

Eye donation in north India: Trends, awareness, influences and barriers

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Purpose: To understand trends, awareness, influences and barriers to eye donation in Indian society. **Methods:** This cross sectional study was conducted in Delhi from March 2017 to February 2018. About 10 hospitals collaborated with the Eye Bank under Human Cornea Retrieval Program (HCRP). Eye Bank recruited Eye Donation Counselors (EDCs) to approach family members of the deceased. A pretested questionnaire was used for this study. Irrespective of whether the next of kin of the deceased consented for eye donation or not, the option of participating in the survey was given. **Results:** Out of 473 potential donors identified, 407 (86%) next of kin consented to participate in the study. Of these, 388 (95.3%) were males and 19 (4.7%) were females. About 168 (41%) consented for eye donation and were assigned to donor group, while 239 (59%) participants refused eye donation and were assigned to non-donor group. Majority of the participants were siblings 170 (41.8%) of the deceased and the mean age of the deceased was 42.71 ± 17.56 years. The foremost concern before decision-making was transparency in how the cornea would be used (32.25%). The concern with regards to whether the body would remain intact after eye donation significantly decreased the probability of consent for eye donation. **Conclusion:** The study highlights that barriers to eye donation in India are not cultural or religious but more due to misinformation and proper utilization of the donated tissue. This study also emphasizes the pivotal role of EDC's in facilitating the eye donation movement.

Key words: Awareness, barriers, corneal blindness, eye bank, eye donation, eye donation counselors, hospital cornea retrieval programme

Blindness is a global health concern, with 90% of visually impaired residing in the developing world.^[1] According to the World Health Organization (WHO), 80% of this blindness is either preventable or treatable.^[2] Corneal blindness constitutes 5% of cases globally, and is second only to cataract and glaucoma.^[3] In India, these numbers are expected to rise from 6.8 million to 10 million by 2020.^[4,5] It is understood that primary prevention strategies would be more cost effective in managing corneal blindness, but visual rehabilitation by corneal transplant still remains the mainstay of treatment for patients suffering from corneal blindness.^[6] The Government of India has, through NPCB (National Programme for Control of Blindness), has tried to reduce the backlog of blindness through comprehensive eye care services, including corneal transplantation.^[7] Over the years, the Eye Bank Association of India has made efforts to increase the corneal procurement rate. This currently stands at 49,000 per year, but still a lot needs to be done to combat the number of corneal blindness cases which are added every year, some studies suggesting that number to be as high as 30,000 cases every year.^[8-10] It is estimated that 277,000 donor tissues are needed every year, and shortage of transplantable tissue is a subject that deserves much attention.^[8]

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Eye donations can be enhanced by increasing public awareness or, by understanding and overcoming the barriers to eye donation. Though the factors determining public attitude and awareness have been discussed at length over the past few years,^[2,6,11-15] little has been done to understand the difficulties and barriers faced in this cause. Many eye banks have adopted Hospital Cornea Retrieval Programme (HCRP) where Eye Donation Counselors (EDCs) approach families and proactively counsel for eye donation. However, family's knowledge and beliefs significantly impact consent, which vary between 20-80%.^[15]

Knowledge and attitude of key family members play a major role in establishing a positive consent for eye donation. However, the outlook of the family members is variable following the loss of a dear one. The purpose of our study was to analyze the major factors and barriers towards consent for eye donation. The results identified could feed actionable nationwide information, education, communication and behavior-change strategies targeting donor families. This could result in an overall increase in the corneal donation rates.

