

# The Lord Mayor of Bristol's blood and organ donation campaign

Work promoting the need for increased blood and organ donations from black, Asian and minority ethnic communities is ongoing and a campaign in Bristol has been fighting the cause. Shahid Muhammad et al describe the objectives and outcomes of project approaches as part of this campaign.

■ organ donation ■ transplantation ■ blood ■ campaign ■ community ■ BAME

In September 2013, a health awareness campaign commenced in the city of Bristol and involved five influential organisations. The Lord Mayor of Bristol set out to highlight the importance of blood and organ donation in black, Asian and minority ethnic (BAME) communities, whom are still not completely aware of how these donations can save lives. Ultimately, the campaign aimed to increase the blood and organ donation pool in Bristol's BAME population.

In this article, the authors summarise seven key campaign strategies: education; awareness and promotion; the science behind blood transfusion and organ transplantation; ethics; religious and cultural beliefs; taking ownership and reporting and dissemination. The Lord Mayor's campaign helped to raise awareness and invited members of BAME communities to sign the blood/organ donation register. The work of this campaign has been extraordinary and extensive—over 200 signatures for blood and organ donation were received from members of different BAME groups.

## Objectives

Following the publication of the All Parliamentary Party Kidney Group (APPKG) and National Kidney Federation (NKF) (2012) manifesto on improving kidney donation and transplantation in BAME communities, and the Faith Engagement and Organ Donation Action Plan (Randhawa, 2013), the Lord Mayor's campaign aimed to encourage people from BAME groups to sign up in greater numbers to the blood and organ donation register. The campaign took place in collaboration with the Bristol Multi Faith Forum (BMFF), Renal Patient Support Group (RPSG), NHS Blood and Transplant (NHSBT) and two radio stations (Ujima Radio 98FM and BCfm 93.2FM) (Box 1). The main objectives were to:

- Advise on issues related to culture and religious sensitivity
- Publicise the campaign widely to BAME and faith communities

- Promote the campaign using community leaders
- Develop and roll out community champions
- Assist the community champions in undertaking their role
- Support community events and forums.

## Seven key campaign strategies

### Education

There is a need to increase BAME communities' understanding of the role of organ donation registries. In the UK, there are two types of registry: donor and non-donor.

### Activities

This objective was fulfilled through broadcasting, web conferencing, workshops and publications. In September 2013 and February/March 2014, the Lord Mayor of Bristol and campaign collaborators took part in a live debate on blood and organ donation on a community interest radio station (Ujima Radio 98FM), with further follow-up interviews in 2014, in which a patient, carer and donor coordinator from North Bristol NHS Trust discussed their perspectives and experiences. The Lord Mayor and campaign collaborators were also interviewed on another community radio station (BCfm, 93.2FM) in (September 2013 and February/March 2014 during a programme highlighting the need for BAME individuals to join the organ donor register.

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On World Kidney Day 2013, NHS Kidney Care hosted a series of e-learning sessions on acute kidney injury and organ donation/transplantation awareness. Two community champion training workshops took place in the same year, hosted by South West organ donation and NHSBT blood donation teams.

Articles were written and published to follow the radio events. Two campaign champions talked about their experiences on waiting for a transplant on BBC Points West News. Finally, a stand was organised at Bristol City Hall where the NHSBT blood donation team raised awareness on blood and organ donation in BAME groups and provided visitors with information on The Lord Mayor's campaign.

### Awareness and promotion

Given that there are now novel methods to promote health awareness and education via the internet, these should be explored and exploited.

