

# A STUDY OF THE DECEASED ORGAN DONATION ENVIRONMENT IN DELHI/ NCR



**ORGAN India**  
an initiative of the Parashar Foundation

in partnership with



**MOHAN**  
FOUNDATION

(Multi Organ Harvesting Aid Network)

Research Agency - **OUTLINE India**



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## ORGAN India: an initiative of the Parashar Foundation

The Parashar Foundation was set up in 2000 by Ashok Parashar, with the aim of helping the poor and less fortunate by providing funds to various schools, health centers and other organisations. While our previous work primarily involved donating to various causes, we commemorated the 7th death anniversary of Ashok Parashar by establishing a specific goal - to create widespread awareness on organ donation in Delhi, which will benefit all those in need, regardless of religion, age, sex, caste, or social standing. This focus gave birth to **ORGAN (Organ Receiving & Giving Awareness Network) India, an initiative of the Parashar Foundation.**

### Our mission is:

- **To increase the number of donor pledges in Delhi through large-scale information dissemination and a massive media awareness campaign about the benefits of organ donation in the case of brain death.**
- **To facilitate the development of an organ sharing network connecting all hospitals in Delhi.**

This initiative stems from the personal struggle of Kirti Parashar, Ashok Parashar's wife, who suffered from cardiomyopathy, and needed a heart transplant. She was unable to find a heart in Delhi due to the lack of an organised donor system in the region which made the wait indefinite. She then moved to Chennai, which has a well-organized system, and received a heart in four months. She could afford to move, but the common man in Delhi cannot. ORGAN India strives to ensure that the common man does not have to suffer this plight.

Apart from commissioning this much needed research on the problems facing the facilitation of organ donation in Delhi/NCR, and what needs to be done to overcome them, ORGAN India has reached out to many organizations who are now helping us to raise awareness on organ donation across Delhi. We have partnered with the MOHAN Foundation to spread awareness across Delhi/NCR. We have also collaborated with advertising agency Wieden & Kennedy, which has created an ad-campaign on organ donation pro-bono. PVR and DDB Mudra have graciously created a media plan for this ad-campaign. We have also reached out to Universal Records to create a music video on organ donation, and we have already created a film on Brain-Death which has been given to hospitals and NGO's across India to help them with counselling people. We are currently creating testimonial films on organ donation.

We sincerely hope that this effort transforms Delhi and the Nation Capital Region into one of the leading organ donation regions in India, and that in the near future, its residents do not have to move cities in search for an organ donor.

## MOHAN Foundation

The MOHAN (Multiple Organ Harvesting Aid Network) Foundation is a Non-Governmental Organization established in Chennai in 1997, which takes up deceased Organ donation as its focal issue to counter the growing demand for organs by patients living with end stage organ failure. The Organization facilitates this with the help of a group of extensively trained and passionate Transplant Coordinators who effectively counsel families in hospitals to encourage them to think about organ donation and save other lives in their moment of grief and loss. The organization works closely with hospitals to increase organ donations.

The organization's activities cater to a specific set of Objectives.

### **Initiating Public Education Programs to promote Awareness**

There is very little public awareness around organ donation. In the absence of fact based knowledge and understanding, people harbour many myths and misconceptions. The Foundation regularly conducts public awareness programs for corporate employees, students, medical professionals etc.

### **Networking with Hospitals to enable Donations to occur**

The Foundation has been successfully creating liaisons with hospitals to help lay down Standard Operating Procedures and guidelines for successfully carrying out a Deceased Organ Donation and Transplantation Programme within the hospital.

### **Training Transplant Coordinators in counselling families of the deceased for enabling more donations**

The Organization has been training Transplant Coordinators who undertake the challenging task of speaking to grieving families of potential organ donors to encourage them to look at donating the organs to save the lives of many others. These transplant coordinators are placed in hospitals which the Foundation is working with. They sensitize the Para-medical staff, conduct activities both within and outside the hospital to generate awareness and most importantly coordinate the entire work of donation if the family consents.

### **Liaising with Government bodies to pass favourable legislations that augment Organ donations**

The Foundations' on-going efforts have been to liaise with Government at the Centre and at the State level. It has been a catalyst in making a few amendments to the existing Transplantation of Human Organs Act, 1994. The Foundation is on the advisory board of "Cadaver Transplantation Coordination Committee" initiated by Government of Tamilnadu and Andhra Pradesh.

Since its inception in Chennai in 1997, the Foundation has set up offices in Hyderabad, Vizag, Jaipur, Cochin, Coimbatore, Bangalore, Nagpur, Chandigarh etc. The New Delhi office was set up in 2011.

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## I. Introduction

Organ donation has been slow to take off in India. In the northern states the pace has been disturbingly sluggish.

More alarming is the glaring absence of any attempts to understand the reasons behind this failure. Research is little. Documents and data which highlight the problem are scarce.

Recognising these dire circumstances, ORGAN India, an initiative of the Parashar Foundation joined hands with the MOHAN Foundation in Delhi & the National Capital Region to commission this report.

When this project was commissioned, the team had difficulty gathering even the bare minimum background information that was needed. Most figures on all aspects of organ donation vary and are mostly guess estimates. This research is a result of interviews with stakeholders, information from hospitals & transplant centres, and information available in the media and online.

We hope that this report motivates and inspires further studies which will improve our understanding and enable wider acceptability of organ donation by our society.

## Objectives

- Understand the organ donation and transplant environment in India with focus on historical trends, challenges faced and scope for change.
- Make recommendations for an effective and functionally efficient organ donation and transplant system in Delhi/NCR

## Scope of Research

- Analyse the current organ donation and transplant environment – facts, trends, processes, opportunities and challenges.
- Conduct extensive research around historical developments, efforts made and lessons learnt.
- Understand the global systems and success stories in the field.
- Recommend action plan/future strategy for growth and effectiveness in Delhi-NCR and India.

## II. Organ Donation and Transplantation in India – Where we are

### Macro Trends & Statistics

India's first organ transplant was conducted in the 1970s (It was a kidney transplant)<sup>1</sup>. India has made a few strides forward since but a lot more needs to be done:

- The number of transplants done annually has been gradually rising
  - Currently around 5,000 kidneys, 1000 livers and around 15 hearts are transplanted annually<sup>2</sup>.
- There is a poor Organ Donation Rate – 0.26 per million in India, compared to some of the better performing countries such as America's 26, Spain's 35.3, and Croatia's 36.5 per million respectively.
  - With a 1 per million-donation rate, India would have 1,100 organ donors or 2,200 kidneys, 1,000 hearts, 1,100 Livers, 1,100 Pancreas and 2,200 Eyes. This should take care of almost all current demands for organs.
  - At a 2 per million-donation rate there would be 2,200 organ donors and the above figures would double. Then there would be no necessity to undertake living kidney donations.
- Quantifying the problem - There is a need of roughly 200,000 kidneys, 50,000 hearts and 50,000 livers for transplantation each year<sup>2</sup>.

### Processes and Regulations

- Organ Transplantation falls under the Ministry of Health and Family Welfare, Government of India.
- The Indian Government passed the Transplantation of Human Organs Act in 1994, clearly highlighting the procedures and regulations to be followed for organ donation and transplantation. The same has been amended/modified periodically.

- However, health is a State subject in India. Hence, all states have their own departments undertaking the policy formulation with respect to Organ Transplantation.
  - o The implementation of the Act discussed above, happened at different points across different states.
  - o States like Goa and Maharashtra adopted the Act in February 1995, while states like Orissa and Uttar Pradesh took around 4 years to adopt the Act in mid-1998.
- There is a clear disparity between the Government and Private Hospitals in terms of infrastructural support needed and presence of trained personnel to carry out the organ transplant.

### **Brief Overview of the Current Scenario and Future Outlook**

- There is a lack of awareness among people with regards to deceased organ donation, the concept of brain death and the process of organ transplantation.
- NGOs and a few State Governments have taken significant steps to create awareness.
- There is a lack of clarity within the medical fraternity with regards to the rules and procedures related to organ transplantation.
- Absence of a centralized agency to maintain a registry of donors as well as recipients, and ensure maximum utilization of organs, as well as their fair and equitable allocation.
- Strong need for developing a centralized organ-sharing network among hospitals for better coordination, timely utilization and avoiding organ wastage.

### III. Processes and Procedures

#### Pledging Organs by a living/deceased person

Any person willing to donate<sup>5</sup> his/her organs can do so by filling out the donor consent form available on the Ministry of Health and Family Welfare, Government of India website ([www.mohfw.nic.in/](http://www.mohfw.nic.in/))

- a. This is a voluntary act.
- b. The donor may also approach a transplant center or other organ donation organisations for a donor card.
- c. The decision to donate organs could also be done by the lawful custodian of the body after the death of the patient.

**Note:** The organ donor card is not a legal document. It is only an expression of a person's willingness to be a donor. In India, at the time of organ donation, the family of the patient will make the final decision on whether to donate organs or not.

#### Procedure for donating & transplanting organs

Any organ donation process must involve the following steps<sup>5</sup> before the actual transplant can occur:

- a. Panel of 4 doctors need to declare the brain death twice in a span of 6 hours. 2 of these doctors must be from a panel approved by the government. This panel includes:
  - i. Registered Medical Practitioner in charge of the Hospital where brain stem death has occurred.
  - ii. Registered Medical Practitioner nominated from the panel of names sent by the hospitals and approved by the Appropriate Authority.
  - iii. Neurologist/Neuro-Surgeon (where Neurologist/Neurosurgeon is not available, any Surgeon or Physician and Anaesthetist or Intensivist, nominated by Medical Administrator In-charge from the panel of names sent by the hospital and approved by the Appropriate Authority shall be included.
  - iv. Registered medical practitioner treating the aforesaid deceased person. The same is recorded on Form 10 of the THO Act 2014. The family's consent is obtained on Form 8.

- b. Healthy organs are transplanted from the body of the patient as soon as possible.
  - i. Heart and lungs are the most sensitive organs, and must be transplanted within four to six hours of retrieval.
  - ii. Liver and pancreas must be transplanted within 12 hours and kidneys within 24 hours of retrieval.
  - iii. In the interim, all organs are stored at 4°C (in a special preservative solution stored in an ice-filled chamber) to help with preservation.
- c. No payment is made to the donor family, and the recipient is not charged for the organs per se. They of course have to pay the transplantation costs of the hospital. All billing for the donor family stops from the time that they give consent for organ donation.
- d. In special medico legal cases, to declare a person dead and to proceed with organ donation, a post-mortem is required. Therefore, there is an additional requirement of a police representative and a forensic person to examine and approve of the process.

## IV. Laws and Rules Governing Organ Transplantation in India

The primary legislation related to organ donation and transplantation in India, Transplantation of Human Organs Act, was passed in 1994 and is aimed at regulation of removal, storage and transplantation of human organs for therapeutic purposes and for prevention of commercial dealings in human organs.

In India, matters related to health are governed by each state. The Act was initiated at the request of Maharashtra, Himachal Pradesh and Goa (who therefore adopted it by default) and was subsequently adopted by all states except Andhra Pradesh and Jammu & Kashmir. Despite a regulatory framework, cases of commercial dealings in human organs were reported in the media. An amendment to the act was proposed by the states of Goa, Himachal Pradesh and West Bengal in 2009 to address inadequacies in the efficacy, relevance and impact of the Act. The amendment to the Act was passed by the parliament in 2011, and the rules were notified in 2014. The same is adopted by the proposing states and union territories by default and may be adopted by other states by passing a resolution.

