



Better
Health
Briefing

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**Overcoming
barriers to
registering as
an organ donor
among minority
ethnic groups**

Jessica Mai Sims
Charlotte Kenten
Sarah Deedat
Gurch Randhawa
Myfanwy Morgan

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Key messages

- 1 Despite the many ways to join the Organ Donor Register (ODR), the effectiveness of particular methods in reaching black and minority ethnic groups is unknown.
- 2 As the final decision of whether to donate or not is made by the next of kin, individuals should discuss donation choices with family members.
- 3 Myths and anxieties about the organ donation process may prevent particular black and minority ethnic individuals or groups from joining the ODR.
- 4 Although black and minority ethnic groups are generally positive about organ donation and transplantation, the ambiguity around their faith's interpretation limits registration.
- 5 Strategies to promote registration should be guided by monitoring and evaluation and emphasise engaging people on individual, local and national levels.

Introduction

There were over 7,500 people on the active transplant waiting list in the UK as of July 2012, with 15.25 per cent of those people coming from a black and minority ethnic background. To fully appreciate the scale of this overrepresentation, 26 per cent of those waiting for a kidney transplant were classified as black or Asian (9 per cent and 17 per cent respectively) whereas these groups comprise only 8.6 per cent of the general population (2.8 and 5.8 per cent respectively) (NHSBT 2012a and ONS 2011).

Deceased donation is very low among these ethnic groups, representing only 4 per cent of donors in 2011/12 (NHSBT 2012a). The low donation rate means that there is therefore a limited availability of organs of blood groups and tissue types (HLA matching) that are more prevalent among these groups. This in turn presents difficulties in achieving an optimal match for transplantation for large numbers of people from minority ethnic backgrounds (Crowe 2003).

The voluntary 'opt-in' system for deceased donation means that, in the UK,¹ donation requires either the individual making their wishes known by registering on the ODR and their family consenting to this at the time of death, or where the deceased's wishes are not known their family may consent on their behalf at the time of death. The low donation rate for black and minority ethnic groups is influenced by both a lower sign up to the Organ Donor Register (ODR) and families from these groups being nearly twice as likely,

compared with white families, to refuse to donate their deceased relative's organs (75 per cent and 38.5 per cent)(NHSBT 2012b).

This paper explores the reasons for the lower rates of ODR registration among black and minority ethnic groups by reviewing relevant UK literature and drawing on findings from a community study of the Donation, Ethnicity and Transplantation (DonaTE) Programme. The community study comprised of 22 focus groups drawn from Nigerian, Caribbean, Indian, Pakistani and Bangladeshi communities in London (stratified by ethnicity, faith, age category and in the case of South Asian groups, by gender) to investigate differences in attitudes and beliefs both within and between ethnic groups.

The paper first outlines evidence regarding the barriers to registering and then identifies ways in which targeted campaigns can improve understanding and awareness of deceased organ donation among black and minority ethnic groups, and increase organ donor registrations.

What do black and minority ethnic groups know about registration?

1

The most common barrier to organ donation is identified as lack of knowledge, in terms of not knowing 'enough' about organ donation or having incorrect information (Davis & Randhawa 2004). Most participants in the DonaTE focus groups felt not knowing enough about organ donation prevented an informed decision to register.

Most were unaware of the particular need for organ donors in their communities and acknowledged that not being personally affected and having busy lives meant that they were not particularly motivated to find out more information, register or carry a donor card; sentiments echoed by other studies (Ahmed *et al.* 1999; Baines *et al.* 2002). When members of the focus group participants were asked if they knew how to register they could speculate where one 'should' be able to register (e.g. at the GP surgery or hospital), but were less sure where one actually 'could' register (e.g. via NHSBT online, the DVLA, or 'Boots' loyalty card scheme). It is not clear how many people from black and minority ethnic groups actually sign up, as ethnic monitoring has not been adopted across all registration methods. Overall only 18 per cent of the total ODR registrations have a known ethnicity, with 3.5 per cent of those reporting a minority ethnic group (1.5 per cent Asian, 1.2 per cent Mixed, 0.5 per cent Black, and 0.2 per cent each from Chinese and Other groups) (NHSBT 2012c).

