

ORGAN DONATION

Breaking Taboos Amongst British BAME Communities

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Winston Churchill Fellow, 2016

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Abbreviations

BAME	Black and Asian Minority Ethnic
CKD	Chronic Kidney Disease
CLOD	Clinical Leads in Organ Donation
CTP	Tamil Nadu Cadaver Transplant Program
DBD	Donation after Brain Death Donor
DCD	Donation after Circulatory Death Donor
DCODP	District of Columbia Organ Donor Program
DDA	Doha Donation Accord
ESRD	End Stage Renal Disease
FORT	Fortis Organ Retrieval and Transplant
HLA	Human Leucocyte Antigen
HMC	Hamad Medical Corporation
INTC	Israel National Transplant Centre
LD	Living Donation/Donor
MOHAN	Multi Organ Harvesting Aid Network
MOTTEP	Minority Organ Tissue Transplant Education Program
NHSBT	National Health Service Blood and Transplant
NNOS	National Network for Organ Sharing
NOTA	National Organ Transplant Act
NOTTO	National Organ and Tissue Transplant Organisation
ODM	Organ Donation per Million
ODR	Organ Donor Register
ODT	Organ Donation Taskforce
OPO	Organ Procurement Organisation
OPTN	Organ Procurement and Transplant Network
ORBO	Organ Retrieval Banking Organisation
ORGAN	Organ Receiving & Giving Awareness Network, India
PMP	Per Million Population
QCOT	Qatar Centre for Organ Transplant
QODC	Qatar Centre for Organ Donation
SNOD	Specialist Nurse Organ Donation
THOA	Transplantation of Human Organs & Tissues Act
TRANSTAN	Tamil Nadu Transplant Authority
UNOS	United Network for Organ Sharing

Glossary*

Brain Death	Brain death is defined as the irreversible loss of all functions of the brain, including the brainstem. The person is ascertained to be clinically and legally dead. The three essential findings in brain death are coma, absence of brainstem reflexes, and apnoea.
Chronic Kidney Disease (CKD)	Chronic kidney disease is a type of kidney disease in which there is gradual loss of kidney function over a period of months or years. Early on there are typically no symptoms. Later, leg swelling, feeling tired, vomiting, loss of appetite, or confusion may develop.
Donation after Brain Death (DBD)	Removal of organs like heart, cornea, liver, kidney, lungs and tissue for purpose of transplantation after total and irreversible loss of brain function has been certified.
Donation after Circulatory Death (DCD)	Donation after circulatory death, previously referred to as donation after cardiac death or non-heartbeating organ donation, refers to the retrieval of organs for the purpose of transplantation from patients whose death is diagnosed and confirmed using cardio-respiratory criteria.
Deceased Organ Donation	The removal, storage and use of organs or part organs for transplantation from a deceased person who has had a brain or circulatory death.
Living Donation	Living donation is when a person donates one of their organs – usually a kidney or part of liver - to someone else, whilst they are still alive. Most often living donors are close relatives or friend of the recipient.
Organ Donation	Organ donation is the process of surgically removing an organ or tissue from one person, the organ donor, and placing it into another person, the recipient. Transplantation is necessary because the recipient's organ has failed or has been damaged by disease or injury.

* Definitions as explained in academic papers, NHSBT literature and expert analyses.

Organ Donor Register

An official database or list of persons who have expressed a will to donate their organs after death. Organ donor registers are often maintained by a central government authority that is tasked with overseeing organ donation and transplantation activities. In the UK the organ donor register is maintained by NHSBT.

Organ Transplant

An organ transplant is a surgical operation in which a failing or damaged organ in the human body is removed and replaced with a functioning one. The donated organ may be from a deceased donor or a living donor.

Organ Donation Per Million Population (PMP)

PMP denotes the rate of deceased organ donation per one million of population of a country. This is the accepted international norm to measure deceased organ donation in a country.

Transplant Coordinator (SN-ODs in the UK)

Transplant Coordinator is a healthcare professional – doctor, nurse, or an allied health science graduate who coordinates activities related to organ donation and transplantation. Transplant coordinators can either be Donor Coordinators or Recipient Coordinators. In the UK SN-ODs or Specialist Nurse – Organ Donation is the official terminology for a clinician who provides support and counselling to the kin of a deceased person who could be a potential organ donor.

1 | Executive Summary

The rate of organ donation in the UK is among the lowest in the developed world. At 63%, the family consent ratio in Britain compares poorly with that in countries like Spain, U.S., Croatia and Portugal, where authorisation rates remain consistently above 80%. Despite changes in policies, clinical practices and an improvement in the overall number of donors in the country over the last decade, three people die every day in the UK due to lack of organs. The paucity of organs is partly attributable to the black, Asian and ethnic minority or BAME communities, who mostly remain opposed to the idea of organ donation due to their deeply-entrenched cultural and religious beliefs discouraging organ donation. The BAME minorities constitute only 11% of the country's population but make up nearly a quarter of the numbers waiting for life-saving transplants.

This Fellowship examined existing practices in the U.S., Qatar, India and Israel where ethnic minority communities have made significant gains in addressing their deeply ingrained taboos surrounding death rituals, increasing awareness about organ donation, and in most cases, consent rates. The four countries were selected for this research largely due to their similar ethnic population makeup and ideological barriers to organ donation as found in the UK's BAME populations. By evaluating existing policy frameworks, community attitudes, engagement strategies and legislative changes in the four countries, this research attempted to find out whether any of the measures could be prescribed to improve BAME organ donation practices in the UK.

A number of key patterns and learnings emerged in the researched communities, which appeared to play a pivotal role in driving change in behaviour and influencing donation rates among the target ethnic groups. One of the most valuable lessons emerged from the research of black communities in the District of Columbia, U.S., that underscored the importance of sustained community engagement through relentless grassroots efforts, culturally-sensitive public education programs and community ownership. The multipronged approach was decidedly responsible for radically changing attitudes and driving donation rates first in the District of Columbia and later in 25 cities across the country. In over three decades, black community's contribution to the total number of deceased organ donors per million has more than quadrupled nationally. The transformation has become possible in part due to a comprehensive non-governmental minority education program that also utilises multi-level evaluation methods to continually analyse and recalibrate its approach towards the targeted communities. As a result, the African Americans are now the top ethnicity contributing the highest number of organ donors per million compared to other groups including Caucasians, Hispanics and Asians. The research shows that for optimum results the engagement with ethnic groups needs to be sustained over a longer period of time rather than piecemeal.

Sustained public education campaigns and youth engagement are responsible for a higher number of registrations and consent rates in Israel, Qatar and India as well. While Qatar built its organ donation program from scratch and achieved 4 donations per million population in just six years, India has seen a remarkable shift in public perceptions across the country as a result of better infrastructural capacity, greater understanding of brain death and youth engagement through sustained public education efforts.

Another important lesson from the U.S. research shows that placing greater emphasis on disease prevention and lifestyle management rather than focusing solely on public awareness about organ donation can have decisive impact on the behaviour of minority populations. The shift is critical in reducing the need for transplantation itself, and is achieved through promotion of better health practices and management of diabetes, hypertension and obesity. The research across the four countries also demonstrate the need for distinguishing cultural barriers from religious ones in data collection methods and crafting public education strategies. Conflating the two has the potential for creating cultural blind-spots and mitigating the effect of minority engagement policies.

A collaboration with cultural icons in awareness drives and public recognition of living and deceased organ donor families in Qatar and India bore a unique influence on the respective minority communities. The events, the research revealed, help reinforce positive public messages about organ donation and create opportunities for family conversations about brain death and consent.

The findings from Israel make a legitimate argument in favour of adopting Reciprocity model that incentivises organ donation by priority allocation to registered organ donors, thus eliminating free-riding behaviour as well as addressing cultural and religious taboos. The introduction of non-clinical criterion has produced extraordinary results, reflected by a sizeable reduction in transplant tourism and a sharp rise in living donations.

On the basis of research in the four countries this Fellowship makes the following recommendations:

- Policy makers and nodal agencies must overhaul their strategy and devote greater time and resources towards longer and sustained public education programs designed for minority populations. Grassroots organisations representing or working with ethnic communities must be allowed a greater role in tailoring and implementing outreach programs, and building community ownership. A multi-level evaluation system must be adopted to assess progress and outcomes of the programs, and strategies should be recalibrated as necessary.
- Strategies and data collection methods targeted at BAME must be redesigned to differentiate and capture culture-based blind-spots. NHSBT must distinguish and record ethnicities along their cultural and national identities as well as respective religious faiths in order to identify specific barriers and gaps, whether in knowledge or outreach, for optimising program outcomes.
- NHSBT must incorporate events and opportunities that facilitate public acknowledgment of BAME donors and families. The events, organised locally or regionally, can be a part of community celebrations and organ donor registration drives, and must be given adequate exposure through social and traditional media.
- Public awareness programs should be geared towards behaviour change rather than just creating awareness. Equal emphasis must be placed on disease prevention in BAME communities to reduce the number of patients needing a transplant, which in turn can bring down the overall costs of renal management therapies such as dialysis, transplantation costs, and post-operative costs for both donors and recipients. The Department of Health must allocate more resources to roll out programs like the Peer Educator Model, with already proven successful outcomes, across BAME communities to promote healthier lifestyle.
- Stakeholders must spend adequate time and resources to assess the suitability of Opt-out model as well as examine the success of alternative programs such as Reciprocity model before adopting presumed consent. The decision to adopt Opt-out must not be made without giving due consideration to alternative models that are better suited to its demographic and ethnic diversities and the resistance to organ donation inherent to them. In particular, the stakeholders must examine the evidence and data from Reciprocity Model as practiced in Israel to make an informed policy decision.
- NHSBT must seek partnerships with cultural icons and celebrities sharing ethnic ties for optimising awareness drives, and actively push for a greater uptake of its educational program designed for children in schools across the country. The nodal agency must also seek partnership and knowledge sharing with organisations like MOTTEP.

2 | Introduction

At 63% the UK has one of the lowest organ donation consent rates¹ in Europe. Each year up to a thousand people die waiting for an organ. In contrast the consent rates in countries such as Spain, Croatia and Portugal routinely exceed 80%. Despite a significant increase in the overall number of organ donors in the UK since 2008 communal attitudes and reluctance to talk about the issue continue to be major barriers to organ donation, resulting in a high number of avoidable deaths. Figures published by the NHS Blood and Transplant (NHSBT) revealed 457 people died² in 2017 while actively waiting for new organs even as another 875 patients were taken off the transplant list in the same period, largely due to poor health, many of whom died shortly afterwards. The data revealed an average of three families per week in the UK were refusing to allow organ donation, potentially preventing 460 lifesaving organ transplants a year.

The perceptions and attitudes of Britain's ethnic minority communities (Asian, Black African, Caribbean, Chinese and Mixed Race) or BAME towards organ donation in particular have long been viewed as a significant challenge to achieving higher rates of consent. As per official data only six out of every 100 people signed up to the NHS organ donor register are from the BAME communities³. Notwithstanding the concerted efforts and targeted public awareness campaigns organ donation in the multi-faith and multi-ethnic BAME communities has remained consistently low, largely due to perceived religious, cultural and social beliefs. The families of potential BAME donors are less likely to consent to organ donation after death than those of the white patients. According to the NHSBT on average 65% of minority ethnic families refuse to donate organs as compared to 44% from the white families. This is in sharp contrast to their overrepresentation on the national transplant waiting list. BAME minorities constitute only 11% of the country's population but make up nearly a quarter of the numbers waiting for a life-saving organ. At 34% the ratio of BAME patients on the kidney transplant waiting list is even higher. This is due to the higher incidence of diabetes, cardiovascular diseases and renal failure among the minority ethnic populations, making them more likely to need transplant organs.



Blood and Transplant

Another, often deadly, consequence of the BAME organ shortfall is the longer waiting times for the minority patients. Solid organs like kidney, which makes up 85% of the total number of transplants⁴ in the UK, need to have matching blood and tissues types for successful transplants. As a result of fewer suitable organs a minority patient ends up waiting for up to 2.5 years⁵ on average for a transplant as compared to the two years for a white patient.

i. Rate of Organ Donation: BAME vs National Average

In the past decade public attitudes towards organ donation across the UK have reflected a positive shift, in large part attributable to government policy and sustained public awareness campaign actioned by the NHSBT as well as ethnic grassroots focus groups. Latest data shows 2017/18 was the best financial year in terms of deceased organ donations in the UK. For the first time more than 1500 people donated organs after death in a single year setting a record⁶. It's the highest increase in deceased donations in 28 years in the country with an 11% rise on the previous year.

The existing policy framework and work programmes in place are mainly the result of two government-sponsored reports on the issue in the last 12 years. The first Organ Donation Taskforce, established in

2006, made over a dozen sweeping policy recommendations in its report released two years later, while also setting an “achievable” target of 50% growth in deceased organ donation rates in the next five years. At the time UK’s rate of organ donation was just 13 per million population (pmp)⁷, with its transplant waiting list exceeding 7200 patients. The list, expected to grow by 8% each year, however, did not reflect the true number⁸ of people in need of organs as clinicians were reluctant to list more patients than were realistically likely to receive organs. The 23% of the patients on the kidney transplant waiting list, the report observed, were from minority communities, which had an overall deceased donation rate of just 3%⁹. It’s interesting to note that a UK Kidney Allocation Scheme had already been introduced in 2006 to help all disadvantaged patients, largely BAME, who had to wait a long time to find suitable organs. The median waiting time for minority communities, which a decade ago represented 8% of the population, was approximately four years.

BAME deceased donors and deceased donor transplants in the UK, 1 April 2011 – 31 March 2017						
Financial Year	No. of BAME Recipients Transplants	% of Transplants¹	No. of Deceased BAME Donors			
			DBD	DCD	Total	% of Total Donors¹
2011/12	499	17.1	35	11	46	4.2
2012/13	595	19.1	38	17	55	4.6
2013/14	706	20.2	54	17	71	5.6
2014/15	701	21.1	54	26	80	6.2
2015/16	782	22.4	49	18	67	4.9
2016/17	809	22.0	62	28	90	6.4

BAME deceased donation and transplant between 2011-17, Data: NHSBT

In 2013, five years after the first Organ Donation Taskforce report, the NHSBT successfully reported a 50% increase in the deceased organ donation rates and 30.5% increase in overall transplants. The policy recommendations and subsequent changes also radically overhauled the infrastructure for organ donation in the UK. The introduction of 250-strong Specialist Nurses in Organ Donation (SNODs), the network of Clinical Leads in Organ Donation (CLODs) and a National Organ Retrieval Service combined to have a significant impact on donor identification, referral, coordination and retrieval across the country, thus delivering an improved rate of success.

