Achieving equality in organ donation and transplantation in the UK: challenges and solutions

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A Race Equality Foundation Briefing Paper

June 2011

www.better-health.org.uk
Introduction

Minority ethnic groups in the UK experience many health inequalities. Transplant services are not immune to this phenomenon and significant variation exists – in relation to demand for, access to, and waiting times for these services – between minority ethnic groups in particular (Roderick et al., 2011). Demand for transplantation can largely be reduced if there is a sustained commitment to public health interventions and tailored management of long-term conditions, recognising the heterogeneity of the UK’s population. Improved access to transplantation and reduced waiting times can be achieved if there are concerted and adequately resourced efforts to increase the number of organ donors from minority ethnic groups.

Key messages

1. Minority ethnic groups are disproportionately affected by inequalities in transplant services in the UK.
2. The UK Organ Donation Taskforce’s explicit recommendations to tackle the needs of the UK’s multi-ethnic and multi-faith population demonstrate the significance of this issue.
3. Policy interventions should take a two-pronged approach: to employ preventive strategies to decrease the number of minority ethnic patients requiring a transplant in the long term; and to increase the number of organ donors from minority ethnic groups in the short term.
4. There are a number of targeted interventions designed to tackle inequalities in transplant services, but increased guidance, training and awareness are still necessary.

Inequalities in transplant services

Minority ethnic communities are at greater risk of developing organ failure for a number of complex reasons. These range from genetic predisposition, increased prevalence of underlying conditions, and poorer access to, and uptake of services. Prevalence of Type 2 diabetes is up to six times greater among South Asians and African-Caribbean communities than in the white population (Riste et al., 2001; Forouhi et al., 2006). Around 20 per cent of South Asians aged 40–49 have Type 2 diabetes, and by the age of 65 the proportion rises to one-third (Forouhi et al., 2006). South Asian and African-Caribbean patients receiving renal replacement therapy (RRT) (either by dialysis or transplantation) have a four times greater relative risk of end-stage renal failure (ESRF) caused by diabetic nephropathy than their white counterparts (Roderick et al., 1996).

There are currently approximately 8000 people waiting for transplants in the UK – with a disproportionately greater number from minority ethnic backgrounds. The majority are waiting for kidney transplants, but there are also long waiting lists for heart, lung and liver transplants. For example:

- People of South Asian origin represent 15 per cent of those waiting for a kidney transplant even though they comprise only 4 per cent of the general population. For African-Caribbean patients, the figures are over 7 per cent on the waiting list compared to 2 per cent of the UK population (Table 1).
- Conversely, only 2.1 per cent of people who donate kidneys after their death are South Asian and 1.2 per cent African-Caribbean (Table 1).
Table 1  Ethnicity of deceased heartbeating kidney donors and recipients (1 April 2007 – 31 March 2009) and transplant list patients at 31 March 2009 in the UK

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Donors</th>
<th>Transplant recipients</th>
<th>Active transplant list patients</th>
<th>UK pop.</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>568</td>
<td>95.6</td>
<td>554</td>
<td>94.9</td>
</tr>
<tr>
<td>Asian</td>
<td>10</td>
<td>1.7</td>
<td>12</td>
<td>2.1</td>
</tr>
<tr>
<td>Black</td>
<td>11</td>
<td>1.9</td>
<td>7</td>
<td>1.2</td>
</tr>
<tr>
<td>Chinese</td>
<td>1</td>
<td>0.2</td>
<td>2</td>
<td>0.3</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
<td>0.7</td>
<td>9</td>
<td>1.5</td>
</tr>
<tr>
<td>Not reported</td>
<td>0</td>
<td>–</td>
<td>0</td>
<td>–</td>
</tr>
<tr>
<td>Total</td>
<td>594</td>
<td>584</td>
<td>1118</td>
<td>1096</td>
</tr>
</tbody>
</table>

(Source: NHS Blood and Transplant, 2009)

- Viral hepatitis – hepatitis B and C – is also more prevalent in the South Asian population, leading to increased likelihood of liver damage and liver failure. South Asians comprise over 10 per cent of the liver transplant list (Table 2).

