as part of its work on how to increase donor rates within the existing legal framework. Additionally, the attitudes of members of the public more generally towards organ donation and opting in and opting out were being established by the Taskforce through a number of deliberative events around the UK.

4.2 The Working Group was mindful that data relating to organ donor waiting lists and organ donors highlighted significant variation between people from different ethnic backgrounds. Empirical studies had shown that both faith and cultural issues were important influencing factors for individuals when deciding to become organ donors or not. The Working Group acknowledged the importance of both factors and recognised that it is often impossible to disentangle one from the other. However, to make the most effective use of the time available to the Working Group, it focussed on how best to engage with faith and belief communities.

4.3 The Working Group agreed that there were a number of challenges in engaging with the different “communities” that make up the UK’s population. The Working Group agreed that before there could be a worthwhile discussion about different consent systems, it would first be necessary to start with engagement on organ donation more generally.

4.4 To help understand how people from different ethnic backgrounds and faith and belief groups within the UK viewed organ donation and how they would feel about a change to the current consent system for organ donation, the Group asked the Department of Health to commission preliminary interviews with senior figures from a number of faith and belief groups. The list of groups was drawn largely from the Faith Communities Consultative Council which had provided valuable input to the work of the Commission on Integration and Cohesion.

4.5 The Working Group felt that the views of each body should be sought sequentially on the following issues:

- the receipt of donated organs
- the donation of organs
- consent systems/models

The Working Group recognised that the views expressed at the meetings would provide a preliminary ‘snapshot’ picture and that continued long-term dialogue was required in order to ascertain a more considered view from people of different faiths and beliefs.
4.6 The Department of Health agreed to fund the interviews which were conducted by the Chairman of the Working Group with support from the Central Office for Information (COI). A copy of the discussion guide used for these interviews is at Appendix B.

5. FINDINGS

5.1 A report compiled by COI setting out the comprehensive findings of the interviews with senior figures in faith groups is at Appendix C. Key findings from the interviews are summarised below:

**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

**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

Views on the idea of an opt out system

• The majority of interviewees were opposed to the introduction of an opt out system. Only three were in favour of a change in legislation, and a further three mentioned no objections with either system.

• 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 a person who has not opted out 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 was 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.

• The majority of interviewees assumed that the opt out system would result in more organs being available, and saw this as the key, and in many cases, the only advantage.

• If opt out were introduced, most felt that the ‘soft’ model, whereby organs are not used if relatives object, would have to be used. It
would also have to be ensured that the family were not inconvenienced in any way (for example by having to wait longer to hold a funeral).

- In the case of a change in legislation, it was agreed that a lot of work would need to be done to ensure that everyone knew about the system, and how to opt out. It would also be important to ensure that people were not made to feel uncomfortable about opting out.

5.2 We considered evidence from two community-based projects. A report on the “Being a Donor” project conducted by the Policy Research Institute on Ageing & Ethnicity (PRIAE) is at Appendix D. This project established a grassroots education campaign in Leeds, London and Manchester to increase the numbers of blood, bone marrow and organ donors from the South Asian, African Caribbean and Chinese communities. The main attitudes and barriers expressed by these communities on being a donor were:

- **Fear**, e.g. having a fear of needles and mutilation of the body. Body/image was raised as being important to the African Caribbean communities

- **Ignorance** and naivety about what it means to be a donor, e.g.
  - there is no age limit to donating organs.
  - people don’t realise there are two different ways to extract bone marrow, or that there are a number of tests carried out on blood before it is used, or you can be a blood donor up to the age of 66. People believe providing this information may increase the number of blood donors from the BME communities.
  - some believe that not everyone can give blood, for example immigrants from third-world countries.
  - There is some controversy within people’s understanding of religion about people being able to donate. For example, different sub groups within the Islamic/Muslim community have different schools of thought, which may lead to confusion, as one will say being a donor is acceptable and others will argue against the point. Or, culture can be more of an obstacle as apposed to religion, as people may be influenced by cultural factors and say it’s due to faith.

- **Lack of trust** with the professionals, e.g. some people felt that there might be incentives for medical staff not to resuscitate patients to obtain their organs.

- **Racism** towards the African Caribbean communities. This issue was raised in all three African Caribbean events. The messages included: “The need for blood, tissue, bone marrow and organs is a white middle-class issue” and “People have long memories. In the
1960s people from the black community were turned away when they wanted to donate blood”.

- Death is a **taboo subject** and is not discussed within families. This was raised as an issue within the Chinese community.
- **No relevance** or significance. People who feel socially excluded also feel “what has this got to do with me – I’m not important.” Many said people don’t have the time to donate (e.g. blood or bone marrow) and don’t think it is important to them.

5.3 A study by a team from Imperial College, London, explored how people from three ethnic backgrounds (British/Irish white, African Caribbean and South Asian), who were positive or ambivalent about organ donation, integrated the concept into their life. A summary of their findings is attached at Appendix E. This project, called “Becoming an Organ Donor: oral histories of people from three ethnic backgrounds”, suggests there is a need to:

- develop campaigns that create a **social narrative** that begins to **outweigh** people’s fears and beliefs about organ donation and what comes after death.
- Make recipients and donors more visible in everyday social environments.
- Support social environments where people can learn through discussion and real interaction how they may be able to integrate a biomedical understanding of the body into their beliefs.
- Understand better how, when and where we should educate young people about organ donation.
- Publicise, alongside the call for donors, those working to save the potential donor’s life.
- Simplify information to address key fears or concerns.
- Seriously engage with a political identity addressing concerns of trust, alienation and equality within the whole medical system, and not just organ donation, for those from an African Caribbean ethnic background.

5.4 Evidence from community-based studies and the deliberative events with members of the wider public commissioned by the Taskforce suggests that people of all backgrounds and faiths or beliefs share a common lack of awareness about organ donation, and have similar fears and misconceptions. There are however particular issues for some communities relating to alienation and experiences of racism that go beyond the realm of organ donation.

5.5 Key themes emerging from the various sources of information we considered are:
• Many people have little or no understanding of the process of organ donation. A certain level of understanding and awareness is very important because attitudes towards organ donation might be influenced by some of the technical aspects involved in donation, for example, the relatively short period of time available to retrieve organs from the donor following death.

• Most people are not engaged with the current consent system. People are unaware of the urgency or need for organ donation. The relatively low level of donation from some ethnic backgrounds is of particular concern because of the higher level of need for organs from people of the same ethnic background.

• The reasons for the lack of engagement with the current system are complex and varied. Reasons include a reluctance to discuss mortality issues, a lack of trust in the medical profession, fears surrounding the possible mutilation of the body, an inability to relate to the concept of gifting for the benefit of strangers and/or “society”, fears of racism and perceptions that organ donation was contrary to religious teachings.

6. CONCLUSIONS AND RECOMMENDATIONS

6.1 An opt out system could possibly “capture” those unmotivated to opt in, but who believe in the idea of organ donation. Indeed, it is probably easier to motivate people to opt out than to opt in. This is because the motivation to opt out will stem from the individual’s values and beliefs about organ donation, rather than external stimuli (for example advertising) that attempt to encourage people to change their behaviour. Should an opt out system be introduced, resources may be best directed both at understanding the reasons why people have opted out and addressing their concerns, and at making sure people are fully aware of the opt out system.

6.2 The evidence from the interviews with senior figures from faith and belief groups suggest that most faith leaders would not support a change to an opt out system, for a variety of reasons. In general, they feel that an opt in system is preferable as it respects individual choice and avoids potentially negative perceptions about a shift in the balance of power between individuals and the state raised by an opt out system. There was a strong consensus that it was premature to consider changing the law when the current system had not been given sufficient attention. For example:

“The question is of personal autonomy, and being able to make decisions for yourself. So for me, we should stay with the opt in” (Mufti Zubair Butt, Muslim Council of Britain)

“Why do we have to go through a process that provokes a profound sense of unease, when other routes of recruitment have not been pushed as hard as they might?” (Sally Masheder, Network of Buddhist Organisations)
6.3 Some clearly fear that introducing an opt out system could provoke negative reactions from some communities and provide a platform for organ donation sceptics to become more vocal. Comments included:

“I would think that you may see a backlash with increased opt out, not only in the Jewish community but also from other communities” (David Katz, Board of Deputies of British Jews)

“It would up the stakes for people who are sceptical. Currently those who are sceptical are happy to grumble on sidelines. It is likely to precipitate an anti-organ transplant movement that doesn’t exist now” (David Jones, Catholic Bishops’ Conference of England and Wales)

6.4 The representatives interviewed are, in general, supportive of organ donation in principle, and express a willingness to help engage with grass-roots members to raise awareness about organ donation and address fears and concerns.

6.5 On the basis of the evidence we have considered, we feel the concerns of people from some ethnic minorities and faith and belief groups would be better addressed within an opt in system. Many cultural groups have not yet engaged with the existing opt in system, and the majority of faith and belief groups are not positive about a move to opt out. Much more work at both a national and grassroots level to address people’s personal, cultural and religious fears can and needs to be done to raise the level of awareness about organ donation and transplantation and the urgency for more organ donors in this population. To introduce an opt out system now could be detrimental to encouraging organ donation in this population.

Recommendations for future activity

6.6 Whatever system is ultimately chosen we feel that it is necessary to have a multi-faceted, sophisticated and properly funded long-term communication strategy for engaging members of the UK’s multi-ethnic and multi-faith population on this issue. For example, peer educators from particular communities can give face-to-face talks about the need for more donors. Meeting donors and recipients and face-to-face discussions with people from the same cultural and ethnic backgrounds have been shown to be effective ways of reaching out to people about organ donation. This is because this technique allows people the opportunity to discuss these issues in a way which is meaningful to them and allows them to make emotional connections with the concept of organ donation.

6.7 In addition, more collaborative research between academics, market researchers and advertising consultants needs to be done on creating effective and evidence based national advertising campaigns that deal with people’s motivations and fears about organ donation – such as the
fear of racism expressed by people of African Caribbean ethnic descent. Such campaigns also need to convey the urgency for donors through showing the real possibility that the need for an organ may one day be a reality for the viewer of the advert and/or a member of their family.

6.8 A dialogue has now begun with some key faith and belief groups. It is essential that this continues as part of the implementation of Recommendation 13 of the Organ Donation Taskforce’s report Organs for Transplant. Continued engagement is imperative to raising awareness of organ donation and sustaining trust between the public and the Government.
Appendix A

Members
Gurch Randhawa, Professor of Diversity in Public Health, University of Bedfordshire (Chairman)
Robert Dunn, National Advocacy Officer, National Kidney Federation
Mark Johnson, Professor of Diversity in Health & Social Care, De Montfort University
Myfanwy Morgan, Reader in Sociology of Health, King's College, London University
Glenn Smith, Research Fellow, Imperial College, London University
Steve Bell, Transplant Co-ordinator
Yolande Watson, Manager of "Being a Donor" Project for Policy Research Institute for Ageing and Ethnicity
Sunita Berry and Rebecca Lloyd, Equality and Human Rights Group, Department of Health
Chris Watson, Consultant Transplant Surgeon, Cambridge

Observer
Harriet Crabtree, Director Inter-Faith Network for the UK
Organ Donation Taskforce: Listening to the voices of faith groups in the Organ Donation Debate

Discussion Guide

A. Your views on organ donation
   - What is your faith’s position on receiving organs?
     - For all people
     - For members of your faith group
   - Are there any conditions attached to receiving organs? What are they?
   - What is the position on receiving organs at a grass roots level? Does this vary from the official positioning? How?
   - What is your faith’s position on donating organs
     - For all people
     - For members of your faith group
   - Are there any conditions attached to donating organs? What are they?
   - What is the position on donating organs at a grass roots level? Does this vary from the official positioning? How?

B. Your views on the current ‘opt in’ system
   - What is your faith’s position on the current ‘opt in’ system, whereby members of the public need to opt in, or volunteer, to become a donor?
   - What are the advantages of this system?
   - What are the disadvantages of this system?
   - Does this pose any particular issues for your faith? What are they?

C. You views on the idea of an ‘opt out’ system
   - What is your faith’s position on the idea of an ‘opt out’ or ‘presumed consent’ system, whereby members of the public are assumed to be donors unless they have formally opted out whilst alive?
   - What would the advantages of this system be?
   - What would the disadvantages of this system be?
   - What impact (if any) do you think introducing this system would have on the volume of donations?
   - And if it did not have this impact, how would your views change?
   - Does this pose any particular issues for your faith? What are they?
   - What response would you expect to this system at a grass roots level?
   - Would any conditions need to be in place? What would they be?
D. Other options to raise organ donation and transplant rates

- What other ways are there for government to raise organ donation and transplant rates (prompt for 14 recommendations)?
- What would be the advantages and disadvantages of these options?

E. UK Transplant Materials

- How successful is the UK Transplant leaflet explaining your faith’s position on organ donation in terms of the following?
  - Information
  - Clarity
  - Tone
  - Provision
  - Anything else

F. Long term engagement with your community

- How would you describe the current level of engagement between the Organ Donation Taskforce and your faith community at a local level?
- How could it be improved?
- What is the best way to engage with your faith community at a local level?
  - With who?
  - Via what means?
  - How often?
  - About what?
The potential impact of an opt out system for organ donation in the UK
A report from the Organ Donation Taskforce

SUPPORTING INFORMATION

ANNEX M
(Cultural Working Group Report)
APPENDIX C
(Listening to the Voices of Faith and Belief Groups in the Organ Donation Debate - Full Report)
Organ Donation Taskforce

Listening to the Voices of Faith and Belief Groups in the Organ Donation Debate

Prepared for:
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Date: 10th October 2008
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1. Introduction

The Organ Donation Taskforce (ODT), an independent panel of legal, ethical, medical and communications experts and patient representatives, was established in 2006 to recommend actions to increase levels of organ donation within the current legal framework. In their report published in January 2008, “Organs for Transplants”, the ODT makes 14 recommendations that could increase levels of organ donation by 50% within 5 years, resulting in an additional 1,200 transplants a year. The government has accepted these recommendations and implementation is underway.

The ODT’s report focused on what is possible within the UK’s current legal framework. Prompted by the Chief Medical Officer’s (CMO) recommendation in his annual report for 2006 to redraw the legal framework to allow for the introduction of an opt-out system, the Secretary of State for Health, Alan Johnson, asked the ODT to stay on and examine the issues raised by the CMO under 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.”

Recognising the complex range of issues and widely differing viewpoints surrounding different systems of consent, the Secretary of State asked the ODT to look at a range of relevant issues. In response to this, the Taskforce has established Expert Working Groups to advise on the following areas:

- Cultural
- Practical
- Clinical Practice
- Legal
- Ethics
- Communications

The Cultural Advisory Sub-Group comprises a range of experts in the fields of organ donation and diversity. The remit of this Group is to “look at prevailing attitudes to organ donation and consent 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)

The Cultural Advisory Sub-Group asked the Central Office of Information (COI) to gather views on the issue of organ donation from around 20 different faith and belief organisations to feed into the final ODT report.

The findings from this work are contained within this report.
2. Methodology

2.1. Interviewees

Interviewees were selected based on the Faith Communities Consultative Council list, supplied by the Department for Communities and Local Government. This list includes the main faith and belief groups in the UK. A decision was taken to interview two further organisations: The Ramadhan Foundation and the Catholic Bishops’ Conference for England and Wales.

The Ramadhan Foundation was included in the study as a result of recent press articles about organ donation, which were attributed to them. The Catholic Bishops’ Conference for England and Wales was included on the recommendation of another interviewee, and to ensure that the Catholic perspective was considered.

The Baha’i Community of the UK were invited to interview, but chose to send their views in written format.

One organisation representing the Jewish community, the Board of Deputies of British Jews, was covered. The Board is a representative umbrella organisation linking most of the Jewish community, apart from the more observant groups. The member interviewed here has been responsible for the recent co-ordination of the Jewish community submissions to the House of Lords Select Committee on this topic, which have included consultations with the Office of the Chief Rabbi. An additional meeting with members of the more observant part of the community, who had not been consulted officially, was suggested, but it was not possible to schedule this meeting within the necessary timeframe.

It should be noted that interviewees gave some views as representatives for their organisations, and others as individuals, either because there is no central viewpoint on organ donation within their faith or belief group, or because they were offering a personal opinion, or a combination of the two factors. When representing organisations, interviewees were keen to stress that the views they expressed would not necessarily be held throughout the faith or belief community.