However, despite achieving the target the health agency acknowledged much more needed to be done to change attitudes across the society. The increase in the donor numbers since 2008, the agency revealed, was



“almost entirely due to expansion of donation after circulatory death (DCD) programmes, not an improvement on family consent rates.”¹⁰ Notwithstanding the gains made the consent rate was found to be 57%; in actual numbers it translated to 19 deceased organ donors per million population. Over a thousand people were still dying each year due to shortage of suitable organs. In the findings, recorded in its new organ donation strategy titled Taking Organ Donation to 2020, the NHSBT underlined amongst other measures the need to boost donation rates in BAME communities in particular. After five years the minority donation rate had only

gone up to 4.6% - a change of just 1.6%. Imminent changes in population demographics meant there would be a greater need for organs and transplants in the coming years. And at the current abysmal rate the gap

¹ Where ethnicity was reported.

between demand and supply of organs could potentially widen for the minority communities. Recognising that public attitude was still the biggest barrier to increasing organ donation the NHSBT, amongst other goals, set a new ambitious target of achieving national consent rate in excess of 80% and deceased organ donation rate of 26 per million population by 2020.

Since the launch of the 2020 strategy a number of changes and new policy initiatives have shaped the debate over organ donation in the UK. In 2015 Wales introduced an opt-out system for consent on organ donation while Scotland is planning to introduce legislation towards adopting presumed consent after positive public consultations. In July 2017 the NHSBT reported that the total number of people alive due to organ transplants had exceeded 50,000¹¹ in a new milestone, reflecting improvements in survival rates and public support. The national organ donor registry too reached a record number in five years; 36% of the UK population was now registered organ donors compared to 30% in 2013. According to the UK Transplant Activity Report, the number of donors have risen by 75% and transplants by 56% in over a decade. The BAME donations, however, still remain in single digit at 6.4%¹².

“My religion doesn’t support it.”

“It’s against my culture. I will be ostracised by my community.”

“Incisions to the body will cause disfigurement.”

“Doctors will not try to save me or my kin if I agree to donate.”

“God created me whole and I want to return to him whole.”

“I will be born without organs in my next life.”

“My organs will be given to a person of different race and/or religion.”

“It’s unnatural and immoral to desecrate a body.”

“I don’t accept (brain) death when I can see the person is warm to touch and breathing (on ventilator).”

“My soul lives in my heart. If I consent to donation after death, my soul will be trapped in the recipient’s body.”

Commonly reported cultural, racial and religious reasons in the UK and Fellowship research countries for refusing organ donation.

In a decisive move in October 2017 British Prime Minister Theresa May announced plans to introduce presumed consent system on organ donation in England, a model that had been previously rejected by the first Task Force on Organ Donation in 2008. Highlighting the BAME communities’ greater need for organs and transplants due to chronic diseases she emphasised that the presumed consent model would help save hundreds of lives across the country. Two months after the prime minister’s public pledge the Department of Health launched a 12-week official public consultation on the Opt Out model. In February 2018 a private member bill titled [Organ Donation \(Deemed Consent\) Bill](#) was brought for discussion before the Parliament. In a landmark moment the bill was unanimously passed in its second reading by the House of Commons and has now moved on to the next stage.

ii. Churchill Fellowship, 2016

In 2014 I joined the BBC Inside Out team in Bristol to research on a special documentary project called [Transplants & Trafficking](#). The 30-minute feature chronicled the personal and emotional journey of Sabet Choudhury, a local BBC news journalist of Bangladeshi ethnicity, who had set out to save his mother's life by donating one of his kidneys. His mother Sakina Choudhury, 70, had been on dialysis for years following total renal failure and was given three years to live unless she received a new kidney. Sakina, the family was told, was likely facing a 10-year long wait for a transplant due to shortage of organs from the same ethnic pool.

In the documentary as Choudhury embarks on a desperate journey to find out whether he is a suitable kidney donor to his mother he also delves deeper into the causes and consequences of the ethnic minorities' refusal to donate organs. Choudhury's quest for answers further sheds light on the thriving black-market in the Indian subcontinent where an acute gap between demand and supply of kidneys combines with poverty, exploitation, trafficking and greed to expose the true human cost of cultural and religious taboos surrounding organ donation. The acclaimed documentary was telecast in July 2015, six months after Sakina returned home with a new kidney from her son and a new life.



**Sabet Choudhury with his mother Sakina Choudhury, 2015,
Photo courtesy: BBC News Online**

My eight-month long research on the BBC project became the basis of an investigative feature for Al Jazeera English shortly afterwards, as I continued to probe the complex network of illicit kidney trade in South Asia, one of the world's leading trafficking hotspots. The investigative feature, [Need a kidney? Inside the world's biggest organ market](#) detailed the nexus between clinicians, hospitals, government officials and kidney brokers in India (my birth country) and Sri Lanka as told through the eyes of three underground agents in Kanpur, Mumbai and Colombo. This particular work has since been consulted and referenced by many regional and international media as well as academic papers.

Having researched the subject as a journalist for over two years and witnessed first-hand the struggles of close family members with cardiovascular and chronic diseases while growing up in India I was able to gain better insights into the challenges facing the UK's BAME communities. My life-long commitment to working on the issue was further cemented by the award of Churchill Fellowship in 2016, allowing me to conduct research in four countries across the world where multi-faith and multi-ethnic communities were breaking identical barriers surrounding organ donation.

India, Qatar, Israel, U.S. and Pakistan have in the past years made significant gains in addressing the deep-seated taboos in their societies surrounding death practices and to increase awareness about organ donation, and in most cases, consent rates. Unfortunately, despite numerous attempts a visit to Pakistan could not be facilitated due to visa issues. However, preliminary research over religion's role in decision-making and inputs (many of which resonate with the findings from other destinations) from experts based in the country, find reflection in the overall recommendations.

This Fellowship research is based on inputs collected between June 2016 and November 2017 from transplant surgeons, organ donors, deceased donor families, patients currently on the transplant waiting lists, organ recipients, transplant coordinators, clinicians, policy makers, grassroots organisations, community health workers and academics. In person interviews were conducted in 10 cities: Doha, Tel Aviv, New Delhi, Chennai, Gurgaon, Washington D.C., Cleveland, Philadelphia, New Jersey and London. Further research inputs and updates came through remote interviews via video links, and in some instances emails, in another eight cities: Bristol, Derby, Blackburn, Luton, Leicester, Liverpool, Karachi and Indianapolis.

iii. Aims and Objectives

- To assess the development and efficacy of the current organ donation infrastructure and policy programs in place in target countries.
- To identifying best clinical and institutional practices for engaging with multi-ethnic and multi-faith communities on organ donation.
- To explore the scope, nature and impact of public education and community outreach programs run by government, and/or independent organisations.
- To examine the impact of cultural and religious beliefs, societal perceptions, role of media and community engagement on decisions guiding organ donation.
- To assess the impact of alternative models of organ donation systems other than presumed consent on increasing minorities consent rates.

3 | Countries of Research

The debate over finding the right system of organ donation and policy in the UK and other countries has been incessantly shaped, and justifiably so, by the success of the Spanish Opt Out model. The west European country has remained the unrivalled world leader in deceased organ donation rates for over quarter of a century. However, to conduct this research it was critical to study communities and regions with similar ethnic population makeup and ideological barriers to organ donation as found in the UK's BAME populations. For that reason, Spain and other countries with higher consent rates like Austria and Croatia were not included in the research visits due to their dissimilar demographics and policy responses. An overview of the organ donation program in each country is detailed below in the order of their visit.

i. U.S.

With 325 million people the U.S. is the third most populous country in the world. The first instance of organ transplant in the country was recorded in 1954 when a living donor successfully donated a kidney to his identical twin.¹³ In 1984 the U.S. Congress passed National Organ Transplant Act (NOTA) and established Organ Procurement and Transplant Network (OPTN) in order to address the critical shortage of organs in the country and provide a regulatory framework for all donation and transplant activities.

The U.S. has a highly advanced organisational structure in place for managing organ donation and transplantation. The transplant system in the country is currently managed by United Network for Organ Sharing (UNOS), a non-profit organisation, since 1986 after being awarded the OPTN contract. Established in 1984, UNOS is mainly responsible for managing national transplant waiting lists, allocating organs, maintaining databases and recording every transplant activity in the country, providing assistance to families and coordinating and developing policies for equitable and efficient use of organs with other stakeholders.¹⁴ Rather than states the country is divided into 58 service areas, with each of them served by an independent non-profit Organ Procurement Organisation or OPO that acts as a frontline agency for evaluation and procurement of deceased donor organs. In addition to working closely with UNOS, the OPS are also responsible for running public education programs and fostering community outreach and participation in the organ donation process.¹⁵



minority organ tissue transplant education program

The focus of Churchill Fellowship research in the U.S. was limited to organ donation practices amongst the African Americans. In particular the research concentrated on the methods and impact of the country's first community-based and culturally specific

education program that has immensely helped boost black and minority organ registration and donation rates over the last 25 years. The Minority Organ Tissue Transplant Education Program (MOTTEP) has its foundations in a grassroots movement that started working with the black community in the District of Columbia in 1978. After promising results and a substantial rise in registration and donation rates among the local population in the following decade the model was formally conceptualised as MOTTEP in 1991 and expanded to include other minorities in the US. It has since reached communities in 26 cities nationwide with remarkable results.

The black community makes up 13.3% of the national population and is the second largest minority group in the country after Hispanic or Latinos. ♣ As of April 2018 there are 114,600 people on the national organ waiting list, of which 30% are black. On the kidney waiting list the black community's representation is even higher and nearly the same as the white majority population.¹⁶ This is attributable to a greater incidence of ESRD in black population; the minority group is 3.4 times more likely to develop chronic kidney diseases.¹⁷

Year	Black	White	Hispanic	Asian
1995	33.1	34.2	31.5	17.9
2010	35.36	27.07	25.59	14.7
2017	38.1	34.29	27.5	15.1

Ethnicity-based Organ Donors Per Million. Data: Organ Procurement and Transplant Network

For the last six years African Americans have accounted for nearly 16% of the total deceased donations in the country. A small percentage of the total national deceased donors, the ratio, nonetheless, represents a big leap for the minority group. At present the black community ranks above all other ethnic groups in the U.S. in terms of organ donation per million (ODM) after overtaking the white majority population in 2010.¹⁸ Based on the latest deceased donation data and population estimates from 2017, black population's ODM stands at 38 as compared to 27.6 for the white population.¹⁹

Even though organ donation rates among black communities are still considered low, the growth in ODM reflects a paradigm shift in the attitudes of the minority group that was for decades known to be most resistant to the message of donating organs despite its relatively higher need for kidney and heart transplants compared to other ethnic communities. Historically, consent rates in black population had been abysmally low. This was in sharp contrast with the incidence of end stage renal disease at the time; more than 50% of the patients with chronic kidney disease were found to be black.²⁰ In 1978, armed with a \$500 grant Dr. Clive O. Callender, a Howard University transplant surgeon who later founded MOTTEP, set out to understand the reasons underpinning the chronic scarcity of African American donors. "When we first became involved, 80% of the people on dialysis were black and their donation rate was less than 10%. The problem was unique to our ethnic group. As we started working with the community we identified a number of obstacles to organ donation amongst the minority group," says Dr. Callender. After a pilot study with a group of 40 black people in District of Columbia, the research group identified the following five main reasons for resistance in the local black population towards organ donation:²¹

- i. Lack of transplantation awareness
- ii. Religious beliefs and misperceptions
- iii. Distrust of the medical community
- iv. Fear of premature declaration of death after signing a donor card
- v. Fear of racism (black donor preference for assurance of black receivership)



Dr. Clive O. Callender, Founder MOTTEP. Photo courtesy: Howard University

While the lack of awareness and religious beliefs were equally applicable to other minorities in the country to some degree, the lack of faith in medical practitioners was unique to African Americans. The distrust of the

♣ Population estimates as of July 2017, United States Census Bureau. Available at <https://www.census.gov/quickfacts/fact/table/US#viewtop>

medical community amongst blacks, both in the U.S. as well as in the UK,* can be traced back specifically to two historical events in the last century.

The first event refers to the infamous and highly damaging Tuskegee Syphilis Experiment in 1932 involving 600 black men in Alabama, who were encouraged to take part in an ongoing medical research in exchange for free healthcare. Hundreds of men were allowed to suffer the disease and its side effects without treatment until 1972, even though penicillin had been discovered as an effective cure, just so the scientists could continue studying the effects of the disease.²²



Henrietta Lacks in the 1940s.
Credit: Lacks Family, via The
Henrietta Lacks Foundation

The second event dates back to 1951 when Henrietta Lacks, a 31-year old black tobacco farmer from Maryland, who was diagnosed with terminal cervical cancer. During routine treatment at John Hopkins Hospital in Baltimore her tumour cells were harvested without permission, as was the practice at the time. Lacks died shortly after starting the treatment. However, it was discovered that her cells were the first human genetic material that could be grown indefinitely. The cells were subsequently used for over 75,000 studies, shared amongst numerous scientific laboratories across the world, and to research countless medical treatments like cancer, fertility treatment and developing polio vaccine. Lacks family remained in the dark about the existence of what came to be known as HeLa cell line until 1973, and never gained financially from the billion-dollar bio industry the cells had helped foster.²³

“Combine the distrust of doctors with fears of racism and religious beliefs, and you are facing a giant wall... a huge mental barrier against donating organs. It was deep-seated within the black community. They were convinced doctors wanted their organs just so they could be transplanted into the whites. Another problem we had to take into account was the low socio-economic background across the community and disparity in their

access to transplants compared to white population,” says Dr. Callender. “But what we eventually found most helpful was the continuous face to face engagement with the community and elaborating on the message specifically tailored to that community. That was a tool more powerful than mass media alone,” he adds.

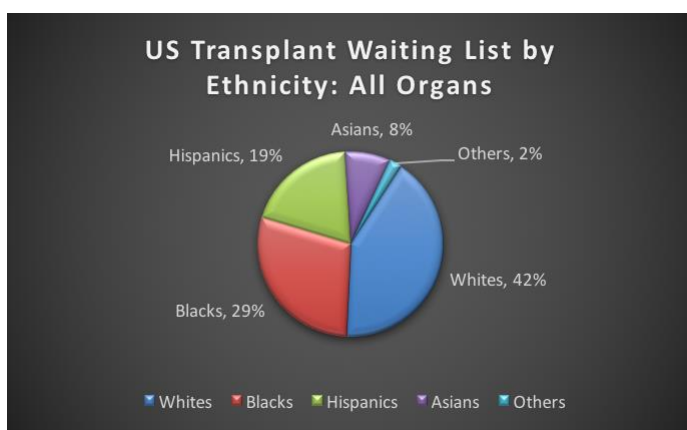
The core strategy, before it was formally adopted as MOTTEP to cover all minorities a decade later, identified a two-fold solution to the main problem at hand – the shortage of organs. Implemented under the newly formed District of Columbia Organ Donor Program (DCODP), it aimed at reducing the number of black patients being added to the transplant list through a grassroots effort emphasising community education, promoting family discussions, better health practices and behaviour change while simultaneously increasing the number of black donors through efforts from community leaders and transplant recipients as ambassadors.

