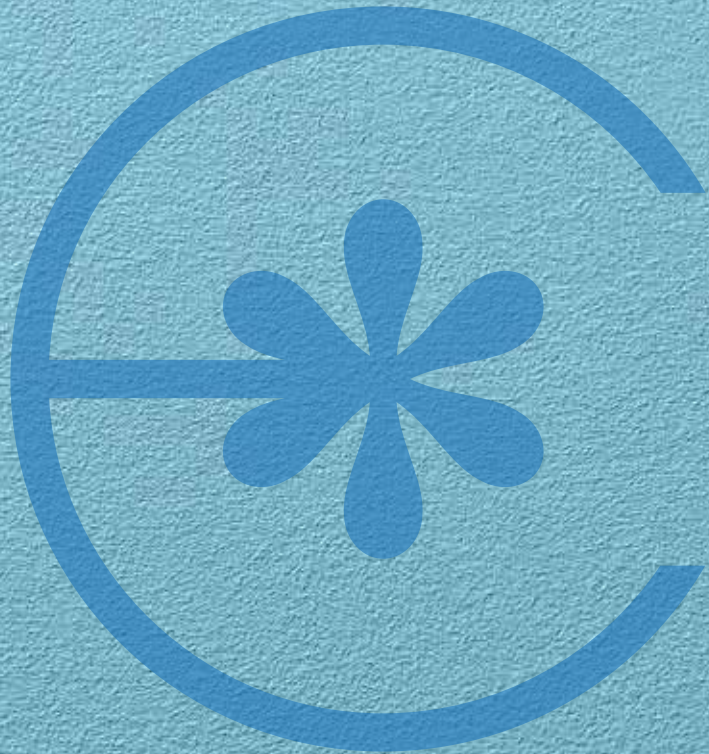




Life After Life

State of organ donation in India





*Dedicated to organ donors the world over,
who have helped make*

#ZindagiUnlimited



Let's Begin

Content

Why us?	1
Lay of the land	3
What did we do	5
Know-how	7
Disposition	11
Myths	15
Fear	19
Ecosystem	23
What defines you	27
In toto	29
I pledge	31

A person is sitting at a desk, leaning their head on their hand in a thoughtful pose. In front of them is an open laptop and a smartphone. The scene is lit with soft, natural light from a window in the background. A dark blue semi-transparent rectangle is overlaid on the left side of the image, containing the text 'Why Us?'.

Why Us?

From MD & CEO's desk

Your future is created by what you do today, not tomorrow! Don't you agree?

As a life insurance company, it is our duty to help people take the right step TODAY and no longer delay securing their future. Life insurance exists so that the lives of our loved ones can go on even in our absence. It is a noble business, through which we are able to make a constructive contribution in people's lives. It helps people secure dreams and aspirations of their loved ones in the long term and helps them live a life without any worry.

Over the past 8 years, we, at Edelweiss Tokio Life Insurance, have been fortunate enough to protect our customers and help them live a longer, more secure life. Through this journey, we have gained several vital insights that have led us to discover a latent crisis that might hit us soon.

Nearly 500,000 people die annually in India due to unavailability of organs. Organ donation could help India reduce this number significantly. We, therefore, believe it is essential for us to support this cause, because much like life insurance, organ donation can also help people live a worry-free life.

With this view, we are flagging off an initiative that will seek to spread awareness regarding the need for organ donation across several states and enable people to take the right step TODAY.

To understand why organ donation is currently low in India, we commissioned a research titled 'Life After Life: State of organ donation in India' to highlight factors impacting the decision-making process of individuals. This has been a fact-finding mission that has brought forth some surprising insights, regarding why the state of organ donation is so abysmal in our country.

As a life insurance firm, we believe it is incumbent upon us to create a platform that can educate, mobilise, and enable the pledging of organs for donation.

Life insurance and organ donation, both, are a fool-proof way of living your #ZindagiUnlimited.



Sumit Rai
MD & CEO

The background is a textured teal color with small white decorative elements like stars and hearts. In the foreground, several hands are raised. One hand on the left holds a red heart. Another hand in the center holds a red heart. A hand on the right holds two red hearts. The hands are rendered in a simple, stylized manner with different colored sleeves (purple, green, dark blue).

Lay Of The Land

Executive Summary

Within the crevices of India's day-to-day life, there is a quiet storm brewing. Like a dormant volcano, it is biding its time to erupt and become a full-blown emergency. Organ donation in India is in a dreadful state, with nearly 4 lakh individuals losing their lives every year due to lack of viable organs. Yet, there isn't enough conversation happening about this issue.

Lack of knowledge, awareness, and infrastructure are among the crucial factors that have translated into an acute shortage of donors in India. Organ donation is marred by several misconceptions that have contributed to the low donation rate. Beliefs like religion prohibits organ donation, or donation of an organ would mean being born without it in the next birth, have stoked people's fear and kept them at bay.

Strangely enough, people believe that they would have to pay to donate their organs. The fact is a donor does not have to spend because an organ in itself does not carry a cost. The recipient does not pay for an organ either, but incurs a surgical transplant expense.

Family is one of the biggest barriers to organ donation. Even in cases where individuals have pledged their organs, the family denies the eventual donation. Beliefs that harvesting of the organs would mutilate the body, or that they would lose all rights to the body of their loved ones perpetuates fear regarding the process. Family, often times, is required to consent to organ donation during a vulnerable time. So, fear that organ harvesting will desecrate the body makes it difficult to take a positive decision.

For those intending to donate their organs, systemic complexities prove to be a challenge. There is negligible understanding on how to follow through on their will to donate and how to register with an authority. Some have an innate mistrust in the healthcare system and believe that their organs would not reach those who are in need.

While there is enough data available regarding the need gap, we, at Edelweiss Tokio Life Insurance, wanted to delve deeper into the emotional factors impacting decision-making for organ donation. This report hopes to spread and deepen awareness among its readers regarding the need to tackle this immense challenge.

As a community, we need to consider pledging our organs and take a step further by educating, informing, and reforming as much as possible.

<https://sites.ndtv.com/moretogive/india-needs-people-step-cause-organ-donation-2695/>

What Did We Do?



Inspired by the revolutionary work of Swiss doctor Jacques-Louis Reverdin in 1869, the first skin graft was performed in 1870.

<https://www.ncbi.nlm.nih.gov/pubmed/20509454>

Our modus operandi

We conducted a combination of qualitative and quantitative interviews with 1565 people across 12 cities to understand factors affecting people's decision-making process of organ donation. These cities were a mix of big (Delhi, Mumbai, Chennai, Kolkata), medium (Lucknow, Ahmedabad, Bangalore, Patna) and small (Jaipur, Indore, Kochi, Guwahati).

Men and women between the age of 20 and 60 years in SEC A and B participated in this study, which was conducted from September 28 to October 11.

The insights gathered can be categorised under below headers.