### **The main provisions of the Act (including the amendments and rules of 2014) are as follows:**

- a. Brain death identified as a form of death. Process and criteria for brain death certification defined (Form 10 )
- b. Allows transplantation of human organs and tissues from living donors and cadavers (after cardiac or brain death)
- c. Regulatory and advisory bodies for monitoring transplantation activity and their constitution defined
  - i. Appropriate Authority (AA): inspects and grants registration to hospitals for transplantation enforces required standards for hospitals, conducts regular inspections to examine the quality of transplantations. It may conduct investigations into complaints regarding breach of provisions of the Act, and has the powers of a civil court to summon any person, request documents and issue search warrants.
  - ii. Advisory Committee: consisting of experts in the domain who shall advise the appropriate authority
  - iii. Authorization Committee (AC): regulates living donor transplantation by reviewing each case to ensure that the living donor is not exploited for monetary considerations and to prevent commercial dealings in transplantation. Proceedings to be video recorded and decisions notified within 24 hours. Appeals against their decision may be made to the state or central government.
  - iv. Medical board (Brain Death Committee): Panel of doctors responsible for brain death certification. In case of non-availability of neurologist or neurosurgeon, any surgeon, physician, anaesthetist or intensivist,

- nominated by medical administrator in-charge of the hospital may certify brain death.
- d. Living donors are classified as either a near relative or a non-related donor.
    - i. A near-relative (spouse, children, grandchildren, siblings, parents and grandparents) needs permission of the doctor in-charge of the transplant center to donate his organ.
    - ii. A non-related donor needs permission of an Authorization Committee established by the state to donate his organs.
  - e. Swap Transplantation: When a near relative living donor is medically incompatible with the recipient, the pair is permitted to do a swap transplant with another related unmatched donor/recipient pair.
  - f. Authorization for organ donation after brain death
    - i. May be given before death by the person himself/herself or
    - ii. By the person in legal possession of the body. A doctor shall ask the patient or relative of every person admitted to the ICU whether any prior authorization had been made. If not, the patient or his near relative should be made aware of the option to authorize such donation.
    - iii. Authorization process for organ or tissue donation from unclaimed bodies outlined.
  - g. Organ retrieval permitted from any hospital with ICU facility once registered with the appropriate authority. Any hospital having Intensive Care Unit (ICU) facilities along with manpower, infrastructure and equipment as required to diagnose and maintain the brain-stem dead person and to retrieve and transport organs and tissues including the facility for their temporary storage, can register as a retrieval center.
  - h. Cost of donor management, retrieval, transportation and preservation to be borne by the recipient, institution, government, NGO or society, and not by the donor family.
  - i. Procedure for organ donation in medico-legal cases defined to avoid jeopardizing determination of the cause of death and delay in retrieval of organs.
  - j. Manpower and Facilities required for registration of a hospital as a transplant center outlined.
  - k. Infrastructure, equipment requirements and guidelines and standard operating procedures for tissue banks outlined.
  - l. Qualifications of transplant surgeons, cornea and tissue retrieval technicians defined.
  - m. Appointment of transplant coordinators (with defined qualifications) made mandatory in all transplant centers.
  - n. Non-governmental organisations, registered societies and trusts working in the field of organ or tissue removal, storage or transplantation will require registration.
  - o. The central government to establish a National Human Organs and Tissues Removal and Storage Network i.e. NOTTO (National Organ &

Tissue Transplant Organisation), ROTTO (Regional Organ & Tissue Transplant Organisation) and SOTTO (State Organ & Tissue Transplant Organisation). Website [www.notto.nic.in](http://www.notto.nic.in). Manner of establishing National or Regional or State Human Organs and Tissues Removal and Storage Networks and their functions clearly stated.

- p. The central government shall maintain a registry of the donors and recipients of human organs and tissues.
- q. Penalties for removal of organ without authority, making or receiving payment for supplying human organs or contravening any other provisions of the Act have been made very stringent in order to serve as a deterrent for such activities.

**The various forms outlined in the rules are as follows:**

- Form 1: Near-relative consent
- Form 2: Spouse consent
- Form 3: Other than near-relative donor consent
- Form 4: Psychiatrist evaluation of the donor
- Form 5: HLA DNA profiling report
- Form 7: Self consent for deceased donation
- Form 8: Consent for organ donation from family (also applicable for minors)
- Form 9: Consent for organ donation from unclaimed bodies
- Form 10: Brain death declaration form
- Form 11: Joint transplant application by donor / recipient
- Form 12: Registration of hospital for organ transplantation
- Form 13: Registration of hospital for organ retrieval
- Form 16: Grant of registration
- Form 17: Renewal of registration
- Form 18: Decision by hospital authorization committee
- Form 19: Decision by district authorization committee
- Form 20: Verification of Domicile for non near-relative
- Form 21: Letter from Embassy

## V. Challenges in Organ Transplantation – India

### A. Systemic issues

- a. In spite of periodic amendments to the Organ Transplant Act in the recent past, there has not been a significant change or increase in the overall donation numbers or to the establishment of a donation system within the country (apart from a few states, discussed later).
- b. In the case of living organ donations (from a living donor to a recipient), if the donor is not related to the patient, the transplant needs to be approved by a state-level committee or hospital committee, including government officials. Naturally these requirements lead to delays in the whole process.
- c. In the case of deceased organ donations, few hospitals declare brain deaths and people are not in place to counsel families, both of which lead to a poor conversion rate. Brain death as a form of death is not widely understood or recognized by the public. Also there is hesitation on the part of the medical fraternity to certify brain death. This has to change if the organ donation rates have to be increased.

### B. Infrastructural and skilled Personnel problems

Few hospitals are equipped in terms of the required personnel (qualified doctors and trained transplant coordinators) and equipment to conduct a successful transplant.

- a. Ventilators for maintaining brain dead persons are not available everywhere. Limited facilities for transport of donated organs aggravate the situation. Very few specialized private hospitals can boast of standard infrastructure for carrying out a smooth organ transplant process. The situation worsens in case of public hospitals, which account for witnessing majority of such cases.
- b. Lack of training for intensive-care unit personnel to maintain brain dead person, is also a constraint according to a number of doctors surveyed in our study.
- c. A big percentage of doctors are unaware of the process as a whole and

about the idea of brain death since it is not part of their formal education curriculum (as told by a respondent).

### **C. Lack of awareness, religious and other issues.**

Lack of awareness remains one of the leading reasons for such low organ donation rates in India. There are no structured/focused awareness initiatives or drives to help people understand the what, why or how of organ donation. While some NGO's are making efforts, these are at best – drops in the ocean.

It is a usual refrain that people in India do not sign up for organ donation, but in reality there are hardly any platforms available for 'sign up'. Most people have never been offered this opportunity in their life time. Many don't know where to go even if they are aware and willing.

Religious beliefs also may be a reason why families do not agree to deceased organ donation. The idea of charity and perceptions about donation varies from one community to another. The religious mindset together with the unpleasant experiences in the health sector faced by people is detrimental to the improvement of the organ transplant scenario in India.

An assurance about the system that these organs will be utilized for good and not be a commoditized in the organ market (more so in the black market rackets) may encourage organ pledges.

The idea of a commodity and charity are viewed as distinct and the donor/donors family would not want their charity to be a monetary gain for someone else.

### **D. Lack of a centralized registry for Organ Donation unlike other countries**

India does not have any centralized system in place to enable/assist donors or medical institutions. There is no centralized list of potential recipients being available to different hospitals so that organs could reach the right people in time. Apart from a few states, there is no sharing protocol in place in the rest of India. This leads to unethical and unhealthy practices. Further, it leads to wastage of organs which is a shame when a family has taken this courageous decision to donate.

## E. Expectation of the possibility of organ rejection

Certain studies reveal that technically there is always a possibility that the patient might face a rejection, wherein the body fights off the newly implanted organ even if the surgery goes well. Rejection is harmful to transplant success because the body fights off the new organ as if it were a virus or bacteria akin to any other harmful foreign invader. The immune system makes proteins called anti-bodies that go to the transplanted organ and try to kill it.

In order to hold back the antibodies that threaten the new organ, transplant patients have to take powerful additional immunosuppressant drugs to keep the level of antibodies down, low enough to allow for the organ to integrate into the body.

In India where health services are seemingly expensive for the average person, the ability to afford a transplant operation is beyond the common man's means, especially at a private hospital. The added risk that the organ may not benefit the patient is a negative add-on. Therefore, a majority of patient and patient parties back out due to the uncertainty quotient clubbed with the amount of financial drain out it leads to. This is also in certain ways connected to the fact that health insurance in India still does not have a good enough reach. Most people are not even aware of how they could arrange funds. Cumulatively, it leads to discouragements in a number of ways.

## VI. Brain Deaths and Deceased Organ Donation & Transplantation – Myths and Facts

### What is Brain Death and Deceased Organ Donation and Transplantation?

A person is said to be brain dead<sup>7</sup> when there is an irreversible loss of consciousness, absence of brain stem reflexes and no spontaneous respiration. Patients classified as brain dead can have their organs surgically removed for organ donation.

A brain death results from a severe irreversible injury to the brain or hemorrhage which causes all the brain activity to stop. All areas of the brain are damaged and no longer function due to which a person cannot sustain his/her own life, but vital body functions may be maintained by an artificial support system. This maintains circulation to vital organs long enough to facilitate organ donation.

In this situation, when the heart is still beating artificially, it makes the acceptance of brain death extremely hard, especially since the concept is unknown to many. Lack of clarity makes the already emotional family unwilling to accept death.

The common belief that the soul remains as long as the heart beats makes the family skeptical about the intentions of the hospital. They feel that it is either due to the lack of motivation on the part of the hospital to continue with the treatment or the hospitals involvement with an illegal organ racket, which is pushing them to declare brain death.

Ideally, after brain death several organs can be retrieved, like heart, liver, kidneys, lungs, pancreas, tissues, eyes, intestine and the small bowel.

**Note:** **Organ donation** is the surgical process of providing one or more organs to be used for transplantation into another person. Organ donors can be deceased or living. **Transplantation** is the process of surgically transferring a donated organ into a patient with end stage organ failure.

Giving an organ = Donation

Getting an organ = Transplantation

### Organ Transplantation Procedures for Brain Death - India

According to the provisions of the Transplantation of Human Organs Act<sup>1</sup>, known as THOA, the protocol for declaration of brain death requires:

- a. Two certifications 6 hours apart from doctors
- b. Two of the doctors examining the condition have to be practitioners nominated by the appropriate authority of the government (discussed before).

## Myths and Facts around Brain Death

### Myth-1 - What if I recover from brain death?

**Fact** – It is not possible to recover from Brain Death. A brain death person is not suffering from Brain Death. He/She *is* dead.

### Myth-2 – How do they know I am really dead?

**Fact** –The medical fraternity follows very strict standards to determine if a person is brain dead or not. In India, a panel of 4 doctors has to declare you brain death before your organs can be harvested. This panel will do so only after a series of exhaustive tests which are repeated twice.

### Myth-3 – How could the organs of a brain dead person be used? The person must have some life for the organs to be usable.

**Fact** - All cells run on electrical energy. The oxygen we breathe is carried to every cell in our body, where it helps the cells in extracting energy. So long as oxygen and glucose are available to the cells, even if the brain has stopped functioning, the cells perform their function.

### Myth-4 – Is Brain Death the same as coma?

**Fact** –No. Coma is a state of deep unconsciousness, where the brain continues to function and the person can breathe on his/her own, without the help of a ventilator. Brain activities can be seen through various tests. Thus the brain still has the capacity to heal, and the person can come out of coma. Brain death results from such severe injury (like a roadside accident or a stroke) that the damage is permanent and all functions of the brain stop totally. Brain death is death.