It should also be recognised that the individuals interviewed here are not a fully representative sample of faith and belief groups in the UK, and that debate on the issue of organ donation is at an early stage for many organisations. For some organisations these interviews represented the first contact they had had with the ODT, and the views given are initial thoughts concerning a complex range of moral and ethical issues.

Finally, it is important to highlight that whilst a faith-based approach was taken in selecting and interviewing the individuals listed below, it is recognised that some of the issues raised within this report relate to both faith and culture.
The full list of interviewees is below:

<table>
<thead>
<tr>
<th>Name</th>
<th>Organisation</th>
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<tbody>
<tr>
<td>Sally Masheder</td>
<td>Network of Buddhist Organisations</td>
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<td>Bryan Appleyard</td>
<td>Buddhist Society</td>
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<td>Dr Indarjit Singh</td>
<td>Network of Sikh Organisations UK</td>
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<td>Jasdev Singh Rai</td>
<td>British Sikh Consultative Forum</td>
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<tr>
<td>Ravinder Singh¹</td>
<td>British Sikh Consultative Forum</td>
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<td>David Katz</td>
<td>Board of Deputies of British Jews</td>
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<td>Dr Malcolm Brown</td>
<td>Archbishop’s Council of the Church of England</td>
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<td>Reverend Debbie Hodge</td>
<td>Churches Together in England</td>
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<td>Bishop Joe Aldred</td>
<td>Churches Together in England</td>
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<tr>
<td>Yinka Adeniyi</td>
<td>Freedom’s Ark Church</td>
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<tr>
<td>Reverend Katei Kirby</td>
<td>African Caribbean Evangelical Alliance</td>
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<tr>
<td>Reverend Janet Murray</td>
<td>Community Family Challengers Project</td>
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<tr>
<td>Pastor Modupe Afolabi</td>
<td>Redeemed Church of God</td>
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<tr>
<td>Sharon Platt-McDonald</td>
<td>Seventh Day Adventist Church</td>
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<tr>
<td>David Jones</td>
<td>Catholic Bishops’ Conference of England and Wales</td>
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<td>Dr Natubhai Shah</td>
<td>Jain Network</td>
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<td>Naomi Phillips</td>
<td>British Humanist Association</td>
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<td>Raj Bharkhada</td>
<td>Hindu Forum of Britain</td>
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<td>Ramesh Majithia</td>
<td>National Council of Hindu Temples</td>
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<td>Ramanbhai Barber</td>
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<tr>
<td>Dr H. V. S. Shastry²</td>
<td>Hindu Council UK</td>
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<tr>
<td>Malcolm M. Deboo</td>
<td>The Zoroastrian Trust Funds of Europe Incorporated</td>
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<td>Mufti Zubair Butt</td>
<td>Muslim Council of Britain</td>
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<tr>
<td>Mohammed Umar</td>
<td>The Ramadhan Foundation</td>
</tr>
<tr>
<td>Khurshid Ahmed</td>
<td>British Muslim Forum</td>
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<tr>
<td>Barney Leith³</td>
<td>Baha’i Community of the UK</td>
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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
2.2. Process

Following an initial introductory letter, 17 interviews were arranged with 25 of the individuals listed above. Views were gathered from a further individual in written format.

The majority of the interviews were conducted as 1:1 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:

- 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.

2.3. House of Lords submissions

A number of the organisations interviewed as part of this study had sent responses to the House of Lords ‘Inquiry into the EU Commission’s Communication on Organ Donation and Transplantation: policy actions at EU level’. These were:

- Board of Deputies of British Jews
- British Humanist Association
- British Sikh Consultative Forum
- Church of England Mission and Public Affairs Division

These submissions have been studied and the views expressed taken into account in this report.
2.4. Timings

The interviews were conducted between 9th June and 26th August 2008 at locations chosen by interviewees.

2.5. Language

Whilst the majority of organisations interviewed to prepare this report represent faith groups, it is important to recognise that some (e.g. Humanism) are not religions, but belief groups. Consequently, the term ‘faith and belief groups’ is used throughout the report when referring to the groups collectively.

As noted in 2.2, most interviews were conducted as 1:1 sessions, but some were held as group meetings. When indicating how widely views were held, quantities given reflect 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 5). 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 (6 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

The spelling ‘gurdwara’ (which means the House of God, and refers to a Sikh place of worship), rather than the alternative ‘gurudwara’, is used throughout the report, although both spellings were used by interviewees.
3. Executive summary

- The majority of interviewees are supportive of the opt-in system, and favour retaining it over introducing an opt-out system. Whilst the shortcomings of the opt-in system are recognised, the majority felt that there is scope to make improvements without changing legislation.

- 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. This was considered to be a key advantage of the current opt-in system, and there was some concern that an opt-out system may remove this freedom of choice.

- If an opt-out system were introduced, it would only be acceptable for most if the ‘soft’ opt-out system were used, whereby even if a person has not opted out, their organs will not be used if there are objections from a relative.

- If the opt-in system is retained, most interviewees recommended creating an awareness and engagement campaign to encourage people to opt in. If an opt-out were introduced, an extensive awareness campaign was considered to be essential.

- 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.
4. Findings

4.1 Summary

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

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
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, and a further three mentioned no objections with either system.
- 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.
- The majority of interviewees assumed that the opt-out system would result in more organs being available, and saw this as the key, and in many cases, the only advantage.
- If opt-out were introduced, most felt that the ‘soft’ model, whereby organs are not used if relatives object, would have to be used. It would also have to be ensured that the family were not inconvenienced in any way.
- In the case of a change in legislation, it was agreed that a lot of work would need to be done to ensure that everyone knew about the system, and how to opt out. It would also be important to ensure that people were not made to feel uncomfortable about opting out.

4.2. Views on organ donation

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 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.

“The texts were written at the time of the gurus... there wasn’t 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)

“The representatives of the community, even in the religious sphere, are not necessarily trained in religious doctrine” (Jasdev Singh Rai, British Sikh Consultative Forum)

“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)

The majority opinion in most faith and belief groups tends to allow organ donation

The majority of 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 Organisations 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)

“Preservation of life is considered to be important, and most Hindus welcome the concept of organ donation” (Hindu Forum of Britain and National Council of Hindu Temples)

“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 ten ‘Niyamas’ (virtuous acts), ‘Daan’ comes third” (Dr Raj Pandit Sharma, Hindu Priest Association UK and Hindi Council UK)

“Zoroastrians consider the concept of death as evil…The purpose of creation in Zoroastrianism is to assist God to defeat evil. Thus Zoroastrians see themselves as warriors of good fighting evil, therefore they are pro-life and pro-organ donation because by donating their organs another life of a warrior can be extended, who in turn will continue to fight the good battle against evil” (Malcolm M. Deboo, The Zoroastrian Trust Funds of Europe Incorporated)

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) firstly because when an organ has been removed from the body it is deemed to be impure. Secondly, because of the honour and dignity that is due to man” (Mufti Zubair Butt, Muslim Council of Britain)

Another interviewee said that he was unaware of any religious objections to organ donation, but emphasised 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)

Grass-roots perceptions that organ donation is forbidden exist even where the faith or belief allows it

Two interviewees from the Muslim community mentioned a perception at grass-roots level that organ donation is not permitted even where scholars have permitted it.

“The majority of Muslim scholars have now given the opinion that it (organ donation) is permissible. It is about educating the grass-roots people” (Mohammed Umar, The Ramadhan Foundation)

“There is a very strong perception in that community (which the majority of Muslims in the UK belong to) that you should not tamper with the body, and that it should return to the Almighty in the form it came in” (Khurshid Ahmed, British Muslim Forum)

A further interviewee from the Hindu community mentioned that an uncertainty at grass-roots level about whether Hinduism allows organ donation results in people choosing not to donate.

“They are not sure; so, to be on the safer side, they might say no to donate” (Dr H. V. S. Shastry, Hindu Council UK)

Faiths or beliefs may not be key drivers of personal decisions about organ donation

It is interesting to note that whilst interviewees stated that the majority of faith and belief groups do not forbid organ donation, they also do not appear to actively encourage it. Faith or beliefs were not described as a key driver for people to opt in.

“In reality, the current situation is a long way from ministers telling their communities it (organ donation) is a ‘good thing’” (Bishop Joe Aldred, Churches Together in England)

On the other hand, another interviewee did not feel that faith is a key reason for people not to opt in.

“The hypothesis is that this is due to religious scruples in the Jewish and Muslim communities, but I am not sure that this is correct” (David Katz, Board of Deputies of British Jews)

The definition and diagnosis of death is problematic for some faith and belief groups

Whilst the majority view permits organ donation, a number of concerns were mentioned.
The definition of death is controversial for some, with interviewees reflecting scepticism about brain stem death in some quarters of Buddhist, Christian and Jewish communities.

“*The issue of brain stem death is still highly controversial amongst those who interpret Jewish law*” (David Katz, Board of Deputies of British Jews)

“*There is an anxiety in some quarters that hasn’t surfaced, but is bubbling under the surface, and that is about the definition of death*” (David Jones, Catholic Bishops’ Conference of England and Wales)

“One particular Tibetan group had great unease about the disturbing of the body in the hours after death (or what in Western medicine would be recognised as death) and would dispute the definition of brain stem death” (Sally Masheder, Network of Buddhist Organisations)

Concern about the diagnosis of death for some people within Christian and Sikh communities was also reflected.

“There is an underlying concern about the medical expertise in determining whether someone has died, or can no longer live, and how fully this is considered by doctors” (Dr Indarjit Singh, Network of Sikh Organisations UK)

Members of some faith and belief groups may have particular objections to organ donation

Concern about interrupting a cycle

One interviewee mentioned that some Hindus may have concerns about receiving or donating an organ as this could interrupt the cycle of reincarnation.

“*By passing your organs on and prolonging another life and therefore interrupting the cycle (of reincarnation) that Hindus believe in, there could be some issues for some people. The religion would not tell people that it is against organ donation, but it would say that there may be implications for the person living or dying*” (Raj Bharkhada, Hindu Forum of Britain)

Another respondent from the Hindu community mentioned a belief amongst some that if they donate an organ in this life, they cannot be liberated from the cycle of reincarnation until it is returned, but considered this view to be erroneous.

“A minority of misinformed Hindus assert that if an individual should donate an organ such as a liver in one life, then they would have to return in another to be repaid the favour by the recipient. This notion is erroneous and though the belief in ‘karma’, or cause and effect, means that our actions in one existence may have repercussions in the next, this single altruistic act of ‘jeevan daan’ (the gift of a life) would verily grant success towards ‘moksha’ or liberation from the cycle of birth, death and rebirth for the willing donor” (Dr Raj Pandit Sharma, Hindu Priest Association UK and Hindu Council UK)

Reluctance to prolong life artificially

Some interviewees mentioned that members of some faith and belief groups may not wish to receive an organ as this would prolong their lives.
“A strong oral culture of divine healing (in Black Majority Churches) would impact on many people’s views” (Bishop Joe Aldred, Churches Together in England)

“Many of the more profound practitioners of Buddhism would not seek to extend their lives by the receipt of organs… on the grounds that the life they have led is the life they have led, and the death they will die is the death they will die” (Sally Masheder, Network of Buddhist Organisations)

The body must remain intact after death
Interviewees mentioned that small numbers of particular faith and belief groups believe that the body needs to remain intact after death.

One interviewee stated that some Zoroastrians would believe that donating organs means that your body will be without them during resurrection. An interviewee from the Buddhist community stated that in China there is a belief that you don’t go to heaven if your body is not intact. A further interviewee from the Muslim community mentioned a belief at grass-roots level that the body should not be tampered with.

One interviewee from the Hindu community mentioned that the belief that the body must be cremated intact is one reason for families refusing to give consent for the organs of relatives to be donated.

“When a body is cremated they (the family) want all the body parts to be intact; unless they are convinced that there is a sanction in their scripture they might object to the removal of any part” (Dr H. V. S. Shastry, Hindu Council UK)

Finally, one interviewee highlighted that this a complex issue for some parts of the Jewish community. The interviewee explained that according to Jewish law, the body should not be disturbed after death, but that there is recognition that there are circumstances in which the body cannot be left intact.

“All interference with a body after death is regarded as disrespectful and is contrary to Jewish law. It is however accepted that there will be, at times, circumstances when the cause of death has to be further investigated. At such times the type of autopsy should be as limited as possible and carefully selected to avoid unnecessary invasive techniques” (Draft Legislative Programme about Death Certification: Jewish Community Response, David Katz, Eleanor Platt QC and David Frei)

The interviewee also referred to a lecture he has given on Judaism and Transplantation in which he mentioned the need to balance the respect due to the body after death with the concern for saving lives (‘pikuach nefesh’).

However, the same interviewee also explained that some members of the Jewish community believe that the body must remain intact because some organs are needed for resurrection. According to the interviewee, this belief is inaccurate.
However, the interviewee mentioned a view that if disturbing the body will cause great distress for the family, then attempts should be made to avoid it.

“The classic objection which is often expressed by Jews is that all organs are needed for eventual resurrection. This was not accepted even in Talmudic times, as it is clear that soft tissues are not required for this. However, there is a view (linked to the autopsy controversy) that if it will cause enormous amounts of distress, upset and emotional anguish for the family if an autopsy takes place, then you should try avoid it. By default this is then applied to the transplantation of organs as well” (David Katz, Board of Deputies of British Jews)

**Burial and cremation requirements**
Issues around the timeframe in which a death ceremony must be held, or the body disposed of, were also raised. One interviewee said that some Hindus believe that the death ceremony needs to be held within 12 hours of death, and another interviewee mentioned that some Zoroastrians believe that the body must be disposed of on the same day as death occurs, or at the latest by dawn on the third day after death.

Another interviewee mentioned that in the Jewish community, the body should be buried either on the day of death, or on the following day.

“Burial / disposal should take place as quickly as possible. The norm for the Jewish Burial Societies is to bury on the day of death or if that is not practicable, on the following day” (Draft Legislative Programme about Death Certification: Jewish Community Response, David Katz, Eleanor Platt QC and David Frei)

Finally, according to a further interviewee, for the Baha’i community, it is important that the body is not carried more than one hour's journey from the place of death.

**Taking an organ is taking a soul**
An interviewee representing the Sikh community reflected some concerns within the Sikh community that taking an organ is taking the soul. However, the interviewee stated that this argument is not supported by religion.

**Concern about transplanting certain organs**
One interviewee said that whilst the Catholic community supports organ donation in general, there may be concerns about the possibility of brain and gonad transplantation, and that some issues regarding face transplantation have been raised.

**Some double standards**
There were also three mentions of double standards, with people being more likely to question their religion’s position on donating than receiving.

“Human nature being what it is, when it comes to receiving an organ, I have not come across anyone who would ask for an opinion… when it comes to giving an organ, that is when an opinion is asked for” (Mufti Zubair Butt, Muslim Council of Britain)
“(Hindus want to have organ donation) but when you ask them to donate, they are not sure because it requires to be examined by the experts of all the skill and experience involved in this debate” (Dr H. V. S. Shastry, Hindu Council UK)

**Personal choice is important**

It was felt strongly across faith and belief groups that organ donation is a personal choice.

“Baha’is are free to volunteer to become organ donors, should they wish to do so, or to refrain from doing this. It is a matter of individual choice” (Barney Leith, Baha’i Community of the UK)

“The idea of options and free choice is very important to Christianity” (Bishop Joe Aldred, Churches Together in England)

“One condition is that it needs to be an informed, personal decision” (Naomi Phillips, British Humanist Association)

Some expressed the view that it is important that organs are donated in conditions of informed consent, and have been acquired honestly.

“From the reformed churches point of view the key is about how do you ensure each individual has the right information to make an informed choice” (Reverend Debbie Hodge, Churches Together in England)

“There is still an issue about exploitation” (David Jones, Catholic Bishops’ Conference of England and Wales)

“Organs should be donated voluntarily, and not trafficked from less developed countries. It is also important that the organs are healthy and free from disease” (Naomi Phillips, British Humanist Association)

**The wishes of relatives must be respected**

It was also recognised that the feelings and wishes of families need to be taken into account.

“It is also important to consider the feelings of relatives. You need to be considerate towards the living, and this includes relatives” (Naomi Phillips, British Humanist Association)

In a letter to the House of Lords Select Committee from the Board of Deputies of British Jews, the need to honour family wishes is also mentioned.