#### Box 1. Campaign collaborators

- Maureen Omondi-Rowland, Campaign Driver/ Champion and Administrator, Renal Patient Support Group, Bristol
- Aneesha Rashid, Campaign Champion, Renal Patient Support Group, Bristol,
- Vicky Gardner, Co-Founder, Chief Administrator and Campaign Champion, Renal Patient Support Group, Bristol
- John Gardner, Co-Founder, Chief Administrator and Campaign Champion, Renal Patient Support Group, Bristol
- Farzana Saker, Campaign Driver/Champion and Development Officer, Bristol Multi Faith Forum, Bristol
- Faruk Choudhury, Campaign Driver/Champion, Bristol Multi Faith Forum and Lord Mayor of Bristol (2013–2014), Bristol
- Caroline Rodaway, Blood Donation Coordinator, NHS Blood and Transplant, Bristol
- Joanne Seddon, Donor Relations Coordinator (Local Marketing), NHS Blood and Transplant, Bristol
- Amanda Herman, Organ Donation Specialist Nurse, South West Organ Donation Team, NHS Blood and Transplant, Bristol
- Anusha Edwards, Consultant Renal Transplant and Endocrine Surgeon, North Bristol NHS Trust
- Adebomi Olaitan, Joint Campaign Coordinator and Community Champion, Ujima Radio, Bristol
- Primrose Granville, Community Champion, Ujima Radio, Bristol
- Paulette North, Joint Campaign Coordinator, Ujima Radio, Bristol
- Sangeeta Dewan, Broadcaster, BCfm Radio, Bristol

### Activities

To record their efforts to promote the campaign, the RPSG invited members of the campaign support group to complete a one-month diary. On World Kidney Day 2011, the British Kidney Patient Association and RPSG jointly sponsored a bowling tournament. All participants were wearing T-shirts with the World Kidney Day 2011 logo and two factsheets were distributed to the public.

In 2014, the Lord Mayor addressed a BMFF health and wellbeing event. In the same year, an awareness day was held at a major shopping centre in the south west of England (Cribbs Causeway, Bristol), in which members of the public were invited to join the blood and organ donation register. Campaign collaborators distributed literature to the public and were available to answer specific questions about organ and blood donation.

Moving forward, with various forms of social media available, many of which are free, different types should be used more effectively to enhance people's understanding of the science behind blood transfusion and organ transplantation.

### Science behind blood transfusion and organ transplantation

The challenge is to provide accessible literature in a variety of languages for patients and their carers in the UK's multifaceted communities. Scientists and clinicians also need to interact better with this community to provide effective health education.

### Background

Primarily, the work-up of a prospective transplant for a recipient is via immunological-based assays to determine antibodies via a recipient's human leukocyte antigen (HLA) system (Jochmans et al, 2010; 2012). If a serum sample is tested against a panel of white cells from donors with a range of different HLA types, it is possible to identify the specificity of the antibodies from the reaction patterns with cells carrying different HLA types (Montgomery 2012a; b). It is important for those from BAME backgrounds and wider society to understand the different concepts of science behind blood and organ donation if there is to be an increase in donations.

### Activities

In one of the World Kidney Day 2013 e-learning sessions, a consultant nephrologist active in all aspects of the care of patients with kidney disease was invited to present insights on the science behind human organ transplantation. In the same year, a 'blood tour' was organised by NHSBT in Filton, Bristol. The event allowed the Lord Mayor and his campaign champions to get a better understanding

both of the science behind blood transfusion and the effort required to ensure different blood products are quality-assured and safely handled before being issued to different centres around the UK.

### Ethical

When individuals are making a decision to go forward with donating blood or an organ, ethics always has a role to play. Health professionals should be actively disseminating key facts on the organ donation process and engaging with the BAME community to ensure the information they receive on organ donation and transplantation alleviates their concerns or misconceptions.

### Activities

In addition to ongoing campaign activities, two health professionals were invited to discuss the ethics of organ donation/transplantation during organised webinars in support of World Kidney Day 2013. During radio interviews, there was discussion about what more needs to be done to aid understanding of blood and organ donation pathways. It is evident that the media can play a greater part in the process.

Many faiths support the principles of organ donation and transplantation and accept that organ donation is an individual choice (Ghaly, 2012a; b; Ghannam and Ismail, 2012). NHSBT has worked closely with religious leaders to produce a series of leaflets explaining organ donation principles. These leaflets are all accessible and downloadable via NHS Blood and Transplant (2015).

### Religious and cultural beliefs

There is an increasing need to include faith in research on perceptions from a wider context, as has been the case in work by Abu-Rayya et al (2009). Several studies suggest that, to be successful, those implementing health changes and attempting to enhance people's understanding of blood and organ donation should recognise the role of spirituality in community health, respect faith sensibilities, and permit appreciation of blood and organ donation from the perspective of faith and community participation (McNabb et al, 1997; Yanek et al, 2001; Morgan et al, 2006; Arriola et al, 2007; Sternberg et al, 2007; Morgan et al, 2008; Röcklinsberg, 2009; Faith and Organ Donation, 2010; Joshi and Lalvani, 2010; Ghannam and Ismail, 2012).