## Insights from the fieldwork pertaining to the declaration of brain death:

- According to the viewpoint shared with us during primary research, collectively by a number of medical practitioners, the process is much simpler and less bureaucratic in the current times. For example, the second condition mentioned above can be relaxed in most cases, with the discretion of the doctors handling the case in order to enable timely transplant process.
- In India, declaration of brain death requires just the documentation of irreversible loss of brainstem function, while in countries like USA, it is necessary to document absent function of all parts of the brain before the declaration of brain death<sup>9</sup>.
- According to law, doctors are required to take the family members' consent before retrieving organs<sup>8</sup>, even if the brain-dead patient has pledged his or her organs. After the Transplantation of Human Organs Amendment Act, 2011 was implemented, the treating physician now has to examine the patient for being brain dead and if found so, he/she must sensitize and make the family aware about organ donation.

## VII. Organ Wastage in India

Medical Science has made tremendous progress in recent times in the field of transplant surgeries and operations, with organ donation from one person after brain death capable of saving up to 9 lives and improving the lives of many others.

However, due to the prevalence of myths surrounding brain death and the lack of awareness in India, majority of people do not take up this noble cause for the benefit of others.

According to medical practitioners, kidney, a part of the lung, a part of the liver, blood and bone marrow can easily be transplanted while the person is alive. But in deceased organ donations (after brain death), more organs and tissues such as the heart, pancreas and cornea can be transplanted if the patient is on the ventilator till the organs are extracted.

Following statistics<sup>10</sup> are alarming in the Indian context:

- a. The total number of brain deaths due to accidents is nearly **1.5 lakhs annually**. Other causes of brain death such as sub-arachnoids' hemorrhage and brain tumors would potentially add more numbers.
- b. There is a need of **2 lakh kidneys, 50,000 hearts and 50,000 livers** for transplantation every year. Even if 5-10% of all brain deaths are

harvested properly for organ donation, technically there would be no requirement for a living person to donate organs.

- c. One person dies of kidney failure every 5 minutes. This amount to roughly **290 deaths every day** due to kidney failure. These numbers suggest that with adequate systems in place, people succumbing to accident-prone injuries could meet a major portion of the demand.

In light of the number of brain deaths that probably take place every year; the number of donations in comparison are abysmally low. This is because most brain death cases go unrecognized and therefore uncertified. This wastage could be prevented by mandating certification of brain death.

In addition, hospitals need to have well-trained personnel who can effectively identify, certify and maintain brain dead patients for organ retrieval to take place. Trained transplant coordinators are an absolute must to counsel families in grief and help them to think about organ donation to save other peoples' lives.

The situation of organ wastage is the most severe in case of hearts. In a recent study<sup>11</sup> conducted in January 2013, it was found that **only 17% of hearts received were used by surgeons** in the state of Tamil Nadu in 2012, according to Tamil Nadu organ transplant registry Convener Dr. J. Amalorpavanthan. The registry received organs from 306 brain dead patients and allotted them to different hospitals based on a waiting list. While 280 livers and 563 kidneys were retrieved for transplant, only 52 hearts and 13 lungs were harvested. The reason for the same was poor coordination among transplant surgeons causing delay in retrieval.

## VIII. Additional Organ Transplant Insights from Primary Research – India

A team of researchers contacted Senior Medical Officers/Doctors at 24 of the top hospitals/research centers in the Delhi/NCR region to gather information about the latest organ transplantation system in India of which 16 responded (In two cases, 2 interviews were conducted at two branches of the same group of hospitals, amounting to a total of 18 interviews overall, across 16 institutions).

Presented below are some of the most interesting insights from the responses Gathered:

**Note: All instances when the respondent could not answer have been excluded from the universe of the sample data. The responses are therefore not incorporated into the graphs.**

### A. Making brain death declaration easier

Today, most of the hospitals face problems conducting deceased organ donation transplants. The primary reason identified for the same is lack of awareness among the patients' near relatives about the concept itself.

Nearly **60%** of the respondents in the primary research believed that increasing awareness would help tackle the issue.

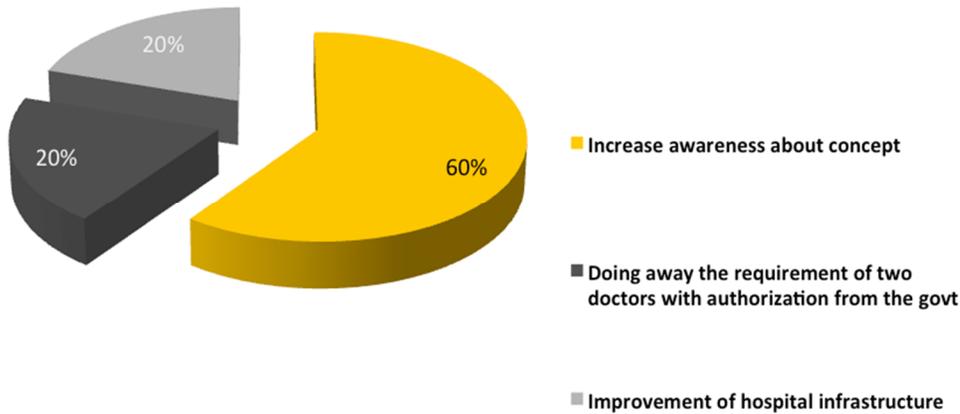


Fig 1: Pie diagram showing changes/steps would make declaration of brain death easier

### B. Making brain death declaration mandatory

Because of lack of awareness surrounding the brain death concept, making the declaration of brain death mandatory is a potential solution. When asked if this would help in increasing organ donations, there was a near unanimous response from the medical fraternity, with **92.3%** respondents agreeing to the fact that if the declaration of brain deaths were made mandatory, it would help in creating awareness and hence, would increase organ donations:

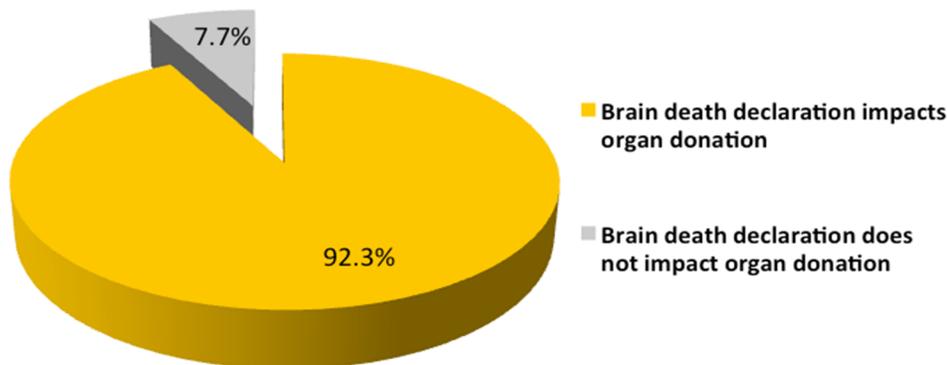


Fig 2: Pie diagram discussing if making brain death declaration mandatory is the way forward

The main reasons for the above, as cited by the respondents are as follows:

- a. If brain deaths declaration were made mandatory, it would facilitate a discussion between the doctor/physicians and the relatives about brain death and organ donations.
- b. It would help other hospital staff like Transplant Coordinators and Personnel from other Departments to intervene and convince the relatives about organ donation.

In terms of deceased organ donation, doctors cited the following reasons *in order of significance* which prevented them from having an effective deceased organ donation program which has been elaborated in the course of the report:

- 1. Lack of awareness among patients and medical staff**
- 2. Lack of counseling given to patients**
- 3. Unavailability of organs**
- 4. Hesitation from patients and their family**

Nearly **83.3%** doctors cited that families did not understand the concept of brain death and hence it was challenging for practitioners to declare brain deaths.

In terms of having a brain death committee, **82.4% doctors** cited that their respective institutions did have an in-house brain death committee.

### **C. Creating awareness about organ donation**

According to some of the prominent doctors in the NCR region, *creating awareness* is one of the most important steps to be taken. This could be done in a number of ways, some of them, in order of priority according to them, are as follows:

- 1. Social Media**
- 2. Celebrity Involvement**
- 3. Organizing Awareness Camps**
- 4. Involving the Government & Public Hospitals**

## D. Improving the current system

There was a clear unanimous opinion among the doctors that the current system is **not** the way forward, with nearly **93.8% doctors** voicing concerns about the same.

As per responses given, a majority of the doctors were of the opinion that significant Government initiatives are required to drive a change in the society.

On the other hand, **28.6%** doctors also believed that better rules and regulations could help change the situation.

A senior transplant coordinator of one of the hospitals who received his training at AIIMS and the University of Cambridge, cited the example of countries such as England, US and Spain where attempts to improve the deceased organ donation

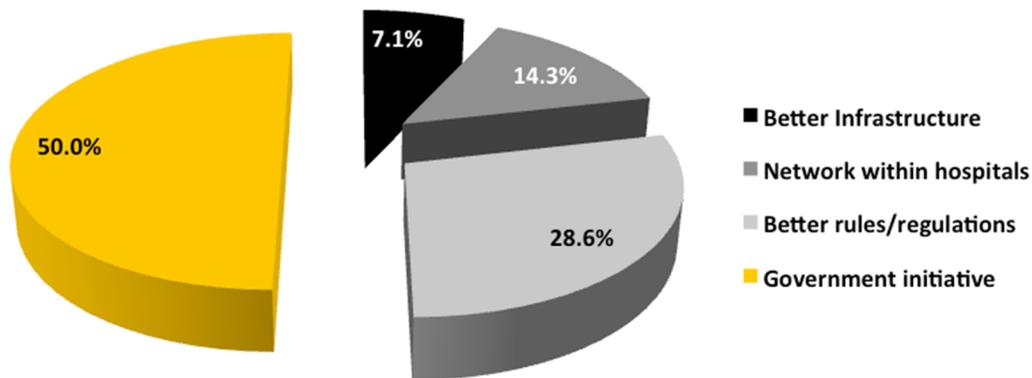


Figure 3: Pie diagram representing opinions about what would improve the current system

scenario is noteworthy. In Spain, the organs of an individual do not belong to the person but to the state. According to him, the infrastructure and the condition of health care in India is so poor that in order to build trust and establish a dialogue between the hospital, the hospital staff and the patient/patient party, first the condition of the health care itself needs to be better. He also said that for every organ, the hospital needs to have separate licenses given by the Directorate of Health Service, Nirman Bhawan, and the presence of the government officials are needed especially in the medico legal cases.

According to another doctor, Health should be a National subject instead of being a State subject. More investment is required from the Government.

Growing the organ sharing network within hospitals and improving the infrastructure were other methods, as cited by them.