Know-how



Disposition



Myths



Fear



Ecosystem



Personas

Significant testing has been factored in for the difference of base in city-specific data



Know-How



The very first kidney procurement from a brain dead donor was performed in 1963 at the Université Catholique de Louvain, Belgium, by Morelle and Alexandre

<https://www.sciencedirect.com/topics/medicine-and-dentistry/collins-solution>

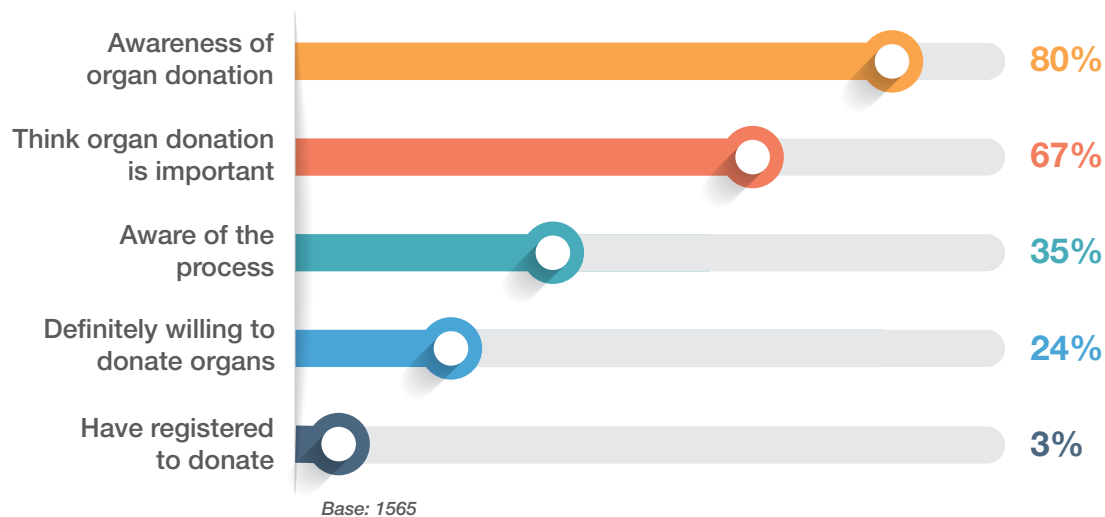
Landscape of organ donation in India

“I saw Kapil Dev do a campaign...that’s how I got to know about it,” said a young Indore resident when asked about organ donation. His comment, while benign, is an indication that organ donation is not a subject discussed widely and far too often in India. To some, the concept of donating organs is quite familiar, and to many, it is quite alien.

India, in fact, has among the lowest organ donation rates in the world. It has a deceased donation rate of about 0.3 per million population compared to some western countries – US has a donation rate of 26 per million population, Spain has 35, and Croatia has 36.5.*

India has seen a significant increase in the number of organ donors in the recent years. As per National Organ and Tissue Transplant Organisation’s recently available data, 2017 recorded 905 donors, almost a three-fold increase from 313 in 2013. While this rise is certainly promising, the number of organ donors in India needs to increase with far more intensity.

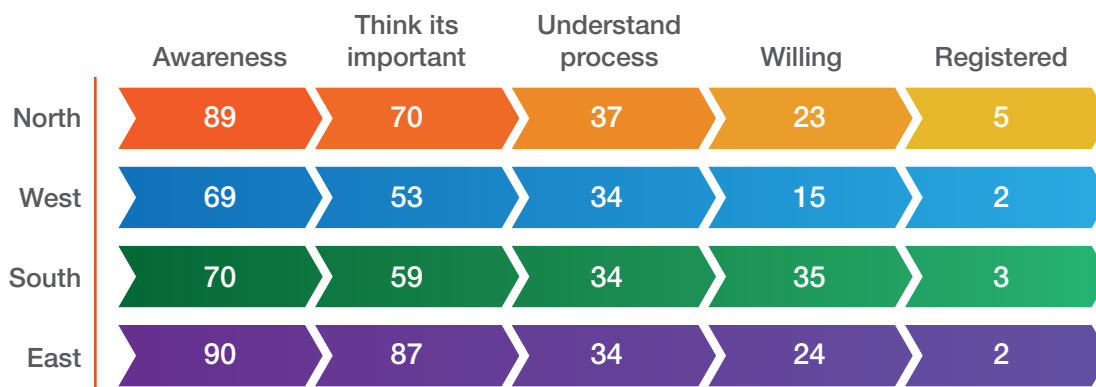
Edelweiss Tokio Life Insurance’s study, conducted in association with Karvy Insights, shows that a majority are aware about organ donation, but only 35% understand the process. While 67% believe that it is important, 24% are willing to donate their organs, and a meagre 3% have registered with an authority.



* <https://www.indiatoday.in/education-today/gk-current-affairs/story/organ-donation-body-parts-you-can-donate-donor-laws-1576069-2019-08-01>

East has high awareness, but low willingness

The study showcases an interesting landscape of organ donation in India. The eastern states emerged as the leader in awareness (90%), and belief that organ donation is important (87%). However, the numbers drop when it comes to understanding of the process (34%), and willingness to donate (24%). The western states fared low on all parameters, showing the lowest willingness to donate at 15%.



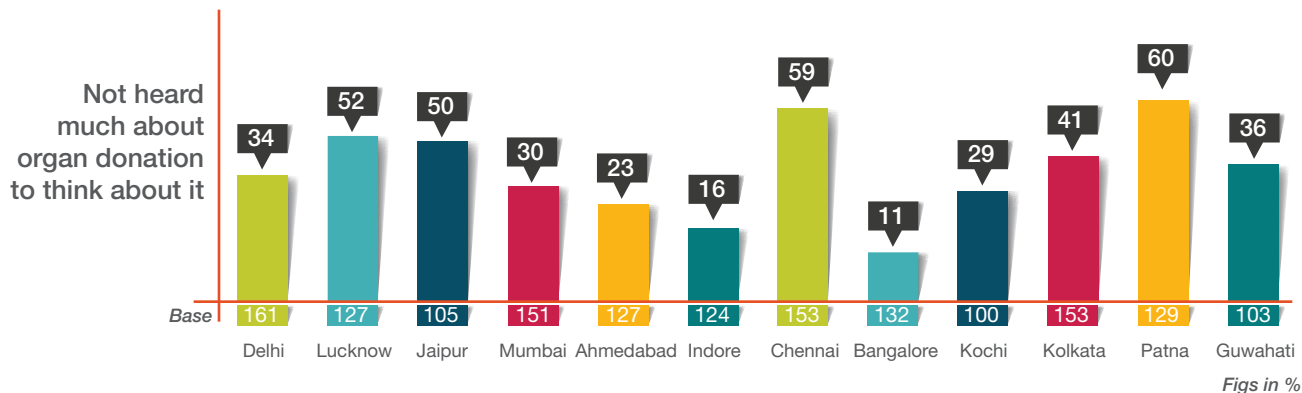
Base: 1565
Figs in %

A superior healthcare system, and a relatively higher access to information in the metro cities would lead one to believe that the disposition in the region would be higher. However, it is the smaller cities that showed intent towards organ donation. As many as 45% respondents said they understand the process and 30% showed willingness to donate. In contrast, 31% respondents in bigger cities understand the process, and only 21% are willing.

