

Highlights

- A growing amount of experience and research evidence from across the world has shown that the role of faith is known to play an important part in the decision to donate organs.
- National Health Service Blood and Transplant seeks to work in partnership with faith leaders, and this culminated in a Faith and Organ Donation Summit held on May 9, 2013.
- The independent comments and recommendations of the summit attendees were collated into an action plan, with consensus at the summit that there needs to be sustained engagement with the issue of organ donation among faith communities and by faith communities.
- All faith leaders value the importance of organ donation as an issue that needs to be acknowledged and debated within their faith communities.
- Faith leaders highlight that there is a need for engagement at both national and local levels concerning organ donation as well as diagnosis and definition of death.



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Role of Religion in Organ Donation—Development of the United Kingdom Faith and Organ Donation Action Plan

G. Randhawa^{a,*} and J. Neuberger^b

^aInstitute for Health Research, University of Bedfordshire, Luton, United Kingdom; and ^bNational Health Service Blood and Transplant, Bristol, United Kingdom

ABSTRACT

At a national policy level, the United Kingdom is at the forefront of recognizing the role of faith and its impact on organ donation. This is demonstrated by the recommendations of the Organ Donation Taskforce, National Institute for Clinical Excellence guidelines on organ donation, All-Party Parliamentary Kidney Group, and National Black, Asian and Minority Ethnic Taskforce Alliance. Evidence to date shows that further thought is required to ensure the active engagement of faith communities with organ donation in the UK. The “Taking Organ Transplantation to 2020” strategy was launched in July 2013 by National Health Service Blood and Transplant (NHSBT) in collaboration with the Department of Health and Welsh, Scottish, and Northern Irish governments and seeks to increase the number of people, from all sections of the UK’s multiethnic and multifait population, who consent to and authorize organ donation in their life. NHSBT seeks to work in partnership with faith leaders and this culminated in a Faith and Organ Donation Summit. Faith leaders highlight that there is a need for engagement at both national and local levels concerning organ donation as well as diagnosis and definition of death.

MANY countries across the world grapple with the challenge of the shortage of organs for transplant. The need for effective public engagement is integral to increasing discussion about organ donation. This paper provides a “route-map” of how the dialog between religion and organ donation can be developed meaningfully and collaboratively.

Explicit recommendations to engage with the United Kingdom’s multiethnic and multifait population were developed by the UK Organ Donation Taskforce in 2008. Its 1st report highlighted “an urgent requirement to identify and implement the most effective methods through which organ donation and the “gift of life” can be promoted to the general public, and specifically to the BAME [black, Asian, and minority ethnic] population” [1]; and its 2nd report recommended that “the Programme Delivery Board builds on the foundations of the interviews with faith and belief groups ... to ensure that the valuable dialogue that was established is maintained” [2].

The National Institute for Clinical Excellence guidelines on organ donation recommend that the multidisciplinary team should include “local faith representative[s] where relevant” when approaching families for consent. [3]. The

All-Party Parliamentary Kidney Group in findings from its BAME transplant summit, recommended “All service providers to ... establish appropriate training for their staff in understanding the religious and cultural aspects of the main BAME groups in this country.” [4]. Most recently, the Taking Organ Transplantation Toward 2020 strategy has set out its ambition to increase the number of people in the UK who consent to/authorize organ donation among all sections of the UK’s multiethnic and multifait population. These recommendations demonstrate national policy recognition of the need for meaningful public and faith engagement regarding the issue of organ donation [5].

Organ failure does not discriminate; it affects people from a wide range of social, age, sex, educational, cultural, faith, and ethnic backgrounds reflecting the diversity of the UK population. Currently, BAME communities constitute ~11% of the UK population but make up 30% of the

*Address correspondence to Professor Gurch Randhawa, Director, Institute for Health Research, Putteridge Bury, University of Bedfordshire, Luton, United Kingdom. E-mail: gurch.randhawa@beds.ac.uk

kidney transplant waiting list. There is a variation in family consent rates for deceased donation, which is 61% for white families and only 33% for families from a BAME background. This variation is also evident on the on the ODR (Organ Donor Register), with only 3.5% of registrations among people of known ethnicity recorded as being from the BAME population [6].

