Who waits longest for a kidney?  
Inequalities in access to kidney transplantation among Black and Asian Minority Ethnic (BAME) groups in the UK

Myfanwy Morgan* PhD  
Professor of Medical Sociology, King’s College London

Jessica Sims MSc  
Research Assistant, King’s College London

Neerja Jain MSc  
Health Improvement Project Manager, Kidney Research UK

Gurch Randhawa PhD  
Professor of Diversity in Public Health, University of Bedfordshire

Shivani Sharma PhD  
Associate Dean (Learning and Teaching), University of Hertfordshire

Kirit Modi PhD  
Joint Chair National Black, Asian and Ethnic Minority Transplant Association

*Corresponding author: Professor Myfanwy Morgan  
King’s College London  
Department of Primary Care and Public Health Sciences  
Capital House, Weston Street, London SE1 3QD  
E-mail: myfanwy.morgan@kcl.ac.uk  
Tel: 0207 848 6641

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Abstract

Black and Asian Minority Ethnic (BAME) groups are over-represented on active kidney transplantation waiting lists and have relatively long waiting times. This inequality arises from a particularly high need for kidney transplantation combined with a low rate of deceased donation among BAME groups which limits the availability of a well-matched graft. This paper outlines the major barriers to both registration as a potential donor and family consent to donation. It then describes initiatives to increase donation and transplantation in terms of system changes, organisational changes and community interventions, and considers requirements for effective strategies.
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Kidney transplantation currently accounts for 82% of all solid organ transplants undertaken in the NHS, with 62% involving a kidney from a deceased donor. However the need for kidney transplantation far exceeds the availability of donor organs, particularly for the Black/Black British population (mainly of African and Caribbean origin) and the Asian/Asian British population (mainly of Indian, Pakistani and Bangladeshi origin) (Table 1). Taken together all Black, Asian and Minority Ethnic Groups (BAME) comprised 30% of transplant patients but around 11% of the population (Table 1).

Waiting times are also relatively long for BAME patients, with a median waiting time for kidney only transplant of over 1400 days or approximately one year longer than for the white population. This has implications for quality of life and survival as well as increasing costs to the NHS given that the majority will be receiving dialysis as an alternative form of renal replacement therapy.

Factors impacting the waiting list ‘problem’
The high unmet need for kidney transplantation among BAME groups partly reflects a high incidence of end stage renal failure (ESRF), with the relative risks of ESRF among the Black and South Asian population estimated to be 3 to 4 times that of the white population. Moreover although rates of living donation are similar to the white population, rates of deceased donation are relatively low among people of Black and South Asian origin who comprise just under 4% of deceased donors.

The low donation rate is associated with a low rate of registration on the Organ Donor Register (ODR), with only 3.5% of registrations among people of known ethnicity recorded as being from the BAME population. In addition only 33% of BAME families approached consented to donation compared with 61% for white families. This is of particular significance for access to transplantation by members of ethnic minorities whose blood group and Human Leucocyte Antigen (HLA tissue type) are less common in the white population, with such matching undertaken to reduce requirements for immunosuppressive medication and risks of graft failure. However the greater emphasis recently given in allocation to waiting time has led to more equitable access by the BAME population.

Another approach to the waiting list problem is to reduce rates of chronic kidney disease (CKD) and its progression to end-stage renal failure (ESRF). This requires public health interventions to reduce rates of type 2 diabetes, obesity and hypertension which have a relatively high prevalence among the Black and South Asian population, together with effective screening and medical management to avoid progression to renal failure. There is some evidence that preventive strategies that specifically target BAME groups may be beginning to yield benefits in reducing risks of CKD.

Reducing the gap between need and the availability of well-matched organs also requires increasing donation rates by the BAME community as highlighted by the Organ Donation Taskforce (ODT):
'There is 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 to the Black and Minority Ethnic population.'  