“The family must be reassured that they will be able to observe the principles of honouring the dead – ‘kavod hamet’; to bury the donor in a Jewish cemetery as soon as possible after donation; and to take organs donated and not used (or rejected), for suitable burial”
Other objections to organ donation, which are not related to faith or beliefs, were also mentioned

Some interviewees recognised that some people will not donate because they are squeamish about donating organs.

“There is a certain “yuck” factor for some people” (Dr Malcolm Brown, Archbishop’s Council of the Church of England)

One interviewee also mentioned some fears about operations being unsuccessful.

“There is a degree of fear in the black community over the failure rate of some transplants, although on the whole individuals generally opt for interventions that help to extend life” (Sharon Platt-McDonald, Seventh Day Adventist Church)

4.3. Views on the current opt-in system

The majority of interviewees support the opt-in system as it respects individual choice

The majority of interviewees that took part in this study are supportive of the current opt-in system.

“Would advocate the current system” (Sally Masheder, Network of Buddhist Organisations)

“The voluntary system is the ideal. It is a much better system than others” (David Katz, Board of Deputies of British Jews)

The key advantage of this system was felt to be that it allows for free choice, and ensures that organs have been donated with informed consent. This system was also considered to be aligned with the concept of the ‘gift relationship’, which was referenced by interviewees in the Christian community.

“The benefit is that it is a more informed decision and doesn’t put the person in a quandary” (Jasdev Singh Rai, British Sikh Consultative Forum)

“The question is of personal autonomy, and being able to make decisions for yourself. So for me, we should stay with the opt-in” (Mufti Zubair Butt, Muslim Council of Britain)

“Advantage is that people have choice, and I think that if there are some deeply held religious views that the body or organs should not be tampered with, then I suppose it is an issue of human rights laws that they should have that right to refuse to donate” (Khurshid Ahmed, British Muslim Forum)
However, there is recognition that the opt-in system is not recruiting enough potential donors

Despite the support for the opt-in system, there was widespread recognition of its shortcomings. In particular, many acknowledged that the opt-in system is not providing enough donors.

“The disadvantage of the opt-in system is that there aren’t enough organs” (Dr Malcolm Brown, Archbishop’s Council of the Church of England)

“Suspect the disadvantage is that there is a shortage of organs” (Sally Masheder, Network of Buddhist Organisations)

“Opt-in is a good system however as there is a shortage of donors this needs to be reviewed” (Malcolm M. Deboo, The Zoroastrian Trust Funds of Europe Incorporated)

“The only disadvantage I would see is that if you leave it to choice then you may not get the required type of organ at the right time. So the supply would obviously be restricted” (Khurshid Ahmed, British Muslim Forum)

One reason suggested is that organ donation is not a priority for many people, and consequently they are not proactive about it.

“It takes a certain amount of moral reflection and active steps to be taken, which is more than most people are prepared to do” (Dr Malcolm Brown, Archbishop’s Council of the Church of England)

“The BHA view is that it is good that we have a system but that the current system isn’t good enough, because not enough people think or talk about organ donation, or what happens to their body when they die” (Naomi Phillips, British Humanist Association)

With this in mind, some felt that the current system does not send out as strong a message as is necessary.

“People don’t automatically think about opting in. It’s not as strong a message as road tax or getting a TV license. You have to opt in to do both of these, and make a positive move to do them but there are incentives to ensure you do” (Reverend Debbie Hodge, Churches Together in England)

Some people do not opt in because of fears that they will receive inferior medical treatment if they are on the list

Some interviewees mentioned that some people do not opt in because of fears that they will receive different medical treatment, or be allowed to die, if they are on the register.

“Have come across people who have said, ‘I don’t want to be an organ donor because they will kill me to get my organs’” (Jasdev Singh Rai, British Sikh Consultative Forum)
“The fear is that being on the register means your death may be hastened by a clinician” (Reverend Katei Kirby, African Caribbean Evangelical Alliance)

“One view within the faith could be that doctors will not save you if they know you are an organ donor” (Malcolm M. Deboo, Zoroastrian Trust Funds of Europe Incorporated)

Families are gatekeepers but not always aware of the donor’s wishes

Two interviewees mentioned that whilst individuals opt in, it is the families who ultimately decide whether or not their wishes are carried out.

“Three quarters of people who donate their organs are not on the register, but donate because their family has given consent. It is via conversation with the relatives” (David Jones, Catholic Bishops’ Conference of England and Wales)

“The donor does not participate in the decision at the time: in Jewish religious terms, the (potential) ‘mitzva’ – obligation – lies with the family, who are the agents of its fulfilment” (David Katz, Board of Deputies of British Jews, in a presentation to UK Transplant in 2004)

However, one interviewee mentioned that in some cases, people opt in, but do not discuss their wishes with their families, which can lead to difficulties after death.

“Because people don’t discuss it with their families, when relatives are asked what the deceased would have wanted, they don’t know what to say” (Naomi Phillips, British Humanist Association)

“Many people may have a donor card but others in the family are not aware of this and this can present issues” (Reverend Debbie Hodge, Churches Together in England)

It was highlighted that discussions with relatives about organ donation need to be handled sensitively.

“At death is a difficult time to be asked about your relative’s organs – think this need to be looked at” (Bishop Joe Aldred, Churches Together in England)

However, the majority felt that the opt-in system has not yet been pushed hard enough

Despite the shortcomings mentioned, the majority view was that the number of donors can be increased without changing the law. There is a sense that opt-in has not yet been given a full chance, and therefore cannot be considered to have failed.

“Why do we have to go through a process that provokes a profound sense of unease, when other routes of recruitment have not been pushed as hard as they might?” (Sally Masheder, Network of Buddhist Organisations)
“It hasn’t brought enough organs, but is the answer to move to the other extreme? I’m not sure it is” (Mufti Zubair Butt, Muslim Council of Britain)

A further interview considered the question of a change in legislation to be premature, as opt-in has not been given a ‘full trial’.

Only the minority felt that the opt-in system needs to be replaced.

“The current system isn’t good enough” (Naomi Phillips, British Humanist Association)

“If the ultimate aim is to save life then we should review this system” (Malcolm M. Deboo, The Zoroastrian Trust Funds of Europe Incorporated)

Interviewees suggested a number of ways to increase the success of the opt-in system.

A. Greater awareness would improve the success of the opt-in system

The majority felt strongly that awareness of organ donation, and the current opt-in system, needs to be increased, and that more needs to be done to inform and educate people about it.

“We are not convinced that sufficient has been done in terms of education and encouragement to opt in. I can’t remember the last time I saw anything urging me to opt in. In the past you could pick up donor cards almost anywhere” (Dr Malcolm Brown, Archbishop’s Council of the Church of England)

“Transplants are now much more common and we need to ensure communications reflect changes in technology and medical advances” (Reverend Debbie Hodge, Churches Together in England)

“Education processes also need to be looked at, especially access to education about organ donation for those who are harder to reach” (Reverend Debbie Hodge, Churches Together in England)

A public campaign was considered to be an effective way to do this.

“Would have thought that a much more active promotion campaign with people asking people questions could be effective” (Sally Masheder, Network of Buddhist Organisations)

“If there was a good information campaign, the government wouldn’t have to pass legislation to take everybody’s organs” (Jasdev Singh Rai, British Sikh Consultative Forum)

“There should be a more vigorous campaign to impress upon people the need to donate and people should be encouraged much more strongly than they are at the moment” (Khurshid Ahmed, British Muslim Forum)
It was also felt that it needs a higher profile in the media.

“When you get something in the television or in the press, then it gets in to the public consciousness” (Bryan Appleyard, Buddhist Society)

One interviewee suggested that in communities where people are not opting in due to a mistaken perception that organ donation is forbidden, faith communities have a role to play in correcting these perceptions, and highlighting religious principles that would support organ donation.

“If there are no strictly religious reasons why people should not donate, then I think it is incumbent upon those faith communities to have an internal, intra-community campaign to get people out of the mindset that their religion or faith would prohibit them from donating their organs” (Khurshid Ahmed, British Muslim Forum)

“Maybe there are even religious reasons for campaigning. Certainly most, if not all, religions would encourage people to save lives. There may well be aspects of their scriptures which could be interpreted to encourage people to donate. Maybe those should be used as levers to get people to donate” (Khurshid Ahmed, British Muslim Forum)

Further details of suggestions on how a higher take-up of the opt-in system could be encouraged are available on request.

It was also felt that supplying more information about organ donation would be helpful.

“Make it clear in what circumstances it is desirable to collect organs, and in which it is not. For example, if you are over a certain age can your organs still be used?” (Sally Masheder, Network of Buddhist Organisations)

“Fear that lots of people don’t know the statistics. If that, and other information were clearer then the current system could work better” (Bishop Joe Aldred, Churches Together in England)

B. We could make it easier for people to opt in

Some interviewees felt that the process of opting in is currently too complex.

“I don’t think that… people really know how to go about it. You have to have the phone number, or visit the website. You can’t just pop into a hospital somewhere. How many people know of these contact points?” (Bryan Appleyard, Buddhist Society)

“Must encourage people to grasp the moment, to make it really easy for them. Need to enable people to do it without it being a major decision that you need to plan for” (Dr Malcolm Brown, Archbishop’s Council of the Church of England)
Particular issues mentioned were older people not being computer-literate, and people losing donor cards.

C. The logistics of donation could be improved

Some interviewees suggested that the process itself might be improved.

“There is an urgent need to increase the transplant coordinator network. The Spanish experience makes it clear that whatever the legislative framework, increased (numbers of) well-trained transplant co-ordinators are essential” (David Katz, Board of Deputies of British Jews)

“There are three medical parties: the recipients, the donors and the transplanters. They need to be ‘in sync’ with one another and trained properly together” (David Katz, Board of Deputies of British Jews)

4.4. Views on the idea of an opt-out system

The majority are opposed to the introduction of an opt-out system

The majority view amongst interviewees is against a change in legislation. Some are only slightly opposed, whereas some expressed strong opposition to the opt-out system.

“I think presumed consent is quite problematic” (Mufti Zubair Butt, Muslim Council of Britain)

“It would be better to prevent legislation at this point” (David Katz, Board of Deputies of British Jews)

It is further stated in a letter from the Board of Deputies of British Jews to the House of Lords Select Committee that:

“A change to the system of presumed consent would not be acceptable, as it would change the climate of the donation process radically”

Only three interviewees are in favour of moving towards an opt-out system, and a further three interviewees expressed no objection to either system.

“I would prefer the new law, where they have to opt out” (Dr H. V. S. Shastry, Hindu Council UK)

Opt-out is seen to remove personal choice

A number of concerns about the opt-out system were expressed.

Many interviewees felt strongly that organ donation should be a personal choice, and consequently there was widespread concern that using the opt-out model, people
would no longer be making an individual, conscious choice to opt in. In particular, the ‘gift relationship’ does not apply under a presumed consent system.

“The gift relationship is a very important point in Christianity. The gift of what we have to others is at the heart of what we believe. But a gift where you have no say whether you give it or not, is not quite a gift” (Dr Malcolm Brown, Archbishop’s Council of the Church of England)

“Individual choice must be the first consideration. The idea that organs could be taken without permission is very worrying” (Ramesh Majithia, National Council of Hindu Temples)

Some interviewees recognised that the opt-out system does still offer choice, in that people would still be able to opt out.

“Of course, the new ‘opt-out’ policy proposed by the Government will allow anyone not wishing to have their organs donated in the event of their death to exercise this right” (Dr Raj Pandit Sharma, Hindu Priest Association UK and Hindu Council UK)

“In a way it is still a voluntary system. You still have the right to refusal, there is still free will” (Bryan Appleyard, Buddhist Society)

“That (an opt-out system) also goes some way in meeting that requirement of choice, that if people have been given the information that their organs would be removed, unless they have themselves expressed the wish for them not to be, then that would comply with the human rights issue” (Khurshid Ahmed, British Muslim Forum)

Nonetheless, many were concerned about the difficulty in establishing whether the donor has consciously decided not to opt out, or whether they were simply unaware of the system, or had not yet had an opportunity to opt out.

“How do we know it’s been done with appropriate and informed consent? If it is opt-in, then consent is there automatically” (Reverend Debbie Hodge, Churches Together in England)

“Those who are harder to reach may not have the information or knowledge to opt out and make an informed choice” (Reverend Debbie Hodge, Churches Together in England)

“Being able to opt out is not enough, because there is a lot of ignorance, and people don’t think about these things until there is a point of crisis for them or their family. It is not quite the same” (Dr Indarjit Singh, Network of Sikh Organisations UK)

One interviewee mentioned concerns that people with a limited knowledge of the English language could give consent for a relative’s organs to be donated, without fully understanding what they were agreeing to.
“The partner can’t speak English, and the hospital struggles to get an interpreter in quick enough. The partner could end up agreeing to donation without knowing what they are agreeing to” (Raj Bharkhada, Hindu Forum of Britain)

Another interviewee felt that consent needs to be given explicitly.

“We would assume that the majority of people in this country would want medical intervention, but when it comes to medical intervention we ask for their specific consent. To totally reverse that, because we can’t find the organs we need, is problematic” (Mufti Zubair Butt, Muslim Council of Britain)

Consequently some felt that this system would also have quite a high potential for error – either where a family objects once an organ has been taken, or where an organ is taken, and it subsequently becomes apparent that the deceased did not wish to donate, or had changed their mind.

“There is a real danger that people’s organs would be taken that would object, and that you will find out later that they did object, and this will be upsetting” (David Jones, Catholic Bishops’ Conference of England and Wales)

“A presumption should be provisional. But here there is no reversal. Once you have taken an organ you cannot put it back” (Mufti Zubair Butt, Muslim Council of Britain)

However one interviewee disagreed with this opinion, and felt that if the change in law is widely publicised, then it can be assumed that those who have not opted out are willing to donate.

“If it has been made known to the individual that their organs will be removed, if the law of the land is that, then ignorance of the law is not a defence. If that is the law and it has been promoted, then one has to assume that they would have wished their organs to be removed” (Khurshid Ahmed, British Muslim Forum)

Some felt that an opt-out system would put a burden on the individual rather than the state

Some felt that opt-out is a way for government to shift the burden of activity on the individual, and be ‘lazy’.

“The whole thing is a failure of information to the public. It is the government being very lazy and saying ‘we will take your organs unless you opt out’” (Jasdev Singh Rai, British Sikh Consultative Forum)

“It places the burden on the individual to let their wishes be known, rather than on the state” (Mufti Zubair Butt, Muslim Council of Britain)
There was even a suggestion that the opt-out system would be reliant on people forgetting to opt out.

“What system would you put in place to determine that someone would not have objected? To know that they consciously decided not to opt out? I don’t think you can do that. It would appear that people just hope that people won’t get round to it (opting out)” (Mufti Zubair Butt, Muslim Council of Britain)

There is also a sense that this system may make people feel uncomfortable about opting out.

“It would sound a bit selfish to say ‘I want to opt out’. It creates a climate in which opting out seems a bit anti-social and selfish. Wouldn’t want this sort of pressure on people” (Jasdev Singh Rai, British Sikh Consultative Forum)

Unease about a perceived shift between the state and the individual

Many felt that a move to an opt-out system was an example of a power shift between the state and the individual. Discomfort was expressed at the level of control that this would give the government, and it was questioned whether the state has the right to claim it. It was also suggested that this power shift could damage the perception of the state.

“It’s the government becoming owners of body parts. It would be going in a direction that many people would be unhappy about” (Dr Indarjit Singh, Network of Sikh Organisations UK)

“If we move to an opt-out system, there is a change in the relationship between the individual and the state. The assumption about whose body it is begins to move” (Dr Malcolm Brown, Archbishop’s Council of the Church of England)

“Does the state have the right to make these laws? Who gives them the right?” (Mufti Zubair Butt, Muslim Council of Britain)

“It is going to be one piece of a whole shift of people’s perception of civic duty and state power. The extent to which they feel controlled by the state or in control of the state. Whether they feel that their compliance and willingness is taken for granted or requested and earned. Whether they see government as authoritarian or liberal. And if put in the context of a number of other elements relating to state power and balance of liberal versus authoritarian view, then it contributes to a perception that is damaging to the role of the state” (Sally Masheder, Network of Buddhist Organisations)

One interviewee suggested that less people may be in favour of organ donation than the current figures suggest.

“The 70% figure that is given (of people in favour of organ donation) may not reflect reality. ‘There is a difference between when you ask a question in a
survey and when it comes to the practical reality of it” (Mufti Zubair Butt, Muslim Council of Britain)

One interviewee expressed a fear that this power could be abused by a future government.