National Health Service Blood and Transplant (NHSBT), a Special Authority responsible to the Department for Health for managing organ transplantation in the UK, Department of Health, policy makers, and transplant professionals continue to strive to make transplantation procedures more successful and more commonplace. The human and economic value of this endeavor is immense because people's lives are saved, quality of life is improved, and the need for long-term organ maintenance treatments is reduced. Indeed, it is estimated that each deceased organ donor saves the NHS an average £351,000 by negating the need for alternate, more expensive treatments. However, the fact remains that in the UK, much like every country that operates a transplantation program, there are insufficient numbers of donor organs to meet the demand. Addressing this matter is complex and requires a fresh perspective as to how NHSBT truly engages with the public regarding organ donation and transplantation. This is particularly pertinent in this case, where the practice of organ donation and transplantation is continuously challenged by new techniques (eg, transplantation of the face and limbs) or ethical issues (eg, allowing organ donation for non-heart-beating donors or after active euthanasia).

POTENTIAL ROLE OF FAITH COMMUNITIES AS ROUTES FOR PUBLIC ENGAGEMENT

A growing amount of literature has shown that the role of religion has been known to play an important part in the decision to donate organs [7–10]. The religious beliefs of the major faiths of the UK's African Caribbeans and South Asians, namely Islam, Hinduism, Sikhism, Buddhism, and Christianity, have been scrutinized in the literature. None of the religions object to organ donation in principle, although in some there are varying schools of thought. What is interesting, however, is that the position of one's religion is used by many people in informing their decision as to whether to donate or not [7,11].

There have been a series of small-scale studies to examine the attitudes toward organ donation and transplantation among a cross-section of the UK's South Asian and African Caribbean population that have shed some light on the matter [7,9,10,12–14]. It was found that far from being a barrier to organ donation, the respondents were more supportive of donation and transplantation, in general, when they were aware of the position of their religion regarding these issues. This highlights the importance of education and raising awareness among faith communities [15,16].

FAITH ENGAGEMENT ACTIVITY TO DATE

In recent years, NHSBT has produced a range of educational materials, including leaflets, posters, videos, and podcasts (all available in a range of languages), to better engage with the multiethnic public and to increase awareness of transplant-related issues. There have also been a series of Public Engagement Campaigns: "Be part of the solution"; "Can we count on you?"; "If you believe in organ donation, prove it"; "Real people, real lives, real action." Additionally, materials have been produced that set out the position of each religion regarding organ donation. These faith-based resources were produced by NHSBT in partnership with faith leaders in the UK and launched in March 2012. A series of faith roadshows also took place during 2012–2013, visiting places of worship in London to encourage discussion about organ donation. However, further action is required to ensure the effective engagement of faith communities with the issue of organ donation. Progressing this matter is of vital importance as it aligns to the ambition of the "Taking Organ Transplantation to 2020" strategy to increase the number of people in the UK who consent to/authorize organ donation in their life among all sections of the UK's multiethnic and multifaith population.

METHODS

With this in mind, NHSBT hosted a Faith and Organ Donation Summit, inviting prominent faith leaders from all faiths to:

- Listen and learn from each other how best to engage with faith communities about organ donation.
- Establish the current position of debates around organ donation within faith communities.

The summit was a seminal event in that it was one of the first times that faith leaders from all of the leading UK faith organizations had come together to discuss a significant health issue and contribute to developing an action plan.

FINDINGS

Analysis of Themes Arising from the Faith and Organ Donation Summit

More Engagement Is Needed. Many attendees said that the organizations they were representing had had little or no contact with NHSBT before the summit or since launching the organ donation and faith leaflets, but all welcomed the summit and were open to future engagement.

There was consensus that this important work requires commitment from faith leaders, NHSBT, Donation Committees, and BAME organizations working collaboratively where possible and feeding back about outcomes so best practices can be shared. Successful engagement will see local communities, whether in the home, in schools, at work, or in places of worship, regularly initiating discussion around organ donation. In some areas (eg, Muslim communities) activity will be multilayered to effect change, eg, briefing scholars and considering writing a fatwa, providing



training for imams, and continuing work at a grass roots level in the community. Messaging must be tailored to the target audience, ensuring, eg, that it is informative rather than heavily persuasive if this is what is required to engage communities.