Table 2  Number registered on list for a liver transplant in UK at 31 December 2008, by age decade and ethnic origin

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>White</th>
<th>Asian</th>
<th>Black</th>
<th>Chinese</th>
<th>Mixed</th>
<th>Other</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>0–9</td>
<td>14</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>15</td>
</tr>
<tr>
<td>10–19</td>
<td>8</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>20–29</td>
<td>15</td>
<td>3</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>22</td>
</tr>
<tr>
<td>30–39</td>
<td>21</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>24</td>
</tr>
<tr>
<td>40–49</td>
<td>55</td>
<td>11</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>68</td>
</tr>
<tr>
<td>50–59</td>
<td>109</td>
<td>16</td>
<td>4</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>131</td>
</tr>
<tr>
<td>60–69</td>
<td>75</td>
<td>4</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>3</td>
<td>84</td>
</tr>
<tr>
<td>70–79</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>298</td>
<td>37</td>
<td>6</td>
<td>2</td>
<td>0</td>
<td>13</td>
<td>356</td>
</tr>
<tr>
<td>Total %</td>
<td>83.7%</td>
<td>10.4%</td>
<td>1.7%</td>
<td>0.6%</td>
<td>0.0%</td>
<td>3.7%</td>
<td>–</td>
</tr>
<tr>
<td>Pop. %</td>
<td>92.1%</td>
<td>4.0%</td>
<td>2.0%</td>
<td>0.4%</td>
<td>1.1%</td>
<td>0.4%</td>
<td>–</td>
</tr>
</tbody>
</table>

(Source: NHS Blood and Transplant, 2009)

- Minority ethnic communities are represented in disproportionately lower numbers on the Organ Donor Register: 1 per cent of people registered are South Asian and 0.3 per cent of people registered are African-Caribbean (Rudge et al., 2007).
- South Asian and African-Caribbean people wait on average twice as long as white people for a kidney transplant. White patients wait on average 719 days, Asian patients wait 1368 days and black people wait 1419 days (Rudge et al., 2007).
Tackling inequalities in transplant services

Explicit recommendations to tackle the needs of the UK’s multi-ethnic and multi-faith population have been developed by the UK Organ Donation Taskforce. 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). These recommendations demonstrate recognition of the inequalities that exist within transplant services. The challenge now is to ensure that there is urgent and appropriately resourced action to ensure a tangible benefit for the population.

Prevention and management of long-term conditions

A range of studies have documented the lower quality of diabetes and renal care, patient compliance, and knowledge of diabetes and its complications among South Asians and African-Caribbeans (Randhawa et al., 2010c; Gholap et al., 2011; Wilkinson et al., 2011a). In an effort to address these inequalities, national policy documents have drawn attention to them with the aim of influencing clinical practice. The Diabetes National Service Framework (NSF) highlights the importance of access to services, in particular to meet the needs of minority ethnic groups (DH, 2002). The Renal Services NSF also focuses on ‘renal disease complicating diabetes’ and emphasises inequalities experienced by minority ethnic groups (DH, 2004). The Quality and Outcomes Framework (QOF) introduced standards for monitoring diabetes and kidney disease in 2006 which were aimed at improving primary care practice among GPs. Preliminary analyses from a UK-wide study suggest that these national policy developments may be beginning to yield some benefits (Wilkinson et al., 2011b).

Increasing awareness of the need for organ donors among the African-Caribbean and South Asian communities

It is evident from Table 1 that there are disproportionately lower numbers of organ donors from minority ethnic communities. Although there are a range of complex reasons for this, one key issue stands out: a lack of awareness concerning organ donation and transplantation among these communities, which then manifests itself in increased refusal rates among non-white families in hospitals (Barber et al., 2006; DH, 2008a; Perera and Mamode, 2010).

Studies consistently demonstrate that while African-Caribbeans and South Asians are supportive of organ donation and transplantation, they are not aware of the specific needs of their community for organs (Exley et al., 1996; Darr and Randhawa, 1999; Hayward and Madill, 2003; Alkhawari et al., 2005; Davis and Randhawa, 2006; Morgan et al., 2006). These studies, however, do not identify what would motivate these communities to come forward as potential organ donors. It is hoped that the Donation, Transplantation, Ethnicity (DonaTE) study, funded by the NHS National Institute for Health Research, will contribute to bridging this knowledge gap in the next few years.

A growing amount of literature has shown that religion plays an important part in the decision to donate organs (Hayward and Madill, 2003; Alkhawari et al., 2005; Davis and Randhawa 2006; Randhawa et al., 2010a). 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 religion is cited by many people as informing their decision as to whether to donate or not (Randhawa et al., 2010a). There is a need to identify how best to encourage religious ‘stakeholders’ to engage with their local community concerning the issue of organ
donation and transplantation. It is encouraging to note that the Organ Donation Taskforce initiated some preliminary meetings with faith leaders in the UK and has recommended that this dialogue should continue (DH, 2008b).