“History shows us that governments can be vulnerable, and we don’t want to give a power that could be fundamentally abused” (Dr Malcolm Brown, Archbishop’s Council of the Church of England)

The erosion of trust in the medical profession was mentioned as an issue.

“The other thing to address is the erosion of trust in the medical profession over last 10 – 15 years” (Sally Masheder, Network of Buddhist Organisations)

Some concern that opt-out could reduce organs to commodities

Some felt that a presumed consent model displays a lack of respect towards individuals, and could be seen as ‘dehumanising’.

“If you assume that you can take people’s organs, then you are not paying them proper respect” (Bryan Appleyard, Buddhist Society)

“If you reduce organs to commodities to be supplied, you have begun the dehumanisation process. And you have also introduced the language of supply and demand, of economics. If supply falls below demand again, then you are justified in taking steps to rectify it… in the context of the gift relationship, supply and demand are not appropriate terms to talk about. If the supply isn’t there, unfortunately demand can’t be met” (Dr Malcolm Brown, Archbishop’s Council of the Church of England)

“If you are supposed to have respect for the body, you are not supposed to treat it like other forms of raw materials. What justifies it is that the giving of it is a human thing, so there is an anxiety about it ceasing to be a human thing” (David Jones, Catholic Bishops’ Conference of England and Wales)

Introducing opt-out could trigger a backlash

Some interviewees felt that introducing opt-out would provoke negative reactions from a number of communities and upset a minority in a number of groups. This could lead to some organ donation sceptics becoming more vocal.

“I would think that you may see a backlash with increased opt out, not only in the Jewish community but also from other communities” (David Katz, Board of Deputies of British Jews)

“By default we could create a promotion campaign that says ‘opt out’ and for this reason opt out is worrying” (Reverend Katei Kirby, African Caribbean Evangelical Alliance)
“There is a danger of people overreacting because they see it as becoming not human anymore. This danger is not overstated” (David Jones, Catholic Bishops’ Conference of England and Wales)

“It would up the stakes for people who are sceptical. Currently those who are sceptical are happy to grumble on sidelines. It is likely to precipitate an anti-organ transplant movement that doesn’t exist now” (David Jones, Catholic Bishops’ Conference of England and Wales)

Benefits of the opt-out system were also recognised – in particular a likely increase in the number of donors

Most interviewees also recognised the advantages of introducing the opt-out system. The most frequently mentioned, and for some the only presumed benefit is that it would increase the number of organs available.

“Advantage of opt-out must be to do with getting more organs – can’t see any other advantages” (David Jones, Catholic Bishops’ Conference of England and Wales)

“The advantage of an opt-out system would be that we can get the necessary organs more quickly” (Dr Natubhai Shah, Jain Network).

“Advantage of that system (opt-out) would be that it would ensure a better level of supply of more suitable organs, and that more lives would be saved… if people have that deeply held view, they would have that choice (to opt out), and the disadvantage would be that again supply would be affected as a result of that, but at least it would be affected to a much lesser extent (than if people have to opt in)” (Khurshid Ahmed, British Muslim Forum)

One interviewee mentioned the difficulty in balancing the concerns about opt-out with the potential increase in lives saved.

“One difficulty for the Synod would be ‘how many lives are we condemning by reducing the supply and sticking with opt-in?’ But this is based on the assumption that moving to opt-out would dramatically increase the numbers” (Dr Malcolm Brown, Archbishop’s Council of the Church of England)

The submission to the House of Lords from the Church of England Mission and Public Affairs Division also states that:

“The undoubted need for more organs to be donated for the healing of others has to be weighed against the changed relationship between persons and the State which moving to an opt-out system might entail”

Opt-out could send a stronger message about organ donation

One interviewee felt that opt-out would send out a stronger message about the need to donate.
“An opt-out system would send a stronger signal out about organ donation”
(Naomi Phillips, British Humanist Association)

Further benefits mentioned in the submission from the British Humanist Association to the House of Lords in January 2008 are that:

“(Opt-out) would decrease the trafficking in organs and human beings, would increase awareness of organ donation more generally and would better assist individuals and families to make decisions about organ donation”

**The opt-out system could solve the question about when people should be asked about organ donation**

One interviewee suggested that it could address the question of at what point people should be asked whether they want to be a donor.

“In favour personally of an opt-out system that assumes that everyone is a donor, as it would address the issue of when the question about donation should be asked” (Bishop Joe Aldred, Churches Together in England)

**However, it would not remove the need to discuss organ donation with relatives**

Another interviewee questioned whether it would remove the need to discuss donation with family members at the point of death, but concluded that it would not.

“Would opt-out make it easier because you wouldn’t need this conversation? No, because you would still have to speak to the relatives” (David Jones, Catholic Bishops’ Conference of England and Wales)

And another interviewee suggested that it would make the situation worse.

“It would lead to debate among family members about whether the organs should be donated and what the person really wanted. If you have a voluntary donation, then someone has said ‘I want to donate my organs’, and it has a bigger impact. There isn’t that dispute amongst the family, because he himself wanted to do it” (Mohammed Umar, The Ramadhan Foundation)

**If an opt-out system were introduced, certain conditions would need to be in place**

As stated earlier, the majority of interviewees expressed a preference to continue with the existing system rather than introducing opt-out. If, however, the opt-out system were to be introduced, it was felt strongly that certain conditions would need to be in place.

**The ‘soft’ presumed consent model would have to be used**

It was felt that the ‘soft’ opt-out system, whereby organs are not donated if the relatives object strongly, would have to be used.
“I suppose that would possibly make it acceptable, in so far as for those people for whom there is the belief about consciousness remaining with the body, the family could veto it” (Sally Masheder, Network of Buddhist Organisations)

“If opt out were introduced, the family must still have a say and be asked for their views” (Ramesh Majithia, National Council of Hindu Temples)

“The BHA supports a ‘soft’ system of presumed consent, whereby even if the deceased has not opted out, their organs will not be used if relatives have strong objections” (Naomi Phillips, British Humanist Association)

“Definitely, the family has invariably to be consulted. The beliefs of the family are very personal and need to be consulted” (Dr H. V. S. Shastry, Hindu Council UK)

However one interviewee who was against the introduction of the opt-out system felt that the ‘soft’ presumed consent model has so many caveats that it is difficult to see the difference from the present situation.

And a further interviewee felt that family members should not be able to challenge an individual’s decision to opt out, or not to opt out.

“I think if the individual has made the decision to opt out, that should be the individual’s decision, and it should not be challengeable by other members of the family… I don’t think the family should have that right (to stop organs from being removed if the person has not opted out)” (Khurshid Ahmed, British Muslim Forum)

In order for it to be acceptable, it was felt that the family would not have to be inconvenienced in any way, for example by being made to wait longer than desired for the funeral to take place. And in the Jewish community, each death would still have to be considered individually, with consultation with the family, who will in turn often wish to consult their Rabbinic authority.

Ensuring that everyone was aware of the new system, and the need to opt out, would be critical

Many interviewees felt strongly that an engagement and awareness campaign, targeting hard-to-reach audiences in particular, would be essential in order to ensure that everyone was aware of the change, and that everyone knew how to opt out.

“If you are going to take an opt-out position, then you must ensure that people are well informed” (Jasdev Singh Rai, British Sikh Consultative Forum)

“One consideration is that public awareness would have to be very high” (Naomi Phillips, British Humanist Association)

“If opt-out were introduced, consultation with the Hindu community would be absolutely essential” (Ramesh Majithia, National Council of Hindu Temples)
“For me that would require a person to have sufficient knowledge of the situation, and know how to opt out” (Mufti Zubair Butt, Muslim Council of Britain)

There was recognition by some that however extensive an awareness campaign would be, it would still not reach everybody.

“No matter how good the campaign is, not everyone will be aware of the new system. Therefore it is important that relatives are fully informed about what will happen to the body of the deceased. Those people whose job it is to question relatives about what the deceased would have wanted will need thorough training” (Naomi Phillips, British Humanist Association)

“(There are) some real concerns about lack of access to information for those who are harder to reach especially” (Reverend Debbie Hodge, Churches Together in England)

There should be no pressure for those wishing to opt out

It was also felt important to ensure that people were not asked about donation at a vulnerable time, and that it was not made embarrassing or difficult to opt out.

“If they opt out there shouldn’t be any further pressure for them” (Jasdev Singh Rai, British Sikh Consultative Forum)

“We would want the maximum safeguards in place to ensure that opting out options were offered at a point when people were not under any pressure” (Dr Malcolm Brown, Archbishop’s Council of the Church of England)

“It needs to be made easy for people to opt out” (Malcolm M. Deboo, Zoroastrian Trust Funds of Europe Incorporated)

Ensuring that legislation would have to be renewed after a set period of time could be helpful

One interviewee said that if opt-out were introduced, they would like time limits for renewal of the system to be set.

“Opting out would stand a better chance if there were time limits around the renewal of legislation, for instance if it had to be renewed every second or third year” (Dr Indarjit Singh, Network of Sikh Organisations UK)
| Summary of positions on opt-in and opt-out systems |
|-----------------------------------|---------------------|---------------------|---------------------|---------------------|---------------------|
|                                   | Opt-in              |                      | Opt-out              |                      |                     |
|                                   | Supportive | No issue | Concerns | Supportive | No issue | Concerns |
| B. Appleyard, Buddhist Society    | X         |          |          |           |          | X        |
| Dr M. Brown, Archbishop’s Council of the Church of England\(^1\) | 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. Masheder, 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\(^2\)  | X         |          |          |           | X        |
| Hindu Forum of Britain and National Council of Hindu Temples | X         |          |          |           | X        |
| B. Leith, Baha’i Community of the UK | X         |          |          |           | X        |
| Dr N. Shah, Jain Network | X         |          |          |           | X        |
| K. Ahmed, Muslim Forum of Britain | X         |          |          |           | X        |
| Rev. D. Hodge (OH), Churches Together in England | X         |          |          |           | X        |
| N. Phillips, British Humanist Association | X         |          |          | X         |
| M. M. Deboo, The Zoroastrian Trust Funds of Europe Incorporated | X         |          |          | X         |
| Dr H. V. S. Shastry, Hindu Council UK | X         |          |          | X         |

\(^1\)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"

\(^2\)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.
4.5. Suggested approaches to long-term engagement on organ donation with faith and belief groups

It should be noted that interviewees are here expressing views about engagement on organ donation in general, regardless of whether the opt-in system is retained or the opt-out system introduced.

The approach to engagement will need to be tailored to each faith and belief group. Full details of recommendations provided for each faith and belief group are available upon request.

More engagement is needed

Many interviewees said that the organisations they were representing had had little or no contact with the ODT 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 opened.

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 centres such as churches and gurdwaras would be a good route for engagement.

"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 non-statutory bodies are 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.

**There is an opportunity to engage those working in the health services**

Some interviewees mentioned an opportunity to engage with hospital chaplains.

> “There are hundreds of Church of England hospital chaplains, all coordinated from the General Synod office. There is an opportunity to look at their training programmes” (Dr Malcolm Brown, Archbishop’s Council of the Church of England)

> “This (multi-faith hospital chaplaincy) is an area that is growing” (Sally Masheder, Network of Buddhist Organisations)

An opportunity to engage with Catholics working in the health system was also highlighted.

> “There hasn’t been a strong engagement with this group. Has been a desire to try to do something, but very embryonic at the moment” (David Jones, Catholic Bishops’ Conference of England and Wales)

There were two suggestions that GPs could help to communicate the message.

> “They (GPs) can do a lot, because patients always listen to their GP. If the GP tells someone that Hindu scriptures are also in favour, then it would add to the conviction in general” (Dr H. V. S. Shastry, Hindu Council UK)

**The debate needs to engage people at many levels**

Interviewees felt that there is a need for the government to engage with the key opinion formers within faith and belief groups.

> “Across the black Christian faith community there are still key individuals who do not highly recommend organ donation yet. One way of working through this is to engage in debate with opinion leaders” (Sharon Platt-McDonald, Seventh Day Adventist Church)

> “There is a need to engage with the strict orthodox part of the Jewish community. This needs to be discussed with the doctors involved in this area and with the Rabbinic authorities that they recognise. This part of the Jewish community will have an impact on the views in the mainstream part of the community” (David Katz, Board of Deputies of British Jews)

Some felt that the government needs to be inclusive and avoid ‘cherry-picking’.
“Government has cherry picked certain ‘obedient’ scholars. This isn’t very effective at all” (Mohammed Umar, The Ramadhan Foundation)

“(Scholars from the Sunni and Deobandi traditions) have not been engaged in debate. Would like to engage this tradition in debate” (Mufti Zubair Butt, Muslim Council of Britain)

It was also felt that more needs to be done to reach people at grass-roots level.

“Need to engage with the community to help them spread the message about organ donation” (Dr Natubhai Shah, Jain Network)

“Dissemination of information through different tiers needs to be improved” (Malcolm M. Deboo, The Zoroastrian Trust Funds of Europe Incorporated)

"You have to go out to the grass roots and educate them" (Mohammed Umar, The Ramadhan Foundation)

One interviewee mentioned that the opinion formers would have to be approached first.

“Can’t immediately go to the grassroots without going through the leaders because you have to be very courteous” (Mohammed Umar, The Ramadhan Foundation)

One interviewee felt that it is more important to engage people outside the realm of faith.

“It needs to be considered throughout life… We learn to be moral people in churches, but also in the day-to-day running of our lives. Needs to be taken beyond the realm of faith” (Dr Malcolm Brown, Archbishop’s Council of the Church of England)

Greater resources will be needed to achieve greater engagement

Some organisations said that they do not currently have enough funding, and that financial support from 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.

“Organisations 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 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)
4.6. Feedback on current UK Transplant materials

As in section 4.5, the findings listed here are general themes, which were common across faith and belief groups. Detailed comments on each leaflet are available on request.

It should be noted that leaflets do not currently exist for Baha’ism, Humanism, Jainism and Zoroastrianism.

Low awareness of leaflets

Among the faith and belief communities for which leaflets have been produced, the majority of interviewees had not seen, or were unsure if they had previously seen the leaflets.

The leaflets are a valuable tool, but won’t work on their own

Many interviewees felt that there is a value in producing these leaflets, but that they are not sufficient on their own.

“Leaflets are useful, but you need to bombard people with the duty to consider organ donation” (Dr Malcolm Brown, Archbishop’s Council of the Church of England)

“People won’t take any notice of leaflets – there are so many of them” (Dr Natubhai Shah, Jain Network)

“The Muslim community does not respond to leaflets. Must adopt a different method. Leaflets are one thing, but not the answer” (Mufti Zubair Butt, Muslim Council of Britain)

A further interviewee commented that leaflets would not be effective unless local bodies start working together.

Mixed views on the content of leaflets

Views on the content of the leaflets varied greatly. Some were positive towards the leaflets, whilst others were more critical, with one interviewee describing the leaflet relating to their faith and belief community as ‘boring’.

“Does provide sufficient information, provides the essence” (Dr Indarjit Singh, Network of Sikh Organisations UK)

“This would be very useful. I wish this would be read by all of my faith community” (Dr H. V. S. Shastry, Hindu Council UK)

“A number of fairly basic rules have been broken” (Sally Masheder, Network of Buddhist Organisations)

There was general agreement that the leaflets need to be updated, as in some cases people who have been quoted are no longer appropriate.
Wider involvement and endorsements could increase credibility

It was felt that more people should be involved in developing the ‘Islam and Organ Donation’ leaflet, as currently the Indian sub-continent tradition is not represented.

“Would be good to mention an organisation from India, because the Arab world is covered, but there is nothing from the sub-continent. The majority of Muslims in this country follow the sub-continent” (Mohammed Umar, The Ramadhan Foundation)

“Haven’t really brought in wider opinion. Need to bring in the opinion of people at grass roots level” (Mufti Zubair Butt, Muslim Council of Britain)

One interviewee suggested that the leaflet could offer a more balanced view.

“Feels a bit like ‘now can I have your organs please?’ They feel like you are being sold something… if this were produced by Catholics, it would have more cautions or negatives or qualifications” (David Jones, Catholic Bishops’ Conference of England and Wales)

Whilst religious leaders are quoted on some leaflets, one interviewee felt that this may not be enough to convince some members of the community, as quotes may be taken out of context. It was suggested that gaining approval from religious institutions would help to give the leaflets credibility.
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Appendix 1: Discussion Guide

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  - For members of your faith (or belief) group
- Are there any conditions attached to receiving organs? What are they?
- What is the position on receiving organs at a grass roots level? Does this vary from the official positioning? How?
- What is your faith’s (or belief group’s) position on donating organs?
  - For all people
  - For members of your faith (or belief) group
- Are there any conditions attached to donating organs? What are they?
- What is the position on donating organs at a grass roots level? Does this vary from the official positioning? How?