### E. Availability & Training of Transplant Coordinators

For both live and deceased organ donation transplantations, **87.5%** of the doctors specified that they had Transplant Coordinators available in their hospitals. Some of the notable hospitals with Transplant Coordinators for both live and deceased organ donation transplants are:

- Medanta, The Medicity
- Army Hospital (R&R)
- Indraprastha Apollo Hospital
- Max Super Specialty Hospital, Patparganj
- Max Saket
- Fortis Research Institute, Gurgaon
- Fortis Flt. RajanDhall, VasantKunj
- Fortis Noida
- Primus Super Specialty
- Sir Ganga Ram Hospital
- AIIMS
- BLK Hospital

The number of transplant coordinators per hospital was 1 in majority of the cases as shown below for both live and deceased transplant cases:

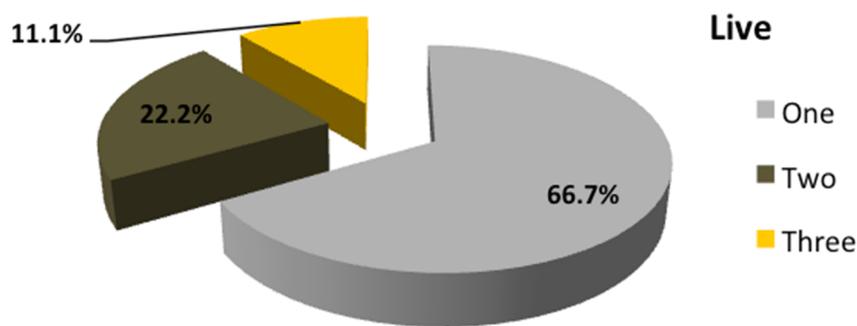


Figure 4: Pie diagram showing the availability of transplant coordinators for live transplants

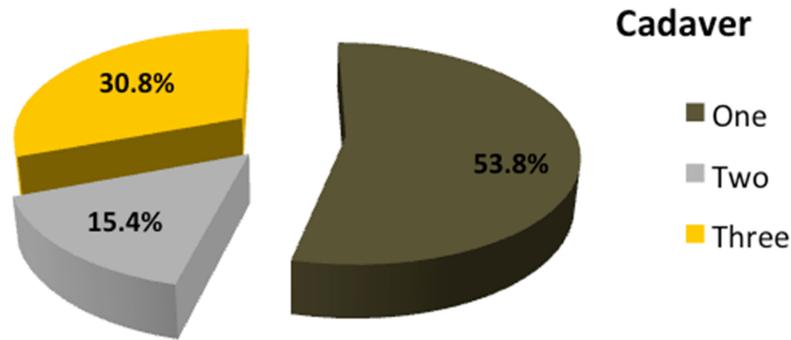


Figure 5: Pie diagram showing the availability of transplant coordinators for deceased organ donation transplants

With respect to the training received, nearly **73.3%** doctors specified that the Transplant Coordinators *are given proper training* regarding the procedures and rules to be followed. This training is imparted in most of the cases (**55.5%**) by NGOs, with the remaining being trained by Government or Private Hospitals.

**Other inputs:** Some respondents stated that the training received is more of an informal process and learnt on the job. By getting involved with the coordination and the legal formalities with the passage of time, the coordinator becomes confident in the job.

One senior doctor however shared that to them, hiring of transplant coordinators is an extremely crucial step, as they are the ones who are directly involved in constantly staying in touch with the patient and the patient’s family. According to him, they should therefore be well trained and at a senior positions at hospitals in order to effectively facilitate deceased organ donation

### F. Transplantation Process Followed

**71.4%** of the hospitals, upon receiving an organ, offered the organ to a patient on their own waiting list. In the remaining cases, respondents mentioned that they contact the nearby hospitals and medical agencies.

**61.5%** hospitals have an existing organ sharing network with other hospitals (primary one being with AIIMS) while others have no such facility.

However, most of the above hospitals either inform the other hospitals **on a random basis or through some NGOs.**

The MOHAN Foundation is one prominent NGO who is an intermediary between hospitals, and is trying to create a sharing network, but the adoption process is extremely slow.

In terms of approach for sharing an organ, hospitals contact Government Hospitals first, with **nearly 2/3<sup>rd</sup>** of the respondents agreeing to that approach while the remaining contact Private Hospitals first.

In terms of the decision regarding the recipient of the organ, the response was *mixed* and hence non-conclusive, with nearly equal proportion of respondents citing the three options – the surgeon taking the call, the Transplant Committee taking the decision, and the organ being offered based on First Come First Served basis:

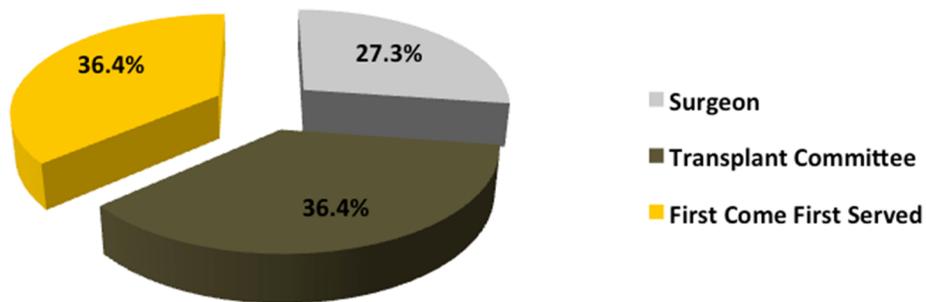


Figure 6: Pie chart showing method followed for organ allocation.

## G. Financial Assistance

In the course of the primary research we were also made aware about the two kinds of funding agencies that assist patients financially with organ transplants.

- a. **Government Funding:** Where the Prime Minister's Office provides funds of Rs. 3 lakhs to patients being treated, in both private and public hospitals. The Chief Minister's Fund and National Illness and Relief fund however, is offered only to patients being treated in public hospitals.
- b. **Non-Government Funding:** Comes from NGOs who offer funds to patients being treated at both public and private hospitals. (discussed in detail later)

## H. Waiting list of patients

In terms of the waiting list for patients, most of the respondents cited this information as restricted. However, for the nearly **50%** cases where the information was available, most of the waiting lists were maintained for **liver and kidney** only.

On average, there were **30-40** people for each hospital, waiting for a kidney or liver transplant across nearly 8 hospitals in the NCR region. Since this information was provided by only 50% of the hospitals, the total number on the waiting list could be somewhere around **700-800** (assuming a total of 20 hospitals with average waiting list of 40 people).

## I. Availability of Ambulances with Ventilators

Nearly **89% of the respondents** cited the availability of ambulances with ventilators. However, the number of ambulances differed from hospital to hospital, with 3 hospitals having 1 ambulance each, 2 hospitals having 2 each, 4 hospitals having 4 to 8 ambulances, while some of the hospitals such as Gangaram had more than 25.

## J. Cost of Transplants

The average cost of the two most commonly transplanted organs among the hospitals in which the fieldwork was conducted are:

1. Liver – 20 to 25 Lakhs
2. Kidney – 2 to 4 Lakhs

We also found out that the government rate for a liver transplant is Rs 14 Lakhs, whereas most of the hospitals charge 6-10 Lakhs more than the government rate.

The data for the other organs transplant operations was not provided to us.

One major private hospital however disclosed that the cost for an intestinal transplant is Rs. 44 Lakhs.

## IX. Doctors' Opinions from Primary Research (As shared with the team)

This section quotes some of the interesting comments we got from the doctors:

- *"Health is a state subject in India. The problem with this model is that some states implement processes vigorously, while others do not. In the field of deceased organ donation Tamil Nadu has the most evolved program with excellent results. There is some state driven activity in Kerala, Karnataka and Maharashtra while in other states it is NGO/individual driven or there is no organ donation at all. The key to organ donation is increasing awareness at all levels. Organs are a national resource and allotment has to be a fair and transparent process"*
  - **Dr. Avnish Seth, Gastroenterologist (Transplant Head), Fortis Memorial Research Institute, Gurgaon**
  - **Director, Fortis Organ Retrieval & Transplantation (FORT)**
- *"Relatives of potential brain-dead donors are reluctant to donate because they do not believe that the patient is dead. This is due to ignorance and lack of trust in doctors"*

**Dr. Prakash Khanduri, Professor at St. Stephens Hospital, Delhi**

- *"Firstly, the concept of organ donation largely is cultural. It has a distinct connection with the cultural perceptions of charity and donation. For example, to people in the Jain community, donating blood or organs or a body is highly acceptable and is not at odds with their religious beliefs. Secondly, it is difficult to declare brain death in India and then talk about organ donation, as the common perception would be that the brain death was declared by the hospital to acquire the organ and make money. Thirdly, it is difficult to communicate and discuss the issue about donation to the family of the deceased because there is a fear of how they might respond to it"*
  - **Dr. Tanmay Pandya, Consultant, DM Nephrology, Primus Super Specialty Hospital**
- *"More work on the awareness front is required. Incentives should be given for organ donation, such as preference to be given to people with an organ donation pledge when requiring an organ"*
  - **Dr. Aman Gupta, Consultant Urology and Kidney Transplant, Fortis VasantKunj, Delhi**

- *“Posters which say “Donate Organs and Save Lives” should be put up at burial places, cremation grounds. The Social and Health Ministries should be involved and appropriate action plan should be prepared for the message to be disseminated through Television and other media”*

**-Dr. S.C. Tiwari, Fortis, VasantKunj, Delhi**

- *“There must be a centrally organized program. India should be divided among different zones with each zone having a Central/Zonal office that could coordinate with the hospitals falling under its ambit”*

**- Dr. P. B. Singh, Director, Institute of Urological Science, Max Super Specialty Hospital, Delhi.**

- *“There is poor infrastructure with regards to deceased organ transplantation in our country, without any centralized system. Poor transportation facilities for accident patients in the extremely congested cities, lack of awareness amongst the people and lack of trust in the fairness of medical system for deceased organ donation are major obstacles to development of deceased donor transplant in our country”*

**- Dr. Vijay Kher, Chairman, Division of Nephrology and Renal Transplant Medicine, Medanta - The Medicity, Gurgaon**

- *“Going by past experience in some pockets of India, it takes 8-10 years of concentrated efforts by a dedicated team (NGO or Govt.) for organ donation, before we can expect a change in the society”*

**- Dr. Ravi Mohanka, Senior Consultant Hepato-biliary and Transplant Surgeon, Medanta - The Medicity, Gurgaon**

### **Key take-away notes from the discussions with the doctors:**

1. Infrastructure needs to be stepped-up. Government hospitals must have the right facilities to conduct organ transplants in a smooth manner.
2. Awareness about the process is the key. Government must come up and take nation-wide initiatives in partnership with NGOs and other national groups. People are willing to donate if they are convinced and made aware.

3. Declaration of brain deaths must be made a simple and straight-forward process without too many bureaucratic hassles for the doctors.
4. Donor cards need to be centralized (using driving license or govt. ration cards)

### Other inputs from the primary research (This section is an anecdotal account, containing insights shared during the fieldwork)

#### 1. The key problems with respect to deceased organ donation:

Public response to deceased organ donation is quite poor in India as suggested by most respondents. In the case brain deaths especially, the first set of problem arises in convincing the patient's relatives before the organ of the deceased can actually be retrieved.

Points to note:

- a. The relatives feel that adequate treatment has not been done, which is probably due to the general perceptions of health care in India.
- b. Due to an over-burden of patients in government hospitals, and infra-structural limitations, the hospital in most cases does not make additional efforts to pursue the matter.
- c. In the case of private hospitals, treatment is so expensive that as soon as the doctors approach the patient's relatives with the proposal of donating the organ, there is unpleasantness. The situation can intensify to the point of vandalism in the hospital, as shared by a consultant at a specialty hospital.
- d. A very senior transplant coordinator from a certain hospital which conducts over 200 transplants in a year said, that unlike what happens in England, where he worked previously, the counseling team (if the hospital has one) here only starts approaching the patients family once the patient is deceased. This is unlike the UK, where the team of counselors builds an informal rapport with the patient/relatives once he/she gets admitted to the hospital. The counselors' work is to enquire about the patient's health progress, and in critical cases, prepare the patient's relatives about the impossibility of the patient's survival (if at all).

With a personal involvement and association early on, the hospital builds up a rapport to be able to approach the patients' family for donation after the patient passes away.

## 2. Decisions on who cannot receive organs:

Based on the primary research here are some of the insights as to what guides the concerned medical practitioners to take a call on who would not get a preference in receiving the organ. These declarations are strictly opinion-based and were shared by some medical practitioners during the interview.

- Patients with terminal cancer.
- Patients with HIV
- Patients with active systematic infection.
- Psychiatric illness.
- The life expectancy of the person is also taken into consideration.
- Elderly who are more than 65 years of age because the chances of them responding positively to organ donation or transplant is low. Although a certain hospital made us aware that this is not really a strict clause as they have performed transplants on people aged above 70 years.

