



Organ Donation Law And The Impact On Black, Asian, Minority Ethnic (BAME) Communities

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Abstract

Opt out will be introduced in England and Scotland in 2020; building on its success in Wales. BAME issues have moved higher up the agenda and will feature in the new post 2020 Strategy on organ donation and transplantation. BAME communities are taking greater leadership roles in engaging with their communities with the establishment of the Community Investment Scheme and the Living Transplant Initiative. Organisation such as the NBTA and BAPIO are involved in influencing future strategies and policies.

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Introduction

Organ transplantation is the gold standard treatment for patients with end organ failure, as it is not only cost effective, but also results in better outcomes in terms of quality of life and longevity (1,2). However, the course of action of transplantation starts with the donation of organ(s) by the donor, living or dead. The process of obtaining and recording consent for organ donation from the donor or the family of the donor is called the 'consent'. Consent is the ethical cornerstone of all medical procedures and is required by law. National authorities define and regulate the process of obtaining and recording consent for organ donation (3). The reason for the paramount importance of consent is due to the declaration



of human rights by the United Nations, which states that, 'all human beings are born free and are equal in dignity and rights'(4). This declaration underpins the ethics of donation and transplantation.

Consent

There are different types of consent laws for organ donation. The explicit consent or opting in is where organs are removed from the deceased individuals, following the consent obtained from them to donate the organs/tissues for transplantation or in some cases for research, sometime during their lifetime. This is usually recorded on a donor card, driver's license, Boots' advantage card, online or filed in Organ Donation Registry (ODR). Presumed consent or opting out is when organs and tissues are removed from the body of a deceased individual for transplantation or research purposes, *unless* the person had categorically expressed their objection to donation whilst alive.

There are further subtypes of consent (5). Hard opt out is where families do not have a say, example Austria. In Singapore, for all communities other than Muslims the law is similar to Austria. However, all Muslims are considered opted out unless stated otherwise. In Belgium and Spain, it is a soft opt out policy, where family's wish matters. However, in Belgium, unless the family initiates the discussion to stop the donation, organs can be removed; whereas in Spain, the family will be consulted before proceeding to donation. Where the donation proceeds regardless of the families wishes, provided the individual had consented to donation whilst living is called the hard opt in. In soft opt in, though the individual has provided consent to donate, the family can withdraw. This is the system which currently exists in the U.K. Apart from the above, there is also a mandated choice where all individuals should register for either opt in or out, whilst living.

Transplant Waiting lists

In the year 2008, number of patients waiting on the list for transplantation in the U.K was 7655, whereas the number of transplants was 2381 and 506 patients died whilst waiting to receive a transplant (6). To understand how to increase the number of patients getting transplanted, a taskforce was created, which included representatives from legal, ethical, medical, surgical and nursing professionals as well as patients and public. On reviewing the available evidence, they concluded that the barriers to organ donation were the processes involved in donor identification and referral, donor co-ordination and organ retrieval arrangements (5). They did not find any convincing evidence that opt out would deliver significant increases in the number of donated organs (7). However, there was another review planned in five years.

The review in 2013, showed that as a consequence of the Taskforce 2008, more donors were identified and referred and people donating organs after death increased by 57% with transplant rates increasing by 30.5%. This was made possible by the formation of a centrally employed team of specialist nurses of organ donation (SNOD), who co-ordinated all donation activities. In addition, organ retrieval became a dedicated national service commissioned by the National Health Service, Blood and Transplant (NHSBT). Nevertheless, the Taskforce 2013, proposed an increase of consent rate in excess of 80%



by 2020, in addition to aiming for increases in deceased donation, transplant and organ utilisation rates (8).

However, the single most important objective of the strategy was to increase consent to organ donation from people from all parts of society.