Further to acknowledging the role of personal faith in donation behaviour, it is important to consider the role of faith and community leaders. The term 'faith-placed programmes' has been used to refer to faith-based health promotion programmes that take place in a religious setting or are organised with

the involvement of a faith group. The success of these programmes is thought to be partly due to the partnership between faith and secular organisations.

### Activities

The Lord Mayor liaised with communities from all faiths, in collaboration with NHSBT, BMFF, RPSG and radio station campaign collaborators, to emphasise the importance of signing up to the register. A number of members from each community signed to donate blood and joined the organ donation register.

### Taking ownership

While there is now more evidence of communities becoming more aware of how blood and organ donation helps save lives, more regional and national approaches can be adopted to enable practice to become more evidence-based. The Lord Mayor of Bristol's campaign is one that addresses the APPKG/NKF (2012) manifesto's first call to action point—the need for more members of the BAME communities to take ownership and sign up to the blood and organ donation register.

### Activities

The introduction of peer professional education programmes have been planned as part of the campaign. Members of a community will be provided with training and education so that they can then share their understanding and awareness about the importance of blood and organ donation with peers. Peer educators can either be contracted or volunteer their services (Jain, 2014).

It has also been proposed to have more training implemented for nursing and medical staff as part of NHS England's continuing professional development (CPD) plan. Accredited CPD sessions could be based at the Royal Society of Medicine in London to help health professionals, teachers and scholars to keep up to date on how to enhance services for individuals from different faiths.

Campaign drivers/champions are also aiming to maximise use of social media platforms (e.g. Facebook) to report and disseminate activities.

### Reporting and dissemination

The campaign aimed to implement social media platforms to disseminate ongoing activities through local and wider organisations, to increase support from BAME communities.

### Activities

To meet the reporting and dissemination objective, the following media initiatives have been proposed:

- Downloadable PDF documents from local radio and collaborators' websites

- A full campaign report and notices about ongoing activities via the Bristol City Council website, collaborator networks and social media pages (e.g. Facebook and Twitter)
- Additional publications and presentations available via the NHSBT website
- A summary of this campaign presented at a European conference for all to learn from and potentially replicate a collaborative approach in other countries.

## Campaign outcomes

### Education

This campaign highlighted the need to create educational packs to provide information about blood and organ donation and transplantation to BAME communities. These educational packs would include literature and DVDs to allow community champions to educate their communities on specific topics. Formal training would be provided by a trained peer coordinator.

One of the community champions working with Ujima Radio is now involved in hosting a new show alongside an advisory panel. The future show will feature two or three patients every month who will be guests on Ujima Radio to discuss their experiences and to answer questions from listeners. This will result in ongoing awareness and promotion of the importance of blood and organ donation in BAME communities.

### Awareness and promotion

There are plans to provide an online platform where patients from various faiths and communities, with different illnesses, and their carers are able to share their personal experiences. Methods of creating awareness and promotion will include: public meetings; personal blogs and/or diaries; working with the local radio stations and prospectively using additional sources of media (e.g. television). There is still a need to educate laypeople on the science behind blood transfusion and organ transplantation in BAME communities, while ensuring information is accessible or made available in different languages.

### Science behind blood transfusion and organ transplantation

Campaign collaborators have discussed proposals for video interviews that aim to provide insight into the work-up and preparation of laboratory tests. Collaborators have also proposed the organisation of regular blood tours for people of all backgrounds and faiths to Europe's largest blood manufacturing and processing centre in Filton, Bristol. People who attend the blood tours would also have an opportunity to ask questions about donation, the

handling of components and the science behind blood transfusion and organ donation. This will also help people to understand the ethical issues associated with blood and organ donation.

### Ethics

The Centre for Islam (CIM) is actively promoting ethics courses for professionals and laypeople on blood and organ donation. Some CIM events have already taken place in Birmingham and Leeds. The CIM courses have been GP-led.