The program in District of Columbia first began by crafting and elaborating a message specifically tailored to the black community, intensively using a network of volunteers, recruiting black transplant recipients and patients on the waiting list as the ideal spokesperson, emphasising on coordination of all educational activities with local community activities, seeking support from the private sector, and collaborative efforts involving both transplantation programs and private community organisations.²⁴

* In Churchill Fellowship research interviews conducted in the UK, members of the black community and grassroots organisations such as ACLT alluded to the same historical events for the distrust of medical establishment.

Publishing his initial findings from the pilot project in the New England Journal of Medicine in 1991, Dr. Callender wrote: *The presentations and educational programs were delivered using ethnically or racially appropriate organ donors, organ recipients, candidates for transplants, and families of deceased donors as well as transplantation professionals. These presentations emphasised the need to increase the rate of organ and tissue donation and the importance of twice-yearly blood pressure measurements after the age of 12 years. The audience was also advised of the absolute need for blood-pressure medication once hypertension had been diagnosed, in order to prevent kidney failure.*

Initial success with black population in District of Columbia saw a jump in its organ donation consent rates from 10% in 1978 to 51% in 1993. The number of donor cards being signed with motor vehicle licence applications shot up from 25 in 1982 to 750 per month by 1989. In mid 1980s the donor education effort rolled out nationally to 22 cities with the largest black populations under the Take Initiative Program, a collaboration between DCODP and Dow Chemical company. The program significantly helped boost the number of black



Transplant Waiting List by Ethnicity, Data: Organ Procurement Transplant Network, April 2018

donors from 3% to 11.6% from 1982 to 1993 in the country.²⁵ In terms of per million donations this reflected a sharp spike; black population's ODM share increased from 8 in 1982 to 20 in 1992.

MOTTEP program director Patrice Miles says the evidence from the extensive work done with the black minority for over 10 years was conclusive and had clearly demonstrated that community-based approach combined with mass media was the most effective tool in delivering the message and subtly enforcing change in attitudes and nudging towards a healthier lifestyle.

“Establishing MOTTEP in 1991 allowed us to take the strategy beyond African Americans. The program was expanded to reach all other American minorities including Hispanics/Latinos, Asians, Alaska Natives, American Indians and Pacific Islanders. MOTTEP also inaugurated the National Minority Donor Awareness Day on August 1, 1996. It is now a nationally recognised event and observed annually by health institutions across the country,” says Miles.

In practice the MOTTEP methodology focuses on four key goals: 1) to increase the number of people within ethnic groups who are knowledgeable about organ donation and transplantation, 2) to increase the number of people in ethnic groups who agree to become donors, 3) to increase the number of people who have family discussions about donation and, 4) to increase the number of people within ethnic minorities who are willing to change their lifestyle and behaviour in order to lessen the need for transplantation.

“The goal is to saturate the community with the necessary information and advice in order to help them make informed decisions about organ donation and transplantation. We focused on empowering them with the right knowledge. In our outreach program we not only focus on face to face counselling, we also conduct workshops, organise presentations at community and cultural events, work with faith leaders and Churches, partner with educational institutes like schools and universities, and design media campaigns. Social media helps reinforce the message but grassroots campaign is the key element here,” says Miles.

According to UNOS data, in 1991 American minorities accounted for a little over 16% of the total deceased donations; in 2017 their contribution stands at 34%.²⁶

“Black population was at the bottom of the table on organ donation. Wherever we went we were constantly told it was impossible to turn it around with African Americans. The attitudes and racial apprehensions were deeply-entrenched. But the numbers are proof that it was always possible,” says Dr. Callender.

Year	Black Deceased Donation	Total Deceased Donation	Percentage
1988	359	4080	8.8%
1998	646	5793	11.2%
2008	1276	7989	16.0%
2017	1603	10,287	15.6%
2018*	408	2569	15.9%

Black Population Organ Donors 1988-2018*, Data: Organ Procurement and Transplant Network

In 2000 MOTTEP expanded its domain to include disease prevention component in order to work exclusively with youth and teenagers. The organisation also established a network of speakers including ethnic celebrities, and created a library of audio-visual and print material for independently organised events.

MOTTEP’s outreach program across several cities in the US has reached more than six million people through 500 volunteers and 10 billion media impressions. At its peak the organisation had 17 sites nationwide but due to lack of funding the number has now reduced to seven across Cleveland, New York, Detroit, Pittsburgh, Chicago, Nashville and Washington D.C.

“Community efforts to bring about behavioural changes need to be sustained over a long period of time to achieve results. Mind-set and behaviour do not change overnight,” says Dr. Callender. “Historically, blacks and ethnic communities here and everywhere have perceptions, beliefs and in many cases fear of racial resentments that go back centuries. That can only be addressed through patience, sustained long-term funding and placing trust in the community-focused organisations themselves,” he says.

(Date Visited: June 2016)

* Deceased donor data until April 2018, National Data from Organ Procurement and Transplant Network, available at <https://optn.transplant.hrsa.gov/data/view-data-reports/national-data/>

ii. Qatar

Located in the Arabian Peninsula Qatar is a small country with vast oil and gas reserves. One of the wealthiest nations in the world it has a population of 2.6 million, of which nearly 88% are migrant workers mostly from South Asia, Southeast Asia, the Middle East and North Africa. All residents including foreign workers and their families are entitled to free (or highly subsidised) access to the public healthcare system, provided by Hamad Medical Corporation (HMC).

The rapid development and growth of Qatar's organ donation program is uniquely remarkable in that it didn't exist 10 years ago. Up until 2009 the prosperous country, despite having excellent tertiary healthcare, state of the art infrastructure and the highest health index²⁷ in the Arab world, did not have an indigenous organ donation and transplantation program in existence. The country's first organ transplantation was done in 1986 when a native patient was transplanted with a kidney from a related living donor. Even though Qatar passed a legislation enabling deceased organ donation in 1997 the country did not see any expansion due to a complete lack of organ donor base, resulting in minimal annual kidney transplant activity.



The lack of organ donors compelled the majority of the patients with end-stage renal disease (ESRD), and solely reliant on dialysis, to procure suitable organs through commercial transplantation in countries like Pakistan, Philippines, Iran, Egypt and China.²⁸ However, most patients returning home after receiving transplants overseas, particularly in Philippines and Pakistan, began to show high rates of post-operative complications and mortality.²⁹

In 2008 as concerns grew over the surge in patients seeking commercial transplantation overseas coupled with a rising incidence of end stage kidney disease at home, the government moved towards establishing an expansive health program that could meet the needs of its multi-ethnic society with diverse socioeconomic backgrounds. This resulted in the creation and launch in 2010 of Doha Donation Accord (DDA), an indigenous framework modelled on the recommendations of Declaration of Istanbul* and aligned with principles laid down by World Health Organisation on human cell, tissue and organ transplantation.

The Accord, developed with guidance from Declaration of Istanbul Custodian Group (DICG) and Transplantation Society, aims at curbing transplant tourism, developing public awareness and support for organ donation, and attaining self-sufficiency in organ transplantation in Qatar through ethical practices. The main provisions in the new framework essentially guarantees all residents in the country including non-citizen migrant workers and their families free and equitable access to renal replacement therapies, living donation program, donor registry, national transplant waiting list, deceased donor organs and transplantation facilities irrespective of their nationality, religion, ethnicity, gender or socioeconomic background.³⁰

* Declaration of Istanbul resulted from an international summit convened in Istanbul in 2008 to address the urgent and growing problems of organ sales, transplant tourism and trafficking in organ donors in the context of the global shortage of organs. Attended by representatives from 160 countries the Declaration is now accepted as a global advisory instrument to guide institutional practices and government policies in different countries aimed at curbing organ trafficking and transplant tourism. For more details, see <https://www.declarationofistanbul.org/>.

The implementation of the new policy led to the creation of Qatar Organ Transplantation Centre (QOTC) in 2011 and Qatar Organ Donation Centre (QODC), locally known as Hiba, a year later. The program became a national healthcare priority receiving large scale financial and governmental support. Even as the small gulf country set out to build infrastructural and clinical capacity its real challenge lay in building an organ donor database and national registry.



Dr. Riadh Fadhil, Director of Qatar Organ Donation Centre. Photo Courtesy: Qatarisbooming.com

“We put together a team of transplant surgeons, clinicians, doctors, nurses, transplant coordinators and support teams. With time the training expertise for our staff came from the U.S., Spain, Australia and Croatia. We had everything but donors. So our biggest challenge was devising a strategy that optimised public education efforts and identifying the most effective culturally and religiously sensitive approach to engage our multi-ethnic population with the new program,” says Dr. Riadh Fadhil, Director of Qatar Organ Donation Centre.

religious and cultural events, and inclusion of education about organ donation in school and university curriculum and the orientation courses designed for the newly-arrived immigrants into the country. The centre has since also made provisions for dissemination of information about organ donation at the time of issuance of driving licence.

The multi-lingual public messages about organ donation and, the right to equitable access to transplant facilities and healthcare have been carefully crafted to reflect religious and cultural sensitivities of the dynamic population. One of the core strategies is to engage directly with the population in public spaces. “Of all the places such as mosques and churches, community centres, universities or offices the most effective so far have been shopping malls. They are frequented by rich and poor alike. That’s also where you get the highest footfall and they have given us the highest donor card registrations,” says Dr. Fadhil.

When approaching visitors in public spaces, the multi-cultural workers follow a strict protocol as set down by the education program guidelines. Members of the public are asked questions first to test their knowledge about organ donation and whether they have ever considered being a donor after death. Each person is then fully explained the concept, implications and rights of Qatari residents in their native language and concerns are addressed through the prism of their culture and religion. In case of a person agreeing to

In 2012 the Centre began to roll out a multi-pronged public awareness program across the country that included public campaigns, community education programs, participation in



Organ Donation Education booth outside Al Meera Supermarket, Doha



Nishtha Chugh with an organ donation campaigner at a public education stall at Villaggio mall, Doha

become a donor, a form is signed in the presence of a witness, photographed and digitally recorded on the national database on the spot. The candidate is able to get their donor card, linked with their Qatari ID number, within minutes. Repeated emphasis is placed on the need to share and discuss the decision with their families. Informational leaflets on organ donation and transplantation program, religious interpretation and commonly asked questions about the procedure are handed out to each person approached regardless of their decision. Every new organ donor card holder is also made aware of their right to withdraw from the national organ register should they change their mind.

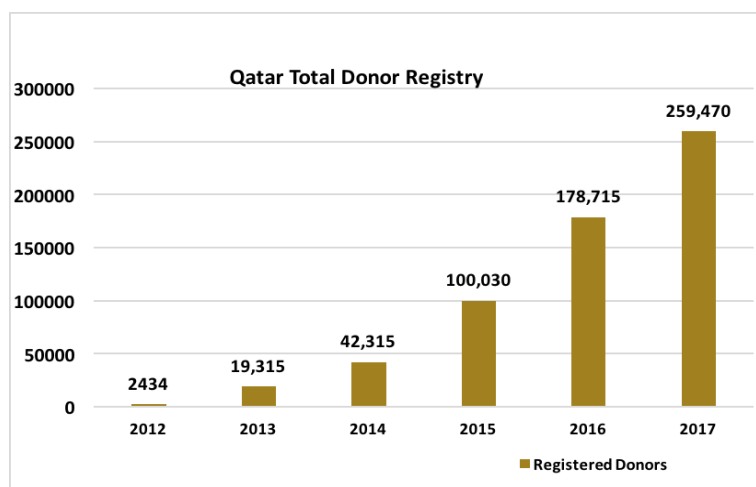


Her Excellency Dr Hanan Mohamed Al Kuwari, Qatar's Minister of Public Health and Managing Director of Hamad Medical Corporation, with her organ donor card. Photo courtesy: HMC

Apart from direct engagement, the public communication program also includes dissemination of information via print journals, newspapers, television channels, radio, online and social media. As per QODC database, from 2000 donors in 2012 the organ donor registry has increased to more than quarter of a million in five years, representing 20% of Qatar's adult population. Specially designed campaigns for the month of Ramadan have typically recorded the highest number of registrations each year. The registry represents more than 100 nationalities including 5% native Qataris. Last year in the month of December alone the Centre registered more than 12,000 pledges. In an effort to increase public trust the HMC launched an internal education drive for its 25,000-strong staff across its eight hospitals and various divisions. According to Dr. Fadhil, more than 2600 staff members have signed up to be deceased organ donors since 2016.

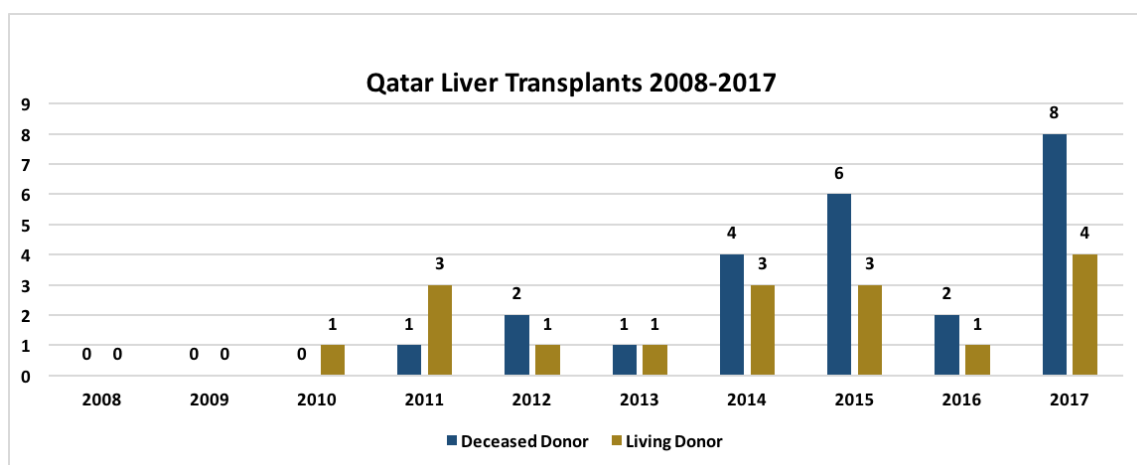
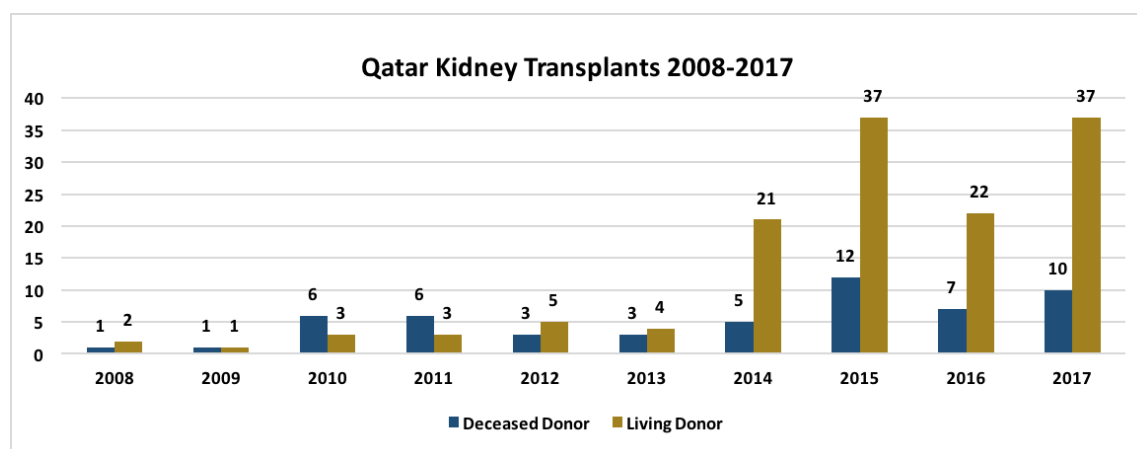
The key focus of the public education is to foster trust in the national organ donation and transplantation program so that none of the residents, citizens or migrant workers, feel the need to go overseas for a transplant, says Dr. Yousef Al Maslamani, Medical Director at Hamad General Hospital and Chairman of the Organ Transplant Committee.