Women show higher willingness to donate

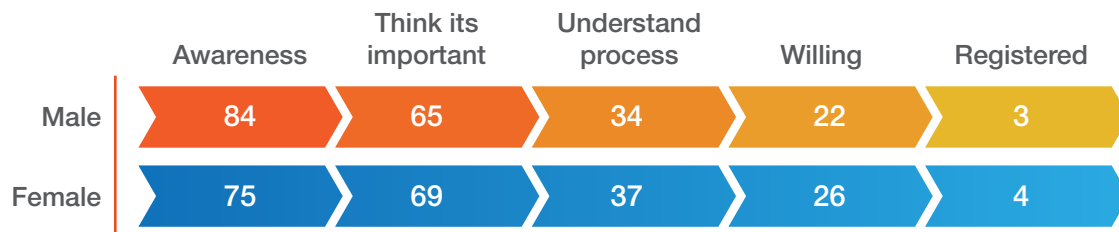
Lack of enough discussion on organ donation also affected consideration of the subject. In Patna, 60% respondents agreed that they had not heard enough about organ donation to proactively think about it. Only 11% respondents in Bangalore and 16% in Indore agreed with this statement.

City-wise split for a total of 37% who agreed



While respondents across age groups showed a similar disposition across most parameters, a higher percentage (42%) of 40-60 year olds said they understand the process. When analysing those who have registered to donate, 31-45 year olds recorded the lowest percentage at 1%.

Similarly, a vast skew was not noticed among male and female respondents on most parameters. However, while awareness is higher among men, women have a higher understanding of the process, willingness to donate, and the actual follow through.



Base: 1565
Figs in %



Disposition



In 1966, the first attempt to cure type 1 diabetes by pancreas transplantation was done by University of Minnesota in Minneapolis.

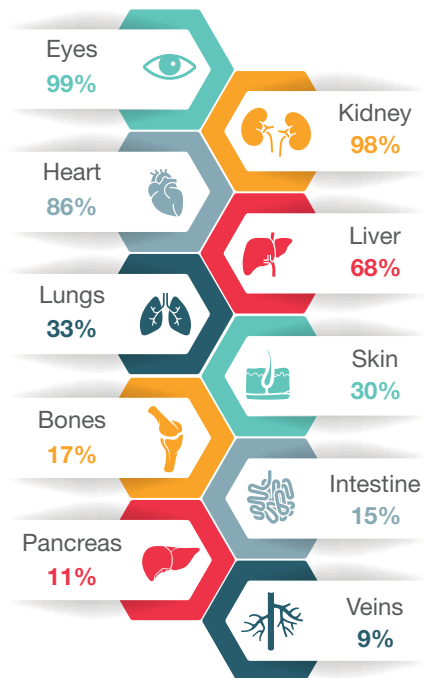
<https://www.ncbi.nlm.nih.gov/pubmed/18710120>

Shallow understanding of the process

“I want to pledge but don’t know how to go about it,” said a respondent, highlighting the most rudimentary barrier to organ donation. There simply isn’t enough information available that can simplify and explain the process to those who are willing to donate. An inertia to take any action or proactively seek information about the process only exacerbates this problem.

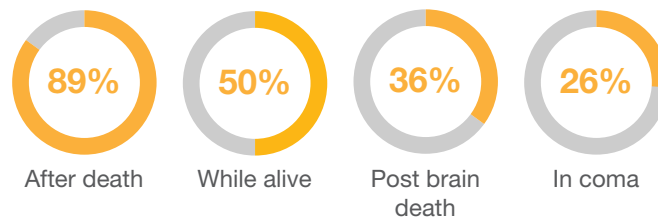
In fact, a majority are unaware which organs can be donated aside from heart, kidney, liver, and eyes. Most people are also unsure as to when organs can be donated – surprisingly 26% believe that being in a coma makes a patient eligible for donation. A coma does not render the patient without any possibility of recovery and therefore does not, by default, make a patient eligible for donation. This lack of understanding about the pre-requisites for organ donation leads to several people mentally giving up on the idea altogether.

Which organs can be donated?



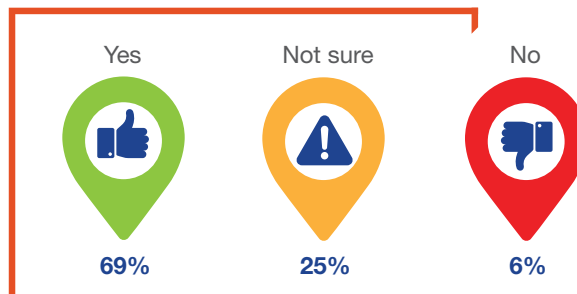
Base: 1565

When it can be donated?



Base: 1565

Does the donor have to pay?



Base: 1565

Family is the leading barrier

While living donation is an option in the case of some organs, most are donated when deceased. In these cases, family plays a crucial role in giving consent to donate organs. In India, 43% people believe that their family would not be comfortable with the idea of organ donation and therefore do not pledge.

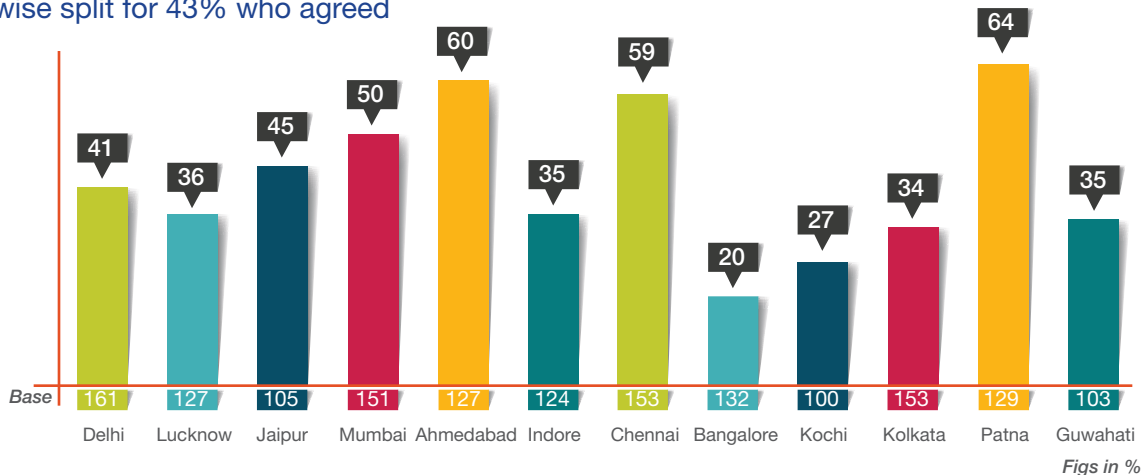
A young Chennai-based man said, “Although I want to donate one day, I am afraid of discussing this with my family...I doubt they will ever allow me.” Much like this Chennai-based man, some believe that mothers especially may never agree to donate organs of their children.



Base: 1565

These concerns were far more pronounced in Patna (64%), Ahmedabad (60%) and Chennai (59%). Bangalore ranked the lowest in comparison, when polled on family being a concern in decision-making process.