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Methods

Background, study design and approval

This community based cross-sectional study was conducted in Delhi and surrounding areas (National Capital Region, NCR) from March 2017 to February 2018. The study was designed, initiated, and implemented by the in-house Eye Bank of a tertiary eye center in Delhi. The eye bank is an actively growing eye bank in New Delhi, India procuring more than 1,500 corneal tissues per year (unpublished data from the Eye Bank Association of India). About 10 multispecialty hospitals from Delhi dealing with all specialties of medicine, including emergency services and Intensive Care Units collaborated with the Eye Bank under the HCRP project. The Eye Bank recruited 6 EDCs for this project who worked as full time staff in close association with the HCRP partner hospitals. EDCs underwent training program at the beginning of their term, and were oriented to the workings of the Eye Bank, the HCRP program, way to approach the family members of the deceased to counsel for eye donation. The study was conducted in accordance with the tenets of Declaration of Helsinki and clearance from the Institutional Ethics Committee was obtained. Further details of Partner Hospitals and EDCs are available in Annexure 1.

Eye donation counseling

In event of any death, the hospital would contact the EDCs. The age and gender of deceased potential donor, cause and time of death were noted. The cause of death was categorized into two groups' namely pathological death, which included cases like cardiac arrest, heart attack, cancer, multiple organ failure. The second group was of accidental death, which included death due to murder; hanging, drowning, fall from height, fire and poisoning. EDCs approached the family members of the deceased to counsel for eye donation based on a pre-designated format of the eye bank. Recordings of the sessions were collected, and it can be made available on request. These deceased were designated as potential eye donors. If the next of kin was willing for eye donation, a written consent was obtained. In-situ corneo-scleral excision was performed under aseptic conditions in accordance with the eye bank protocol. Those who donated the eyes were assigned into donor group and those who did not give consent for eye donation were placed in the non-donor group.

Survey questionnaire

A pretested semi structured, self-administered (in a pilot study conducted in 35 participants) questionnaire was developed and used for this study (Annexure 1). Irrespective of whether next of kin of the deceased consented for eye donation or not, option of participating in the survey was given. If the person consented to participate in the study, a telephonic call was made 1-2 week after the first contact and the survey questionnaire was administered. Telephonic consent was taken and the audio calls were recorded for future reference. The respondents completing the survey were termed as participants. The demographic details of the participants in the survey were documented which included their age, sex, relationship to deceased, religion, knowledge about eye donation, willingness for eye donation, strongest influence for decision and barriers to eye donation. The respondents were asked specifically whether they were concerned about disfigurement of face following donation. In order to assess economic status, it is understood that consumption and material assets can be measured instead of income. This is termed as wealth index. We used the KoBoToolbox (Harvard Humanitarian Initiative,

the Harvard TH Chan school of Public Health and the Brigham and Women's Hospital) to determine the wealth score of the participants.^[16-19] With this score, 5 wealth quintiles are created wherein the poorest 20% were placed in quintile 1, the second poorest in quintile 2, and so on. The tool used 13 survey questions, which were incorporated in our questionnaire.

Statistical analysis

Statistical analysis was performed using SPSS statistical software (SPSS version 21. Inc., Chicago, IL, (USA)). Patient demographics were reported as mean and standard deviation for continuous variables and percentages for categorical variables. Chi-square test was used to compare categorical variables and independent sample *t*-test was used to compare continuous variables between the two groups. Statistical significance was defined at a level of 5% ($P < 0.05$).

Results

Sociodemographic variables of the Potential donors

During the study period, a total of 473 potential donors were identified. Out of these, 407 (86%) next of kin consented to participate in the study. Of the 407 participants, 168 (41%) consented for eye donation and were assigned to the donor group, while 239 (59%) participants refused eye donation and were assigned to the non-donor group. Fig. 1 shows the mean age of the deceased was 42.71 ± 17.56 years (3 – 92 years) of which 332 (81.57%) were males and 75 (18.43%) were females. Maximum eye donations were in the 32-52 years age group. Age did not have any correlation to willingness for eye donation ($P=0.64$). Out of 407 deceased, 332 (81.57%) were males and 75 (18.43%) were females. In the donor group 31 (18.45%) were females and 137 (81.54%) were males. Most common cause of death was cardiac arrest (39.55%) followed by road traffic accident (22.85%) and hanging (20.63%). Out of the 407 deceased potential donors, 5 (2.98%) in the donor group and 1 (0.42%) in the non-donor group had expressed a wish for eye donation during their lifetime. Prior wish to donate eyes, however, had no effect on the family's decision for eye