"The number of patients traveling abroad has come down by 70% after we tightened the law in 2015. Our clinicians continue to emphasize the legal, ethical and medical hazards of the commercial transplant to those on the waiting list. The diversity of our population is both a bane and boon, and cultural resistance still remains one of our biggest challenges. Of all the nationalities and ethnic groups, the Arabs and Pakistanis are still most difficult to convince especially with the deceased donations due to perceived social stigma. The Filipino community, our biggest donor group, has set the best example. We are using their experience to spread the message and try to change perceptions," says Dr. Al Maslamani. Even though the donor registry has grown manifold, the number of actual deceased donations are still low, and that's something we are keen to improve, he says.



Qatar Organ Donor Registry, 2012-17. Data: Qatar Organ Donation Centre

Donated organs are allocated based on the UNOS/OPTN point system followed in the U.S. The transplantation program, initially started with liver and kidney, has over the years added bone marrow, cornea and stem cell to its range of procedures. Last year, Qatar reached a new milestone with its first successful allogeneic hematopoietic stem cell³¹ transplant. More than 50% of the patients accessing dialysis are non-citizen residents of Qatar. Similarly, analysis of the deceased donation transplant activity in the country from 2011 to 2017 shows that majority of the waitlisted candidates, and recipients of donor organs are foreign workers.



Qatar Centre for Organ Transplantation statistics 2008-2017, Data: HMC

“There’s a unified national organ transplantation list for citizens and migrant workers. It is part of the equitable access principle espoused by the Doha Accord. One national transplant list for the entire population is distinct to Qatar in the region and differentiates its program from those of the neighbouring countries,” says Dr. Fadhil.

³¹ Allogeneic stem cell transplantation is a complex procedure involving the transfer of stem cells from a genetically similar healthy person (known as the donor), to a patient (known as the recipient), following high-intensity chemotherapy or radiation. It is used to eliminate cancer and restore a patient's blood and immune systems. Due to the time it takes to build the immune system back up after the transplant, several months of close expert monitoring are needed to prevent complications following the procedure.



Ismail Abdullah Ibrahim, 56, from Hargeisa in Somaliland hasn't seen his family for 14 years. The former soldier, who served in Qatar's national army for a decade, has end stage renal disease and been on dialysis since 2004. A resident of Qatar for 36 years now Ibrahim is unable to visit his wife and three children in Hargeisa because a single session of renal therapy in his hometown can cost up to \$100. A less suitable candidate for transplant after a previous graft failure, Ibrahim is fully dependent on the free 24-hour dialysis service provided by Hamad Medical Corporation. "I am unable to work and can't support my family. If it wasn't for this Centre I won't be alive today. I hope no one has to choose between seeing their family or staying alive," he said.

Data compiled from 2011 to 2017 shows that 80% of kidneys and 94% of livers from deceased donors went to foreign workers.³² In the same period deceased kidney donation saw an eight-fold increase while the living kidney donations went up 20 times.³³ The program has had its best results in the year 2017. In a single week in June HMC conducted eight liver and kidney transplants. The year also saw highest overall number of organ donations in a single year including 41 living donors and eight deceased donors in the country since the program began.³⁴

A sharp increase in the living donations in Qatar underscores the evolution of the country's organ donation and transplantation program since it began six years ago. The program was conceptualised to emulate the Spanish model with its primary focus on deceased organ donations, but the dynamics of Qatar's largely migrant-worker population and its socio-economic background has impacted the actual consent rates differently than how the policy envisaged.

"The Spanish system still remains our model. But the demographic make-up of our country makes deceased donation a greater challenge for us than a living donation," says Abdul Hadi, who leads the deceased donor coordinators team at HMC.

"Almost 75% of our migrant population are workers with poor socio-economic backgrounds. In case of brain death, reaching out to their families living in remote villages in their native countries is as big a hurdle as explaining everything to them and getting their consent, something clinicians in countries like Britain don't have to deal with. For us geographical and language barriers often mean the difference between a refusal or consent," says Hadi.



However, protocols followed in our transplant centres conform to the same ethical principles and practiced with the same rigour as those followed by UNOS or other successful systems in the world to obtain consent following brain death, he adds. At HMC, according to Hadi, a set of guidelines along with resources such as a language bank have helped override the obstacles posed by literacy and language barriers when approaching migrant worker families living overseas.

Litti Matthew, a senior transplant coordinator from India and skilled in three languages, explains the process demands a lot of patience and requires working with the families at every level.

“Families are never rushed and any conversation about organ donation is not initiated until we are certain they would be able to understand the nature of our request. We always ask the families to involve someone at their end who’s literate, who can read the form and explain every single thing to them. We write down every detail and go through the form word by word in their native language over the phone. Sometimes it can take 1-2 days. We never accept even if half of the family members agree. Unless it’s 100% consent from every first-degree relative, legally witnessed and signed, we don’t go ahead with the deceased donation,” she says.

“Often we have lost opportunities even after getting the family’s consent on the phone because of the remoteness of their location. It may take them 6-7 hours just to reach the nearest fax machine to send us the form by which time it may be too late,” Matthew says.

As per the latest data available with HMC, Qatar has a deceased donation rate of 4 per million population and a consent rate of 20% approximately, a four-fold increase from 2011. Living donation, on the other hand, has seen an unforeseen boost since the organ donation and transplantation program began.³⁵



New registrants with their organ donor cards, Doha. Photo courtesy: HMC

“Continuous public education has produced some interesting results. Living organ donation has gone up substantially. Of all the nationalities, Qatari natives, once completely resistant to the idea, are now our largest group of living donors. Almost 80% of the Qatari patients with renal failure are now bringing their relatives as donors. This is a high point for us,” says Dr. Fadhil.

A crucial aspect defining the success of living donation in the country is the removal of any financial disincentives associated with the process. This essentially provides all living donors exemption from any expenses incurred as part of their donor evaluation, reimbursement for any loss of wages associated with their time spent during operation and recovery, and health insurance for life.

The program also allows financial assistance for the related living donors of migrants, who live overseas. The transplantation program fully funds the cost of travel, accommodation, loss of income, living cost and medical expenses of matching medically-fit first degree related living donors who come to Qatar to donate organs, thus removing any financial disincentive that may exist.³⁶

In 2015 Qatar amended and replaced its 1997 transplantation law to formally incorporate the Doha Donation Accord that forms the foundation of, and now globally recognised as, Doha Model of Organ Donation. In 2016, the country launched Doha International Academy for Organ Donation, an international hub to help other countries establish their own organ donation programs from scratch. Backed by an advisory panel of experts from the U.S., Australia and Europe, the Academy aims to provide resources and training material, and share its extensive experience to help other countries achieve self-sufficiency in organ donation.

(Date Visited: Sep - Oct 2016)

iii. India

The second-most populous country in the world, India is home to 1.3 billion people with six main-stream religions and 23 official languages. The first organ transplant in the country was performed in 1965 in Mumbai (then Bombay), Maharashtra, after a kidney from a deceased donor was transplanted into a non-renal failure patient suffering from hypernephroma.³⁷ The legislative framework for transplanting organs and tissue in India is provided by the Transplantation of Human Organs Act (THOA) 1994 with subsequent amendments in 2011 and additional rules in 2014 regarding organ donation and certification of brain death.³⁸ For many decades organ and tissue transplantation across the country was largely managed by state governments independently since health is not a federal responsibility in India. The National Organ and Tissue Transplant Organisation (NOTTO), a central agency established in 2010 and functional since 2014, is now the apex national body tasked with coordinating procurement, distribution and enforcing all aspects of organs and tissue transplantation.

Often known as the diabetes capital of the world, India has an alarming prevalence of hypertension, cardiovascular disease and chronic kidney disease in its population. The middle-income country has one of the highest mortality rates due to heart failure in the world while number of deaths caused by renal failure has climbed by 50% in the last decade, primarily as a result of poor diet and unhealthy lifestyle, and often late presentation of disease.^{39 40}

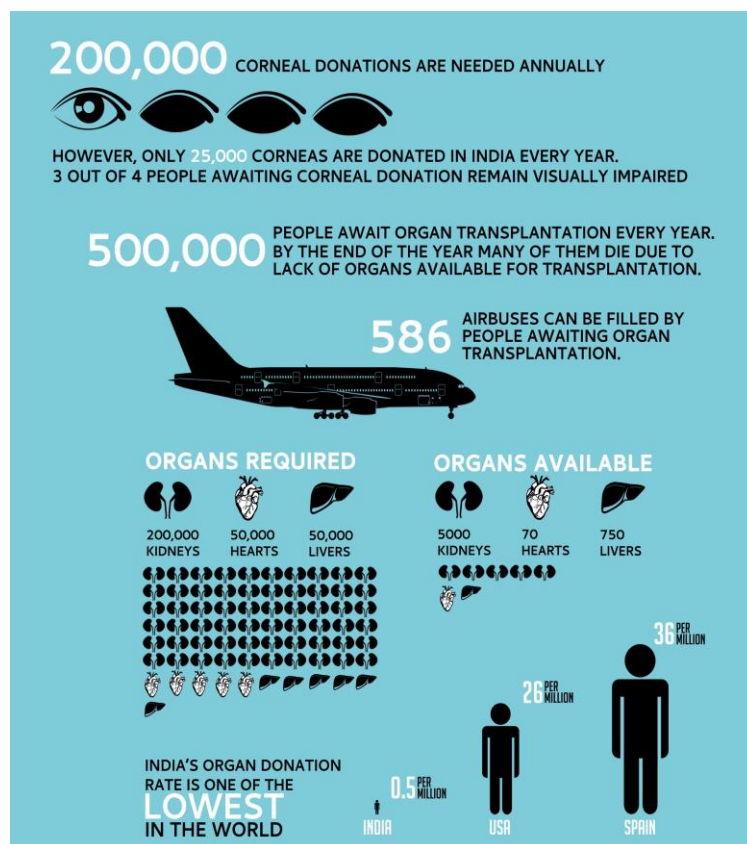


Fig. Organ shortage in India, Factsheet, Data & Image provided by: ORGAN India, New Delhi

Like many other rapidly developing countries the growing burden of chronic diseases in India is correlated to significant improvements in socio-economic conditions, greater purchasing power, increased life expectancy and surging demographics over the past decades. As a consequence, the demand for vital organs like heart, kidney, lungs and liver has shot up while the supply has steadily fallen behind. A person in India is six times more likely to need a transplant than be a donor.⁴¹

According to Organ Receiving & Giving Awareness Network (ORGAN) India, a New Delhi-based NGO, every year nearly 500,000 people die in the country due to an acute shortage of donated organs. This includes approximately 50,000 deaths from heart failure, 100,000 from liver disease and 20,000 from lungs disease. It is estimated that 220,000 patients in India with end-stage renal disease currently need a kidney transplant; in contrast, the number of transplant procedures carried out each year is less than 10% of the total requirement.⁴²

The ever growing gap between the demand and supply of kidneys has fostered enclaves of illicit organ trade across the country. Despite government efforts the black-market in kidney continues to thrive under the radar, in large part fuelled by poverty, exploitation, transnational criminal networks and unscrupulous medical practitioners.⁴³

Barriers to organ donation in India are based in its heterogeneous character, a highly diverse social, religious and ethnic landscape, and poor awareness about the phenomenon. Studies to understand low organ donation rates in India show that families' refusal to authorise organ donation after death stems from chiefly the following four reasons:⁴⁴⁴⁵

- i. Lack of understanding about brain death,
- ii. Cultural and religious reservations,
- iii. Mistrust of healthcare professionals, and
- iv. Personal beliefs.

However, the aforementioned reasons are based in community behaviour and only partially reveal the scale of the challenge in India. The constraints to organ donation in the country are not solely limited to factors like cultural and religious beliefs or poor public awareness. Crucially, the lack of infrastructural capacity in India is seen as an enormous hurdle to achieving a higher rate of deceased donations.

Currently ranked the seventh largest economy globally, India's public health expenditure has remained constant at approximately 1.3% of its GDP since 2008, marginally growing to 1.4% in 2016-17.⁴⁶ (In contrast the world average stands at 6% of the total GDP). As a consequence of inadequate government spending, patients in India typically bear 70% of the healthcare costs and only 5% of them are able to afford medical insurance.⁴⁷ This out of pocket expenditure pushes 7% of the country's population below the poverty line each year. The extreme disparity in access to healthcare between rural and urban areas also means three-quarters of the country's mostly poor population is forced to spend a higher share of income on healthcare needs than their urban counterparts.⁴⁸

In this context the field of organ donation and transplantation in India faces even greater barriers than other countries covered in this research.

Dr. Avnish Seth, Director of Fortis Organ Retrieval and Transplant (FORT), Gurgaon, points to a number of impediments in the area. "One of the foremost issues is the immense capacity gap in medical infrastructure across the country. Of the 29 states only a third have advanced facilities that support organ retrieval. You need a well-functioning system in place in order to initiate organ donation. The lack of Intensive Care Units, critical equipment like ventilators, brain death committees and organ donation counsellors in hundreds of hospitals in the remaining parts of the country means it's impossible for clinicians to even bring up the subject with families."