It was raised by some attendees that organ donation is currently not a priority for some groups, and it is felt that the debate needs to be opened at both national and local levels. There was also consensus that any engagement needs to be ongoing if it is to be effective.

A number of summit attendees highlighted that NHSBT must continue and build on promotional work to the wider BAME community that lies beyond the influence of faith leaders as some of these are simply not receptive to promoting organ donation.

There is a Need to Engage at a Local Level. It was thought that engaging with people at a local level via events and meetings would be most effective. It was suggested that religious centers, such as churches, mosques, and gurdwaras, would be a good route for engagement and that major festivals, such as Diwali, Eid, Vasant Navrati, and Vaisakhi, were an opportunity to promote organ donation to vast gatherings of followers. Local faith leaders would require educational training and support. The potential for working with Donation Committees was mentioned by many of the attendees as a means to progress local level action.

There Is an Opportunity to Engage Those Working in the Health Services. Some attendees mentioned an opportunity to engage with hospital chaplains and medical students. An opportunity to engage with Catholics working in the health system was also highlighted. There were two suggestions that general practitioners could help to communicate the message. This could involve prompting discussion of organ donation as part of the new patient registration process (NHSBT is seeking to pilot this in Enfield) or educational outreach to all patients via displays in the surgery or attendance at local events.

The Debate Needs to Engage People at Many Levels. Attendees thought that there is a need for NHSBT to engage with the key opinion formers within faith communities and that the summit was an excellent step forward in this regard.

Some thought that NHSBT needs to be inclusive and avoid “cherry-picking” only those that are supportive of organ donation. It was highlighted that several faiths can be further divided into different factions and thus comprise a complex network of different ideologies and beliefs. It is therefore crucial to engage with a broad spectrum of faith leaders.

It was also thought that more needs to be done to reach people at the grassroots level: faith-based community workers.

Greater Resources Will Be Needed to Achieve Greater Engagement. Some attendees said that they do not currently have enough funding, and that financial support from NHSBT would enable them to communicate more effectively with their respective communities. Additional

resources could be used to employ more part-time staff. It was suggested also that community volunteers (eg, through a peer educator program) should be identified and trained to attend outreach events.

Engagement—Measuring Success. Evaluating the effectiveness of the action plan can not be simply based on new registrations to the NHS ODR, where it is not possible to capture faith data. Nor would registration targets necessarily be a suitable measure of success for engagement with faith communities where there are more perceived religious barriers to supporting organ donation. It was generally agreed that success criteria should be tailored to each activity included within the action plan with the overall intention to increase support for organ donation within faith communities and increase the proportion of families that agree to donation. Therefore positive outcomes could be measured in terms of quantity and tone of media coverage, number of outreach events held and footfall, number of followers reached via an article in a faith publication, etc.

KEY STRATEGIC PRINCIPLES AGREED TO AT THE FAITH AND ORGAN DONATION SUMMIT

Faith leaders’ commitment to organ donation and to:

- Work with NHSBT and take on spokesperson roles encouraging debate on organ donation via communication channels available through their faith/local community. Also to be available, where convenient, for interview by the national/regional media in specialist titles.
- Become faith ambassadors for organ donation (see Table 1) to include proactively seeking opportunities (eg, faith-led events, media partnerships, etc) within their organization(s) to promote organ donation and facilitate debate among their supporters/local communities.
- Act as spokespersons for major organ donation campaigns, eg, National Transplant Week, and to help promote these via their network of followers.
- Identify possible support required from NHSBT, such as financial support or helping to gain access to/appeal for case studies to assist with faith outreach.
- Work internally among their communities to clarify issues relating to definitions and diagnosis of death (with the support of NHSBT where necessary).

For all attendees to:

- Acknowledge that faith communities are not homogeneous.
- Accept that faith communities are at different stages of engagement, eg, concerning the diagnosis of death and at what point in time organ donation is appropriate.
- Agree to continued dialog and to meet again together as a group in 12 months when progress can be reviewed and the faith leaders can share, in an open forum, issues, and queries that have been raised by their congregations in the preceding months.
- Collaborate to increase the number of living as well as deceased donors.