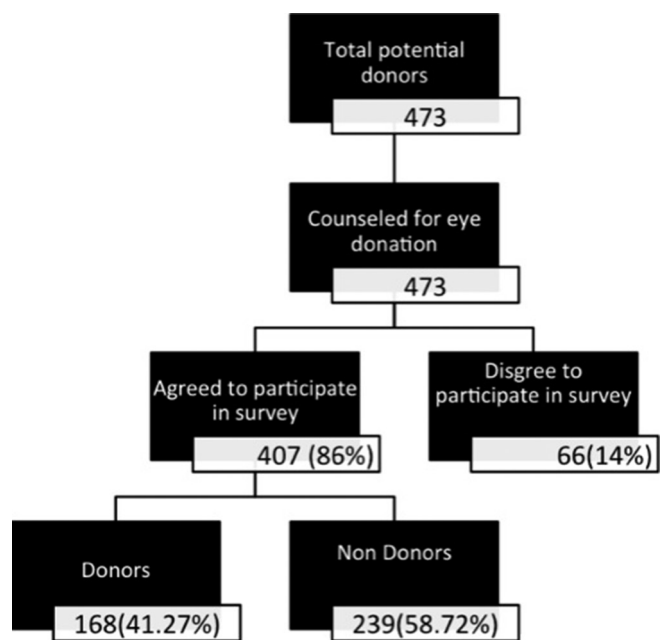


Figure 1: Distribution of potential donors

donation ($P = 0.09$). All of the 6 participants who had expressed their wish to donate eyes belonged to the fifth urban quintile in the wealth index. Tables 1 and 2 show the consolidated data of the potential donors and participants.

Sociodemographic variables of participants

Out of the 407 participants, 388 (95.3%) were males and 19 (4.7%) were females. The mean age of the participants was 39.78 ± 11.5 years. The age and gender was not significantly associated with the consent for eye donation ($P = 0.23$, $P = 0.63$). Amongst the 407 participants, 240 (59%) belonged to the 5th socio economic quintile, followed by 137 (34%), and 27 (7%) in the 4th and 3rd quintiles respectively i.e. majority of the participants belonged to upper middle class. The socioeconomic status of the participants in terms of urban and national quintile also didn't have any impact on the consent for eye donation. Majority of the participants belonged to Hindu religion (375 (92%)) followed by

Table 1: Consolidated analysis of potential donors

Consolidated analysis of the eye donors and non-donors group			
	Non Donor	Donor	P
Age	44.76±17.07	39.80±17.90	0.005
Gender			
Female	44 (18.41%)	3 (18.45%)	
Male	195 (81.5%)	137 (81.55%)	1.000
Cause of death			
Pathological	104	59	
Accidental	135	109	0.1

Table 2: Consolidated profile of participants

Profile of participants	Non Consent	Consent	P
Age (SD)	39.21 (±10.88)	40.60 (±12.33)	0.232
Gender			0.63
Females	10 (4.2%)	9 (5.4%)	
Males	229 (95.8%)	159 (94.6%)	
Relationship with deceased			0.29
Children	72 (30.1%)	38 (22.6%)	
Parent	36 (15.1%)	36 (21.4%)	
Relatives	8 (3.3%)	6 (3.6%)	
Siblings	97 (40.6%)	73 (43.5%)	
Spouse	26 (10.9%)	15 (8.9%)	
Religion			0.194
Buddhism	1 (0.4%)	0 (0%)	
Christianity	2 (0.8%)	0 (0%)	
Hinduism	219 (91.6%)	156 (92.9%)	
Islam	12 (5%)	4 (2.4%)	
Sikhism	5 (2.1%)	8 (4.8%)	
Consultation			
Children	38 (15.9%)	23 (13.7%)	0.636
Parent	80 (33.5%)	60 (35.7%)	0.717
Relatives	177 (74.1%)	124 (73.8%)	1.000
Siblings	28 (11.7%)	17 (10.1%)	0.730
Spouse	15 (6.3%)	4 (2.4%)	0.111
Others	196 (82.0%)	136 (81.0%)	0.888