Due to lack of comprehensive insurance covers organ transplantation remains a prohibitively expensive healthcare procedure for most Indians. They are mostly performed by private institutions, and are restricted to capital cities across the country.

The absence of any education about brain death in the standard medical curriculum in the country is another issue that further aggravates the problem, he says. "The knowledge gap not only exists for the common people, which is expected, but also surprisingly for a significant number of newly-graduated doctors. We are pushing hard to have it included in the curriculum nationally," says Dr. Seth.

Despite the magnitude of resource and infrastructural deficiencies the biases against organ donation in India have seen a phenomenal positive shift in the past decade. The momentum built by southern Indian state of Tamil Nadu since 2007 has gradually expanded to Kerala, Maharashtra, Andhra Pradesh, Telangana, Karnataka, Gujarat, New Delhi, Rajasthan and Madhya Pradesh.

Once considered sacrilegious and worthy of stigma, organ donation is increasingly being viewed as a legitimate, and in some sections of the society highly honourable, decision after brain death. The gradual change has come about as a consequence of combined private-public partnership, relentless work by grassroots organisations, large scale corporate social responsibility initiatives by private medical institutions, media participation and community awareness programs in schools and universities.

State/Union Territory	Number of Deceased Organ Donors				
	2013	2014	2015	2016	2017 [▲]
Tamil Nadu	131	136	155	185	166
Kerala	36	58	76	72	18
Maharashtra	35	52	60	142	132
Andhra Pradesh/Telangana*	41	51	89	106	150
Andhra Pradesh			--	48	--
Karnataka	18	39	60	70	68
Gujarat	25	28	45	57	34
Madhya Pradesh	--	--	4	22	30
Uttar Pradesh	--	7	4	9	1
Delhi/NCR	27	20	23	35	16
Puducherry	2	13	9	11	15
Chandigarh	10	7	26	27	44
Rajasthan	--	--	8	8	9
Total	313	411	573	807	691

Deceased Organ Donations in India by States. Data: NOTTO/ORGAN India/MOHAN Foundation

Tamil Nadu, a territory with the same population size as the UK, has been at the forefront of organ donation and transplantation in India. It was the first state to successfully start the living kidney transplantation and deceased organ donation program in the country, the first to make the certification of brain death mandatory and also successfully create green corridors[♣] for transportation of organs.⁴⁹

The turning point for Tamil Nadu came in 2007 when a large-scale illicit kidney scandal targeting the victims of 2004 Indian Ocean Tsunami came to light. The tsunami had killed more than 7000 people in the state and destroyed dozens of poor coastal fishing communities forcing the survivors, mainly women, to sell their kidneys to foreigners. In the immediate aftermath of the scandal the local government issued new guidelines for

[▲] Data for 2017 is yet to be fully collated.

* The state of Telangana was formerly part of Andhra Pradesh and came into existence as a separate state in June 2014.

♣ In India green corridors refer to cleared ground routes through road traffic to facilitate the unhindered passage of a designated vehicles like ambulances. Green corridors are being used increasingly in Indian cities for transporting human organs like hearts for transplantation.

medical institutions and introduced numerous state-wide measures to promote deceased organ donation and stifle commercial organ trade. The establishment of Tamil Nadu Cadaver Transplant Program (CTP) helped standardise and streamline procedures for all transplant hospitals on brain death certifications, donor families, recipients, NGOs and police (in case of road accident victims), thus creating the country's most organised organ-sharing network. A year later Tamil Nadu government's efforts were further galvanised by what is locally known as 'Hithendran Effect,' causing a sharp rise in public enquiries about organ donation.⁵⁰ The effect refers to a 15-year old boy Hithendran, whose doctor parents decided to donate his organs after his death in a road accident.

A definitive measure underpinning the success of Tamil Nadu's model, however, has been its collaboration with NGOs like National Network for Organ Sharing (NNOS) and Multi Organ Harvesting Aid Network (MOHAN) Foundation for ensuring standard outcomes through ethical donations and transplantations. The latter is known as the most prominent organ donation advocacy group in the country with extensive experience and exemplary record in running public awareness programs, lobbying for reforms in medical institutional practices regarding organ donation, community-specific research work and, most importantly, pioneering culturally-sensitive training programs for medical teams involved in organ recovery and transplants across India and now other South Asian countries. The organisation has trained over 1800 transplant coordinators, 600 intensive care clinicians and reached 20 million people through donor card distribution and media campaigns in the last 22 years. In 2015 MOHAN Foundation also signed a Memorandum of Understanding with the NHSBT in the House of Lords, agreeing to share best practices on promoting organ donation and improving consent rates in both countries.



In 2014 the CTP program led to the creation of Tamil Nadu Transplant Authority (TRANSTAN) which currently oversees all organ donation and transplantation activities across the state. Under the system the poor can access transplantation in government hospitals free of cost. The state sponsored health insurance scheme also provides financial assistance up to three million rupees (£32,650) for those admitted in private hospitals.⁵¹

According to TRANSTAN, deceased organ donors in Tamil Nadu have increased from seven in 2008 to 166 in 2017. Last year it launched a mobile app making it easier to pledge organs digitally within minutes.

In recent years, Tamil Nadu's model has become a template for starting deceased donation program from scratch for many Indian states. "Just 6-7 years ago Kerala, Andhra Pradesh and Rajasthan had zero donations. We gave them a roadmap to develop the system and trained dozens of transplant coordinators. Today it's evident from their numbers how quickly they are expanding their capacity," says Dr. Shroff, managing trustee of MOHAN Foundation.

"The progress in Kerala has been phenomenal. In some places they have 90% conversion rates. It's one of the best examples we have in the country after Tamil Nadu," he adds.



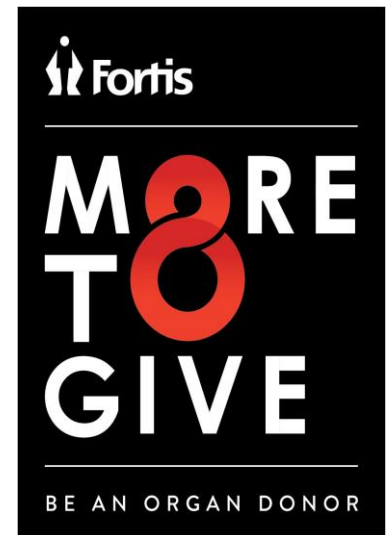
TRANSTAN Organ Donation Mobile App.
Image: Google Play Store

Arguably, a more remarkable feat of the Tamil Nadu model has been its impact in shifting deeply entrenched cultural biases against organ donation in the north of India. While a favourable environment grew in the south supporting organ donation, the northerly states had remained largely impervious to the idea.

“The north just didn’t have the culture that even allowed any conversations about donating organs. Social attitudes have always been rigid. In places like Haryana people wouldn’t even donate blood for fear of losing virility. Most people dismissed the concept as *unnatural* and would insist that it desecrated the body,” says Dr. Atamjot Grewal, the former Chief Patient Experience Officer with Fortis Healthcare.

The cultural resistance, predominantly amongst the older generation, was often disguised as religious reasons to refuse consent. “In our experience with families it invariably came down to emotions, social stigma and most importantly, not being able to understand what brain death actually meant. The family elders would often mask disagreement or lack of knowledge with religious beliefs, something that’s not easy to challenge in a country like India. In the north, places like New Delhi have a number of advanced hospitals with cutting-edge facilities but the infrastructure will be of no use if people don’t believe in donating organs in the first place. To change perceptions entrenched for decades you need to invest in public awareness campaigns,” says Dr. Grewal.

In recent years a mass movement of public education programs, health camps, nationwide walkathons, community-based events, multi-media campaigns and celebrity endorsements has swept parts of the country, including many northern cities, to transform negative societal perceptions surrounding organ donation. The growing momentum is the result of a collective collaboration between multiple public, private and non-governmental agencies like ORGAN India, Fortis More to Give Campaign, MOHAN Foundation, private media channel NDTV, national dailies like the Times of India and NOTTO.



The impact of [ORGAN India](#), established in 2013 following a heart recipient’s difficult journey, has been exemplary. The NGO has filled a gaping knowledge hole for millions of people in India who didn’t have a unified source or agency for accessing advice on transplantation, counselling, laws, information on medical facilities across the country, or options for seeking financial assistance. In just five years after being founded in New Delhi the NGO has created a nationwide directory of medical centres with transplant facilities, audio-visual and print material to create public awareness on organ donation, integrated regional NGOs across India to develop an online network, designed educational material for schools, recently developed the country’s first comprehensive patients guide on transplants, lobbied government bodies for streamlining procedures and public awareness programs, and partnered with numerous entities on community events and media campaigns.

In another major initiative, Fortis Healthcare Ltd, one of India’s largest private healthcare companies, has taken up the cause of promoting organ donation in the country on a mass scale. The group is already known for voluntarily adopting practices aimed at reducing transplantation inequities between public and private

healthcare sector by offering one organ (per deceased donor) to a government hospital. In 2016 Fortis Healthcare launched [More To Give](#), a multi-city public awareness campaign walkathon in partnership with NDTV, a leading English TV news channel, local FM radios, NGOs, and national film and sports celebrities. The annual More To Give walkathon event along with over 50 talks about organ donation has reached more than 20 million people in several Indian cities through on-ground, digital and social media impressions. The group reported 45,000 organ donation pledges* after two walkathons until December 2017.



More to Give Walkathon events in Mohali and New Delhi. Photos Courtesy: Fortis/NDTV

The impact of organ donation awareness campaigns across India is gradually becoming visible, through steady increments in donation rates as well as instances of social examples. The Organ Retrieval Banking Organisation (ORBO) at New Delhi's All India Institute of Medical Sciences recorded a 42% consent rate for donation in 2015 compared with 10% in 2010.⁵²

Setting a unique example, the deputy chief minister of Bihar set up an organ donation stall for the guests at the wedding of his son in December 2017. Bihar, the third most populous state with 99 million people, did not have a single transplant facility until recently. Rajasthan Haryana, the state usually known for rigid patriarchal attitudes and worst gender ratio in the country, recently announced plans to open a state organ and tissue transplant organisation.

"Each year traffic accidents in India kill approximately 150,000 people, of which typically 67% sustain head injuries as the cause of death. That's more than 95,000 potential organ donors. If we continue to optimise our infrastructural capacity as well as foster a culture that supports organ donation, we can reach a much higher deceased donation rates in the country," says Dr. Shroff.

Currently, India's deceased donation rate is 0.8 per million population,^{*} reflecting a 10-fold increase in the last decade.⁵³ "It may seem low on the PMP scale but the number waters down India's success story and real progress on the ground. Comparing some of the Indian states that are as large as the UK or Spain the PMP would be at par. But our reality is different. Three-quarters of the world has conditions like India. The success of Tamil Nadu model and now states like Kerala show what is possible in a developing country," Dr. Shroff adds.

(Date Visited: October 2016)

* Pledges made with Fortis group only.

♣ AS reported by FORT and MOHAN Foundation.

RELIGIOUS VIEWS ON ORGAN DONATION



Hinduism encourages the noble act of organ donation. There are many references in ancient Hindu text citing the merits of organ donation. The Manusmriti reads, "Of all the things that it is possible to donate, to donate your own body is infinitely more worthwhile."

HINDUISM



Many Islamic religious leaders accept organ donation in order to save lives. As early as 1967, the Senior Ulama Council of Saudi Arabia permitted cornea transplantation. In 1982 they also permitted deceased organ donation as long as there was no other option.

ISLAM



The Sikh religion teaches that life continues after death in the soul, and not the physical body. The Guru Granth Sahib reads, "The dead sustain their bond with the living through virtuous deeds". The final act of giving and helping others through organ donation is both consistent with, and in the spirit of Sikh teachings.

SIKHISM



Sacrifice and helping others are key themes across all forms of Christianity, and therefore a decision to donate organs is seen as a positive act by most Christians. The Archbishop of Westminster has described organ donation as a "true act of generosity".

CHRISTIANITY



Buddhism looks at organ donation as a form of charity, a final act of generosity which can only have positive ramifications on future lives. As the enlightened Buddha himself said to his followers upon seeing an unwell and uncared-for monk, "Whoever would care for me, let him care for those who are sick".

BUDHISM



Jainism teaches its followers to practice unattachment towards all worldly possessions in order to heal the soul. Our organs are but part of our worldly possessions. As Lord Mahavira said, "Let me give up attachment through unattachment. My soul will be my only support (in this practice of unattachment). (Hence) let me give up everything else."

JAINISM

Views on organ donation in different religions: Image courtesy ORGAN India

iv. Israel

The majority Jewish state of Israel is home to 8.5 million people from different ethnicities and religions including Christians, Muslim and Druzes. The organ transplantation program in the country goes back to 1964 when a kidney was transplanted from a related living donor, shortly followed by the first deceased donation a year later. In 1994 the government established Israel National Transplant Centre (INTC), a central body to oversee donor management and organ allocation across six major medical centres in the country.

Consent rates in Israel remained stagnant for many decades despite its advanced healthcare infrastructure and abundant economic resources. The resistance to donating organs was primarily rooted in strong religious views and orthodox interpretation of death in the Israeli society. The ultra-orthodox Jewish school of thought rejects the concept of brain death – the stage at which organs are normally harvested from a non-living donor, and proscribes the desecration of the body after death. The Halacha laws at the time defined the time of death as the moment the cardiac and respiratory functions stopped in the body. The view held sway over the wider Jewish society for many decades affecting decision-making of even moderately traditional and religious families at the time of death.⁵⁴ Similar religious beliefs and practices surrounding death among the 1.7 million Israeli Arabs, most of whom are Muslims, presented additional barriers to organ donation in the country.⁵⁵

With only 10% of the adult population registered as organ donors and national consent rates averaging 45% - one of the lowest in the developed world⁵⁶ – patients at home in need of life-saving transplantations began to look overseas for more readily available alternatives. Until 2008 Israelis accounted for one of the highest numbers of transplant tourists globally, routinely travelling to countries like China, Philippines, Costa Rica and Sri Lanka for commercial transplantation.⁵⁷ While organ procurement from executed prisoners in China⁵⁸ in particular offered a reliable supply of organs like heart, full reimbursement by Israeli health insurance companies of transplant expenses incurred overseas stymied any hope of boosting consent rates at home.