B. Your views on the current opt-in system

- What is your faith’s (or belief group’s) position on the current opt-in system, whereby members of the public need to opt in, or volunteer, to become a donor?
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  - Via what means?
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Appendix 2: House of Lords submissions

Board of Deputies of British Jews

It should be noted that an initial submission to the House of Lords Select Committee was sent by David Katz on 2nd October 2007. The submission letter was accompanied by two appendices, ‘General Jewish principles relating to organ donation and transplantation’, and a document on Spirituality and End of Life issues. The submission and Appendix 1 can be found on the House of Lords website: http://www.parliament.uk/documents/upload/Board%20of%20Deputies%20of%20British%20Jews.doc

Following this initial submission, a response was sent to the Board of Deputies of British Jews, requesting further detail on the following areas:

- Please would you describe any particular aspects of organ donation and transplantation which are considered ethically problematic within the context of your organisation’s religious beliefs—as these are perceived: (a) within the UK; or (b) in other EU Member States?
- Please would you explain if there is any significant tendency for individuals from your faith group to oppose organ donation either for themselves or for a family member on the basis of their own interpretation of the religious teaching of the group, rather than on the basis of how that teaching is more generally interpreted. If so, how, if at all, do you think this tendency might best be addressed?
- To what extent would a change to a system of presumed consent for organ donation in the UK (under which everyone would be assumed to have consented to donate their organs after death unless they explicitly opted-out from the system) be ethically acceptable for your faith group?
- If presumed consent were to be introduced in the UK, what would be your views about the idea that members of any particular groups should be assumed to be opted out as a whole without the need for individual opt outs? (An example of this is the case in Singapore, where Muslims are assumed to have opted out unless they expressly opt in)

The letter contained in the following pages is a response to these questions.
12th March 2008

Barry Werner
Clerk to European Union Sub – Committee G,
Committee Office,
House of Lords,
London SW1AOPW

Re House of Lords inquiry into the issues raised by the European Commission Communication: organ donation and transplantation – policy actions at EU level

Dear Baroness Howarth

Thank you for your letter of 30th January asking the Board of Deputies of British Jews for further comment following our earlier submission on this subject.

Although there are four specific questions posed, which we intend to address, we also believe that there are some underlying issues raised in your letter that need to be clarified.

The impression given (last paragraph, page 1) is that, while in general both the faith groups and their religious leaders support organ donation, there are particular issues which might be of concern to some members of the faith groups, which might make them reluctant to consent; and that this is then linked to self-perception of religious law. These comments tend to diminish the role that personal faith may play in the core decision making process, and to propound the view that total subjugation to religious authority should be the norm. Ignoring the personal faith dimension, and focussing entirely upon the pragmatic issues, does not do justice to the individual and their concerns. It is strange that these assumptions are stated at this point as your “understanding”, thus prejudging the responses to question 2.

There are two other issues which these same introductory comments raise. Firstly, it is unclear where the phrase “substantial number of cases” derives. One would need to know how many realistic potential donors there are in total, and how many refusals there are from amongst each faith group. The Board has the impression from your letter that it is the most observant parts of the Jewish community from which those who refuse might be presumed to be drawn. They may also be the least affluent. It would be of interest to know whether or not a control cohort of similar financial and social status will behave in the same way. There are also potential comparative Christian, Muslim and Hindu groups in the same socio-economic cohorts. Anger at the time of the Alder Hey investigation reflected a deep-seated sense of betrayal and mistrust which was not necessarily based upon religion. In earlier discussions it was made clear to the Jewish community that there are also racial issues and that it is the Afro-Caribbean donation rate that is the lowest.

Secondly not all Jews share the same view of this issue and other matters relating to organ donation. However, although for this reason widespread consultation amongst the Jewish community may be needed, there is a documented tendency amongst Jews to revert to certain religious “norms”, when confronting death, which can be based upon misunderstandings of the religious position, but which are nonetheless sincerely held, and should not be dismissed. For example, families will insist on immediate registration of death and facilities for early funerals, and then opt for cremation. Studies of Jewish opinion document that the reason why many Jews who oppose autopsy and cremation, and presumably donation, is based on the notion that “soft tissue” body parts will be necessary in the event of resurrection of the dead,
despite the fact that there is Talmudic discussion reflecting that after a period of time only bones will remain. This pattern of reversion to religion, which might occur even amongst Jews who regard themselves as secular, will have an impact on donation rates. People change when confronted with mortality, and this can act as an impetus either for or against organ donation.

In answer to your specific queries, therefore:

Question 1

Religious beliefs are those of people, not of organisations. Thus this question is difficult, and probably inappropriate, for a representative organisation to answer, and would perhaps be so even if that organisation were to be composed solely of a group of synagogues. There is no difference between the UK and the EU in this context. Taking the observant Jewish view as the “median” norm there has been a continuous debate about problematic issues ever since transplantation was first suggested. Issues such as relative risk of the procedure, relative risk to live donors, how live donation should be regulated etc have all been posed and discussed in terms of religious law (“halacha”). The most major problematic area relates to determination of the death of the donor, and in particular to the definition and acceptability of brain death. Whether or not brain death defines the Jewish – legal moment of the death of an individual is debatable. Those who do not accept the definition of brain death cannot become organ donors until respiration has ceased, because this constitutes the killing a “still-alive” donor. One can foresee that this will pose problems if UK (or any other) authorities act without due consideration to the sensitivities of the donor and their families.

Question 2

The problems raised by this question have been noted already above. The “solution” which would help to address this tendency (without prejudice to a decision whether or not to donate) has already been formulated, with three main principles:

1. There must be opportunity for adequate consultation with Rabbinic authorities expert in this field during the decision making process.
2. There should be suitably trained transplant co-ordinators, fully conversant with issues of concern to Jews: as noted by the Spanish authorities “the laws are necessary frameworks but they do not make organisations function……transplant organisations should be based on credibility, efficiency, impartiality and transparency”.
3. The family must be reassured that they will be able to observe the principles of honouring the dead - “kavod hamet”; to bury the donor in a Jewish cemetery as soon as possible after donation; and to take organs donated and not used (or rejected), for suitable burial.

Question 3

In the light of the comments above, a change to a system of presumed consent would not be acceptable, as it would change the climate of the donation process radically. The concept of presumed consent that has been introduced in some European jurisdictions is only accepted by orthodox Jews because it is the law of the land, not because they regard it as the best way to regulate transplantation. The term “presumed consent” is in such instances factually wrong. The proposed change would not provide reassurance to the Board that the religious rights of a very significant number of Jews in the UK are protected along the lines suggested in our answer to question 2 above.
Question 4

This question moves entirely from issues of faith perspective to practicality. As noted above, Jewish views are not monolithic and Jews can change these views with time; how Jewishness is defined would be a problem; and the opportunities for stigmatization are considerable. The Select Committee may not be aware that the issue of religion and donation was brought to the fore for the first time in the UK when a newly-appointed renal physician was refused a place for a Muslim patient on a transplant list “because Muslims do not donate”. We are informed that there are also differences in the Muslim community on this issue. The opportunities for discrimination would be increased considerably in an "opt-out" system.

Finally, in preparation of these comments, it has been very helpful to have a memorandum at hand from Mr David Frei, Registrar of the Court of the Chief Rabbi, available to us, and therefore I am also attaching this memorandum for your consideration.

I hope that these documents and comments are useful; and I reiterate my offers of undertaking further consultation and arranging additional submissions should it be necessary.

Yours sincerely
David R Katz
(Prof of Immunopathology, University College London)
(on behalf of the Board of Deputies of British Jews)
British Humanist Association

Inquiry into the EU Commission's Communication on organ donation and transplantation: policy actions at EU level.

British Humanist Association response to the House of Lords Select Committee on the European Union’s call for evidence.

1. The British Humanist Association (BHA) welcomes the opportunity to submit evidence to the inquiry into organ donation and transplantation.

2. The BHA is the principal organisation representing the interests of the large and growing population of ethically concerned but non-religious people living in the UK. It exists to support and represent people who seek to live good and responsible lives without religious or superstitious beliefs. It is committed to human rights and democracy, and has a long history of active engagement in work for an open and inclusive society. The BHA’s policies are informed by its members, who include eminent authorities in many fields, and by other specialists and experts who share humanist values and concerns.

Our position

3. Humanists generally support scientists and researchers in their quest for knowledge, and support scientific and medical advances for the improvement of our health. Most of us would not object to our body parts and organs being donated and used for good ends. We believe that better public education about organ donation and transplantation is essential, and that policy actions at both state and European levels are needed in order to increase the number of organ transplants and so save lives.

4. We are also very concerned that the low number and availability of organs donated across Europe is contributing to unnecessary deaths for want of transplants and to an increased trafficking in organs, and in human beings for the purpose of removal of organs, from outside of Europe and that this will create serious ethical issues and is contributing to systematic human rights violations of some of the most vulnerable people from across the world.

5. This response is from a humanist perspective and covers in particular issues arising from that view, the health and social welfare benefits and ethical issues of organ transplantation, the use of living donors and, especially, the ‘presumed consent’ approach and the arrangements for taking into account the views of relatives. We wholly oppose general policy being made on the basis of religious dogma or superstition – though we recognise that provision must be made to accommodate the personal wishes of individuals based on such considerations – and we support policy-making based on evidence, rational decision-making and that which seeks to maximise the well-being of individuals and so society more generally.

6. With any change to the approaches for organ donation for transplantation, there must be appropriate safeguards in place to protect the wishes of the deceased individual, and the health of both living donors and those needing an organ transplantation.
Presumed consent

7. Humanists are concerned with the maximisation of well-being of individuals for the social good and benefit of society as a whole. Humanists believe in individual rights and freedoms - but believe that individual responsibility, social cooperation and mutual respect are just as important. In terms of organ donation and transplantation, most humanists would consider that we have a moral responsibility to allow our organs to be used for transplantation, if that will improve the quality of life for others and contribute to the well-being of the human family.

8. The BHA holds that the current system where individuals must ‘opt in’ to have their organs removed for donation after their death has contributed to the present shortage of organs and so to many preventable deaths every year. We fully support the replacement of the opting in approach to one of ‘presumed consent’, whereby individuals must actively opt out should they not wish their organs to be used for donation after their death.

9. The presumed consent approach would better match the fact that the majority of the population support organ donation for transplantation, would be likely to vastly increase the number and availability of organs suitable for transplantation, would decrease the trafficking in organs and human beings, would increase awareness of organ donation more generally and would better assist individuals and families to make decisions about organ donation.

10. Under the present system, unless someone has actively opted in, it is usually left to relatives to consent to donation of the deceased’s organs. There is a range of reasons why relatives may not wish the individual’s organs to be donated – historical, cultural, social, religious and so on – but these may actually have been in direct conflict with the views of the individual. Under a system of presumed consent, supported by good public information, education and awareness of that system, if an individual has particularly strong objections to organ donation after death, then she is able make her feelings clear and opt out, while she is alive. Moreover, the presumed consent system seems better able to protect the wishes of someone who had not opted-out, even if the relatives themselves have strong views against organ transplantation, because the individual should have been given good enough information to make an informed choice when she was alive and the presumed consent should usually be taken as paramount.

11. This is not to say that relatives’ views should never be taken into account. We would support the British Medical Association’s ‘soft’ system of ‘presumed consent’, whereby organ donation (for those over the age of 16) is the default position, but where relatives would not be asked to consent to donation (as in the present system), but would be told that the individual had not opted out and would be asked if they are aware of any unregistered objection1. We believe that this would help decrease the number of objections from relatives.

Living volunteers

12. The BHA would support a policy move to promote the altruistic donation of organs, such as kidneys, from living donors. As with any change to the organ donation after death system, this would need to be accompanied by raising public awareness through comprehensive education and information. If someone wishes to be a living volunteer donor, that must be an individual choice. She must have enough information to make a rational choice for herself about the risks of such a procedure to her well-being and life compared with the benefits to the well-being and health of
the person needing that organ. We wholly endorse the present ban on a sale of organs.


British Humanist Association
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020 7079 3585
January 2008
Baroness Howarth of Breckland  
Chairman of Sub-Committee G  
European Union Committee  
House of Lords  
London SW1A 0PW  

6th March 2008  

Dear  

House of Lords  European SubCommittee G Inquiry in Organ Donation  

The British Sikh Consultative Forum (BSCF) welcomes this opportunity to contribute to the House of Lords European SubCommittee G (Social Policy and Consumer Affairs) inquiry on the European Commission Communication on Organ Donation and Transplantation COM (2007)0275.  

BSCF welcomes the Commission’s proposal that European policy should concern itself primarily with guaranteeing the quality and safety of transplants and with the organization of cross-border cooperation. We welcome the recognition that the procedures for organ donation should continue to be determined by the Member States under domestic legislation. We also welcome the fact the Commission is proposing to act under Article 154 of the Treaty rather than the internal market provisions of the Treaty.  

From a Sikh perspective the body after death has to be respectfully handled as per Sikh customs and tradition before cremation. Organ donation is permissible with the family’s consent if the deceased has not made a prior Will. The gift of organs from living donors is also permitted with consent. Many Sikhs may freely give consent for organ donation regarding it as an act of mercy and compassion.  

There can be no question of payments being made to donors and families for this act of kindness. Organ trafficking should remain illegal and we welcome the Commission’s proposal to target and stop the trade in organs. We endorse the draft report of the European Parliament Committee on the Environment, Public Health and Food Safety (2007/2210(INI) which insists that altruism must be the guiding principle of organ donation and transplantation.  

We have some reservations about a system of presumed consent. We are uncomfortable with the underlying logic of presumed consent which suggests that the individual and his/her body belong to the state. We also strongly believe that a system of presumed consent would only be acceptable to the extent it does not undermine the principle of informed and freely given consent. It would therefore be necessary to put in place sensitive and confidential systems which would allow people to opt out without being subject to any form of pressure or embarrassment.
One possible method of doing so would be for GPs to discuss the issue with their patients and make a record of their decision on opting out.

BSCF’s members believe that the major problem behind the low level of organ donation is the lack of public understanding of the issues involved, especially on the part of ethnic minorities. A public information campaign targeted at ethnic minorities would help to dispel fears and increase the level of organ donation from those communities. Such a campaign, highlighting the contribution of organ donation to society and encouraging the take-up of donor cards or other methods by which individuals can make their wishes known, would not be incompatible with the principles of Sikhi.

We hope this statement of views will be of value to your inquiry and will help to clarify the views of the Committee.

Yours sincerely

Dr Jasdev Singh Rai

General Secretary
Church of England Mission and Public Affairs Division

G. Response to the House of Lords EU Social Policy and Consumer Affairs sub-committee call for evidence

Inquiry into the EU Commission’s Communication on organ donation and transplantation: policy actions at EU level

Introduction

1. The terms of reference of the Church of England’s Mission and Public Affairs Unit require it to assist in the Church in making a constructive and informed response to issues facing contemporary society. The Unit reports to the Archbishops’ Council and, through it, to the General Synod, the Parliament of the Church of England.

2. The Mission and Public Affairs Division warmly welcomes the opportunity to respond to the House of Lord’s Committee’s call for evidence on organ donation and transplantation. In particular we would like our responses to be seen as addressing your request to consider questions that may arise from a Faith-based point of view, even though they also largely address the issues raised in the first part of your call for evidence. We would like to emphasise that Christian faith is a positive motivation for organ donation and a powerful incentive for many people to donate.

Consent to organ donation

3. For Christians, acts of mercy are a part of the self-sacrifice that God requires of us. Christ is the paradigm of self-giving. Giving oneself and one’s possessions voluntarily for the well being of others and without compulsion is a Christian duty.

4. Christians have a mandate to heal, motivated by compassion, mercy, knowledge and ability.

5. The Christian tradition both affirms the God-given value of human bodily life, and the principle of putting the needs of others before one’s own needs. Organ donation is a striking example of this.

6. 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. The opt-in system reflects our concern to celebrate and support gracious gifts, freely given. The opt-out approach stresses Christian concern for human solidarity and living sacrificially for others. We are also concerned to understand moral questions like this in their wider social and political context and, here, the undoubted need for more organs to be donated for the healing of others has to be weighed against the changed relationship between persons and the State which moving to an opt-out system might entail.