Muslim (16 (4%)), Sikh (13 (3%)) and other religions. There was no significant difference in eye donation between the religious groups ($P = 0.194$). Majority of the participants were siblings 170 (41.8%) of the deceased followed by children 110 (27%), parents 72 (17.69%) and spouse 41 (10.07%). When parents were approached they consented 50% of the times for eye donation of their child. This was followed by siblings (42.9%), relatives (41.6%), spouse (36.5%) and children (34.5%). However, relationship of the person making the decision did not have any significant effect on the consent for eye donation ($P = 0.29$). Most of the participants consulted more than one individual. The decision for eye donation was mainly self-driven (36.97%), followed by consultations with relatives (33.52%) and parents (15.59%). The EDC who approached the next of kin significantly influenced the consents for eye donation ($P = 0.05$). Consulting the siblings ($P = 0.03$) was found to reduce the probability of consent. However, consulting anyone else (parents, child, relatives, others) was not associated with willingness for eye donation.

Awareness about eye donation and role of EDC

About 360 (88.45%) participants had heard about eye donation and 47 (11.55%) had never heard about it [Fig. 2]. However, there was no statistical correlation between eye donation and prior awareness of eye donation ($P = 0.13$). Many participants had heard about eye donation from multiple sources. The most common source of information were healthcare facilities (34.96%), followed by friends and relatives (22.07%) mass media (14.45%), brochures (9.96%), social gathering (9.57%) [Fig. 3] The counseling by EDC's influenced the consent in 277 (68%) donor families. The decision to donate eyes was the direct impact of the counseling by the EDC in 61 (15%) families. However 175 (43%) donor families were initially hesitant to consent, but the EDCs could clear their doubts.

Barriers to eye donation

The foremost concern before decision-making was transparency in how the cornea would be used (32.25%). The participants wanted corneas to be utilized for the purpose it was being