In recent years, the DH and NHS Blood and Transplant (formerly known as UK Transplant) have produced a range of educational materials (including leaflets, posters and videos) in the main South Asian languages to increase awareness of transplant-related issues, as well as launching some specific black and minority ethnic campaigns since 2009. Additionally, materials have been produced that set out the position of each religion regarding organ donation. However, current evidence shows that further thought is required with regard to the dissemination of this literature among African-Caribbean and South Asian populations (Morgan et al., 2006; Perera and Mamode, 2010). There are indications from pilot work in the UK, and research overseas involving minority ethnic groups, that appeals for African-Caribbean and South Asian donors may be more effectively communicated by employing a grassroots, community networking approach (Morgan et al., 2010). The Organ Donation Taskforce places great emphasis on achieving equity in organ donation and transplantation and has consequently recommended that further consideration should be given to ensuring that organ donation is relevant to all of the UK’s multi-ethnic and multi-faith population (DH, 2008b).

The Potential Donor Audit (an audit developed to identify the true potential for organ donation from deceased donors, together with the reasons for non-donation) has highlighted that the refusal rate for non-white potential donors is 69 per cent, compared to 35 per cent for white potential donors (Barber et al., 2006). The DonaTE study hopes to provide an improved understanding of the reasons why non-white families have a higher refusal rate than white families.

**The way forward**

It is evident that minority ethnic groups are disproportionately affected by renal health problems, both in terms of access to appropriate services, a higher prevalence of renal complications, reduced likelihood of a transplant, and longer waiting times on the transplant waiting list.

Kidney Research UK has recently launched the ABLE (‘A better life through education and empowerment’) campaign, which aims to redress some of the renal health issues through education and by raising personal awareness of kidney health issues among minority ethnic groups. Professor Gurch Randhawa led a national pilot study (with colleagues from Imperial College and the University of Leicester) to explore the above issues and the study was completed in September 2010. Initial findings from this study suggest low levels of awareness of kidney disease and risk factors among diabetic patients despite familiarity with diabetes (Wilkinson et al., 2011a). However, the study does provide some evidence that quality of care for South Asian patients with diabetes is improving (Wilkinson et al., 2011b).

Concomitantly, there needs to be an increase in the supply of organs from the African-Caribbean and South Asian populations to alleviate the burden on current waiting lists and for those patients on dialysis. This process can only begin if the public are in an informed position to consider and debate the issues surrounding organ donation and transplantation as part of their everyday lives. The need for informed debate has been given further impetus by the present government’s emphasis on ‘behaviour change’ as a key method of increasing organ donation as described in the discussion paper Applying Behavioural Insight to Health (Cabinet Office, 2010). An example of its practical application has been to ask people to consider organ donation when they register for a driving licence (Cabinet Office, 2010).

The evidence in this paper suggests, however, that central to attaining this goal are increased levels of health education and awareness of the specific problems within the African-Caribbean and South Asian populations. This is a difficult challenge, as many of these communities live within the most deprived (and hard-to-engage) communities in the UK. Not only should health professionals engage the public with the
discourse of ‘disease prevention’ as well as ‘organ donation’, but there is a need to identify whether the social class of a patient and/or their family influences live donation, as this may have implications for current reimbursement arrangements. This issue may have particular relevance to minority ethnic groups who experience the greatest levels of deprivation in the UK.

Religion is used by many individuals to guide their decision as to whether to donate or not (Randhawa et al., 2010a). The introduction of community-based information programmes needs to be evaluated to assess whether this impacts upon the number of African-Caribbeans and South Asians on the Organ Donor Register. Indeed, all public organ donor campaigns should be formally evaluated to identify which members of the public benefit from such campaigns and which are still not being reached. Moreover, research should be commissioned to identify how best to unravel public concerns that are ‘cultural’ as opposed to ‘religious’ (Randhawa et al., 2010b).

Within hospitals also, there need to be clear guidelines on how to approach individuals with requests for the donation of their loved one’s organs, coupled with specific training and counselling relating to working with families from a range of ethnic and faith backgrounds (Randhawa, 1997). The Organ Donation Taskforce has implemented training for all Specialist Nurses for Organ Donation (SNODs) and Clinical Leads for Organ Donation (CLODs) in how to approach families. The DonaTE study is considering how families from minority ethnic groups should most effectively and appropriately be approached regarding requests for organ donation.

Conclusion

There has been substantial recognition of the need to improve organ donation rates among minority ethnic groups in the UK, as evidenced by the plethora of initiatives led by NHS Blood and Transplant, including the following.

