

# Faith Engagement and Organ Donation Action Plan

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December 2013

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## Strategic Overview

### What is already known?

- A growing amount of experience and research evidence from across the world has shown that the role of faith has been known to play an important part in the decision to donate organs.
- At national policy level, the UK is at the forefront of recognising the role of faith as demonstrated by the recommendations of the Organ Donation Taskforce, NICE Guidelines on Organ Donation, All Party Parliamentary Kidney Group and National BAME Transplant Alliance (NBTA).
- 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 NHSBT in collaboration with the Department of Health, Northern Ireland, Scottish and Welsh Governments and seeks to increase the number of people, from all sections of the UK's multi-ethnic and multi-faith population, who consent to and authorise organ donation in their life.

### What does this Action Plan add?

- NHS Blood and Transplant (NHSBT) seeks to work in partnership with faith leaders and this culminated in a Faith & Organ Donation Summit held on 9th May 2013. It is the independent comments and recommendations of the Summit attendees that have been collated in this action plan with consensus at the Summit that there needs to be sustained engagement with the issue of organ donation amongst 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 in relation to organ donation, but also in relation to diagnosis and definition of death.
- The action plan is concerned specifically with faith communities and as these comprise followers and worshippers from a wide range of ethnic backgrounds, it is not exclusively targeting the Black, Asian and Minority Ethnic (BAME) community. However this is the predominant audience given the urgent need for more Black and Asian donors. It is also recognised that many people in the UK do not follow a faith so this plan should form part of a broader educational and promotional strategy encompassing all sections of society.

## Rationale for the Faith Engagement and Organ Donation Action Plan

Explicit recommendations to engage with the UK's multi-ethnic and multi-faith population were developed by the UK Organ Donation Taskforce in 2008. Its first 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 BME (Black and minority ethnic) population' (Department of Health (DH), 2008a); while its second 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' (DH, 2008b).

The NICE Guidelines on Organ Donation recommend that 'The Multi-Disciplinary Team should include: '....local faith representative(s) where relevant (when approaching families for consent).' (NICE, 2011). The All Party Parliamentary Kidney Group in findings from its BME Transplant Summit, recommended 'All service providers to [...] establish appropriate training for their staff in understanding the religious and cultural aspects of the main BME groups in this country.' (APPKG, 2012). Most recently, the Taking Organ Transplantation Towards 2020 Strategy has set out its ambition to increase the number of people in the UK who consent to/ authorise organ donation among all sections of the UK's multi-ethnic and multi-faith population. These recommendations demonstrate national policy recognition of the need for meaningful public and faith engagement regarding the issue of organ donation.

Organ failure does not discriminate – it impacts upon people from a wide range of social, age, gender, educational, cultural, faith and ethnic backgrounds reflecting the diversity of the UK's population. NHSBT, DH policy makers and transplant professionals continue to strive in their efforts to make transplantation procedures more successful and more common place. The human and economic value of this endeavour is immense as people's lives are saved, quality of life is improved, and the need for long-term organ maintenance treatments is reduced. Indeed, work undertaken in 2010 identified that the transplant programme delivered a cost saving to the NHS of £316 million and that savings have the potential to increase further as the number of transplant procedures rise (West Midlands Specialised Commissioning Team 2010).

However, the fact remains that in the UK, much like every country that operates a transplantation programme, 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 on 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 (e.g. transplantation of the face and limbs) or ethical issues (e.g. allowing organ donation for non-heart-beating donors or after active euthanasia).

## **The 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 (Randhawa, 1998; Hayward & Madhill, 2003; Alkhawari et al, 2005; Davis & Randhawa, 2006). 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 scrutinised 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 to inform their decision as to whether to donate or not (Randhawa, 1998; Oliver et al, 2011).

There have been a series of small-scale studies to examine the attitudes towards 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 (Randhawa, 1998; Alkawari et al, 2005; Davis & Randhawa, 2006; Morgan et al, 2006; Randhawa et al, 2010; Morgan et al, 2012). 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 with regards to these issues. This highlights the importance of education and raising awareness among faith communities (Randhawa, 2011; Sims et al, 2012).