New Legislation

Thus, the new legislation, the opt out law or the Keira and Max's Law, in recognition of all the campaigning Max Johnson and his family have done whilst Max was waiting for a heart transplant and continue to do so, came into being. Max's gift of life came from a young nine-year old girl called Keira Ball, who tragically passed away following a road traffic accident (9). This soft opt out law like in Spain will be in place from 20 May 2020 in England and from autumn 2020 in Scotland. Wales has changed to this law since December 2015.

Out of the forty three percent of the families who refused to allow donation, 66% were from BAME population. Though the donor identification and referral rates by the SNODs was similar in both potential white and BAME organ donors, the consent rate last year was 42% for BAME and 71% for white donor families. The main reason given by the BAME families were that donation was against their religious and cultural beliefs and they were unsure whether the deceased person would have agreed to donation if they were alive (10).

BAME Communities

In general, white patients wait less time for an organ transplant than BAME patients, with the exception of pancreas and non-urgent adult hearts. BAME patients tend to wait the longest. From 2007 to 2016, the median waiting time for a kidney transplant has come down from 1047 to 640 days for white, 1330 to 830 days for Asian and 1363 to 965 days for black patients. There has been an increase in the transplant rate for BAME patients from 892 to 1148 in the last five years. Though there has been an increase in the number of BAME deceased organ donors over the same period from 80 to 121, the number of BAME living donors has remained at 140-160 per year (10). Thus, it does not account for the concomitant increase in the transplant rate. One of the reasons for the increased transplants in the BAME group, especially kidneys, is the change in the allocation policy of organs which has significantly reduced the waiting time between white and BAME groups(11). The other significant reason is that the more than 80% of transplant donors to the BAME patients are from white donors.

Currently, BAME represent 11% of the population, but 31% of those on the waiting list with only 7% of donors. Last year 21 per cent of people who died while waiting for an organ to be donated were from BAME groups. BAME communities have a higher incidence of hypertension and diabetes; both of which are predominant causes of end stage renal failure. Similarly, chronic viral hepatitis and non-alcoholic hepatitis are more common in BAME patients. Thus, BAME patients are more likely to need a transplant



due to increased incidence of end stage organ disease. A good blood group and tissue type match between donor and recipients, especially in kidney transplants, have a much better long-term graft and patient survival (12 -14). This is more likely if the donor and the recipient are from the same ethnicity.

Though the evidence is not strong (15-19), change in law is anticipated to increase the number of transplants by around 700 per year in five years' time. It is recognised that we need to take a strategic approach to tackling the BAME challenges and one of the key themes of the post 2020 national strategy on donation and transplantation being developed at present will most likely be "Diversity and Inclusion". If the decision to opt out of donation has not been expressed, it will be considered that the individual has consented to donate organs. Thus, it is important that BAME individuals are not only aware of this changing law but also spread the message within their communities about enabling the gift of life to patients and families through organ donation. NHSBT are working with the National BAME Transplant Alliance (NBTA) on the most effective way of spreading the message. It is widely acknowledged that the reach is far better if the message to the BAME groups is given by individuals from the same ethnicity. This has therefore led to schemes which empower local BAME community groups to take leadership in engaging on organ donation with their targeted communities. The Living Transplant Initiative (LTI) (20) and the Community Investment Scheme (CIS) are now well established. Currently there are 26 separate CIS projects (21) and five large LTI projects, funded by NHSBT. This approach needs to be developed further so that it involves all major BAME communities and covers all areas with significant BAME population.

In summary, we are currently going through an exciting period in relation to organ donation and transplantation in the UK. Opt out will be introduced in England and Scotland in 2020; building on its success in Wales. BAME issues have moved higher up the agenda and will feature in the new post 2020 Strategy on organ donation and transplantation. BAME communities are taking greater leadership roles in engaging with their communities with the establishment of the Community Investment Scheme and the Living Transplant Initiative. Organisation such as the NBTA and BAPIO are involved in influencing future strategies and policies. Clearly, we need to ensure that the Governments provide sufficient additional resources so that we can transform organ donation and transplantation in the UK, especially amongst the BAME communities.

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