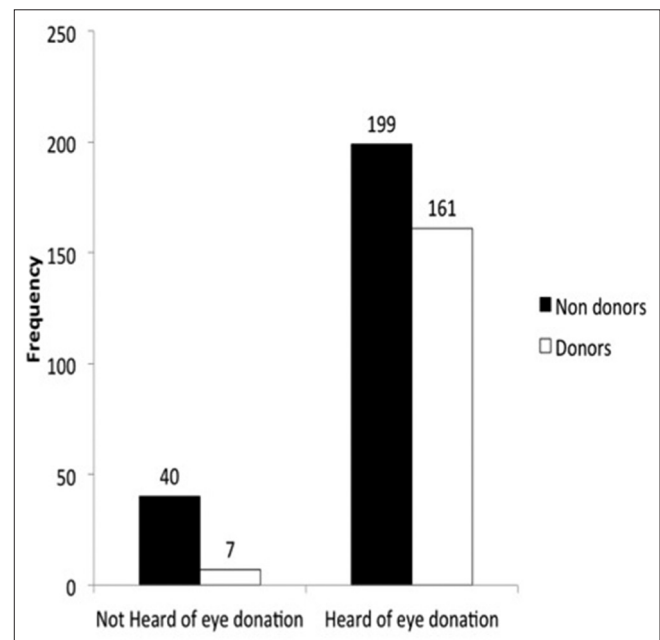


Figure 2: Participants who had heard of eye donation

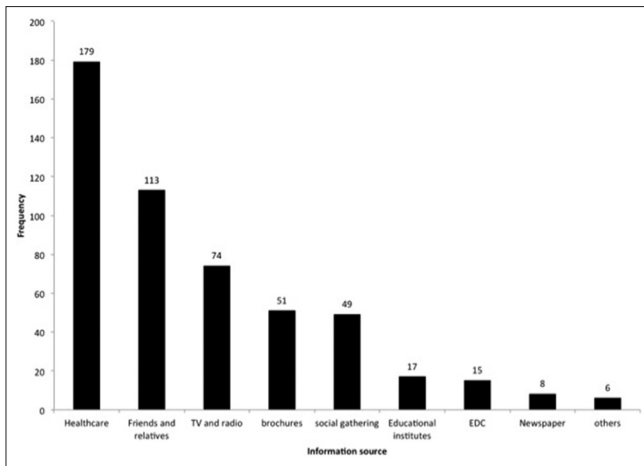


Figure 3: Source of information for the participants

donated for and this lack of trust was found to be one of the most important factors influencing decision-making. Other concerns were family would be upset (27.38%), body should remain intact (23.67%), the fear that body would not be treated properly during eye donation (7.19%) and religious factors (2.7%). The concern with regards to whether the body would remain intact after eye donation ($P < 0.05$) significantly decreased the probability of consent for eye donation. Similarly, family becoming upset ($P < 0.05$), concerns on whether body would be treated properly ($P < 0.05$), and religious reasons ($P < 0.05$) also significantly impacted (negatively) the chance of getting consent for eye donation [Fig. 4].

Discussion

For any community, increasing awareness amongst people about eye donation is essential, and understanding the trends and barriers that determine eye donation is of paramount importance. Most of the eye banks function on dual strategy of voluntary donations and proactive counseling of family members. The HCRP is a proactive approach wherein the EDCs actively counsel the families of the deceased for eye donation.

In our study counseling by EDCs influenced the consent in 68% of donor families. 15% of donor families said that their decision to donate eyes was the direct impact of the counseling by the EDC. However 43% donor families said that they were initially hesitant to donate but the EDCs could clear their doubts (discussion details available on request). This highlights the pivotal role of EDC's in enhancing eye donations in India. Tandon *et al.* highlighted similar pattern, where counseling teams in hospital mortuaries motivated families for eye donation.^[11]

In our study, 41% of the counseled families consented for eye donation. This is comparable to other Indian studies.^[11,15,20,21] However, the consent rates in developed countries like Singapore and Toronto were found to be 67% and 63%, respectively.^[12,22] This has been attributed to greater education level and higher socio economic status in the developed countries.^[12] Our study was conducted in an urban area i.e. Delhi and the National Capital Region (NCR), and interestingly we did not find socio- economic status to influence consent for donation. This is in conformance with study by Tandon *et al.*^[11] Probably, in India, cultural variations influence eye donation more than socio economic status, as opposed to the developed countries.

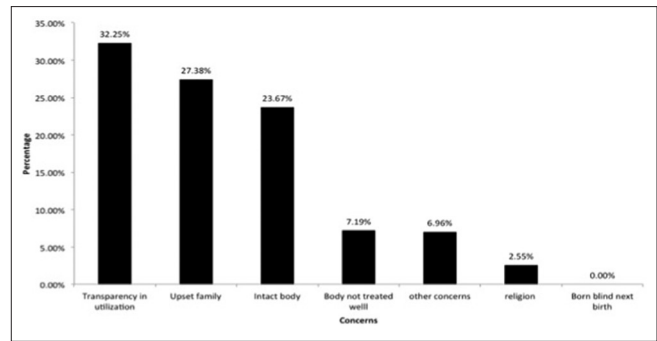


Figure 4: Main concerns of participants prior to decision making for eye donation

Awareness rates have been an important aspect of eye donation studies, and all major studies have spoken about this in great depth.^[6,11,23,24] 88.45% of our patients were aware about eye donation. This is high compared to other Indian studies and a study from Singapore where the awareness was found to be from 33% to 80%.^[6,2,12,13,21] Various information portals have been described for patients to gather information from, and the most common source of information in our study was health care facilities. This signifies that healthcare staff is an important link in disseminating information about eye donation. The perception and knowledge of healthcare staff could help narrow the gap between potential, and actual donors. Mass media including television and newspaper were also noted as common source of information for eye donation. Hence, it would be prudent to increase information in these modes to further strengthen awareness leading to increased eye donations. Other studies have mentioned the importance of publicity campaigns and mass media in improving the awareness levels.^[23,25] We also feel that in today's day and age, the youth should be informed about eye donation through active publicity and advertisements on social media.