### Timeline

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000</td>
<td>A multi-faith symposium organised by donor and transplant professionals aimed at the eight major faiths in the UK, supported by DH (Lord Hunt) and senior religious leaders (Bradford: 250 delegates from all major faiths).</td>
</tr>
<tr>
<td>2001</td>
<td>Debate arranged for Muftis and Imams in the Muslim school. Unable to go forward with this project for political reasons.</td>
</tr>
<tr>
<td>2002</td>
<td>Appointment of project worker by UK Transplant, to look at organ donation and ethnicity. Leaflets and booklet produced and another seminar held (Birmingham: 200 delegates).</td>
</tr>
<tr>
<td>2003</td>
<td>UK Transplant take over running of all black and Asian donor campaigns developed by DH. Black and Asian celebrities used to highlight the importance of organ donation and transplantation.</td>
</tr>
<tr>
<td>2005</td>
<td>Training developed for donor transplant coordinators and clinicians (Hospital development, Breaking bad news) with a significant component of the training applied to cultural differences.</td>
</tr>
<tr>
<td>2006</td>
<td>Research into attitudes of ethnic minority groups to organ donation, run and commissioned by NHS Blood and Transplant.</td>
</tr>
<tr>
<td>2006</td>
<td>Cultural guide developed for health care professionals as an aid for use in interviews when speaking to families with differing and diverse cultural backgrounds.</td>
</tr>
<tr>
<td>2007</td>
<td>NHS Blood and Transplant launch the ‘Can we count on you?’ campaign, an organ donation campaign targeted at minority ethnic groups.</td>
</tr>
<tr>
<td>2009</td>
<td>Two-year research study commissioned to explore how to make the gifting of organs relevant and meaningful to the UK’s multi-ethnic and multi-faith population.</td>
</tr>
<tr>
<td>2009</td>
<td>DH commissions a two-year programme of faith-based engagement on organ donation.</td>
</tr>
<tr>
<td>2010</td>
<td>NHS Blood and Transplant launch the ‘If you believe in organ donation, prove it’ organ donation campaign for black and Asian people.</td>
</tr>
<tr>
<td>2011</td>
<td>NHS Blood and Transplant appeal for more minority ethnic organ donors on World Kidney Day.</td>
</tr>
</tbody>
</table>
Many of these initiatives are recognised to be at the forefront worldwide in the development of culturally competent organ donation educational materials. However, their success has been limited by the lack of a focused strategy that would bring together the various strands of a multifaceted problem and lead to a coherent implementation plan. It is hoped that the recent specific recommendations by the Organ Donation Taskforce, focusing on the needs of the UK’s diverse population, will enable the development of a clear action plan to achieve equity in organ donation and transplantation. It is further hoped that this briefing paper contributes to beginning and shaping the framework for such a process, not only in the UK but for many other countries with a multi-ethnic and multi-faith society.

**Resources**

**WEBSITES**

**African-Caribbean Leukaemia Trust**  
www.aclt.org  
Promoting bone marrow and blood donation.

**Anthony Nolan Trust (Be a Match, Save a Life)**  
www.anthonynolan.org/Existing-Registry-Donors.aspx

**Centre of Evidence in Transplantation, The Royal College of Surgeons of England**  
www.transplantevidence.com

**Donor Family Network**  
www.donorfamilynetwork.co.uk  
Run by donor families for donor families.

**Kids Kidney Research**  
www.kidskidneyresearch.org  
Information and updates on kidney disease.

**Live Life Then Give Life**  
www.lltgl.org.uk

**NHS Blood and Transplant**  
www.organdonation.nhs.uk  
www.organdonation.nhs.uk/ukt/how_to_become_a_donor/religious_perspectives/religious_perspectives.jsp  
Religious perspectives on organ donation.

**Give and Let Live, a resource for schools and educators.**  
www.giveandletlive.co.uk/en

**Organ Donor Campaign**  
www.theodc.org.uk

**Transplant Sport UK**  
www.transplantsport.org.uk  
Organises sports and social events for transplant recipients.

**Transplant Support Network**  
www.transplantsupportnetwork.org.uk/about.htm  
Provides support for patients and their families.

**UK National Kidney Federation**  
www.kidney.org.uk  
Run by kidney patients for kidney patients.
References

References (continued)


Gurch Randhawa is Professor of Diversity in Public Health and Director of the Institute for Health Research at the University of Bedfordshire and an international expert on the development of patient-centred care pathways in diabetes, kidney disease, transplantation, and end-of-life care among diverse communities. He is Co-Chair of the European Working Party on Public Issues and Organ Donation; and a Member of the UK’s NICE Guidelines Development Group on Organ Donation. In his other ‘life’, Gurch is Chairman of NHS Luton, a Member of the UK Donation Ethics Committee and a Non-Executive Director of the Human Tissue Authority.

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We welcome feedback on this paper and on all aspects of our work. Please email briefings@racefound.org.uk