City-wise split for 43% who agreed



Religion plays a key role

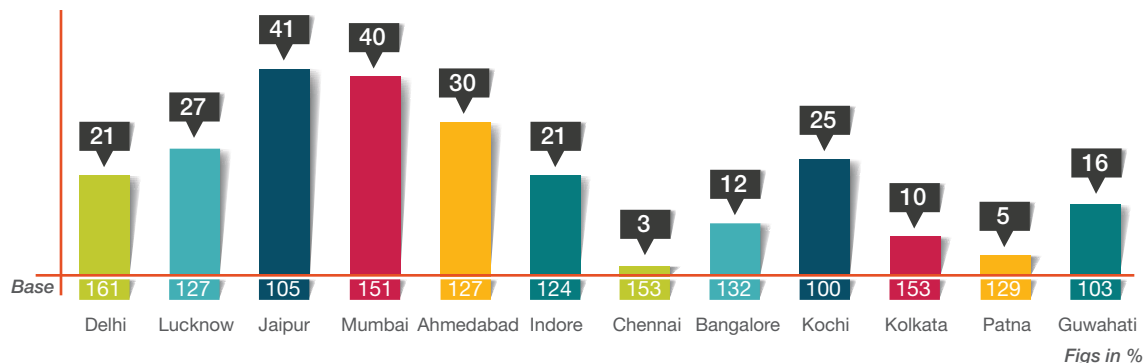
Religion, typically, plays a huge role in an individual's life especially when making crucial decisions. So, undoubtedly, religion has a huge role to play in promoting positive attitude towards organ donation and dispelling any concerns that their faith doesn't allow it. A majority of respondents said that their religion does not pose as a barrier to organ donation. However, the low rate of willingness supports an argument for the role religious leaders can play in creating awareness and a positive disposition to pledge and register.

In fact, in 2017, NOTTO had brought together religious leaders to talk about organ donation and dispel myths about organ donation impacting religious rituals around death.



Base: 1565

City-wise split for 20% who agreed



<https://sites.ndtv.com/moretogive/religious-leaders-dispel-myths-about-organ-donation-1711/>



Myths

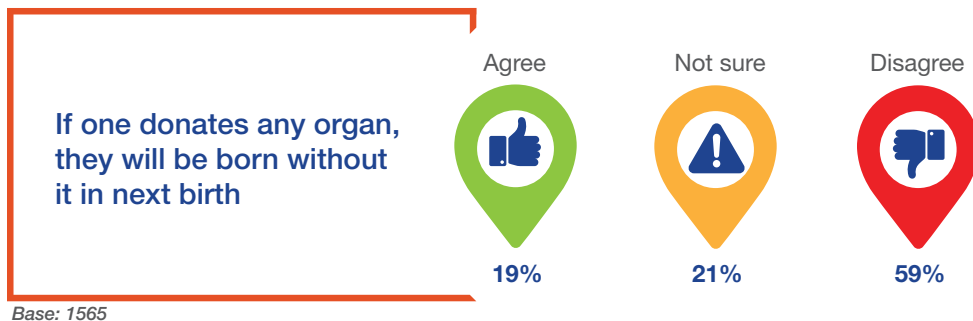


On December 3, 1967, 53-year-old Louis Washkansky receives the first human heart transplant at Groote Schuur Hospital in Cape Town, South Africa

<https://www.history.com/this-day-in-history/first-human-heart-transplant>

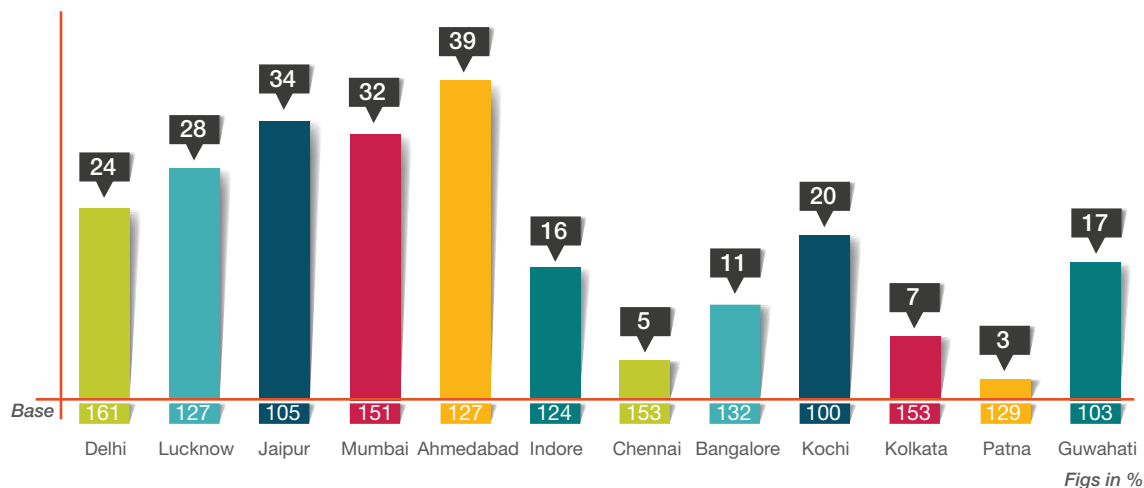
Concept of rebirth

“People are worried about appearance after death, if I donate my eyes, I’ll transition into next birth without eyes,” an elderly gentleman from Kolkata said. He was, however, among a minority of 19% who believed that they will have to forego an organ in next birth as an effect of organ donation in this one. However, an equally worrying number of people (21%) were not sure, indicating that they could be susceptible to this myth if not dispelled by a relevant authority.



Ahmedabad (39%) recorded a higher number of respondents who believe this myth to be true, followed by Jaipur (34%) and Mumbai (32%).

City-wise split for 19% who agreed



Prejudice tips the scale against LGBTQ

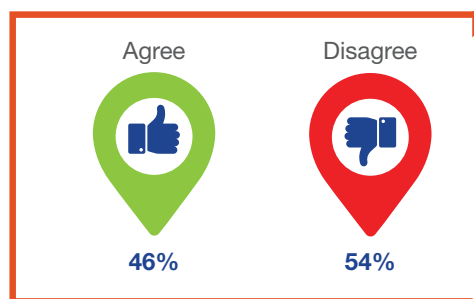
Antagonistic sentiment against the Lesbian, Gay, Bi-sexual, Transgender or Queer (LGBTQ) seem to be pervasive, with about 54% people in favour of disallowing them from donating organs.

The LGBTQ community has had a mixed past with the Indian medical community. While Supreme Court decriminalised Section 377 last year, the LGBTQ community continues to be ostracized. In September last year, following Supreme Court's landmark verdict, the Maharashtra chapter of National Blood Transfusion Council sparked a debate when it issued a new screening questionnaire that seemingly looked at weeding out the LGBTQ community from donating blood.

In fact, 2017 guidelines by the National Blood Transfusion Council reiterate that transgenders, bisexual men, and female sex workers can never donate blood as they have a higher risk of contracting HIV, and Hepatitis B and C.

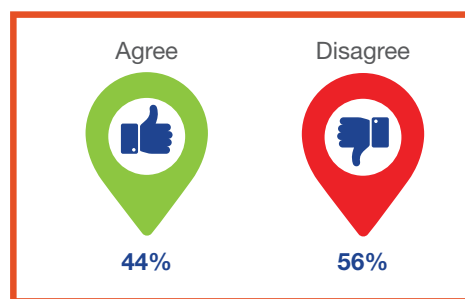
In fact, for almost a decade now, many private hospitals have been apprehensive about homosexual donors. In 2017, in response to an RTI query, the Blood Safety Division of National Aids Control Organisation had said that LGBTQ community cannot donate blood because they are a 'high risk' group. This certainly raises questions about them being able to donate their organs.