## **Faith engagement activity to date**

In recent years, NHTSBT has produced a range of educational materials (including leaflets, posters, videos, and podcasts) to better engage with the multi-ethnic public and to increase awareness of transplant related issues (available in a range of languages). 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 NHTSBT in partnership with faith leaders in the UK and launched in March 2012. A series of faith roadshows have also taken place during 2012/13 visiting places of worship in London and using these as a platform 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/authorise organ donation in their life among all sections of the UK's multi-ethnic and multi-faith population.

## The Faith and Organ Donation Summit – May 2013

In May 2013 NHSBT hosted a Faith & 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 organisations had come together to discuss a significant health issue and contribute to developing an action plan.

There were a number of strategic principles agreed to at the Summit as well as commitment to supporting organ donation.

### Faith leaders' commitments

- work with NHSBT and take on spokesperson roles encouraging debate on organ donation via communication channels available through their faith/local community. To also be available, where convenient, for interview by the national/regional media in specialist titles.
- become faith ambassadors for organ donation (see appendix 1) to include proactively seeking opportunities (e.g. faith-led events, media partnerships etc) within their organisation/s to promote organ donation and facilitate debate amongst their supporters/local communities.
- act as spokespersons for major organ donation campaigns e.g. 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 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).

### Attendees' commitments

- acknowledge the faith communities are not homogeneous.
- accept that faith communities are at different stages of engagement – for example around the diagnosis of death and at what point in time organ donation is appropriate.
- agree to continued dialogue 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 proceeding months.
- collaborate to increase the number of living as well as deceased donors.

## **Analysis of themes arising from the Summit**

### **More engagement is needed**

Many attendees said that the organisations they were representing had had little or no contact with NHSBT prior to 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 organisations – working collaboratively where possible and feeding back on outcomes so best practice can be shared. And 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 (for example Muslim communities) activity will be multi-layered in order to effect change e.g. briefing scholars and considering writing a fatwa, providing training for Imams and continuing work at a grass roots level in the community. And messaging must be tailored according to the target audience ensuring, for example, it is informative rather than heavily persuasive if this is what is required in order 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 level. 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 upon 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 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, mosques, and gurdwaras would be a good route for engagement and using major festivals such as Diwali, Eid, Vsant Navrati and Vaisakhi as 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 a healthcare setting**

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 GPs could help to communicate the message. This could involve prompting discussion of organ donation as part of the new patient registration process (NHSBT seeking to pilot this in one or more boroughs) 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 felt that there is a need for NHSBT to engage with the key opinion formers within faith communities and the Summit was an excellent step forward in this regard.

Some felt 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 therefore 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 felt that more needs to be done to reach people at grass-roots level such as 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. Additionally it was suggested that community volunteers (e.g. through a peer educator programme) should be identified and trained to attend outreach events.

## **Engagement – measuring success**

Evaluating the effectiveness of the Faith Action Plan can not be based simply on new registrations to the NHS Organ Donor Register 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 going ahead. 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.

## Proposed Action Plan

| Deliverables before September 2014 |  |
|------------------------------------|--|
| 1                                  | Faith leaders commitment to working with NHSBT and taking on spokesperson roles.   |
| 2                                  | Faith leaders agree to become faith ambassadors (see appendix 1) for organ donation for NHSBT.   |
| 3                                  | Faith leaders agreeing to be spokespersons for key organ donation campaigns.   |
| 4                                  | 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).  |
| 5                                  | 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. |
| 6                                  | Faith leaders and relevant organisations to continue to identify and share with NHSBT possible faith-led events (community-based, media-based etc) to help promote organ donation so a coordinated and targeted schedule of activity can be developed over the coming months and shared early with all key stakeholders so everyone has the opportunity to work together to ensure their success.  |
| 7                                  | Faith leaders to provide access to their own network of organisations via which NHSBT can distribute educational materials and/or organise outreach activity.  |
| 8                                  | Faith leaders to help, where practical, to identify local spokespeople/community leaders to assist with faith media enquiries or to support local outreach.  |
| 9                                  | 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.   |
| 10                                 | NHSBT to ensure all faith-based media are actively engaged with organ donation via interviews with faith leaders, news stories, paid-for TV features etc.  |