## 3. Pre-transplant evaluation for live donations:

There are certain pre-transplant evaluations, which are done before the transplant happens to get a clearer idea on the individual's health profile. These are:

- a. Tests done to understand if the patient has any urological problem.
- b. Test if blood transfusion is required.
- c. Test for chronic infections.
- d. Psychiatric evaluations are done to understand the patients' mental health.

This also involves laboratory investigations which simplistically saying are the following:

### Stage 1: Blood group of the patient –

- a. HBsAG antigen test, HCV and HIV test
- b. Urine research and monitoring

- c. CMV (Cytomegalovirus) serology
- d. X-ray and Bladder checks.

### Stage 2: Tissue type and PRA (Panel Reactive Antibody)

To decide on who can donate, the following types of donations are allowed (according to the Human Organ Transplantation Act):

- a. Blood Relative, called 'near relative'
- b. Altruistic Donation which is 'non-near relative'
- c. Deceased organ donation

### Stage 3: Donor Investigation-

- a. Determining compatibility in terms of blood group:

RECIPIENT	DONOR
O	O
A	A/O
B	B/O
AB	AB/O/A/B

In case of kidney transplants HLA matching is also done. Now, even blood group incompatible, swapping methods can be used in the case of transplants, wherein the donor and recipient need not be compatible according to the above scheme.

### 4. Forms required in the Donation Transplant process:

We were told that the following are the type of forms that must be filled out as a legal necessity. Both the parties, i.e. the hospital and patient/patient party need to fill up the following forms in order to go ahead with the process of donation:

- a. Donor authorization form
- b. Donor statements of health, giving evidence that he/she is in a condition to donate
- c. In case the donor is a near relative then HLA clearance has to be given by the Genetics lab.

- d. Form required in case of spousal donation.
- e. Forms must be filled out for deceased donors.

5. We were also informed that according to the legal guideline, every hospital is required to have Government registration to declare brain death. Moreover, the Directorate General of Health Service gives authorization separately for each organ. Without having separate registration for each organ, it is illegal to carry out any transplantation within the hospital.

## 6. Pitfalls of the Centralized Registry System in the context of the Delhi-NCR

In case the central government registry system becomes functional there are a few factors which we need to be carefully looked at. Delhi for instance will fall under the central as well as the state domain. Noida and Gurgaon which are part of UP and Haryana respectively will be registered under their respective states. This is likely to generate another level of complication since health is a state subject. Therefore in this case an organ in Medanta will not go to someone in Delhi, but will be routed through Chandigarh to go to somewhere in Haryana. This according to a very senior doctor who was associated in transplantation says that something of this sort will make the process complicated which doesn't make sense. According to him there will have to be intense political negotiations with Haryana and UP governments as to which hospitals fall in which area. At the moment there are no zonal divisions, but only in terms of states.

## 7. In the case of non-transplant hospitals and nursing homes

These medical centers are crucial because a lot of accident victims are taken here for treatment. However these centers aren't equipped adequately as there are no transplant coordinators, no battery-operated ventilators, no ambulances, no way to declare a brain-death or even identify a brain-death. Also, they have no incentive to cooperate right now with the Organ Donation programme. So the pertinent questions are:

- What incentives can the government give to them so as to equally involve them in the organ donation process?
- What facilities can they sanction for these centers? (Note: They should also have a transplant coordinator at least on call).

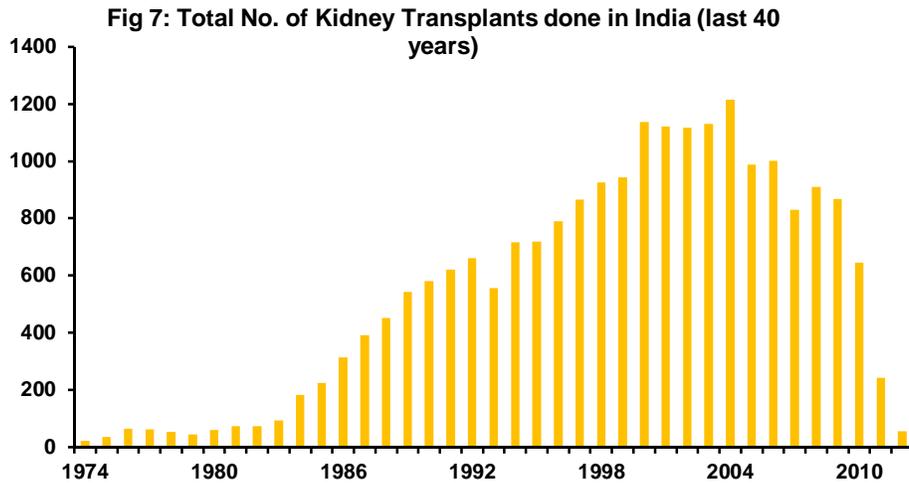
So the government will have to provide all these facilities (or monetary incentives) to these places and work out a system for them to be actively involved.

## X. Organ Transplantation Insights from Secondary Research – India

### a. Indian Transplant Data (Kidney) - Overall

The data available from **the Indian Transplant Registry website**<sup>12</sup> provides the following key insights:

- The number of kidney transplants shows a decline post 2004. This could be because of incomplete reporting by the registry.
- The number of kidney transplants has been roughly around 1,200 per year annually (for 2004), which is nearly **2% of the total requirement** for kidney transplants in the country.



### b. Indian Transplant Data (Kidney) – By Procedure Type

Nearly 13 hospitals account for close to **80%** of the total kidney transplant data available with the registry. These hospitals<sup>13</sup> are as follows:

Hospital Name	City	State
Sanjay Gandhi PG Instt. Of Medical Sciences	Lucknow	Uttar Pradesh
Apollo Hospitals	Chennai	Tamil Nadu
Devaki Hospital Ltd.	Chennai	Tamil Nadu
Vijaya Health Centre, Vadapalani	Chennai	Tamil Nadu
Sri Ramachandra Medical College & Research Instt.	Chennai	Tamil Nadu
CMC Hospital	Vellore	Tamil Nadu
Jaslok Hospital & Research Centre	Mumbai	Maharashtra
Manipal Hospital	Bangalore	Karnataka
Karnataka Nephrology & Transplant Instt.	Bangalore	Karnataka
Muljibhai Patel Urological Hospital	Nadiad	Gujarat
Sri Ganga Ram Hospital	New Delhi	Delhi
Global Hospital	Hyderabad	Andhra Pradesh
Mahavir Hospital	Hyderabad	Andhra Pradesh

The data from these 13 hospitals shows that only **1.9%** (2.0% in case of Males and 1.5% in case of Females) of the kidney transplants in the 40 year period has been from deceased organ donors, clearly highlighting the opportunity for increasing organ donations post brain death:

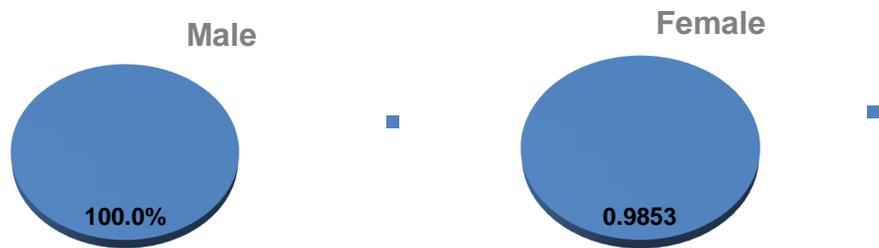


Fig 8: Pie charts showing ratio of live and deceased donor transplants for both males and females.

### c. Indian Transplant Data (Liver) – Overall

Liver Transplant data is not available in a standard format on the **Indian Transplant Registry** website. A brief snapshot constructed from the data obtained from is shown below:

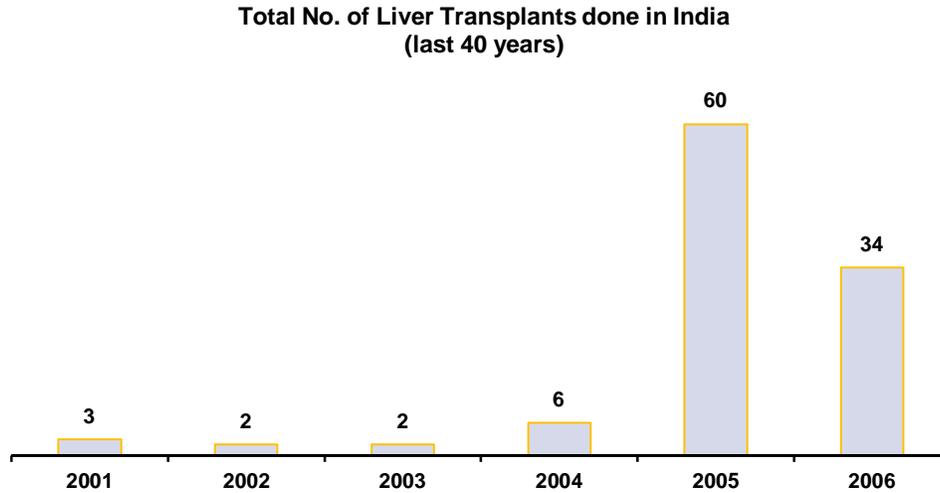


Fig 9: Graph depicting total number of transplants done in India in the last 40 years

Another source lists that till May 2007, **343 Liver Transplants** had been performed in India. These transplants were performed by **19** of the top hospitals of the country.

### d. Indian Transplant Data (Liver) – By Procedure Type

According to a report on Liver Transplant activity in India till May 2007<sup>14</sup> across 19 of the top hospitals in the country, more than **72% of the 343 transplants were done** through living procedures, the rest being deceased donation transplants.

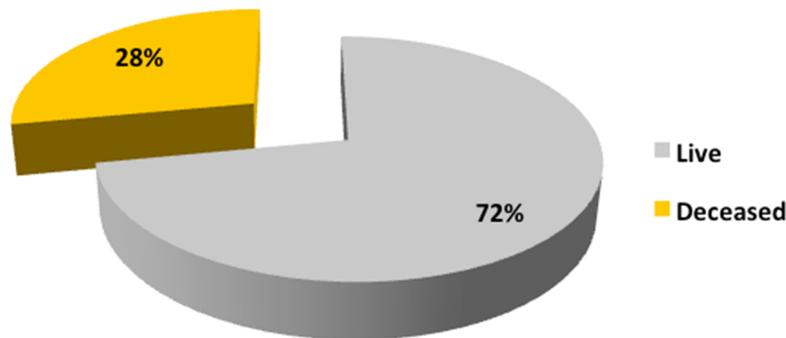


Fig 10: Pie chart showing the ratio of live and donor transplants for liver

### e. Indian Transplant Data (Other Organs) – Heart, Lungs & Cornea

A majority of the solid organ transplants in the country are either kidney or liver. Apart from the two, other major organs currently transplanted in India include heart, lungs, intestines and cornea. Some of the major statistics about these organs are as follows:

#### Heart, Lung and Bone Marrow Transplants<sup>15</sup>

- a. Nearly 150 heart transplants have been done in the country till date.
- b. Lung transplants are not common and only a handful (**2 to 5 transplants**) are done throughout the country annually.
- c. As per the latest data, there are 120+ transplant centers in the country performing around **15 heart transplants annually**.
- d. One of the most successful bone marrow transplant programs in India is run by the Apollo Transplant Institutes, which has conducted **51 bone marrow transplants in the year 2010**.

#### Cornea/Eye Transplants

- a. According to the Eye Bank Association of India<sup>16</sup>, the number of eyes donated annually is roughly around **45,000**. However, only a little more than 50% meet all the medical criteria as per the requirement for quality control of eye banks.
- b. According to Dr. Nag Rao<sup>17</sup>, president of the International Agency for the Prevention of Blindness, more than **100,000 corneas** are needed for transplants each year in India. To remove the backlog, the annual need stands at 2.5 lakhs.