Anyone who is LGBTQ should be allowed to donate



Base: 1565

I would be comfortable to receive organ from LGBTQ person



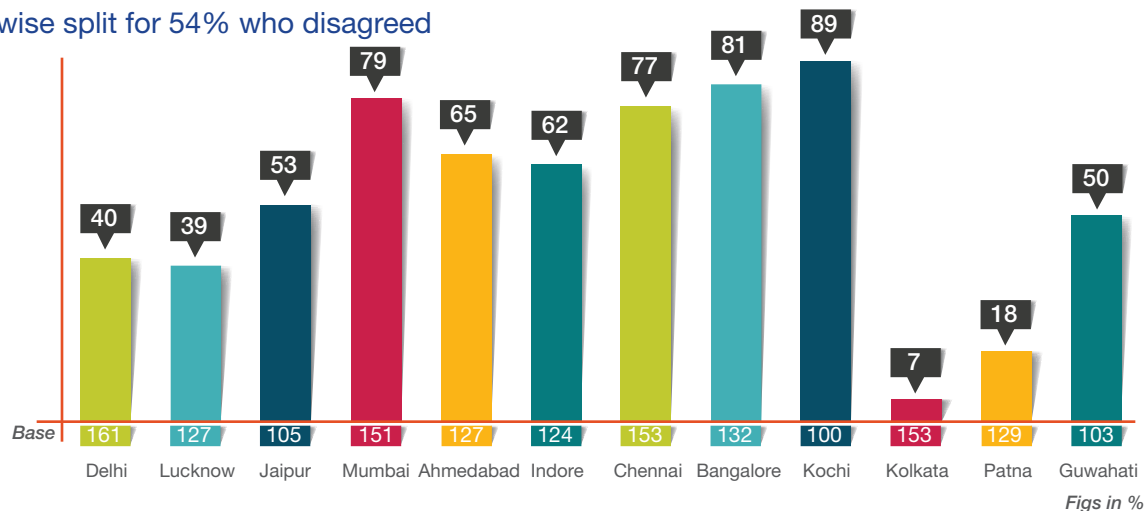
Base: 1565

https://www.business-standard.com/article/health/despite-section-377-verdict-blood-banks-refuse-homosexuals-donation-118092600267_1.html
<https://thewire.in/health/male-blood-donors-lgbtqia-naco>
https://www.huffingtonpost.in/2017/07/18/why-nacos-ban-on-blood-donation-by-the-lgbtq-community-smacks-o_a_23035306/

Prejudice tips the scale against LGBTQ

Anyone who is LGBTQ should be allowed to donate

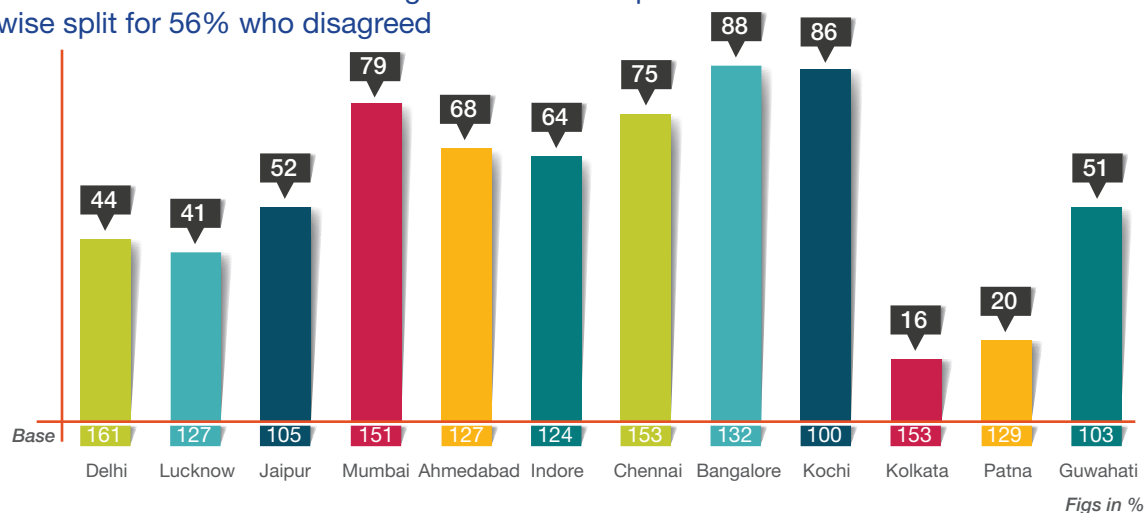
City-wise split for 54% who disagreed



Interestingly, this was the only factor that prompted a definite affirmative or negative answer. Concerns over LGBTQ were more pronounced among the older age group of 40-60 years (61%). Kochi, Bangalore, Chennai, and Mumbai showed the most negative disposition on both factors.

I would be comfortable to receive organ from LGBTQ person

City-wise split for 56% who disagreed



A person is walking a tightrope over a dense forest. The person is wearing a dark long-sleeved shirt and colorful, patterned pants. They are balancing on a thin white rope. The background is a lush green forest with many trees.

Fear



Trivia

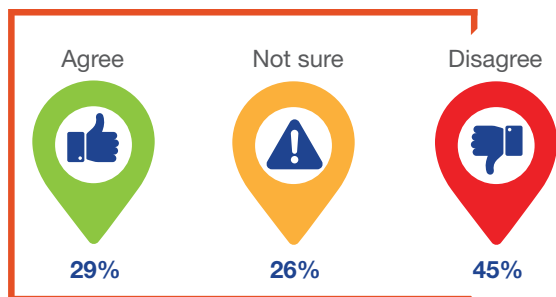
On March 9, 1981, Dr. Bruce Reitz led the team at Stanford Medical Centre to perform the first-ever successful heart & lung transplant.

<https://125.stanford.edu/first-heart-lung-transplant/>

Perceived as a hassle for family

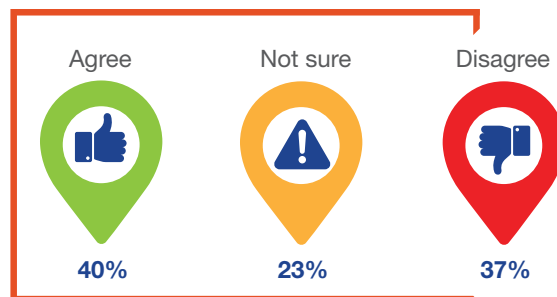
Aesthetics post death is a grave worry for some that severely impacts their decision-making process. Individuals worry that the organ harvesting procedure might denigrate the body. Families, especially, do not trust strangers to handle the body of their loved ones with care and respect. While a majority disagreed that organ donation would mutilate body, they agreed that it would prove to be an additional hassle for their family.