¹ The Welsh Government is seeking to change their system for deceased donation by 2015 through a proposed Human Transplantation (Wales) Bill. The proposals would introduce an 'opt-out' system, with residents over the age of 18 years presumed to have consented to deceased donation unless they had opted out, although the family of the deceased might be able to refuse consent to donation. For more information see: Welsh Government 2012.

NHS Blood and Transplant (NHSBT) – and its previous incarnation of UK Transplant – have implemented campaigns to increase ODR registrations for both the general and black and minority ethnic populations. The first of these campaigns were targeted to South Asian groups in 1999 and to black groups in 2002-05. Integrated black and minority ethnic campaigns were then launched in 2006, 2010 and 2011. These campaigns have been accompanied by informational leaflets in different languages, outreach at community venues (e.g. community centres, places of worship, shopping centres and GP surgeries) and utilised a range of news and social media. Despite the many black and minority ethnic campaigns, there has been very limited formal assessment of their impact. However one example is the 'Real People, Real Lives, Real Action' campaign (2011-12) in Birmingham that involved a pre and post campaign survey to gauge the impact of the campaign on the areas targeted. Altogether 41 per cent had seen or heard of one or more elements of the campaign (e.g. leaflets, posters, radio) (Coleman 2012). Many of the people surveyed reported that they planned to take some kind of action, with one in ten of the primary audience planning to join the ODR.

In general, research points to black and minority ethnic groups lacking information on registration and donation. Systematic ethnic monitoring is needed to identify the most effective registration methods and campaign evaluations are needed to identify and build on promising initiatives.

2 The role of the family in donation decisions

Knowledge of the deceased's wishes or attitudes towards donation is identified as having a key influence on families' consent to donate (Sque *et al.* 2005; Siminoff *et al.* 2001). For example in the UK during the 2011-12 period, the overall family consent rate for organ donation was 94 per cent when the deceased's wishes were known but only 41 per cent when their wishes are not known. Despite the importance of family discussions, only 48 per cent of over 2000 adults surveyed by YouGov had told their donation wishes to their friends and family (NHSBT 2012d).

While reluctance to discuss with family is shared among all groups, this appears to be more common or more strongly felt among black and minority ethnic groups (Morgan *et al.* 2006; Hayward & Madil 2003; Davis & Randhawa 2004). This is often associated with the perception that death should not be discussed with older relatives, especially as they may be less familiar with organ donation and transplantation. Superstitions around discussing death were voiced particularly by participants in the DonaTE Nigerian and Caribbean focus groups, who described registration as 'tempting fate', and 'signing my life away'.

3 Anxieties and myths about registration and donation

DonaTE focus group participants recounted many anxieties about organ donation. One was whether medical professionals can be trusted to do their best to prolong life if they know the patient is on the ODR.

Stories in the media also contributed to anxieties, such as unethical practice in the health service and the commercial and illicit organ economies. Lack of trust also arose from experiences of marginalisation in society; participants questioned whether the organ allocation system was fair in terms of need. These concerns have been well documented among all minority ethnic groups (Morgan *et al.* 2006; Morgan *et al.* 2008; Davis & Randhawa 2004; Exley *et al.* 1996; Poonia 2006).

Body disfigurement after donation was another anxiety. Caribbean and Nigerian focus group participants spoke of their personal preference of not wanting the body to be cut, often framed around religion and wanting to 'return' whole. For the Bangladeshi, Pakistani and Indian groups, body disfigurement was of particular concern through causing distress to close family during intimate burial rituals involving washing and dressing the body. There was also a fear that the body would not look right in an open coffin. In addition, as Muslims traditionally bury the dead quickly, they had concerns about organ donation delaying the burial.

Faith-based concerns to organ donation

4

None of the major religions in the UK expressly prohibits organ donation, although research has frequently indicated that people from black and minority ethnic groups are less likely than their white counterparts to regard organ donation as acceptable to their religious beliefs (Morgan *et al.* 2006). When exploring this further we find that attitudes vary across groups. One study researching the views of Muslim, Sikh and Hindu South Asians in Luton, found that people had varying needs for spiritual guidance in relation to organ donation (Randhawa 1998). For example, while Sikhs lacked definitive spiritual evidence, they felt that organ donation was viewed positively by their faith. Similarly in the DonaTE study sample, Indian participants of Sikh and Hindu faiths were most likely of all groups to believe that donation was permitted; believing that since the soul leaves the body for reincarnation there should be no problem with organ donation.