Lack of awareness is the primary reason behind the shortfall with regards to cornea transplants. Out of the **7.5 lakh deaths** annually, roughly **20,000-25,000 (0.3% to 0.4%) of people donate eyes**. Hence, India witnesses not more than 12,000-15,000 corneal transplants annually (with a fraction of these being wasted)<sup>17</sup>.

## XI. Indian Success Stories – How these States did it?

### Tamil Nadu

Tamil Nadu, as a state, has been the heart of all the activity surrounding the organ transplantation cause in the country, primarily due to the efforts of MOHAN foundation that initially started from Chennai in the year 1997. Following are some of the salient steps taken up in the state in the last decade:

- a. In 1999, a meeting of six of the top hospitals conducting deceased donations on a regular basis was arranged by MOHAN foundation. The hospitals decided to form a network to share organs. This was the evolution of the **first formal organ sharing network in India**<sup>23</sup>.
- b. In 2008, the Government of Tamil Nadu passed seven special orders, which were expected to streamline the activity of deceased donors and help increase, their numbers. The Government also brought in a few new amendments as a Gazette with the purpose of putting a stop to organ commerce.
- c. In 2009, the Dept. of Health of the Government of Tamil Nadu decided to build a network with 54 hospitals that had license for organ transplants and promote deceased donation program in the state.
- d. A Tamil Nadu web based organ sharing waiting list registry has been launched where the hospitals can punch in their waiting list data ([www.tnos.org](http://www.tnos.org))
- e. The Government General Hospital in Chennai signed an MoU with the MOHAN foundation according to which the foundation would place its Transplant Coordinators in General Hospital to do grief counseling, motivate the families of brain dead patients and facilitate the organ donation and retrieval process.
- f. The Principal Secretary of the Government of Tamil Nadu addressed hospital administrators to permit certified transplant coordinators to visit the intensive care units and develop relationships with the professional staff to increase organ donation.
- g. Declaration of brain death was made compulsory in the three main government hospitals in Chennai. The other hospitals, both public and

private were also encouraged to certify brain death. The Director of Medical Education and the Director of Medical and Rural Health Services have been directed to periodically organize awareness workshops on the provisions of the above order.

### **The Tamil Nadu model of deceased donor transplantation<sup>24</sup>**

- I. Realizing the role of transplant coordinator.
- II. Availability of transplant coordinator round the clock to coordinate all aspects of transplantation in the hospitals.
- III. Uploading the details of the transplantation on the hospital web site and the government web site ([www.tnos.org](http://www.tnos.org)).
- IV. Maintain a waiting list of patients awaiting transplants that is frequently updated
- V. In the absence of an organ sharing network, automatic allocation of one kidney, liver, and heart where the deceased donor organs are harvested.
- VI. Performing the postmortem of the brain dead deceased donors in the premises of the organ retrieval hospital to save time and worry for the donor family.
- VII. Sending a full recipient report to the central convener of the transplant program within 48 hours of discharge of the recipient and upload it onto the website: [www.dmrhs.org](http://www.dmrhs.org)

This combined effort resulted in the harvesting of **223 deceased donors** in the state of Tamil Nadu during the period October 2008 to December 2012.

Moreover, 5 hospitals in Tamil Nadu and approximately 8 hospitals in Hyderabad from the year 2000 to 2008 have successfully shared **over 450 organs** (170 organs in Hyderabad and 280 in Tamil Nadu) under the Organ Sharing Network that was initiated by MOHAN Foundation<sup>1</sup>.

## Maharashtra

The state of Maharashtra has witnessed one of the most recent turnarounds in the Indian content with regards to the success of organ retrieval and transplantation. The incident that triggered this change was the death of former Chief Minister, Mr. Vilasrao Deshmukh, who passed away due to the unavailability of organs on time.

Maharashtra government made it compulsory<sup>18</sup> for all non-transplant hospitals equipped with an ICU and operation theatre to retrieve organs for harvesting and made it mandatory to officially identify brain dead patients. This would allow hospitals which don't have organ transplant facilities to harvest organs from brain dead patients for use by the facilities.

The state also passed four resolutions<sup>19</sup> in 2012 based on the Human Organ Transplantation Act, 1994. The first mandates certification of "brain dead condition" by a Brain Stem Death Committee, the duty of which is to confirm if a patient is brain dead and, if so, to inform the Zonal Transplantation Coordination Committee that oversees the work.

The state government is also going to set up dialysis centres<sup>19</sup> in all district hospitals from May 1, 2013. The dialysis process is the first step before the need for a transplant arises and can help create awareness about the same. Three such centers have already been made functional at the district hospitals in Satara, Amaravati and Nashik.

Dr. Bharat Shah, nephrologist at Lilavati Hospital, Bandra, had in early 2013, approached the Bombay High Court<sup>20</sup>, seeking direction from the state to clarify that donor or recipients of organ transplants who are related and not from Maharashtra need not get approval from their home state. This is essential to avoid unnecessary delays in the process and support those who are willing to donate.

In addition, NGOs like MOHAN foundation helped spread awareness by organizing Maharashtra Cadaver Organ Donation Day<sup>21</sup>, where the following steps were taken to encourage people to come forward and pledge organs:

- a. Use of Press:** Newspapers like Daily Sakal, Times of India, Indian Express and Maharashtra Sakal were approached for coverage, with Daily Sakal dedicating a full page in the Sunday Supplement to this cause.
- b. Use of Electronic Media:** Radio Mirchi, Doordarshan and Akashwani Pune telecasted dedicated programs for promotion of deceased organ donation.
- c. Motor Rally:** An open vehicle with a sound box and a microphone (with loudspeaker) was used for a motor rally. The rally progressed to various

parts of Pune where multiple events were being organized with an exhibition via posters, banners, and street plays to promote organ donation and distribution of donor cards to the public, inviting them to pledge organs.

With these changes in place, things have started to change in Maharashtra. Some of the recent positive developments that have happened in the state are as follows:

- a. In the nine month period between April 2012 and-December 2012, Maharashtra recorded **381 kidney transplants and 21 liver transplants**. Of these, 332 were live kidney transplants and 2 were live liver transplants<sup>19</sup>.
- b. The number of deceased organ transplants has doubled in the state in 2012-2013 (nine months) compared to 2011-2012. According to the figures from the Directorate of Health Services of the state government, there were **70 deceased organ transplants** in the state between April 2012 and December 2012 (9 months), compared to **32 transplants in 2011-2012**. Of the 70 transplants, 49 were for kidney, 19 for liver and 2 for lungs. The state had earlier recorded an abysmal 355 donations in the past 15 years<sup>22</sup>.
- c. In just three months (Jan-Mar 2013)<sup>20</sup>, the city of Mumbai saw **16 deceased kidney transplants and 9 liver transplants**, compared to a total of 43 transplants in the whole of 2012, according to the figures put out by the Zonal Transplant Coordination Committee, a state body which liaises between patients awaiting an organ and the deceased donations made.

## Gujarat

The state of Gujarat has had considerable amount of success in the case of cornea transplants<sup>1</sup>. The eye donation program in the state has worked well primarily due to the large population of the Jain community in the state. This community considers eye donation as a sublime form of charity and believes in a powerful link between '*daan*' (charity) and '*moksha*' (salvation).

More recently there has been a spurt of deceased kidney donation in the state. If properly organized the deceased organ donation programme has the potential to take care of the majority of the demands of kidneys, liver and heart of that state as stated by the MOHAN foundation.

It should also be noted that unlike Tamil Nadu, both Gujarat and Maharashtra has not been able to establish an organ sharing programme with other states within the country.

## XII. Global Success Stories in Organ Transplantations

### United States of America/European Union



Both the United States and the EU have streamlined the Organ Transplantation process<sup>25</sup>. There are specialized agencies from various medical departments involved at each of the steps for a smooth transplantation process. This results in a positive experience for the donor's family at a crucial juncture of their lives. The process followed consists of the following steps:

- Donor Enrolment
- Maintaining Recipient registry
- Patient Admission
- Testing for Brain Death
- Alerting the Organ Procurement Organization (OPO)
- Speedy and transparent system of organ allocation
- Obtaining consent
- Maintaining the Donor
- Recovering and Transporting Organs
- Transplanting the Organs

In 1984 the National Organ Transplantation Act (NOTA) was passed in the US which called for an Organ Procurement and Transplantation Network (OPTN) to be created and run by a private non-profit organisation under federal contract. In 1986

the Organ Procurement and Transplantation Network (OPTN) was created. Its aim: to increase and ensure the effectiveness, efficiency and equity of organ sharing in the national system, and increase the supply of donated organs available for transplantation.

The OPTN gave the initial federal contract to the United Network for Organ Sharing (UNOS), a non-profit organization. Since then, UNOS has been the only organization to get the contract. Within the next three decades, UNOS coordinated more than 460,000 transplants from deceased organ donors. (As reported in the UNOS website)

In 1995 UNOS helped found Donate Life America to build public support for organ donation, and in 1995 UNOS launched its first website. In 2006 UNOS launched UNet, a secure internet based system in which organ procurement coordinators send out offers of newly donated organ to a Transplant Hospitals with compatible candidates. UNet connects all transplant centers (member hospitals) and OPO's (Organ Procurement Organisations) in a secure real-time environment. Transplant professionals can access their computer network 24/7.

## Israel



Israel has implemented the "Pay It Forward" Scheme<sup>27</sup>. Under this scheme, if more than one person is on the list for obtaining a transplant, the person who had earlier agreed to donate his/her organs would be the recipient of the transplant.

This makes sure that people step forward and donate so that they can benefit should there arise a need. This is an important step to encourage proactive organ donations.

## Singapore



Singapore is one of the few countries where it is legal to pay the donor for their organs, where the government even follows-up with the donors regularly and provides them health insurance<sup>28</sup>. The government makes sure that the people who donate are looked after and this encourages others as well to take this step.

On the contrary, the Indian govt. terms payment for organ donation as illegal because of ethical issues surrounding it such as exploitation of people who may do so out of poverty.

## Spain



The Spanish system provides a markedly different alternative to other organ donor management systems utilized globally. It allows for more government involvement in individual healthcare, and also enables the government to easily collect data and build a donor registry. It is managed by the *Organizacion Nacional De Transplantes (ONT)* and utilizes the “opt out” method of registration<sup>29</sup>; all Spanish citizens are assumed to consent to organ donation upon death, and doctors at hospitals are able to operate under that premise unless families explicitly refuse. Spanish hospitals have specially trained staff members in charge of interacting with the families of deceased patients whose organs are suitable for donation.

It is estimated that 5,500 citizens died while waiting for a donor organ in the EU (which has the highest rates of organ donation in the world) in the year 2011. Spain's current rate of organ donation is 35.3 donations from deceased patients per Millions of population (pmp). Spain's recent success in increasing donor rates and galvanizing national support for the organ donation movement rests on ONT's reliance and focus on recruiting and utilizing the Spanish national media to convey their message. The ONT has a very comprehensive and well organized website, and has published best practices for the processes of organ donation in multiple languages.

## United Kingdom



In UK, the focus has been on spreading the word, creating awareness and counseling the people concerned. This is done through multiple channels and initiatives. There are multiple Transplant Coordination Services in different parts of the country catering to the hospitals in their respective regions<sup>30</sup>. These organizations perform the following functions:

- Multi-professional education and support
- 24 hour referral service for all organ and tissue donations
- Consultation and advice
- Family counseling and support
- Organization and facilitation of donations
- Follow-up information

- Assistance with procedures and guidelines relating to the donating process

In addition, organ donor forms and leaflets are distributed along with carry bags in retail stores, by grocers and vegetable merchants while delivering at houses, by dairy marts through bottle labels and by other people using a donor sticker on their cars. This is a cost-effective way of making the general public aware about the initiative and spread information about the process. This is an easily replicable step and many countries are taking a cue to practice the same.