It will mutilate the body



Base: 1565

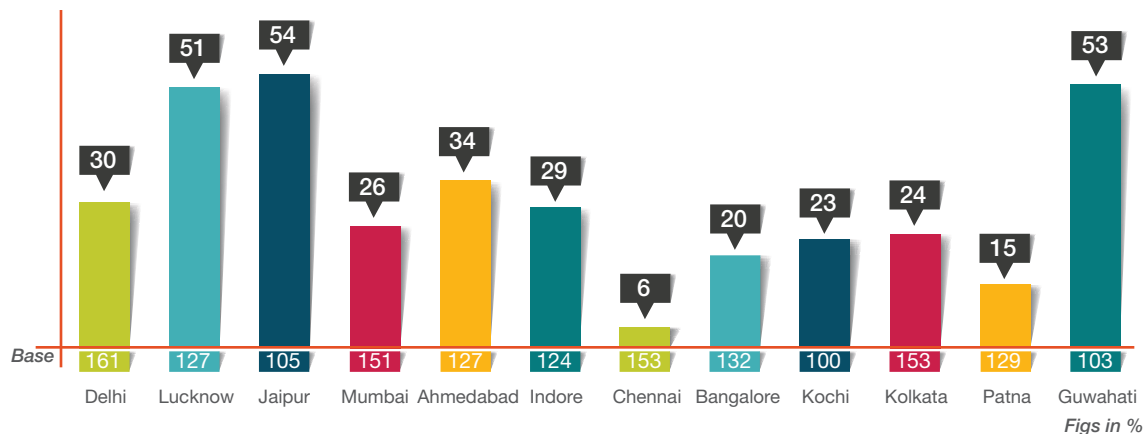
It is an additional hassle for the family



Base: 1565

“Will the hospital quickly help in the process if I want to cremate a dear one’s body within the next 2 hours...I don’t think so. My family will already be in so much stress and grief to deal with more hospital troubles,” said a concerned Delhi resident. Her comment also showcase a low understanding of the process as well as a dearth of confidence in the healthcare system.

City-wise split for 29% who agreed that it will mutilate the body



Impact on doctor's efforts

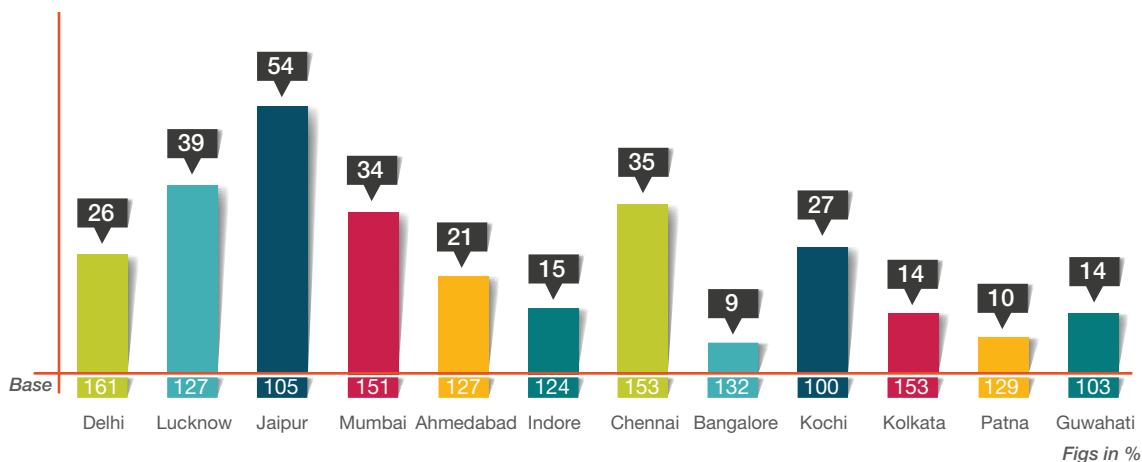
In a positive indication, 51% disagreed that their pledge to be an organ donor would in any way hamper doctors' efforts in saving them in a life-threatening situation. However, it must be noted that a similar percentage either believed (25% this to be true or were uncertain (24%) that it would not play a role.



Base: 1565

Jaipur proved to be an aberration, with 54% respondents agreeing that becoming a donor would impact the hospital's efforts in saving them in a near-death situation.

City-wise split for 25% who agreed

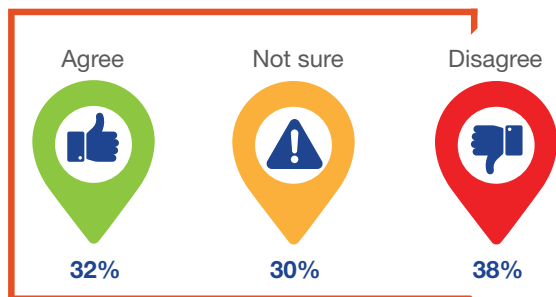


Opt-in or Opt-out?

While 38% disagreed that there was no way out, a greater majority either believes (32%) or is unsure (30%) whether they can opt out of becoming an organ donor once they have registered. This, in fact, is a myth. If you are a registered organ donor and have changed your mind, you can withdraw your registration by informing the organ donor registry, tearing up your organ donor card, and informing your immediate family about your change of decision.

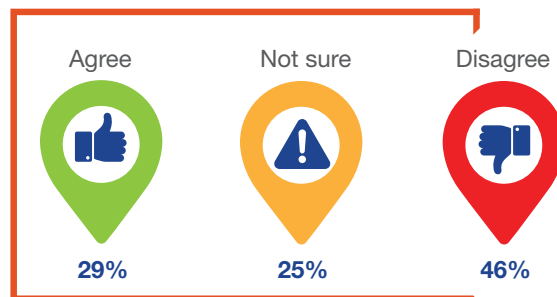
It is important to note that India has a voluntary 'opt-in' system, wherein people have to specifically inform their consent for organ donation in the event they die. Countries like Austria, Belgium, Finland, Israel, Spain, Poland, Sweden and more have 'Opt-out' policies. This, simply put, means that the citizens of these countries are assumed to be registered for organ donation and have to specifically 'opt-out' in case they do not wish to donate.

Once I register, I cannot change my mind



Base: 1565

If one agrees for donation, they or family loses rights to the body



Base: 1565

A higher proportion in bigger cities believe that they or their family would lose all rights to their bodies, once they become an organ donor. This factor also adds onto the concerns that individuals have regarding discussing the subject of organ donation with their families.

<https://www.who.int/bulletin/volumes/93/3/14-139535/en/>

<https://www.mohanfoundation.org/organ-donation-transplant-resources/Myths-Misconceptions-and-the-Reality-of-Organ-Donation.asp>

Ecosystem



The first partial face transplant was carried out in France in 2005, followed by a full face transplant in 2010.

<https://www.theguardian.com/world/2010/jul/26/full-face-transplant-patient>

Low trust in healthcare system

There is a wide-spread distrust in the healthcare system in India. Several factors have contributed to this erosion of trust including negligence, lack of transparency, poor responsiveness, and no concern for patient feedback. In fact, several studies in the recent years have attested to this lack of faith in the system.

A recently unveiled study the industry body FICCI shows that at least 60% patients believed that hospitals did not act in their best interest compared with 37% in 2016. It highlighted concerns over inaccessibility and unaffordability of healthcare for many, and identified the rural primary health, where 70% India resides, as a key area of development. Another study in 2018 painted a horrid picture, with over 92% people saying they did not trust the healthcare system in India.

This mistrust has also contributed to the lower donation rate in India. Despite being the second-most populous country in the world, India has only 412 hospitals across the country that are equipped to perform organ transplants and retrievals. While these registered as approved hospitals with NOTTO, it must be noted that not all hospitals are equipped with carrying out transplants and retrieval for all organs permissible for donation.

The picture gets gloomier when you realise that several hospitals do not declare brain death, which is a prerequisite for deceased donation. The process as mentioned in the Transplantation of Human Organs Act, 1994 might have something to do with it. The law states that before a person's organ can be removed, the patient's death must be certified twice by a board of 4 medical experts within 6 hours.