|    | <b>Deliverables within 12 - 18 months</b>   |
|----|---|
| 11 | 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 practice 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.   |
| 12 | NHSBT to ensure all staff involved with organ donation ranging from SNODs, CLODs, Organ Donation Committee members are provided with appropriate training in understanding the religious and cultural aspects of organ donation. For NHSBT to also consider development of an educational programme for faith leaders that can be delivered by specialist nurses or other designated professionals from donation committees.  |
| 13 | NHSBT to review findings from the Birmingham Pilot Peer Educator Project with the Muslim Community when the project is completed in February 2015.  |
| 14 | Budget permitting, 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.   |
| 15 | NHSBT to consider making available funds and resources for dedicated organ donation engagement project workers (see appendix 1). Each faith group would be invited to bid to NHSBT for funding in order to select, recruit and manage their own organ donation engagement project worker who would co-ordinate activities listed in the action plan and liaise between faith organisations and NHSBT. In order to maximise the success of this proposal, an infrastructure within each faith organisation 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). |
| 16 | NHSBT to consider making available funds for BAME and faith organisations, Donation Committees and peer educators to bid for in order to progress faith-based activities at local level. For NHSBT to control this funding stream and also be able to draw from it to support a coordinated and strategic programme of outreach activity at a local level and/or national scale.  |
| 17 | NHSBT to consider funding a Pilot Peer Educator Project with the Sikh community as requested by two Sikh attendees. This draws from the experience of Kidney Research UK which has recruited and trained peer educators for more than a decade.   |
| 18 | NHSBT to provide organ donation information and training to healthcare chaplains (e.g. 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.  |

| <b>Deliverables within 12 - 18 months</b> |  |
|---|--|
| 19  | NHSBT to further develop work on school-based organ donation events. This might include updating of educational resources (Give and Let Live Teacher pack), coordinating an outreach programme in schools coordinated by volunteers or seeking to ensure organ donation is included on the national school curriculum. |
| 20  | NHSBT and faith ambassadors to consider developing a best practice guide or toolkit for faith engagement which could inform the work of the project workers and any faith outreach activity.   |
| 21  | Faith-based organ donation engagement project workers to utilise role of medical students from different faiths in becoming faith ambassadors.   |
| 22  | 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 go ahead.  |

## **APPENDIX 1**

### **Faith Ambassador role and activities:**

- to increase the number of people, from all sections of the UK's multi-ethnic and multi-faith population, who consent to/authorise organ donation in their life.
- to be a national faith lead for organ donation.
- to act as spokespersons 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 organisations via which faith-based organ donation engagement project worker can distribute educational materials/organise events.

NHSBT to keep faith leaders informed regarding new developments in donation and transplantation, implications of organ failure and disadvantages of dialysis to ensure they are able to demonstrate the relevance of organ donation within their communities and have an understanding the issues. By ensuring 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 of 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 Register and give consent for organ donation to go-ahead. Targets will be agreed on an individual basis.
- to make organ donation more of a priority amongst their faith.
- to facilitate and establish ongoing contact and mutual support between NHSBT and faith organisations.
- to work with NHSBT Regional Managers and Donation Committees to organise 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 organisations on organ donation.
- to recruit faith ambassadors (including medical students). Target number of recruits will be agreed on an individual basis.
- to support faith ambassadors in organising faith and organ donation events for the public to increase the number of people on the Register.
- to organise awareness and training at national and local level to ensure their faith leaders understand and debate issues related to organ donation.

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