In our study, the mean age of the deceased was 42.7 years. We did not find age of the deceased to be statistically significant in relation to families agreeing for eye donation. However, it's seen in earlier studies that age is a significant factor for willingness towards eye donation.^[6,15,26] Also, we categorized the cause of death into two groups- Pathological and accidental. The consent rate for eye donation in both groups was comparable. Accident deaths are always associated with greater emotional shock, as the grief of sudden and young demise is much more to the family members when compared with pathological deaths. But when the family members of accident death groups were counseled by EDCs for eye donation, their consent rate was similar to that of the pathological death group, signifying the pivotal role of EDCs and their proactive counseling.

There are about 95% of the participants in the study were males. In our society, where male members are the decision makers, this was an expected observation. This could also be because the male members of the family usually do all the legal formalities in the hospital and mortuary. However this was not the case in Australia,^[24] highlighting the cultural difference between the two countries. In our study we found that when parents were approached they consented 50% of the times for eye donation of their child. The parents were more likely to donate eyes than when the siblings, relatives, spouse and children were the decision makers. In a similar study by Lowel

et al.^[14] mothers and fathers more likely to donate than siblings, and siblings more likely to donate than children and spouses. Most of the participants consulted more than one individual. This emphasizes the importance of family members' advice in Indian society and the need of counseling of several family members to increase consent for eye donation. In our experience, these are complex, emotional issues, and it is hard to predict the trend of consenting when the family is under such grief.

The barriers, which rest in the minds of the society, which prevent them from eye donation, were studied separately. The most frequent barrier (32.25%) was lack of surety that the donated tissue would be put to proper use. This included the thought of tissue being sold, wasted or illicit trafficking of the tissue. Tandon *et al.* also reported that 5% families expressed the fear of organ trafficking.^[11] This barrier can be overcome by organizing eye donation fortnights where the recipients of corneal transplants express their gratitude and share their success stories. People were also concerned about the issues that 'body should remain intact' (23.67%), and fear that body would not be treated properly during eye donation 31 (7.19%). To tackle these issues continuous awareness programs, in the form of promotional advertisements and even official Internet platforms, giving adequate scientific knowledge about eye donation and encouragement should be promoted. All eye banks should be encouraged to shift to in-situ corneo-scleral rim excision instead of whole globe enucleation to minimize trauma to the body of the deceased.

Conclusion

The present study is one of the most comprehensive researches on the awareness, influences and barriers to corneal donation in a section of the Indian society. The study highlights that the barriers to eye donation are not cultural or religious but more due to misinformation and proper utilization of the donated tissue. There is a need to correct these misconceptions, which can be done by actionable nationwide strategies when devising information, education and communication tools to boost up the eye banking movement in India. This study also emphasizes the pivotal role of EDC's in facilitating the eye donation movement.

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Conflicts of interest

There are no conflicts of interest.

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Annexure 1: Questionnaire

EDC name: Suresh Manish Rawat Amir Khan R D Sharma Sombir Prem Chand EDC's age: _____

Gender of EDC: Male Female

Hospital Name : Maharaja Agarsen Hospital Jaipur Golden Hospital Saroj Hospital Sri Balaji Action Medical Institute Dharmshila Hospital BJR Hospital Mortuary BSA Medical College Hospital Mortuary Sanjay Gandhi Memorial Hospital Mortuary Fortis Hospital Pushpanjali Hospital, Ghaziabad Artemis Hospital, Gurgaon

Date/Time of Counselling : _____ What type of case: MLC Non-MLC

Name of Deceased _____ Age of Deceased _____ Gender of Deceased Male Female

Date and Time of death _____ Cause of Death _____

Family Member of the deceased

Name of person being interviewed _____ Phone no: _____

Relationship with deceased Children Parent Spouse Siblings Relatives Others

Age of family member _____ Gender Male Female

Religion Hinduism Islam Christianity Sikhism Buddhism Jainism Other religions

State _____

If state is Delhi then which zone and locality?