Commercial arrangements for organ transplant

7. Selling organs for commercial gain would never follow from a Christian ethic. It confuses the notion of an organ as gift and turns it into a commodity.
Living donors
8. However, altruistic organ donation from a living donor would flow from a Christian ethic, provided there was no coercion, no commercial gain, and above all no harm to the living donor. That the organ might go anonymously to a recipient, unknown and unrelated to the donor, only heightens the self-giving of the donor.

Public awareness
9. If the present opt-in system is to continue, it will need to be backed by a properly resourced programme of public awareness-building and education.

Respect for the dead
10. Our experience as pastors at the time of the Bristol and Alder Hey enquiries has shown us that the body is crucially important to bereaved parents and friends. There were numerous requests for burial services for body parts of children that had already been buried. The body is to be respected and the continuity between life and death in the form of what is done with the body matters. The body at its burial or cremation should ideally be recognizably the body of the person who has died.

11. However, though body parts must always be treated reverently, they should not be mistaken for the person him or herself. The reverence is perhaps expressed best in the use of body parts only and always for healing others. The harvesting of organs should not be such as to violate this continuity or to cause unnecessary distress to the mourners.

12. It is extremely important to be clear about the point of death, particularly when there is a pressure to maintain organs in a healthy state before harvesting them. This, again, is of vital importance to the bereaved.

European-wide organization of transplant services
13. We welcome the potential for Europe-wide organization of organ transplant services if a just system can be devised: member states will need to ensure that there is a balance between the organs they can provide and those their citizens need for transplant otherwise some nations will be jeopardized and worse off than hitherto. For example, all member states would need to adopt the same opt out or opt in approach to consent for organ donation.

Rt Revd Tom Butler
Bishop of Southwark
Vice-Chair, Mission and Public Affairs Council
4th October, 2007
The potential impact of an opt out system for organ donation in the UK
A report from the Organ Donation Taskforce

SUPPORTING INFORMATION

ANNEX M
(Cultural Working Group Report)

APPENDIX D
(PRIAE Summary Report of the Being a Donor Project)
Summary Report of the Being a Donor Project

July 2008

Executive Summary
PRIAE has established a grassroots education campaign in Leeds, London and Manchester to increase the numbers of blood, bone marrow and organ donors from the South Asian, African Caribbean and Chinese communities.

The campaign involves all the national donor agencies in delivering community-based events which present the facts of being a blood, bone marrow and organ donor. These events are also an opportunity for the black and minority ethnic (BME) community to ask questions and clarify any misunderstandings.

More than 230 individuals from the BME communities have attended these events. They believe a word of mouth campaign with a strong cultural context is the most effective method to increase the numbers of donors from their communities.

Consequently, PRIAE has created a 3-day programme to train local people as Donor Champions. This training will equip local people with the skills to stimulate discussions on being a blood, bone marrow and organ donor in their communities as well as being key ‘links’ within the communities for the donor agencies. Sixty people from the BME communities have come forward to undertake this training. The first (pilot) training programme for twenty of these individuals is in Leeds from September – October 2008.

1. Introduction
In May 2007, the Department of Health awarded the Policy Research Institute on Ageing and Ethnicity (PRIAE) with Section 64 funding for three years to develop a campaign to increase the number of blood, bone marrow and organ donors from the minority ethnic communities as well as build further knowledge and experience of good practice in the area.

2. Background
Year One has involved collating and co-ordinating good examples of practice, including engaging recipients, donors and those awaiting transplantation as well as those who work in the field of ‘being a donor’. The Project uses a community development approach, i.e. identifying and working from the needs and understanding of the BME communities.
This information - in addition to the community-based events - will be integrated into planning and developing 3-day health education campaign in collaboration with the key partners.

Before outlining the purpose and learning from the community-based events, it is necessary to demonstrate the collaborative element of the Being a Donor Project – working alongside organisations that share a remit to increase the number of blood, bone marrow and organ donors within the minority ethnic communities.

2.1. **National Multi-agency Being a Donor Group**

To avoid duplication of effort and ensure good practice was shared across the donor sector, PRIAE established a national Multi-agency Being a Donor Group. This Group comprises the following key partners:

- UK NHS Transplant (and Blood)
- National Blood Service
- Transplant Trust
- Anthony Nolan Trust
- Transplant Support Network
- UK Transplant Co-ordinators Network
- African-Caribbean Leukaemia Trust
- METRAN
- Transplant Sport UK
- UK Diabetes
- Sickle Cell Society
- GIFT (a Children’s Transplant Charity)

The Group meets on a three monthly basis and has already met three times: January 2008, April 2008 and July 2008.

The aim of the Group is to enhance the number of blood, bone marrow, organ and tissue donors in the UK, which will reflect the diversity of the UK population.

This aim will be achieved by:

- Educating the public and raising the public’s awareness of being a donor, particularly in the black and minority ethnic (BME) communities, by working collaboratively and delivering multi-agency campaigns
- Educating the public, private and third sector organisations by bringing feedback and learning from the grassroots campaigns into our respective organisations, networks and forums
- Building relationships of trust with the public, particularly BME communities, and related donor organisations by integrating the

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1. The community events are explained in more detail under item 4: Creating Donor Champions.
2. Please note that the National Blood Service only covers England and North Wales. Whilst PRIAE and Transplant Trust are UK-wide
3. BME communities include all ethnic groups such as Eastern European, African, Middle Eastern etc.
public’s comments and feedback into the practice of our respective organisations, networks and forums

• Keeping up to date with developments in the donor sector by sharing information and resources as well as networking and keeping in regular contact with each other

Some members of the Group are actively involved in the community events as well as creating the 3-day training for Donor Champions⁴.

2.2. Expert Working Group
In addition to ensuring the learning from the project is shared with key donor agencies, PRIAE is also a member of the Organ Donation Taskforce Cultural Expert Working Group. This has provided PRIAE with the opportunity to keep up to date with the latest research and developments in the field of organ donation as well as share its learning with other key organisations promoting organ donation within the BME communities.

3. Community Events
PRIAE carried out an appraisal of previous campaigns that have raised the awareness of being a blood, bone marrow or organ donor in the UK-based BME communities.

3.1. Assessment of Good Practice
Only one UK-based campaign has been evaluated for impact, i.e. has evidence to show its campaign increased awareness of being an organ donor within the BME communities. The UK Transplant Service (UKT) carried out an evaluation on the ‘Why every person needs to know about organ donation’ (2002). UKT found investing time early in the project to understand the cause of the problem was vital to increasing awareness as well as understanding the emotional barriers.

Other reports have only identified the attitudes and barriers to being an organ donor. The UK Transplant ‘Can we count on you’ campaign (2004) identified the barriers for ethnic minorities to donate. Furthermore, UK Transplant’s qualitative Research Project ‘South Asian and Black Organ Donation: Report of Key Findings’ report (May 2006) identifies the key issues, barriers and attitudes within the BME communities from all its UK-based campaigns as well as a way forward. Evaluation and monitoring information from other UK blood and bone marrow campaigns are unavailable.

To ensure impact can be demonstrated, PRIAE requested and has been allocated a tracking number by the UK Transplant to ‘track’ the number of donors who come forward from the PRIAE managed community events and its community-based campaign. The PRIAE code for UKT donor leaflets is: 1589.

⁴ This is explained in more detail under Year Two subsection of this report.
The National Blood Service and Anthony Nolan Trust are monitoring where people heard about ‘being a donor’ – particularly those coming forward from the BME communities. It is envisaged this information will be fed back to PRIAE.

The UK Conference of Organ Donation, Faith and Culture, which was held on the 22nd June on 2005 at the University of Central Lancashire, did not retain any of the conference materials. None of the members of staff who were employed to organise the conference are now working at the University. However, the UK Transplant leaflet ‘Organ Donation and Religious Perspectives’ was developed from this conference and is promoted to persons attending the community events.

PRIAE also carried out a brief appraisal on academic publications on being a donor, which have been carried out in the UK and abroad. Key learning from the appraisal included:

- using a grassroots community network approach with culturally sensitive language is most effective (Davis et al, 2004)
- educating the health professionals to help them approach the subject of being a donor (Frezza et al, 1999)
- involving adolescents in the campaign (Sirois, B et al, 2005)
- designing situational manipulation to arouse value-expressive needs (Julka, D. et al, 2005)
- targeting parents and families (Saub, E.J, 1998).

This information was embedded in designing the community events.

3.2. Community Event Programme
In brief, the events are an opportunity for the community to:

- learn about what it means to be a blood, bone marrow, tissue or organ donor
- meet the ‘experts’ from the various donor organisations
- have an opportunity to ask questions to dispel any myths as well as tell us what they think are the barriers (within their community) to being a donor.

In addition to national donor agencies, partnerships were also developed with community-based organisations.

3.2.1. Community Partnerships
Over the past ten years, PRIAE has established links with over 1500 community groups across the UK. PRIAE engaged nine community-based organisations to deliver the project, i.e. three ethnic communities within three localities across England.

The three ethnic communities comprise the South Asian, African Caribbean and Chinese communities. Three geographical areas were also identified in

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5 A copy of the programme can be found in Attachment One of this report.
the application to the Department of Health. It was agreed within PRIAE to focus the campaign in Leeds, London and Manchester. This was to determine whether there were any common themes of attitudes and barriers to being a donor within the different ethnic groups and/or any geographical variations.

A partnership contract was agreed and signed with the individual community organisations. In brief, the agreements outlined the professional boundaries. For example: community organisations are responsible for hosting the event, i.e. preparing the venue for the presentations, workshops and food. PRIAE is responsible for supporting the community organisation as well as liaising with the presenters and preparing the delegate information packs\(^7\).

### 3.2.2. Community Engagement

From November 2007 – August 2008, seven out of the nine community events have been held: two in Leeds, two in Manchester and three in London\(^8\).

233 people from local BME communities have attended seven events. The following table outlines the number of attendees, speakers and those who want to undertake the Donor Champions training.

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<th>African and African Caribbean Events (3)</th>
<th>Chinese Event (1)</th>
<th>South Asian Events (3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attendees</td>
<td>88</td>
<td>17</td>
<td>128</td>
</tr>
<tr>
<td>Speakers</td>
<td>21</td>
<td>10</td>
<td>19</td>
</tr>
<tr>
<td>Total</td>
<td><strong>109</strong></td>
<td><strong>27</strong></td>
<td><strong>147</strong></td>
</tr>
<tr>
<td>Local Persons interested in being ‘Donor Champions’</td>
<td>25</td>
<td>9</td>
<td>26</td>
</tr>
</tbody>
</table>

Evaluations are completed on the day. Overall feedback show that the events have provided people with an opportunity to talk about an unfamiliar subject and have learned ‘what is means to be a blood, bone marrow, tissue and organ donor’.

Comments included:

> “The programme was well put together, interesting and well delivered”

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\(^6\) These were identified in the proposal and application submitted to the Department of Health

\(^7\) Delegate packs include a programme, speakers’ profiles, organ donation leaflet, a brief on the 3-day training programme and an evaluation form.

\(^8\) The community events within the Chinese communities had been provisionally booked for early July. However, owing to the earthquake in May in China, it was agreed to postpone these events until August 2008.
“Everyone got involved in the discussions and wasn’t afraid to ask questions”

“The content of the presentations helped to dispel a lot of fears and myths, particularly about giving blood”

“Real life experiences very moving and gave the event a human feel”

“The venue because it is in the community”

“Attendees able to make contact with key organisations”

“This is a great programme to raise awareness in the Asian/Black communities”

3.2.3. **Attitudes and Barriers to Being a Donor**

The morning of the community-based events enabled the donor agencies to present the facts of being a blood, bone marrow and organ donor to the community. The afternoon programme included participatory workshops to ask the community’s perspective on barriers and attitudes to being a donor as well as asking their advice on appropriate cultural messages and approaches to include in the campaign.

The main attitudes and barriers that have been expressed by the Chinese, South Asian and African Caribbean communities in Leeds, London and Manchester on being a donor have been:

- **Fear**, e.g. having a fear of needles and mutilation of the body. Body/image was raised as being important to the African Caribbean communities

- **Ignorance** and naivety about what it means to be a donor, e.g.
  - there is no age limit to donating organs
  - people don’t realise there are two different ways to extract bone marrow or that there are 38 tests on blood are carried out before it is used or you can be a blood donor up to the age of 66. People believe providing this information may increase the number of blood donors from the BME communities
  - some believe that not everyone can give blood such as third world immigrants
  - there is some controversy within peoples understanding of religion if people are able to donate. For example, different sub groups within the Islamic/Muslim community have different schools of thought, which may lead to confusion as one will say being a donor is acceptable and others will argue against the point. Or, culture can be more of an obstacle as apposed to religion, as people may hide behind culture and say it’s due to faith
• **Lack of trust** with the professionals, e.g. some people felt that there might be incentives for medics not to resuscitate patients to obtain their organs
• **Racism** towards the African Caribbean communities. This issue was raised in all three African Caribbean events. The messages included: “The need for blood, tissue, bone marrow and organs is a white middleclass issue” and “People have long memories. In the 1960s people from the black community were turned away when they wanted to donate blood”
• Death is a **taboo subject** and is not discussed within families. This was raised as an issue within the Chinese community
• **No relevance** or significance. People who feel socially excluded also feel ‘what has this got to do with me’ – I’m not important. Many said people don’t have the time to donate (e.g. blood or bone marrow) and don’t think it is important to them

3.2.4. **Increasing the Number of Donors**
The afternoon workshops were also an opportunity for the audience to offer their suggestions on approaches that might increase the number of blood, bone marrow and organ donors from the BME communities. These included:

• **HAVING A CULTURAL CONTEXT:**
  o Have more ‘Being a Donor’ community events in the community. Nearly all attendees felt that this was the best way to raise awareness and stimulate discussion within families. Word of mouth was seen to be the most effective way of increasing the number of donors from the BME communities
  o Have speakers from the cultural community, e.g. the South Asian event in Leeds involved a South Asian donor relative (husband of a wife who died suddenly from a brain haemorrhage), the African Caribbean event involved two African Caribbean persons who had received a kidney, the Chinese event involved a Chinese person awaiting a bone marrow transplant – this made it very real for the audience
  o Include speakers from the cultural community, e.g. at the South Asian event in London – the workshops were conducted in English and Gujarati. This enhanced the participation and discussion of the audience
  o Influence people through the religious leaders. If a religious leader signs up to the idea, s/he will influence others
  o Use talent within the community such as plays, writing poetry, songs, dance
  o Campaigns to target key events and social centres such as:
    - Churches
    - Community centres
    - Charity balls/functions
    - Elderly African Caribbean societies
    - Local newspapers and radio
    - Carnival/festivals
• BEING CULTURALLY SPECIFIC
  o African and African Caribbean communities: to only have clinical screening. Don’t have the social screening system, as it discriminates against black people. For example: the question of having a sexual partner from an African country excludes a lot of the community. AIDS and HIV is an international problem. National Blood Service needs to change is ‘social screening’ and only have ‘clinical screening’ in place. If this was the case, more black people would come forward to be donors.
  o Throughout all the campaigning that is carried out for encouraging better take up of donors (blood, bone marrow, tissue and organ), there is a need to include more people from the actual communities themselves to sell it to others.

• HAVING A HUMAN TOUCH
  o More promotion/campaigning done via personal stories and case studies such as having recipient’s talking at the events. Please note that this is integral to the PRIAE Project – involving donor recipients and donor families to raise awareness in BME communities.

• MARKETING APPROPRIATELY
  o have marketing (e.g. blood, organ, bone marrow) leaflets that show the diversity of the UK rather than have separate leaflets for the individual racial groups. Having separate leaflets segregates the community from the mainstream.
  o keep the campaign visual – have lots of pictures rather than text. The African and African Caribbean community suggested having cartoons instead of text.
  o In the African Caribbean community most people are from the Christian faith, so need to cascade the information through the church hierarchy. For example: Campaign ‘Hope 2008’ – addressing this issue of utilising churches to reinforce the message of being a donor.
  o Target unemployed people, they have more time to give blood and ‘feel good factor’ for them as they are doing something worthwhile.

• USING THE MEDIA
  o Media can be positive or negative. There needs to be a positive image about being a donor throughout the media. Most people agreed that bad news travels faster/quicker than good news. Impact from the bad news stays longer in people’s mindset and may be harder to challenge.