However, the introduction of two new laws in 2008 radically altered organ donation practices in the country. First, the Brain-Respiratory Death law lay down the legal definition, circumstances and conditions determining brain death, harmonising the differences between medical community and religious authorities. And second, the Organ Transplantation Law introduced a point-based system that gave transplant priority to those already committed to contributing to the organ pool. The law also banned any reimbursement of overseas commercial transplant costs by health insurers.⁵⁹

The new policy framework essentially ensures legal priority on organ waiting list to mainly those candidates who are: a) living donors and have previously donated a kidney or liver-lobe; b) have registered as organ donors for at least three years prior to joining the waiting list; and c) are first-degree relatives of deceased donors.⁶⁰ The new point-based system, however, does not override the clinical priority. Clinical parameters being equal between two patients the donated organ goes to the one who meets one of the three priority conditions. The law came into effect on the 1st of April 2012 following two countrywide intensive multi-media and multi-lingual campaigns to create awareness about the new policy, making Israel the first country in the world to have a legal non-clinical criterion into the allocation of organs.

Israel's radical approach is credited to Professor Jacob Lavee, a cardiothoracic surgeon and the head of Heart Transplant Unit at Sheba Medical Centre in Tel Aviv, who was compelled to challenge the contradictory practices and views held by many of his patients.

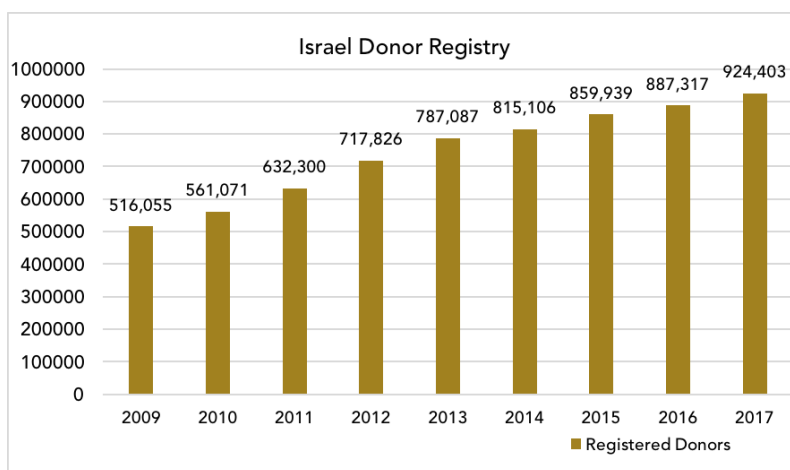
Dr. Lavee's campaign to reform the Israeli transplant laws came about after a chance conversation with a Haredi Jewish patient who had been waiting for a heart transplant for months. "My patient desperately hoped



Dr. Jacob Lavee, Sheba Medical Centre, Tel Aviv. Photo courtesy: Dr Lavee

for someone to consent to heart donation but confessed that he wouldn't donate the organs of a deceased family member if the situation was reversed, simply because it was against his religious beliefs. I found the hypocrisy appalling," he recounts. Many of his orthodox patients, he says, likened the practice of retrieving organs from a brain dead person to murder but did not have any moral issues accepting those organs. "This view of us, the doctors, as murderers was unacceptable. This mindset also reflected the challenge we faced regarding the free-riders in the society; those who are willing to accept but never give. Granting priority to those who donate organs is the only effective way I could imagine to make the system fair and just for everybody."

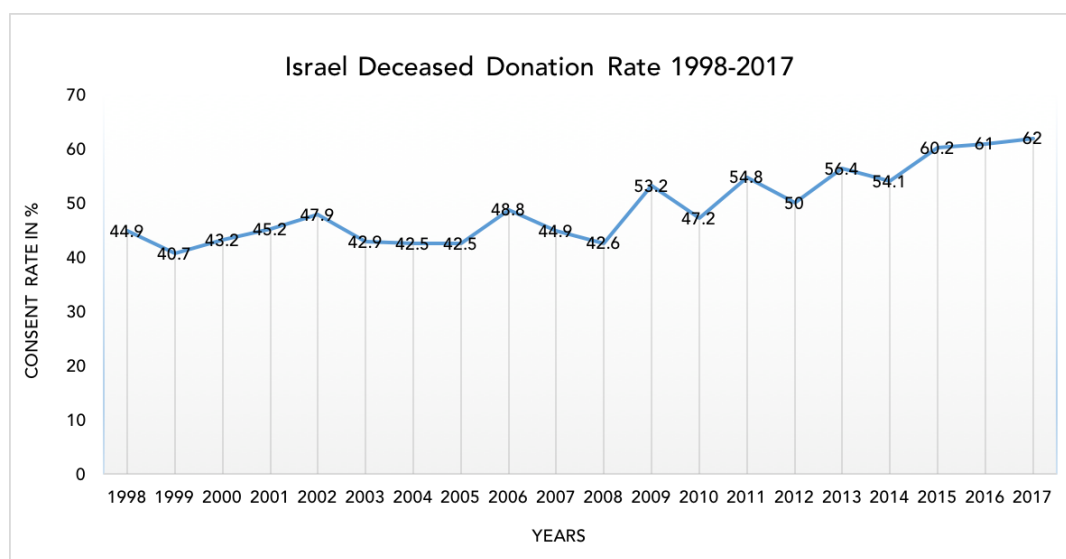
For Dr. Lavee the idea of his patients traveling to China to receive heart transplants on "pre-determined dates" in agreement with their health insurers was equally reprehensible and immoral. He became aware of forced organ harvesting from executed prisoners in the communist country in 2005 when one of his patients, hospitalised for over a year and with top priority to receive a heart, travelled to China for a transplant procedure on a scheduled date arranged two weeks in advance by his medical insurance company. "I was aware of hundreds of Israeli patients who had received kidneys in China. But this was the first time someone got a heart. By allowing Israeli insurance companies to operate like that we were in fact recognising such immoral practices in China as legal and ethical. As a nation we were letting our patients be complicit in human rights abuse in another country. That needed to change. That's what we tried to address with the new law," says Dr. Lavee.



Israeli organ donors with ADI card, Data: Israel National Transplant Centre, Ministry of Health.

The adoption of the reciprocity model in Israel has since produced considerable results. The data collected before and after the law was passed by the Israeli parliament, and analysed by a team of academics and economists including Nobel Prize winning Alvin E. Roth, demonstrates that the priority policy has had a

substantial effect on organ donor registrations in Israel.* The rate of authorisation by families of deceased donors between 2011-2015 jumped to 55%; in contrast it had remained stagnant around 45% on average from 1998-2010⁶¹. In 2015 alone the consent rate touched 60.2%. According to the latest figures released by the National Organ Transplantation Centre, 2017 had the highest number of transplants in Israel with a consent rate of 62%⁶². Last year the priority law allowed 37% of the recipients to move up the queue as a result of their organ donor status.⁶³



Israel Deceased Donation Rate 1998-2017, Data: INTC, Ministry of Health, Israel

While the change in law has significantly cut down transplant tourism it spurred a marked increase in the living organ donation.⁶⁴ In 2017, patients received 113 kidneys from related living donors while 109 came from



ADI Israeli Organ Donor Card.
Image courtesy: INTC

unrelated altruistic donors.⁶⁵ The number on the organ donor register since 2009 has nearly doubled; currently 14% of the country's adult population is signed up to the register.⁶⁶ According to Dr. Lavee, Israeli organ donor cards, known as ADI, have become quite popular since the new policy took effect. The cards had been re-designed and re-launched to reflect the change in the law and to embody a positive social message.

Israel's reciprocity model remains unique in the world due to its structured approach to incentivise organ donation. Previously, only Singapore had a similar policy that granted priority to candidates registered as organ donors but did not include next of kin of deceased donors. In 2015 Chile amended its organ donation policies to incorporate the Israeli reciprocity clause.⁶⁷ However, unlike Israel both Chile and Singapore have opt-out models. In the U.S. living kidney donors are given priority status for organ transplants if they ever need one.

(Date Visited: September 2017)

* The measurement of change in terms of actual donation per million population in Israel after the laws came into effect was not taken into account in this paper due to fluctuations in data in the studied period, although an earlier study found the per million population donation rate had increased from 7.8 to 11.4 in just a year. The change in rate of authorisation by next of kin of deceased donors was found to be a more accurate indicator of impact of the priority law in the country.

4 | Key Findings

The disparities in policy frameworks, clinical infrastructure, availability of resources, public funds, and prevalent socio-economic conditions in each country researched on this Fellowship mean the development and achievements of their respective organ donation and transplantation programs with respect to ethnic consent rates cannot be measured against the same benchmarks. The state of social welfare and public health expenditure in India, for example, is far inferior than those seen in the UK, U.S. or Israel. Similarly, healthcare sector and government spending in the West has seen more constraints than that in the oil-rich state of Qatar, in the aftermath of 2008 global financial crisis and subsequent economic austerity. Notwithstanding these uncontrolled differences, key patterns and lessons emerged in the communities researched across the four countries that appeared to play a pivotal role in driving change in behaviour and influencing donation rates among the ethnic communities. Those relevant to the experience and challenges unique to the UK's BAME communities have been summarised below.

i. Community Engagement, Ownership and Evaluation

The success of MOTTEP's model, first with African Americans and later with other minorities, presents many valuable lessons for the UK on how best to engage with communities with unfavourable attitudes towards organ donation for successful outcomes. The entire program and its extraordinary results can be summarised as the combination of three main principles: a) relentless community engagement, b) ownership by communities and, c) constant evaluation and recalibration of strategies.

The key word that formed the lynchpin of the program throughout its 25-year history is 'empowerment.' The primary focus is trained at empowering the communities to first understand the issues and risks reflected by their over-representation on the transplant waiting lists, recognise the underlying causes and barriers as posed by cultural and religious beliefs, using the knowledge and resources to tailor community education programs, and take control of their health by embracing better diet, lifestyle and health practices for prevention of chronic diseases.

The core philosophy of the program is inspired by the 5-stage model of community organisation for health promotion devised by social scientists and community health scholars Neil Bracht and Lee Kingsbury, who stressed the importance of community empowerment and ownership to achieve long-lasting and self-sustaining positive health policy outcomes.⁶⁸

"One of the things we learnt very early on is that it's absolutely vital for the engagement with the community to be sustained over a long period of time. Any gaps or lack of consistency tends to offset the progress and lessen the efficacy of public education. In terms of cost analysis, we found it offered suboptimal value for money and of course manpower. MOTTEP had to secure grants every few years but we were able to demonstrate that financial support to a national donor education program with a sustained community work model like ours could actually save millions of dollars to the government in dialysis, transplant and donor costs" says Dr. Callender.

In that respect NHSBT faces similar budgetary constraints in the current economic environment and cuts in public spending. Multiple stakeholders working directly with BAME minorities in the UK recognise that NHSBT has gone further than any other governmental agency to work with minority populations. Despite its commitment and continued efforts, many stakeholders, however, also feel the agency's engagement with communities still remains inadequate and infrequent. Its strategies, they argue, need to focus more on broadening the scope of engagement with BAME populations given they account for 30% of the national

transplant requirements. Their argument finds resonance in the research conducted in the U.S. where funding challenges and engagement objectives were similar in nature to those in the UK. The findings show that a consistency in campaigning and engagement was critically responsible for not just a rising number of organ donor registrations (through community campaigns and driving licence) among African Americans but also creating regular opportunities for prior family conversations, widely considered the key predictor of consent at the time of brain death. Observations in Qatar, Israel and India also strongly agree with the need for a sustained engagement. While it directly led to an unforeseen increase in the number of living donors in Qatar and Israel, in India the change has reflected through a greater degree of awareness in the northern parts and incremental growth in consent rates in Andhra Pradesh, Kerala, Tamil Nadu, Gujarat and Maharashtra.

Approach	Brief Description
Community participation and direction	Because every community is different, the program involves diverse community persons in varied levels in the planning and implementation of their own community-based activities designed to meet MOTTEP's mission and goals.
Face-to-face presentations	MOTTEP makes presentations at social, civic, and faith-based events, especially to smaller audiences where there are more opportunities for discussion.
Collaboration and partnerships	Collaborating with religious, social, civic, and other local organizations to promote the program's mission and goals while encouraging viable partnerships is extremely important and productive. MOTTEP has collaborated with more than 300 organizations since 1995.
Media promotion	The media (radio, television and print) play a critical role in the promotion of MOTTEP's message. MOTTEP has generated more than 10 billion media impressions since 1995.
Information dissemination	MOTTEP has developed culturally sensitive and informative brochures, videos, PSAs, flyers, fact sheets, and other information for community dissemination.
Evaluation	MOTTEP has developed comprehensive quantitative and qualitative surveys to gauge the effectiveness of its programs.

Minority Organ Tissue Transplant Education Program Community Education Strategies. Data Provided by National MOTTEP, Washington D.C.

Community ownership, as the MOTTEP model demonstrated, is the second pillar of a successful minority education program. In a true adaptation of Bracht and Kingston model, the MOTTEP programs first in District of Columbia, and later in other sites across the country, fostered community ownership in order to sustain the momentum initially built with intensive public education activities. In their model Bracht and Kingston argue that *'communities must shape their own program directions and emerge with the necessary skills and resources to manage continued efforts.'*

"First we have to customise campaigns according to ethnicities. Every community has its own life and blood. After the first stage of educating the communities with the help of healthcare professionals, recipients, donors and their families we step aside and let the community take over from there. You don't interfere after you educate them. That's what our community *educate and empower effort* is all about. Let them decide what's appropriate. The representatives we train in our program then go back to their communities and educate their own people and empower them to become part of the solution to the problem. A group determines how they will move and take their grassroots efforts forward, which means communities customise strategies in their own way," says Dr. Callender

“It’s very important that the message comes from their own people, and from within their own community. Afterwards we only help build the momentum from the margins, providing whatever guidance and education they need for the community to listen, adapt and feel empowered and take the right decisions. As a result, across our sites in Detroit, Chicago, Cleveland, Tennessee, New York and Pittsburgh, we saw big transformation in community behaviour. We call this the *Triple A Effect* – from *Awareness* to *Action* to *Accountability*. This showed us why community ownership is absolutely vital,” he adds.

A critical factor underpinning the success of MOTTEP programs is its focus on behaviour change rather than just community awareness. Educating the communities on what the issues are or why they should donate organs is not the goal in itself. Unless the campaigns produce change in behaviour across different sites they are not considered successful or over. The change in behaviour is measured by *outcome*. “For MOTTEP the outcome is mainly donation, living or deceased, registration as an organ donor and family conversations. When all these numbers start to go up in a community we know the outcome has been positive,” says Patrice Miles.

The third and arguably the most important lesson to emerge from MOTTEP model’s success is the adoption of an evaluation system. The organisation heavily utilised pre and post intervention questionnaires to continually evaluate their programs and outcomes. The surveys were designed to answer whether the communication and communicators (from the same ethnic group) were making any difference in knowledge, attitudes, beliefs and behaviour within a minority community. Through the data, MOTTEP analysed whether targeted individuals were likely to become donors and consent to deceased donation in their family. Later the same tool was used in a program specially designed to engage with over 6500 youth participants. The questionnaire helped determine whether the youth participants led a healthy lifestyle measured on indicators such as smoking, drinking, exercising etc. The evaluation system, inserted at different stages within a program, also provided data revealing actual impact of the community education programs through the number of individuals reached, community events organised and participated in, and the effect of media events.