1. Central Delhi Ballimaran Burari Chandni Chowk Karol Bagh Matia Mahal Sadar Bazaar Timarpur
2. East-Delhi Gandhi Nagar Kondli Krishna Nagar Laxmi Nagar Patparganj Trilokpuri
3. New Delhi Delhi Cantt Greater Kailash New Delhi Patel Nagar R K Puram Rajinder Nagar
4. North Delhi Adarsh Nagar Badli Bawana Model Town Narela Rohini Shakur Basti Wazirpur
5. North-East Delhi Ghonda Gokalpur Karawal Nagar Mustafabad Seelampur
6. North-West Delhi Kirari Mangol Puri Mundka Rithala Shalimar Bagh Sultanpur Majra Tri Nagar
7. Shahdara Babarpur Rohtas Nagar Seema Puri Shahdara Vishwas Nagar
8. South Delhi Ambedkar Nagar Chhatarpur Deoli Malviya Nagar Mehrauli
9. South West Delhi Bijwasan Dwarka Matiala Najafgarh Palam Uttam Nagar Vikaspuri
10. South-East Delhi Badarpur Jangpura Kalkaji Kasturbha Nagar Okhla Sangam Vihar Tughlakabad
11. West Delhi Hari Nagar Janakpuri Madipur Moti Nagar Nangloi Jat Rajouri Garden Tilak Nagar

Socioeconomic status questions

1. Does your household have a pressure cooker? Yes No
2. Does your household have a colour television? Yes No
3. Does your household have a table? Yes No
4. Does your household have an electric fan? Yes No
5. Does your household have a chair? Yes No
6. Does your household have a refrigerator? Yes No
7. Does your household have windows with glass? Yes No
8. Does your household have a mattress? Yes No
9. What type of toilet does your household use? Any type of latrine or toilet Bush/no facility
10. What is the main material that the roof of your household is made of? Concrete/Cement roof Any other material
11. What is the main material that the walls of your household are made of? Cement wall Any other material
12. What type of fuel does your household use for cooking? LPG, natural gas for cooking Wood Other
13. Does any member of your household have a bank account or post office account? Yes No

Knowledge and attitude questions

1. Have you heard of eye donation before today? Yes No
 - a. If yes, from where, when, and from whom have you heard of eye donation?
 - i. Where (State): _____ ii. When (no of years): _____
 - iii. From whom: Friends and relatives Eye Donation Counsellors Social gatherings Educational institutes Hospital/Healthcare sector Brochures/fliers/ banners etc. TV/ Radio advertisements Newspaper Others
2. Did the deceased discuss about his/her wish to donate eyes? Yes No
 - a. If yes, when (specify year) _____ b. what organs _____
3. Who else did you consult when making your decision? Children Parents Spouse Siblings Relatives Others
4. Who had the strongest influence on your decision? Children Parents Spouse Siblings Relatives Others
5. What were the main concerns before making your decisions? It is important that body remains intact after death Family would be upset Body would not be treated with proper respect Transparency in how the cornea would be used Religion Person will be born blind in next birth other reason
6. Are you bothered about disfigurement of face? Yes No
7. Was the details of the study like the objective of the study, maintenance of patient's confidentiality discussed with you? Yes No
8. Did the family give consent? Yes No
9. Based on the family's responses, please add anything else that may be helpful to know about this case (i.e. secondary reasons for decision). _____

I understand that my participation in this research is voluntary. I also understand that sponsor of this research, others working on sponsor's behalf, ethics committee and the regulatory authorities will not need my permission to work at my personal details both in respect of current research and any further research that may be conducted in relation to it. I agree to this access however, I understand that my identity will not be revealed in any information released to third parties or published.

Signature/Record ID

Survey coordinator

Date