## Australia



Kidney Health Australia<sup>31</sup> organized BBQ events to raise funds for families who cannot support organ transplant because of financial constraints. This is another important step considering the financial implications of an organ transplant procedure. India could design specific events targeted towards raising funds for this cause and partner with the local State Governments, Community Groups and Social Organizations/NGOs.

Australia will also pay cash grants of more than \$3,600 (\$4,700) to donors of organs such as kidney or liver under a plan to encourage donations and reduce spiraling public health costs<sup>32</sup>.

## Croatia



Croatia had one of the lowest organ donation rates in the world until 2000, when the organ donation rate increased from 2.7 million donors per million population to 35 donors per million population. The legal system is presumed consent.

In the past decade or so, the national transplantation system in Croatia has improved significantly. The Croatian model has been recognized as extremely successful. The reasons for this turnaround are: the appointment of hospital and national transplant coordinators, implementation of a new financial model with donor hospital reimbursement, public awareness campaign, international cooperation, adoption of new legislation, and implementation of a donor quality assurance program.

### XIII. Recent Initiatives for creating awareness about Organ Donation in India

#### Promotion and Awareness by famous personalities/ambassadors

- a. Actress and Former Miss World Aishwarya Rai Bachchan has promoted eye donation for a long time through various channels including print media, television advertisements and through events organized by the medical fraternity.
- a. Actors Aamir Khan and his wife Kiran Rao have pledged to donate his organs. Priyanka Chopra has also pledged to donate her organs.
- b. Sports celebrities like Kapil Dev and Gautam Gambhir have also pledged their organs.

Considering the fact that public figures have the potential to attract media coverage, social causes when promoted by celebrities have proven to have greater reach than a regular event. The personalities themselves hold immense brand value and the cause he/she upholds also becomes an attribute of their overall value.

#### Student/college initiatives towards creating awareness

- a. More than 1,500 students of Shivaji College, Delhi University, organized a walk around their campus in early **September, 2013**, creating awareness about importance of organ donation by holding placards and banners<sup>33</sup>.
- b. Faculty members of BMS department of Western College in Mumbai set an example for the students by donating their organs and initiating the same leading to 150 students coming forward for the cause in **August, 2013**<sup>34</sup>

#### Increasing involvement of National Media in awareness campaigns

Times of India ran a campaign on organ donation, garnering more than 50,000 organ donation pledges in August, 2013. This included 1,000 CRPF Jawans, a large number of students and elderly people<sup>35</sup>.

## Pledging donation through Driving Licenses

The Road Transport and Highways Ministry<sup>36</sup> is formulating a norm to include the provision of pledging organs through application forms used for obtaining a driver's license. This drive has already been implemented in cities like Bangalore, Mumbai and Pune; and other cities will follow soon.

The success of the program can be judged by the fact that organ donation pledging went up by 40 times in the first ten months of its launch in the pilot cities, thereby accomplishing the dual goals of creating awareness and increasing the number of potential organ donations. This initiative has now been taken up by the Central Road Transport and Highways Ministry for implementation across the country.

## XIV. Government Bodies Involved in Organ Donation and Transplantation policies

According to the Indian law, Organ Transplantation is a State subject and is under the direct control of the respective State Governments. However, the Union Health Ministry is responsible for making amendments to the Transplantation of Human Organs Act, so that the organ transplantation system in the country runs effectively.

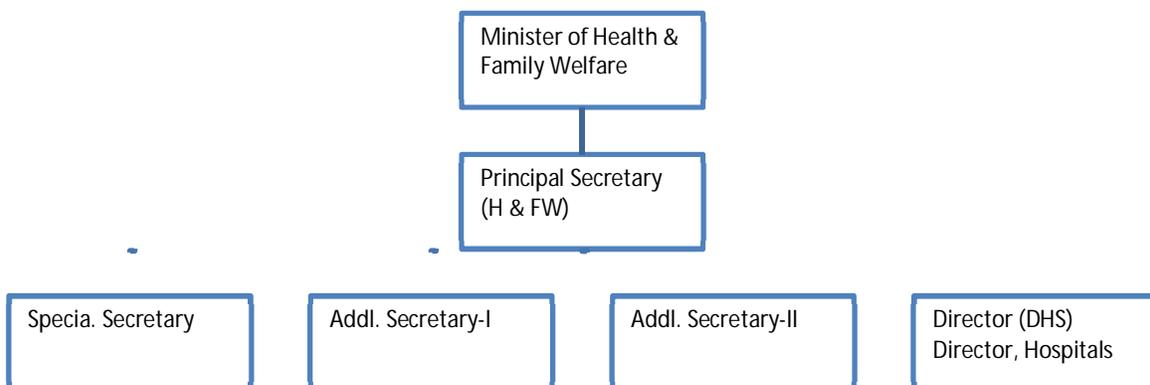
### Central Government

In case of the **Central** Government, the **Ministry of Health and Family Welfare** is the body looking at decisions related to the organ transplantation processes in the country. The Ministry comprises of four departments, each headed by a Secretary, out of which the **Department of Health & Family Welfare** is responsible for taking actions related to organ donation and transplantation. In addition, there is the **Directorate General of Health Services (DGHS)** which is the attached office of DH&FW. It renders technical advice on all medical and public health matters and is involved in implementation of various health services.

There is also a need felt to incentivize the process of donation, even told to us by one of our respondents. The ministry as reported has been contemplating on measures such as 50% discount on second class railway tickets, provision of lifelong free medical test and care in the hospital where the organ has been donated.

### Delhi State Government

The health care responsibilities of the 160 lakh people residing in Delhi state lies with the **Health & Family Welfare Dept.** Of the Govt. of NCT of Delhi. The Principal Secretary heads the Department. The organizational structure of the H&FW Department is follows:



Since Health is a State subject in India, any initiatives related to creating awareness and promoting organ donation and transplantation should be carried out in partnership with the respective State Governments

In March 2012 the Delhi Government launched DORSO.org as an online registration system for voluntary organ donation. Voluntary donors would be able to register their names on the website and registered hospitals in Delhi will have a registered password and can access the website to determine brain dead persons as a result of road traffic accidents. Institute of Liver and Biliary Sciences was given the responsibility of initiating and supervising the framework for Deceased Organ and Retrieval Organization (DORSO).

In the past, NGOs and social bodies contacted their respective State Governments for such activities. With proper implementation and Government support, these activities could help increase awareness and in increasing organ pledges.

Examples of such activities are widespread in the Indian context, especially in the states of Tamil Nadu, Andhra Pradesh, Maharashtra and Karnataka, where NGOs like MOHAN foundation have not only partnered with the State Governments to carry out activities, but also made recommendations to be incorporated in the respective State Laws and Governing Policies.

## XV. Role of Non-Government Organizations & other groups

### MOHAN Foundation – A case study

MOHAN (Multi Organ Harvesting Aid Network) is one of the front-running NGOs promoting and taking up the cause of organ donation in India, especially in the case of deceased donors. The organization believes that the shortage of organs can be overcome if the plans are executed properly.

MOHAN foundation has taken up state-by-state implementation of the organ transplant awareness initiatives, starting with the southern parts of the country. They have essentially followed a three-step approach:



The organization has had significant success with the above approach. Of the 1,300 deceased donations in India, MOHAN foundation has been responsible for **33% (one-third)** of the donations<sup>37</sup>. To give some examples:

- a. They undertook 22 deceased donations in Andhra Pradesh in 2007 and obtained almost 80 organs, without much support from the Government Hospitals<sup>37</sup>.
- b. In Tamil Nadu, they facilitated distribution of over 350 organs between half a dozen hospitals

This was primarily achieved because of the wide-scale awareness created by the organization. They were responsible for distribution of over 300,000 donor cards in the two states<sup>37</sup>. To add momentum to the deceased organ donation program, MOHAN foundation has sent its recommendations to both the central and the state governments<sup>38</sup>. These recommendations are as follows:

1. Making it compulsory for the hospital staff to ask for organs in case of brain death.
2. Provide an Organ donation clause in the driver's license cards.
3. Conducting Post-Mortem Examination during the same time as Organ Retrieval Surgery to avoid unnecessary delays.

4. To reduce the hassle of transporting the donors from hospitals where organs can be retrieved to hospitals where they can be transplanted.
5. Making it compulsory to appoint Transplant Coordinators in the ICUs of hospitals.

In addition, the organization has also made recommendations to improve live transplant situations.

Currently, MOHAN Foundation is taking initiatives to create awareness and encourage organ donations in Delhi/NCR region as well.

### **AORTA (Armed Forces Organ Retrieval and Transplantation Authority)**

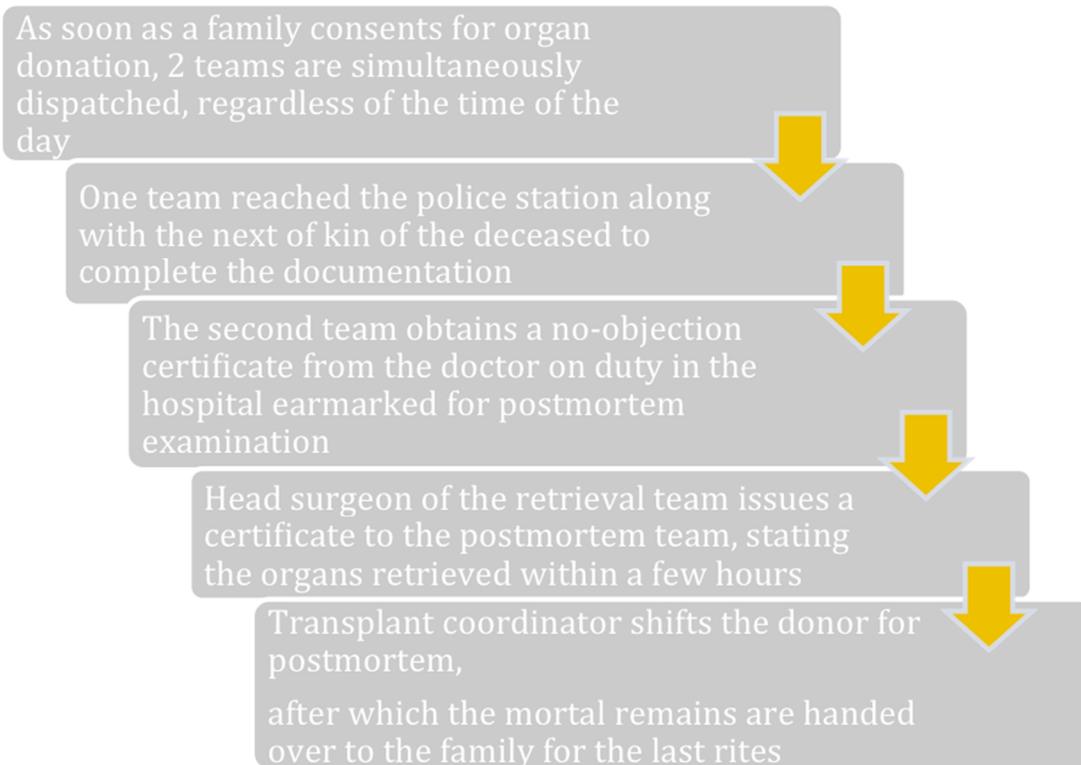
AORTA or the Armed Forces Organ Retrieval and Transplantation Authority have been actively pursuing the cause of Organ Donation, Retrieval and Transplantation in the country. They had organized an extensive drive to promote deceased organ donation in India. During the drive, information was disseminated on brain death and organ donation through various lectures, posters, billboards and extensive coverage via local and national newspapers and periodicals in the country. Some of the steps taken up by AORTA are as follows<sup>7</sup>:

1. Establishing organ donor registry at the hospitals
2. Issuing donor cards to the individuals to help them pledge organs in case of brain death
3. Conducting organ pledging ceremonies involving prominent personalities (including movie stars and athletes)
4. Honoring families of organ donors to spread the message of organ donation

Many firsts have been achieved through the initiatives taken by AORTA:

1. For the first time in India, a liver was flown from New Delhi in the north to Hyderabad in the south and transplanted, thereby diminishing geographical boundaries with regards to organ transplantation.
2. Kidneys were transported by air from New Delhi to Mumbai, Pune, Lucknow and Bangalore.

