

PRESS RELEASE

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Organ Donation and Transplantation data for Black, Asian and Minority Ethnic (BAME) communities

**Report for 2015/2016
(1 April 2010 – 31 March 2016)**

The National Black, Asian and Minority Ethnic Transplant Alliance (NBTA) is a forum of organisations, set up by the Department of Health, who work together on behalf of Black, Asian and Minority Ethnic (BAME) patients and communities. NBTA's aims to address the disproportionality in stem cell, blood and organ donation through raising awareness of inequalities, promoting the importance of transplantation; with the aim of increasing the number of BAME donor registrations and consent to transplantation.

This press release is the NBTA's response to the released 1st September report *NHS Blood and Transplant Organ Donation and Transplantation data for Black, Asian and Minority Ethnic (BAME) communities*. This supplementary report of the released 1st September *Organ Donation and Transplantation Activity Report 2015/16* highlights the continuing struggle by all associated organisational, cultural, religious and public stakeholders in increasing the number of Organ related registrants, consenting individuals/families leading ultimately to increased levels of transplants.

While the overall UK national consent rates have risen slightly, there still remains a significant gap between the proportion of white families agreeing to donate and those from Black, Asian or other minority ethnic communities. This BAME Report indicates that more radical measures need to be undertaken by NHS Blood and Transplant and its stakeholders to reverse the overall widening negative chances of a BAME patient receiving a lifesaving transplant in comparison with their white counterparts.

To address this growing problem it is necessary that NHSBT works even more closely with the NBTA and its member organisations in order to achieving the ultimate outcome of more registrants and consenting donors, and to evolve the learnings of successful like Kidney Research UK's Birmingham Peer Educators, ACLT's Being African Caribbean stem cell & Giving the Gift of Life and Derby and Leicester Organ Donation Committees Community Link BAME Community Ambassadors initiatives, etc.

The BAME communities are historically and culturally more inquisitive of the medical processes and background involved in donation and transplantation of all kinds (stem cell, blood and organ), and the awareness cycle has been of a much more recent timeline in comparison of the equivalent generations of their white counterparts. That is however not to say that there are some high levels of apathy, common within all races, which in certain BAME communities needs to be continuously addressed.

One particular and potential ray of light is the need for more focus on Living Organ Donation. This form of donation such as a kidney is a relatively easier selling point or buy in for certain BAME people as it does not impinge directly on sensitive religious and social etiquette. Because of the high levels of blood and tissue matching, the educational awareness campaigns will have to emphasise the importance of racial/ethnic matching. As the success of the BAME (African, African Caribbean, and Hindu) stem cell initiatives of the last 20 years have shown, this key factor of pride and importance of an individual's racial background becomes even more of a positive tipping point to registering and consenting to donate.

NBTA believes that NHSBT should focus on more living kidney donation and areas/communities where there is the greatest need and/or potential, which should also be in line with the main Metropolitan cities where large BAME populations reside in the UK.

The NBTA has actively supported the NHSBT initiatives such as the following:

- Saving and Improving Lives Strategic Plan 2015-2020 June 2015 (**Increase BAME Community Awareness of the need for donation, to benefit their own communities and provide better support for people in these communities to donate**).
- Behaviour Change Strategy implementation (**A strategy for delivering a revolution in public behaviour in relation to organ donation by 23rd March 2014**) ;
- Recommendations from the Optimisa Research on BAME Organ Donation 2014 (**Gaining a deeper understanding of attitudes, cultural and lifestyle influences and behaviours towards organ donation within BAME Communities in UK**). NBTA already works on the principles identified by Optimisa which is to Inform, Encourage, Include and Empower.
- Faith Engagement and Organ Donation Action Plan (**Professor Gurch Randhawa December 2013**).

The NBTA believes that despite the above initiatives that there is still much work to do to address the health inequalities experienced by black and minority ethnic people in need of transplants. The coordinated approach of more NHSBT commissioned NBTA living donor awareness initiatives will address the inequality in donation and transplantation for BAME communities, and aim to widen the impact of effective practices that improve and save lives.

The overall outcome for focussing on BAME living donation work is to close the gap between black and minority ethnic communities and white communities in securing transplants at the same time as securing savings to the NHS on the costs of healthcare. To reach these goals the outcomes NBTA will deliver:

- Better awareness amongst BAME communities of health inequalities and the need for donation
- More collaborative working, and sharing of best practice amongst organisations including NHS Blood and Transplant working on donation and transplant to improve health outcomes for BAME communities
- Incremental change in the numbers of BAME people represented on donation registers and agreeing to transplantation.
- Collation of resources of effective interventions and materials on donation and transplant issues with BAME communities
- Behaviour change and increased BAME and Faith Community Engagement.

In summary, the above NBTA proposal(s) will make a significant difference in terms of transplants for those in the BAME community.

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