As well as courses dealing with the ethical issues facing patients from different faith backgrounds, there are plans to introduce organ donation and transplantation consent questions onto medical admission forms. A further opportunity may arise when considering the content of the do not attempt resuscitation (DNAR) form. This particular ethics process should also initially be GP-led according to General Medical Council (2013) guidelines. In summary, the guidelines state that in cases where health professionals assess that treatments or route of care is unlikely to be clinically appropriate, they may conclude that cardiopulmonary resuscitation (CPR) should not be attempted (GMC, 2013). Some patients with the capacity to make their own decisions may wish to refuse CPR, or in the case of patients who lack capacity it may be judged that attempting CPR would not be of overall benefit to them. Before the point where DNACPR route becomes inevitable, health professionals should consider family consent and ethical issues in relation to patients donating their organs at the end of life.

### Religious and cultural beliefs

This campaign actively involved the Lord Mayor of Bristol who led engagement events to invite members of the BAME community to sign the organ donation register and give their consent for blood donation. The events took place at venues such as the Bristol Easton Jamia Mosque, Bristol Jamia Mosque, Bristol Tawfik Mosque, Bristol Shah Jalal Mosque, Bristol Hindu Temple and Bristol Gurdwara. Engagement events were organised by BMFF.

BMFF's magazine has already provided a summary of this campaign and has been made available for viewing via the BMFF/Bristol City Council websites (BMFF, 2014). NHSBT will also be presenting a summary of the campaign on its website.

### Taking ownership

It is proposed that the Royal Society of Medicine has a formal faith and medicine or equality and diversity subsection, with CPD-accredited sessions, in which health professionals present topics to students, faith leaders and representatives from organisations

representing faith and health-care. This initiative is also being discussed with colleagues at NHS England and the NHS England's equality and diversity division. The equality and diversity division helps to promote equality and equity, ensuring that health-care is widely accessible and that no community or group is hindered. Improvements are made where necessary so that health outcomes across the country are continuously upheld (NHS England, 2015). At a local level, the BMFF is aiming to implement educational sessions for health professionals, patients, carers, faith leaders and teachers with an interest in blood and organ donation.

### Reporting and dissemination

The main campaign report was forwarded on to the Director of the Institute for Health Research at the University of Bedfordshire, who is also the author of the Faith Action Plan (Randhawa, 2013). In 2014, a summary of this campaign was also presented at the joint European Society of Paediatric Nephrology (ESPN) and European Working Group on the Psychosocial Aspects of Children with Chronic Renal Failure (EWOPA) conference in Porto, Portugal. The presentation was warmly received and the co-chair has requested the full report to be made available via the EWOPA website for all to learn from and potentially replicate in other countries.

### Conclusion

Over 200 signatures for blood and organ donation have been received from members of different faiths and BAME groups. This has been a remarkable achievement. The Lord Mayor's campaign highlights the importance of all faiths and communities engaging in the issues surrounding blood and organ donation. In general, what has made this campaign successful is that it adopted a bottom-up approach to ensure blood and organ donation awareness and understanding issue was addressed. The campaign has been developed through numerous practical, educational activities, most of which involved enjoyed a high level of participation. If the blood and organ donation supply and demand issue is to be thoroughly addressed, everyone needs to take ownership to ensure that communities are properly represented. The Lord Mayor's campaign in Bristol has been an exceptional example. **JRN**

### References

- Abu-Rayya HM, Abu-Rayya MH, Khalil M (2009) The Multi-Religion Identity Measure: a new scale for use with diverse religions. *Journal of Muslim Mental Health* **4**(2): 124–38. doi: 10.1080/15564900903245683
- All Party Parliamentary Kidney Group, National Kidney Federation (2012) *Improving Kidney Donation and Transplantation Within UK Black and Minority Ethnic Communities*. <http://tinyurl.com/ogum9ln> (Accessed 2 September 2015)

### Key points

- The Lord Mayor of Bristol's blood and organ donation campaign was in collaboration with Bristol Multi Faith Forum (BMFF), the Renal Patient Support Group (RPSG), NHS Blood and Transplant (NHSBT) and two local radio stations
- The campaign aimed to increase the blood and organ donation pool from black, asian and minority ethnic (BAME) communities
- The campaign promoted the principle of taking ownership and was underpinned by seven key strategies: education; awareness and promotion; the science behind blood transfusion and organ transplantation; ethics; religious and cultural beliefs; taking ownership and reporting and dissemination