In contrast, people of Muslim faith surveyed in Randhawa's study were often uncertain and wished for guidance from religious scholars (Randhawa 1998). This was similar to the views of many of the participants in the Bangladeshi and Pakistani DonaTE focus groups; very few could recall a definite example of what their religion had to say on organ donation. Knowledge and beliefs about harming one's body and whether bodies feel pain after death were cited as reasons to prohibit donation. In general, people of Bangladeshi background were more likely than their Pakistani counterparts to believe that their faith did not allow donation.

Other studies researching black Caribbean and West African groups have found that participants were unsure if organ donation was 'right with God' (Davis & Randhawa 2004). However, some participants among the DonaTE focus groups who were of Christian faith and Caribbean and Nigerian origin compared the act of donation with the sacrifice of Christ, extrapolating that Christ would have or would want other Christians to donate. Few thought that donation was definitely not allowed by their religion, while people in the older group were again most likely to be uncertain about this.

5 Recommendations for policy and practice

Black and minority ethnic groups have specific concerns about organ donation that can be targeted through engagement strategies at individual, local and national levels.

Individual

Strategies at the individual level need to focus on encouraging donor families and transplant recipients to talk publicly about their experiences with family, friends, their local community and media with national coverage. Personal stories from all sides of donation may promote more positive attitudes to signing up to the ODR and a recognition that transplantation depends on other families overcoming cultural or faith reservations to donation. Publicising personal and family experiences of donation and transplantation and the provision of training for such 'Speakers' (LLTGL [accessed October 2012]), would assist in raising awareness among people from black and minority ethnic groups and may also prompt others to speak about their wishes with their family.

Local

Strategies on the local level should focus on engaging people in the context of their communities whether defined geographically, via faith or ethnicity. Previous policy recommendations have highlighted local engagement strategies (ODT 2008; Organ Donation Campaign 2010) and NHSBT has been active in promoting engagement at the local level through road shows in shopping centres and places of worship. In Birmingham outreach events were identified as more successful in challenging active rejection of organ donation than visual or radio elements (Coleman 2012).

It is known that successful engagement requires that local stakeholders take ownership of this issue. Many local elements of national initiatives have promoted 'social marketing' models of engagement, where people are trained to promote organ donation among their local community, such as 'Donor Champions' or 'Peer Educators' (Kidney Research UK 2010; PRIAE [accessed October 2012]). These participatory models are promising as they aim to build on communities' social capital in promoting attitudinal and behavioural change. In the DonaTE focus groups participants felt that if organ donation was allowed, and their local faith leaders publicly support this, people would be more likely to register to donate. Though, the effectiveness of these projects is unknown as, of the time of writing, they have not been formally evaluated.

Aside from creating formalised arrangements of 'Donor Champions', the need for organ donation and transplantation can be incorporated into existing outreach work in community centres and organisations. For example, many local faith communities engage in health promotion among their communities (e.g. healthy eating, smoking cessation, sexual health) and could add the importance of organ donation to their established health promotion work. Likewise, primary care providers in areas of migrant and minority ethnic residential concentration could consider ways to engage and promote awareness among their catchment population. These providers are in a position to raise awareness and answer health questions among their existing patients and among those who are either new to the area or the health service.

National

National strategies should make general information and campaigns inclusive of diversity to ensure that organ donation and transplantation is regarded as relevant among all groups in the population. Research has shown that black and minority ethnic groups have similar habits as their white counterparts in terms of watching television, listening to radio and reading newspapers and accessing the internet (Fletcher 2003; Turnstone Research 2003). It is therefore important to have a broad representation in visual materials, as relying on predominately white actors in general campaigns risks giving the impression that organ donation is only a 'white' issue. For example, a participant in one of the Caribbean DonaTE focus groups (men and women, 18-40) cited a road safety campaign that was successful in capturing his attention because the image of a black boy was used. Whereas targeted black and minority ethnic campaigns can elaborate on the specific concerns certain groups hold, inclusive general campaigns can highlight the need in all communities.