Barriers to organ donor registration

Research has identified five main barriers to registration as an organ donor by minority ethnic groups. These are briefly summarised below:

1. **Knowledge of organ donation and registration:** Lack of knowledge in terms of not knowing enough about organ donation and about the process of registration is identified as the major factor limiting registration. Such limited knowledge has continued in the UK despite five major national campaigns since 1999 and a range of community based activities focusing on informing BAME groups about organ donation. This situation appears to be associated with a lack of perceived ‘relevance’ of campaigns and their visual representations that may therefore ‘pass by’ unnoticed rather than being actively rejected.

2. **Faith and cultural beliefs:** All faith groups in the UK formally support organ donation in principle, although people from minority ethnic groups are significantly more likely to be uncertain regarding whether organ donation is acceptable to their faith. This reflects both their limited knowledge and familiarity with the topic as well as differing interpretations of scriptures. For example, certain verses in the Quran lead to a positive interpretation of donation as doing good for others whereas some passages relate to doing harm to one’s body which is prohibited under Islam.

3. **Bodily concerns:** Some reservations regarding organ donation are linked to concerns about the body both during and after donation. This includes not wanting the body to be cut so as to return to God ‘whole’, and a desire by some people to return to their ‘home’ country at death with their body intact. Worries about bodily disfigurement causing distress among family members are also common, particularly when faith or cultural requirements involve the deceased being displayed in an open casket or an expectation that relatives will wash and dress the body.

4. **Influence of family:** Reluctance to discuss organ donation with one’s family is common and reflects superstitions around discussing death and notions of ‘tempting fate’, as well parents not wanting to think about their children dying and younger people worrying about offending their elders.

5. **Trust in doctors and the health system.** People from Caribbean minority ethnic groups have been identified as having particular concerns about whether medical professionals can be trusted to do all they can to prolong life if the patient is known to be registered to the ODR. Other concerns relate to possible unethical practice involving the use or retention of organs linked with media scandals and worries about the fairness of the organ allocation system.

Barriers to family consent to donation.

Family consent is known to be influenced by existing beliefs and attitudes to donation together with satisfaction with end-of-life care and the organ donation process. Positive influences on family consent include having a clear understanding of brain death, satisfaction with communication and support and the donation discussion, and whether family members believe that everything possible
was done for their relative. Relatives are also more likely to consent when the deceased’s wishes are known to support this, either because they have joined the ODR or discussed their attitudes and wishes with family members.  

**Conclusions: The way forward**

Providing equitable access to kidney transplantation is challenging and requires both effective measures to reduce rates of end-stage renal failure and increasing rates of deceased donation. Strategies to increase donation rates occur at three levels:

**System changes.** Increasing donation and transplantation rates is often argued to require a fundamental change from the current system that exists in the NHS (opt-in system) of ‘informed consent’ to donation to a form of ‘presumed consent’ in which individuals are considered to be potential donors unless they take the steps required to ‘opt-out’. The ODT examined this issue in detail and concluded that on balance there was not sufficient evidence to justify a move to presumed consent and that evidence identified the major influence on donation rates as the organisation of donation services rather than a system of presumed consent.

The health systems in England, Scotland and Northern Ireland have retained an opt-in system of informed consent and implemented a series of changes recommended by the ODT to increase the efficiency, acceptability and effectiveness of the donation service. However the introduction of a presumed consent model in Wales is planned for September 2015 and will provide information on the acceptability and outcomes of this system in a NHS context.

Another innovative system change is the Israeli model introduced in January 2010 that aims to motivate organ donation through giving preferential status in the allocation of organs for transplantation to those people who have signed a donor card or whose first degree relative has signed a donor card consenting to procurement of organs after death. The effects are currently being followed with interest although there are concerns that it shares many of the ethical and practical disadvantages of an opt-out system and moves from principles fundamental to the NHS of allocation based on medical need.