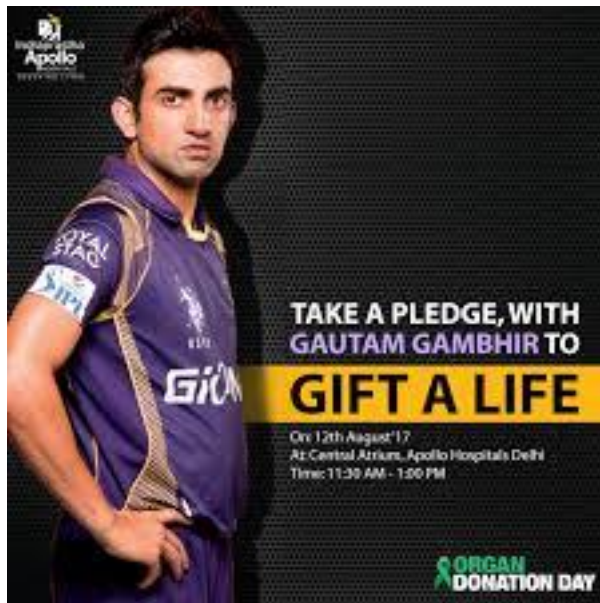
Numerous examples of sustained community engagement were found in India, Qatar and Israel as well. Even though they differed in nature, they invariably reinforced the case for continued engagement as a means to achieve better results with minority communities on organ donation.

Practitioners in Israel have repeatedly emphasised the importance of sustained mass media drives for public education before adopting a new system. In the 10 weeks of public awareness campaign, also offering online and phone registrations, nearly 70,000 Israelis had signed for organ donor cards. The carefully designed awareness program took advantage of the opportunities presented by the general election in 2013. Nearly 700 INTC workers were stationed next to ballot booths across the country providing voters the opportunity to register as an organ donor at the same time. As a consequence, over 27,000 registrations were collected in a single day. The INTC credits the success of the drive to increased awareness due to a sustained and intensive mass media campaign.

Community engagement in the UK can take many forms. A highly effective method can be through collaboration with film and sports icons. Britain’s culturally vibrant BAME community with over eight million people continues to engage with icons and celebrities from sports, films, art, literature and politics from their native countries, many of whom already have strong commercial interests in the UK and visit frequently. A partnership with cultural icons in organ registry drives and related media campaigns, as numerous examples in India showed, can deliver astonishing results.

“Public health campaigns like eye donation or polio drops had little traction in India before super celebrities like Amitabh Bachhan and Aishwarya Rai got involved. Suddenly there was a huge jump in awareness about these important issues. Eye donation took a while to show results because there was no culture of organ donation in

India 15 years ago. But in terms of creating awareness their involvement created thousands of media impressions and got everyone to sit up and notice,” says Dr. Shroff.



India cricketer Gautam Gambhir as an ambassador of organ donation. Photo courtesy: Apollo Hospitals Delhi

India, known for its love of cricket and films, has in recent years been swept by a number of private and government public awareness campaigns about organ donation featuring superstars like Priyanka Chopra, Amir Khan, Irfan and Gautam Gambhir. The icons, each with a following of millions on social media, have often endorsed social causes and public messages without any remuneration. Their ambassadorship has drawn greater community participation in walkathons, health camps, friendly matches and public events, and helped drive awareness programs further than traditional methods.


To ensure such endorsements were effective, stakeholders in India and the U.S. were observed to be leaning increasingly towards a higher engagement with young adults and school children. The practitioners argued the young audience were better at initiating conversations in families and more likely to break taboos passed down through generations later in life. “Adolescents and children are future agents of change.


They can break decades of taboos in a family on matters like organ donation. They are not afraid to ask questions, speak their mind and also sometimes challenge us, which makes them the best catalysts of change we want to see in organ donation practices in the society,” says Sunayana Arora Singh, CEO of ORGAN India.

ORGAN India lobbied the Delhi government for allowing the NGO initiative to run its *Let's Get ORGANized* awareness program in schools across the capital. In less than a year the program has reached nearly 9,000 students and 250 teachers across 42 schools, with many educators signing up on organ donation pledges as a direct result of the initiative.

The strategy finds resonance with experiences of Angela Ditchfield, NHSBT's Diversity Lead Nurse for organ donation, who worked with Pakistani community in Blackburn a few years ago. According to Ditchfield, the slow but gradual change in views became more visible among the younger age groups than the older members of the community in the course of her work. The generational change was only possible with a continued engagement with the community, especially the youth, she said.

Evidence from researched countries as well as those such as [the Netherlands](#) and [Japan](#) shows strong support for proactive engagement with adolescents to achieve higher rates of family conversations and a

**Make a Gesture.
Save a Life.**
Blood Donation & Organ Donation awareness camp.
Calling all Pawan Kalyan fans to show that you truly care and can make a difference in the society!
A few **CELEBRITIES** to join this event too
Our Gift to King Kalyan on his Birthday
Date: 31st August-2014
Venue: KBR PARK.
Contact: Suneal Patel (9603987898)
In Association with  **MOHAN FOUNDATION**



Indian film actor Pawan Kalyan is a known advocate of organ donation.

gradual shift towards consent. In that respect, NHSBT has already developed and made available on its website an excellent, and much admired, education program with a variety of teaching resources targeted at school children. The agency must push for a greater uptake of its program in schools across England through a partnership with Department of Education.

ii. Identity-based Approaches: Separating Culture from Religion

In Qatar, India and Israel, the public message relied significantly on the position of different religions and interpretation of holy texts over organ donation. While religion is a handy tool for the effective delivery of messages and providing theocratic clarity on the issue, it wasn't the primary reason why people refused to join organ registry or consent to deceased donation. Cultural practices and outlook were found to have greater influence than religion, and a number of practitioners agreed the greater challenge lay in former rather than the latter.

In Qatar, for example, most migrant workers from Yemen, Egypt, Pakistan, Sudan, Syria, Iran, Indonesia, India, Sri Lanka, and Bangladesh shared the same religion of Islam but their response or apprehensions to the public messages on organ donation were not identical. Arabs, including a sizable number of Qatari natives, and Pakistanis are often the most reluctant groups, and least likely to consent to organ donation after brain death due to cultural practices, according to HMC practitioners. Burial of body without delay or 'desecration' are two main doctrines guiding death rituals in Islam. In that context, migrant groups from Pakistan and Arab countries have a more rigid view of retrieval of organs post death than other Muslim groups in the country in spite of assurances and explanations from clinicians, campaigners and clerics alike.

Similarly, Hindu communities from the south and the north in India hold disparate views on organ donation. While the southern communities are now more agreeable to the idea of donation – Tamil Nadu's consent rate is 15 times that of the national average - communities in northern states like Haryana even balk at the idea of donating blood for fear of losing virility. "A study conducted by Rajiv Gandhi Government General Hospital in Tamil Nadu revealed religious reasons were cited in only 13 out of 69 cases between 2012-2015 to refuse organ donation after brain death, that's just 19%. Often within the same religious group you would see different perceptions. Muslim sub-sects like Bohras, Ismailis, or Shias would generally be more open to organ donation than those from Sunni or Wahhabi school of thought. Religion is an important factor indeed, but often times with highly diverse groups it would often come down to cultural notions steeped in a community," says Dr. Shroff.

In the UK, the term BAME, now officially recognised, has been a shorthand to refer to non-white minority populations in the country for years. On official forms for equal opportunities and survey results the non-white ethnicities are bracketed under the term. (The BAME label itself has come [under fire](#) for obscuring or under-representing identities. During this research a senior official with NHSBT showed his disagreement over lumping of minorities under a single label, calling it less effective and wasteful). While the term may serve the purpose for a broad spectrum of public repositories requiring identification of ethnicities, it may not fully reveal the hidden biases and influences exerted by factors such as culture and heritage.

All members of a certain ethnic group across the UK may not necessarily share the same cultural beliefs on issues like organ donation. For example, an entire community identified as British Indian is less likely to have homogenous views or cultural practices. An Indian Muslim from Kerala may not share the same cultural beliefs as another Indian Muslim (or Hindu) from Uttar Pradesh or West Bengal, despite being identified under the same ethnic group as per the current BAME categorisation. Similarly, heritage, family history and socioeconomic background of a person from Karachi may influence his decisions differently than someone from Lahore or Peshawar. While religion continues to be an important consideration in personal matters, blanket

categorisation of ethnic groups in the UK may have created blind spots hindering deeply entrenched cultural disparities, and could explain to some extent the slow progress of minority groups on the uptake of organ donation year on year.

Multiple stakeholders in the UK have long recognised the role played by faith in decisions regarding organ donation. In that respect Dr. Gurch Randhawa's scholarly work has already demonstrated the need to engage more closely with multi-faith and multi-ethnic communities. However, identifying and addressing cultural blind spots along with faith-based reservations may give even deeper insights into the resistance found in the ethnic minority populations over organ donation. A revision of data collection methods, analysis and potentially inclusion of parameters that record or help account for disparities in cultures, heritage and legacies of distinct BAME populations may provide critical clues on how best to design education programs targeting minorities in future. A greater collaboration with organisations that work closely with different groups and cultures on the ground will be vital in discovering and scrutinising these hidden layers and formulating better policies.

iii. Public Recognition of Organ Donors

Public recognition of living donors and deceased donor families is one of the salient features of organ donation programs both in Qatar and India. Stakeholders in both countries place high value on acknowledging the 'courage and magnanimity' of donors and donor families, and strongly believe the gesture immensely helps



Organ donors and families at the honouring ceremony in Doha 2016. Photo courtesy: HMC

complement public education campaigns on the issue.

In Qatar the event is organised annually by Hamad Medical Corporation, and often attended by scientists and researchers from countries such as Spain, Croatia, Austria and the U.S. Living

donors and kin of deceased donors are *honoured* for their altruism and presented with a medallion. In 2016 the honouring ceremony was held at the launch of Doha International Academy for Organ Donation, and attended by eminent scientists and renowned academics including Dr. Francis Delmonico, Dr. Gabriel Danovitch and Dr. Dominique Martin among others. "It can be difficult to measure but we have seen the impact of lauding donors publicly on their communities. For some families, as we have heard a few times, it has helped in reconciling with their loss. They take heart in knowing that the unexpected death of the person did not go waste. They show attachment to the medallion. The gift of life to others becomes their legacy after death," says Dr. Fadhil.

In India the recognition of donors has almost become integral to several public and private organ donor awareness and public education initiatives. Families and individuals are now routinely felicitated by NGOs and local governments in states like Maharashtra, Tamil Nadu, New Delhi, Andhra Pradesh, Telangana at public events, with press in attendance. Taking the initiative to a new level, Fortis Healthcare, the largest provider of private healthcare in the country, has in recent years erected enormous Walls of Tribute in many of its hospitals across the country. The Walls, with names of deceased donors inscribed next to a silver star each, are part of its wider public education campaign called *More To Give* and have received wide media attention of late.

In a diverse society with multiple ethnicities and one that has been resistant to the idea of donating organ for a long time such events can act as a powerful catalyst, says K R Balakrishnan, a heart transplant surgeon with Fortis Malar in Chennai, Tamil Nadu.



The Wall of Tribute at Fortis Gurgaon. Photo courtesy: Fortis Healthcare

“It is important to understand that in India faith-based beliefs play a decisive role in life and in death. Rituals around death tend to be rigid, and donating organs was not part of them for decades. But recognising their decision as acts of nobility in public sphere and acknowledging their altruism sends out a hugely positive message. You are celebrating their bravery for going against the social norms, the centuries-old traditions. It helps in breaking down the cultural stigma. When people read about it in the newspapers or see the Wall, it adds to the momentum,” he says.



Ambulance carrying Thota Manikanta's organs to Gannavaram airport, Vijayawada. Photo courtesy: V. Raju, The Hindu

To illustrate the degree to which public acknowledgement of organ donation can help influence societal perceptions Dr. Balakrishnan recalls the example of [Thota Manikanta](#), a 22-year old driver from Vijayawada in Andhra Pradesh who was declared brain dead following a road accident in 2015. As the news of his family's decision to donate his organs spread, probably via social media, people came from nowhere and lined up the streets in order to pay their respect, says Dr. Balakrishnan.

“They threw flowers at the convoy carrying his organs and chanted Manikanta’s name. It was an enduring image. In that moment you could glimpse the transformation of their attitudes, their admiration and recognition of the family’s decision as noble. It was powerful and emotive. I showed the video to a team of experts from Ukraine, who were visiting to study the Tamil Nadu model. And they found the public outpour of emotions rather astonishing. They had never seen anything like that,” he says.

Manikanta’s organs were shared between eight patients across Chennai, Hyderabad and Guntur. The decision to donate his organs, his family said, was motivated by Manikanta’s love for film actor Pawan Kalyan, a staunch advocate of organ donation.

In the UK NHSBT has acknowledged the altruism of and paid tribute to organ donors at several occasions but it does not have a dedicated program or media event that could be used to publicly recognise organ donors and families, especially from BAME backgrounds. Specific case studies are known to have been used sporadically in marketing materials and social media across different locations and communities but their exposure and penetration is arguably likely to have less impact than a dedicated event to *honour* the memory of deceased donors, as was observed in the researched communities. There is a volume of examples in countries like India and Qatar that demonstrate the impact such events can have on reinforcing positive public messages on organ donation. While budgetary constraints may pose a challenge, it is, nevertheless, worthwhile for the NHSBT and Department of Health to consider investing in the idea and organising community specific recognition events, even when organised at a small scale.

This also calls for a better organised database or directory of BAME specific donors and coordination between the NHSBT hospitals and grassroots organisations. Often families want to come forward and share their stories through a public platform or at community events but may not be aware of the right channels. Establishing a database would allow community organisations to connect with BAME families, with consent, and use the case studies for awareness events and local engagement.

iv. Disease Prevention and Better Health Practices: The Way Forward

A gradual shift towards strategies emphasising disease prevention and lifestyle management rather than a single-minded focus on public awareness about organ donation in minority populations emerged as one of the key lessons during this research. Practitioners across the visited countries recognised the infeasibility of meeting the demand for organs cent percent in light of growing burden of chronic disease, lack of capacity, clinical challenges, and external factors including but not limited to cultural and religious taboos.

To address the gap between demand and supply of organs, the community organisations are increasingly turning their attention to the root cause of the problem itself. Once again the best examples and practices in the course of this research were found in the black communities visited in the U.S. Educating minorities about disease prevention and better health practices is now being seen as more effective tool than creating awareness about organ donation alone. The disease prevention programs are being designed and implemented through a network of carefully chosen workers and volunteers who are ethnically and culturally similar to the targeted communities for effective delivery.