• CONNECTING WITH YOUNG PEOPLE
  o target the young people – have an education campaign in schools. This is already in place but is voluntary.
  o There needs to be a social responsibility in school to help with highlighting the issue for the younger generation. This has
already been raised and implemented at some schools with information packs on blood and organ service.

- **STIMULATING DISCUSSION WITHIN FAMILIES**
  - It was agreed that families need to talk about ‘being a donor’ but need the facts to start those discussions. Consequently, nearly all attendees thought that the 3-hour morning session of the Being a Donor community event (followed by lunch) was an effective method for the donor agencies to give facts to the audience and the opportunity for the audience to ask their questions.

- **EDUCATING THE PUBLIC ON THE FACTS**
  - Time is vital! People can’t take time to decide about donating organs after a death. People need to understand that they have to make an ‘asap’ decision.

- **WORKING TOGETHER**
  - There needs to be a connected ‘web’ of agencies working together to promote ‘being a donor’. Please note that this is integral to the PRIAE Being a Donor Project – connecting the donor agencies to raise awareness in BME communities. It is the first time that a charity such as PRIAE is involving all the donor agencies in a strategic and operational approach to planning, developing and delivering a community-based, community-focused education campaign on being a blood, bone marrow and organ donor within the BME communities in the UK.

3.2.5. **Partners Actively Participating**

The National Blood Service, Anthony Nolan Trust, Transplant Support Network Transplant Trust and the African Caribbean Leukaemia Trust have actively participated in and attended all the events.

To date, very few clinicians from the Transplant community have engaged in the Project. For example: only two UK Transplant Co-ordinators (regional and local representatives) attended the African Caribbean event in Leeds.

Support and commitment to the Project have been received from the UK Transplant Service (Marketing Department) and the Chair of the UK Transplant Co-ordinators Network (TCN) but there has been no response by clinicians to e-mails being sent by the Chair of the TCN or telephone contact initiated by the UK Transplant Service.

PRIAE believes active participation of clinicians at a local level (e.g. in the community-based events) may help to build relationships of trust. The Chair of the UK TCN will be leading and involving her transplant colleagues in the 3rd day of the training programme for Donor Champions.

4. **Creating Community Donor Champions**
Nearly all attendees agreed that a word of mouth campaign, which has a strong cultural and social context, would be the most effective method to increase the number of blood, bone marrow and organ donors within the BME communities.

As one person, who attended the South Asian event in Manchester, wrote:

- "Communication is key – but has to be tailored to the specific audience, group you are addressing. It varies from group to group their specific barriers or issues which can be problematic which reinforces the need for 2 way communication programme. An opportunity to say what's on your mind and share/build bridges".

During the community events, PRIAE introduced the idea of a three-day training programme to the BME communities. The three-day programme includes:

- an opportunity to see the process of being a blood and/or bone marrow donor (e.g. from taking the blood/bone marrow being taken through to it being tested and to being stored)
- meeting and discussing about ‘being a donor’ with the various religious leaders and health professionals
- having an opportunity to talk about death and dying as well as learn ‘how to approach’ the subject within the family

This programme follows the Organ Donation Taskforce report (and particularly recommendation 13). Therefore, the training is being aligned with creating Donor Champions. Once completing the 3-day training, the Donor Champions will:

- be able to speak with better knowledge and understanding in order to explain being a blood, tissue, bone marrow and organ donor in their communities
- understand the professional boundaries between the different agencies that are involved in being a blood, bone marrow, tissue and organ donation
- know who to contact in their local area as regards being a blood, bone marrow, tissue and organ donor
- receive the ‘Being a Donor Community Event Programme Pack’ to enable them to organise community events
- support the Radiodonation Project\(^9\)
- work alongside staff from the donor agencies - offering help, support and advice on appropriate cultural/social context at local community events
- be linked to donor agencies that have a volunteering programme such as Anthony Nolan Trust and the National Blood Service.

The concept of training Donor Champions from the community was very well received. To date, PRIAE has the contact details of sixty individuals who

\(^9\) This project is being led by a Transplant Co-ordinator in the South West. He intends engage the Donor Champions in promoting organ donation through local community radio.
would like to attend the 3-day training programme\textsuperscript{10}. The first (pilot) programme for twenty individuals will be in Leeds on the 30\textsuperscript{th} September, 7\textsuperscript{th} October and 27\textsuperscript{th} October 2008.

It is intended that the 3-day training will give motivated members of the community - the knowledge and links to stimulate discussions within their communities about being a donor. It is anticipated that this approach will create a focused, appropriate campaign which results in a significant rise in the numbers of ethnic minority donor registrations.

The first year of the ‘Increasing BME Donor Registration’ Project has been challenging and rewarding. Feedback from the events has been very positive. And, through PRIAE, partner donor agencies have been able to make direct links to and listen to the needs of BME communities about being a donor.

References:


\textsuperscript{10}An outline of the 3-day programme can be found in Attachment Two of this report.
‘Being a Donor’ Project

Welcome to the ‘Being a Donor’ event! We hope that you will enjoy the day – learning something new as well as meeting new and old friends.

The agenda for the day is as follows:

10.00 – 10.15am: Registration and Refreshments

10.15 – 10.30am: Introduction to and Purpose of the Day
Yolande Watson, Project Manager of the Project

10.30 – 10.45am: Introduction to Being a Blood Donor
Andrew Calvert, National Blood Service
Zeeshan Asghar, National Blood Service

10.45 – 11.00am: Introduction to Being a Bone Marrow Donor
Azra Iqbal, Anthony Nolan Trust

11.00 – 11.15am: Refreshments

11.15 – 11.30am: Why being a Donor is Important
Sue Pearson, Transplants in Mind

11.30 – 11.45am: What ‘Extra Life’ Really Means
Liz Hosford, Transplant Support Network and Kidney Recipient

11.45 – 12.30am: Questions and answers session
PANEL

12.30 – 1.30pm: LUNCH

1.30 – 1.45pm: Introduction to the Purpose of the Workshops

1.45 – 2.45pm: Workshop 1: What are the current attitudes and barriers to being a blood, tissue, bone marrow and organ donor in the South Asian community?

Workshop 2: What sort of messages and activities would increase the number of people from the South Asian community signing up to being a donor?

2.45 – 3.00pm: Refreshments

3.00 – 3.30pm: Feedback from Workshops
3.30 – 3.45pm: Close
<table>
<thead>
<tr>
<th>LEEDS</th>
<th>DAY 1: 30/09/08 Lecture Hall, National Blood Service, Seacroft Hospital</th>
<th>DAY 2: 07/10/08 Thackeray Medical Museum</th>
<th>DAY 3: 27/10/08 Thackeray Medical Museum</th>
</tr>
</thead>
<tbody>
<tr>
<td>10am – 10.45am</td>
<td>Introduction to the Project and Day The role of Donor Champions Ice breaker – getting to know each other</td>
<td>Recap of the Project. Introduction to the Day Feedback since last training day. Any new blood donors?</td>
<td>Recap of the Project. Introduction to the Day Feedback since last training day.</td>
</tr>
<tr>
<td>10.45am – 11am</td>
<td>Discussion on Project: fears, concerns, opportunities</td>
<td>Being a Blood Donor Quiz (fun!)</td>
<td>Introduction to Organ Donation: Facts (when can you give what) and Figures</td>
</tr>
<tr>
<td>11am – 11.15am</td>
<td>Refreshments</td>
<td>Refreshments</td>
<td>Refreshments</td>
</tr>
<tr>
<td>12midday – 12.45pm</td>
<td>Group 1: W/shop Group 2: Tour</td>
<td>Group 1: W/shop Group 2: Tour</td>
<td>Group 1: W/shop Group 2: Tour</td>
</tr>
<tr>
<td>12.45pm – 1.30pm</td>
<td>LUNCH</td>
<td>LUNCH</td>
<td>LUNCH</td>
</tr>
<tr>
<td>1.30pm – 2.00pm</td>
<td>Why giving blood is important. Introduction to Sickle Cell and Thalasemia</td>
<td>Why do people need bone marrow? Meeting bone marrow recipients and bone marrow donors</td>
<td>Faith Discussion: Christian and Judaism Knowing what I know now - what are the implications of being a blood, bone marrow or organ donor for my community from a faith/cultural perspective? Feedback</td>
</tr>
<tr>
<td>2.00pm – 3.00pm</td>
<td>Faith Discussion: Hindu and Sikh What are the implications of being a blood, bone marrow or organ donor for my community from a faith/cultural perspective? Feedback</td>
<td>Faith Discussion: Islam and Buddhist What are the implications of being a blood, bone marrow or organ donor for my community from a faith/cultural perspective? Feedback</td>
<td>2.30pm – 3.15pm The role of TIM and TSN. Meeting donor families and donor recipients</td>
</tr>
<tr>
<td>3.00pm – 3.15pm</td>
<td>Refreshments</td>
<td>Refreshments</td>
<td>3.15pm – 3.30pm: Refreshments</td>
</tr>
<tr>
<td>3.15pm – 3.45pm</td>
<td>Mini W/shop: What can we do to promote blood donation in our community (having NBS marketing materials to hand)</td>
<td>Mini W/shop: What can we do to promote bone marrow donation in our community (have ANT and ACLT marketing materials to hand)</td>
<td>3.30pm – 4pm: Mini W/shop: What can we do to promote organ donation in our community</td>
</tr>
<tr>
<td>3.45pm – 4pm</td>
<td>Close Evaluation</td>
<td>Close Evaluation</td>
<td>4pm – 4.15pm: Evaluation Next Steps</td>
</tr>
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</table>
The potential impact of an opt out system for organ donation in the UK
A report from the Organ Donation Taskforce

SUPPORTING INFORMATION

ANNEX M
(Cultural Working Group Report)
APPENDIX E
(BECOMING AN ORGAN DONOR: ORAL HISTORIES OF PEOPLE FROM THREE ETHNIC BACKGROUNDS)
BECOMING AN ORGAN DONOR: ORAL HISTORIES OF PEOPLE FROM THREE ETHNIC BACKGROUNDS

Glenn Smith, Sonia Saxena, Josip Car, Neerja Jain, Pauline Reece, Harvinder Dulku and Anthony Warrens

Key Words: Organ donation, ethnicity, identity, social environment, oral history

Summary

Background

This study aimed to explore how people from three ethnic backgrounds who held a positive attitude towards organ donation had integrated the concept into their ethnic identity. We wanted to understand how they incorporated the concept of organ donation into their cultural and religious beliefs, overcame their fears and what fears they continued to struggle with.

Methods

We undertook in-depth oral history style interviews with 50 participants (18 - 68 years) from a white British/Irish, African Caribbean and South Asian ethnic
background who held a positive attitude toward organ donation. Interviews were recorded and transcribed. Data were coded and emerging themes explored using Giddens’s theory of ‘identity as narrative.’

**Findings**

There were currently and historically more social resources available in more social environments for participants of white British/Irish descent to draw on to integrate organ donation into their identity. With less exposure to fewer resources, participants of African Caribbean and South Asian descent also had to manage feelings of social isolation, and negotiate racial prejudice and definitions of ethnic identity. Overall, the availability of resources was weak in most environments apart from those related to medicine.

**Interpretation**

These oral histories provide insight into the social processes by which people integrate the idea of organ donation into ethnic identity. Our findings have implications for the direction of local and national organ donation campaigns and government policy, to bridge the gap between a willingness to donate and actual donation, particularly for ethnic minority populations.

**INTRODUCTION**

Despite the success of transplantation as a medical treatment, there remains a gap between people’s willingness to donate and actual donation rates (33). The size of that gap is argued to be related to ethnicity, with a particular shortage of
donations from people of South Asian and African Caribbean descent (18). Since some organs are matched by tissue type and blood group, an organ donated from, and to, a person of the same ethnic background is more likely to be successful (18, 27). Unfortunately, within the United Kingdom (UK) people from South Asian and African Caribbean ethnic backgrounds are more likely to need an organ transplant because of higher rates of high blood pressure and diabetes than their white British/Irish peers (6, 7, and 10).

Studies looking at the relationship between ethnic identity and organ donation have largely focused on ‘attitudes’ and ‘beliefs’ that may prevent donation (22). They have also focused on the psychological and demographic profiles of people willing to become organ donors (23). This research has highlighted a lack of knowledge and a ‘non-specific disinclination’ (19); fear of not receiving optimal medical treatment because of low social status (25, 35); knowledge of medical experimentation on people of African Caribbean descent (28); concern about transgressing or devaluing cultural and religious beliefs (3, 9, 14); and difficulty talking about organ donation with family (19, 26). Several interventions to tackle these negative ‘attitudes’ and ‘beliefs’ have been proposed and implemented. These include: educating ethnic minorities (9); promoting culturally and religiously sensitive information and media (2, 5); using celebrities in campaigns; educating young people (31); obtaining an official religious stance on organ donation (29); informing religious leaders to teach organ donation (13); and encouraging more conversations about organ donation with family (19).

However, these interventions have had a limited success and there remain disproportionately low rates of organ donation among ethnic minorities, the
cause of which is clearly not fully understood (22). Morgan and Morgan, suggest that future work to improve donation rates should explore the social context of ethnic minorities, since low rates of donation are not adequately explained by cultural or religious beliefs (21, 22). Sque also argues that the act of donation depends more on the factors present at the time of donation than the positive views of donation held by relatives of the deceased, or the deceased in life (33).

This project aims to understand better the relationship between a willingness to donate and ethnic identity to identify how actual donation rates could be improved. We considered that a fruitful avenue of inquiry would be to explore and contrast how people from a South Asian, African Caribbean and white British/Irish ethnic background integrated the concept of organ donation into their identity over their lifetime.

**METHOD**

**Study design**

One way of understanding the complex social processes involved in integrating organ donation into ethnic identity is to use a life story method. Giddens proposed the concept of ‘identity as narrative’ which considers the stories we tell about ourselves as defining who we are (15). These stories are influenced by our ability and the availability of ‘resources’ within our social environment which enable us to assimilate life changes into the narratives we tell about ourselves (15). The importance of understanding the social environment in constructing identity is also supported by the work of Bondi (8), Harvey (17) and Soja (30). Furthermore, storytelling has a long history of conveying ethnic identity fluidly
“determined by history and interpreted in response to history” (1, page 1). As Ciancio and Morgan suggest, future research should acknowledge ethnic identity as fluid, dynamic and diverse (11, 22).

Participants
We obtained ethical approval from Hammersmith Hospitals NHS Trust ethics committee. We advertised the study throughout the UK to attract participants who held a positive attitude toward organ donation and who self-identified as from a South Asian, African and Caribbean (African Caribbean) and white British/Irish ethnic background. We recruited through articles in multi-ethnic newspapers, newsletters and websites of transplant charities, interviews on several ethnic minority radio programmes, using a local GP research network (WeLRen), messages posted on ethnic minority internet forums, snowballing, leafleting the public, mass email on a city councils’ intranet, approaching members of churches, mosques, temples and ethnic minority community organisations, and advertising on our study website. We sampled purposively until we felt we had captured the range of themes that reflected the social resources that enabled people to integrate organ donation into ethnic identity, taking into account differences between ethnic backgrounds. Participants came from the Sikh, Hindu, Muslim, Seventh-day Adventist, Catholic and Church of England faiths. Fifteen participants of South Asian and African Caribbean descent had been born abroad; however most came to the UK as a child or adolescent (See Table 1.1 for a breakdown of our sample). GS undertook oral history style interviews with participants that traced their experiences, thoughts
and feelings from the first time they remembered hearing about organ donation through to the present.

Analysis

We analysed the data concurrently with our sampling of participants assisted by qualitative analysis software. Using Gidden’s (15) theory of ‘identity as narrative’ the data was explored for social resources that influenced the integration of organ donation into participants’ lives. The resources were then coded and assigned to social environments; we identified six social environments. The authors participated in a series of discussions about resource themes to resolve discrepancies and to reach a consensus on interpretation.

Results:

The Home Environment – the childhood and adult home

Several participants from a white British/Irish ethnic background recalled their parents being blood donors and/or working within the National Health Service (NHS). They also recollected watching television programmes about organ donation as a child:

“Honestly, when I was growing up Prof. Yacoub at Harefield used to be on the news every other week with the next heart transplant!”

*Harold, 38, white British/Irish ethnic background (EB)*
Fewer participants of South Asian and African Caribbean descent were exposed to these social resources as children. As adults, many participants expressed indifference to television and radio programmes about organ donation, apart from those few that touched on their concerns, fears and/or challenged their views. Indeed, watching other people of African Caribbean descent integrating organ donation into their lives helped one participant from an African Caribbean ethnic background to question her fears about becoming an organ donor:

“I saw black people donating [for a local bone marrow appeal on television]. And I thought maybe I should go and have a look, but I wasn’t quite ready. I just wanted to know a bit more.”