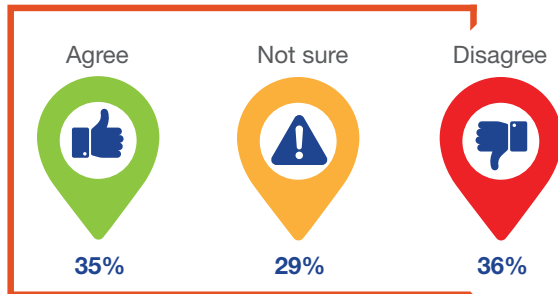
Even in cases where hospitals do this audit, the task of coordination and planning, which requires scrupulous amount of eye for detail, is crucial. Several times, if done poorly, it can lead to organ wastage. In a country that has a lamentable donation rate, wastage of organs is severely distressing.

<https://www.hindustantimes.com/india-news/most-indian-patients-don-t-trust-hospitals-survey-report/story-vvIAbTLuBEsaYsJppGu6ZI.html>
<https://health.economictimes.indiatimes.com/news/industry/over-92-people-dont-trust-healthcare-system-in-india-study/62517023>

Believed to be a scam

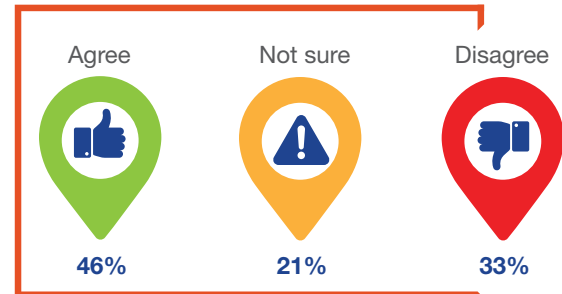
As many as 35% believe that hospitals are not efficient when handling donation and 29% were uncertain whether they can effectively carry out this process.

Donated organs will not reach recipient efficiently



Base: 1565

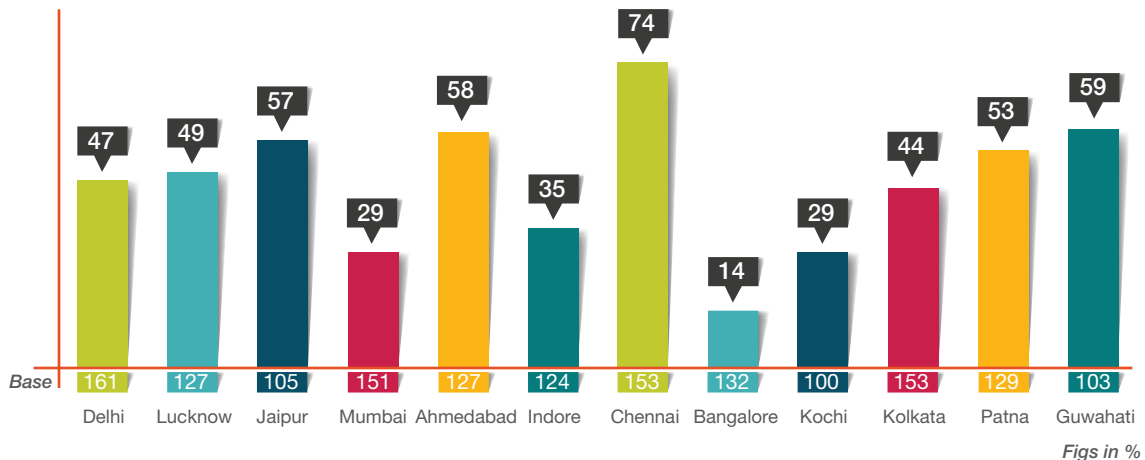
It's a scam & donated organs may not reach recipients



Base: 1565

As many as 46% respondents believe that organ donation in our country is a scam and an untrustworthy process. In fact, the organ rackets busted over the past several years have added to people's scepticism and rendered a bad aura to the entire process. Chennai, Guwahati, and Ahmedabad polled the highest.

City-wise split for 46% who agreed to it being a scam



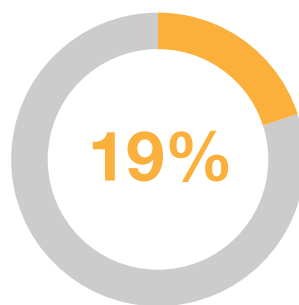
Low awareness on insurance

Insurance is among the most crucial elements of protection, especially in the health space. Currently, insurance companies offer cover for major transplantation costs through critical illness products. However, the study revealed that only 19% were aware that an insurance cover was available for the purpose of organ transplantation.

Surprisingly, several said they were unsure (27%), or disagreed (15%) when asked if insurance is required for organ transplantation. These statistics show the abhorrent level of awareness regarding organ donation and shows lack of clarity regarding the financial burden of organ transplantation.

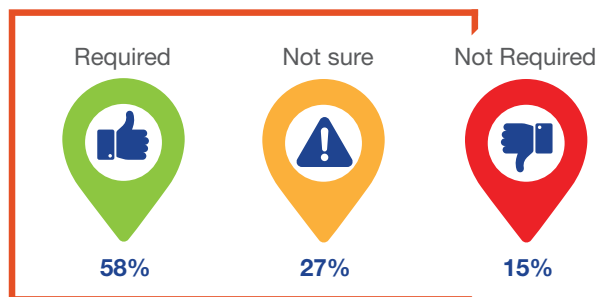
While about 70% (ref: pg 12) people believe that organ donors have to shell out money to the hospital for the process, only 58% said that an insurance product is necessary to cover these expenses. Donors, however, do not have to incur any expenses.

Awareness of insurance product



Base: 1565

Need for insurance product



Base: 1565



What Defines You?



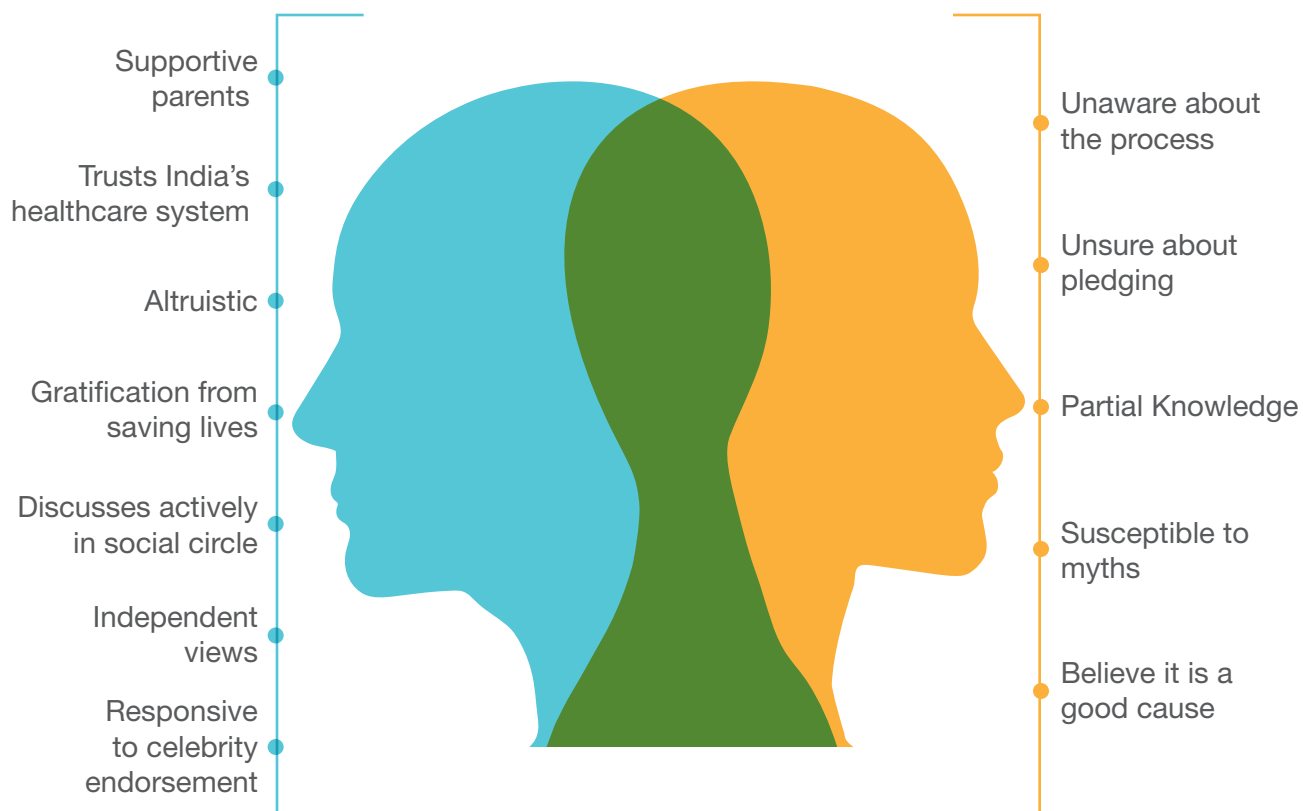
In 1989, there were 8,890 kidney, 2,160 liver, 1,673 heart, 413 pancreas, and 67 heart-lung transplants performed in the United States alone