All the DonaTE focus group participants – regardless of ethnic or age group – cited the internet as one of the primary access points for health and public service information. This is unsurprising considering black and minority ethnic groups are more likely than their white counterparts to be connected to and search for information on the internet (Ofcom 2008). Since 8 per cent of ODR registrations come from the internet, (NHSBT 2012b) it is vital that the NHSBT website is seen as relevant to all groups by providing information that addresses different ethnic and faith groups' concerns in a user-friendly format. As discussed above, these concerns include the reluctance to discuss death and organ donation with older family members, whether people can trust medical professionals, what happens during the donation process, and the implications of organ donation on faith observance.

Social media and networking is another powerful engagement tool which NHSBT are beginning to engage with on the national level, e.g. their 2012 campaign theme, 'Pass it On,' which explicitly links the act of registering on the ODR and 'passing on' their donation wishes to family and friends (NHSBT [accessed October 2012]). In 2012 NHSBT collaborated with Facebook to create a Facebook page for ODR registration, communicate wishes among family and friends and potentially influence them to also register (NHSBT 2012e).

Future online initiatives should consider how different ethnic and faith groups engage with media in order to promote awareness and registration campaigns among different black and minority ethnic groups. There is also the need for more systematic ethnic monitoring across all registration methods, as currently less than one-fifth of registrations have a known ethnicity.

Conclusion

To meet transplant needs among black and minority ethnic groups it is important to tackle low rates of registration and increase the potential donor pool. These groups have specific concerns about organ donation which in turn influence their willingness to register. Addressing this requires opportunities for different groups to engage with information that is relevant to them. In addition, all methods of registration should monitor ethnicity and interventions should be evaluated to ensure that good practice can be identified and widely implemented.

Resources

1999-01	<i>Department of Health</i> South Asian Community Organ Donation Campaign	South Asians	Public campaign to raise awareness of the need of organ donors, address issues people may have and provide opportunities for registration. Campaign was targeted through black and minority ethnic media, regional press and community centres. Leaflets explained how major faiths support organ donation in English, Punjabi, Bengali, Urdu, Gujarati and Hindi.
2002-05	<i>UK Transplant</i> 'Be Part Of The Solution'	Black	Public campaign to raise awareness of the high need among black groups. The wider campaign appealed for help to 'be part of the solution' through black and minority ethnic radio programmes, celebrity endorsements (Curtis Walker) and health professionals and a campaign road show. The leaflet, 'Why every Black person needs to know about organ donation', was distributed among chemists, community and social centres, educational establishments, health centres and clinics, cafes and restaurants; etc.
2006-07	<i>NHS Blood and Transplant</i> 'Can We Count On You?'	Black and South Asian	Public campaign to targeted Black and South Asian groups. Teams visited 5,000 black and Asian businesses, community centres and places of worship to distribute leaflets in towns and cities across England.
2007-10	<i>Policy Research Institute on Ageing and Ethnicity (PRIAE)</i> 'Being A Donor' Project	Black and minority ethnic	Project raising awareness among local communities in different cities (e.g. London, Leeds and Manchester) about the need for blood, tissue, bone marrow and organ donation, while addressing cultural, social and health taboos. Worked with different community groups (Chinese, African, Caribbean and South Asian) to train 'Donor Champions' who would raise awareness about donation among their local minority ethnic community. Project relayed public views back to statutory services.
2009-10	<i>NHS Blood and Transplant</i> 'If You Believe In Organ Donation, Prove It'	General population and black and minority ethnic	The first multi-media public campaign to promote organ donation. The campaign ran in 2009 for the general population and in 2010 for black and minority ethnic groups. Leaflets, in English and