Table 1. ■■■■



Faith Ambassador role and activities:

- To increase the number of people, from all sections of the UK's multiethnic and multifait population, who consent to/authorize organ donation in their life.
- To be a national faith lead for organ donation.
- To act as spokesperson for major campaigns and during National Transplant Week.
- To identify possible faith-led events: community-based, media-based, etc.
- To provide access to network of organizations through which faith-based organ donation engagement project worker can distribute educational materials/organize events.

National Health Service Blood and Transplant (NHSBT) to keep faith leaders informed regarding new developments in donation and transplantation, implications of organ failure, and disadvantages of dialysis to ensure that they are able to demonstrate the relevance of organ donation within their communities and have an understanding the issues. By ensuring that the ambassadors are included on NHSBT's stakeholder database, they will automatically receive the NHSBT newsletter and an invitation to a special stakeholder event to learn more about NHSBT matters. NHSBT to also explore how it can facilitate meetings between faith leaders and patients, donor families, and recipients to deepen their understanding of the issues.

Faith-based organ donation engagement project worker roles and activities:

- To be responsible for an increase in the number of people from their faith who join the Organ Donor Register (ODR) and give consent for organ donation to proceed. Targets will be agreed on an individual basis.
- To make organ donation more of a priority among their faith.
- To facilitate and establish ongoing contact and mutual support between NHSBT and faith organizations.
- To work with NHSBT Regional Managers and Donation Committees to organize a series of local faith-based organ donation activities.
- To develop and put in place a framework for effective engagement on organ donation within their faith.
- To work closely with national and local faith organizations on organ donation.
- To recruit faith ambassadors (including medical students). The target number of recruits will be agreed to on an individual basis.
- To support faith ambassadors in organizing faith and organ donation events for the public to increase the number of people on the ODR.
- To organize awareness and training at national and local levels to ensure that their faith leaders understand and debate issues related to organ donation.

PROPOSED ACTION PLAN

Deliverables Within 6 Months

- Faith leaders' commitment to working with NHSBT and taking on spokesperson roles.
- Faith leaders agree to become faith ambassadors (see Table 1) for organ donation for NHSBT.
- Faith leaders agree to be spokespersons for key organ donation campaigns.
- NHSBT to review the range of languages that its faith leaflets are translated into to reflect an increasingly diverse population [Polish, Arabic, Somali, Tamil, etc].
- NHSBT to encourage all staff involved with organ donation ranging from Specialist Nurses in Organ Donation (SNODs), Clinical Leads for Organ Donation (CLODs), and Organ Donation Committee members to share new examples of best practice relating to effective faith engagement. NHSBT to also provide Donation Committees with contact details of Faith Summit attendees where relevant to local planned activity and where those leaders have given consent for their contact details to be shared.
- Faith leaders and relevant organizations to continue to identify and share with NHSBT possible faith-led events (community-based, media-based, etc) to help promote organ donation so that a coordinated and targeted schedule of activity can be developed over the coming months and shared early with all key stakeholders so that everyone has the opportunity to work together to ensure their success.

- Faith leaders to provide access to their own network of organizations through which NHSBT can distribute educational materials and/or organize outreach activity.
- Faith leaders to help, where practical, to identify local spokespeople/community leaders to assist with faith media enquiries or to support local outreach.
- NHSBT to liaise with the Faith Communities Engagement Team at the Department for Communities and Local Government to learn from their experiences of faith engagement.
- NHSBT to ensure that all faith-based media are actively engaged with organ donation via interviews with faith leaders, news stories, paid-for TV features, etc.

Deliverables Within 12–18 Months

- NHSBT to support SNOD regional managers across the UK (or ideally identify a BAME SNOD lead for each region) to enable them to share best practices with Organ Donation Committee chairs and help them achieve their potential outreach/public engagement role or build on the work already being carried out locally.
- NHSBT to ensure that all staff involved with organ donation, –SNODs, CLODs, Organ Donation Committee members—are provided with appropriate training in understanding the religious and cultural aspects of organ donation. NHSBT also to consider development of an educational program for faith leaders that can be delivered by specialist nurses

or other designated professionals from Donation Committees.