“If we can’t meet the need for organs then a great way to tackle the problem is to reduce the need for transplantation itself. When communities start taking care of themselves and work to prevent health issues like hypertension and diabetes, they are not going to have problems like end stage renal disease and need dialysis or kidneys in the first place. This means fewer people from minorities will go on the waiting list, gradually bringing down the numbers,” says Linda Kimble, Executive Director of MOTTEP Cleveland.

MOTTEP Cleveland's programs are among many across several cities in the U.S. that are engaging with communities on disease prevention. The site's *Healthy Teen, Healthy Tomorrow*, a special health program designed for educating minority youth about their disproportionate risks of developing chronic diseases and averting the need for a transplant through healthy lifestyle choices, has been one of the most successful projects in the city. The site's community outreach programs focus as much on the need for organ donation as disease prevention across different age and gender groups, and have been responsible for reaching over 90,000 people over a period of three years.

Love Yourself, Take Care of Yourself, a flagship program designed in 2001 by National MOTTEP in Washington D.C., has reached over 100,000 people each year to help understand the risks caused by obesity, hypertension and diabetes. Through a network of community health workers, volunteers, educators and partnerships the program provides a wide array of resources, services and information on the minority populations' need for regularly measuring cholesterol, hypertension and maintaining healthy weight. To expand its reach, the disease prevention program has forged partnerships with educational institutions, healthcare providers and celebrities to produce culturally appropriate promotions and organise community events emphasising disease prevention through better health practices.

"At first the shift away from organ donation awareness towards disease prevention education was met with resistance and criticism by stakeholders, OPOs and health agencies. They did not think it was the right approach to address the paucity of ethnic minority organ donors. With time, however, the programs have proven their merits and efficacy by educating minorities about preventing chronic diseases," says Patrice Miles.

A critical reason the education programs have been successful, says Miles, is because of a gap in information and resources targeted at the minority populations. According to MOTTEP, black communities covered under the program had access to clinical interventions and healthcare professionals but the public health model did not provide for any culturally-specific guidance, advice or resources about the need for health or lifestyle management. "Obesity, diabetes, hypertension – all of them are preventable diseases and largely the result of individual lifestyles and dietary habits. During our initial organ donation work with the African Americans we discovered the major reason for the high incidence of chronic diseases among them was due to a big gap in resources and information about better health practices available to them to even understand the risk these diseases posed to them," says Miles.

"We decided to fill this gap by shifting our focus to disease prevention, so the community could first learn about these health issues even before we asked them to consider organ donation. With the help of community workers and necessary information we put them on the path of self-care management. That's the guiding principle behind *Love Yourself, Take Care of Yourself* program," she says.

Another factor vital to the success of the disease prevention component was to acknowledge that even though ethnic groups battled similar health concerns, they were different in their lifestyles and needs. "Lifestyle and dietary habits of African Americans are culturally different from, say, Latinos or Asians, but end-result health issues can often be the same, like high blood pressure or diabetes. But the correct way to impart advice for each ethnic group is to address it differently. It has to be specific to their culture, foods and lifestyles. How a black family cooks and eats their food is not the same as how an Asian or white family will. That's why it's very important to take into account the cultural and lifestyle differences between different communities before customising your approach," says Miles.

Evaluation of the MOTTEP's disease prevention programs shows a considerable impact on communities that were engaged with across seven sites. The programs, combined with organ donation awareness campaigns,

have produced measurable outcomes, including (tracked) increases in organ donation registries across Ohio, Michigan, Pennsylvania, Tennessee and Washington D.C.

MOTTEP's community-based intervention approach is strikingly similar to the one espoused by Peer Educator model in the UK, which has produced identical outcomes in select BAME communities across the country. Devised by Kidney Research UK the model relies on 'peers' drawn from the minority populations to effectively raise awareness about key issues surrounding chronic diseases, promote healthy lifestyles and organ donation. The Peer Educator employs the same two core principles as embodied in the various MOTTEP programs: a) the need for awareness about disease prevention and better health practices geared towards the minority communities to reduce transplantation requirement, and b) the delivery of culturally competent message through a network of peers/practitioners drawn from the same minority groups and with ethnic and lingual similarities for effective dissemination.

The emphasis on disease prevention in strategies and outreach programs designed for minority populations in the researched communities in the U.S. and their successful outcomes make the case for initiating a broader shift in policies targeted at BAME in the UK. According to the Peer Educator project as well as ethnic grassroots organisations, there exists a similar gap in the knowledge of the UK's BAME communities about healthier lifestyle and self- management practices. While the NHS continues to be one of the best healthcare systems in the world offering excellent clinical interventions and care, it is yet to fully appreciate the impact and potential of culturally-competent policies, care and advice in order to effectively meet the healthcare needs of the BAME communities and ease their struggle with chronic diseases.

In that respect the Peer Educator model has already provided a template for community based-intervention that goes beyond the clinical care system currently in practice in the country. The model's organ donation projects with BAME and research on end of life care with South Asian communities provide a repository of experience to stakeholders and national policymakers on the merits of placing greater emphasis on disease prevention component in order to address low BAME organ donation rates.

v. Alternative Models: Opt-out vs Reciprocity

Incentive has become a dirty word in the field of organ donation and transplantation. A reference to incentive of any kind is widely viewed as unethical or morally reprehensible by clinicians and policy makers alike. While financial gains or transactions over human organs disguised as incentives are indeed worthy of criticism and censure, the incentive-based model of organ donation as adopted in Israel presents a case starkly contrarian to the widely held notions on the issue.

The story of transformation in societal perceptions in Israel is one that underlines the deep human psychology of self-preservation and rational choice. The country's incentive-based model of organ donation, commonly known as the Reciprocity model, solved a long standing problem by introducing a system that arguably allows a just and fairer allocation of organs across the society. In doing so Israel not only curbed the invidious and rampant practice of transplant tourism, it also dramatically eliminated the cultural and faith-based resistance to organ donation in the country almost overnight. In the space of six years the consent rate in the Jewish state has gone up from 45% to 62%, with a sharp rise in living donations.

The point-based system giving preference to donors and their kin for organ transplantation over non-donors makes for a fairer allocation system, for it negates the irrational hypocritical behaviour, also known as free-riding, that allows individuals to take organs but not give on various grounds, thus hurting the whole society. (Even so the clinical need of a non-donor patient is never overruled, in compliance with ethics underpinning the

transplantation practices). The same contradictory behaviour has been integral to many societies, including the UK, constantly struggling to meet the ever growing demand for transplantable organs and improve consent rates. The resistance found in the Jewish majority society for decades before the law was changed is conspicuously similar to the cultural and religious barriers defining BAME's response to organ donation in the UK. Most minority communities are reluctant to change their perceptions about donation even though they desperately depend on others in the society to donate organs just so they can receive life-saving transplants.

In this context, Israel's successful experiment with introducing incentive or point-based system offers a rich source of experience, data, and outcomes for the UK to examine and learn from. While the UK government's decision to move towards an Opt-out system is well-intentioned, the model can only go so far without actually addressing the root cause of cultural barriers, especially those found amongst the BAME communities. On the contrary it may in fact completely fail to replicate the same extraordinary results as Spain, the inspiration for most countries to adopt presumed consent.

In comparison with the Reciprocity model the Opt-out system has two fundamental flaws. First, driven by their belief system the BAME can still choose to opt-out and yet still be able to receive organs should they need them under the presumed consent model. The Opt-out system by design does not provide them with any incentive or constant positive reinforcement to consider organ donation. Secondly, the system will not influence outcomes in any way that are different from the status quo under the current Opt-in system. The version of Opt-out being considered in the UK, and already implemented in Wales in 2015, still places the final decision in the hands of the family at the time of brain death. In other words, the family of a BAME person will still be able to refuse donation even if the person chose not to opt out of the register when alive. The outcome will not be different from the status quo, thereby, completely rendering the change in system unnecessary. Unless the change in law is matched with a change in unfavourable beliefs, attitudes and positive family conversations the organ donation rates in the BAME are not likely to change.

The point-based system, on the other hand, provides a strong motivation for considering organ donation. The decision then not only benefits the person but their first degree relatives too, thus making sure the choice to register as a donor is well thought out and deliberate. The model has also provided positive reinforcement in support of organ donation, first through the two initial waves of intensive mass media campaigns preceding the adoption of law, and secondly, via annual publication of transplant numbers (similar to NHSBT's annual transplant activity report) including those who received priority based on their donor status over non-donor patients. Each year the publication acts as a constant public reminder of the merits associated with becoming a donor. In 2017, nearly 37% patients were moved up the transplant list and received life-saving organs based on their donor status. Members of the ultra-orthodox Haredi Jewish sect still reject the idea of brain death and have chosen not to sign up the donor register. As a consequence, the patients from the sect have pushed down to the bottom of the transplant lists. There is, nevertheless, a wide acceptance of this decision in the community, with some members describing it as their chosen will. However, their non-donor status does not bear any impact on the clinical criteria of allocation of organs, meaning they can still receive life-saving transplants before a designated donor patient.

The results since the priority law was adopted have been extraordinary. The constant rise in donations year on year is a direct consequence of the mass appeal and the change in law subsequently disadvantaging the free-riders. It reflects a complete transformation of a society that could not for decades overcome the deeply entrenched religious and cultural taboos surrounding donation of organs.

The Israeli priority law has also made provisions to remove any disincentives to altruistic living donations, in the same fashion as Qatar. Incentives offered by the point-based Reciprocity model to living donors include reimbursement of lost earnings for 40 days based on the donor's average income (average market salary in the

case of unemployed donors), transportation costs, health insurance and other medical costs related to donation.

In India, Fortis Healthcare ceases all billing once a family makes the decision to donate organs. Often the entire medical bill is waived off as a goodwill gesture and to show support to the grieving family. In the U.S. living kidney donors are given priority on the waiting list in case they need a transplant in future.

Incentive does not need to be a dirty word. Incentivising organ donation can correct the imbalance between takers and givers in a society, where a few weeks or months longer on the waiting list for organs can mean the difference between life and death. It can force the conservative communities to re-examine their priorities and rationality of their choices, thereby nudging them towards the greater good. Based on the findings from Israel, the UK is more likely to benefit from adopting the Reciprocity model and incentivising organ donation rather than embracing Opt-out, and achieve better consent rates across all ethnicities and racial groups.

5 | Conclusion and Recommendations

Since 2008 the UK has made a steady progress on improving its rate of organ donation. A greater number of people in the country are now aware of the importance of saying yes to donating organs after death. The gradual rise, responsible for saving more than 50,000 lives in the country, can be attributed to longstanding commitment and efforts by multiple stakeholders and policy makers. In that respect NHSBT's diligence and relentless pursuit to achieve an ever greater number of deceased organ donations through better practices each year is worthy of praise and recognition. In 2017-18 the agency recorded 1413 number of deceased donors, the highest ever in the UK. In the same period the organ donor registry added over a million people and the overall consent rate went up to 63%.

Despite this progress organ donation rates among the BAME groups have been consistently low. While most of the policy and public awareness initiatives have been successful with white majority population, the strategies targeting minority populations have not yielded satisfactory results. Considering their overrepresentation on the transplant waiting lists the minorities' resistance to donate organs remains a big hurdle to achieving better authorisation rates overall and preventing hundreds of unnecessary deaths each year.

This Fellowship examined and scrutinised organ donation programs in Qatar, Israel, India and the U.S, where similar challenges to organ donation amongst the ethnic groups have been addressed successfully. The research offered a number of valuable lessons on how best to devise strategies that engaged ethnic populations effectively, addressed their cultural and religious barriers, nudged them towards family conversations about organ donation and helped them adopt better lifestyle to reduce the need for transplantation in the first place. Some of the best practices to emerge from the researched countries also highlighted the value of working with young adults and adolescents, engaging with cultural icons, allowing communities to build ownership and incentivising donation in the society through an arguably more equal and fairer system of allocation of organs for transplantation.

Based on the 18-month long research and findings from the four countries this report makes the following recommendations to improve BAME consent rates in the UK.

- Policy makers and nodal agencies must overhaul their strategy and devote greater time and resources towards longer and sustained public education programs designed for minority populations. Grassroots organisations representing or working with ethnic communities must be allowed a greater role in tailoring and implementing outreach programs, and building community ownership. A multi-level evaluation system must be adopted to assess progress and outcomes of the programs, and strategies recalibrated as necessary.
- Strategies and data collection methods targeted at BAME must be revised to differentiate and capture culture-based blind-spots. NHSBT must distinguish and record ethnicities along their cultural and national identities as well as respective religious faiths in order to identify specific barriers and gaps, whether in knowledge or outreach, for optimising program outcomes.
- NHSBT must incorporate events and opportunities that facilitate public acknowledgment of BAME donors and families. The events, organised locally or regionally, can be a part of community celebrations and organ donor registration drives, and must be given adequate exposure through social and traditional media.

- Public awareness programs should be geared towards behaviour change rather than just creating awareness. Equal emphasis must be placed on disease prevention in BAME communities to reduce the number of patients needing a transplant, which in turn can bring down the overall costs of renal management therapies such as dialysis, transplantation costs, and post-operative costs for both donors and recipients. The Department of Health must allocate more resources to roll out programs like the Peer Educator Model, with already proven successful outcomes, across BAME communities to promote healthier lifestyle.
- Stakeholders must spend adequate time and resources to assess the suitability of Opt-out model as well as examine the success of alternative programs such as Reciprocity model before adopting presumed consent. The decision to adopt Opt-out must not be made without giving due consideration to alternative models that are better suited to its demographic and ethnic diversities and the resistance to organ donation inherent to them. In particular, the stakeholders must examine the evidence and data from Reciprocity Model as practiced in Israel before making an informed policy decision.
- NHSBT must seek partnerships with cultural icons and celebrities sharing ethnic ties for optimising awareness drives, and actively push for a greater uptake of its educational program designed for children in schools across the country. The nodal agency must also seek partnership and knowledge sharing with organisations like MOTTEP.

About Author

Nishtha Chugh is an award-winning global development journalist and has reported from eight countries across Africa, Europe, the Middle East, South Asia and North America. Her work has been published in The Guardian, Al Jazeera English, BBC World Service, Forbes, Channel 4 News, Africa News, The Dhaka Tribune, The Indian Express, and Open Democracy among others. In 2014, Nishtha worked on a BBC documentary highlighting the link between low organ donation rates amongst UK's minority communities and organ trafficking in South Asia. In 2015 her investigative news-feature about organ traffickers in India and Sri Lanka was published on Al Jazeera English Online. This volume of work became the basis for Nishtha's Churchill Fellowship in 2016, allowing further research in Qatar, Israel, India and the U.S. She remains committed to the cause of creating awareness about organ donation in conservative communities in the UK and overseas.

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