<https://www.nobelprize.org/prizes/medicine/1990/murray/25012-joseph-e-murray-nobel-lecture-1990/>

Personas

Who is a positive donor ?

Who is a skeptical donor ?





In Toto

Concluding remarks

It is obvious that there are several deep-seated concerns regarding organ donation in our country. The fact that there is high awareness and belief in the importance of organ donation, yet an abysmal level of willingness is quite discerning.

When we embarked on this study, it was our belief that religious superstitions and myths relating to the process might be the leading factors responsible for people staying on the fence. However, lack of awareness and family's beliefs on the subject have emerged as the most pervasive causes for the low donation rate.

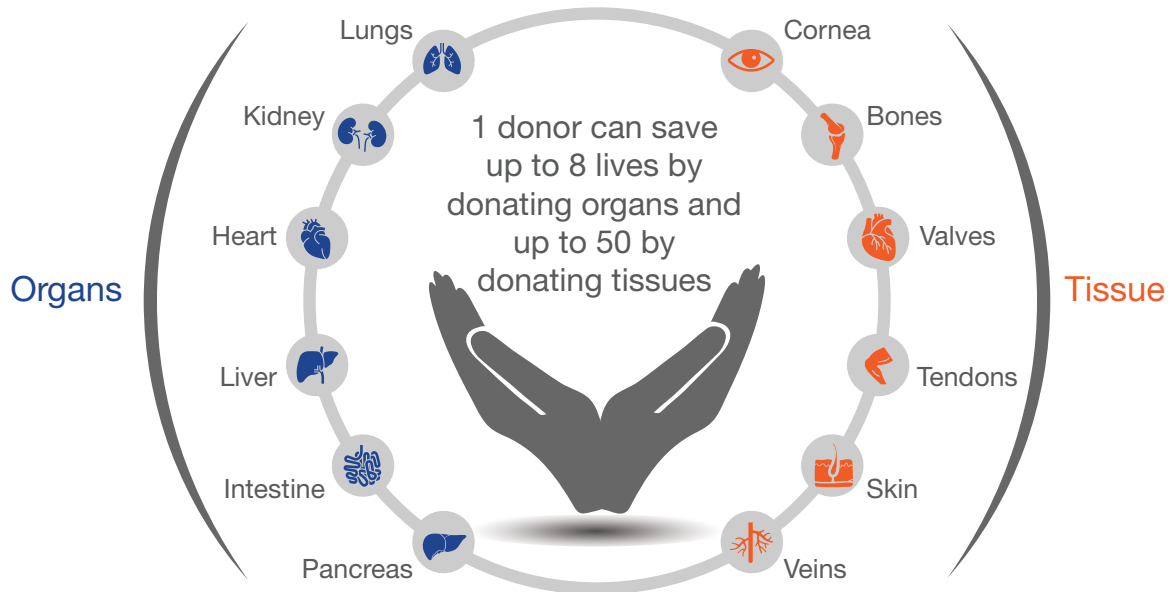
While there are institutional concerns like the distrust in the healthcare system, this study has made it clear that the factors negatively contribution to people's decision making are actually personal in nature and not institutional. Simply put, there is a considerable level of inertia to think and learn more about organ donation and concerns that it would not fit the family's beliefs.

There is an urgent need for Indians to recognise the altruism in donating their organs. We all need to consciously put aside our personal fears to make a positive difference in someone's life.

A close-up photograph of a hand in a dark suit jacket, with the index finger pointing upwards. The background is a blurred, teal-colored wall. Overlaid on the image is a dark blue rectangular box with a white border. Inside the box, the text "I Pledge" is written in a white, sans-serif font. The letter "I" is significantly larger than the other letters and has a yellow outline.

I Pledge

A guide to pledging



Follow this process to pledge your organs

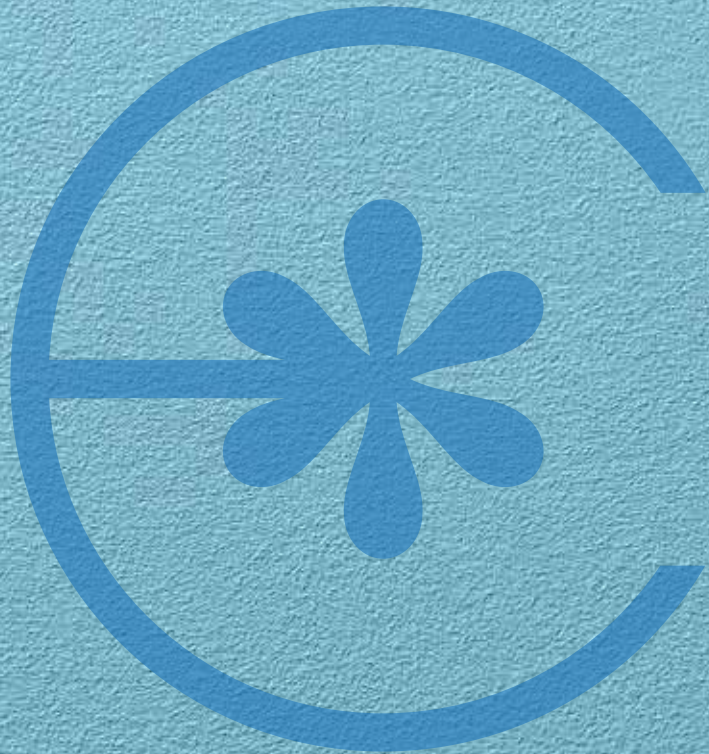


In case you find this tedious, simply visit us at edelweisstokio.in/organdonation

Death is a
Comma
not a full stop

-Anonymous





Edelweiss Tokio Life partnered with Karvy Insights for conducting this research on factors affecting decision making of individuals regarding organ donation.

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