

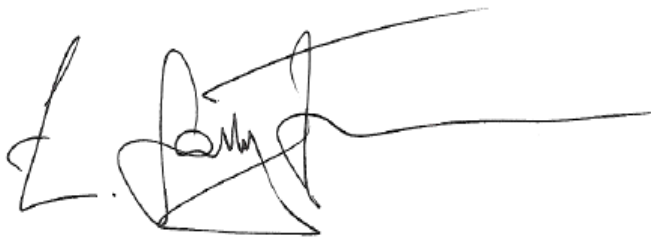
NHS Blood and Transplant response to publication of the Faith Engagement and Organ Donation Action Plan

Right now there is an urgent need to encourage more people from BAME communities to join the NHS Organ Donor Register and share their donation decision with their loved ones. Two thirds (66%) of BAME families refuse to give permission for their loved ones organs to be donated and so the number of patients from their communities on the transplant waiting list stays high, or, in the case of kidney waiting list, continues to rise.

Religious beliefs can play a major role in an individual's decision to donate organs. We have been working closely with many of the leading faith groups in the UK to raise awareness of the importance of organ donation, particularly within Black, Asian and Minority Ethnic (BAME) communities.

We welcome publication of the Faith Action Plan as a major contribution to our collaboration to increase donation from all members of society. The Plan incorporates recommendations from faith leaders and campaigners on how to actively engage with faith communities and encourage debate on, and support for, this issue.

NHSBT is committed to making the improvements called for in this plan and we look forward to working together with the faith leaders to improve consent rates and thereby increase the number of BAME patients receiving a life-saving transplant.

A handwritten signature in black ink, appearing to read 'Sally Johnson', with a long horizontal line extending to the right.

Sally Johnson
Director of Organ Donation and Transplantation, NHSBT

December 2013

NHSBT will support ALL recommended activity which is deliverable by September 2014 and will build these actions into our plans for 2014/15. Namely:

- 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) (Action Point 4).
- 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 (Action Point 5).
- 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 (Action Point 9).
- 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 (Action Point 10).

With respect to recommendations to be delivered within the next 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 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 (Action Point 11).

NHSBT is establishing a SNOD for each region who will act as a BAME lead and take on some additional responsibility to work with Donation Committees and assist with local community engagement.

- 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 (section Action Point 12)

NHSBT will ensure appropriate training for the audiences cited above. This will be a phased programme of activity that begins with training for SNODs and then is rolled out to other staff. The focus is on targeting those working in urban, ethnically diverse communities where the need for more donated organs is most urgent.

- NHSBT to review findings from the Birmingham Pilot Peer Educator Project with the Muslim Community when the project is completed in February 2015 (Action Point 13).

NHSBT will review evaluation from this project as soon as it is available. This, along with evaluation from previous peer educator projects, will inform our approach to potential future schemes.

- 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 (Action Point 14).

NHSBT supports this recommendation. With consensus from the Muslim community that this will aid engagement we will take steps to explore what support is required from us and the timeframe for delivery so that we can facilitate in the most appropriate way the development of a new fatwa.

- NHSBT to consider making available funds and resources for dedicated organ donation engagement project workers. 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. (Action Point 15).

NHSBT will investigate funding streams, scope out project processes and develop a specification in partnership with representatives from the faith communities (based on the Project Worker role outlined in appendix 1 of the Faith Action Plan) against which organisations can submit their requests for funding.

- 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 (Action Point 16).

NHSBT is in the process of developing its campaign strategy to increase consent for deceased donation and will consider this recommendation as part of developing that strategy which is due to go to the NHSBT Board on 27 March 2014.

- 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 (Action Point 17).

NHSBT will establish a process to consider funding requests such as this and will work with representatives from the faith communities to promote the approach.

- 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 (Action point 18).

NHSBT will support this recommendation as part of a phased programme of training (see response to Action Point 12).

- 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 (Action Point 19).

NHSBT sees reaching school age children as crucially important. It is a commitment of the 'Taking Organ Transplantation to 2020' Strategy for each of the UK Health Departments to raise this with their education departments. The Strategy Oversight Committee, chaired by Elizabeth Buggins CBE, will monitor progress. We will also consider educational initiatives as part of the new campaign strategy.

- 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 (Action Point 20).

NHSBT to take this recommendation forward and build into business planning for next year.

- 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 (Action Point 22)

NHSBT has recently carried out audience research which included interviews with people from BAME communities. The research, to be published shortly, also explored the impact of faith on attitudes towards organ donation. NHSBT is receptive to undertaking more detailed research amongst BAME communities and will consider this and what other research would be useful in discussion with faith representatives.