**Organisational changes.** One of many changes introduced following the ODTs report has been the appointment of Specialist Nurses for Organ Donation (SN-OD). A key aspect of their role is to provide long contact with families beginning when their relative is identified as a potential donor and ideally involves collaboration with clinicians in the consent discussion and post-donation follow-up. Families place considerable value on such support and consent rates are shown to be higher when the consent discussion involves a SN-OD than when undertaken by the clinician alone. However it is also important that other members of the Intensive Care Unit (ICU) team also have the training and resources to be able to provide appropriate cross-cultural communication and support. Such training has not traditionally been available in the UK. However, a new video based training package to promote cultural competence was developed as part of the DonaTE programme and is now freely available for use in ICUs and Trusts.

**Community interventions.** There is considerable experience in adapting mainstream health promotion interventions to minority ethnic groups, including the Programme Theory of Adapted
Health Promotion Interventions that aims to achieve health promotion interventions directed to minority ethnic groups that are feasible, acceptable and equitable.\textsuperscript{16} Research evaluating interventions to increase registration as an organ donation among minority ethnic groups has produced similar findings and indicates that educational interventions are more effective than mass media interventions alone. It also identifies key requirements of effective educational interventions to increase deceased donation among minority ethnic groups. These are summarised in Table 2 and have informed two ongoing projects utilising Kidney Research UK’s Peer Educator initiative.

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**Key points**

1. Black and Asian ethnic minorities are over-represented on the active waiting list for kidney transplantation.
2. Reducing waiting times requires addressing both the relatively high rate of end-stage renal failure among minority ethnic groups and low rate of deceased donation that reduces availability of well-matched organs.
3. Community education is more effective than mass media campaigns alone in increasing registration as an organ donor and needs to be targeted at the beliefs and concerns of specific groups and their stage of readiness to change.
4. Consent to donation is influenced by family satisfaction with end-of-life care and the quality of communication, with on-going developments in culturally sensitive training for health professionals and enhanced service provision recommended to address this.

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Tables

Table 1: Active kidney transplant waiting lists by known ethnicity, March 2013

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>% of active kidney transplant waiting list, 2013</th>
<th>% of UK population, 2011 census</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>69.8%</td>
<td>87.2%</td>
</tr>
<tr>
<td>Asian/Asian British: Indian, Pakistani, Bangladeshi</td>
<td>17.1%</td>
<td>4.9%</td>
</tr>
<tr>
<td>Black/Black British</td>
<td>9.8%</td>
<td>3.0%</td>
</tr>
<tr>
<td>Asian/Asian British: Chinese</td>
<td>1.4%</td>
<td>0.7%</td>
</tr>
<tr>
<td>Other ethnic group</td>
<td>1.7%</td>
<td>2.3%</td>
</tr>
</tbody>
</table>

Notes: a) Excludes transplant patients with ethnicity not reported. b) The census figures include Mixed Multiple ethnicity as a separate category and are not identified here. b) Group referred to in this paper as South Asian whereas BAME includes all non-white minority ethnic groups.

Table 2: Requirements of effective community interventions to increase deceased donation among minority ethnic groups

- General minority ethnic campaigns could be replaced or complemented by messages that focus more specifically on the concerns of particular ethnic, cultural or faith groups – i.e. not ‘Asians’ but ‘Indian’ or ‘Sikh’ etc, and recognise that Muslim populations include Pakistani, Bangladeshi, Somali and Turkish, etc.
- Creating a bank of personal case studies relating to the experiences of families who consented to donation, recipients of a deceased donor organ and those on the waiting list, would enhance the perceived relevance and acceptability of deceased donation and are therefore likely to have greater impact.
- Trained members of the local community are generally related to more readily and have an important role both in delivering educational messages and serving as ‘champions’ for donation.
- Educational approaches tend to be more effective where there are immediate opportunities to join the ODR.
- Initiatives to promote deceased donation could build on and partner with other sister campaigns, such as those for blood, tissue or bone marrow, and drawing on the lessons of effective approaches in other countries.