*Paula, 44, African Caribbean EB*

Several participants spoke of their experience of bereavement within the family helping them manage fears of mortality. However, most conversations about mortality and organ donation were brief and uncomfortable, particularly for participants of South Asian or African Caribbean descent:

“The only concerns I had [about signing the organ donation card] was what the reaction would be from people at home – that was a major concern. I felt isolated a little bit.”

*Bandha, 56, South Asian EB*

Conversations for several participants of African Caribbean descent also involved feelings of mistrust toward the medical profession:
“Two things he [the participants’ brother] said were, ‘They would take my kidneys before I was dead and that they would only give my kidneys to a white man.’”

_Yolande, 50, African Caribbean EB_

On the other hand, a few participants of South Asian descent observed discussions within the home that resolved tensions between organ donation and cultural and religious beliefs:

“My grandmother was like, ‘You will hinder him [the participants’ father] in his next life, because of the reincarnation thing of Hindus.’ My mum said, ‘His reincarnation will be based on how good he was when he was living.’”

_Zahida, 22, South Asian EB_

This participant witnessed how her mother integrated organ donation into her religion through emphasising values over beliefs.

There were more resources over the life course within the home for participants from a white British/Irish ethnic background. Participants of African Caribbean and South Asian descent often found discussing organ donation with family members involved conflicts about ethnic identity which caused feelings of social isolation and discord. However, a few participants were able to witness ways of adapting beliefs to organ donation. Media that questioned beliefs and addressed fears about organ donation engaged with participants on an emotional level.
Educational Environments – schools, colleges and universities

Only a few participants had been educated about organ donation at school. One participant recalled having confused feelings when taught about the idea of organ donation:

“In primary school my teacher used to talk about donations. She explained there were [different] types. I thought it was a bit weird. I did not really understand the concept.”

Sara, 18, African Caribbean EB

A participant of white British/Irish descent described how his introduction to organ donation at school was presented in a far more engaging way as a social narrative of scientific achievement:

“It would be in school - when Dr Barnard performed the first heart transplant in the 60s - when I heard of it [organ donation]. It sticks in my mind. It was announced at school assembly in a new technology way.”

John, 53, white British/Irish EB

Several participants spoke of higher educational environments as providing a non-judgemental space in which to explore and discuss issues surrounding organ donation:
“I got a wider friend circle [at university] and they were more multicultural and open-minded. They wouldn’t come out with, ‘You can’t donate your organs because of your culture or your religion.’ It was discuss it and see.”

*Mina, 24, South Asian EB*

Only a few participants obtained resources about organ donation within the school environment. How and when these participants were taught about organ donation appeared to make a difference to their ability to engage with and embrace the idea. Higher education provided a unique space for participants to freely discuss, reassess and integrate organ donation into their ethnic identity.

**Medical Environments – the GP, pharmacy and hospital**

Most participants encountered the concept of organ donation within medical settings such as their GPs’ surgery, a pharmacy or within hospital. Participants described how organ donation campaign materials in these settings connected with their feelings, experiences and/or their values:

“I was sitting in a doctors’ surgery. I saw the organ donation leaflet and it caught my eye because it was red and red just happens to be my favourite colour! And it made sense.”

*Dalpinder, 29, South Asian EB*

Several participants who were transplant recipients or employees of the NHS described how witnessing people with organ failure within the hospital environment touched them emotionally:
“I think the fact that I started nursing patients who was on the machine, the length of time they’re on the machine, the things they went through; made me sort of think, appreciate the fact that they could come off this, it could be better for them; rather than this taboo thing.”

_Yolande, 50, African Caribbean EB_

On the other hand, donor family members spoke of how their welfare was emphasised over that of potential transplantees within hospital, in that they were not approached to donate their loved ones organs or their consent to donate was repeatedly asked for. Most participants with no experience of donation felt that the welfare of the donor within hospital was equal to that of the recipient. They rationalised this by reflecting on positive experiences of health care - a finding in line with Mocan (20), having family or friends working within the NHS, and acknowledging that medical decisions are influenced by political and economic context. However, for some participants of African Caribbean descent fears of unequal treatment within medical environments remained:

“I think there is a lot of issues in terms of how ethnic minorities generally - but specifically African Caribbean people - are treated in the mental health system and in other aspects of health.”

_Tracy, 30, African Caribbean EB_

For a participant of South Asian descent, medical environments were also difficult places in which to adapt religious and cultural beliefs with the concept of organ donation.
“I have a science background, and that makes it worse because you know [organ donation] it is going to save someone’s’ life. And you actually have [medical] students playing around with it [the dead body]. I wanted to be a doctor - that was twenty years ago - and things have changed, but personally that had a real backlash and I didn’t do medicine.”

Anita, 42, South Asian ethnic background, born in Uganda

Medical environments provided participants with many resources to engage with the idea of organ donation. These included campaign materials that connected with people sympathetic toward organ donation, resources to overcome a fear of not receiving optimal medical treatment as a donor, a space where the need for donors could be emotionally experienced, and an environment in which the donor was acknowledged equal to, if not more important than, recipients. However, these resources were not always able to fully resolve fears of racism or the adaptation of spiritual beliefs with a biomedical view of the body.

‘Communities’ – social relationships, social networks and public spaces

Most participants did not discuss organ donation with people beyond their immediate family. A few participants that sought out support for organ donation from amongst their social circle found it a difficult issue to discuss and these conversations sometimes left them feeling socially isolated:
“They [my friends] are from different [ethnic] backgrounds. I am unlikely come across another person who'd say, ‘I’d do it, yes, yes!’ When I want a discussion about it, they have hummed and arid a little bit. I understand why they do it; a lot of people do not like thinking about death.”

_Dalpinder, 29, South Asian EB_

Few participants recalled organ donation advertised in public spaces in comparison to other medical conditions. However, a few participants of white British/Irish descent described how the organ donation card played a part in socialising them about organ donation:

“We all had them [organ donation cards] at the same time - 17 and 18. You saw them when people opened up their wallets when you used to go to the pub.”

_Harold, 38, white British/Irish EB_

Despite a few participants of African Caribbean descent having friends sympathetic toward organ donation, several participants recalled encountering concerns amongst their social circle about racism within transplantation medicine. One young participant conveyed how this socialised fear of racism changed her positive view of organ donation:

“I had a [organ donation] card and threw it away! You go through the underground, networking as a black person, and you get the truth or some part of the truth. I thought, ‘Yeah, there could be a great probability [of taking organs prematurely] after all the things that have happened to a lot of black people in this country.’”

_Trisha, 44, African Caribbean EB_
Furthermore, a few participants from an African Caribbean ethnic background felt that using celebrities to promote organ donation failed to connect with this African Caribbean social history of inequality. Other participants were suspicious of appeals for organs requested, but not donated on the basis of ethnic identity; and felt that promotional materials using people of African Caribbean descent to appeal for donors of African Caribbean descent, conveyed stereotyped images of Black people and reinforced a notion of racial segregation.

Only a few participants had met a donor or transplant recipient. These meetings were usually at charity events in aid of organ donation. However, participants felt that meeting donors and recipients created an emotional connection with the idea of organ donation:

“I did a charity walk for the local hospital and the chap we were walking for had had a transplant. I met his wife and children and from talking to her you really felt for her because she was like, ‘Our life had just been on hold.’”

Zahida, 22, South Asian EB

The availability of resources was limited within public spaces. Some resources enabled white British/Irish participants to become more accustomed to the idea of organ donation as a social norm. Other participants found obtaining social support for their positive view of organ donation difficult, particularly those participants of African Caribbean descent who had to negotiate concerns about racism within medicine. Campaign materials were largely invisible in public spaces and those observed failed to tackle issues of racism, in some cases
causing further sources of mistrust. Emotional contact with donor families and transplant recipients was missing in everyday social environments.

**Work Environments – workplaces**

Several participants recalled being encouraged to donate blood within their working environment. This experience gave one participant the confidence to register as an organ donor. Several participants also spoke about discussing and defending with work colleagues controversial issues relating to organ donation:

“The George best thing - people did mention that in work. There were a couple of negative comments on wasting it on someone like him. I would not go along with it because I’ve seen a lot of people [friends and family] who have developed habits on drugs and alcohol over the years.”

*John, 53, white British/Irish EB*

This participant drew upon his personal knowledge of addiction to inform his defence of the complex ethics involved in allocating an organ to George Best. However, a few participants of South Asian and African Caribbean descent, also using past social experiences, found that the issue of ethnic identity became the focus of this discussion with colleagues:

“The other [African Caribbean] colleagues of mine say this is the problem in the Western world. If this was in Africa there was no way” [George Best would be transplanted].

*Gary, African Caribbean EB*
Resources for blood donation within the workplace introduced the idea into some participants’ lives. The workplace provided a unique public space to discuss issues related to organ donation in the media. However, participant’s positive about organ donation had to defend its practice with unsympathetic colleagues using their own social resources. This sometimes involved rejecting values not associated with their ethnic identity.

**Religious Environments – temples, churches, mosques and spiritual spaces**

Nearly all participants attended a church, temple or mosque on a regular basis as a child. A few participants continued to regularly attend a place of worship as an adult, but only one participant recollected hearing about organ donation within a religious environment. This was due in part to the strong philosophical relationship between medicine and his faith:

> “I had heard about it [organ donation] before I came here [UK], because as Adventists we have a huge medical care system.”

*Paul, 46, African Caribbean EB*

However, most participants’ in adulthood emphasised practising religious values in everyday environments over attending places of worship and performing religious rituals:

> “I think it is very much what you do day-to-day, day in, day out, that counts. There is no point being a terrible person but going weekly to the Temple.”

*Zahida, 22, South Asian EB*
Nonetheless, participants spoke of their desire for further opportunities to discuss the relationship between religious beliefs and organ donation. For some - particularly those of African Caribbean descent - this meant exploring other religions, philosophies and spiritual spaces to discuss and resolve fears about organ donation and the afterlife:

“I believe in the soul, but I don’t go to a religious church. Buddhism has taken a big part of my life. That debate about the soul and spirituality is ongoing for me, before I can say, ‘Oh, I will go one step further’ [to become an organ donor]. It would be easier just having that debate in the right company.”

Kiley, 45, African Caribbean EB

Participants grounded their religion in everyday environments, emphasising religious values over beliefs and rituals to achieve this. To reconcile any conflict between organ donation, the afterlife and religious identity, participants sought out resources and environments in which they could discuss and resolve the complex relationship between individual, social and spiritual feelings.

Discussion

Participants of white British/Irish descent enjoyed more social resources over longer periods of time to enable them to integrate organ donation into their identity. With fewer resources, the ability of South Asian and African Caribbean participants to integrate organ donation into their lives, frequently risked social isolation. It also required people of South Asian, and in particular African
Caribbean descent, to attempt to reconcile the perception of racism within medicine without any external support. However, our research illustrates that the availability of resources overall to support the integration of organ donation into participants’ lives was weak in most environments apart from medical ones.

This study also shows that integration in a multicultural society is often dependent on the availability to obtain different perspectives and discuss the concept of organ donation freely, to experience beliefs being challenged and to witness how others adapt their beliefs to these challenges. This observation is in contrast to much previous research and subsequent suggestions as to how to improve donation rates which have viewed cultural and religious beliefs as fixed, vulnerable and taught, and ethnic identity as homogenous and/or collective. As evidenced here this approach can racially stereotype people and, it could be argued, may associate unfairly an unwillingness to donate organs with some ethnic minorities, subsequently contributing to the hesitancy of medical staff to request donation from them (16). It could even be suggested that this collective approach may have bolstered the perceived culture of non-donation for some ethnic minorities, and created mistrust if appeals for organs are based on ‘ethnic grouping,’ and then allocated on biological need.

The advertising of organ donation and the visibility of living donors and recipients of transplants was missing in most participants’ social and cultural environments. Furthermore, campaigns and the media failed to reflect and deal with participants’ fears, the issue of racism in medicine and did not engage and challenge those people who feel organ donation is not for them.
Limitations

While the mean ages for participants from a white British/Irish and African Caribbean ethnic background are similar, the mean age for those from a South Asian ethnic background reflects a younger cohort; so contrasting historical resources across ethnic backgrounds may have some limitations. There were fewer male participants from all ethnic backgrounds, so it was difficult to discern the impact of gender on people’s decision making. More focused research on gender would help unpick the relationship between gender, organ donation and identity across the life course, and build on understanding the relationship between age and social resources across different ethnic backgrounds. The reliance on memory is always a concern in oral history studies. However, the in-depth nature of the interviews, the saturation of data, and the importance of emotions and perception in understanding people’s experiences of organ donation we feel provides validity and credible evidence.

Conclusion

Future campaigns and research to improve donation rates in a multicultural society should re-focus their attention away from attempting to understand ‘attitudes’ and ‘beliefs,’ to improving and supporting the social resources and environments which aid the integration of organ donation into those ‘beliefs’ and which shape ‘attitudes.’ Whether we have an opting-in or opting-out consenting system, this focus would create a stronger social awareness and feeling about organ donation currently absent even in people who are positive. Below, we make several policy suggestions to illustrate how organ donation can be made
more “usual than unusual” (32) not only in medical environments, but also in peoples’ everyday social environments.

Firstly, the government should focus on supporting, expanding and creating new social environments in which organ donation can be discussed freely at a grassroots level, so that people learn from others how to adapt ‘beliefs’ to the concept of organ donation. This would create a social narrative about donation that sits comfortably with their individual identity. These findings resonate with Khan and Randhawa’s (21) recent work.

Secondly, campaigns should support more opportunities to meet donor families and transplant recipients in everyday social environments, so that the publics’ knowledge of donation is grounded in reality and emotion. Organ donation in the media should be conveyed in a more sophisticated way to provoke informed, frank and balanced discussions and help people overcome fears.

Thirdly, further research should be undertaken to develop a better understanding of how and when to educate young people about mortality and organ donation; and to explore, as Morgan (26) also concludes, techniques that people can use to initiate, maintain conversations and manage emotions that emerge when the topic of organ donation is broached not just with family, but with friends, work colleagues, religious leaders and medical professionals.

Fourthly, national campaigns should publicise the medical specialities working to save the potential donors’ life. The welfare of the donor is only seriously addressed within the medical environment of hospital at the time of donation.
Fifthly, national campaigns need to engage with and challenge those people who do not wish to become donors. This may mean creating campaigns that are based on several theories of human motivation and which draw upon a wider expertise within and across academia and the advertising industry.

Sixthly, those in authority need to reflect on their use of collective social identities (4). The promotion of organ donation should reflect the diversity and social politics of ethnic identity, avoid racial stereotypes, tackle the persistent perception of racism within medicine, and clearly explain the allocation process of donation. We suggest that an independent body made up of lay and professional members from ethnic minorities is established to oversee the welfare of ethnic minority donors and recipients at the macro level.

Lastly, we must not forget that there are already people of South Asian and African Caribbean descent who are positive about organ donation. It is essential that these people are supported, recognised and valued, for they are the advocates of organ donation for future generations, and the key to closing the ethnic gap between a willingness to donate and the act of donation.

Contributors
All the authors devised the protocol. G. Smith, A. Warrens, S. Saxena, J. Carr, N. Jain, P. Reece and H. Dulku, analysed the data and authored the paper.

Conflicts of Interest
We declare that we have no conflicts of interest.

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* This paper is a ‘working’ draft. Permission for written quotation should be obtained from the authors.

References


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TABLE 1.1

Sample of Participants

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<th>Participants</th>
<th>South Asian</th>
<th>white British/Irish</th>
<th>African Caribbean</th>
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<tbody>
<tr>
<td>n=50</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>15</td>
<td>19</td>
<td>16</td>
</tr>
<tr>
<td>Age 18 - 68</td>
<td>35 SD 11.6</td>
<td>45 SD 13.1</td>
<td>41 SD 9.3</td>
</tr>
<tr>
<td>Women</td>
<td>9</td>
<td>12</td>
<td>10</td>
</tr>
<tr>
<td>Men</td>
<td>6</td>
<td>7</td>
<td>6</td>
</tr>
<tr>
<td>Recipient of a transplant</td>
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<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Member of a donor family</td>
<td>2</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>NHS employee</td>
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