			<p>South Asian languages, were sent out to shops, black and minority ethnic businesses, cinemas, GP surgeries, faith organisations and community groups. Adverts appeared mainly in black and Asian TV channels, radio stations and newspapers. A number of discussions were held at faith organisations/places of worship. There were also a number of street plays in areas with relatively high black and minority ethnic populations.</p>
2011-12	<p><i>NHS Blood and Transplant</i> 'Real People, Real Lives, Real Action'</p>	<p>General black and minority ethnic</p>	<p>Public campaign to raise awareness of the need of organ donors, address issues people may have and provide opportunities for registration. The campaign engaged media on local and national levels (community radio, regional print, and national print), coordinated outreach events (e.g. places of worship, supermarkets, shopping centres), and disseminated information through social media and leaflet drops at homes and shops.</p>
2011-12	<p><i>Channel4 'Battlefront'</i> 'Speak Up, Save Lives'</p>	<p>General population</p>	<p>A youth-led campaign developed for the Channel4 television show 'Battlefront'. The multi-media campaign promoted registration for organ donation registration through raising awareness about the need, celebrity interviews and endorsements, social media and online video content. The campaign was not specifically targeted to black and minority ethnic groups but rather was ethnically and culturally diverse in terms of its programme content, actors/presenters and celebrity endorsements.</p>
2009-12	<p><i>Kidney Research UK</i> Peer Educators</p>	<p>General population and black and minority ethnic</p>	<p>Project which lay members of the local community undergo accredited training about the risks of kidney disease and how to reduce this risk through behavioural changes to lifestyle. These trained individuals become 'Peer Educators' and engage local communities on the subject of kidney health and/or organ donation at community organisations and local events. Kidney Research UK received an Association of Medical Research Charities Award for this work in 2011.</p>

The DonaTE Programme

The Programme of research on Donation, Transplantation and Ethnicity (DonaTE) is funded by the National Institute of Health Research (2009-14). The Programme specifically responds to the Organ Donation Taskforce's Recommendation 13 for research to address the '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 population' (Department of Health, 2008: para. 4.46).

The DonaTE Programme is led by Professor Myfanwy Morgan at King's College London and involves both community and hospital based studies. The final phase then develops a staff training intervention to support organ donation choices for bereaved families from minority ethnic groups.

Community and Hospital studies

An initial systematic literature review identified significant barriers to deceased organ donation among minority ethnic groups in the UK and North America. This informed 22 focus groups held with older and younger generations from Caribbean, Nigerian, Indian, Pakistani and Bangladeshi communities. This briefing draws on this evidence and identifies its implications for policies and practice at national, local and individual levels to increase registration as an organ donor.

The second component of the Programme focused on consent by the next of kin. This is a key requirement for deceased donation and is known to be strongly influenced by families' views of the quality of care the patient has received, and whether the patient is on the Organ Donor Register. Ethnographic methods involving observations of intensive care units (ICU) and interviews with ICU staff were used to examine important organisational aspects of end of life care and deceased donation. Interviews were also conducted with bereaved donor families from minority ethnic groups about their ICU experiences and donation decisions.

Training intervention

All the data collected for DonaTE have informed the development and evaluation of a video based training module ('Life after Death: Supporting organ donation choices for ethnic minority families') that aims to enhance ICU staff confidence in communicating and responding to the needs of families from minority ethnic groups around end of life care and organ donation. This package is currently being evaluated with the aim of national roll-out.

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Jessica Mai Sims

Researcher and Programme Coordinator,
King's College London

Charlotte Kenten

Research Fellow,
King's College London

Sarah Deedat

Research Associate,
King's College London

Gurch Randhawa

Professor of Diversity in Public Health,
University of Bedfordshire

Myfanwy Morgan

Professor of Medical Sociology,
King's College London

Readers

Neerja Jain

Professor Anthony Warrens

Robert Higgins

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on all aspects of our work. Please email
briefings@racefound.org.uk

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Race Equality Foundation

Unit 17

Deane House Studios

27 Greenwood Place

London NW5 1LB

T: 020 7428 1880 F: 020 7428 0912

www.raceequalityfoundation.org.uk

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The Programme of research on Donation, Transplantation and Ethnicity (DonaTE) is led by Professor Myfanwy Morgan and aims to identify the social and cultural attitudes to organ donor registration among minority ethnic groups and the range of influences on the donation process and consent to donation within hospital ICUs. These initial studies inform the development and evaluation of a video based training module to promote staff competence and confidence in responding to the needs of families from minority ethnic groups.

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