- Arriola KR, Perryman JP, Doldren MA, Warren CM, Robinson DH (2007) Understanding the role of clergy in African American organ and tissue donation decision-making. *Ethn Health* **12**(5): 465–82.
- Bristol Multi-Faith Forum (2014) Blood and organ donation campaign. <http://tinyurl.com/qxkqriv> (accessed 7 September 2015)
- General Medical Council (2013) End of life care: when to consider making a do not attempt CPR (DNACPR) decision. <http://tinyurl.com/olyc5lt> (accessed 7 September 2015)
- Ghaly M (2012a) Religio-ethical discussions on organ donation among Muslims in Europe: an example of transnational Islamic bioethics. *Med Health Care Philos* **15**(2): 207–20. doi: 10.1007/s11019-011-9352-x
- Ghaly M (2012b) The ethics of organ transplantation: how comprehensive the ethical framework should be? *Med Health Care Philos* **15**(2): 175–9. doi: 10.1007/s11019-012-9379-7
- Ghannam O, Ismail S (2012) *Organ Donation and Islam*. <http://tinyurl.com/nwxjkw> (accessed 27 August 2015)
- Jain N (2014) Increasing black, asian and minority ethnic (bame) patient & community awareness—using the peer educator model. *J Ren Care* **40**(Suppl 1): 36–40
- Jochmans I, Darius T, Kuypers D et al (2012) Kidney donation after circulatory death in a country with a high number of brain dead donors: 10-year experience in Belgium. *Transpl Int* **25**(8): 857–66. doi: 10.1111/j.1432-2277.2012.01510.x
- Jochmans I, Moers C, Smits JM et al (2010) Machine perfusion versus cold storage for the preservation of kidneys donated after cardiac death: a multicenter, randomized, controlled trial. *Ann Surg* **252**(5): 756–64. doi: 10.1097/SLA.0b013e3181ffc256
- Joshi MS, Lalvani A (2010) 'Home from home': risk perceptions, malaria and the use of chemoprophylaxis among UK South Asians. *Ethn Health* **15**(4): 365–75. doi: 10.1080/13557851003729098
- McNabb W, Quinn M, Kerver J, Cook S, Karrison T (1997). The PATHWAYS church-based weight loss program for urban African-American women at risk for diabetes. *Diabetes Care* **20**(10): 1518–23
- Montgomery JR, Berger JC, Warren DS, James NT, Montgomery RA, Segev DL (2012a) Outcomes of ABO-incompatible kidney transplantation in the United States. *Transplantation* **93**(6): 603–9. doi: 10.1097/TP.0b013e318245b2af.
- Montgomery RA, Warren DS, Segev DL, Zachary AA (2012b) HLA incompatible renal transplantation. *Curr Opin Organ Transplant* **17**(4): 386–92. doi: 10.1097/MOT.0b013e328356132b
- Morgan M, Hooper R, Mayblin M, Jones R (2006) Attitudes to kidney donation and registering as a donor among ethnic groups in the UK. *J Public Health (Oxf)* **28**(3): 226–34
- Morgan M, Mayblin M, Jones R (2008) Ethnicity and registration as a kidney donor: the significance of identity and belonging. *Soc Sci Med* **66**(1): 147–58
- NHS Blood and Transplant (2015) What does my religion say? <http://tinyurl.com/nk9h282> (accessed 8 September 2015)
- NHS England (2015) Equality and diversity. <http://tinyurl.com/pbphobw> (accessed 7 September 2015)
- Randhawa G (2013) *Faith Engagement and Organ Donation Action Plan*. <http://tinyurl.com/nefpxbp> (accessed 2 September 2015)
- Röcklinsberg H (2009) The complex use of religion in decisions on organ transplantation. *J Relig Health* **48**(1): 62–78
- Sternberg Z, Munschauer FE, Carrow SS, Sternberg E (2007) Faith-placed cardiovascular health promotion: a framework for contextual and organizational factors underlying program success. *Health Educ Res* **22**(5): 619–29
- Yanek LR, Becker DM, Moy TF, Gittelsohn J, Koffman DM (2001) Project Joy: faith based cardiovascular health promotion for African American women. *Public Health Rep* **116**(Suppl 1): 68–81