AORTA argued that the previously held concerns about social and religious beliefs as a cause for lack of organ donation in India were found to be untrue contrary to what the existing argument is. Their suggestion was based on the outcome of their own practice. The protocol followed by the group resulted in timely retrieval and is shown in the following manner:



### **ORBO (Organ Retrieval Banking Organization) by AIIMS**

ORBO has been setup by the All India Institute of Medical Sciences (AIIMS) Delhi with the purpose of encouraging organ donations across the country. It aims to achieve fair and equitable distribution and utilization of organs. ORBO is concerned with the following primary activities<sup>39</sup>:

- a. Maintaining donor registration
- b. Coordination from procurement of organs to transplantation
- c. Dissemination of information to all the concerned hospitals in the network
- d. Creating awareness about organ donation and transplantation



- e. Organizing promotional activities directed towards helping the cause of organ donation

ORBO has established a network of 20 hospitals (8 Government and 12 Private) in the NCR region and is now moving towards expansion of the same, with both national and international groups on the agenda. Each of the participating hospitals has the infrastructural support from ORBO. An officer from the hospital is also nominated as a nodal officer to coordinate with ORBO.

## **XVI. Recommendations – Future Strategy & Action Plan**

### **a. Large-scale awareness building**

It is only through awareness programmes that the number of deceased donations can be increased. What is needed is a large scale campaign which only the government can undertake or fund. Clear messaging by the government will also add credibility to the cause. In fact all messaging in public places and hospitals in the form of standees, video spots etc. have to have the government logo along with that hospital in order to increase people's trust.

Large-scale advertising campaigns should aim to educate people about benefits of organ donation, clearing all prevalent myths and misconceptions. The concept of brain death needs to be adequately dealt with so that organs of the deceased which can be retrieved and utilized and do not go waste.

Positive messaging on organ donation can be done using the following mediums:

Advertising campaigns across all media (TV, Print, Radio, In-cinema ads)

Social Media

Celebrity endorsements

Theater & Street Plays

Events to promote organ donation (Marathons, Concerts etc.)

On-ground awareness drives at Schools, Colleges, Corporate offices, Clubs etc.

### **b. Setting up of a National registry and a centrally managed Organ Donor-Recipient Network**

A central organ sharing registry or a recipient registry is an absolute must, so that donated organs can be shared in a fair and transparent manner. This has already been initiated in the Transplantation of Human Organs Act, which has made a provision for the same. However there is no such system yet. Apart from a few states, there are no sharing protocols in place. This leads to unethical and unhealthy practices. Further, it leads to wastage of organs which is a shame when a family has taken a courageous decision to donate. The sharing of cost between hospitals also has to be clearly defined.

This system however will not work in the current scenario with seemingly unhealthy and negative attitudes amongst the various stakeholders. There needs to be a spirit of cooperation, sharing and the willingness to adopt from successful practices in other parts of the country.

The concerned agencies would be recommended to look into the practices and policy measures undertaken by the states such as Tamil Nadu and Maharashtra.

This could enable them to build a model that could be implemented in other parts of the country as well.

### **c. Make Brain Death declaration mandatory**

Making the declaration of brain death mandatory will increase instances of organ donation. It will help facilitate a discussion between the doctor/physicians and the relatives about brain death and organ donations. It would help Transplant Coordinators and personnel from other Departments to intervene and convince the relatives about organ donation.

### **d. Recognizing the pivotal role of the Transplant Coordinator in the Organ Donation/Transplant Process**

It is imperative to understand and acknowledge the pivotal role that the Transplant coordinator plays in the entire process of organ donation and transplantation.

It is only when that the hospital is able to establish a personal rapport with the patient and the patient's relatives, can they create a precondition necessary to establish talk regarding organ donation later on. The role of the Transplant Coordinator is to reach out to potential donor families and explain to them the need and importance of the act of donation. His/her task would be to facilitate and enable the retrieval of the organ from the deceased patient's body in a smooth and quick manner so the organ does not go waste.

An increased number of Transplant Coordinators would help in creating awareness and also help in counseling the relatives to manage the system of organ donation.

Higher numbers of Transplant Coordinators are required in a public set-up as the amount of patients there are significantly higher.

### **e. Improve Infrastructure within public hospitals for transplantation**

Transplantation as a service should be readily available in all Government hospitals as the majority of patients go there for treatment and many cannot afford treatment at private hospitals. The Government also needs to take the necessary steps to improve the infrastructural set-up at all public hospitals to store/transport organs and train the hospital staff/personnel for organ transplantation procedures and on the subject of brain death, and how to increase awareness regarding the same.

#### **f. Non-transplant hospitals need to be involved in organ retrieval**

These medical centers (which have ICU's but are not transplant centers) are crucial because a lot of accident victims are brought here for treatment. They should be geared up for brain death declaration. They need to be given an incentive to be participants in organ retrieval, and a system has to be worked out wherein they are compensated adequately for their active involvement in the Organ Donation programme.

The government will have to provide all the facilities (or monetary incentives) to ensure that brain deaths are identified in these hospitals and organs retrieved.

#### **g. Sensitizing police personnel and forensic experts**

Sensitization of police personnel and the forensic experts has to be taken up on a war footing to make all medico-legal cases smooth. Most brain death cases are accident cases and therefore medico legal cases. They usually are difficult to handle as they do not get cooperation from these quarters. We can recognize and highlight some police people who have been cooperative.

#### **h. Provision of more opportunities for donor pledges**

Provide the public with organ donor intent forms and brochures while issuing driving licenses, Aadhar cards and college ID cards, so they can choose to express their intent on the cards.

#### **i. Emulate successful practices from other states:**

States such as Tamil Nadu for instance have recorded an 80% conversion rate<sup>40</sup> when it comes to donating the organs of one kin. Through a motivated network of doctors who declare brain death, personnel who maintain the deceased on life support, and transplant coordinators who convince the near relatives of the patient, the state has a record organ donation which is 15 times the national average. An important step in this direction was the creation of a network of hospitals for sharing organs. The same should be replicated in other cities, like Delhi.

The Maharashtra government made it compulsory for all non-transplant hospitals equipped with an ICU and operation theatre to retrieve organs for harvesting and made it mandatory for them to officially identify brain dead patients. This was a crucial point highlighted in the primary research as well and hence, needs to be implemented in the Delhi/NCR region.

## XVII. Methodology

- **Primary Research** – Given the sensitivity of the study, the methodology was as follows:
  - A contact list for all hospitals in the sample was compiled based on the client's contacts, and secondary research. This list included the doctor/ transplant coordinator/business development officer to be contacted.
  - The list of hospitals included both public and private hospitals.
  - To set up interviews, the team contacted the coordinators and requested for an appointment with the doctor/consultant. If no coordinator was available, the team tried setting up appointments by calling the main respondent/Doctors Personal Assistant/ Department/ Hospital reception based on information availability. If no contact was available, the team visited the hospital to get a contact and meet with the relevant person.
  - The primary respondent was the medical practitioner i.e. the doctor or the consultant. However, in their absence/unavailability the transplant coordinator was spoken to as well. In some cases, we were referred to the Business Development Officers who were responsible for the organ donation process and maintaining data records. They were extremely knowledgeable about the organ donation process within the medical institution.
  - In some cases, more than one doctor was spoken to at a hospital. Two interviews were recorded in such cases. However, the data centric questions were recorded only once since responses to these would be standard across any particular institution.
  - Face to face interviews were conducted with the respondents.
  - In some cases the respondent refused to answer certain questions. Such fields were left blank. If the respondent was busy or out of town for the coming few weeks, we worked around their schedules. If however, they were unavailable for a long period of time, we offered to interview over the phone.

- Post-interview, follow ups were done with the chief respondent/transplant coordinator/assistant/office to procure answers to the data centric questions and draft a list of surgeons/coordinators to be uploaded onto the Organ India website.
- **Secondary Research** – A thorough research of the market landscape, both in India as well as for the global markets was done. A variety of sources including articles, news releases, print media, online journals, research reports and others were used.
- **Data Analysis** – This involved placing some of the key metrics concerning the organ transplant industry under the lens through statistical approaches and techniques

## XVIII. Questionnaire Design for Primary Research

Given the sensitivity of the study, the questions were designed to allow for the respondent's i.e. doctor/transplant coordinator et al, opinion to come through while aiming at maximum data procurement to get a better understanding about the organ transplant market in Delhi/NCR.

- An initial framework of questions was prepared based on secondary research and discussion with the client.
- These questions were mostly multiple-choice questions to allow for clarity and analysis.
- The first draft was shared with the client for their inputs and insight. Based on the discussion, the questionnaire was revised and a few more iterations were done with the client.
- The questionnaire was piloted with a local doctor (not in the sample) to incorporate additional insights and further changes
- The survey allowed for a notes column and a comments section at the end to record the respondents viewpoint to assist with the deep dive.
- The questionnaire had three types of questions:
  1. **Opinion focused:** To get a better understanding of the current organ donor market, the lacuna, and areas of improvement
  2. **Data centric:** Questions that focused on the number and type of organ donations and operations, number of coordinators at the hospital et al. These would be responses that are standard across a particular medical institution.
  3. **Notes:** The team of surveyors was trained to encourage the doctor/coordinator to express their personal opinion and share their perspective about the constraints and problems within the organ donor market, how to improve the number of pledges and increase awareness, among other things.

## XIX. About the research agency.

OUTLINE India provides solutions for executing High-Quality, Authentic Field surveys across India.

We work with international research institutes, Universities, PhD students, NGOs, donor agencies, governments and corporate organizations.

We also provide research and policy advisory services pertaining to India and Asian economies. Outline India is foraging into technology based field surveys to minimize time and cost, and improve on efficiency and accountability.

By following a rigorous methodology with quality checks at each stage of the data collection process, we are committed to providing high quality field survey data. We believe accurate results from a well- designed research experiment depend intrinsically on the quality and authenticity of data.

We strive to build a brand that incorporates scientific and statistical mechanisms to check for quality. We have in place systems of accountability, streamlined processes and incentives for people at the grass roots level to engage them in the process of data collection, to maximize survey response rates and ensure robustness.

We have strong partnerships across States and districts to support and build on local strengths. Our Core Team is involved at every step of the survey process, from inception and planning to execution.

### Our Services

OUTLINE India provides the following services:

- Primary and secondary research
- Survey tool designing
- Monitoring and Evaluation
- Research and policy consulting

We work with:

- Research Institutions
- Think tanks
- Individual Researchers
- NGOs and
- The Indian Government
- Corporate Houses

*We broadly cover the following areas of study (among others):* Health, Education,



Technology, Finance, Gender, Environment & Energy, Labor Market, Finance, Infrastructure, Trade, Banking and Governance.

Our team members have worked across states, districts, and villages, in rural and urban areas over the last few years.

We build on local experiences of Partner Organizations who understand the demographics of the region, speak the local language, are well connected with the local administration and have an understanding of the vagaries of weather, safety, transportation and other key factors that are critical to any survey.

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