- NHSBT to review findings from the Birmingham Pilot Peer Educator Project with the Muslim community when the project is completed in February 2015.
- NHSBT to support the plans proposed by one attendee to convene a gathering of UK-based shariah scholars and key Muslim stakeholder groups with the intention of developing a new fatwa in support of organ donation.

Deliverables Within 12 Months Subject to Budget and Staff Resources Being Available

- NHSBT to consider making available funds and resources for dedicated organ donation engagement project workers (see Table 1). Each faith group would be invited to bid to NHSBT for funding to select, recruit, and manage their own organ donation engagement project worker who would coordinate activities listed in the action plan and liaise between Faith organizations and NHSBT. To maximize the success of this proposal, an infrastructure within each faith organization and NHSBT would need to be developed to support the project workers. This includes access to training and regular meetings for planning, implementation, and evaluation (some Donation Committees have appointed a community organ donation project worker).
- NHSBT to consider making available funds for BAME and faith organizations, Donation Committees, and peer educators to progress faith-based activities at the local level. NHSBT to control this funding stream as well as be able to draw from it to support a coordinated and strategic program of outreach activity at a local level and/or national scale.
- NHSBT to consider funding a Pilot Peer Educator Project with the Sikh community, as requested by 2 Sikh attendees. This would draw from the experience of Kidney Research UK, which has recruited and trained peer educators for more than a decade.
- NHSBT to provide organ donation information and training to health care chaplains (eg, via College of Health Care Chaplains) and other national/local faith leaders to include definition and diagnosis of death, personal stories, and examples of best practice. One hospital chaplain recommended that engagement with chaplaincies is perhaps best undertaken by SNODs instead of, or certainly in addition to, engagement via local faith leaders.
- NHSBT to further develop work on school-based organ donation events. This might include updating of educational resources (My Life, My Gift Teacher pack), coordinating an outreach program in schools coordinated by volunteers, or seeking to ensure that organ donation is included on the national school curriculum.
- NHSBT and faith ambassadors to consider developing a best practices guide or toolkit for faith engagement which could inform the work of the project workers and any faith outreach activity.

- Faith-based organ donation engagement project workers to use role of medical students from different faiths to be faith ambassadors.
- NHSBT to investigate further and develop a system to capture the faith issues/opinions that influence families when considering whether to give consent for donation to proceed.

Limitations

The Faith Action Plan recognizes that there are challenges in distinguishing the effect of religion from that of culture and local belief. Consequently, the plan should not be seen as a vehicle for addressing cultural issues. It is important to develop clear, measurable, and relative objectives for new initiatives that are outlined in the plan, but there is a challenge of knowing what the relevant measurable outcomes are. It would be inappropriate to use the numbers of people joining the ODR as a measure, because the plan clearly highlights that there is a need for deep and meaningful dialogs within faith communities before consideration of joining the ODR. In the longer term, however, the measurable outcomes will need to relate conversations about organ donation and support for and eventual consent for organ donation. The plan also needs to learn from faith engagement initiatives in other countries. The plan does not account for the effect of generations; we have insufficient data to know whether 1st-generation migrants are more likely to refuse/consent to organ donation than 2nd-generation migrants. It must also be acknowledged that the ethnic group descriptors used in the UK are only a starting point for recognizing diversity. The ethnic classifications are crude; eg, within minority groups such as Asians, there are many different cultural and religious groups.

CONCLUSION

NHSBT is resolute in its commitment to improve organ donation rates in all sections of the UK population. The Faith and Organ Donation Action Plan is being taken forward at national and local levels. Examples of the range of activities that have resulted are available to staff and public to share at www.odt.nhs.uk/donation/deceased-donation/professional-resources/faith-action-plan/.

There will continue to be resistance to discuss organ donation among the public unless effective and meaningful actions are taken by policy makers to initiate collaborate conversations with their diverse communities. The Faith and Organ Donation Plan provides a “route-map” that enables a dialog about organ donation among faith communities that is led by faith communities themselves and supported by policy makers if and when required. This collaborative approach may also be useful in other countries where there are low consent rates to organ donation and enable greater understanding of the need for all sections of the population to discuss and consider organ donation.

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